


# Frozen in Time, a Focused Review of Autism Prevalence in Canadian Indigenous Communities

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**Abstract:** The unprecedented global continuous rise in autism prevalence is often referred to as a *Pandemic* while its parallel cost increase to society portrays a *Tsunami*. Autism data originates mostly from industrialized *High-Income* geopolitical regions in Europe, North America, and Asian regions. Although efforts to determine autism data from regions in *Low* and *Mid*-economies are ongoing, prevalence information from geographically remote and economically vulnerable communities *within* the privileged regions is largely undetermined, as is the case of the Canadian Indigenous communities, the *First Nations*, *Inuit*, and *Métis* highlighted in this focused review. The underlying theoretical approach adopted here is *Transcultural Psychiatry* with its emphasis on *Context* including sociopolitical circumstances, considered the gateway to understanding health, illness, and recovery in groups and individuals. Accordingly, the review includes a concise relevant government system description and history of the relations with Indigenous peoples to provide context to present indigenous relations to Canadian government agencies. Scores in these communities face a myriad of survival challenges encompassing meagre health resources and services. Establishing autism prevalence data in these communities are exceedingly difficult due to multiple factors. While prominent among them are their strong ties to traditional approaches to health, illness, and autism conceptualization, the crucial obstacle is Crown and Provincial government authorities' and agencies' historically rooted colonial response to the needs of families with autistic members. It embodies a posture of *infantilization*, an attitude that is "frozen in time" in the approach, practice, accommodations, and services for these families. The review provides the preferred autism terminology, information sources, article flow, and Future Directions, all found in the Introduction's first paragraphs.

**Keywords:** focused review, autism prevalence, indigenous peoples, infantilization, sociopolitical context, cultural competence

## Introduction

### Autism Terminology, Information Sources, and Flow

In this focused review, the term Indigenous is used as opposed to aboriginal which has a colonial history connection (unless aboriginal is present in a government document), the terms autism and Autism Spectrum Disorder (ASD) are employed interchangeably, and identity-first language is applied in line with the preferred language of autistic individuals across the globe.<sup>1</sup> The Canadian data sources for this article relied on reported medical-administrative data, provincial health agencies, Government of Canada statistics and reports, Public Health Agency of Canada, Indigenous Services, and a manual search of Canadian journals and relevant articles. American studies were based on Federal and State databases, the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC), while global autism studies were obtained from World Health Organization (WHO) websites. The article begins by broadly defining the epidemiological term *Prevalence* and its uses. The subsection, the rise of autism and the parallel cost highlights the unbridled rise in autism prevalence globally, followed by the subsection Canadian indigenous under-identified and under-served communities, ie, the peoples of focus here.

The major obstacles to their autism prevalence determination are identified at this point, as is the theoretical underpinning, *Transcultural Psychiatry*, specifically, the importance accorded to context in exploring health issues. The next major heading, Canada's Parliamentary System explains the duality of the governing system, the judiciary

system, and their operation in dual official languages. The systems are replicated in the 10 Canadian provinces and three territories that compose the vast geopolitical region. It accentuates the cumbersome complexity and divided bureaucratic responsibilities indigenous peoples must navigate when trying to access services. A Concise History of Crown–Indigenous Relations provides the context for their present relationship with the government agencies, followed by the subsection, “*The 165 years of horror for Canadian Indigenous Children and their families*” that identifies the root and the result of the “Cultural Genocide” indigenous communities suffered, with debilitating intergenerational mental health outcomes. An example of a dire consequence is provided in the 2019 reported prevalence of Fetal Alcohol Syndrome Disorder (FASD), a lifelong disability identified in indigenous children and youth living on and off reserves, followed by an example of marginalization of indigenous peoples. The next major section, “Canadian non-indigenous and indigenous autism prevalence” presents the issues in prevalence determination in indigenous children in the context of non-indigenous autism prevalence data. The discussion that follows includes a description of the indigenous approach to “healing” their autistic loved ones and the changes their communities encourage and is followed by a Conclusion centering on the importance of using approaches that resonate with the communities in the role of individuals or groups invested in learning and/or providing needed services and supports to indigenous autistic populations.

The Future Directions section rounds off the article with recommendations to facilitate cultural competence in those intending to form a partnership with the community in which the population of interest is nested. It provides an alternate model that may serve three goals: 1. to instruct cultural competence, 2. to serve as a model for designing meaningful treatments for families and their autistic children and adolescents, and 3. to function as the gateway to facilitation of literacy acquisition in their community language as well as their school language(s).

## The Rise of Autism Prevalence and Parallel Cost

Prevalence of a disease refers to “the proportion of individuals in a population who have a particular disease or attribute at a specified period of time” –it includes both new and preexisting cases.<sup>2</sup> Determining autism prevalence is exceedingly difficult due to dynamic conditions such as unequal distribution of socio-economic resources, the diversity of cultures with unique views and approaches to autism, and a meager or lack of available health infrastructures that may be accessed in the geopolitical region. The application of complex algorithms is required for factoring these conditions into the calculations when establishing prevalence data. These are of utmost importance, especially in autism, with mostly lifetime serious impacts and the evolving needs of the affected individuals and their families. Prevalence data facilitate formation of policies and resources such as education, establishment of specialized centres, and development of professional training programs to provide essential services to autistic populations of any age. Moreover, since the data permit calculating risk of occurrence or number of new cases in a specified time, it increases possibility of early autism diagnosis, a factor that was shown to positively influence their adult quality of life.<sup>3</sup>

An examination of worldwide autism prevalence data obtained from health and educational records for the past years exposes a constant rise in numbers of affected individuals and highlights great variability.<sup>4</sup> In fact, differences in ASD prevalence were found in the same geopolitical region within different local school districts with high rates of socio-economic disadvantaged ethno-cultural minority groups.<sup>5</sup> The unprecedented prevalence growth of autism across geopolitical regions was characterized by some researchers as an autism “Pandemic”.<sup>4</sup> Others, using a population projection model spanning from 2015 to 2025 in the USA,<sup>6</sup> a region with the greatest autism prevalence among the privileged economies, forecasted the cost of autism at a staggering \$461 billion by 2025, a veritable “Tsunami” in terms of cost to society. Autism, a high need condition with attached developmental and physical comorbidities<sup>7</sup> tends to span from early childhood to adulthood with significant loss of productivity, requiring tremendous family and societal resources, hence the attached high costs. A study using data from US, UK, Australia, Canada, Sweden, the Netherlands, Egypt, and China<sup>8</sup> examined the nature of economic costs to the public and individual families provoked by autism. Six types of costs were identified, 1. medical and health care services, 2. therapeutic interventions, 3. special education, 4. autistic adults’ productivity loss, 5. family caregivers’ productivity loss, and 6. accommodation, respite care, and sundries costs. Education, the greatest cost to families, should serve as a red flag warning public agency that some families may not have sufficient economic resources to access effective educational and therapeutic programs.

The projected rise in autism costs tends to exceed that of some physical diseases on their own. For instance, scores of people are affected by diabetes, a serious condition that may lead to heart and kidney disease, and limb and vision loss.<sup>9</sup> The out-of-pocket costs for people living with type 1 diabetes are estimated in Canadian dollars at \$18,306 per year, and type 2 cost at \$10,014 per year.<sup>10</sup> Autism in contrast costs \$60,000 (about US \$45,000) per year for quality treatment.<sup>11</sup> A 2019 Canadian Health Survey on Children and Youth aged 1–17 years reported significant differences in optimal general and mental health between those with ASD and non-ASD peers: in those with ASD 59.3% showed optimal general health and only 39% optimal mental health while in the non-ASD optimal health occurred in 89.5% and optimal mental health in 84%.<sup>12</sup> In addition, a recent longitudinal study exposed noted comorbidities in autism.<sup>13</sup> Autistic girls exhibited higher levels of mental health issues in behaviour, attention, and anxious-depressed symptoms than their neurotypical peers. The authors consequently recommend the integration of mental health assessment in clinical practice. Although valuable advice, it is certain to increase the cost. A more prudent cost curbing approach to detecting elevated mental health signs is embedding probing questions into caregivers' initial interviews, a strategy meant to identify only high risk individuals as requiring a complete mental health assessment. Furthermore, evidence<sup>14</sup> is mounting that despite life-style factors, adult autistic individuals carry greater risk for comorbid physical diseases that increase the possibility of premature death than the general population. Autistic women, in fact, experience a higher incidence of cardiovascular and respiratory conditions, arrhythmias, low blood pressure, asthma, and prediabetes than non-autistic ones, and autistic men are more likely to have arrhythmias than neurotypical men. A decidedly more distressing statistic is the reported rates of suicide attempts and death by suicide amongst autistic youth and adults,<sup>15,16</sup> and greater vulnerability to suicide based on residence, eg, higher suicide rates in rural versus urban regions.<sup>17</sup>

Autism prevalence rise was evident a decade earlier, report researchers.<sup>18</sup> Since it was difficult to tease out the causative factor leading to the rise, the authors proposed an underlying combined effect of “multifactorial independent components”, and elaborated that no matter what is driving increases in autism prevalence, the growth in numbers of ASD identified children is indisputable, as is its serious impact on individuals, families, and communities. A worldwide systematic prevalence data update study reported a decade later,<sup>19</sup> confirmed a persistent global rise in prevalence with 1/100 children diagnosed with autism, attesting to a significant increase in prevalence over time. Diverse results were found across and within sociodemographic populations, reflecting the combined effect of multiple factors including changes in autism definitions and methodologies, contexts and increase in community awareness and capacity and public health response globally. Understanding the relative contribution of the underlying multiple factors including the potential changes in risk factors is vital for CDCs and autism monitoring systems.<sup>18</sup> These agencies require accurate prevalence data to facilitate early risk factor identification, to guide laws and policy development, and to plan services for affected individuals and their families' immediate and changing needs over their lifespan. However, prevalence accuracy, note the authors, hinges on the type of data accessed. Service-based data lead to prevalence underestimates since only individuals diagnosed with the service criteria receive Special Education Resources while the ones with a medical diagnosis of autism tend to be excluded from the count, warn the authors. Conversely, population based estimates, grounded on epidemiologic studies that include systematic screening of the population, may achieve higher and more accurate prevalence results as they are more likely to uncover individuals not yet identified, conclude the researchers. Systematic early screening, however, was not recommended by US health authorities as the costs tended to exceed the benefits, unless children are signaled by their primary caretakers and/or diagnosed with a developmental delay (p.32).<sup>20</sup>

## Canadian Indigenous Under Identified and Under Serviced Communities

Despite the availability of prevalence data from across the globe, serious uncovered autism incidence exists in various underserved and often geographically remote communities within the privileged regions. Our knowledge of autism and the applied diagnostic instruments, however, is mostly based on data from industrialized high-income geopolitical regions, observe researchers.<sup>21</sup> Although more recent data tend to include some degree of awareness of geographic and cultural aspects of understudied and underserved communities, the key to providing them with substantive services is a more profound understanding of their socio-political context, culture, and how disorders are manifested and managed in their communities.<sup>22,23</sup> This knowledge is crucial in identifying autistic individuals' needs with meaningful

ethnoculturally sensitive screening and diagnostic instruments, applied by culturally competent professionals, and answering these needs by adopting and adapting culturally appropriate interventions to benefit their autistic populations.

This focused review targets Canadian First Nations, Inuit, and Metis communities that face a myriad of survival challenges, including meager health resources and services as do the non-status Indians. These are essentially First Nations individuals who were not granted indigenous status under the Indian Act. Now, under the Constitution Act (1982), they are able to apply to the Indian Register and First Nations membership to benefit from Treaty annuities, estates and trusts.<sup>24</sup> In all, these communities form the indigenous peoples of Canada. They represent geographically remote and economically vulnerable communities within a privileged region. Establishing autism prevalence data in these communities are exceedingly difficult, encompassing a number of serious factors. Primary among these is the authorities' historically rooted colonial stance of infantilization of native peoples whereby crucial decisions are made "for them" rather than "by them" or even "with them", including defining for them who is an indigenous person to verify their status vis a vis community membership and benefits.<sup>25</sup> The exclusion of indigenous views and practices in health and diseases from databases and prevalence studies provides further evidence that these agencies are "frozen in time" in their attitude and approaches. A conclusion best expressed in a Canadian scoping review abstract,

In Canada, indigenous families and children experience structurally rooted marginalization due to longstanding and ongoing histories of colonization and discrimination.<sup>26</sup>

Transcultural Psychiatry's emphasis on Identifying the socio-political-economic context of an issue as paramount in defining and understanding health and illness in individuals and communities adopted in this focused review motivated the inclusion of a concise description of Canada's governing structures and their history as context for the relationship with Canadian indigenous peoples, including ASD manifestation and its management in their families and communities.

## Canada's Parliamentary System

Transcultural Psychiatry recognizes that cultural history, politics, and economy are the contexts underlying diverse approaches to health, illness, and recovery in any milieu.<sup>22,27</sup> In keeping with the importance accorded to context in transcultural disciplines, this section elaborates on the Canadian parliamentary system and presents a brief history of government or Crown–Indigenous relations and its impact on how health, including autism, is viewed and managed.

Canada, composed of 10 provinces and three vast territories, personifies duality with its constitutional monarchy, parliamentary democracy, and a bicameral system, ie, the upper house or the Senate, and the lower house or the House of Commons (from the Latin *communes*). The Prime Minister is the Head of Government, and the British monarch King Charles III, is the Head of State in Canada as well as the Commonwealth countries, Australia, New Zealand, and United Kingdom (UK). However, his role in each differs and is independent from the others. In Canada, the monarch's powers and responsibilities are limited by the Canadian Constitution mainly, and the government acts in the name of the Crown, with authorization from Canada's parliament. On the Prime Minister's advice, the monarch appoints his representatives, the Governor General who then appoints 10 provincial lieutenant governors to act in his name.<sup>28</sup> The system, modeled on the British parliament, consists of the Crown, the House of Commons, and the Senate which serves as a counterbalance to the House of Commons' representation by population power. Currently, the Senate engages mainly in advocacy for vulnerable groups, including Indigenous peoples. The Federal Government's two houses, the House of Commons and the Senate, and the ten provincial and three territorial governments comprise the legislature or lawmaking body. The laws, presented to these bodies in both official languages, English and French, are adopted once the Governor General gives it "Royal Assent" or approval, usually with a head nod.<sup>29</sup> The Prime Minister, chosen by his elected political party, confers ministerial roles on selected party members to form his Cabinet, and allocates selected ministers an individual portfolio or department (with parliamentary secretarial assistance). The Cabinet forms the executive council responsible for policy development and bill introduction that becomes law upon acceptance by the legislature, ie, the elected parliament.

The Canadian justice system represents a legal duality with two legal traditions, common law, a system based on precedence (dates back to 1215 with the signing of the Magna Carta; considered the origin of the Common Law system), and civil law based on the French Napoleonic Code (named for Napoleon Bonaparte who in 1804 revised an old ineffectual legal system), and operates bilingually with Canada's two official languages.<sup>30</sup> Canada's supreme law is

embodied in its Canadian Constitution.<sup>31</sup> The country was an independent British Colony created in 1867 but right to amend the charter or constitution remained in the UK until its patriation in 1982 with amendment rights embedded in the Canadian Constitution. The Federal government is responsible for various services and constitutional matters across Canada, including three territories, Yukon, Northwest Territories, and Nunavut – a huge sparsely populated territory separated from Northwest territories in 1999 to form the Inuit homeland. The territories' accorded powers are equivalent to the provincial legislatures in matters of education, property, civil rights, justice administration, hospitals, municipalities, and other local or private matters within the provinces. Each province and territory has its own judiciary system with a superior court. The Supreme Court of Canada presides over the entire complex and esoteric judiciary system; its main function is to settle disputes and ensure crimes are “prosecuted in accordance with Canada’s legal and constitutional structure”. The superior court’s jurisdiction and proceedings are considered a continuation from the first courts in England since the signing of the Magna Carta.<sup>32</sup> In the Canadian system, the appointed judicial head minister is assigned two portfolios: the Minister of Justice role includes ensuring the bilingual and bijural national legal framework and some other legal policy areas including Indigenous justice, and as Attorney General the minister is a Crown litigator, and legal advisor to the government, its departments, and its agencies.<sup>33</sup>

Indigenous matters are currently managed by two departments, each headed by its own minister: the Indigenous Services Canada supports the delivery of health care, childcare, and education to Indigenous communities; the Crown–Indigenous Relations and Northern Affairs Canada department administers Indigenous-government relations delineated by treaty rights and self-government agreements, and the concerns of Northern communities.<sup>34</sup> The Canadian constitution recognizes three groups of Indigenous peoples as noted earlier: First Nations – the historically named *Indians*, Inuit – the people of the North, and Métis – those with mixed European and Indigenous ancestry.<sup>35</sup> These are three distinct peoples with distinct communities, originating from a large diversity of nations with unique histories and a myriad of languages and cultural practices, in fact, there are more than 600 First Nation communities in Canada constituting more than 50 nations and 50 indigenous languages, embodying a huge diversity with some commonalities but many differences especially in their experience with life in Canada that differs by age and region. This reality appears to be a little known fact in settler populations although it replicates their own families’ histories and experiences in their European roots, a continent populated by a collection of nations with diverse languages, cultures, and interests, flecked with inter-nation alliances, frequent feuds, and devastating wars.

## A Concise History of Crown–Indigenous Relations

Canadian history is complex with a timeline marked by frequent conflicts and wars between imperial French and English colonialists, entangled with US history and its civil war, the *Seven Year* global war fought in Europe, India, and North America, and hundreds of signed treaties with indigenous nations spanning 300 years.<sup>36</sup> Here, the concise history commences with the British creation of the *Indian Department* in 1755 (without Metis and Inuit peoples) from which originated the current Canadian Federal Departments responsible for Indigenous affairs. The British military administered *Indian Department* primary role was to gain First Nations military aid for the Colonial British, a need that diminished by the end of the war with the American colonies, and the catalyst to the shift in the Indian Department’s (with its agents) role. Their focus recentered on “civilizing” indigenous peoples by persuading them to adopt the two commitments embodying *British civilization*, Christianity and Agriculture. These were meant to displace their traditional “savage” existence, ultimately. Following the union of the various British colonies and formation of Canada as an independent entity, the British transferred responsibilities for indigenous affairs to the Federal government. The British Indian Department’s colonial rationale and aspirations of assimilating indigenous into settler society formed the basis of the 1876 Indian Act, introduced by the Canadian parliament.<sup>37</sup> In essence, the Act stripped indigenous peoples from their rights to exist with their lifestyles, spiritual and cultural traditions, including self-governing practices such as election of chiefs of bands, and determining who is to be considered an Indian with legal rights attached to the Indian status delineated by the British Indian Department.

The Indian Act was highly discriminatory and remained so despite several amendments over the years, with the last discriminatory clause against women repealed only in 2019 allowing Indian status to their offspring. Although the term Indian is considered offensive, the Indian Act continues to exist and is pivotal in the relation of the government with



Indigenous communities. In 1996, the government determined to start a new era in relations with indigenous, drafted the Royal Commission on Indigenous People which laid out a set of recommendations meant to define and recognize “who is an indigenous”, with self-governing plans, and allocated funds. However, it continued to base decisions on the Indian Act.<sup>25</sup> In keeping with the persisting government’s attitude of indigenous infantilization where decisions are made for them, they were not consulted on the drafting of Royal Commission’s recommendations, and without explanation of the preservation of Indian Act treaty rights, they feared losses, and so they withheld repeal consent; hence, the Royal Commission recommendations were not activated.<sup>37</sup> Nonetheless, the relationship with the government evolves continuously, and a change in its approach was spurred recently by the *United Nations Declaration on The Rights of Indigenous Peoples Act*<sup>38</sup> which received Royal Assent in Canada, and forms a new basis for a respectful relationship with indigenous communities,

[it] provides a framework for reconciliation, healing and peace... relations based on the principles of justice, democracy, respect for human rights, non-discrimination and good faith. (Statutes of Canada, 2021, c.14)

## The 165 Years of Horror for Canadian Indigenous Children and Their Families

In Canada, the Child Welfare system, a relatively new entity, is the responsibility of Provincial and Territorial governments.<sup>39</sup> The services are concerned with social and environmental difficulties that impact the well-being of families and their children directly attributed to *Poverty*, identified across the globe as the primary causative factor correlated with child welfare problems. Social services have tremendous decision powers, including removal of children from their homes and placing them in state care. Although the indigenous population in Canada constitutes only 7.7% of the population (Statistics Canada 2016 Census), indigenous children constitute 52% of all children in state care, a staggering overrepresentation, and a damning fact. The colonial policies, views, and management of indigenous populations are undoubtedly at the very roots of this dire situation as well as the exceedingly worse reality whose consequences continue to haunt indigenous communities.

Attitudes to indigenous peoples were shaped by historically deep-rooted colonial views that accorded no value to their cultures and languages, a view shared by government and religious institutions. They were depicted as no better than *savages* and viewed as “unfit parents to remove the savagery” from their children, the ultimate goal of these institutions. This spurred the 165-year long (1831 to 1996) appalling act of tearing away countless children from their homes, subjecting them to despicable horrors in *State and Church* operated *Residential Schools*,<sup>40</sup> effecting the darkest chapters in Canadian history. Thousands did not survive and their unmarked graves on former residential school properties continue to be uncovered and excavated. A Canadian scoping review concludes, “the empirical literature confirms the negative health effects of residential schooling on both former residential school attendees and subsequent generations”.<sup>41</sup>

A prime example of *intergenerational consequences of residential schools* is the 2019 Canadian Health Survey on Children and Youth *Fetal alcohol syndrome disorder* (FASD) reported prevalence. FASD, a lifelong disability attributed to maternal alcoholism, is often accompanied by long-term physical and mental health conditions.<sup>42</sup> Both FASD and ASD exhibit neurodevelopmental impairments which may account for their noted clinical overlap that may lead to misdiagnosis of ASD as an FASD and so distort prevalence.<sup>43</sup> The survey of non-indigenous Canadian children aged 1–11 showed FASD prevalence was 1/1000 and 2/1000 in 12–17-year olds. Pooled prevalence (meta-analysis of various samples) in indigenous children and youth living on and off reserves was 8.7% vs 0.5% in non-indigenous living in the general population, a staggering ratio of 58/1000, a difference statistic difficult to explain with the usual suspected factors. An interesting, reported statistic is that indigenous children and youth living *off reserve* had a significantly higher prevalence of FASD than those *on reserves* (1.2% vs 0.1%), implying a more protective role of life on the reserve. Furthermore, a 2015–2016 survey reported FASD prevalence in children and youth in 2002–2003 showed a significant prevalence decrease from 1.8 to 0.5 for children and youth living on reserve with their families. This significant decrease in FASD prevalence statistics reinforces the evidence for the undeniable positive effect of children and youth living on reserves with their families, a welcome statistic that should serve as a guideline for preferred FASD intervention management occurring within the indigenous community rather than outside it. Based on published evidence, the authors conclude that among the multiple underlying factors is *the devastating effects of colonization, residential school*

experiences, and the ongoing economic and social marginalization that Indigenous peoples experience.<sup>40,42</sup> Evidently, the horrors of Residential Schools continue to haunt the families and their offspring. As one survivor sums up, “it wasn’t a school, it was a place to kill the Indian in us”.<sup>44</sup> When considering indigenous educational accomplishments as attested by a national survey of educational attainment of Indigenous peoples in Canada,<sup>45</sup> no doubt remains about their marginalization. The survey included indigenous people aged 25–64 representing 3.7% of the total population, in comparison to the same non-indigenous group. The proportion of indigenous people aged 25 to 64 with ‘no certificate, diploma or degree’ was 29% compared to 12% in the non-indigenous group. In addition, ~48% in the indigenous group had post-secondary qualification vs ~65% in the non-indigenous group. In the indigenous group, ~14% had ‘trades certificate’, ~21% a college diploma, ~4% a university certificate or diploma below the bachelor level, and ~10% a university degree. In the non-indigenous group 12% had a trades certificate, ~21% a college diploma, ~5% a university certificate or diploma below the bachelor level, and ~27% a university degree, ie, a significantly higher proportion of university degree attainment was evident in the non-indigenous sample. Furthermore, an examination of indigenous proportion of high-school graduates showed 68% of 35–44-year olds vs ~59% of 55–64 age group graduated high school, ie, more graduations occurred in the younger group. The non-indigenous high school graduates aged 35–44 was ~89% vs ~80% in those aged 55 to 64. This indicated relatively equal age group attainment between the indigenous and non-indigenous groups, but a significant disparity in the proportion of high-school graduates favouring non-indigenous peoples in all age groups was evident.

An official *Commission for Truth and Reconciliation* (TRC) collection of evidence of the wrongs committed against indigenous communities culminated with a plan and an agreement for Reconciliation, ie, highlighting truth about institutions’ colonial practices, including indigenous peoples in all institutions of modern life in respect for their cultures and their land rights and indigenous-administered child welfare and education systems. In 2007, the *Indian Residential Schools Settlement Agreement*, the largest class-action suit in Canadian history, was launched against the government. The TRC final report was accepted by the Prime Minister in 2015, and an official apology issued, “*The Government of Canada sincerely apologizes and asks forgiveness of the Indigenous peoples of this country for failing them so profoundly*”. The statement elaborates that the leaders of First Nations, Métis Nation, Inuit, in all provinces and territories as well as all parties involved in the *Indian Residential School Settlement Agreement*, will form the new relationship that will take part in *developing and implementing a national reconciliation framework*, to be guided by the TRC recommendations.

Fortuitously, a *long fought battle* of Metis and non-status Indians against the Canadian government was won in Supreme Court in 2016, named *Daniels Declaration* (SCC 12 File: 35945. 2016). It confirmed the federal and provincial judicial feuds denying their obligations for these groups resulted in dire consequences for them. The court declared the Federal Government and its designated departments responsible for these peoples. Moreover, the court stated that the Constitution Act’s (1867, 1982), *historical, philosophical, and linguistic contexts* establish that “Indians” clearly refers to all Indigenous peoples, including non-status Indians and Métis (in s.91–24, October 8, 2016).<sup>46</sup> This declaration enhanced the spirit of reconciliation as numerous children from these communities too were victims of the Residential School system. The admission of “cultural genocide”<sup>39</sup> practiced by the colonial institutions of Canada is contained in many documents and statements.<sup>47</sup> The TRC’s role, in collaboration with the Crown–Indigenous Relations and Northern Affairs Canada’s department, is promoting reconciliation among former residential school students, their families, their communities, and all Canadians. On June 21, 2017, encouraged by indigenous requests for a national indigenous people day, the government declared June 21, the summer solstice, chosen as it represents a new life in indigenous culture. The purpose of the dedicated day is to celebrate the history, heritage, resilience and diversity of indigenous peoples across Canada.<sup>48</sup>

## Canadian Non-Indigenous and Indigenous Autism Prevalence

The Public Health Service of Canada’s 2019 Autism survey on Children and Youth report inner cover states its mission: “To promote and protect the health of Canadians through leadership, partnership and innovation, and action in public health”,<sup>49</sup> a lofty mission indeed with expectations that it includes all children and youth in Canada. The document

reports the autism survey as representative of the Canadian 1- to 17-year-old population living in private dwellings in Canada's ten provinces and three territories. Shockingly, the report's Executive Summary clarifies that,

Excluded from the survey's coverage are children and youth living on First Nation reserves and other Indigenous settlements in the provinces, and children and youth living in foster homes and in institutions (these too are replete with indigenous children)

Furthermore, the Public Health Agency's 2023 evaluation report on Canada's autism program activities for years 2018–2019 and 2021–2022<sup>50</sup> does not address these exclusions from surveillance and prevalence studies, although a recommendation included a reference to the indigenous community collaboration on needs identification, but concluded that Indigenous Services Canada, the funding agency, “does not currently have an ASD-specific program”. No explanation for the exclusions is provided in any noted report or consequences explored. However, a research letter in a Canadian journal by prestigious universities' researchers stated that identifying barriers to appropriate timely care in Canada cannot be achieved when vulnerable populations are excluded as it creates a critical gap that will affect future research.<sup>51</sup> Other researchers note that exclusions of vulnerable populations tend to imply underestimates of FASD and ASD prevalence in the Canadian public.<sup>42</sup>

Establishing accurate prevalence data in the second-largest country on this globe, with ten provinces and three territories with layers of administrations in each province and territory and each with its own privacy laws, is no mean challenge for epidemiology scientists and researchers.<sup>52</sup> The Federal government's Public Health Service of Canada's efforts in overcoming obstacles succeeded in producing valuable data on the state of Autism in non-indigenous child and youth populations across Canada and territories, albeit, without addressing the indigenous and other exclusions. The reported prevalence data included the individual provinces, but the three territories were excluded due to small sample sizes, the reason given. The explanation is directly related to the territories' indigenous population distribution, the very people excluded de facto from the survey: 86% in *Nunavut*, 51% in the *Northwest Territories*, and 23% in the *Yukon*, while the non-indigenous inhabitants constitute a numerically insignificant and inadequate sample for surveying, yet another consequence of exclusionary policy.<sup>53</sup>

## Non-Indigenous Autism Prevalence

The 2019 comprehensive report<sup>54</sup> includes data on non-indigenous children and youth aged 1–17. The survey, based on responses to a *Person Most Knowledgeable about the child* questions, examined autistic children and youth and their non-autistic comparison group. It reports age at diagnosis, prevalence, physical and mental health status, co-occurring long-term health conditions, functional and adaptive difficulties, and school experiences, a veritable treasure trove for any epidemiologist or clinical scientist.

The prevalence showed 1/50 diagnosed with autism. The highest was in the 5–11-year group (1/40), followed by the 12–17-year olds (1/53), and the lowest was in the 1–4-year olds (1/91). Males outnumbered females 4/1 in all age groups, and the largest difference was in those aged 5–11. The Age of diagnosis exam showed statistically significant differences in all three age groups: 54% were diagnosed between 0 and 4 years, 40% between ages 5–11, and only 6% were diagnosed between ages 12–17. No statistically significant results were noted when the following were examined: associations between ASD prevalence and household income; population type: visible minority, not a visible minority, and indigenous identity; household education: less than high school to post-secondary; and location of residence: urban vs rural. An exploration of life satisfaction, perceived happiness, and self-perceived stress comparing those with ASD to non-ASD peers showed that those with ASD had less optimal general and mental health, they were three times more likely to have other long-term health condition: ADHD mostly, learning disability, and anxiety disorder, and many more with ASD had difficulty in functional domains. Depression in 12–17-year olds was the lone statistically significant difference factor among the groups.

## Indigenous Autism Prevalence

The fact that Canadian governments tend to omit indigenous children and youth from autism surveys, data bases and reports demonstrates a glaring neglect that is responsible for non-existent autism prevalence data, and consequently, under-detection.<sup>26,55</sup> This incomprehensible phenomenon in earlier and later instances attests to inequitable government



response to indigenous children's health which clearly does not match the one to non-indigenous populations. For example, the 2006 Canadian parent/guardian survey<sup>56</sup> reporting on the state of health in 12,845 Inuit children under age 6 representing about 135,022 indigenous children under age 6 in Canada showed that 77% of Inuit children's reported health was *very good to excellent* vs over 90% *excellent* reported health in non-indigenous counterparts, evidence for a clear disparity. Chronic conditions in 23% of diagnosed and treated Inuit children with poor health included Asthma in ~99%, speech and language problems in 72%, and while ~76% were diagnosed with hearing impairment, only 65% received treatment. Autism, clearly not a great concern to the authorities and/or not consistently identified by the Inuit community, was lumped under *Other chronic conditions* with visual impairment, ADHD, heart condition, epilepsy, and lastly autism. Only asthma and allergies were the noted co-occurring chronic conditions in this survey for both the indigenous and non-indigenous children.

The 2016 Census Canada states that more than 1.67 million people in Canada identify themselves as an indigenous person. They constitute the fastest growing population in Canada with 42.5% growth occurring between 2006 and 2016, and the youngest population in Canada as measured in 2016 with ~44% aged under 25.<sup>57</sup> Nonetheless, the 2019 Statistics Canada disability survey included data from a previous report (2017) showing higher disability prevalence (includes physical and mental burdens affecting wellness and mortality) among Indigenous peoples in Canada than in the non-Indigenous population.<sup>58</sup> The Inuit were included in the data; however, a significantly lower disability prevalence was found for those residing in their territory than for those residing outside their territory. A study of indigenous youth<sup>59</sup> showed many exhibit serious health issues, and face glaring inequities in accessing health services and social stereotyping, leading to more frequent incarceration compared to non-indigenous peers. In all, given that indigenous peoples constitute Canada's *youngest population*, the disability data reported for them are disheartening and imply that their quotidian lives are replete with mostly morbid challenges.

The disability research focus is on persons' with disabilities' "experienced barriers to participation in society and the economy". The framework applied to Canada is a social model that views the disability within an environmental context and includes, among others, an examination of discrimination and exclusion factors. It showed Indigenous people experience significantly more trauma and barriers than the non-indigenous populations, although they constitute only 5% of Canada's population.<sup>57</sup> The challenges they face were identified as limited or non-existent access to health care and supports, the colonization history and the residential schools, and forced relocation of their communities, all challenges with an indelible impact on their general and mental health, and contributors to early mortality. A flagrant neglect of health authorities' nebulous management of indigenous children is exemplified by the case of the First Nation's Cree child, Jordan River Anderson. Born with multiple disabilities, he remained hospitalized for five years until his last breath at age 5. Although at age two his physicians recommended a home-based care equipped for all his needs, the *no-man's-land* created by the feuding Provincial and Federal governments over who should pay, a common trap researchers identified as causing "under-diagnosis and potentially life-threatening",<sup>60</sup> resulted in his living out his short years in the hospital without experiencing the joy of life with his family. The House of Commons passed *Jordan's Principle rule* in memory of Jordan, a legal obligation, without an end date, to ensure that indigenous children get the health supports and services they need, when they need them, without worries about payment.<sup>61</sup> Nonetheless, the jurisdictional feuds are ongoing and are documented in other studies and so does the resulting suffering of indigenous children with little alternatives to health care.

Researchers observe that prevalence data on indigenous autism is largely absent despite the rise in autism data availability broadly and increased autism public awareness.<sup>26</sup> The severe lack of studies in Canadian indigenous autism was examined by University of Alberta researchers in a scoping review.<sup>62</sup> The research team was led by a university PhD candidate with membership in an indigenous community, a father to autistic children, while an indigenous autism advocacy group formed one of the research partners, rather a unique team in the context of Canadian research. The research is therefore viewed from an indigenous lens while the examined available autism literature represents non-indigenous or traditional research. The literature screening involved an adapted *indigenous quality of research tool* to determine Indigenous people inclusion in each article, and feedback on the review process from the indigenous advocacy group. The literature acceptance criteria included an autism focus, indigenous people specific component, and a Canadian milieu. Three study questions were posed: 1. the knowledge gained about autism in Indigenous communities in Canada:

It was determined as rather limited, and lack of clarity was evident on who should perform the suggested additional research. 2. identifying areas of focus in studies on autism and Indigenous peoples in Canada: Most screened research focused on program delivery including special education, barriers to diagnoses, etc.; however, an important finding was lack of equitable access for indigenous children and their families to diagnostic assessment, services, and intervention support. The obstacles identified were geographical distance, legal status, and funding; however, the researchers identified provincial and federal governments' feuding over funding as the major underlying obstacle associated with serious negative impacts as identified in earlier research.<sup>63</sup> 3. examining the quality of the screened articles: The overall poor quality of the selected articles confirmed for the researchers that indeed there is *a critical need* for quality research focused on autism in indigenous communities within Canada. Furthermore, it highlighted the importance of carrying out research with full Indigenous participation led by indigenous people or as research partners.

A Policy Practice review article<sup>63</sup> authored by a team that included indigenous academics and other autism invested individuals, proposed an approach meant to address the persisting obstacles to equitable resources and services to benefit autistic indigenous peoples as well as other vulnerable communities. Although the inclusion of communities other than indigenous is valuable in itself, it is beyond the scope and focus of this review, and so only indigenous specific information is retained from the researchers' proposal. The proposal's stated goal is determining appropriate care strategies for the autistic indigenous individuals in their community that are meant for inclusion in Canada's planned National Autism Strategy. Priority was given to ending the intergovernmental feuds, a major obstacle to timely health care, by clarifying the federal agencies' constitutional responsibility for indigenous health and welfare. In actuality, this was declared/stated by the Supreme Court in 2016 in a case named Daniels Declaration<sup>46</sup> and included a resolution to the dispute denying services to unregistered Indians and Metis people: the supreme court clarified that *Indians* refers to all Indigenous peoples; ergo, non-status Indians and Métis are included (in s.91–24, October 8, 2016). Despite the decree, an insistence on proof of indigeneity, which limits their access to health and services, is a perpetuation of historically practiced systemic discrimination that devalues indigenous peoples, and degrades their lives.

The Policy Review authors put forth an autism care plan based on the indigenous holistic approach to health and wellness within a community milieu, known to benefit its vulnerable members, using identified articles' themes: *Inclusion and Acceptance* – refer to the indigenous embracing of autism from a strength perspective as opposed to a medicalized deficit stand, ie, autistic individuals are treated as valued members of the community which readily supports them, hence they live in a healing environment of acceptance and inclusion; the *Supportive Network of Family and Community* theme reflects “the indigenous way of living” with emphasis on reciprocal connectedness of family and community and the individual's challenges' impact includes a shared responsibility of family supported by the community; and lastly, the *Engaging in Indigenous cultural identity* theme highlights the need for culturally safe services and support strategies that optimize well-being as it facilitates participation in the indigenous community's traditions, ie, practicing one's cultural identity is considered a protective factor. Moreover, a distinction-based approach is imperative as it respects the indigenous communities' diversity of distinct cultural and linguistic differences rather than one-fits-all strategies and protocols that fail to benefit them. In addition, communities' physical environmental needs such as access to clean water, safe housing, etc. were prioritized as they benefit the entire community, as was a strong recommendation for indigenous community led projects. These culminated in a non-exhaustive list of thematically based recommendations described in the discussion.

## Discussion

The focused review set out to investigate Canadian indigenous autism prevalence. The subsequent journey revealed difficult and convoluted relations between indigenous and government bodies directly attributed to colonial heritage of devaluing indigenous history, languages, and cultural-spiritual practices interwoven with their concepts of health and wellness. In tandem, the journey highlighted the evolving nature of indigenous-government relations with the large majority of the regions in favour of putting an end to historic rooted colonial systemic discrimination and practices, and accepting indigenous existence, not as a collective, but as three independent peoples who must be addressed according to their distinct cultures and needs (with some shared by all).

The various government documents examined showed an unexpected lack of data on autism in any of the country-wide surveys, stating outright that indigenous populations are excluded, with no explanation, and yet, Indigenous FASD prevalence was addressed. A plausible explanation, the cultural-spiritual driven indigenous autism conceptualization does not consider autism a health issue, may have been a triple-edged factor: the community failing to seek services, the obstacles encountered when they do so, and the intergovernmental feuds over who is responsible for these peoples' health. Nonetheless, struggles experienced by individuals and families with autistic loved ones are often accentuated by documented limited and difficult to access resources. The major culprit identified in the various examined papers as causing them "to fall between the cracks" was attributed to the feuds between governments over who should pay.<sup>63,64</sup> Furthermore, when access is finally gained, they are confronted with intervention approaches antithetical to indigenous "Way of Living" which harbors acceptance of autistic individuals as "different thinkers" and approaches them from a strength-based health view rather than deficit-based one, allowing them to flourish.<sup>65,66</sup>

The *Policy Practice* review article<sup>63</sup> findings culminated in viable recommendations that reflect indigenous views of their needs, added here in a nutshell: 1. Develop an Indigenous autism network with autism advisory groups to benefit First Nations, Inuit, and Metis, respectively. 2. Identify health care barriers and develop a report focused on the barriers and solutions in partnership with indigenous groups. 3. Provide support for research led by indigenous researchers in collaboration with communities and organizations with the goal to provide empirical evidence of the needs of indigenous peoples in Canada. 4. Create and pilot culturally informed autism services including assessment and interventions in collaboration with Elders and Traditional Knowledge Keepers (culturally knowledgeable individuals taught to transmit knowledge about their traditions, ways of living, values, language, etc.), community members, indigenous autistic individuals, and Indigenous service providers. Lastly, 5. Provide equitable funding across Canada for Indigenous communities and organizations charged with building culturally safe autism services and the needed tools, including autism awareness and education. In addition, it is highly recommended for documenting any jurisdictional disputes between authorities with an indigenous autism focus and explores how these can be solved.

The Canadian government recently introduced the *Federal Framework Act on Autism Spectrum Disorder*<sup>66</sup> indicating that the proposed recommendations were included. The act preamble (S.C. 2023, c. 2) states that the absence of a coordinated national strategy hinders the solutions to benefit autistic individuals and families' lifelong needs. It is a legally binding document meant to ensure consistency and timely direct and ongoing access to resources for autistic individuals throughout their lifespan. The detailed measures of the act include fair and timely access to screening and diagnosis for autism (activation of Jordan's Principle), financial support for autistic persons and their families including tax benefits as needed, support for caregivers, a national research network to promote and improve research and data collection, fostering inclusivity of autism and understanding the need for sustained, accessible and culturally relevant resources, and much more. Consultations with relevant stakeholders included *service providers and representatives from the medical and research communities and organizations that focus on autism spectrum disorder in Indigenous communities*. It seems the issue of paucity of indigenous autism data has reached the higher echelons of government. However, given the plethora of ministries with their corresponding complex of mammoth bureaucracies named in the act (inter-departmental feuds a noted barrier), hope is reserved for speedy or "timely changes" to benefit the indigenous autistic community and their families in a reasonable time period, especially crucial when striving for early identification of autism. The communities must therefore (as always) count on their resilience and creativity to put forth their demands for speedy activation of the strategy. However, a positive sign may be the ongoing long-term reforms of family services and Jordan's Principle agreements (which hopefully include all indigenous groups).<sup>60,61</sup>

One of the obstacles indigenous communities must face is lack of *admission of guilt of systemic discrimination* in health care, as it was not forthcoming from all governments in the land, despite strong evidence for its existence. A news release by Indigenous Services Canada<sup>67</sup> highlighted the tragic death of a First Nations young woman, Joyce, prompted the ministers to work on eliminating discrimination in health services. Joyce, a mother to seven, hospitalized miles from her home, was stereotyped as a drug addict and suffered ridicule and withholding of essential treatment by staff despite her history of chronic illness and her complaints of severe pain. She videorecorded this cruelty, and hours later she died of her serious medical problem. In response to this unacceptable tragic death, the Minister of Indigenous Services supported legislature named *Joyce's Principle* meant "to guarantee all Indigenous Peoples the right to equitable access

to social and health services, as well as the right to enjoy the best possible physical, mental, emotional and spiritual health". The bill was promptly stymied by one party who found the incident 'regrettable' but felt it does not constitute proof of systemic discrimination. The Indigenous Services Minister responded with a sizable contribution to Joyce's community "to advance their work and advocacy for the implementation of Joyce's Principle", a Sisyphean challenge indeed, when trying to battle an inbred structured negative attitude toward indigenous peoples.

## An Indigenous Lens on Autism: The Way of Living

Grant Bruno, a registered member of Samson Cree Nation, one of the reserves in the province of Alberta, set out to study autism from a Cree lens. Having two autistic children of four and confronted with a meager knowledge of indigenous autism, he created the *Indigenous Relations Circle* with an attached foundation that includes members with autistic loved ones and/or who are autistic. The Circle's aim is to unite diverse experiences of autism in Indigenous peoples in Alberta, and through listening, discussion, narratives, and sharing help identify barriers, examine solutions, and form connections.<sup>68</sup> The indigenous concept of health is synonymous with harmony between physical, mental, emotional, and spiritual aspect of life. The circle symbolizes all of these encompassing harmonious aspects, whereas ill health implies a "break" in the circle requiring healing. This takes place in "healing circles" led by community Elders and the Knowledge Keepers of the community. As Bruno notes, autism in indigenous community is accepted as someone *who thinks differently* as opposed to Western attitude where autism is approached from a deficit perspective that must be treated, and then (perhaps) accepted, diametrically opposing views that may explain the large incidence of autistic indigenous people who do not thrive in a deficit-driven culture. Bruno provides an example of an indigenous woman with a 30-year-old autistic daughter who left the city and chose to return to the reserve when her daughter failed to thrive in the deficit-based interventions even when complemented with mom's support. Bruno notes that by leaving the reserve, she was also leaving family and community support and was then confronted by a new set of difficulties. The Relations Circle has two overarching goals: to offer the needed support to indigenous communities and inform Western views and thinking about indigenous autism and the healing practices.

## A Renewed Public Health System in Canada

The *National Collaborating Centre for Indigenous Health (NCCIH)*<sup>69</sup> part of a network of national Collaborating Centres, is an organization established in 2005 by the Government of Canada, funded through its Public Health Agency mandated to support the renewed public health system in Canada. Its host, the University of Northern British Columbia, named the centre, and promoted it through its Health Research Institutes Seminar Series. In this author's view, their guiding principles stated here verbatim, merit informing any project aimed at benefiting indigenous peoples in Canada: *Guiding Principles*:

1. Respect diversity and the unique interests of First Nations, Inuit and Métis peoples.
2. Support the inclusion and participation of First Nations, Inuit and Métis peoples in the public health system.
3. Incorporate Indigenous knowledge and holistic approaches.
4. Encourage collaboration and capacity building.

The organization's written work is peer-reviewed and promotes oral and visual indigenous identity through use of images, landscapes, and videos capturing Elders and other community member discussion of traditional health healing approaches, and storytelling; a strong indigenous tradition is continuously developing by the centre.

## Researchers and Other Stake-Holders Role: A Hybrid Indigenous Friendly Approach

A factsheet provided by the NCCIH<sup>70</sup> states indigenous health determinants reside in access to health services. Barriers to health result in significant disparities compared to non-indigenous populations, accompanied by serious health consequences. In autism, early detection is known to have protective long-term effects.<sup>7,71</sup> Achieving this requires a non-discriminatory health care system, and robust prevalence data so no autistic child is missed. The flagging and treating autistic indigenous children and youth require invested individuals and groups who are "culturally competent", ie,

knowledgeable in indigenous values, traditions, and healing practices, while additionally acting as ethnographers. The problem with cultures is their dynamic nature that results in constant mutations that ebb and flow, while ethnographic approaches may result in stereotyping that could derail accurate efficient understanding of the individual problems and needs or even worsen their condition.<sup>22</sup>

An approach that reflects a viable hybrid role resides in *Narrative Medicine*, a therapeutic approach easily adapted to any clinical and rehabilitation discipline. It hinges on the recognition of “*human capacity to tell stories as central to health care*”, note researchers.<sup>72</sup> Patient narratives are essential to understanding their health concerns, life experiences, and circumstances. They provide a platform for patient active engagement in their own treatment and development of coping mechanisms, while the clinician develops listening skills that enhance the portrait of the health problem. Through the narrative, the patient and clinician arrive at a treatment plan whose choice is understood by the patient. Narratives are a way of organizing experience from the past and present that make sense when communicated to the clinician. McGill University researchers created a set of interview questions to stimulate narrative sharing by patients. The instrument named, *McGill Illness Narrative Interview* (MINI),<sup>73</sup> is easily accessible at McGill Transcultural Psychiatry website. The questions, available in various languages, serve to guide a narrative interview and may be easily adapted and used in indigenous dialogues seeking information about their autistic family in a respectful and effective manner.

According to a Canadian family physician,<sup>74</sup> Narrative-Based Medicine helps the physician shift from a problem solving need to the need to understand the patient more thoroughly, resulting in improved health outcomes. Narrative medicine may resonate with indigenous communities whose strong story-telling traditions are instrumental in knowledge and culture transmission to their youth and all members, a tradition shared by Canada’s three indigenous communities. Researchers<sup>75</sup> developed a methodology for understanding indigenous youth and young adults through the context of story telling. They note that “storytelling is a way of reclaiming identity and reclaiming one’s own stories, rather than being defined by hegemonic forces”. Finally, narrative medicine is used in both clinical encounters with patients and for educating clinicians. For example, researchers note,

cultural competency and narrative medicine are approaches that assist medical educators in teaching effective, empathetic communication and service delivery to a variety of patients.<sup>76</sup>

Using this approach, medical educators employed an activity in which pediatric residents participated in a monthly reading and discussions of literary texts with community centre members. Results showed the texts facilitated attention to power and promoted sharing personal and professional experiences in both groups. Evaluation of participants showed improved self-reported understanding of issues of culture, of medical culture, and physician attitudes and behaviours in practice.

Finally, the recommendations delineated in the Renewed Public Health System, serve as a guide to any clinician and researcher to ensure their contribution is welcomed by indigenous peoples as it considers their needs and rightful demands for partnerships. Researcher and clinicians may begin the journey by asking themselves how their work is going to benefit the community and the population of concern in that community. It is essential that a narrative approach is used, and community Elders, Keepers of knowledge as well as grandparents and parents are encouraged to participate – an expected respectful approach in indigenous cultures.

## Future Directions

The diversity of individuals in need of effective cultural competence is growing, while answers to what is the most efficient way to supply them with meaningful treatment are not obvious. It is known that many individuals from diverse communities do not respond to mainstream approaches which are less beneficial than those that are adapted to make them more culturally meaningful and effective, a phenomenon pointed out in the case of psychosocial treatment of Asian Americans.<sup>77</sup> In fact, in a culturally diverse society, the dominant culture dictates the concerns of social institutions such as education, health care, and welfare, and

regulates what sorts of problems are recognized and what kinds of social or cultural differences are viewed as worthy of attention (p.150)<sup>22</sup>



Researchers suggest<sup>78</sup> that cultural competence training presents problems. Culture is often confounded with ethnicity, resulting in stereotyping, as was the case of Joyce, the indigenous woman who died as a result of stereotyping by hospital staff to the neglect of her medical history and serious life-threatening presenting symptoms. Furthermore, point out the researchers, cultural aspects may not be the relevant factor in each case, while social-economic constraints, for example, may be the major factor underlying parents' hesitancy in seeking diagnosis for their children as when resources are distant, and accessing them are costly. Finally, culture is part and parcel of all human conditions impacting sociopolitical, religious, and secular activities and conditions of existence and may have specific meaning for individuals and different meaning for those they encounter in societal institutions. As a more viable option that circumvents the difficulties posed by training "cultural competency", the researchers promote training clinical and research staff as *ethnographers* by applying observation, listening, and description of individuals, and how they experience life. In this approach culturally appropriate terminology is used rather than a rigid adherence to bio-medical terms, the individual is posed questions regarding ethnic self-identity, the narrative of the illness or challenges they face, and the psychosocial stresses they are experiencing, among other issues, these are encouraged for discussion. An important aspect is determining how their problems affect their relationships with loved ones, their life in all their settings, and the level of well-being they experience.

An approach which seems especially appropriate for families with autistic individuals is applying Bronfenbrenner's (bio)-ecological systems theory<sup>79</sup> which views the developing child as shaped by proximal and distal processes through a complex system of dynamic interactions with immediate and larger societal systems, in mutually influencing capacities. Viewing them within the context of their ecological systems, the child is impacted by 1. the *Microsystem* – The first level of contact are the family and school as the major influencers, 2. the *Mesosystem* – The interaction between the child's microsystems, eg, school and home, peers and siblings, 3. the *Exosystem* – does not have a direct influence but does impact development: neighborhood, parents' and their workplaces, friends of the family, and the mass media, 4. the *Macrosystem* – includes the larger society cultural elements, socioeconomic status, and ethnicity, and 5. the *Chronosystem* – includes changes and transitions over specific time periods and over one's lifetime. The use of this model can facilitate identification of mental and physical high-risk factors such as forced displacement as when children are made to attend residential schools or death of a parent, as well as protective factors as when individuals thrive in the face of adversity or illness. Each system may be examined via dialogue, surveys, and collection of narratives and used to design appropriate targeted treatment or programs to benefit their families of interest in particular situation.

Cultural competence is meant to facilitate researchers and clinicians in providing diagnosis and treatment to a diversity of individuals or groups encountered in the clinic or educational settings, among others. Although this is seemingly a clear goal, no one definition captures this complex domain. Nonetheless, researchers were able to identify provider qualities such as nurturing attitudes of "I'm your ally" and an "empathic" stand as the qualities that were appreciated as "competency" by ethnic clients. The corollary to this finding was a recommendation that providers' training focus on relationship building and in communicating empathy, the very basic qualities in any provider working on affecting changes in their client be it psychological, rehabilitation or educational professions.<sup>80</sup> However, these qualities must be augmented with actual knowledge of the client's culture to be effective. One quick way to get to know the culture in which the client is immersed is by reading literary works by authors from their community or about their community. For example, while reading Amy Tan's essay *Mother Tongue*,<sup>81</sup> we can hear her mother's immigrant English – Tan refers to "all her mother's Englishes". We learn about the Chinese American community and difficulties they experience when trying to access services since they are "disrespected" because of their accented English, and we learn of the resilience in coping with these indignities. In James Seilsopour's essay "I forgot the words to the National anthem",<sup>82</sup> we learn about the discrimination he faced when he returned from Iran where he was "a proud American", but in America, he discovered he was seen as an "Iranian enemy". He was caught in a political quagmire where he had to endure the pain of displacement, daily taunting, and question his identity and existence. Through the novel *April Raintree* by Beatrice Culleton (Mosiouner) (see your local library),<sup>83</sup> a Metis woman whose story is an autobiographical fiction, we learn that Culleton spent most of her life in state foster care away from her family and that her path briefly crossed that of her two sisters who eventually committed suicide. But more importantly, we learn about her hope, resilience and the fate of the Canadian Metis indigenous community, their struggles with abject poverty, loss of family, and efforts to regain

their identity. Book reading need not be in the client's home language (impossible to achieve acquisition of a foreign language given the diversity of languages one encounters in the clinic or school and the paucity of time) since many literary works are translated into the *lingua franca* of our universe, English. It is important to note that readings from a culture, however, should be shared and discussed so that insights are collected and enhanced.

The use of literary texts is not confined to adults. Indigenous children's literature is sure to resonate with children, pre-teens, and adolescents (<https://goodminds.com/collectons>; available in English and French) as they will listen/read and interact with you, the provider to stories written by indigenous authors from their nation or other nations in the land with illustrations that add to the context; children need instruction in learning to "read" illustrations/pictures and symbolism of colour and shape as it adds to text comprehension. Each book can be used for oral retell, converted to didactic material by designing vocabulary pages including idiomatic expressions and comprehension topics to share, and rounding these off with writing and art based on the book. These then serve as gateway to instructing literacy. Literacy development is expedited when all sessions include reading and writing instruction and art – the child is asked to create pictures inspired by the story; the final product is the child's book about the story they read, and the child is then encouraged to retell it to his family and community. Books can teach children empathy, appreciation of other's lives and minds, and the fact that all people share the same needs and face similar challenges. These strategies are suitable for the entire age range when appropriately adapted; they are sure to resonate with the community to which a provider is invited to provide their expertise, since "story telling" is the foundation of indigenous culture. Caveat: it is important to involve the family and community Knowledge Keepers in your plans.

In sum, according to the online etymology dictionary the word Culture in the mid-1500 referred to agricultural cultivation of crops, but by 1805 it denoted the intellectual aspects of civilization, and by 1867 it was understood as people's collective customs and achievements. Indeed, a complex concept with a history of transformation. Competence, on the other hand, by mid 1630s referred to meeting together, symmetry or agreement, and is now understood as the sub-visible sum of knowledge we accumulated regarding culture. We are immersed in it, we use it, and we represent it just by existing: how we dress, what we eat, where we live, the friends we choose, and what books we read are all expressions of the culture we live in or adopted. To be an excellent clinician, we make sure we have the needed knowledge, we treat our clients with the respect they merit, and with a humble attitude and consideration as we would our house guests, for at the end of the day, we too may need a knowledgeable caring empathetic provider as our ally.

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