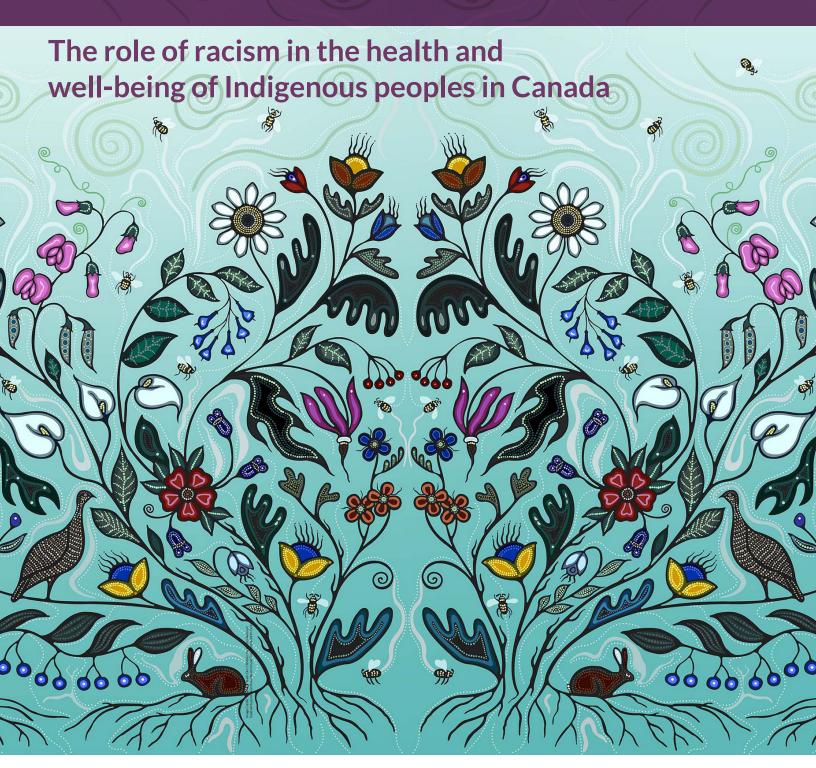
# First Peoples, Second Class Treatment







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#### A Note on Terminology

In this paper we use the word "Indigenous" as an inclusive and international term to describe individuals and collectives who consider themselves as being related to and/or having historical continuity with "First Peoples", whose civilizations in what is now known as Canada, the United States, the Americas, the Pacific Islands, New Zealand, Australia, Asia, and Africa predate those of subsequent invading or colonizing populations. We note that globally, no universal definition of Indigenous peoples has been accepted (Bartlett, Madriaga-Vignudo, O'Neil, & Kuhnlein, 2007) and chose this term over the constitutionally defined Canadian term "Aboriginal" partly because it is commonly understood that in using the term "Indigenous," individuals and communities will be supported in self-defining what it means to them. Exceptions to our use of the term Indigenous have been made of necessity when we are citing specific statistics that used other terms for data collection. For example, Statistics Canada uses the term Aboriginal in its data collections, drawing on the 1982 Constitution Act definition, which includes "Indian, Inuit, and Metis" (Government of Canada, Constitution Act, 1982, section 35 (2)). We further note that there is an incredibly rich diversity of Indigenous peoples in what is now known as Canada (i.e. Pre-European contact the linguistic diversity of the Americas was ten-fold that of Eurasia) (Nettle, 1999). Out of respect for this diversity we have attempted to ensure that it is represented at least partially in the text and that specific Indigenous groups are correctly referenced in examples and citations. For more information about the terms used to describe Indigenous peoples see Textbox A.

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# Textbox A: Terms used to describe Indigenous people in Canada (excerpt from Smylie (2014) Indigenous Child Health in Canada, In A.C. Michalos (Ed.) Encyclopedia of Quality of Life and Well-being Research. Dordrecht, Netherlands: Springer)

Globally, no universal definition of Indigenous peoples has been accepted (Bartlett et al., 2007). Being able to define one's community on one's own terms is a central part of self-determination. Definitions of Indigenous also change over time and are not static. Most definitions will include reference to the relationships of Indigenous peoples to a collective kin group and a current or historic land base (Pinto and Smylie, 2012). A commonly employed definition of Indigenous emerging from the United Nations commissioned study by Martinez Cobo (1987) defines Indigenous as: "communities, peoples and nations...which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing on those territories, or part of them. They form, at present, non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as a basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal system" (p. 17).

Aboriginal is a government imposed, legally defined term collectively referring to all of the Indigenous peoples of Canada and their descendants. The Canadian Constitution Act of 1982 specifies that the Aboriginal Peoples in Canada consist of three groups: Indians, Inuit and Métis.

The term First Nations came into common use in the 1970s to replace Indian, which some people found offensive. Despite its widespread use, there is no legal definition for this term in Canada.

The Canadian government classifies First Nations/Indian people according to whether or not they are registered under the federal Indian Act. Status Indians are registered under the Act. First Nations/Indian people who are not registered under the Act are referred to as non-status Indians.

The Inuit traditionally lived above the tree line of what is now Canada, and are part of a larger circumpolar Inuit population that includes Greenland, Alaska, and Russia. Inuk refers to an individual Inuit person.

The Métis are a group of Aboriginal peoples whose ancestry can be traced to the intermarriage of European men and First Nations/Indian women in Canada during the 17th century. Individuals of mixed Indigenous and non-Indigenous ancestry who are not directly connected to the Métis of the historic northwest may also identify themselves as Métis.

Indigenous peoples in Canada also refer to themselves by their specific tribal affiliation (such as Mi'kmaq, Cree, Innu, Ojibwa) or First Nations, Native, Indian, Inuit or Métis.

#### Introduction

This paper was prepared for Wellesley Institute by Dr. Billie Allan and Dr. Janet Smylie of the Well Living House, an action research centre founded to develop and share knowledge and practices that promote the health and well-being of Indigenous infants, children and their families. The Well Living House is housed within the Centre for Research on Inner City Health and the Li Ka Shing Knowledge Institute of St. Michael's Hospital, in Toronto, Ontario, Canada. The Well Living House is co-governed by the Counsel of Indigenous Grandparents and St. Michael's Hospital, and strives to promote excellence and innovation in Indigenous health research practices and Indigenous health knowledge translation. The Counsel of Indigenous Grandparents (Grandmothers Madeleine Kētēskwew Dion Stout, Jan Kahehti:io Longboat and Carol Terry) helps to guide the work of Well Living House and these grandparents have generously contributed to the conceptualization and text of this document.

#### **Scope And Purpose Of The Review**

Racism has played a foundational role in the development and maintenance of the Canadian nation state. The colonization of Indigenous lands and peoples was fueled by racist beliefs and ideas about Indigenous peoples, values, ways of knowing and being, customs and practices. These race-based beliefs served to justify acts of racial discrimination, including violence, cultural genocide, legislated segregation, appropriation of lands, and social and economic oppression enacted through such policies as the Gradual Civilization Act and the Indian Act. Policies and practices emerging from imperialistic and colonial ideologies have been extremely destructive to the health and well-being of Indigenous peoples, cutting across the broad spectrum of social determinants of health, impacting access to education, housing, food security, employment and health care, and permeating societal systems and institutions that have profoundly impacted the lives and well-being of Indigenous peoples including the child welfare and criminal justice systems. The discriminatory treatment of Indigenous peoples within these systems is evidenced on one hand in the egregious overrepresentation of Indigenous children and youth in the care of child welfare agencies and Indigenous youth and adults in the custody of detention centres and federal prisons<sup>1</sup>, and on the other hand, in the lack of political and societal response to the ever growing number of missing and murdered Indigenous women in Canada (Human Rights Watch, 2013; Mathysen, 2011; The Sisterwatch Project of the Vancouver Police Department & The Women's Memorial March Committee, 2011).

This paper explores the role of racism in the health and well-being of Indigenous peoples in Canada. It provides an overview of the historical and contemporary contexts of racism which have and continue to negatively shape the life choices and chances of Indigenous peoples in this country, and then examines the ways in which racism fundamentally contributes to the alarming disparities in health between Indigenous and non-Indigenous peoples. Indigenous peoples experience the worst health outcomes of any population group in Canada (Royal College of Physicians and Surgeons of Canada, 2013), underscoring the urgency and importance of understanding and addressing racism as a determinant of Indigenous health.

Racism is a complex social construction. In order to elucidate the ways in which racism contributes to

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<sup>1</sup> The rate of incarceration of Indigenous adults is approximately 10 times that of non-Indigenous adults (Statistics Canada, 2013), while the rate of Indigenous youth incarceration has been estimated to be eight times that of non-Indigenous youth (Latimer & Foss, 2004).

current and future health disparities and vulnerabilities among Indigenous peoples, this paper is composed of three key sections. First, we examine racism and colonization as root determinants of Indigenous/non-Indigenous health inequities. We draw on Indigenous approaches to the social determinants of health and focus on describing specific colonial policies and how these policies have historically shaped and continue to shape Indigenous health determinants, outcomes and access to care. Second, we review the literature documenting and describing Indigenous peoples' experiences of racism in Canada and the links to health, well-being and access to health care. Third, we review responses and interventions aimed at addressing the impacts of racism at the individual, community, health services and policy levels. We conclude with emerging ideas and recommendations for moving forward that we hope will contribute to broader discussions and collaborative action.

Indigenous peoples' experiences are too often omitted in discussions of racism and subsequently antiracism (Lawrence & Dua, 2005). The reasons for such omissions typically includes a rationale that argues for recognition of the unique histories, policies and contemporary circumstances shaping the lives of Indigenous peoples (Nestel, 2012; Levy et al., 2013); a recognition that is indeed important. However, these omissions may contribute to a continual "writing out" or "writing over" of Indigenous experiences of racism, marginalization and violence in what is frequently and disturbingly referred to as a nation of immigrants or a "country built by immigrants" (Citizenship & Immigration Canada, 2011, p.3). These characterizations of the Canadian nation state fail to acknowledge the existence or sovereignty of First Nations and Inuit communities prior to colonization by Europeans, or recognize the unique experiences and contributions of the Métis peoples. They also effectively obscure the continual structural and systemic violence and marginalization of Indigenous peoples required to create and maintain the settler society of Canada.

It is important to consider the ways in which experiences of racism, marginalization, and exclusion are shared and unique amongst and between Indigenous peoples and peoples of colour, in order to build solidarity and expand the collective knowledge and skills available to advocate for and enact anti-racist and decolonizing perspectives and practices in health programming, policies and services. This is even more important in recognizing and responding to the challenges faced by those who carry mixed racial identities from both Indigenous communities and communities of colour. We, therefore, advocate for an approach that builds these bridges while at the same time respecting the diversity and uniqueness of both Indigenous populations and communities of colour, drawing on existing community and nation-based protocols to guide this work<sup>2</sup>.

#### **Methods**

#### **Telling Our Own Stories**

Racism has inserted non-Indigenous peoples as the authors of not only who we are, but also how we are. De Leeuw, Greenwood & Cameron (2010) point to the role of Canadian state documents, beginning

<sup>2</sup> The contemporary protocols used when diverse Indigenous nations come together at international gatherings such as Healing Our Spirit Worldwide provide an example of how this type of solidarity building may be achieved. These gatherings are commonly structured to ensure that each individual nation is honoured and respected while at the same time establishing a collective forum.

in the mid-1800s, that described Indigenous peoples as mentally inferior, child-like, unpredictable, untrustworthy and violent. These painfully derogatory descriptions informed official beliefs about Indigenous peoples and were used to justify colonial policies of, paradoxically, both exclusion and assimilation. Exclusion was enacted socially, geographically and economically through legislation and policies that restricted the movement and activities of Indigenous peoples (e.g. the reserve and pass card systems; restrictions on the economic participation of Indigenous peoples). Assimilationist policies were enacted largely through measures meant to "civilize" Indigenous children by removing them from their "savage," inferior cultures and the languages, families and communities through which they received their traditional knowledge and practices (Dickason, 1997). These measures included residential schools, mass child welfare intervention and cross-racial adoption (Pon, Gosine & Phillips, 2011; Sinclair, 2004, 2007; Stabler, 2010).

The rippling effects of the trauma and rupture caused by colonial policies have served to reinforce or seemingly legitimize racist stereotypes about Indigenous peoples. The damage caused to Indigenous communities by colonization illustrated through stigma created by poor physical and mental health, high rates of substance abuse, suicide, poverty, unemployment, under-housing and homelessness, and overrepresentation in incarceration and child welfare, may be used as justification for continuing racist beliefs, paternalistic policies and inequitable treatment. Racist stereotypes have found steady employment beyond policy documents, showing up in public education systems and media coverage, contributing to and reinforcing a naturalized kind of racism that permeates Canadian society (Browne, 2003, 2005; Clark, 2007; Gilchrist, 2010; Neegan, 2005; Watters, 2007).

Stereotypes of the "drunken Indian" or the hyper-sexualized "squaw," the casting of Indigenous parents as perpetual "bad mothers" (Kline, 1993) or "deadbeat dads" (Ball, 2010; Bell & George, 2006), or media portrayals of Indigenous leadership as corrupt and/or inept, all serve to justify acts of belittlement, exclusion, maltreatment or violence at the interpersonal, societal and systemic levels. They have shaped how Indigenous peoples are received and treated by child welfare agencies (Kline, 1993), health care providers (see for example: Tang & Browne, 2008; Browne et al., 2011; Kurtz, Nyberg, Van Den Tillaart, Mills & Okanagan Urban Aboriginal Health Research Collective, 2008) and police (e.g. in a lack of response to reports of missing Indigenous girls and women) (Canadian Feminist Alliance for International Action & Canadian Labour Congress, 2012; Talaga, 2012). These stereotypes are examples of the ways in which the dominant stories in Canadian society of who we as Indigenous peoples are and how we are, are told about us and not by us.

Following the direction of the Well Living House Counsel of Grandparents in preparing this paper, we attempted as much as possible avoid the perpetuation of deficit-based stereotyping of Indigenous peoples. Rather, we set out to support the telling of our own stories as Indigenous people about our experiences of racism and the impact of racism on our health and well-being. To accomplish this we have used a mixed methods approach. First, we have included narratives shared by our Counsel of Indigenous Grandparents with the aim of grounding our paper in their knowledge and experience and

The stereotype of the "squaw" portrays Indigenous women as dirty, uncivilized, savage, lazy and hypersexual; this stereotype has been linked to efforts to undermine the roles and responsibilities of Indigenous women during the early stages of colonization and to justifying the historical and ongoing physical and sexual violence experienced by Indigenous women (Anderson, 2004; Gilchrist, 2010; Larocque, 1994).

to prevent our discussion of the reality of racism in the lives of Indigenous peoples from being reduced to an intellectual exercise. Where racism has attempted to dehumanize our peoples, the inclusion of the narratives of our Counsel of Indigenous Grandparents is an effort to ensure that our humanity remains visible and central in the consciousness of our readers. These narratives were transcribed verbatim and subsequently edited and approved by Counsel of Grandparents. Second, in contextualizing our discussion of the role of racism in Indigenous health in Canada, we utilize a critical Indigenous lens to examine colonial policies and practices and their impacts on Indigenous health and well-being (Smylie, Kaplan-Myrth & McShane, 2009). This lens reflects our responsibility as Indigenous scholars to locate information about the health and well-being of our families, communities and Nations within the context of our past and the vision of our future; this approach also counters prevailing portrayals of Indigenous health that have pathologized Indigenous peoples as sick, disorganized and dysfunctional (O'Neal, Reading & Leader, 1998; Reading & Nowgesic, 2002).

Finally, keeping in mind that the indexed published literature systematically prioritizes non-Indigenous voices and perspectives (Smylie, 2014), we draw on the results of a systematic search of multiple databases of published literature using search terms designed to identify publications regarding Indigenous populations in Canada that addressed the interface of racism/discrimination and health/health care. The findings from this review primarily inform the second half of the paper, which focuses on current day assessment of and responses to racism within the context of Indigenous health and health care access. This literature is integrated and presented using the same critical Indigenous theoretical lens applied to the policy analysis in the first half of the paper.

With respect to our systematic literature search, our specific search terms and searched databases are listed in Appendix A. Identified abstracts were screened for relevance and full articles were retrieved if the article included a discussion of attitudinal or systemic racism (including colonization and colonial policies) as it impacted the health of Indigenous individuals or populations in Canada. Data abstraction included identifying the geographic location(s) and Indigenous population(s) included in the article, the type of study and study method, and key findings across the three areas of health determinants including racism as a determinant of health; health status/health status inequities and colonization; and health care use/access/barrier to access. We identified 64 articles from our original literature search and five additional articles drawing on the references of the original 64 articles. See Appendix A for a complete listing of retrieved articles.

#### **Textbox B: Defining Racism**

#### Defining racism

Paradies, Harris and Anderson (2008) broadly define racism as "avoidable and unfair actions that further disadvantage the disadvantaged or further advantage the advantaged" (p. 4). There are multiple mechanisms through which racism operates to perpetuate the uneven distribution of advantage and disadvantage, a brief description of some key forms of racism is provided below.

#### Systemic racism

Also known as structural or institutional racism, systemic racism is enacted through societal systems, structures and institutions in the form of "requirements, conditions, practices, policies or processes that maintain and reproduce avoidable and unfair inequalities across ethnic/racial groups" (Paradies et al., 2008). Systemic racism is not only enacted proactively in efforts that create racialized inequality, but also in the failure by those in power (e.g. policymakers, funders) to redress such inequalities (Reading, 2013). It is commonly manifested in social exclusion and isolation that limits or prevents political and economic participation, or access to and participation in other social systems such as education and health (Reading, 2013).

#### Interpersonal racism

Also known as relational racism, this is perhaps the most commonly understood form of racism and refers to acts of racism that occurs between people. This may include discriminatory treatment in employment or educational settings or in relational contact that occurs in day-to-day interactions (e.g. in stores, on public transportation, on the sidewalk), ranging in severity from being ignored, to poor treatment, to more overt and severe forms such as name-calling and physical or sexual violence (Reading, 2013). Interpersonal racism also includes 'racial microaggressions' which are defined as "brief and commonplace daily verbal, behavioral and environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults to the target person or group" (Sue et al, 2007).

#### Epistemic racism

Epistemic racism refers to the positioning of the knowledge of one racialized group as superior to another, it includes a judgment of not only which knowledge is considered valuable but is considered to be knowledge. In the context of Indigenous health, the imposition of western knowledge systems and particularly the use of western "science" to demonstrate the supposed inferiority of Indigenous peoples and Indigenous ways of knowing constitute acts of epistemic racism (Reading, 2013). The continued legacy of epistemic racism is reflected in the dominance of western biomedical knowledge and marginalization of Indigenous ways of knowing and practicing in the Canadian health care system.

#### Internalized racism

Internalized racism refers to the acceptance and internalization of negative, stereotypical beliefs, attitudes or ideologies about the inferiority of one's racial group (Paradies et al., 2008).

# Racism, Colonization And The Roots Of Indigenous Health Inequities

Colonization is recognized as a foundational determinant of Indigenous health globally (Cunningham, 2009; Mowbray, 2007), and the relationship between racism and colonization are inextricably intertwined as Reading (2013) notes that the use of race as a category of identity began with European colonization of other continents (p. 1). Despite the fact that race is a socially constructed category with no biological basis, it has been used for hundreds of years to argue for and promote hierarchies of supposed superiority and civility among "races" of people (Reading, 2013). The construction of different races, and more specifically the hierarchal organization of race to support white supremacy, was used as the basis for racist legislation such as the "Jim Crow" and blood quantum laws of the United States (US), the apartheid laws of South Africa, and the Indian Act of Canada. These legislations engendered massive human rights violations through varying means such as segregation, theft of lands, removal of children and restriction of economic and civic participation. Racism not only justified historic colonization but compounds its contemporary effects (Cunningham, 2009), contributing to, for example, the obstruction of Indigenous self-determination and failure to recognize treaty and land rights, the lack of access to services and resources, and over-surveillance by criminal justice and child welfare systems. The continued marginalization and criminalization experienced by Indigenous peoples and people of colour occurs in direct relationship to the continued societal and systematic privileging of white people in Canadian society. Textbox B offers definitions of racism informing our discussion paper that are drawn from both domestic and international literature addressing racism and Indigenous health (Paradies et al., 2008; Reading, 2013). While interpersonal racism is the most obvious form of racism, structural racism is argued to have the most significant role in driving health disparities among Indigenous peoples globally (Cunningham, 2009; Paradies et al., 2008).

### Telling Another Story: Indigenous Understandings Of Social Determinants Of Health

Social determinants of health approaches seek to understand not only the causes of health inequities, but the causes of the causes (Rose, as cited in Marmot, 2005), such as access to income security, employment, education, food and shelter (Smylie, 2009). The social determinants of health mark an important departure from strictly biomedical and health behaviour paradigms (Raphael, 2009), which can further stereotype and pathologize marginalized people by inferring that the health inequities they face are a matter of personal choice or poor genetics. The application of a social determinants of health lens in global public health has helped to illuminate the ways in which social and economic marginalization impacts health and well-being. For Indigenous peoples it allows for a linkage between histories, policies and practices that have fostered and sustained marginalization, which in turn has contributed to disproportionate rates of illness, disease, disability, infant mortality and premature death (King, Smith & Gracey, 2009).

In Canada, there have been significant contributions towards understanding the specific determinants

<sup>4</sup> Canada has a protracted history of racist policy practices including the enslavement of Indigenous and Black people, the Chinese Head Tax and Exclusion Act, and the use of the War Measures Act to intern Japanese Canadians; however, only the Indian Act remains an active piece of legislation.

of Indigenous peoples' health and well-being through Indigenous worldviews (Greenwood & de Leeuw, 2012; Loppie Reading & Wien, 2009; Reading, 2009; Smylie, 2009). These Indigenous conceptualizations of the social determinants of health emphasize the fundamental role of colonization, racism, social exclusion and a lack of self-determination in the alarming disparities in Indigenous and non-Indigenous peoples' health. For example, Loppie Reading & Wien (2009) specifically identify colonization, racism, social exclusion and the impact on Indigenous self-determination as "distal" determinants of health that inform both "intermediate" and "proximal" determinants of health. Intermediate determinants are described as including the availability and accessibility of health care and educational systems; community infrastructure, resources and capacity; cultural continuity; and environmental stewardship of land (p. 15-18). These intermediate determinants, in concert with distal determinants, inform the proximal determinants of Indigenous health which are those that directly "impact on physical, emotional, mental or spiritual health" (p. 5). The authors identify a range of proximal determinants including physical environments (including housing and infrastructure), health behaviours, education, employment, income and food security.

This framing of European colonization as a fundamental determinant of Indigenous health is not unique to Canada. In April 2007, an international delegation of Indigenous representatives from the Americas, Asia, Australia, New Zealand, and the Philippines met as part of the ongoing consultations linked to the World Health Organization's Commission on Social Determinants of Health. The proceedings from this meeting included the statement: "Everyone agrees that there is one critical social determinant of health, the effect of colonization" (Mowbray, 2007).

#### Textbox C: "It must be genetic" - Genetics and the race to justify racialized health disparities

Efforts to address racialized health disparities must include a critical analysis of the ways in which historical and contemporary approaches to health research and research in the area of "race" have contributed to problematic views of the causes of disproportionate illness and disease among racialized populations. From the global history of eugenics research (Nestel, 2012) to the persisting assumption that persons from the same racial group have similar genomes and share gene-based predispositions to common diseases such as diabetes, hypertension and cancer, the reductive genetic attribution of differences in health and well-being between racial groups has served to justify persisting racialized health inequities even though we know that there is greater heterogeneity of genes within racial based groupings than across them (Haynes & Smedley, 1999). This includes, for example, the continued use of the thrifty gene theory (Neel, 1962) to explain the extremely high occurrence of type 2 diabetes in Indigenous populations (as opposed to examining social determinants of health (food insecurity, poverty and the denigration of traditional food practices or environmental degradation) despite the fact that this theory has long since been recanted and proven highly problematic (Paradies, Montoya & Fullerton, 2007; Poudrier, 2007). While some diseases may be the result of kin-based genetic variants, many racebased groupings include persons who have no kin relation. Further, only a small proportion of the burden of common chronic diseases can be explained on the basis of a specific genetic variant (i.e. 5-10 percent of breast cancer) (National Cancer Institute, 2014).

An undue focus on genetics in explaining health disparities can effectively obscure meaningful attention to and action towards addressing disparities in the social determinants of health and the impact of structural racism in fostering and sustaining these disparities. Moreover, race-based approaches to identifying disease linked genes can serve to contribute towards problematic public health policies and practices with racialized populations (Muntaner, Nieto & O'Campo, 1996). For example, during the global H1N1 pandemic, Indigenous populations across a range of geographies including Canada, Australia and New Zealand, experienced disproportionate rates of hospitalization and experienced greater severity of symptoms in comparison to non-Indigenous populations (Mousseau, 2013). A theory of genetic susceptibility surfaced even though these Indigenous populations share no common ancestry (Zarychanski et al., 2010). What these populations do share is a common experience of colonization that has resulted in and sustained disparities in health status and the social determinants of health (Mousseau, 2013; Zarychanski et al., 2010) including substandard housing, overcrowding and a lack of running water, all of which serve to increase risk of transmission for respiratory viruses. In Canada, being Aboriginal was communicated to be a risk factor during the pandemic and Aboriginal peoples were prioritized for vaccine receipt during the 2009 outbreak (Driedger, Cooper, Jardine, Furgal & Bartlett, 2013; Rubenstein et al., 2011). However, in analyzing the impact of public health messaging to First Nations and Métis populations in Manitoba during the outbreak, Driedger et al. (2013) found that the failure to adequately explain how Aboriginal peoples came to be identified as high risk or their prioritization for vaccination resulted in confusion and mistrust; including fears that Aboriginal people were being used as "guinea pigs" for the H1N1 vaccine, and perpetuating experiences of stigmatization, vulnerability and discrimination already experienced by Aboriginal peoples as a result of colonial policies and practices. The authors emphasize the importance of accounting for the historic and ongoing impacts of colonization in public health strategies and communications with Aboriginal peoples, as well as the need for more detailed explanations for why particular groups are identified as at-risk. Moreover, they recommend increased specificity in identifying priority groups by attributes that increase risk (e.g. lower socioeconomic status, overcrowded housing) as opposed to ethnicity to decrease experiences stigmatization and discrimination.

Indigenous approaches to the social determinants of health also offer a significant contribution to health knowledge in centering holistic perspectives of health which may include consideration of the four aspects of self (body, heart, mind, spirit); the lifecycle; the importance of understanding our past, in the present for our future (Greenwood & de Leeuw, 2012; Loppie Reading & Wien, 2009; Smylie, 2009); and the understanding of ourselves in relationship to the land and our natural environment (Blakney, 2009). These considerations reflect and honour Indigenous worldviews and help to remind us of our relationships to our Ancestors and the little faces yet to come. They also remind us that the health disparities faced by Indigenous peoples must be understood in a broader context of the histories, policies and practices that have and continue to shape our life choices and chances; this includes employing a socioecological lens that recognizes the inextricable relationships between people and their environment (see for example: Reading, 2009; Reading & Wien, 2009; Willows, Hanley & Delormier, 2012). The importance of taking care to contextualize Indigenous peoples' health cannot be overstated since, as noted by Greenwood and de Leeuw (2012), a failure to do so may result in a presumption that the extremely poor health status and socioeconomic challenges faced by many Indigenous peoples is a matter only of physiological or biomedical failure (n.p.).

There are alarming disparities in health status, social determinants of health and access to health care experienced between Indigenous populations in comparison to non-Indigenous populations in Canada; these disparities cut across First Nations, Indian, Inuit, and Métis population groups and urban, rural and remote geography. Data limitations (discussed further on p. 55) mean that most available and cited statistics actually underestimate the degree of these disparities and that there are significant gaps in data, especially for urban, Métis, and non-Status populations. Despite these limitations, there is overwhelming evidence that all Indigenous populations in Canada experience a disproportionate burden of social challenges across the core social determinants of health (i.e. income, employment, education, housing, food security) compared to the general Canadian population (Smylie, 2009; Wilson et al., 2013). Detailing the exact disparities for specific Indigenous population groups in specific regions is an essential first step towards ensuring appropriate health policy and service responses and we encourage the reader to engage with and contribute to the growing literature in this area (Loppie-Reading & Wien, 2009; Smylie et al., 2011). In the following sections we will continue to explore colonization as a root determinant of Indigenous health by examining specific colonial policies and their health impacts.

# Canadian Policies And The Institutionalization Of Racism Against Indigenous Peoples

#### The Indian Act

"Canada is one of the only nations in the world that continues to use legislation to limit access to services and benefits for Aboriginal peoples on the basis of a descent criterion. This practice has served to create artificial distinctions among Aboriginal people, sometimes even within the same extended families, and serves mostly to exclude Aboriginal people who are not "registered Indians" from access to distinctly Aboriginal services and the power of self-determination, with no concern for how individuals define themselves" (Bourassa & Peach, 2009, p. 1)

The colonization of what is now known as Canada required at its core, racist beliefs about and practices towards Indigenous peoples. While racist treatment prior to confederacy included the enslavement of Indigenous peoples, the entrenchment and enactment of racism through policy occurred most intensely during the era of Confederation (Moss & Gardner O'Toole, 1987/91). The Gradual Civilization Act of 1857 and the Gradual Enfranchisement Act of 1869, served agendas of assimilation and control of "Indians," and the erosion of Indigenous land rights. These two pieces of legislation were consolidated in the Indian Act of 1876, which remains an active statute in Canada. The Indian Act is a race-based legislation that provides the federal government of Canada with the right to determine who can and cannot be an "Indian." This act includes stipulations for enfranchisement in which Indians could gain some of the same rights

as other British subjects, such as the right to vote,<sup>5</sup> but in doing so would lose their Indian status, ceasing to be recognized as Indians and revoking their treaty rights (Furi & Wherrett, 2003). In its earliest form, enfranchisement was constructed as a voluntary act. However, legislative amendments were made to effect automatic enfranchisement for any Indian who earned a university degree or became a doctor, lawyer or Christian minister (Furi & Wherrett, 2003). Military service received unique treatment under the enfranchisement provisions; those who joined the military were able to enfranchise without losing their Indian status (Elections Canada, 2007). Although a great many First Nations people fought in the First and Second World Wars on behalf of Canada, this did not exempt them from the effects of racist policy efforts. Until 1924 First World War veterans choosing to return to their reserve lost their right to vote (Elections Canada, 2007). Canada's practice of race-based legislation has had a lasting and enormous effect on Indigenous identity, health and well-being, creating painful divisions in families and communities and impairing the ability of many to access their Indigenous rights and cultures (Bourassa & Peach, 2009; Lawrence, 2004; Smylie, 2009).

In addition to entrenching government control of Indigenous identity, the Indian Act enabled the movement of First Nations peoples from their homelands onto "reserve lands" which were also controlled by the federal government on behalf of those they identified to be "Indian" (Smylie, 2009). This removal to reserve lands began a system of segregation that would become the template for apartheid in South Africa<sup>6</sup>. The reserve system shifted tremendous power into the hands of Indian agents who could govern the movement of Indians on and off reserve through a pass system (Coates, 2008). Removal to reserve lands had a devastating impact on Indigenous ways of knowing and being in relation to land, for example, the restriction of traditional hunting and gathering practices which were replaced by social welfare constructed to create reliance on government rations of European foods. The Indian Act included mechanisms to limit the economic and political participation of First Nations peoples, including stipulations that barred legal representation for Indians or gathering to discuss Indigenous affairs, and banned the use of mechanized farm equipment, the slaughter of livestock on-reserve for sustenance, and the sale of agricultural goods off-reserve (Coates, 2008; Harry, 2009).

The Indian Act was instrumental in undermining women's roles and status within First Nations societies, since it not only controlled "Indian" identity, but rooted it in male lineage: "[a]n Indian was defined as any male person of Indian blood reputed to belong to a particular band; any child of such a person; and any woman lawfully married to such a person" (Furi & Wherrett, 2003). The Act removed the real property rights of Indian women and regulated their status through blatantly sexist practices such that women who married non-Indian men (or non-status Indian men) lost their status as "Indians," as did their children. In contrast, status Indian men who married non-Indian women conferred their status onto their wives and children. The enactment of this legislation engrained sexism towards First Nations women in Canadian policy, according them a lower class of citizenship in relation to both non-Indigenous peoples and First Nations men.

Grandmother Mary Two-Axe Earley, a Kanien'kehá:ka woman from Kahnawake, was a strong activist in advocating for the rights of First Nations women who lost their Indian status by "marrying out." These

<sup>5</sup> Status Indians were finally granted the unconditional right to vote in federal elections in 1960 by Prime Minister John Diefenbaker.

<sup>6</sup> A South African delegation visited western Canada in 1902 to study the reserve pass system as a mechanism for social control; see Barron (1998) for further information on the pass system.

women not only faced eviction from reserves, subsequently resulting in separation from their families and communities, but could not even be buried on reserve with their ancestors (Brown, 2003). In Grandmother Mary's home reserve of Kahnawake, there were three graveyards, one for Protestants, one for Catholics and one for dogs (Brown, 2003). The installation of the Indian Act meant that dogs could be buried on-reserve while women who "married out" could not (Allan, 2013; Brown, 2003).

In 1985, following significant and prolonged activist and legal efforts by Aboriginal women, including Mary Two-Axe Earley, Sandra Lovelace and Jeanette Corbierre-Lavell, the federal government passed Bill C-31 which rescinded the "enfranchisement" provisions of the Indian Act and allowed for those who had lost their status to be re-instated (Daniels, 1998). The bill was intended to address gender inequality and ensure conformity of the Indian Act with the Canadian Charter of Rights and Freedoms by enacting a gender-neutral approach (Daniels, 1998). However, the removal of the patrilineal line of eligibility did not result in status Indian women possessing the same right as status Indian men to confer status onto their spouses and children. Instead, it situated status men in a similar position to status women under the old Indian Act; as a result, children of status women or men who married non-status or non-Indigenous individuals could not confer their status to their own children if they too married a non-status or non-Indigenous partner (also called the "second generation cut-off rule") (Daniels, 1998; National Aboriginal Law Section, Canadian Bar Association, 2010).

Notably, Bill C-31 also accorded Bands the power to determine their own membership and by-laws, such that those who re-gained status via Bill C-31 would not necessarily be recognized or "re-membered" by the Bands from which their families had originated. Band by-laws determine important issues including who can reside on-reserve (members and non-members), and benefits and protection accorded on reserve (for example, the decision to provide or deny health or educational benefits to non-member spouses and children of members living on reserve) (Furi & Wherrett, 2003), both of which can act as social determinants of health for Bill C-31 re-instatees, their children and grandchildren. While Bill C-31 was framed as a means to restore gender equity for First Nations women, it actually serves to speed the extinction of status Indians, as hundreds of thousands of descendants of current status Indians will be disqualified from status rights over the coming decades (Daniels, 1998). A reduction in status Indians serves the interests of the federal government in decreasing costs and obligations associated with its fiduciary duty to provide for those with status (Daniels, 1998). The gendered impact of colonial policies and practices on the lives of Indigenous women is further explored on page 15.

#### **Colonial Policies And The Métis**

The Métis peoples originated in the 17th century with the intermarriage of the early waves of European men (mainly French and Scottish) and First Nations women in the western provinces (Smylie, 2009). In the following two centuries the Métis nation grew substantially, birthing a distinct language (Michif) and culture, and occupying a key economic role in the fur trade (Smylie, 2009). Despite significant efforts to advocate for formal recognition of their distinct identity and of their rights as Aboriginal peoples, the Métis peoples have faced colonial violence, exclusion and erasure. This includes police and military violence intended to quash the development of independence and demand for recognition of the Métis nation that culminated in the bloody battle at Batoche in 1885, and the linked legislative violence (including the

Indian Act) which Desmarais (2013) argues legally erased the Indigeneity of the Métis peoples.

The persecution of the Métis leading up to and following the battle of Batoche (Saskatchewan), led many to flee their homelands, change their names and suppress their identity (Smylie, 2009). Moreover, the failure of the Canadian government, the Hudson Bay Company and subsequently the province of Manitoba government to recognize Métis land claims and the imposed scrip system of land grants meant that most fell to extreme poverty, with landlessness leaving many to live in what Lawrence (2004) refers to "semi-squatting existence on marginal lands" or face the poverty, racism and violence of Native urban ghettos (p. 95). While on one hand they have faced legislative efforts to obscure their Indigeneity, the Métis have been continuously subjected to the assimilationist and exclusionary policies and practices of the Canadian government towards Aboriginal peoples, including land dispossession, political persecution, economic exclusion, residential schooling, the Sixties Scoop<sup>7</sup> and ongoing invasive child welfare intervention (Desmarais, 2013; Smylie, 2009).

The Métis were not formally recognized as Aboriginal peoples within Canadian policy until the passing of the Charter of Rights and Freedoms in 1982. The formal recognition of the Métis did not, however, bring forward any efforts on the part of the federal government to restore a land base for the Métis, or to acknowledge a fiduciary obligation to the Métis peoples (Lawrence, 2004). The lasting effects of land dispossession, exclusion, racism and race-based persecution are reflected in the gross disparities in health status and social determinants of health that the Métis peoples suffer alongside First Nations and Inuit peoples. The use of state imposed definitions of the Indigenous identity, particularly via the Indian Act, means that Métis peoples and non-Status First Nations people are excluded from many Aboriginal-specific health entitlements and services, including the Non-Insured Health Benefits (NIHB) program, further exacerbating health disparities both in terms of access and outcomes (Bent, Havelock & Haworth-Brockman, 2007; Bourassa & Peach, 2009; Ghosh & Spitzer, 2014; Haworth-Brockman, Bent & Havelock, 2009; Wilson et al., 2013).

#### Colonial Policy And Its Impacts On Inuit Health And Well-Being

Inuit peoples traditionally resided in the territories above the treeline on the lands presently known as Canada, and compose part of the broader circumpolar Inuit population with traditional lands spanning Alaska, Greenland and Russia (Smylie, 2009; Smylie, 2001). Canada now recognizes four Inuit regions settled through extensive land claims, including Inuvialuit, Nunavut, Nunatsiavut and Nunavik (Inuit Tapiriit Kanatami, n.d.). While the presence of the federal government on Inuit territories only began in 1903, its colonial practices have caused tremendous damage to traditional Inuit knowledge and practices, health and well-being and relationship to the land (Moller, 2005). Since the 1950s and 60s, Inuit peoples have experienced a rapid transformation of their lifeways as a result of a federal program of forced relocation to remote permanent settlements, compounded in some communities by the mass slaughter of Inuit

<sup>7</sup> The Sixties Scoop refers to the mass apprehension of Indigenous children into the care of child welfare that began in the 1950s and peaked during the 1960s. Further discussion of the Sixties Scoop may be found on page 13.

<sup>8</sup> Contact between the Inuit and Europeans dates as far back as the 11th century (Dickason, 1992).

sled dogs, <sup>9</sup> all of which dramatically affected their previously nomadic ways of life (Smylie, 2009). Forced relocation and settlement, the restriction of hunting and gathering practices, and the transformation of social and family structures through the introduction of European and Christian norms and values and the advent of residential schools have all contributed to contemporary disparities in the social determinants of health and health outcomes of Inuit peoples. This includes the construction of poverty, food insecurity and decreased consumption of country foods associated with hunting and fishing quotas, the introduction of drugs and alcohol, and elevated rates of violence associated with transition to settlement life and the rupture of intergenerational transmission of Inuit language, knowledge and practices (Healey & Meadows, 2008; Inuit Tapiriit Kanatami, 2007; Pauktuutit, 2006, 2010).

Inuit peoples face some of the most extreme health disparities in the Canada. These disparities and the colonial violence and marginalization that seeded them are viscerally reflected in the rates of suicide which are approximately 11 times the national average among the Inuit generally (Pauktuutit, 2009), and as high as 40 times the national rate among young Inuit men specifically (Hicks, 2006, 2007). Moreover, Inuit peoples face epidemic levels of illness and disease, such as tuberculosis which occurs in the Inuit population at a rate that is 185 times higher than the non-Indigenous population (Demmer, 2011). Cancer is the second leading cause of death among Inuit peoples (Cameron, 2011), who have the highest rates of colorectal and lung cancer in the country (Government of Nunavut, 2008).

#### Assimilation, Cultural Genocide And The Rippling Effect On Indigenous Identity, Health And Well-Being: Residential Schools, The Sixties Scoop And Contemporary Child Welfare

Racist beliefs about Indigenous peoples underlie the historical and ongoing overrepresentation of Indigenous children in the care of child welfare agencies. Indigenous children were historically removed from the care of their families and communities to residential schools, a system of institutionalized education and care that lasted well over 100 years¹⁰ and aimed to assimilate Indigenous children into European and Christian cultural norms, beliefs and practices. The residential school system was intended to "kill the Indian in the child" and many, including former Prime Minister of Canada Paul Martin,¹¹ have since recognized the implementation of the schools as an act of cultural genocide (Miller, 1996; Neu, 2000) which has had rippling, intergenerational effects not on only survivors, but their children, grandchildren and great-grandchildren. The sexual, emotional, physical, mental, spiritual and cultural abuse experienced by generations of Indigenous children who survived residential schools has resulted in profound impacts on the physical, emotional, spiritual, and mental health of survivors, their families and communities. This does not acknowledge the effects of the tremendous loss experienced by those families and communities whose children never returned, whose precious lives did not survive the horrors of these schools.

<sup>9</sup> While the slaughter of Inuit sled dogs has long been denied by the federal government and the RCMP, the province of Quebec acknowledged and offered compensation of \$3 million for the slaughter of sled dogs to the people of Nunavik in 2011 (Brennan, 2012; "Premier Charest's apology for dog killings", 2011-2012).

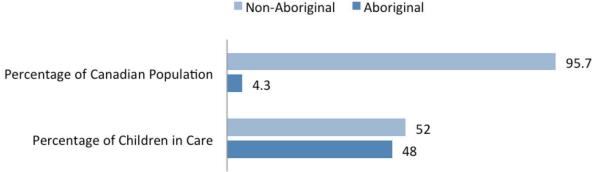
<sup>10</sup> The last residential school in Canada closed in 1996 on Gordon's First Nation in Saskatchewan; It was also the longest running residential school in Canada operating for 107 years (George Gordon First Nation, 2014).

<sup>11</sup> Former Prime Minister Paul Martin referred to residential schools as using education for cultural genocide during hearings of the Truth and Reconciliation Commission ("Paul Martin accuses residential schools of cultural genocide", 2013).

As concerns about poor conditions and widespread abuses surfaced, support for residential schools began to wane in the late 1940s and into the 1950s. This gave way to a new wave of assimilationist practice taken up by child welfare agencies and the social workers they employed. Beginning in the 1950s and peaking in the 1960s, there was an enormous influx of Indigenous children taken into the care of child welfare agencies which is now known as the Sixties Scoop (Sinclair, 2004). This era of mass apprehension meant that in the matter of a decade approximately one in three Indigenous children was apprehended from the care of their families and communities (Fournier & Crey, 1997; Sinclair 2007). By 1970, Indigenous children accounted for between 30 and 40 percent of children in the care, an astounding and alarming number since Indigenous peoples accounted for less than 4 percent of the national population at that time (Fournier & Crey, 1997). The vast majority of these children were adopted into non-Indigenous homes both inside and outside of Canada (Fanshel, 1972; Timpson, 1995; Fournier & Crey, 1997; Sinclair, 2007; York, 1992). The removal of children from their homes and the impact of cross-cultural adoption not only had damaging effects on the identity and well-being of adoptees, but on the families from whom they were taken (Carriere, 2005; Sinclair, 2007; Alston-O'Connor, 2010).

Overrepresentation of Indigenous children in child welfare is not a vestige of the past, but in fact remains an urgent and ongoing challenge facing Indigenous communities across Canada. While the most recent Statistics Canada population estimates suggest that Aboriginal people accounts for slightly more than 48 percent of the general Canadian population, Aboriginal children represent 48 percent of children in care (Figure 1 (Statistics Canada, 2013a)). The number of Aboriginal children in care is even higher in some provinces, including Manitoba, British Columbia and Saskatchewan, with the latter seeing First Nations and Métis children account for approximately 80 percent of children in care (Sinclair & Grekul, 2012). A recent population based study in Hamilton, Ontario, found that 40 percent of self-identified First Nations adults had experienced involvement of a child protection agency in their own personal care as a child and 34.5 percent had experienced involvement of a child protection agency in the care of their own children. Of those adults reporting child protection agency involvement, 49 percent felt that it had a negative effect on their overall health and well-being (Smylie et al., 2011). Participants in this study also identified dislocation from traditional lands (29 percent) and residential school attendance by a family member (34 percent) as having negative impacts on their health and well-being (Smylie et al., 2011).

Figure 1. Aboriginal Children in the Care of Child Welfare (Statistics Canada, 2013a)



The rupture of identity, family and community perpetrated through residential schools and the Sixties Scoop has had lasting and intergenerational effects, substantially interfering with or completely impeding the transmission of values, beliefs and practices, including parenting practices. The ways in which intergenerational trauma and the damage to Indigenous identity resulting from colonization founded on racist ideologies have affected the health and well-being of Indigenous peoples has been heavily documented (Allan, 2013; Brave Heart, 1998; Desmarais, 2013; Menzies, 2008; Smith, Varcoe & Edwards, 2005; Wesley-Esquimaux & Smolewski, 2004). For example, the abovementioned study of self-identified First Nations adults in Hamilton, Ontario, found a population prevalence of post-traumatic stress disorder of 34 percent using the primary care PTSD screen (Firestone, 2013).

It could be argued that there is a tendency to frame trauma as historical (for example, examining intergenerational or race-based trauma as resulting from residential schooling) and not necessarily recognizing the ongoing contemporary trauma generated by present-day child welfare practices. Tait, Henry and Loewen Walker (2013) identify child welfare as a social determinant of health for First Nations and Métis children, an assertion supported by research findings emerging from the Cedar Project in British Columbia that found among their sample of Indigenous youth ages 14-30 years old involvement with child welfare was associated with suicidal ideation, having at least one parent who attended residential school, and having ever been on the street for three or more nights (Clarkson, 2009). For participants using injection drugs, being removed from their parents was associated with injecting with used needles, self-harming and overdose (Clarkson, 2009).

## The Gendered Impact Of Colonial Racism: Indigenous Women's Health And Well-Being

Indigenous women in Canada carry a disproportionate burden of ill-health and disease, including higher rates of hypertension, heart disease, diabetes, cervical and gallbladder cancer, HIV/AIDS, substance abuse, mental illness and suicide (Bourassa, McKay-McNabb & Hampton, 2005; Dion Stout et al., 2001; Gatali & Archibald, 2003; Ghosh & Gomes, 2012; Grace, 2003; Kirmayer et al., 2007). In addition to higher infant mortality rates and shorter life expectancies, Indigenous women are not only more likely to experience chronic disease in comparison to our non-Indigenous counterparts, but also in comparison to Indigenous men (Bourassa et al., 2005). An intersectional approach (Crenshaw, 1989) is important in attempting to understand and contextualize Indigenous women's health as it compels attention to the ways in which colonialism, racism and sexism intersect and interact in shaping social determinants of health, health status and health care access (Bourassa et al., 2005).

Indigenous women face severe marginalization in Canadian society, reflected in the increased likelihood of living in poverty, experiencing under-housing or homelessness, under or unemployment, violence and incarceration (Allan & Sakamoto, 2014; National Association of Friendship Centres, 2012; Statistics Canada, 2013b; Wesley, 2012). While our children are taken into the care of the child welfare system in mass numbers, our women are similarly being removed into the hands of the state through mass incarceration. Indigenous women account for one third of all women in federal prisons, reflecting a 90 percent increase in the number of Indigenous women in federal incarceration over the past ten years (Wesley, 2012). Amnesty International (2004) has described Indigenous women in Canada as being simultaneously over-policed

and under-protected: more likely to be arrested for crimes in which white people would not be likely to receive the same treatment, and less likely to receive support in response to their safety needs and concerns.

The epidemic of violence against Indigenous women profoundly threatens our health and subsequently that of our families. Aborigional women experience higher rates than non-Aborigional women of both spousal and non-spousal violence, and report more severe forms of violence including being sexually assaulted, choked, beaten, or threatened with a knife or gun (Mathyssen, 2011; Statistics Canada, 2013b). Aborigional women in Canada are more likely to be victims of homicide and unlike their non-Aborigional counterparts (Statistics Canada, 2013b); they are as likely to be murdered by a stranger or acquaintance as they are by an intimate partner (NWAC, 2010). The severity of violence against and apathy towards Aborigional women is most painfully demonstrated in the mass numbers of missing and murdered Indigenous girls and women in Canada, an issue which has garnered failed calls for a national inquiry by international bodies such as the United Nations Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and Amnesty International. The racism embodied in the steady disappearance and deaths of our sisters, daughters, mothers, aunties, grandmothers, nieces and friends, is compounded by the failure of the Canadian state to adequately investigate and address the epidemic of violence against Indigenous women.

"If there is something that is even more shocking than the violence itself, it is the silence within which this violence is allowed to continue. It is that silence which is perhaps the greatest shame of all. It is the silence of those of us in the majority who chose to turn a blind eye to this violence—cases of missing Aboriginal daughters and mothers which never make the headlines; epidemics of suicide which don't elicit an outpouring of concern and outrage from the non-Aboriginal community. It is this silence which is complicit in allowing the situation to continue. It is this silence which sends the message that we don't care, that we don't want to care, that we won't pull all the stops to say 'enough.'" (Mathyssen, 2011)

In accounting for the intersections of colonization, racism and sexism in understanding the health and well-being of Indigenous women, it is critical to attend to how both historic and ongoing colonial policies and practices work to shape our social determinants of health and health outcomes. This would mean, for example, examining contemporary rates of infant mortality, maternal morbidity and mortality, and overall poorer health of Indigenous women, in the context of the history of forced sterilization (Grekul, Krahn & Odynak, 2004), the undermining of traditional midwifery, the mandatory medical evacuation for pregnant Indigenous women in remote communities, and the historic and ongoing racism evident in the disproportionate rates of violence and child welfare intervention experienced by Indigenous women and their families.

Indeed, the historic and ongoing invasive role of child welfare in our communities has direct implications for access to health care and health-related decision-making. Denison, Varcoe & Browne (2014) found that while fear of child welfare apprehension did not affect whether Indigenous women would access health care for their children, fear of apprehension in combination with experiences of racism, discrimination and prejudice did serve as deterrence for accessing health care for their own health. Moreover, the Society of Obstetricians and Gynaecologists of Canada recently released a newly revised set of clinical practice

guidelines for health professionals working with First Nations, Inuit and Métis highlights which notes in its clinical tips that some women may choose to terminate their pregnancy in fear that if carried to term their child would be apprehended by the child welfare system (p. S31, Wilson et al., 2013). Addressing the alarming health disparities and barriers to health care experienced by Indigenous women and supporting our right to reproductive justice foundationally requires understanding the historical and contemporary racist policies and practices that shape our lives, health care access, health and well-being.

"Racism, the oppression of Indigenous people, is built into the fabric of Canada. It is the foundation of the Indian Act and has become the justification for the legacy of residential school and for the theft of culture, lands and language. Colonization has perpetrated racism to become personal among Indigenous women, and as a result, some have used self-hatred to deny their children their cultural root. Colonial laws and policies have created a structure to erode the practice of holistic preventative well-being among Indigenous people across Canada. Indigenous women speak of the way in which the hurt of racism has led to the oppression of our children, and children's health. The experience of racism then turns targets of oppression into perpetrators. Our once circle of balance has now become fragmented with a colonized burden of racism: post-traumatic stress, loss of language, alcohol abuse, parenting issues, and the lack of well-being. Today, the Elders/wisdom keepers are sending out the message to reverse the circle and once again recall our voice as Indigenous women and renew our whole circle of life as it once was and can still be. Nia:wen." *Grandmother Jan Kahehti:io Longboat, Well Living House Grandparents Counsel* 

# What We Know About The Magnitude Of Racism Experienced By Indigenous Peoples In Canada And Its Impacts On Health, Well-Being And Access To Health Services

In Canada, there is a range of survey data documenting the experiences of racial discrimination of Indigenous people (e.g. Regional Health Survey (RHS), Aboriginal Peoples Survey (APS), Urban Aboriginal Peoples Study (UAPS), Toronto Aboriginal Research Project (TARP), and the Our Health Counts (OHC) study) and a small but growing body of research focused on delineating the relationship between racism and Indigenous health and health care access. In this section, we provide a brief overview of existing information documenting the burden of racism experienced by Indigenous peoples followed by a synopsis of what is known about the impacts of racism on Indigenous health and well-being.

It is important for the reader to keep in mind that the interpretation of data regarding self-reported experiences of racism is extremely complex and that under-reporting has been commonly reported among African and Latino American populations (Krieger et al., 2005). With respect to Indigenous populations in Canada, we know from the census that there is fluidity to Indigenous self-identification that is particularly marked for certain subpopulations, including the Métis. There is empirical evidence that masking of Indigenous identity is contextually dependent and linked to the perceived attitudinal and systemic racism of the context in which questions of identity are being asked (Anderson, Smylie, Anderson, Sinclair & Crengle, 2006; Richardson, 2006; Yoshioka, 2006). We also know that denial or non-acknowledgement of

racism has been documented among African Americans living in an environment where day-to-day racist interactions have been observed as the norm (Caughy, O'Campo & Muntaner, 2004). This masking of identity and/or non-acknowledgement of racism could be interpreted as adaptive responses to chronically racist environments. Given this, it follows that there will be a predictable under-reporting of perceived experiences of racism and that the size of this under-reporting will be linked to who is asking the question, how they are asking it, and the context in which the question it is being asked. Textbox D further details current efforts and measures available to assess the magnitude and impacts of racism.

### A Snapshot Of Available Information Regarding Indigenous Peoples' Experiences Of Racism In Canada

The Urban Aboriginal Peoples Study (UAPS) drew on an income stratified convenience sample of Aboriginal people across 11 Canadian cities. Non-Aboriginal participants from these cities were also interviewed regarding their attitudes and knowledge about Indigenous people in Canada. Of the Aboriginal participants, 43 percent reported poor treatment as a result of racism and discrimination, and 18 percent reported negative experiences of racism and discrimination resulting in shame, lower self-esteem or self-confidence, or the hiding of one's Aboriginal identity (Environics, 2010). Among non-Aboriginal participants, 39 percent believed that Indigenous peoples experienced discrimination often, and additional 44 percent believed that Aboriginal peoples experienced discrimination sometimes (Environics, 2010). The reported rate of racism was similar to that of a 2006 national telephone survey of Inuit, Métis and First Nations peoples living off-reserve commissioned by Aboriginal Affairs and Northern Development Canada<sup>12</sup> (AANDC) to examine key issues and concerns and awareness and perceptions of government programs and services. Of participants in this AANDC survey, 42 percent reported experiencing racism in the past two years, 74 percent of which was enacted by non-Indigenous people (EKOS, 2006).

At the provincial level in Ontario, the Urban Aboriginal Task Force (UATF) used a mixed-methods approach involving a convenience sample survey, key informant interviews, life histories, focus groups and plenary discussions to engage Aboriginal peoples across five Ontario cities. In this study 78 percent of participants identified racism as a problem for urban Aboriginal peoples (McCaskill & FitzMaurice, 2007). The UATF Final Report describes the racism faced by Aboriginal peoples in urban areas as widespread and systemic, impacting access to housing and employment, interactions with police and school systems, and treatment in public spaces like restaurants, shopping malls and buses (McCaskill & FitzMaurice, 2007).

The Toronto Aboriginal Research Project (TARP) collected information using a convenience sample community survey of 623 self-identified Aboriginal individuals in Toronto/GTA and in-person interviews with 436 Aboriginal key respondents (McCaskill, FitzMaurice & Cidro, 2011). This study also identified racism and discrimination as an area of concern, most severely felt in terms of encounters with the justice system, as well as in housing and employment. Interestingly, there were surprisingly similar numbers of participants who reported experiences of (48 percent) and concerns about racism (43 percent), as those who did not (41percent reported no experiences of racism, and 37 percent reported that racism was not a concern). While rates of experiences of racism varied among sub-samples (e.g. men, women, elders/seniors, youth, Two-Spirit, middle class), youth were more likely to report experiencing internalized racism.

<sup>12</sup> Aboriginal Affairs and Northern Development Canada was then known as Indian and Northern Affairs Canada (INAC)

The Our Health Counts (OHC) study of First Nations Adults and Children in Hamilton, Ontario, used respondent driven sampling to achieve population based estimates and found that more than half of participants reported having experienced unfair treatment as a result of racism, while another 40 percent reported experiencing a racially/ethnically motivated verbal attack (35 percent) or physical attack (15 percent) (Smylie et al., 2011). Racism was also reported in relation to community violence; among the 58 percent of participants reporting the presence of any kind of violence in the community, 67 percent reported violence related to racism and discrimination while 81 percent reported the presence of lateral violence.<sup>13</sup>

The First Nations Regional Longitudinal Health Survey (RHS) is a national health survey developed by and for on-reserve First Nations and uses a population based sampling method. In the 2002-2003 RHS 39 percent of participants reported experiencing racism, with experiences of racism more likely to be reported by those with a completed high school education, those employed for 15 hours or more a week, and those with a disability (First Nations Centre, 2005). Findings in the 2008-2009 study indicated a slight reduction in reported racism (33 percent); reported racism data was not stratified by education, employment or disability in the RHS 2008-2009 National Report (FNIGC, 2012).

Finally, in a study examining experiences of racism among Aboriginal university students in Edmonton, Alberta, 80 percent of participants reported experiencing racism in their lifetime, with two-thirds experiencing high levels of racism (Currie et al., 2012a). This study utilized an in-person survey with a small convenience sample (n=60) of Aboriginal university students. The survey included the Experiences of Discrimination scale (Krieger et al., 2005) and compared its findings to those from the United for Health study in the US which used the same tool with a sample of Latino and African American people. The researchers found that the lifetime experiences of discrimination for Aboriginal university students were 2-3 times that of African Americans and Latinos in the US. Further, the researchers suggest that the students' reactions to racism were indicative of racial battle fatigue (Smith, Allen & Danley, 2007), described as the depletion of mental and physical resources due to the constant engagement of stress response systems to cope with ongoing discrimination (Currie et al., 2012a; Smith, Allen & Danley, 2007). Pointing to the growing body of research in the US and Australia that identifies racism as a chronic stressor implicated in the health of African Americans and Indigenous Australians, the researchers argue for increased research attention to examining the contributions of racism to the persistent health disparities experienced by Indigenous peoples in Canada.

Racism has undeniably had a negative impact on Indigenous identity (McCaskill & FitzMaurice, 2007), with one of the most painful outcomes reflected in the racism experienced among Indigenous peoples which is sometimes referred to as intra-group racism, internal racism or lateral violence. Data from both the UATF and the TARP studies identify racism between Indigenous people as a serious concern (83 percent and 30 percent respectively), which is echoed by the number of OHC study participants reporting the presence of lateral violence in their community (81 percent). Understanding and addressing the impact of intra-group racism on individual and community health and well-being of Indigenous peoples is an important area for future research and anti-racism efforts. However, Paradies et al. (2008) point to the challenges inherent to the concept of intra-group racism in its "potential to reinforce 'victim-blaming'

<sup>13</sup> Lateral violence may be described as oppressive behaviours and actions enacted by members of marginalized communities toward one another, replicating and resulting from the oppressive behaviors and actions they have experienced from dominant groups (NWAC, n.d.; Goodleaf & Gabriel, 2009).

discourses that characterise racism as an Indigenous 'problem' rather than recognising it as a consequence of systemic racism within non-Indigenous society" (p. 13).

### **Understanding The Impacts Of Racism And Discrimination On Indigenous Health And Well-Being**

At present, the data addressing racial discrimination against Indigenous peoples in Canada and its effects on health is limited and piecemeal, utilizing cross-sectional samples that cannot address issues such as exposure and lag time (e.g. examining exposure to discrimination and the development of chronic diseases that develop over time) (Williams & Mohammed, 2009). With the exception of the RHS, First Nations people living on-reserve are for the most part excluded from the pre-2011 census based surveys administered by Statistics Canada, including the Canadian Community Health Survey (CCHS). These census based surveys almost certainly under-sample socio-economically disadvantaged Indigenous people in urban areas, for example those who are homeless or moving frequently. The recent Our Health Counts study has produced a population based socio-demographic profile of self-identified First Nations people living in the city of Hamilton that strongly supports this hypothesis (Smylie et al., 2011; Firestone, 2013, 2014). The CCHS also has an inadequate Indigenous sample size to produce meaningful sub-provincial/territorial level analysis disaggregated by Aboriginal population group (i.e. First Nations, Inuit and Métis). While this pre-2011 situation is troublesome with respect to the quality of population based social demographics and health information, it is getting worse, since in the 2011 census the Indigenous identity question was removed and instead placed on the linked voluntary National Household Survey.

In addition to the CCHS based on the 2006 census sample, there have been multiple studies examining the experiences of urban Indigenous people (Currie et al., 2012b; Environics, 2010; McCaskill & FitzMaurice, 2007; McCaskill, FitzMaurice & Cidro, 2011; Smylie et al., 2011). This attention to urban Indigenous peoples' experiences may also be reflective of the increased contact with non-Indigenous peoples (FNIGC, 2012) who may have limited exposure to or understanding of Indigenous peoples and the historical and contemporary social, political, economic and environmental contexts of our lives (Environics, 2010).

Relatively few studies have utilized standardized instruments to measure discrimination or directly linked experiences of racial discrimination to health and well-being (Smylie et al., 2011), although recently published research indicates that this trend is shifting (see for example, Currie et al., 2012a, 2012b; Bombay, Matheson & Anisman, 2010, 2014). Despite the limitations described above, the body of research knowledge addressing the relationship between racism and Indigenous health and health care access in Canada is slowly but steadily growing. With respect to the perceived link between experiences of racism and health and well-being more generally for example, one in five participants in the OHC First Nations Hamilton study believed that racism affected their health and well-being (Smylie et al., 2011).

Using data from the 2003 CCHS, Veenstra also (2009) argues that racialized health disparities are demonstrative of the impact of racism on the health and well-being of Indigenous peoples and people of colour in Canada. Specifically, Veenstra examined the relationship between racialization and health, focusing on self-rated health, diabetes and high blood pressure among nine of the "racial" groups included in the CCHS – Aboriginal, Aboriginal/White, Black, Chinese, Filipino, Latin American, South Asian and

White (reference group)<sup>14</sup> and exploring potential impact of socioeconomic status and residential locale. Significant difference in health risks in comparison to the White reference group were identified for a number of racialized groups. Respondents with Aboriginal or Aboriginal/White identifications reported some of the highest risks for diabetes and fair/poor self-rated health in the sample and these risks persisted in models that included SES and residential locale, although SES was uniquely implicated as an explanatory factor for Aboriginal and Aboriginal/White respondents. Residential locale had no explanatory power for the health disparities experienced by any of the nine groups. Veenstra (2009) highlights the unexplained health disparities experienced by racialized groups in Canada as evidence of the "wear and tear of experiences of racism and discrimination in regular encounters with societal institutions and in everyday life" (p. 542), advocating for further research in this area. This call has been echoed Lamont (2009), who has highlighted the need to better understand social meaning and cultural structures as factors which may mediate resilient responses to racism by affected groups.

In the first half of this paper, colonial policies and practices that enforced the multi-generational disruption of Indigenous families and the physical, mental, emotional, and cultural abuse of Indigenous peoples, including residential schools, child apprehension policies, and forced relocations were clearly linked to adverse and multigenerational mental health consequences for Indigenous people in Canada. The extreme burden of Post Traumatic Stress Disorder (PTSD), 15 suicide and other mental health conditions that is increasingly being documented across diverse Indigenous communities in Canada (Currie et al, 2012b; Hicks, 2006, 2007; Kirmayer, Brass & Tait, 2000; Moniruzzaman et al., 2009; Pauktuutit, 2009) can thus be considered an impact of systemic racism against Indigenous peoples in the form of past and current colonial policies and their implementation. The persisting, intergenerational impact of trauma in the lives of Indigenous peoples as a result of colonization has received significant scholarly attention both within Canada and internationally (Bombay, Matheson & Anisman, 2011, 2014; Brasfield, 2001; Brokenleg, 2012; Brave Heart, 1998; Brave Heart & DeBruyn, 1998; Duran & Duran, 1995; Duran, Duran, Brave Heart & Yellowhorse-Davis, 1998; Evans-Campbell, 2008; Gone, 2013; Mohatt, Thompson, Thai & Tebes, 2014; Walters & Simoni, 2002; Wesley-Esquimaux & Smolewski, 2004; Whitbeck, Adams, Hoyt & Chen, 2004).

Recent research by Currie et al. (2012b) examined the relationship between racial discrimination, PTSD and problem gambling among Aboriginal people in Edmonton, Alberta. Guided by an Aboriginal Community Advisory Council, the study engaged a community-based convenience sample of 371 self-identified Inuit, Métis, First Nations or Aboriginal adults recruited through the use posters placed in Aboriginal organization, non-Aboriginal specific service organizations (i.e. organizations offering services such as childcare, employment, housing, education, etc.) and general public spaces (i.e. shopping malls, grocery stores). The study modified the Experiences of Discrimination (EOD) scale (Krieger et al., 2005) to shift from asking about lifetime experiences of discrimination, to experiences within the past twelve months. <sup>16</sup> Of the more than 80 percent of participants reporting past year experiences of racism, more

<sup>14</sup> Southeast Asian, Arab, West Asian, Japanese and Korean participants were excluded from the analysis due to their small representation in the multivariate analysis.

<sup>15</sup> In the OHC study with First Nations adults in Hamilton, Ontario, 34 percent of participants screened positively for PTSD utilizing the Primary Care PTSD (PC-PTSD) Screen developed by Prins et al. (2003); for further description of the findings, see Firestone (2013).

<sup>16</sup> This modification was based on a precursor study with Aboriginal university students which found that their life experiences of discrimination was 2-3 times that of Latinos and African Americans in the US (Currie et al., 2012a), as such this modification was used to account for data variability.

than half reported high levels of racism. The authors underscore the burden of racism experienced by participants in juxtaposition to existing US data, noting that the frequency and number of situations in which participants had experienced racism in the past year exceeded the lifetime rates reported by African American and Latino Americans using the same instrument (Currie et al., 2012a; Krieger et al., 2005). PTSD symptomology was measured using the PTSD Check List (PCL) Civilian version (Weathers et al., 1991), while problem gambling was measured using the Problem Gambling Severity Index (PGSI) (Ferris & Wynne, 2001). PGSI scores of 1-2 are considered low risk, 3-7 medium risk, and > 8 high risk. The mean score in this study was 3.0 (SD 4.9).

The researchers found a graded association between experiences of racial discrimination and problems gambling. The fully adjusted model examining the association of racial discrimination and problem gambling showed a statistically significant increase of 0.26 (CI: 0.05, 0.48) in the PGSI score for each additional situation in which racial discrimination was experienced in the past 12 months. Past year experiences of racial discrimination were statistically significantly associated with both PTSD and problem gambling to escape. In these analyses, the researchers utilized a bootstrapped linear regression adjusting for socio-demographic covariates, gambling frequency and the number of kinds of gambling activities undertaken in the past year (i.e. bingo, lottery tickets, video lottery terminals) to replicate the findings of Stewart and Zack (2008) which linked gambling to escape negative affect with problem gambling regardless of variations in levels or frequency of gambling. Second, to determine whether experiences of racial discrimination were associated with an increased likelihood of gambling to escape, the researchers employed a bootstrapped logistic regression adjusting for socio-demographic covariates. Subsequent mediation analysis, with PTSD included as a mediator in the theorized causal pathway linking experiences of racial discrimination to gambling to escape, showed that PTSD symptoms partially explained the association between experiences of racial discrimination and gambling to escape.

The findings of the study suggest that gambling may be a response that some Aboriginal adults use to escape the negative effects of racial discrimination. Citing past research that has established a temporal relationship between discrimination and the development of substance addiction among minority groups, the researchers recommend future research examining the role of racial discrimination in the disproportionate burden of substance abuse issues experienced by Aboriginal peoples. Future research utilizing a longitudinal cohort approach would also contribute to a deeper understanding of the complexity of the relationship between experiences of racial discrimination, PTSD and problem gambling (or substance-based addictions). The authors suggest that their findings could be applied to support efforts in urban centres to reduce racism towards Aboriginal peoples and to enhance services to assist Aboriginal peoples in dealing with the impact of racism.

Bombay, Matheson & Anisman (2010) examined the role of identity in the relationship between perceived discrimination and depressive symptoms among First Nations peoples from across Canada<sup>17</sup> utilizing the Perceived Ethnic Discrimination Scale<sup>18</sup> (Contrada et al., 2001), the Beck Depression Inventory (Beck & Beck, 1972) and the Social Identity Scale (Cameron, 2004). An overwhelming 99 percent of participants reported

<sup>17</sup> This study included 220 participants from across Canada (Ontario, British Columbia, Saskatchewan, Alberta, Quebec, New Brunswick, Manitoba, Nova Scotia, Newfoundland and Yukon) who participated either online our through mail survey.

<sup>18</sup> After piloting the tool with Aboriginal adults in Ottawa, Ontario, the researchers adjusted the instrument to add one Aboriginal-specific question based ("How often has it been suggested that because you are Aboriginal you must drink or use drugs?").

experiencing discrimination in the past twelve months. This study drew on a convenience sample of 220 participants form across Canada who participated either online or through mail survey; participants were recruited through emails sent to Aboriginal organizations and posters placed in Aboriginal community centres inviting Aboriginal adults<sup>19</sup> aged 18 years or older to participate in a study about Aboriginal peoples' well-being in Canada. The majority of participants utilized the online survey and the authors note that their study participants had higher levels of education and income in comparison to the general Aboriginal population in Canada mirroring data from national Canadian survey indicate that Aboriginal people with internet access are more likely to have at least a high school education as well as higher income levels than Aboriginal people without internet access.

The authors identified aspects of identity that served as points of resiliency and vulnerability in either reducing or increasing the impact of perceived discrimination in terms of depressive symptomology. Specifically, centrality (how important one's Indigenous identity is them) was associated with increased depressive symptomology in relation to perceived discrimination, while in-group affect (pride in being Indigenous) resulted in reduced depressive symptomology; and in-group ties (sense of emotional involvement or attachment to other Indigenous people) served to reduce the impact of perceived discrimination for men but not for women. Given the findings and that fostering connections to Indigenous identity and culture has been identified as an important factor in promoting health and well-being (Gone, 2013; Whitbeck et al., 2002), the authors advocate for further research to better understand how different aspects of identity operate in order to inform culturally appropriate interventions that promote resilience (p. 514).

The studies of Currie et al. (2012a, 2012b) and Bombay et al. (2010) highlight the need for research that addresses the complex relationship between racism, trauma, Indigenous identity and Indigenous health. Expanding research in this area will contextualize and articulate an understanding of the collective, race-based traumas that have profoundly shaped the lives of Indigenous peoples, and examine the impact on identity, health and well-being. This includes research applying or expanding the concepts and theoretical frameworks of, for example, historic trauma, historic loss trauma, soul wound, residential school syndrome, and intergenerational trauma. Understanding the impact of historic, collective and intergenerational trauma in the lives of Indigenous peoples is a necessary precondition to improving health care access and service delivery. Moreover, it is foundational to informing anti-racist efforts addressing the pathologizing and dehumanizing stereotypes that have fueled the marginalization and poor treatment of Indigenous peoples in Canadian society, and to advancing awareness of how these stereotypes are reinforced by the ongoing social exclusion and inequities faced by Indigenous communities subsequent to these traumas, including poverty, unemployment, homelessness and poor health.

<sup>19</sup> Data for Métis and Inuit identified participants were excluded from the analysis due to the relatively small number who participated.

#### **Textbox D. Measuring Racism**

There are increasing research efforts aimed at measuring and understanding the impacts of racism on health internationally (Paradies, 2006; Williams & Mohammed, 2009). Recent systematic reviews reveal that the vast majority of research has focused on self-reported racial discrimination (also referred to as perceived discrimination), linking it to a range of health outcomes and behaviours across a range of racialized populations, including self-reported health, mental health, physiological functioning, uterine myomas, breast cancer, self-reported cardiovascular disease, and alcohol and tobacco use (Paradies, 2006; Williams & Mohammed, 2009). Among quantitative studies, racism has most consistently and strongly connected to negative mental health and health behaviors (Paradies, 2006). A multitude of tools have been developed to measure self-reported racism as one avenue towards advancing understanding the relationship between racism and health disparities (see, for example: Williams, Yang, Jackson & Anderson, 1997; Krieger, Smith, Naishadham & Hartman, 2005), including those that address racism specific to the experiences of Indigenous people such as the Microaggressions Distress Scale (Walters, 2005; Chae & Walters, 2013), and those that address racism as an aspect of historical trauma (Whitbeck, Adams, Hoyt & Adams, 2004; Brave Heart & DeBruyn, 1998; Brave Heart, 2003).

In Canada, limited self-report information on experiences of discrimination is available through Statistics Canada surveys that draw on the census for their sampling frame prior to 2011 and the voluntary National Household Survey (NHS) from 2011 on (since in 2011 questions regarding race, ethnicity and Aboriginal identity were moved from the census to the NHS). These include the General Social Survey (Victimization), the Aboriginal Peoples Survey, the Ethnic Diversity Survey and the Canadian Community Health Survey Mental Health module. Additional Aboriginalspecific data regarding experiences of discrimination may be found in the First Nations Regional Longitudinal Health Survey (RHS), and through additional survey research studies such as the Urban Aboriginal Peoples Survey (Environics, 2010), Toronto Aboriginal Research Project (McCaskill, FitzMaurice & Cidro, 2011), and Our Health Counts (OHC) (Smylie, 2011). Of these surveys only the RHS and OHCs study provide population level prevalence estimates. In an attempt to more directly examine the impact of discrimination on health, the most recent Canadian Community Health Survey included a rapid response module with questions addressing discrimination adapted from the Everyday Discrimination Scale (Williams et al., 1997); this data is now available through Research Data Centres (RDCs).2 Unfortunately the move of racial, ethnic, and Aboriginal identifiers from the census to the NHS in 20011 will impact the ability of Statistics Canada Surveys to accurately produce high quality population level rate estimates for racial discrimination, as the NHS has a significantly reduced response rate compared to the census.

As the field of research addressing racism and health grows, leading scholars have identified a number of key priorities for future research, including the development of means to measure and interventions to address various forms of racism (e.g. systemic/institutional, internalized,

<sup>1</sup> Experiences of discrimination data is also collected through the Longitudinal Survey of Immigrants to Canada and the Census follow up Survey on Disability.

<sup>2</sup> This Rapid Response Module was developed and supported by the Social Determinants and Science Integration Division of the Public Health Agency of Canada.

vicarious and intra-racial racism, as well as intersecting forms of discrimination and race-related macro-stressors) (Paradies, 2006; PHAC, 2012; Williams & Mohammed, 2009), as well as the need to understand factors that mediate the impact of discrimination on health (Paradies et al., 2008). Further, the development of approaches to understanding and addressing the impact of discrimination on health that emphasize strengths and resilience will offer an important contribution to the field (PHAC, 2012).

#### Race-Based Policies, Racism and Access to Health Care

In the preceding sections of the paper we have described the historical policy context and the current state of knowledge regarding the burden of racism in the lives of Indigenous peoples in Canada. In the following sections, we turn our attention to the ways in which racism appears in Indigenous-specific health policies and within the interactions between Indigenous peoples and the Canadian health care system.

#### State-Imposed Indigenous Identity And Access To Health Care

The Constitution Act of 1867,<sup>20</sup> particularly section 91(24) which refers to the federal government's responsibility for "Indians and lands reserved for Indians," followed by the Indian Act of 1876, dealt a destructive blow to Indigenous identity and the health and well-being of Indigenous peoples in Canada (Smylie, 2009). The advent of the Indian Act cemented a restrictive state-imposed definition of Indian identity, creating significant divides between those with and without status, and serving to encourage and support assimilationist policies and to reduce the number of status Indians to whom the government would hold responsibilities to, including responsibilities with regard to health care services.

Like the Métis, the Inuit were not included in the Constitution Act of 1867; however, in 1939 the Supreme Court of Canada recognized Inuit peoples as "Indian" for administrative purposes thus compelling federal responsibility for Inuit peoples (Aboriginal Affairs and Northern Development Canada, 2011). Indigenous peoples in Canada have not been passive recipients of state-imposed identities; our agency and resistance is reflected in hundreds of years of protest, activism, lobbying and legal challenges. In fact, in January 2013, a fourteen year legal battle led to a federal court ruling that recognized non-status First Nations and Métis peoples as "Indians" within section 91(24) of the Constitution Act in the case of Harry Daniels et al v. Her Majesty the Queen et al. The federal government promptly appealed the decision which was upheld by the federal court of appeal in its ruling released in April 2014. At first glance, it would seem that this finding could have massive implications for supporting and improving the health and well-being of Métis and non-status First Nations peoples. However, being recognized as "Indians" within the Constitution Act (as opposed to the Indian Act) does not ensure and likely will not result in access to the Indigenous-specific health services and entitlements provided by the federal government to status Indians and Inuit peoples through the First Nations and Inuit Health Branch of Health Canada. This recognition does clarify the federal government's legislative jurisdiction over Métis and non-status Indians which it has

<sup>20</sup> Originally enacted as the British North America Act of 1867.

long denied and resisted. It remains unclear as whether the ruling will compel the federal government to act differently in relation to Métis and non-Status Indians (particularly in relation to health), or if the federal government will further appeal the ruling to the Supreme Court of Canada.

#### **Non-Insured Health Benefits (NIHB)**

In the context of contemporary Indigenous health, Canada's race-based legislation has normalized the uneven distribution of health funding, resources and services according to state-constructed Indigenous identities, such that only status First Nations and Inuit peoples are entitled to the NIHB program and to the Indigenous health services and support provided through the federal government via the First Nations and Inuit Health Branch. Métis and non-status First Nations lack access to these services and resources while facing the same determinants of health that have created egregious disparities in health in comparison to non-Indigenous people, such as lack of access to secure, affordable or adequate housing, increased rates of unemployment and underemployment, food insecurity, poverty, and disproportionate rates of incarceration and child welfare apprehension (Greenwood & de Leeuw, 2012; Loppie & Wien, 2009; Smylie, 2009; Smylie & Adomako, 2009; Statistics Canada, 2008).

The NIHB program provides coverage for status Indians and Inuit people registered with a recognized Inuit Land Claim organization to access a range of medical goods and services. This includes dental and vision care, prescription medications, specified medical supplies, equipment and transportation, short-term crisis intervention and mental health programming (Health Canada, n.d.). However, simply being eligible for NIHB does not necessarily ensure access since some services require on-reserve residency in order to receive funding for or access the service or program, and the roster of approved services and medications is constantly changing (Haworth-Brockman et al., 2009; Mother of Red Nations, 2006). Moreover, the delivery of NIHB also poses challenges to equitable access to health services in comparison to non-Indigenous people, particularly in northern and remote communities:

"My sister has been going into Winnipeg for different specialist appointments and so she has to wait for them (NIHB) to call her. It's a flight she usually takes, but they won't even bother and I think that's a scenario for everybody, booking you back...they used to make a return flight, but now they only do a one way trip over to where you need to go. When you've done your appointment, you're supposed to call them and say I'm done my appointment I want to go home now. So my sister has to phone them and wait for them to make arrangements to come back home. What happens to the Elders who can't even speak English? They are to call Non-Insured and say okay I'm done here? My issue about Non-Insured is the power that's been given to them....I don't even know when that policy started about the one way tickets. I think it's almost on the verge of violating peoples' rights to access to care that they need. The other scenario I hear about all the time is that when Non-Insured calls you, you're expected to travel from your house, leave your job, leave your kids, leave your husband and come out to this appointment within hours or the next day. And if you can't make it out, you get penalized for missing that flight. The policies of Non-Insured are really impacting the access to specialists that they need to see."

Grandmother Carol Terry, Well Living House Grandparents Counsel

#### **Racism In The Health Care Experience**

In addition to the uneven access to health services and resources created through the NIHB and other race-based policies, experiences and anticipation of racist treatment by health care providers also acts as a barrier to accessing needed health services for Indigenous peoples (Kurtz et al., 2008; Tang & Browne, 2008; Browne et al, 2011). Qualitative studies documenting the health care experiences of Aboriginal peoples highlight anticipated and actual poor treatment. For example, in examining the experiences of Aboriginal and non-Aboriginal persons accessing an inner-city emergency department, Browne et al. (2011) found that Aboriginal participants described anticipating that being identified as Aboriginal and poor might result in a lack of credibility and/or negatively influence their chances of receiving help. This was such a common experience that participants actively strategized on how to manage negative responses from health care providers in advance of accessing care in the emergency department.

The research of Tang and Browne (2008) examined how stereotypes of Aboriginal people impact the care they receive, with participants describing being denied treatment or access to hospital care based on assumptions that they were drunk or that they were "troublemakers." Participants further described how the anticipation or experience of being blamed for one's own health problems prevented some from even trying to access hospital care at all; being perceived as poor was also cited as a basis for slow or differential treatment. Research addressing the health of urban Indigenous women indicates that health care access is significantly affected by past experiences and subsequent anticipation of poor treatment by health care providers including the presumption that they are intoxicated or using substances, having their concerns ignored or discounted (i.e. having health care providers ignore pain symptoms with the assumption that they are narcotics-seeking), belittlement, and, for women with children, fear of child welfare intervention or poor treatment due to racist assumptions that they are bad mothers (Allan, 2013; Kurtz et al., 2008). Racism serves as a serious barrier to health care access that can lead to delayed treatment or a lack of treatment altogether, either of which can have devastating effects on Indigenous people, their families and communities.

#### Fatal Racism: The Death Of Brian Lloyd Sinclair

Grandmother Madeleine Kētēskwew Dion Stout of the Well Living House Grandparents Counsel asked that our paper include the story Brian Sinclair's tragic and unnecessary death at the Winnipeg Health Sciences Centre. Her reflections follow the narrative below.<sup>21</sup>

Brian Sinclair was a 45 year old Indigenous man who died after a 34 hour wait in the emergency room of the Winnipeg Health Sciences Centre in 2008. He was referred to the ER by a community physician for a bladder infection, which the Chief Medical Examiner of Manitoba has suggested would have required approximately a half hour of care to clear his blocked catheter and to prescribe antibiotic treatment (Puxley, 2014a). Instead, Mr. Sinclair died slowly and unnecessarily of bladder infection in the waiting room of the ER without ever receiving treatment, despite vomiting several times on himself, and despite pleas from other ER visitors for nurses and security guards to attend to him (Puxley, 2013a, 2013b). Mr. Sinclair's

<sup>21</sup> This account of Mr. Sinclair's death is drawn from media accounts and the press release of family member Robert Sinclair. Further information about provincial inquest into Mr. Sinclair's death, including transcripts of witness testimony may be found at <a href="http://ignoredtodeathmanitoba.ca/">http://ignoredtodeathmanitoba.ca/</a>

body was already cold and stiff, demonstrating the onset of rigour mortis by the time staff responded and attempted to resuscitate him (Puxley, 2014).

Mr. Sinclair was a double amputee, having lost his legs to frostbite after being found frozen to the steps of a church in 2007. He suffered a cognitive impairment from previous substance use and had endured homelessness, although he had housing at the time of his death. The Sinclair family, their legal counsel and local Indigenous leaders asked the provincial inquest into the matter to strongly consider the ways in which Mr. Sinclair`s race, disability and class resulted in his lack of treatment and subsequently his death (Puxley, 2014a). In fact, several staff testified they had assumed Mr. Sinclair was in the ER simply to warm up, watch TV or sleep off intoxication, while others have reported that they never saw Mr. Sinclair despite the fact that his wheelchair partially blocked the same part of an aisle of the ER for more than 24 hours (Puxley, 2013a, 2014a, 2014b). During inquest testimony, hospital staff and the Chief Medical Officer of Manitoba, Dr. Thambirajah Balachandra, vehemently denied the role of racism in Mr. Sinclair's death, with Dr. Balachandra blithely suggesting that even Snow White would have received the same treatment as Mr. Sinclair under the circumstances ("Brian Sinclair dead for hours," 2013). Racism, the refusal of care and poor treatment of Indigenous peoples in the Canadian health care system are well documented in health research. For Mr. Sinclair, the impact of racism proved fatal. On February 18th 2014, the family of Mr. Sinclair withdrew from the provincial inquest because its failure to examine and address the role of systemic racism in his death and in the treatment of Indigenous peoples in health care settings more broadly (Sinclair, 2014).

"The story is horrific and is being examined now-shockingly the staff said Mr. Sinclair didn't ask for help. But, it just makes you think...what do we look like to others? Do we look like a person even? Do we look like a people? Especially when both our legs are missing and we're sitting in a wheelchair and we're vomiting all over ourselves and on the floor? Clearly we as a people aren't even looked at as human beings. Of course the family is upset about his treatment and think it is a case of racism. That day, a hundred and fifty people had moved through emergency and Mr. Sinclair was ignored and didn't receive any service. The family really believes he was ignored because he was disabled and marginalized and Aboriginal, rightfully so. I mean imagine just being forty-five, he'd had many negative life experiences and he died just the way he'd been treated, just what he'd known all his life: rejection and racism. It's really such a sad story and it really needs to go in your paper, that's why I'm not going to talk about my relatively insignificant experiences with racism when Brian Sinclair died because of racism."

Grandmother Madeleine Kētēskwew Dion Stout, Well Living House Grandparents Counsel

#### **Racism Versus Culture: Implications For Access To Health Care**

We argue here for consideration of how Indigenous peoples' experiences of racism in health care systems are mischaracterized as and/or reduced to matters of "cultural difference" that are best addressed through cultural sensitivity or cultural competence approaches as opposed to anti-racism. The critique of a reliance on culture as a way to diffuse or avoid addressing racism in Canada is not new (Browne & Varcoe, 2006; Fiske & Browne, 2006; Henry, Tator, Mattis & Rees, 2000). However, it is central to advancing understanding

of and responses to Indigenous peoples' experiences of racism since Indigenous peoples have become synonymous with "culture" in the Canadian consciousness (personal communication, Grandmother Madeleine Dion Stout, 2014).

Browne and Varcoe (2006) assert that culture-focused approaches to working with Indigenous peoples (i.e. cultural sensitivity, cultural competence) require a critical analysis of how we understand culture in the first place, in order to account for the impact and influence of racism, colonialism, and our historical and contemporary contexts. This is necessary to understand and respond to the ways in which Indigenous peoples endure a disproportionate burden of ill-health and experience poorer access to social and economic determinants of health and health care that have been structurally created and maintained through historical and ongoing racism (Browne & Varcoe, 2006). Moreover, it is important to draw attention to how models such as cultural sensitivity or cultural competence maintain a focus on interactions between service users and health care providers, downloading matters of racism (under the guise of "cultural difference") to the individual and interpersonal levels and failing to address the role of systemic, institutional and organizational racism in shaping the encounters between service users and health care providers. Cultural safety, a more recent and Indigenous model of health care, directly addresses the role and impact of racism in Indigenous inequities in health care access and health outcomes and attends to power dynamics in the interactions between health care provider and service user (see Textbox E).

#### Racism, Health And Health Care: Responses And Interventions

The published Indigenous-specific literature on interventions aimed at addressing racism within the context of Indigenous health and health care is very scant. Indigenous health scholars in Australia and New Zealand have produced seminal papers demonstrating personal experiences of racism as an important factor in explaining Indigenous/non-Indigenous health disparities (Harris et al., 2006) and exploring the causal pathways that link personal experiences of racism to mental health outcomes (Paradies & Cunningham, 2009, 2012). Specific interventions to address racism within the context of Indigenous health and health services are beginning to emerge in these two countries (Durey, 2010; Roe, Zeitz & Fredericks, 2012; Ellison-Loschmann & Pearce, 2006).

Our systematic literature search for articles, which focused on racism and discrimination against Indigenous people and health or health care in Canada (but did not include "disparities" more generally) identified only descriptive literature, with not a single indexed article describing or evaluating an intervention specifically focused on addressing racism within the context of Indigenous health or health care. We did, however, locate published literature describing initiatives designed to train health care professionals to improve their "cultural competence" or their ability to provide "culturally secure" care (Saylor, 2012). For further description of the literature search, please refer to Appendix A.

# What Do We Know About The Impacts Of Racism On Health Services And Interventions To Address These Impacts With Respect To Indigenous Peoples In Canada?

In this section, we provide an overview of multiple examples of responses and interventions (including policy recommendations) aimed at addressing racism (including colonial policy and practice) and the

impacts of racism on the health and health care of Aboriginal peoples in Canada. Our examples are drawn primarily from the grey literature as we have noted above the paucity of published literature on this topic. We first acknowledge the strong individual, family and community strategies and resiliencies that are employed by Indigenous people. We then examine health care service and deliver responses; health professional and training responses (including cultural safety training); national, provincial/territorial level interventions both specific to Aboriginal health and/or health care and impacting Aboriginal health (see also Tables 1-4).

#### Individual, Family, And Community Strategies And Resiliencies

At the individual, family and community level, Indigenous people have been managing racism and its impacts on their health for hundreds of years, demonstrating resilience and resourcefulness in the face of exclusion and marginalization. Traditional Indigenous community-based systems of reciprocal economic and social support such as community food sharing and intergenerational and extended family child-rearing roles have been and continue to be important mitigating factors (Food Secure Canada, n.d.; Castellano, 2002). The community-based fundraisers held in some rural Métis communities to raise funds to cover the travel cost for community members to access required specialist health services located outside of their home communities serve as a specific example of the diverse ways in which Indigenous communities come together to bridge gaps in federal and provincial/territorial financial and policy support and to improve access to health care.

In the US, recent research by Chae & Walters (2009) explored the relationship between racial discrimination, racial identity attitudes and self-rated health (specifically physical pain and impairment) among urban two-spirit American Indian and Alaska Natives and found that self-reported physical pain and impairment was significantly impacted by experiences of racial discrimination for participants with low actualization (defined as positive integration between self and group identity based on the Urban American Indian Identity scale). Moreover, they found that the impact of racial discrimination had little relationship to self-reported physical pain and impairment for participants with high levels of actualization, suggesting that enhanced levels of actualization (positive evaluation of oneself as an Indigenous person and of Indigenous peoples in general) may mitigate the impact of discrimination on health (Chae & Walters, 2009). This work echoes and extends existing community and scholarly knowledge (Gone, 2013) about the powerful role of identity and culture in the health and well-being of Indigenous peoples.

Table 1 identifies examples of different levels and types of health care service delivery responses developed to improve the health and well-being of Indigenous peoples in Canada.

Table 1. Health care and service delivery responses

Level/Type of Response	Examples
Community-directed Aborigional services and programs specific to health	<ul> <li>First Nations controlled health services</li> <li>Inuulitsivik Health Centre, (Nunavik, Quebec)</li> <li>Anishnawbe Health Toronto and subsequent urban Aboriginal health centres</li> <li>Native Youth Sexual Health Network</li> </ul>
Community-directed Aborigional services and programs that generally impact health	Community based programs (support coming from local, regional, provincial and federal sources, many of which draw on local ways of knowing and doing). A full description of such programs is beyond the scope of this document, however, some examples include:  • The Aboriginal Mother Centre Society • The Assembly of Manitoba Chiefs CEPS (Culture, Economic, Political and Social) Youth Leadership Development Program. Additional information about the CEPS program may be found under the Youth Secretariat section of the AMC website: www.amc.manitobachiefs.com
Community level health and health impacting services and programs (not Aborigional-specific or Aborigional-directed)	Community Health Centres  • Canadian Mental Health Association (CMHA) Housing First/Chez Soi program (This program inleuded partnerships with Aborigional organizations to develop Aborigional-specific programming such as the We Che Win program delivered by Ma Mawi Wi Chi Itata Centre in Winnipeg, MB. For more infomation: <a href="https://www.mamawi.com">www.mamawi.com</a>
Mainstream health institution level efforts to improve access	<ul> <li>Aborigional specific services, for example:</li> <li>First Nations Health Programs at the Whitehorse Hospital</li> <li>Aboriginal Service at the Centre for Addiction and Mental Health (CAMH)</li> <li>Aborigional supports/outreach workers including Aboriginal patient navigators and patient liaisons in hospitals, and Aborigional cancer care navigators. See, for example:</li> <li>Vancouver Coastal Health Aboriginal Patient Navigators Program</li> </ul>

### **Health Care Service And Delivery Responses**

### Community-directed Indigenous services and programs specific to health

At the level of health care service and delivery, there has been a variety of developments aimed at increasing access to health care for Indigenous peoples and mitigating the impact of racism they experience in attempting to manage their health and well-being in the Canadian health care system. The emergence in recent decades of health services and programs directed by the Indigenous communities that they are designed to serve is of fundamental importance to improving the health inequities faced by Indigenous peoples in Canada. The development of Indigenous-directed services is tied to the provincial/territorial and national policy initiatives aimed at returning the control of Indigenous health services to Indigenous peoples (see Table 3 and accompanying text) and therefore represents an important reform of colonial policies and practices which actively undermined and disrupted pre-colonial systems of Indigenous health (Smylie, 2001). First Nations (on-reserve) communities have been involved in taking over control of their health services and programs from the federal government in varying degrees since the 1970s (Lavoie, Forget & O'Neal, 2007). For example, the Community Health Representatives (known as CHRs) and the National Native Alcohol and Drugs Addictions Program (NNADAP) have been managed by First Nations

since inception (ibid), and presently, a large majority of First Nations communities are administering and managing their own health services according to one of several federal contribution agreement funding models (Health Canada, 2012a). A key challenge and risk in assuming management and administration of health services rests in future budget allocations. Given the inequities in Indigenous health determinants and status, it is necessary to ensure that program budget funding includes annual funding increases to keep pace with increased cost of living, population growth, and increased burden of illness. Transfer of program and service plans that adequately ensure for escalating future costs have been notoriously difficult for First Nations to negotiate with the federal government. Below, we describe four key examples of community-directed health systems, organizations and services.

### First Nations Health Authority (FNHA)

The establishment and implementation of the First Nations Health Authority (FNHA) in British Columbia has broken new ground in the efforts of First Nations communities to control their health services. The FNHA is governed by a tripartite agreement between BC First Nations and the Federal and Provincial governments. Guided by principles of respect, discipline, transparency, and culture, the overarching goal of the FNHA is to achieve better health outcomes for all First Nations in BC. As part of the implementation of the tripartite agreement, the administration, design, management, and funding of federal health services and programs were transferred to the FNHA from the Pacific Region FNIH of Health Canada in the fall of 2013.

Through a process of ongoing community engagement and collaboration, seven community-defined directives have been established that describe standards and instructions for a new health governance relationship; these include:

- · Community-driven, Nation-based program, service, and policy development
- Increased First Nations decision-making and control in health program and service philosophy, design, and delivery
- · Improved services that incorporate Indigenous ways of knowing
- Fostering meaningful collaboration and partnerships between First Nations and non-First Nations organizations, as well as within communities
- · Developing human and economic capacity
- Being without prejudice to First Nations' interests
- Functioning at an accountable, transparent, high operational standard

### Indigenous midwifery: Inuulitsivik Health Centre

The initiation of the maternity program at the Inuulitsivik Health Centre in Puvirnituq, Quebec also represents an important landmark example of Indigenous community controlled health services. The program was initiated in 1986 by a local Inuit women's group in response to dissatisfaction with federal policy change that had for decades required all Inuit women to travel away from their communities to southern hospitals for childbirth (i.e. Montreal) at 37 weeks of pregnancy for childbirth (Epoo & Van Wagner, 2005; Houd, Qinuajuak & Epoo, 2004). Now, only 8 percent of women have to travel to Montreal to give birth (Epoo & Van Wagner, 2005). The Inuulitsivik Health Centre maternity program is also home to a midwifery training program that has successfully trained a number of Inuit midwives from the local area.

### **Urban Indigenous health centres: Anishnawbe Health Toronto**

In the urban context, the establishment of multiple urban Indigenous health centres represents Indigenous community-controlled health services, the large majority of which are run by Indigenous boards of directors and offer both traditional healing and medical services (Association of Ontario Health Centres, n.d.). Anishnawbe Health Toronto, established in 1984, was the first such centre, and importantly modelled health services and programs that are foundationally based on traditional Indigenous practices and approaches to health and well-being (Anishnawbe Health Toronto, 2011).

## Indigenous youth leadership in health and well-being: Native Youth Sexual Health Network

The Native Youth Sexual Health Network (NYSHN) is an Indigenous for youth, by youth organization serving Indigenous youth across Canada and the US, emphasizing empowerment, cultural safety, reproductive justice, sex positivity and health sexuality (NYSHN, n.d.). While there is a significant focus on sexual health and reproductive justice, NYSHN staff and youth leaders have also undertaken a broad range of work to address urgent issues in our communities, including: youth in child welfare, custody, jail and prison; environmental justice and environmental violence; sex trade, sex work and street economies; reclaiming coming of age ceremonies, rites of passage and traditional knowledge; healthy relationships and violence prevention; Two-Spirit and Lesbian, Gay, Bisexual, Transgender, Transsexual, Intersex, Queer, Questioning and Asexual (LGBTTIQQA) advocacy and awareness raising; and harm reduction (NYSHN, n.d.).

### Community-directed Indigenous services and programs that generally impact health

There are thousands of community-directed Indigenous services and programs across the domains of housing, education, employment, language, and culture that impact health more generally. These programs are the result of decades and decades of advocacy, organizing, implementation and expansion work by Indigenous leaders from across Canada and representing diverse Indigenous population groups. Many of them are exemplar in their reflection of local community ways of knowing and doing and all aim to impact Indigenous health and well-being. Although a full summary of these programs is beyond the scope of this paper, we highlight a few key examples below.

In Vancouver, British Columbia, the Aboriginal Mother Centre Society (AMCS) provides a transformational housing program for Aboriginal women and their children who are at risk of homelessness or child welfare intervention (AMCS, 2012). AMCS not only supports women who are at risk of child welfare intervention, but also those who are seeking to reunite with children already apprehended by child welfare authorities. In addition to housing, AMCS provides advocacy, counselling, education, training and social support, as well as daycare services, a food bank program, free clothing, a community kitchen, a drop-in centre and access to office and technical support (e.g. internet and fax access). AMCS includes a social enterprise component, The Mama's Wall Street Studio, <sup>22</sup> intended to provide employment training and opportunities for Aboriginal mothers, as well as generating revenue to support the programming provided by AMCS. Given the devastating impact of invasive child welfare intervention in Indigenous communities described

<sup>22</sup> Mama's Wall Street Studio produces customized sewn, knitted or crafted promotional products. For more information about the Studio or the AMSC programs, see: <a href="https://www.aboriginalmothercentre.ca">www.aboriginalmothercentre.ca</a>

in this paper, the AMCS represents an innovative model of service aimed at preventing or mitigating the involvement of child welfare authorities in the lives of Aboriginal women and their families and supporting their overall well-being and success.

There has been significant leadership and innovation by Indigenous youth in the development and implementation of Indigenous-determined programming and services that broadly impact health and well-being. In addition to the work of NYSHN described above, a further example of innovative programming designed and implemented by Indigenous youth for youth is the CEPS (culture, economic, political, social) leadership development program delivered by the Youth Secretariat of the Assembly of Manitoba Chiefs (AMC, n.d.). The objectives of this program emphasize self-determination, youth empowerment, revitalization and fostering of re-connection to cultural knowledge and practices, education about the histories of First Nations peoples, as well as skills and knowledge development (cultural, economic, political and social) (AMC, n.d.). The CEPS program further offers train the trainer sessions to prepare youth to deliver the curriculum in their own and other communities (AMC, n.d.).

### Community level health and health impacting services and programs (not Indigenousspecific or Indigenous-directed)

There are many important non-Indigenous specific community level health and health impacting services and programs that are making important inroads with respect to Indigenous access to health care. For example, many of the non-Indigenous specific community health centres in Ontario are important health care access points for Indigenous people, particularly in places where there is not an accessible Aboriginal health centre. Some of these mainstream centres, such as the Queen West Community Health Centre<sup>23</sup> in Toronto, also offer Indigenous-specific programming to meet the needs of Indigenous community members living in their catchment. The "At Home/Chez Soi" housing first research demonstration project showed that immediate access to a variety of housing options combined with appropriate mental health supports is an effective way to address homelessness and improve access to community services. The core program was successfully adapted to serve Indigenous populations; We Che Win ("Come walk with me") delivered in partnership with Ma Mawi Wi Chi Itata in Winnipeg, Manitoba, is one example of an Indigenous-specific adaptation of the At Home program (Goering et al., 2014).

#### Mainstream health institution level efforts to improve access to health care

Within some mainstream institutions, efforts to improve access and service for Indigenous clients has included the development of Indigenous-specific programs or services (e.g. the Aboriginal Services of Centre for Addictions and Mental Health (CAMH) based in Toronto, Ontario; the First Nations Health Programs based in the Whitehorse Hospital), or the employment of Indigenous staff in specialized roles such as Aboriginal patient navigator (APN) or Aboriginal patient liaison (APL) intended to improve access to and outcomes of health care by serving as a bridge between Indigenous patients and the health care system. These specialized roles provide support and advocacy for Indigenous patients, which may include attending appointments or health care team meetings alongside the patient. While specific duties may vary across organizations, APNs/APLs also generally work to connect patients to resources within the

<sup>23</sup> Queen West Community Health Centre, part of the Central Toronto Community Health Centres, offers an Aboriginal diabetes program.

hospital/health centre or community, facilitate access to cultural health resources and support (e.g. Elders, ceremony, etc.), provide instrumental resource support (e.g. helping to access transportation, accommodations to attend appointments, assisting with FNIHB paperwork, etc.), and provide workshops and in-service training for health care staff to improve awareness of and cultural sensitivity to the needs and experiences of Indigenous. These specialized roles may help to mitigate the impact of systemic and interpersonal level racism by improving communication between health service providers and Indigenous service users, by improving awareness and understanding of Indigenous health issues among health service providers (including the impact of colonization), improving cultural and language awareness of health services providers, and enhancing the sense of safety of Indigenous service users during health care provision (Foreman & Stewart, 2011). The positive impact of these specialized roles on health care outcomes and improved access to care is highlighted in emerging program evaluations of Canadian Aboriginal patient navigator programs (Dicker, 2012; Foreman & Steward, 2011) and data from the US suggests that such programs may help to reduce disparities for Indigenous people in access to cancer screening and improve adherence to cancer treatment programs (Whop et al., 2012).

## Textbox E: Cultural safety: An Indigenous approach to improving Indigenous access to health care

Cultural safety emerged in the context of Maori health in Aotearoa (New Zealand) in the 1980s, finding its way into the standardized nursing and midwifery curricula of New Zealand by the 1990s. It has since enjoyed significant international uptake across multiple health care professions and systems, particularly in Canada. Developed by Dr. Irihapeti Ramsden, a Maori nurse, cultural safety was first imagined as a model for nursing practice with Maori peoples in response to the egregious health disparities faced by Maori peoples, emphasizing the importance of recognizing the colonial, historical, and sociopolitical context in which these disparities had been created, and the ongoing racism and poor health care treatment in which they were maintained. Where cultural sensitivity and cultural competence focused on learning about the culture of the service user, cultural safety directed health care providers to viewing everyone, including themselves, as bearers of culture. It requires health professionals to examine their own culture, history, lived experiences, beliefs and attitudes and the ways in which these not only shapes their approach to practice, but impacts how others (i.e. service users) respond to them (DeSouza, 2008).

Cultural safety emphasizes explicit attention and action to address power relations between service user and service provider, charging the service provider with the responsibility to consider and address the role of their professional and institutional power in contributing to culturally safe or unsafe care. Addressing the power imbalance between service provider and service user requires the following: 1) that the service user's way of knowing and being is valid; 2) that the service user is a partner in the health care decision making process; and 3) that the service user determines whether or not the care they have received is culturally safe or not (Health Council of Canada, 2012; DeSouza, 2008). Cultural safety has been endorsed and adopted by multiple health professional organizations, health professional training programs and health service organizations in Canada as a step towards addressing the health inequalities of and inequitable access to

health care experienced by Indigenous peoples (see for example: University of Victoria School of Nursing Cultural Safety Modules; Canadian Health care Association Cultural Competence and Cultural Safety in Health care program; Anishnawbe Health Toronto Aboriginal Cultural Safety Initiative). The Indigenous Cultural Competency Training Program offered through the Provincial Health Services Authority of British Columbia is a longitudinal, participatory online set of modules grounded in a non-judgmental approach (<a href="https://www.culturalcompetency.ca">www.culturalcompetency.ca</a>). It has been identified as an exemplar training program, accredited by The College of Family Physicians of Canada and the Canadian Counseling and Psychotherapy Association (for continuing education credits).

### **Health Professional Education And Training Responses**

Since 2000, there has been a steady emergence of policy statements and guidelines for medical professional and medical training organizations in Canada towards identifying and developing the competencies needed by health professionals in order to optimize the care that they provide to Indigenous individuals and communities, followed by the development of educational guidelines, curricula and training programs for medical and nursing professionals and trainees. This includes the Society of Obstetricians and Gynaecologists of Canada (SOGC) Policy Statement: A guide for health care professionals working with Aboriginal peoples (Smylie, 2001); the Indigenous Physicians Association of Canada and Association of Faculties of Medicines of Canada (2009) First Nations, Inuit and Métis health core competencies: A curriculum framework for undergraduate medical education; Aboriginal Nurses Association of Canada, Canadian Association of Schools of Nursing and the Canadian Nurses Association Cultural competence and cultural safety in nursing education: A framework for First Nations, Inuit and Métis Nursing; Indigenous Physicians Association of Canada and the Royal College of Physicians and Surgeons of Canada (2009) First Nations, Inuit and Métis health core competencies: A curriculum framework for postgraduate medical education; the SOGC Clinical Practice Guideline: Health professionals working with First Nations, Inuit, and Métis consensus guideline (Wilson et al., 2013); and the Royal College of Physicians and Surgeons of Canada (2013) Indigenous health values and principles statement. Some of the core key concepts and frameworks that have emerged in preparing health care providers and students in the health professions include cultural competence, cultural safety (see Textbox E for a further description) and trauma-informed care, resulting in exemplar programs such as the Indigenous Cultural Competency Training Program of the Provincial Health Services Authority of British Columbia, 24 and the Cultural Safety training modules developed by the University of Victoria School of Nursing in British Columbia.<sup>25</sup>

<sup>24</sup> Further information about the program may be found at <a href="http://www.culturalcompetency.ca/">http://www.culturalcompetency.ca/</a>

<sup>25</sup> These modules may be accessed through the following link: http://web2.uvcs.uvic.ca/courses/csafety/mod1/resource.htm

Table 2. Health professional education and training responses

Level/Type of Response	Examples
Health care professional standards, guidelines and core competencies	<ul> <li>Society of Obstetricians and Gynaecologists of Canada (SOGC) Policy Statement: A guide for health professionals working with Aboriginal Peoples (Smylie, 2001)</li> <li>SOGC Clinical Practice Guideline: Health professionals working with First Nations, Inuit, and Métis consensus guideline (Wilson et al., 2013)</li> <li>Indigenous Physicians Association of Canada and Association of Faculties of Medicines of Canada (2009) First Nations, Inuit and Métis health core competencies: A curriculum framework for undergraduate medical education</li> <li>Indigenous Physicians Association of Canada and the Royal College of Physicians and Surgeons of Canada (2009) First Nations, Inuit and Métis health core competencies: A curriculum framework for continuing medical education</li> <li>Aboriginal Nurses Association of Canada, Canadian Association of Schools of Nursing and the Canadian Nurses Association Cultural competence and cultural safety in nursing education: A framework for First Nations, Inuit and Métis Nursing (Hart-Wasekeesikaw, 2009)</li> <li>Royal College of Physicians and Surgeons of Canada (2013) Indigenous health values and principles statement</li> </ul>
Recruitment and retention of Indigenous health professionals	• Affirmative admissions policies, Aboriginal-specific supports within health professional training programs (see for example IPAC & AFMC, 2008)
Training responses by health service organizations	• Indigenous Cultural Competency Training Program, Provincial Health Services Authority (British Columbia)

Following recommendations that began to emerge in the mid-1990s (MacMillan, MacMillan, Offord & Dingle, 1996; RCAP, 1996) and were strengthened in the 2000s (Smylie, 2001), there has been significant efforts and initiatives to increase the number of Indigenous health professionals in Canada. This includes the Aboriginal Health Human Resource Initiative (AHHRI), a \$100 million five year program initiated by the federal government in 2004 (Health Canada, 2012b). AHHRI not only aimed to increase the number of Indigenous health professionals in Canada, but to improve the retention of health care providers in Indigenous communities and enhance the educational curriculum of health care professional programs through the development of cultural competencies (Health Canada, 2012b). This program was renewed again in 2010 on a two-year basis, with a more recent commitment by the federal government to extend an additional \$80 million of funding set to begin flowing in 2015 (Atlantic Policy Congress of First Nations Chiefs Secretariat, n.d.). Moreover, there have been significant efforts over the past decade to address medical school admissions policies to increase access for Indigenous students (see for example: IPAC & AFMC, 2008).

# National, Provincial Or Territorial Level Policy Responses Specific To Health And Impacting Health

In addition to federal policies regarding transferring the control of First Nations health services to First Nations communities and the First Nations Health Authority, there are several other sets of policies and policy recommendations aimed at increasing Indigenous governance and management of Indigenous health services. These efforts represent important restitutions with respect to the systemic colonial

policies that have historically and currently undermined Indigenous rights to Indigenous-determined health services in Canada. At the national level both the Royal Commission on Aboriginal Peoples (1996) and the Kelowna Accord (2005) deliberations advocated for fundamental shifts in the governance and management of Indigenous health services from the federal government to Indigenous communities (First Ministers and National Aboriginal Leaders, 2005; RCAP, 1996). The Aboriginal Healing and Wellness Strategy (AHWS) was tabled and implemented by the Aboriginal organizations and provincial ministries in Ontario in 1990, bringing Indigenous people and the provincial government together in partnership to combat poor health and family violence, an exemplar that has resulted in multiple Indigenous-led health services and programs (Anishinabek Nation, 2008).

Aboriginal and treaty rights are recognized and affirmed as constitutionally protected rights under section 35 of Canada's Constitution Act of 1982, and are inclusive of Indian, Métis and Inuit peoples. These rights are linked to the agreements signed between First Nations communities and the Canadian government. In addition to the constitutional rights of Aboriginal peoples, there are many federal and provincial/territorial governmental statutes. Existing international governmental obligations regarding Indigenous health which Canada has signed include: the United Nations' International Covenant on Economic, Social and Cultural Rights; the United Nations Declaration on the Rights of Indigenous Peoples; and the United Nations Convention on the Rights of the Child.

Despite these treaties and agreements, in Canada, ongoing jurisdictional disagreements between the federal government and the provinces and northern territories have resulted in major challenges to Indigenous health assessment, health policy, and equitable access to adequate health services.

One of the most egregious examples of these jurisdictional conflicts lies in the story of Jordan River Anderson. Jordan was a First Nations child born with complex medical needs, who died in a Winnipeg hospital in 2005, far from his family home and community in northern Manitoba. As a result of a more than two year long dispute between the federal and provincial governments about which jurisdiction would be responsible for the cost of his at-home health care upon discharge, Jordan died without ever having had the chance to reside in his family home (NCCAH, 2011). In response to this situation, Dr. Cindy Blackstock of the First Nations Child and Family Caring Society of Canada led the development of Jordan's Principle; a child first approach to resolving jurisdictional disputes within and between the federal and provincial/territorial governments. Jordan's principle was carried forward as a federal private member's bill and unanimously approved by parliament. This legislation requires that the government of first contact pay for the service to the child without delay or disruption (NCCAH, 2011).

It is important to note that evaluation of the interventions listed above in terms of impacts on Indigenous health (determinants, status or health care service access and quality) seems to be the exception rather than the norm. For example, despite the significant investment by health care professional organizations and schools in the training of health care professionals with the goal of enhancing their communication with and care provision to Indigenous people, we were unable to identify any evaluations of these programs beyond immediate pre-post surveys of the participants (Zhou et al., 2012) with respect to acquired knowledge and perceived impacts. We note that existing international evidence supporting the longer term efficacy of cultural education programs for health care providers with respect to sustained change in practice and enhance patient health outcomes is quite weak (Durey, 2010). Further assessment, especially in Indigenous contexts, is urgently required to better understand the efficacy of these training initiatives. Baba (2013)

recommends the development of standardized assessment criteria for these educational and training programs, alongside the development of a national set of core competencies in Indigenous public health.

Table 3. National, provincial or territorial level interventions or recommendations specific to Indigenous health and/or health care

Level/Type of Response	Examples
Policy interventions aimed at increasing Indigenous governance and management of Indigenous health services	<ul> <li>Federal transfer of health services (the federal transfer of health services was initiated in 1989 and aims to transfer the provision of community-based health services and programs from the federal government to First Nations and Inuit communities through transfer payments.)</li> <li>Recommendations from the Royal Commission on Aboriginal Peoples (1996), Volume 3, Chapter 3</li> <li>First Nations Health Authority (British Columbia)</li> <li>Aboriginal Healing and Wellness Strategy (Ontario)</li> <li>Kelowna Accord</li> </ul>
Policy interventions aimed at addressing federal, provincial and territorial jurisdictional disputes	• Jordan's Principle
Policy interventions aimed at increasing Indigenous health capacity	<ul> <li>Aboriginal Health Human Resources Initiative</li> <li>Institute of Aboriginal Peoples Health, Canadian Institutes of Health Research</li> <li>Networks for Excellence in Aboriginal Health Research (NEAHRs) recently defunded*</li> </ul>

Table 4. National and provincial/territorial policy interventions/ recommendations and program initiatives impacting Indigenous health (including efforts by national and provincial/territorial Indigenous organizations, federal, and provincial/territorial governments)

Level/Type of Response	Examples
Policy interventions aimed at increasing Indigenous self-determination	<ul> <li>United Nations Declaration of the Rights of Indigenous Peoples</li> <li>Royal Commission on Aboriginal Peoples (1996)</li> <li>Aboriginal Affairs and Northern Development Canada transfer payments for education and social development</li> <li>Inuit land claim territories</li> </ul>
Policy interventions aimed at restitution of Indigenous social, linguistic, cultural, land-based, and economic rights and well-being	<ul> <li>Truth and Reconciliation Commission</li> <li>Resolution of land claims</li> </ul>

There has been some tracking of impacts of the implementation of policy recommendations although in most cases, the track record is not encouraging. For example, in 2006 the Assembly of First Nations published a ten year report card examining the implementation of the recommendations of the 1996 Royal Commission on Aboriginal Peoples, giving the federal government a failing grade on 37 of the 62 recommendations included in their report card. Similarly, there has been recent criticism about the failure of the federal and provincial/territorial governments to honour their commitment to Jordan's principle (Blackstock, 2012; Canadian Paediatric Society, 2012). An external review of the federal health transfer program found that there were significant inequalities in per capita financing between and across First

Nations regions that could not be explained by the responsibilities each community had assumed. This study also found temporal differences in levels of community funding related to the year that the community signed their transfer agreement. A needs based funding formula was recommended (Lavoie, 2007).

# What Do We Know About The Impacts Of Racism On Health Services And Interventions To Address These Impacts More Generally?

Over the past decade there has been an increased research, policy and practice interest in interventions that address (Chin et al., 2012), primarily focused on African American and Latino populations in the United States (Chin, Walters, Cook & Huang, 2007). Racism, including prejudice and stereotyping is identified as an underlying determinant in conceptual modelling of racial and ethnic disparities (Chin et al., 2008, Institute of Medicine, 2002). The majority of the literature however is still descriptive and documents disparities in specific health outcomes or health service utilization without specifically exploring the causal pathway linking racism to these outcomes or assessing interventions to address racism (Paradies, 2006; Chin et al., 2008).

Drawing on a series of systematic reviews focusing on interventions aimed to reduce racial and ethnic disparities in health care for specific chronic diseases, Chin et al. (2012) present an overview of intervention strategies and eight best practices. Strategies are grouped and include: patient and provider education and training; community engagement; psychological support for patients and their families; reminders and feedback for patients and providers; restructuring of the health care team; improved language and literacy services; increased access to testing and screening; financial incentives for both patients and providers; cultural targeting; and use of technology. Best practices included:

- assessing organizational capacity to ensure that organizations are equipped to implement and sustain the intervention;
- fostering a culture of equity so that staff share a definition of equitable care and place a high value on its delivery;
- appointing staff to disparities reduction initiatives to ensure the intervention is given adequate time and effort and staff are not overtaxed;
- securing buy-in across organizations and consistent and accurate uptake of interventions by identifying and appealing to equity rationale that are most important to one's audience;
- incorporating disparities interventions into existing systems and anticipating ripple effects;
- involving members of the "target" population during program planning to ensure that programs are relevant and effective;
- striking a balance between adherence and adaptability so that programs are consistent yet flexible; and
- being realistic about the time necessary to "move the dial" on disparities (Chin et al., 2012).

Other frequently identified characteristics of promising interventions included: cultural tailoring to patients' needs; the use of multidisciplinary teams of care providers; multiple intervention points along the patient's pathway of care; patient navigation; and active engagement of family and community (Chin et al., 2012). Interactive health education was deemed more effective than didactic teaching.

### Implicit bias and racialized health disparities

"For example, while knowledge in the health field is thought to be research-based, it is usually based upon White eurocentric [sic] norms. Consequently, there is a tendency for

many professionals to assume that ethnocultural minority groups are irrational, primitive, and less than scientific. The embeddedness of racism also means that professionals may not consciously notice their assumptions." (McGibbon & Etowa, 2009, p.125)

Implicit bias refers to attitudes and stereotypes that occur unconsciously and inform our thinking, beliefs and behaviours (Staats, 2014). In contrast to explicit bias which one might try to suppress under the guise of political correctness, implicit bias occurs involuntarily and beneath the level of conscious awareness which also makes it more difficult and challenging to address (Staats, 2014). Early life experiences, media and news programming are frequently linked to the development of implicit bias; moreover, implicit bias can be present even where one consciously holds and expresses non-prejudiced beliefs (Devine, Forscher, Austin & Cox, 2013; Staats, 2014).

There is an emerging body of research examining the role of health care provider implicit bias in racialized health disparities; this literature is overwhelmingly based in the US context and most heavily focused on contrasting service providers' perceptions and treatment of Black vs. white patients as Black people experience some of the most egregious and persistent health disparities among all marginalized people in the US. This rapidly growing area of research highlights the ways in which implicit bias (i.e. pro-white/anti-Black or anti-Latino bias) can impact interactions with the patients and treatment decisions even when no explicit bias is expressed. This includes studies that demonstrate that Black and Latino patients are less likely to receive pain treatment (i.e. analgesics) than white patients (Todd, Samaroo & Hoffman, 1993; Todd, Deaton, D'Adamo & Goe, 2000), including Black children who were less likely to receive postoperative pain treatment than their white counterparts (Sabin & Greenwald, 2012).

The research of Green et al. (2007) suggests that implicit bias (specifically pro-white bias) may also impact on treatment recommendations for acute coronary syndrome, with a decreased likelihood of Black patients receiving appropriate therapies (i.e. thrombolysis). In this study, greater implicit bias was associated with a decreased likelihood of recommending thrombolysis for Black patients; however, awareness of the research attention to implicit bias also impacted treatment recommendations. A subsample of participant physicians in study who were aware that implicit bias was a focus were more likely to recommend thrombolysis for Black patients even if they held a higher level of pro-white implicit bias. Health care provider implicit bias also impacts the health care relationship and interaction with patients, affecting patient evaluation of and satisfaction with care which is in turn linked to treatment adherence, follow up with their physician and health outcomes (Blair et al., 2013). Blair et al. (2013) found increased physician implicit bias to be associated with decreased patient satisfaction by Black patients.

### Interrupting implicit bias: promising interventions

Devine et al. (2013) developed and an evaluated an implicit bias intervention in a random control trial study with non-Black undergraduate psychology students. The intervention was composed of training strategies pulled from the research literature and adapted for the intervention including: 1) stereotype replacement; 2) counter-stereotype imaging; 3) increasing opportunities for contact; 4) perspective taking; and 5) individuation. This study demonstrated significant reductions in implicit bias as well as increased awareness of both personal bias and societal discrimination, as well as increased levels of concern about discrimination and prejudice. Research specifically examining the use of strategies to address health

care provider implicit bias also offer some promising findings; for example, nurses asked to take the perspective of patients in pain ("perspective taking") offered equal levels of pain treatment regardless of race, whereas those not asked to use perspective-taking recommended significantly higher levels of pain treatment for white patients (Drwecki, Ward, Moore & Prkachin, 2011). Summarizing the literature on physician implicit bias to better understand and decrease its contributions to health care disparities, Chapman et al. (2013) suggest that perspective taking and individuation (focusing on the individual patient's information apart from their social group) as key strategies. They note that this requires that physicians must first acknowledge their susceptibility to implicit bias in order to effectively apply these strategies; indeed there are efforts underway to incorporate content addressing implicit bias and its role in health disparities into the curriculum and training of medical students (Gonzalez, Kim & Marantz, 2014; Teal et al., 2010).

Given the extensive level of multigenerational, systemic racism experienced by Indigenous peoples in Canada, and specifically the challenges of racism in the health care system articulated by our communities and increasingly documented in the literature, attention and efforts targeted at addressing health care implicit bias and reducing its contributions to the severe health disparities experienced by Indigenous communities represent an urgent and significant research priority.

### **Looking And Moving Forward**

## **Count Us In: Transforming The Conversation About Racism And Health In Canada**

The field of research addressing racial discrimination and health has grown rapidly over the past decade (Williams & Mohammed, 2009), linking a range of health disparities to experiences of racial discrimination and highlighting the importance of addressing racism in health policy, research, and service provision, as well as within the training and continuing education of health professionals. Despite longstanding recognition of the presence and impact of racism on Indigenous peoples and their health and well-being in Canada, there has been relatively little research specifically focused on the role of racism in Indigenous peoples' health (Currie et al., 2012b). Given that much of the existing research on racism and health has been led by scholars in countries with colonial histories similar to Canada (i.e. the US, Australia and New Zealand) in which Indigenous health disparities are strikingly similar to those of Indigenous peoples in Canada, there is much that can be learned in drawing from this work to adapt existing or establish new research instruments, approaches to policymaking, programming, service provision and anti-racism interventions. In addition to connecting and collaborating with international colleagues addressing racism in Indigenous health, there is a need to focus a concerted effort towards developing collaborative and coordinated efforts with other racialized communities to help move the agenda forward in addressing racism as a determinant of health in Canada. Not only can Indigenous communities benefit from the research and knowledge gathered by other racialized communities and researchers, but Indigenous approaches to understanding and addressing racism and health offer important, complex understandings of the context and impact of colonization in Canada which may also prove helpful to other racialized communities in addressing their own health disparities.

Moving the conversation of race and health forward in Canada requires engaging in a decolonizing approach to anti-racism that centres colonization in discussions and knowledge production about race and racism, fundamentally acknowledging the historic and ongoing colonization of Indigenous peoples (Lawrence and Dua, 2005). This is necessary to ensure that Indigenous peoples are no longer left out of or sidestepped in conversations of racism and health. It can also contribute to bridging silos of knowledge about the racism experienced by Indigenous people and people of colour which currently lack complexity and sophistication in being able to account for the experiences of mixed-race individuals who are both Indigenous and from communities of colour (e.g. a person of Cree and African Caribbean descent, Mohawk and Chinese descent, etc.). The devastating health disparities experienced by Indigenous peoples in Canada underscore the need for comprehensive anti-racism efforts to address systemic and structural racism, as well as the development of services, programming and interventions that recognize the impacts of racism on Indigenous peoples' health and well-being and assist them in dealing with it (Bombay et al., 2013; Currie et al., 2012b).

This work demands a foundational shift in how matters of racism and racialization are taken up by Canadian social institutions beyond the health care system, including education, child protection and justice, as well as how these issues are accounted for and addressed by public policies and formal legislation. It requires a departure from the cherished image of Canada as the well-meaning, international peacekeeper and the imagined harmony of the multicultural mosaic, and a long walk towards truth and reconciliation in a country that our current Prime Minister Stephen Harper claims has "no history of colonialism" (Henderson & Wakeham, 2009).

"A troubling factor in the field of social justice pedagogy and activism is the widely held notion that Canada has always stood solidly for the acceptance of diversity. This oft cited observation about Canada belies a hidden and not-so-distant national litany of hatred and discrimination based on racism and xenophobia. Boyko (1995) notes our national tendency toward whitewashing our racist history, observing that 'Canadians are often guilty of ignoring or warping our past while sanctimoniously feeling somewhat removed from, and superior to, countries struggling with racial problems and harbouring histories marked by slavery or racial violence' (p. 15). Acknowledging specific sources and manifestations of contemporary racism, as painful as these may be to face, will be instrumental to our understanding of crafting effective pedagogical responses to racism." (Lund, 2006, p. 206)

## Count Us In: Improving Indigenous Health Data Collection In Order To Address Racism As A Driver Of Indigenous Health Disparities

Data challenges pose a significant barrier to improving Indigenous health generally and for understanding the impact of racism specifically. The available population health data for Indigenous peoples in Canada is a patchwork, drawing largely on sources with significant limitations. This includes Statistics Canada survey data, such as the National Household Survey, the General Social Survey and the Aboriginal Peoples Survey, <sup>26</sup> which are limited by sampling frameworks that rely on voluntary participation subsequent to the

<sup>26</sup> The Aboriginal Peoples Survey only surveys off-reserve Indigenous peoples.

elimination of the mandatory long form census in 2006. The significantly reduced response rate of the 2011 National Household Survey (77 percent), compared to the 2006 long form census (93.5 percent) will add to existing challenges regarding the enumeration of Indigenous people in Canada including the incomplete enumeration or non-participation of several First Nations (Anderson et al., 2006), the reluctance of Indigenous people to self-identify to the federal government, and barriers to participation for homeless and highly mobile persons, both groups of which are over-represented in Indigenous populations. None of the other primary population health data sources (vital registration, surveillance, health service administrative files) consistently, inclusively, or reliably gather Indigenous identity information (Smylie and Anderson, 2006).

The First Nations Longitudinal Regional Health Survey (RHS) is an exemplar of an Indigenous-driven data source but collects data only for First Nations people living on reserve. There has also been significant advancement using database linkage approaches that match the registries of Métis Nations and First Nations communities. However these linkage approaches are limited in that there is usually only one source of Indigenous identity which precludes the quantification and adjustment of misclassification. Finally, developments in population-based estimates for urban Indigenous peoples through the use of respondent-driven sampling methods are promising (Smylie et al., 2011). Despite these advancements, there remains a significant and urgent need to advance Indigenous population level health data through the improvement of existing systems of public health surveillance and the development of Indigenous-driven measures of population health.

The need for meaningful data is critical to understanding and addressing the role of racism in creating and sustaining the health disparities experienced by Indigenous people in Canada. This echoes the work of scholars from Australia and New Zealand who are at the forefront of advancing knowledge addressing the impact of racism on Indigenous health (Paradies et al., 2008) and their call for research in four key areas: 1) the prevalence and experience of racism experienced by Indigenous peoples across the life course; 2) the impact of racism on Indigenous health across the life course; 3) the development of measures to assess systemic racism against Indigenous peoples; and 4) identifying best practices in addressing systemic racism against Indigenous peoples (p.16). We especially argue for concerted effort to develop or adapt effective interventions addressing attitudinal/interpersonal and systemic racism towards Indigenous peoples, and to undertake bold and brave evaluation of existing anti-racism strategies and interventions.

### **Telling Another Story**

We end where we began: we as Indigenous peoples must be the authors of our own stories. It is necessary to interrupting the racism that reduces our humanity, erases our histories, discounts our health knowledge and practices, and attributes our health disparities and social ills to individual and collective deficits instead of hundreds of years of violence, marginalization and exclusion. The stories shared here describe the ways in which racism has shaped the lives of generations of Indigenous peoples and contributed towards our contemporary health disparities. It is time for stories of change: change in how we imagine, develop, implement and evaluate health policies, services and education, change in how we talk about racism and history in this country. This is fundamental to shifting what is imagined and understood about our histories, our ways of knowing and being, our present and our future, and to ensuring the health and well-being of our peoples for this generation and generations to come.

### **Appendix A: Literature Search Process**

### Search Strategy: Databases, Terms And Inclusion Criteria

We undertook a systematic search of the published, peer-reviewed original research that addresses racism and its impact on Aboriginal/Indigenous peoples' health status/outcomes and health care access within the Canadian context. We comprehensively searched Medline (OVID), Ebsco (St. Michael's Hospital network; University of Toronto network), Proquest, Canada Thesis Portal, Bibliography of Native North Americans, First Nations Periodical Index, UNM Native Health Database, and Indigenous Studies Portal (iPortal) databases for the time period 1970-2013. In consultation with an experienced medical librarian, the following search terms were identified, and were used to search for relevant literature within these databases: (Aborigin\* OR Eskimo\* OR Inuit OR Inuk OR Métis OR First Nation\* OR "North American Indian\*" OR "American Indian\*" OR "Native American\*" OR Indian OR Indigenous) AND (racis\* OR prejudice OR race relations OR discrimination OR stereotyp\* OR colonial\* OR coloniz\* OR inequity OR inequality) and (health OR health care OR cultural safety OR cultural competence OR tradition cultur\* OR nursing OR medicine OR "social services" OR midwife\*), limiting for geography (Canada), time of publication (after 1970), and language in which the document was published (English).

Our initial systematic search identified 64 potentially relevant abstracts. After fully reviewing these 64 publications, we identified 44 publications that met the necessary inclusion criteria. Publications were selected for inclusion in that they:

• Involved/reflected and/or examined Indigenous/Aboriginal/First Nations/Metis/Inuit populations/ persons who self-identify as Indigenous/Aboriginal living in Canada

AND

• Involved general or specific health-related information (i.e., health service access, health status, holistic health, wellness/well-being, or social determinants of health)

AND

 Addressed racism, or prejudice, or discrimination, or health inequities, or differential access to health care, or the impact of historic and/or ongoing colonial policies on the overall health of Aboriginal/ Indigenous peoples

Each paper was then summarized according to three broad categories that reflected key findings from the publication: Health Determinants/Racism as a Determinant of Health; Health Status/Health Inequities/Colonization; and Health Care Use/Access/Barriers. Drawing upon the work of Richmond & Ross (2009), Smylie (2009), and Loppie & Wien, (2009) we include: racism, colonialism, environmental dispossession, and self-determination in our search and review of health determinants.

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