

# **Autism and Indigenous peoples in Canada: a scoping review**

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## Declaration of Committee

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## Abstract

**Background:** Indigenous leaders have identified supporting the well-being of autistic individuals and their families as a growing concern in First Nations communities across British Columbia. Decades of research have demonstrated that access to timely and appropriate evidence-based diagnostic and support services are essential to autistic well-being. Yet, Black, Indigenous, and People of Colour (BIPOC) are diagnosed with autism later, report lower satisfaction and greater difficulty accessing services, and remain underrepresented in autism research compared to their white counterparts. Research on the unique experience and impact of autism in Indigenous communities is critical step towards achieving equity in autism services.

**Method:** A scoping review of the peer-reviewed and grey literature was conducted to identify what information has been published to date on autism among Indigenous peoples in Canada. The review elucidated key gaps in current knowledge, and priorities for future research. Included publications were analyzed for the type of research, stated objectives, methodologies, and level of engagement with Indigenous communities.

**Results:** The scoping review identified a total of 27 reports published since 2007, which included information relevant to autism among Indigenous peoples in Canada. Of these, only 11 focused specifically on autism in Indigenous communities. Notably, the publications contained a near absence of active involvement of Indigenous communities in research decisions or dissemination of results.

**Conclusions:** A lack of community-led research on autism among Indigenous peoples in Canada is a major ethical concern, particularly in light of disparities in access to autism funding programs and service providers. Further research conducted in collaboration with Indigenous communities is imperative to addressing these disparities and developing supports and services that are responsive to the unique perspectives, experiences, and needs of autistic Indigenous people.

**Keywords:** Autism; Canada; Indigenous; First Nations; Métis; Inuit; Intersectionality; Scoping review

## **Dedication**

For my Tatuś, the King of Fun. Your jewels of advice are dearly missed.

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## List of Acronyms

ASD	Autism Spectrum Disorder
ADDL	Autism and Developmental Disabilities Lab
ADHD	Attention-Deficit/Hyperactivity Disorder
BIPOC	Black, Indigenous and People of Colour
CONSIDER	<b>CON</b> Solidated cri <b>ER</b> ia for strengthening the reporting of health research involving Indigenous Peoples
JB	Joanna Briggs Institute
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified
SFU	Simon Fraser University

## **Preface on Research Context, Research Positionality, and Terminology**

This project sought to address calls throughout the autistic community for inclusive and diversity-focused autism research (e.g., Broder-Fingert et al., 2020; Giwa Onaiwu, 2020; Jones et al., 2020) by exploring the intersections of sociocultural identity, ethnicity, and disability as experienced by autistic Indigenous peoples in Canada. Throughout this project report, I am intentional in the language and approach to research I have chosen to adopt. And I have tried to be as transparent as possible in describing my rationale for my choice of words and guiding methodologies, as well as, any perceived biases that have influenced these choices. Prior to delving into a standard description of the research project itself (i.e., introduction, methods, and so forth), I do my best to situate my personal background and opinions that invariably influenced the development and production of this research project, as the broader context is critical to understanding both the sensitivity of my role as the project's primary researcher and the ethical and methodological considerations that informed my approach to this project (Anderson, 2019; Hyett et al., 2018). I begin the preface with an explanation of the language used throughout this report.

### **Notes on Terminology: Indigenous**

I use "Indigenous" as an inclusive and collective term to describe individuals and groups who consider themselves to be descendants of the original peoples of a geographic region (including the lands now known as Canada), whose societies in that region predate those of other invading or colonizing populations (United Nations Forum on Indigenous Issues, 2007). I note that, globally, there is no single and universally accepted definition of "Indigenous peoples" and that, in the settler-colonial nation of Canada, two systems of definitions (one autonomously-declared and the other settler government imposed) continue to operate simultaneously on parallel and often conflicting paths (Bartlett et al., 2007; International Work Group for Indigenous Affairs, 2013). "Indigenous" was chosen over the constitutionally defined and government imposed term "Aboriginal", which is often also used to refer to original inhabitants of Canada and includes "Indian, Metis, and Inuit", because: a) the term Indigenous is more internationally recognized, and b) using the term Indigenous is a recognized means of supporting Indigenous people's right to determine how they would like to be named and,

therefore, is the preferred term of identification for many Indigenous people and groups in Canada (Allan & Smylie, 2015; Bartlett et al., 2007; Carpenter, 2017).

It is also important to note that I use “Indigenous peoples” in a general manner, when referring to various Indigenous groups collectively, without regard to their separate origins and identities. The Indigenous population in Canada is incredibly diverse, comprised of hundreds of distinct groups, each with their own name and historical experiences (Smylie, 2014). Therefore, when referring to a specific Indigenous group or an Indigenous person, I use the name they use to refer to themselves (whenever possible) [e.g., a Omushkego (Cree) teacher from Weenusk First Nation (Peawanuck)].

## **Notes on Terminology: Autism**

Autism is neurodevelopmental condition that affects the way a person thinks, acts and feels. Within the autism community, preferences differ on the use of person-first (i.e., person with autism) vs. disability-first or identity-first language (i.e., autistic person). I use the later (disability/identity-first language) throughout this report because identity-first language is the preferred form of self-identification among a considerable majority of autistic adults, as well as their family members, friends, and broader support networks (Kenny et al., 2016). As suggested by Dunn and Andrews (2015), the American Psychological Association (APA) now recommends researchers follow the preferences of disability groups by using the terms they prefer to describe themselves (APA Style Guide, 2021). Further, I use the DSM diagnostic term, Autism Spectrum Disorder (ASD), sparingly and only when referring to information from specific sources. Instead, I use the more neutral terms ‘autism’ or ‘on the autism spectrum’ when referring to ASD or individuals who have an autism diagnosis.

## **Study Context and Researcher Location**

Indigenous communities across Canada are immensely diverse, with distinct histories, languages, cultures, and rich and complex knowledge systems that shape each community’s understanding of, and approach to supporting, health and wellbeing (Anderson, 2019; Barker et al., 2017; Gallagher, 2019; Leeuw & Greenwood, 2007). Despite these differences, what unites the diverse population of approximately 1.8 million Indigenous people living across Canada (Statistics Canada, 2021), is a shared

experience of settler colonialism (Kim, 2019b; MacDonald & Steenbeek, 2015). Though historical and ongoing colonial experiences vary widely between different Indigenous groups, in general, social inequities stemming from colonialism are considered a foundational determinant of Indigenous health in Canada; linked to disproportionately high rates of mental and physical health problems and disability (Gracey & King, 2009; Greenwood et al., 2015; Kim, 2019b; Smylie, 2014). The hegemony of a colonial worldview has also been implicated in Indigenous health outcomes, in that health services are based on a set of colonial norms and definitions that identify, document, and treat illness and disability from a Western medical model of health, and which do not necessarily correspond to Indigenous experiences of health and wellbeing (S. Nelson, 2012; Smylie et al., 2004; Waldram, 2004). In addition, research into the health of Indigenous populations in Canada has historically been undertaken using colonial and Western concepts and methodologies (Hyett et al., 2018). Disregard for Indigenous views of health continues in much present-day health research in Canada (S. Nelson, 2012), further creating the potential to misrepresent rates as well as types of health problems among Indigenous communities (S. E. Nelson & Wilson, 2017), and resulting in research that is poorly aligned with communities' own conceptions of health and specific health needs (Horrill et al., 2018). Thus, while research into the health of Indigenous peoples in Canada is valuable, it is important that this research be undertaken carefully and with attention to the bigger picture of colonialism and the values and perspectives of the specific Indigenous communities involved (Lock et al., 2021).

It follows that a crucial consideration for researchers engaged in research on the health and wellbeing of Indigenous peoples is to approach research from an Indigenous paradigm (Datta, 2018). One aspect of this involves discussing the research context; situating the researcher/research group, their values and practices, and their relationship to power, as well as the data source(s), and the Indigenous groups involved in the research (Bergeron et al., 2021). This differs fundamentally from Western approaches to research, which are often highly standardized, and where removing context from the research is considered to be 'best practice' (Cameron et al., 2014). By explicitly reporting the researcher's own social and historical position and political and ideological assumptions, the reader can better understand how the researcher approached research questions and interactions with the data, both of which ultimately shape

emergent findings and discussions. They then can render their own judgements about the utility and authenticity of the findings in line with their own worldview (Aveling, 2013).

So here are the parts of my story I believe to be most relevant to this project:

I write this report from the position of a white woman of mixed Indo-European ancestry, born a first-generation settler on the traditional territories of Anishinabewaki ᐱᓆᓂᓴᑦᐅᑦᐃᑦ Peoples that were ceded to the Canadian government in Saugeen Treaty No. 45 ½ (1836) in exchange for “economic assistance and protection from settler encroachment” (Saugeen Ojibway Nation Environment Office, 2019). I do not know racism in my lived experience. I consider my whiteness and the various forms of privilege that accompany my racial identity to be one of the factors that has most shaped the course of my life, especially in terms of opportunities I have been afforded and the systems and structures surrounding me that were built to favour me and other white folk.

Other than my racial identity, I consider the historical experiences of my family and the land on which I was raised central to the way I experience the world. As the first generation on both sides of my family to be born in Canada, I was raised listening to the stories of my parents and grandparents who had escaped political prosecution and poverty in Poland and come to Canada to build a better life for their families. I grew up with a sense that I was lucky to have had a family that emigrated to Canada, an ‘empty’ land that was ripe with opportunities for settlers from abroad, especially those fleeing instability in their own homelands. My parents were (and remain) immensely proud of becoming Canadian citizens, and as a family, we never discussed Canada’s settler-colonial history or the Indigenous peoples who had already built a good life for their families and communities in Canada for thousands of years prior to my family’s arrival.

It was not until my mid-twenties I began my learning journey towards a better understanding of Indigenous experiences in Canada after becoming dear friends with Mi'kma engineer from Woodstock First Nation. Throughout our friendship, he has generously shared some of the ways in which the historical and ongoing processes of colonization have adversely impacted his daily life. Until I met him, I was oblivious to the historical atrocities committed against Indigenous peoples in Canada, and the ways in which systemic racism and discrimination continues to oppress many Indigenous peoples in this country every day. Though I am ashamed to say that I had never heard of

residential schools or considered that someone may experience anti-Indigenous racism in mundane daily interactions, such as with the cashier at the grocery store or the boarder officer when driving to the USA for a vacation, prior to my early twenties; I am forever grateful to my friend for opening my eyes to experiences outside the social context I was raised (something that should not be his responsibility to share) and taking the first steps with me towards understanding how my identity as a white European settler has shaped the course of my life, and my worldview. Though I was raised to be proud of my Canadian citizenship and am deeply attached to the 100 acres of farmland on which I was raised until my early teens, there is a now a certain sense of shame I feel associated with this pride and attachment knowing that these lands were actually home to Saugeen Anishnaabek since time immemorial. The conflicting feelings I have about my love for Canada and the stolen lands I grew up on is not yet something I have been able to figure out how to reconcile. What I can say is that the lands we now call Canada offered my family and I the opportunity to live a life characterized by stability and privilege, of which I am immensely grateful for. My journey continues – and I am committed to continuing to reflect and examine how my own racial identity and social biases inform how I approach my life and my work.

Another aspect of my identity that I feel is important to mention in the context of this project is my family history and lived experience of neurodevelopmental conditions. My two younger brothers are autistic, and I was diagnosed with attention deficit hyperactivity disorder (ADHD) at the age of 11. Thus, I come to this project from the position of both an ‘outsider’ and ‘insider’ to the neurodivergent community – my insight and understanding of autism are informed by first-hand experiences, both with autism and neurodivergence more generally. I am immensely grateful to have grown up in family that accepted and celebrated neurodivergence as a natural part of the human experience, and supported one another to thrive in our own ways. I am keenly aware that this is not the case for many people, and I consider myself to be very lucky. In many ways, my personal experience with neurodivergence has made me a more creative, accepting, and empathetic person and has been instrumental in my decision to pursue a career in clinical psychology. I believe that there are many ways to live in this world, none are better than the other, and that, as people, we must support one another on our individual journeys of self-discovery, healing, and personal growth, to live the version of life we feel is best for ourselves.

For the past five years, I have lived and studied in Vancouver, British Columbia on the unceded territories of the Coast Salish peoples, including the territories of the xwməθkwəy̓əm (Musqueam), Skwxwú7mesh (Squamish), Stó:lō and Səl̓ílwətaʔ/Selilwitulh (Tsleil- Waututh) Nations. Here, I have worked as a graduate level university student and training psychologist at Simon Fraser University (SFU). Clinically and in research, I am primarily interested in issues related to accessing supports and services for autistic people, particularly those who have ‘other’ marginalized identities (e.g., co-occurring mental health issues, people of colour). This interest stems from my personal experiences noted above. As a graduate student working in the Autism and Developmental Disabilities Laboratory (ADDL) at SFU, I have had the opportunity to work with members of the autistic community on various projects related to autism and co-occurring mental health issues. I have also had the opportunity to work as a practicum student at the Ayás Méhmen Shewaynewas Family Program with members of Squamish Nation, and as a research assistant on a collaborative project with with Nzen'man' Child and Family Development Centre and members of the Nlaka'pamux Nation. In these contexts, I am often perceived as an authority figure and hence interact with autistic individuals and their families from a position of power. I am keenly aware of the privileged position that has enabled me to have these opportunities, and am grateful to the individuals and families who have shared their experiences and perspective with throughout my research and clinical training.

The scoping review described in this report is the result of a larger collaborative research partnership between my senior supervisor, Dr. Grace Iarocci, who is a professor of clinical psychology and the director of the ADDL at SFU; Rona Sterling-Collins (Quist'letko) a Nlha'7kapmx social worker and consultant from Joeyaska Reserve; Deborah Pugh, the Executive Director of Autism Community Training (ACT); and Romona Baxter, a member of Nlha'7kapmx Nation and the Executive Director of Nzen'man' Child and Family Development Centre Society. Through their own personal and professional experiences in Nlha'7kapmx communities across BC, Rona and Romana identified the need for research focused on Indigenous autistic peoples in Canada. The scoping review is a preliminary component of this larger research project. Though I was (and remain) hesitant to conduct a project exploring the experiences of Indigenous autistic people and their families as a white non-autistic person, I have tried my best to “go forward in a good way”; to reflect on my own social position and

assumptions and to design a project that is (1) an identified need by an Indigenous community, (2) includes both Western and Indigenous research frameworks (3) and results in findings that are relevant and respectful to the community that identified this need. I in no way assert to be an expert on the lived experience of autistic Indigenous peoples. The expertise I can lend to this project is to use my training as a graduate level researcher to highlight the perspectives, experiences, and needs of some autistic people that have been underrepresented in the research literature to date in a way that is digestible to the academic community. My hope for this project is that the findings can raise awareness of the need for Indigenous voices in autism research, and that it can act as a starting point for the development of autism-related supports and services that meet the needs of Indigenous communities in Canada. I am passionate about how we can best support neurodivergent folk from all backgrounds to live the life they desire in a respectful and responsive way.

In addition to the original idea for this project coming from members of Nlaka'pamux Nation, a member of the North Fraser Métis Association was hired as a research assistant for the project. He worked on developing the method, data analysis plan, and interpretation of results for the scoping literature review component on the project. He also chose the standardized critical appraisal tool used to evaluate the methodological quality of studies included in our review from an Indigenous perspective. I also sought to include Indigenous voices in reporting on this project by adding an Appendix (see Appendix D) with quotes from Indigenous participants involved in the primary studies included in this scoping review. I have adhered to the ethical guidelines for conducting research with Indigenous communities put forth by the preeminent research funding agencies and various Indigenous organizations in Canada including: the 2015 Truth and Reconciliation Commission of Canada's (TRC) final report; the Royal Commission on Aboriginal Peoples: Ethical Guidelines for Research; Ownership, Control, Access and Possession (OCAPTM): The Path to First Nations Information Governance; Principles of Ethical Métis Research; the National Inuit Strategy on Research; and the Tri-Council Policy Statement for Research Involving Humans 2 (TCPS2) Chapter 9 "Research involving First Nations, Inuit, and Métis Peoples of Canada"; in writing this report.



# Chapter 1.

## Introduction

Conceptions of autism have changed dramatically in the 70 odd years since it was first recognized as a distinct diagnostic category. Whilst early reports suggested that autism was an impairing psychiatric condition characterized by early language delays, social challenges, and co-occurring intellectual disabilities (e.g., Kanner, 1943), the autism 'spectrum' has since widened substantially to include individuals with a broad range of social, language, and (neuro)cognitive abilities (Autistic Self Advocacy Network, 2021; Crane et al., 2021; Leadbitter et al., 2021). Not only has our understanding of the diagnostic characteristics of autism evolved, but so have traditional assumptions regarding the sociodemographic characteristics of autistic individuals. Autism has historically been studied and diagnosed in white, cisgender males in North America and Western Europe. However, as the prevalence of autism has risen substantially in the last few decades in many international jurisdictions, so has the gender, racial, and ethnic diversity of those being identified (Cascio et al., 2020; Chiarotti & Venerosi, 2020; Elsabbagh et al., 2012). Now more than ever, stereotypical descriptions of autism as a white male pathology are being challenged, as autism is increasingly recognized as a natural and valuable expression of human diversity in neurocognitive development and functioning that impacts people of all ages, gender-identities, and ethnocultural backgrounds (den Houting, 2019).

Despite these huge conceptual shifts within the field of autism theory/research and practice, there is agreement amongst most of the autistic community that a variety of psychosocial supports and services should be available to help autistic people of all ages thrive and reach their desired potential (den Houting, 2019; Leadbitter et al., 2021; Nicolaidis, 2012). In a world designed for non-autistic people, autism is often a disabling condition. When compared to non-autistic people, autistic people and their families report a number of psychosocial challenges throughout the lifespan, including: higher rate of co-occurring mental health issues, increased lifetime exposure to bullying and victimization, high levels of family stress, school and employment problems, social isolation and loneliness, and poorer health and overall quality of life outcomes (Graham Holmes et al., 2020; Mannion et al., 2014; Mason et al., 2018; Matson et al., 2016;

Taylor et al., 2015; Weiss & Fardella, 2018). Fortunately, research has consistently demonstrated that many of the psychosocial challenges and impairments often associated with autism can be mitigated by timely access to neurodiversity-informed autism interventions (e.g., EMPOWER-ASD intervention, McKenzie et al., 2019; Systemic Autism-related Family Enabling intervention, Pegasus, Gordon et al., 2015) and services offered through multiple systems (e.g., speech and occupational therapies, mental health and community support programs, psychoeducation; specialized medical care, educational strategies, and supported employment programs; ; Ip et al., 2019; Lai & Weiss, 2017).

However, research also suggests that not all autistic individuals and their families have equal opportunity to foster their desired outcomes through timely participation in both ASD-related and other psychosocial supports and services. There is a growing literature base that highlights stark racial and socioeconomic disparities in the study, diagnosis, and treatment of autism (Broder-Fingert et al., 2020). Studies have consistently documented the underrepresentation of individuals from racialized (i.e., racial and ethnic groups other than non-Hispanic white) and low-income groups in both autism research and also among people diagnosed with autism (Carter & Sheldrick, n.d.; Cascio et al., 2020; Mandell et al., 2009; Sullivan, 2013; Tromans et al., 2020; West et al., 2016). Research has also found that race and class-based disparities are evident in autism clinical practice, influencing the age at which autism is diagnosed as well as the quantity and quality of autism services received. Despite autistic people of all backgrounds reporting first concerns about autism at similar ages (Jang et al., 2014), low-income autistic Black, Indigenous, and people of colour (BIPOC) are more likely to initially be misdiagnosed with other psychiatric disorders (Mandell et al., 2007) or diagnosed much later than people from more socially advantaged groups (i.e., whites and those of high socioeconomic status; Aylward et al., 2021; Durkin et al., 2017; Mandell et al., 2009; Winter et al., 2020).

Autistic individuals from socially and economically disadvantaged groups are also more likely to have difficulty accessing, and thus are less likely to use, the psychosocial supports and services they need, both immediately following an autism diagnosis (Lim et al., 2018; Pearson & Meadan, 2018), and throughout their life (Benevides et al., 2021; Eilenberg et al., 2019; Jones & Mandell, 2020). Those who do manage to access relevant services are less likely to report receiving quality care and more likely to report

numerous unmet needs, as compared to their white, higher-resourced counterparts (Smith et al., 2020). Further, though causality can be difficult to demonstrate, especially in the case of evidence from cross-sectional data, various authors have speculated that the challenges experienced by low-income and/or racialized autistic people (i.e., lower rates of employment, social participation, and post-secondary education compared to white and economically advantaged groups) are suggestive of structural racism in autism service provision (Broder-Fingert et al., 2020; Eilenberg et al., 2019).

Despite this documented pattern of inequities, there are significant gaps in our understanding of how different ethnocultural backgrounds and social positions interact to influence the unique perspectives, experiences, and needs of autistic people from marginalized communities (either through the inclusion of diverse samples or the implementation of cultural adaptations to services and supports; Davenport et al., 2018). In particular, studies that go beyond simply identifying autism disparities to explore the complex, cumulative ways in which the effects of multiple forms of discrimination (i.e., ableism, racism, classism) impact both the daily lived and service experiences of autistic people with additional marginalized identities are needed (Papoudi et al., 2021). Developing a better understanding of specific socio-cultural orientations towards autism and needs is critical to developing contextually responsive approaches to diagnostic and psychosocial services (Hoekstra et al., 2018). Although research on the experiences of certain multiply marginalized autistic people, such as Black autistic people in the United States (e.g., Burkett et al., 2015, 2017; Dababnah et al., 2018; Pearson et al., 2020; Stahmer et al., 2019), are emerging, our knowledge of other marginalized autistic groups, particularly in Canada, is extremely limited (Decoteau, 2021; Khanlou et al., 2017).

Indigenous peoples are among the most socially and economically disadvantaged people in Canada, subject to systemic marginalization brought about by the European colonial invasion of the Indigenous lands, now called Canada, and perpetuated by strategies of dispossession and displacement instituted by the Canadian government and other institutions (Schultz et al., 2021). Further, cultural genocide and intergenerational trauma caused by policies such as the residential school system, and ongoing child welfare practices have robbed Indigenous peoples of their culture and contributed to the erosion of familial and community ties (Kim, 2019b). Together, these atrocities committed against Indigenous peoples continue to have profoundly negative

consequences for many, including high rates of disability, unemployment, poverty, physical and mental health problems, and involvement both as survivors and accused persons in the criminal justice system (Fang & Gunderson, 2015; Greenwood et al., 2015; Kolahdooz et al., 2015). On virtually all measures of health and quality of life, Indigenous peoples experience significantly worse outcomes than other people in Canada (Greenwood et al., 2015). This divide is exasperated by disparities in the accessibility, availability, and acceptability of health and social services to Indigenous peoples related to historical and ongoing manifestations of colonialism (i.e., mistrust of health/social care system and providers, geography, human resources and system deficiencies, structural racism in care provision, jurisdictional disputes; Cauchie, 2019.; Davy et al., 2016; Goodman et al., 2017). Rather than being rooted in biomedical or cultural causes, the health and social outcomes of many Indigenous people stem from how colonial society continues to sustain the political, economic, and social oppression of Indigenous communities (Browne, 2017; Horrill et al., 2018). For example, although Indigenous peoples have genetic disabilities at about the same rate as the general Canadian population (Durst, 2006), in some Indigenous communities, the disability rate is over twice (32%) the national average due to environmental and trauma-related disabilities (Government of Canada, 2019).

Despite the relevance of research on issues facing Indigenous peoples with specific health conditions and disabilities (N. Di Pietro & Illes, 2016a; Durst, 2006; Truth and Reconciliation Commission of Canada, 2015), there are no known statistics on the number of autistic Indigenous peoples in Canada (Canadian Academy of Health Sciences, 2022; Government of Canada, 2007) and Indigenous people have largely been excluded from autism research (Di Pietro & Illes, 2014). For example, the Public Health Agency of Canada's latest autism prevalence estimates (which suggest an overall autism rate of 2.0% (1 in 50) among children and youth aged one to 17 years old in Canada) are based on parent-reported data from the 2019 Canadian Health Survey on Children and Youth, which did not include individuals living on First Nations reserves and in foster homes (Public Health Agency of Canada, 2021). Further, little is known about the ways in which autism is conceptualized in Indigenous communities across Canada, and how Indigenous autistic people and their families can be best supported to reach their desired potentials (Canadian Academy of Health Sciences, 2022).

## **1.1. The current study**

To address the current gap in knowledge on Indigenous autistic people in Canada, the purpose of this project was to provide an overview and commentary on the extent and quality of research on autism among Indigenous peoples in Canada. This objective was addressed in a literature study. Specifically, a scoping review of the peer-reviewed and grey literature mapped the key themes in existing and emerging research on autism among Indigenous peoples in Canada. The review also assessed identified empirical studies for quality of Indigenous engagement, as community engagement is acknowledged as an effective method to mitigate potential harms to Indigenous peoples through research (Drawson et al., 2017; Forbes et al., 2020; Hall et al., 2015). While there is an array of review methodologies to choose from, a scoping review was chosen for two distinct reasons. First, we were specifically interested in determining the extent and quality of available evidence on autism and Indigenous peoples in Canada, a topic which spans multiple disciplines. Second, we endeavoured to explore conceptualizations of autism among Indigenous peoples in Canada. Unlike a systematic review, a scoping review identifies the entire relevant scope of the grey and academic literature, regardless of study design, and is recommended when the research focus is much broader and at the conceptual stage. (Munn et al., 2018).

## **Chapter 2.**

### **Methods**

This scoping review was conducted according to the methodology and guidance for the conduct and reporting of systematic scoping reviews developed by the Joanna Briggs Institute (JBI; Peters et al., 2015, 2017, 2020) and outlined in the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-SRC) statement (Liberati et al., 2009; Tricco et al., 2018). Building on the scoping review frameworks proposed by Arksey and O'Malley (2005) and later enhanced by Levac and colleagues (2010), the JBI framework incorporates nine distinct phases: (1) defining and aligning research objective/s and question/s, (2) developing and aligning the inclusion criteria with the objective/s and question/s, (3) describing the search strategy and inclusion criteria, (4) searching the evidence, (5) selecting the evidence (6) extracting the evidence, (7) analysis of the evidence, (8) presentation of the results, and (9) summarizing the findings, making inferences from the findings, and noting implications of the findings (Peters et al., 2020).

#### **2.1. Defining and aligning research objective(s) and question(s)**

The purpose of this scoping review (as described above) was to assess the extent of research and other literature on autism among Indigenous peoples in Canada. A secondary objective of this review was to appraise the quality and rigour of relevant empirical research. A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews and JBI Evidence Synthesis was conducted in February 2019 and no current or underway systematic reviews or scoping reviews specifically on the topic were identified.

The impetus for the review came out of preliminary findings from a larger study titled "Autism and Aboriginal families: bridging the cultural gap through collective dialogue" conducted by Nzen'man' Child and Family Development Centre and the Autism and Developmental Disorders Laboratory at Simon Fraser University, which I was involved in as a research assistant (Iarocci et al., 2018). The study gathered

community and service-provider perspectives on autism, diagnostic experiences, support needs, and areas for service improvement among members of Nlaka'pamux Nation in the interior of British Columbia, Canada. Our community co-researchers for the project expressed concerns regarding a lack of available information on Indigenous approaches to autism in general, as well as limited information on the acceptability and relevance of existing empirically supported autism diagnostic/service models to Indigenous communities. The intended outcomes for this scoping review were to identify research relevant to these concerns and to better understand the current state of literature related to autism and Indigenous peoples in Canada more generally, in order to identify gaps in current knowledge and priorities for future research. To meet these outcomes, the review sought to address the following primary research questions:

1. What are the characteristics of the literature related to autism and Indigenous peoples in Canada (e.g., literature type, focal topic, aim, methodology, key messages/findings)?
2. What is the quality and cultural rigour of this research through the lens of an Indigenous framework?

The review built on the previous scoping and systematic review work of Bailey and Arciuli (2020), and Di Pietro and Illes (2014) by: (1) specifically targeting sources of evidence relevant to autism and Indigenous people(s) in Canada, and (2) evaluating research quality vis-à-vis guidelines for Indigenous health research. In addition to providing an overview of the literature, our intention in conducting this review was to guide priorities for future research and clinical efforts based on the experiences and perspectives of autistic Indigenous peoples in Canada (and the communities that support them) included in the literature to date. Further, information on cultural rigour can assist in the interpretation of research findings on the topic in line with Indigenous communities' experiences and values. In other words, this review endeavoured to map and assess the literature on autism among Indigenous communities in such a way that centres Indigenous worldviews. Rather than evaluating rigour using Western frameworks, we applied Indigenous knowledges to explore whether research has been conducted “with” Indigenous communities or “on” Indigenous communities.

## **2.2. Inclusion Criteria**

Given expressed concerns regarding the paucity of research focused specifically on autism and Indigenous peoples in Canada (e.g., N. C. Di Pietro & Illes, 2014b; Iarocci et al., 2018; Lindblom, 2014a), broad inclusion criteria were employed to maximize the breadth of our search and capture all potentially relevant evidence sources. The Population-Concept-Context (PCC) framework was used to define the constructs of interest encompassed by our review, which were then used to guide the development of inclusion criteria and key search terms that aligned with our research question (M. D. J. Peters et al., 2020). Sources were considered eligible for inclusion if they reported on autism or any other autism spectrum condition (e.g., autism spectrum disorder, Asperger syndrome, childhood disintegrative disorder, pervasive developmental disorders, autistic disorder) among any Indigenous population in Canada (e.g., Aboriginal, Inuit, Métis, First Nations; status and non-status, on and off reserve, and those living in urban settings), either as the main focus or a component of the article. For example, sources that focused on developmental disabilities more generally but specifically mentioned one or more of the autism terms noted above among Indigenous people or groups in Canada were included in our review. Table 1 includes the PCC constructs of interest and their associated operational definitions, inclusion criteria, and key search terms that we selected a priori to guide this review.



**Table 1. Summary of the Population-Concept-Context (PCC) framework used to guide our search strategy of the literature on autism among Indigenous peoples in Canada**

PCC Component	Construct of interest	Operational Definition	Inclusion Criteria	Keywords
Population	Indigenous people(s) in Canada	Individuals and collectives who consider themselves as being related to and/or having historical continuity with the original peoples of the land now known as Canada. The original peoples of Canada are often collectively referred to as Aboriginal and include Inuit, Métis, and First Nations (Allan & Smylie, 2015).	Explicitly included information on an Indigenous population in Canada, either at the individual (children, adolescents, adults) or group level (families, communities, organizations, Nations)	Aboriginal, First Nation, Native Canadian, Indigenous, Inuit, Inuk, Metis, Métis, First People of Canada, the University of Alberta Health Sciences Library's list of search terms for specific Indigenous groups in Canada ( <a href="https://guides.library.ualberta.ca/health-sciences-search-filters/indigenous-peoples">https://guides.library.ualberta.ca/health-sciences-search-filters/indigenous-peoples</a> )
Concept	Autism	Autism or any other autism-related condition listed in current or previous versions of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, DSM-IV, DSM-III, DSM-II; American Psychiatric Association, 2013)	Explicitly included information on autism AND a component of the autism information reported focused on an Indigenous population in Canada	autism, autism spectrum disorder, ASD, autistic disorder, pervasive developmental disorder not otherwise specified, PDD-NOS, Asperger's syndrome, childhood disintegrative disorder, Rett syndrome, childhood schizophrenia
Context	Canada	Any setting in Canada (e.g., communities, provinces, territories, on or off reserve, urban centres, geographic regions)	Explicitly examined populations, communities, or regions in Canada  International sources if conclusions were drawn specific to Canada	Canada, Canadian, North America, Alberta, British Columbia, Manitoba, New Brunswick, Newfoundland and Labrador, Northwest Territories, Nova Scotia, Nunavut, Ontario, Prince Edward Island, Quebec, Saskatchewan, Yukon

NOTE: The PCC framework illustrates the eligibility criteria and associated main search terms for the scoping review. In addition to the classic PCC elements, there were other eligibility criteria regarding source/study type, languages, and the availability of full-text versions (described in the main text).

To ensure our search captured a broad range of voices and perspectives, including those outside academia (where there tends to be more Indigenous authorship, community engagement and representation), we did not impose any a priori limits on the types of evidence we considered eligible for inclusion. Academic and grey literatures of all types (i.e., published and unpublished) including research of any study design, dissertations and theses, reviews and meta-analysis, conference proceedings, editorials, book chapters, theoretical and conceptual papers, position statements, expert opinions, debate/discussion pieces, reports from government agencies and non-profit organizations, and policy documents were screened provided they included some discussion of autism among Indigenous people or groups in Canada and the full-source could be retrieved. No date restrictions were applied, as both recent and older documents could be relevant. For feasibility reasons, inclusion was limited to English and French documents.

## **2.3. Search Strategy**

The search strategy was designed iteratively by the review team (MJR and KT) in consultation with a psychology and a health sciences librarian at Simon Fraser University, and peer reviewed by an Indigenous initiatives librarian, using the Peer Review of Electronic Search Strategies (PRESS) checklist (McGowan et al., 2016).

We employed a three-step systematic search strategy to locate both published and unpublished sources relevant to autism among Indigenous peoples in a Canadian context. First, a preliminary basic search of MEDLINE (Ovid) and PsycINFO (EBSCOhost) using the search string (Autism AND Indigenous AND Canada) was conducted to identify all relevant keywords and subject headings for each of our constructs of interest (Table 1). Our search terms for Indigenous peoples in Canada were also informed by the University of Alberta Libraries' search term filters for Indigenous Peoples in Canada (Campbell et al., 2022). Second, advanced searches using all identified search terms were undertaken in the following electronic databases from inception onward: MEDLINE (Ovid), MEDLINE: Epub Ahead of Print, In-Process & Other Non-Indexed Citations (Ovid), PsycINFO (EBSCOhost), CINAHL (EBSCOhost), ERIC (EBSCOhost), Web of Science (Clarivate), Canadian Research Index (ProQuest), Academic Search Complete (EBSCOhost), Bibliography of Indigenous Peoples in North America (EBSCOhost), Scopus (Elsevier), and Sociological Abstracts (ProQuest). For

each databases searched, keywords within each construct of interest (described in Table 1) were mapped on to relevant subject headings (unique to each database; e.g., APA thesaurus of Psychological Index Terms in PsycINFO, Medical Subject Headings in MEDLINE) and combined using the Boolean operator “OR”, following which the terms between each construct of interest were combined using “AND”. These were truncated, exploded, and adjusted for each included database to maximize the breadth and efficacy of our search. Though the specific search string differed slightly depending on the database, keywords describing Indigenous peoples in Canada and keywords describing autism were combined and applied to the multi-purpose field throughout our search. No publication status, language, or date restrictions were applied.

To ensure the comprehensiveness of our search strategy, we also searched relevant non-indexed and grey sources. This involved a manual search of Indigenous, health, and/or disability organizations in Canada’s websites; non-indexed databases; and online portals and repositories (see Appendix A for a full list of all grey and non-indexed sources). Search strings were tailored to each individual source. As a third and final step, the reference lists of all included documents were screened for additional sources of evidence relevant to our review. Further details of our search strategy for all sources, and an example our search strategy in MEDLINE (Ovid) can be found in Appendix A.

## **2.4. Searching and selecting the evidence**

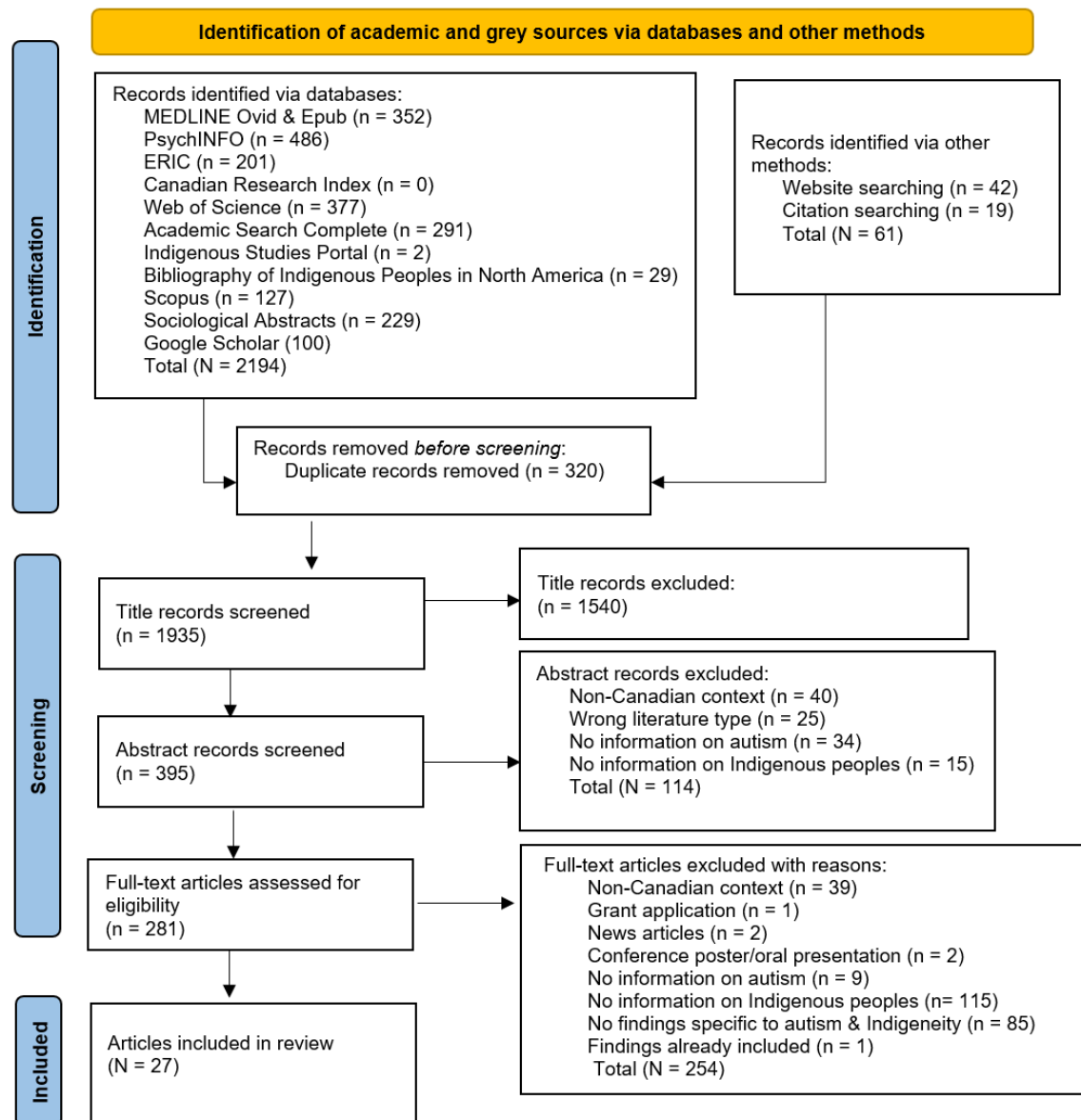
All searches were executed by MJR. The preliminary search, which informed our full search strategy, was conducted in February 2019. Online database, repository, portal, and manual website searches, using our full search strategy, were conducted in March 2019, and an updated search of all peer-reviewed and grey sources was run in November 2021. We used the same search strategy for each included database and information source in our updated search as we had in our February 2019 search, except we date restricted the search to citations published from February 2019 onward. Following the completion of all searches and prospectively to data screening, review, and extraction, the protocol for this scoping review was registered in Open Science Framework (record link: <https://osf.io/>).

Results from all searches were exported into Zotero for Mac version 5.0 citation management software (Corporation for Digital Scholarship, VA, USA) where all identified citations were collated and duplicates were removed. After duplicates were removed, 1935 citations were manually screened for inclusion through title, abstract/summary and full text review stages by two independent raters (MJR and KT). To ensure a consistent approach across raters, citations at each stage were assessed against the review's predetermined inclusion criteria using a citation screening form (Appendix B). Prior to the title screening stage, the review team (MJR and KT) collaboratively developed and pilot tested the citation screening form. For the pilot test, the two reviewers (MJR and KT) screened five articles, discussed ratings, and the screening form was revised based on discussions. The reviewers met prior to each stage of screening to discuss challenges and questions encountered.

Particularly in the title stage, if it was unclear if an article met inclusion criteria (i.e., contained explicit information on autism among Indigenous people in a Canadian context), then it was retained and screened based on further information in the subsequent stage. For example, article titles that included terms relevant to autism and terms such as "ethnic minority" and/or "demographics", but did not explicitly include terms related to Indigenous peoples (e.g., such as "Child Demographics Associated with Outcomes in a Community-Based Pivotal Response Training Program for Autism"), were moved to the abstract screening stage to access for potential relevancy based on further information provided in the abstract.

As advised by Arksey and O'Malley (2005), exclusion criteria were dynamically revised during the article selection process to exclude conceptual articles discussing culture or cultural safety and autism that were nonspecific to Indigenous peoples. We also decided to exclude articles that discussed childhood schizophrenia (now termed childhood-onset schizophrenia) among Indigenous peoples during the abstract screening stage, as this condition has been conceptualized as a distinct and unrelated diagnostic entity from autism since the publication of the DSM-III in 1980. For practicality of data synthesis, we also decided to exclude social media, blog posts, fact sheets, news/media articles, and oral presentations. Finally, publications that provided a summary of findings from already included articles, without adding any new information related to autism and Indigenous peoples in Canada were excluded.

Following completion of the abstract/summary screening stage, all selected abstracts/summaries were retrieved in full and their citation details imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; Munn et al., 2019). The full texts (n = 281) were then assessed in detail against the inclusion criteria (using the citation screening form, Appendix B) by the same two independent raters, who were involved in the title and abstract review stages. During the full-text phase, articles were either marked as “included” or “excluded”. For an article to be excluded, a rationale must have been provided: 1) wrong population (i.e., no Indigenous sample included) 2) wrong concept (i.e., no information on autism); 3) insufficient information (no results specific to autism among Indigenous peoples in Canada or articles where results specific to autism and Indigenous peoples could not be separated out from the rest of the sample); 4) wrong literature type (i.e., social media, blog posts, fact sheets, news/media articles, oral presentations); 5) non-Canadian context; 6) article inaccessible; or 7) findings already included (i.e., article presented redundant study data without presenting further information and/or conducting further analyses). At each stage of the selection process, discrepancies between raters were resolved through discussion and consensus decision. An agreement rate of 93% for full-text review was achieved, indicating a high degree of inter-rater reliability. Notably, though many of the articles we retrieved for full-text review did include autistic Indigenous participants (or their family members/service providers), results specific to this population were either not reported or could not be separated from the rest of the sample and were therefore excluded from our analysis. In cases where study data were presented across more than one article, articles that reported on novel analyses on the data were included (e.g., Lindblom, 2021, 2017a, 2014a, 2017b; Shochet et al., 2020). In total, 27 publications were deemed to have met the inclusion criteria and were included in our analysis. See Figure 1 for the PRISMA flow diagram of the search and selection process.



**Figure 1. PRISMA 2020 flow diagram of search and selection process**

## 2.5. Extracting the evidence

Prior to extracting the evidence, a data extraction form was developed by MJR and collaboratively tested and revised with the other member of the review team (KT). We (MJR and KT) pilot tested the form by independently extracting five randomized articles and then reviewing our extractions together to a) ensure we were consistent in how we extracted the data, and b) modify the data charting form where necessary. Following the pilot test, initial data extraction was completed independently (i.e., MJR

and KT each extracted data from 50% of included articles selected at random), followed by a duplicate review by the other researcher to confirm reliable interpretation. Disagreements between the reviewers were resolved through discussion until consensus was reached. Where required, authors of included articles were contacted to request missing or additional data.

For all eligible sources retrieved, the following data were extracted: (1) publication date; (2) author(s)/publishing source; (3) source type (e.g., journal article, dissertation/thesis, government report, book chapter); (4) aim/purpose; (5) main focus of article; (6) population of interest; (7) geographic scope (i.e., geographic region on which the article was focussed); and (7) key findings/messages, as relevant to our review questions. For empirical sources, data were also extracted on: (1) study design (e.g., review, qualitative, quantitative, mixed methods), (2) participant characteristics (e.g., age/sex, number, setting, specific Indigenous group/s involved); and (3) methods (i.e., data collection and analysis). For primary research studies, additional information on study quality was also extracted (described below). If the focus of the article was not on autism among an Indigenous population in Canada specifically (e.g., studies on the experiences of Indigenous families supporting children with developmental disabilities, including autism), only findings specific to autism among Indigenous peoples in Canada were extracted. For example, if an overall autism sample was divided into subsamples based on participant ethnicity, only the reported results pertaining to the Indigenous subsample were recorded.

Though not a required component of JBI informed scoping reviews, we also appraised the cultural rigour of primary empirical sources included in our review. Akin to scientific rigour or methodological quality in the context of research involving Indigenous peoples, cultural rigour is defined by Lock et al. “as the detailed attention to protocols of engaging *with* Indigenous peoples in all research processes (e.g., research design, governance, and evidence-based recommendations) to ensure the cultural validity of the results” (pg. 211, 2021). Culturally rigorous research purposefully and explicitly incorporates contextually-specific Indigenous perspectives, knowledge systems, and priorities throughout the research process to achieve culturally appropriate, high quality, and relevant research that benefits participating Indigenous communities (Lock et al., 2021). Given the extended legacy of Western approaches to health research exploiting and misrepresenting Indigenous peoples (Hyett et al., 2018), critical appraisal of

included empirical sources based on Indigenous standards of research quality was central to addressing the objectives of our review examining the conduct and quality of autism research involving Indigenous peoples in Canada. Assessing the cultural rigour of included studies was also considered important in the context of our review given the author's Western settler lens and potential for associated biases.

In lieu of a validated critical appraisal tool designed specifically to assess the quality of Indigenous health research in a Canadian context (Lock et al., 2021), studies were evaluated based on the “consolidated criteria for strengthening the reporting of health research involving Indigenous Peoples (CONSIDER) statement” (Huria et al., 2019). In line with the concept of cultural rigour, the CONSIDER statement provides criteria for the reporting of research with and involving Indigenous peoples with the aim of improving the quality of research design and conduct from an Indigenous lens. Developed collaboratively by a working group of Indigenous and non-Indigenous health practitioners and researchers with expertise in Indigenous health equity, the CONSIDER criteria are a conceptual synthesis of Indigenous standards for ethical health research and community-based Indigenous research protocols from countries in which ongoing colonization is present (Australia, Canada, Hawaii, New Zealand, Taiwan, United States of America, and Northern Scandinavia). The criteria are focused on the reporting of Indigenous engagement (i.e., a process that establishes collaborative interaction between researchers and the Indigenous peoples relevant to the research project; Canadian Institutes of Health Research et al., 2018) in the following eight research domains: (i) governance; (ii) relationships; (iii) prioritization; (iv) methodologies; (v) participation; (vi) capacity; (vii) analysis and findings; and (viii) dissemination. Within each domain, criteria focus on principles of culturally rigorous research practice, such as: reciprocity, respect, relational accountability, contextual responsiveness, community relevance, Indigenous self-determination, incorporating and promoting Indigenous worldviews, strength-based analysis and interpretation, and researcher reflexivity (Table 2). See Huria et al., (2019) for a full description of the development of CONSIDER reporting criteria.



**Table 2. CONSIDER Appraisal Criteria for Empirical Sources (Huria et al., 2019)**

Domain	Criteria
<b>Governance</b>	<p><b>Partnership agreement between the research institution and Indigenous governing organization or collective</b></p> <p><i>Does the article describe how partnership agreements between the research institution and the relevant Indigenous-governing organization for the research, (e.g., informal and symbolic agreements through to MOU (Memorandum of Understanding) or MOA (Memorandum of Agreement)) were negotiated and agreed upon? Collaboratively developed protocols may also be considered outlining shared understanding of research processes and responsibilities.</i></p> <p><b>Protection of Indigenous ownership and control over intellectual property and knowledge</b></p> <p><i>Evidence that the partnership agreement specifies how Indigenous rights to ownership and control over intellectual property and cultural knowledge are respected including management of researchers' rights to access, collect, store, and use data (e.g., adherence to OCAP, ITK policies)?</i></p> <p><b>Indigenous research leadership</b></p> <p><i>Did the research team include Indigenous researchers in a leadership role? (e.g., Indigenous research leads, principal investigators, authorship, etc.)</i></p>
<b>Prioritization</b>	<p><b>Research grounded in community identified need/priority</b></p> <p><i>Evidence that the research aims emerged from priorities identified by either Indigenous stakeholders, governing bodies, funders, non-governmental organizations, participating communities, and/or empirical evidence.</i></p>

Domain	Criteria
Relationships	<p><b>Adherence and honouring Indigenous ethical guidelines, processes, and approvals</b></p> <p><i>Evidence that the research conduct met relevant ethical guidelines, including a description of the process of approval from all relevant to Indigenous stakeholders (e.g., Indigenous ethics committee approval, regional/national ethics approval processes).</i></p> <p><b>Involvement of Indigenous stakeholders in the research process</b></p> <p><i>The article describes how Indigenous participants and stakeholders were involved as partners in the research process (i.e., funding, research design, recruitment, implementation, data collection, analysis, interpretation, dissemination). This includes evidence of engagement through research processes such as community consultation, involving Indigenous health workers, Elders, Indigenous funding sources, and community control organizations (e.g., band councils) or community engaged research designs (i.e., community based participatory action research and community engaged research).</i></p> <p><b>Research team expertise in Indigenous health research</b></p> <p><i>Evidence that the research team has specific expertise relevant to research involving Indigenous peoples (e.g., partnership capacity, knowledge of the impacts of colonization and racism on Indigenous health outcomes, participatory research skills, policy and funding relationships, methodological experience, and intellectual and property knowledge). Research groups should seek the necessary expertise they are lacking at the inception of the project.</i></p>
Methodologies	<p><b>Research guided by Indigenous methodological approach</b></p> <p><i>Evidence that the research process was informed and guided by Indigenous research frameworks/methodologies/theoretical approaches specific to the values and context of the participating Indigenous communities, including the incorporation of Indigenous quantitative and qualitative methods (e.g., relational accountability, two-eyed seeing, sharing circles).</i></p> <p><b>Rational of methods and consideration of implications for Indigenous stakeholders</b></p> <p><i>Does the article provide a rational of the methods used and incorporate considerations of the physical, social, economic and cultural environment of the participants and prospective participants (e.g., impacts of colonization, racism, and social justice)? When discussing indigenous health, researchers need to provide the context necessary to avoid deficit narratives and placing the locus of responsibility for health inequities on Indigenous peoples.</i></p>

Domain	Criteria
<p><b>Participation</b></p>	<p><b>Individual and collective consent to research participation and conduct analyses on collected data</b></p> <p><i>The article specificizes the informed consent process for the use of all data collected from Indigenous participants, including secondary data, the future use of data, and/or for third-party use of data.</i></p> <p><b>Resources demands (present/future/cultural/emotional/intellectual) placed on Indigenous participants and participant communities are appropriately compensated</b></p> <p><i>Evidence that the researchers considered and addressed the burden of research participation on Indigenous participants and communities, including providing adequate time and funding to ensure that the benefits are greater than the demands placed on Indigenous peoples involved in the project (e.g., appropriate compensation for Indigenous participants, remuneration for the work and expertise of Indigenous advisory committees/consultants/reference groups, employment of local Indigenous peoples, gifts). This is essentially the give-back to relevant communities and is especially important when there has not been full consultation/partnership to align the research with Indigenous priorities.</i></p> <p><b>Indigenous data sovereignty</b></p> <p><i>Evidence the researchers were transparent in how data will be stored, governed, and used in the informed consent process.</i></p>
<p><b>Capacity-building</b></p>	<p><b>Development and maintenance of Indigenous research capacities</b></p> <p><i>Evidence that the research team supported the development and maintenance of Indigenous research capacities (e.g., research education and training as part of the research agreement/protocol, specific funding of Indigenous researchers)</i></p> <p><b>Professional development by the research team to develop a capacity to partner with Indigenous peoples</b></p> <p><i>Evidence that non-Indigenous researchers undertook professional development activities that strengthened their work with Indigenous partners (e.g., relevant language courses, cultural learnings, understanding of Indigenous worldviews and values, research on relevant protocols and customs, time spent in the community).</i></p>

Domain	Criteria
<b>Analysis and Interpretation</b>	<p><b>Analysis and reporting supported critical inquiry and strength-based approach</b></p> <p><i>Evidence of critical inquiry and strength-based approaches to the research analysis, including the incorporation/valuing of cultural beliefs or values into the research findings (e.g., inclusion of Indigenous stakeholders in the analysis, interpretation, and reporting of the research; community validation of results; results that identify and build on positive attributes of Indigenous communities). Findings regarding Indigenous health disparities should be presented within the context of the ongoing impacts of colonization on the social determinants of health for Indigenous peoples.</i></p> <p><b>Recognition of Indigenous contributions to research outcomes</b></p> <p>Did the researchers acknowledge the knowledge, expertise, and contributions of Indigenous stakeholders to research outcomes (e.g., Indigenous authorship, acknowledgements)</p>
<b>Dissemination</b>	<p><b>Dissemination of results to relevant Indigenous stakeholders, policy makers, health service providers, Indigenous communities and organizations, and other relevant stakeholders</b></p> <p><i>Researchers describe the process by the research findings were disseminated to relevant stakeholders, including those who participated directly in the research project (or the plan for future knowledge exchange activities).</i></p> <p><b>Results translated into practical outcomes for Indigenous communities</b></p> <p><i>Were there action-based responses to the research that were relevant and of benefit to Indigenous Peoples, and that support indigenous health advancement? (e.g., policy, funding, program development)</i></p>

Two reviewers (MJR, KT) independently rated included studies on compliance with each of the criteria as either “Yes”, “Partially”, or “No”. “Yes” was marked if evidence that the underlying principle posed by the criterion was considered, addressed, and described explicitly in the text. “Partially” was marked if there was some evidence that the criterion was addressed. “No” was marked if the reported research practices opposed the criterion, there was insufficient evidence to support the study’s compliance with a criterion, or no information relevant to the criterion was reported. For example, “Yes” was marked for the criterion: “Did the researcher respond to a need or priority determined by the community?” for articles that described an Indigenous group or organisation approaching the researcher(s) with a research question or project. Due to the lack of research into the research topic, no publications were excluded from the review based on critical appraisal, however a summary of each articles’ cultural rigour was added to the data extraction form and quality concerns for included publications were noted when reporting specific study results. Further, trends related to community engagement in each appraisal domain were summarized across empirical studies and reported in our results section.

## **2.6. Analysis of the evidence**

To identify patterns in the literature, descriptive content analysis of extracted data fields (from our data extraction form) was conducted across included articles. Content analysis is a systematic coding and categorizing approach used for exploring the content of documents on a given topic unobtrusively (i.e., descriptively as opposed to analytically) in order to determine trends and patterns in the data, their frequency, and their relationships. This method emphasizes the description and summary of recurring elements in the data, without the external interpretation or synthesis characteristic of thematic analytic approaches. This descriptive approach to analysing data extracted from included articles was selected as it is well-suited to exploratory research in areas where not much is known, and can be used for the simple reporting of common issues mentioned in the data (Elo & Kyngäs, 2008). Not only does content analysis align with scoping review methodology, but it also aims to limit the subjective interpretation of themes potentially biased by researchers’ positionality.

Following the data extraction process, the main author (MJR) and undergraduate research assistant (KT) re-read all included articles. They identified and discussed initial

codes in each data extraction field. Coding consistency was ensured by both MJR and KT agreeing on a final set of codes and by the main author completing a second round of coding. Articles that discussed each of the identified codes were tallied. Analysis proceeded with categorisation of extracted data guided by the research questions and frequency of recurring codes. Findings from the content analysis were tabulated (Table 3) and summarized descriptively as relevant to each of our review questions in the results section below. Thematic synthesis was not conducted on identified codes as such analysis is beyond the scope of scoping reviews methodology (Peters et al., 2020).

**Table 3. Summary of qualitative content coding of included publications based on our research questions (RQ)**

Category/theme	Sub-themes or recurring elements (Number of included studies)	Sources [reference number from Table 4]
<b>RQ1: Source characteristics</b>		
Publication date	≤2009 (5)	[2, 8, 15, 20, 23]
	2010-2015 (9)	[1, 3, 4, 6, 7, 10, 11, 17, 24]
	2016-2021 (13)	[5, 9, 12, 13, 14, 16, 18, 19, 21, 22, 25, 26, 27]
Literature type	Peer-reviewed journal article (18)	[1, 3, 4, 5, 6, 8, 9, 11, 12, 13, 14, 15, 17, 18, 19, 25, 26, 27]
	Conference paper (1)	[10]
	Editorial (1)	[16]
	Thesis/dissertation (2)	[2, 7]
	Book chapter (2)	[20, 23]
	NGO report (3)	[21, 22, 24]
Methodology	Review (6)	[4, 11, 18, 19, 21, 27]
	Quantitative (6)	[1, 3, 6, 7, 15, 22]
	Qualitative (11)	[2, 5, 8, 12, 13, 14, 17, 23, 24, 25, 26]
	Mixed qualitative & quantitative (1)	[23]
	Opinion/discussion (2)	[9, 16]
	Narrative account (2)	[10, 20]
Area of focus	Autism/developmental disabilities (9)	[1, 3, 7, 8, 15, 16, 17, 26, 27]
	Indigenous health/disability (7)	[2, 6, 20, 22, 23, 24, 25]
	Indigenous peoples and autism (11)	[4, 5, 9, 10, 11, 12, 13, 14, 18, 19, 21]
Geographic scope <sup>a</sup>	Alberta (5)	[1, 3, 5, 23, 26]
	British Columbia (9)	[3, 5, 10, 12, 13, 14, 20, 23, 26]
	Manitoba (8)	[2, 3, 5, 8, 15, 23, 24, 25]
	Newfoundland & Labrador (1)	[3]
	New Brunswick (1)	[23]
	Ontario (3)	[3, 7, 23]

Category/theme	Sub-themes or recurring elements (Number of included studies)	Sources [reference number from Table 4]
	Prince Edward Island (2)	[3, 15]
	Quebec (2)	[23, 27]
	Saskatchewan (1)	[23]
	Cross-Canada <sup>b</sup> (10)	[4, 6, 9, 11, 16, 17, 18, 19, 21, 22]
Population/sample <sup>c,d</sup>	Children (12)	[1, 2, 6, 7, 8, 12, 13, 14, 15, 20, 24, 25]
	Youth (4)	[2, 12, 13, 14]
	Adults (1)	[22]
	Family members (11)	[2, 3, 8, 12, 13, 14, 17, 20, 24, 25, 26]
	Researchers/policy makers/advocates (7)	[5, 10, 16, 17, 24, 25, 26]
	Service providers (7)	[12, 13, 20, 23, 24, 25, 26]
	Previous literature (7)	[4, 9, 11, 18, 19, 21, 27]
Indigenous specific population <sup>e</sup>	First Nations (11)	[2, 10, 11, 12, 13, 14, 20, 22, 23, 24, 25, 26]
	Métis (2)	[2, 22]
	Inuit (2)	[6, 22]
	Indigenous (14)	[1, 3, 4, 5, 7, 8, 9, 15, 16, 17, 18, 19, 21, 27]
Context/setting <sup>f</sup>	On-reserve (1)	[25]
	Off-reserve (4)	[3, 8, 9, 15]
	Both on and off-reserve (14)	[1, 2, 5, 6, 7, 12, 13, 14, 16, 17, 22, 23, 24, 26]
	In foster care (1)	[23]
	Rural/remote (4)	[23, 24, 25, 26]
<b>RQ2: Cultural rigour</b>		
Governance	Community-university research partnerships (3)	[24, 25, 26]
	Partnership agreements (1)	[25]
	Indigenous authorship (2)	[2, 22]
	Research-specific advisory committee (2)	[23, 25]
	Ownership (0)	
	Indigenous funding sources (1)	[23]



Category/theme	Sub-themes or recurring elements (Number of included studies)	Sources [reference number from Table 4]
	Indigenous research leadership (2)	[22, 26]
Prioritization	Community initiated (1)	[25]
	Response to need identified by Indigenous organizations/leaders (2)	[5, 6]
Relationships	Researcher reflexivity (4)	[2, 12, 13, 14]
	Respect for community customs & codes of practice (6)	[2, 12, 13, 14, 23, 26]
	Building trust & respect (4)	[2, 12, 13, 14]
	Engagement with Elders/knowledge holders/leaders (7)	[2, 13, 14, 22, 24, 25, 26]
Methodologies	Research incorporates Indigenous methodologies and worldviews (5)	[2, 13, 14, 24, 26]
	Methods vetted by Indigenous stakeholders (4)	[2, 22, 23, 25]
Participation	Recognizing diverse perspectives within communities (3)	[2, 22, 24]
	Individual consent (5)	[2, 5, 12, 13, 14]
	Culturally appropriate recruitment (2)	[2, 12]
Capacity-building	Indigenous research capacity (3)	[2, 22, 23]
	Autism treatment/support (1)	[26]
Analysis & Interpretation	Member checking (7)	[2, 8, 12, 13, 22, 25, 26]
	Strength-based & critical reporting (11)	[2, 5, 6, 12, 13, 14, 22, 23, 24, 25, 26]
Dissemination	Finding shared with participants (2)	[2, 24]
	Action-based response (3)	[24, 25, 26]
	Provide recommendations for policy change (4)	[2, 23, 24, 25]

<sup>a</sup> Number reported may be more than the total number of included studies (N = 27). If articles reported a geographic focus on multiple provinces/territories, each province/territory reported was tabulated.

<sup>b</sup> Geographic scope was tabulated as cross-Canada, if articles geographic focus was Canada-wide and/or specific provinces/territories under examination were not reported (e.g., Shepherd & Waddell, 2015)

<sup>c</sup> Number reported may be more than the total number of included studies (N = 27). If articles included participants from multiple populations (e.g., parents of autistic children, and autistic youth), each population group reported was individually tabulated.

<sup>d</sup> Based on Statistics Canada's classification of life cycle groupings, we defined children as individuals aged 0-14 years old, youth aged 15-24 years, and adults those aged 25-64 years (<https://www23-statcan-gc-ca.proxy.lib.sfu.ca/imdb/p3Var.pl?Function=DEC&Id=25363>).

<sup>e</sup> Number reported may be more than the total number of included studies (N = 27). If articles included a focus on multiple Indigenous groups, each specific Indigenous group reported was tabulated. If articles focused on Indigenous peoples in Canada generally, or identified participants as “Indigenous” or “Aboriginal”, the Indigenous specific population was tabulated as Indigenous.

<sup>f</sup> Participant setting (i.e., hospital, community dwelling, in the care of child welfare agencies, community clinic) was only recorded for original research reports (N = 17).

## Chapter 3.

### Results

#### 3.1. Presentation of the results

A total of 27 articles were included in the analysis. This section begins with a high-level overview of the findings pertaining to the two primary research questions described above. We then shift our attention to a more in-depth discussion of the patterns that emerged from the articles under review in three broad categories. To illustrate those patterns, we provide, first, an opening overview of the literature in the given category, and second, a descriptive synopsis containing key information of each article. We organize these article synopses into three categories of studies based on their area of focus:

- (1) Autism diagnosis and prevalence in Indigenous populations (e.g., epidemiological studies reporting on autism prevalence rates)
- (2) Descriptive experiences pertaining to autism in Indigenous communities (e.g., family member and service provider qualitative perspectives)
- (3) Supports and services for autism in Indigenous contexts (e.g., examinations of access, intervention programs, diagnostic services, and other autism supports).

Analysis of each article is organized based on the above categories and identified by article type (e.g., literature review, epidemiological study, qualitative study). Patterns across articles within each focal category are summarized in Table 4. It should be noted that, given the dearth of information available on autism among Indigenous people in Canada, the types of literature were considerably varied across topics, methods, and frameworks. Such variability in the types of literature created the necessity to summarize each article as opposed to interweaving them in a narrative synthesis format. Although several studies could plausibly be organized under two different areas of focus, in any cases where this occurred, we explicitly outlined their relevance to the chosen category and why they were organized as such. Further details on the included sources can be found in the completed data extraction form (Appendix C). In presenting the descriptive summaries of included articles, we adhere to any originally reported

specificity and terminology. We concluded the results section with an interpretative summary of our findings in relation our research questions and the three identified categories of focus.

**Table 4. Patterns across articles within each focal category (N = 27)**

Focal category	Diagnosis & prevalence (n = 11)	Descriptive/lived experiences (n = 4)	Supports & services (n = 12)
Article characteristics	<ul style="list-style-type: none"> <li>• 6 epidemiological studies</li> <li>• 3 literature reviews</li> <li>• 1 narrative account</li> <li>• 1 qualitative study</li> </ul>	<ul style="list-style-type: none"> <li>• 1 narrative account</li> <li>• 2 qualitative studies</li> <li>• 1 mixed-methods</li> </ul>	<p>Subcategory 1 (n = 7): Access and barriers to autism-related supports and services for Indigenous peoples in Canada</p> <ul style="list-style-type: none"> <li>• 1 community-based qualitative study</li> <li>• 1 participatory action qualitative study</li> <li>• 2 qualitative studies</li> <li>• 3 literature reviews</li> </ul> <p>Subcategory 2 (n = 5): culturally appropriate autism interventions</p> <ul style="list-style-type: none"> <li>• 3 qualitative studies</li> <li>• 2 literature reviews</li> </ul>
Key findings	<ul style="list-style-type: none"> <li>• lower rates, later age of diagnosis among Indigenous children compared to non-Indigenous children</li> <li>• higher rates of autism among Indigenous boys compared to Indigenous girls</li> </ul>	<ul style="list-style-type: none"> <li>• Indigenous conceptions of autism</li> <li>• impacts of autism on community life and family well-being</li> <li>• views on diagnosis</li> <li>• importance of community support and traditional cultural practices</li> </ul>	<ul style="list-style-type: none"> <li>• socioeconomic, racial, geographic disparities in access to autism-related services</li> <li>• cultural, social, systemic barriers to service utilization specific to Indigenous autistics</li> <li>• recommendations to address service access disparities and/or barriers</li> <li>• unique cultural needs and values</li> </ul>

Focal category	Diagnosis & prevalence (n = 11)	Descriptive/lived experiences (n = 4)	Supports & services (n = 12)
	<ul style="list-style-type: none"> <li>elevated male to female ratio among Indigenous autistic samples compared to non-Indigenous autistic samples</li> <li>underrepresentation of Indigenous populations in Canadian autism prevalence data</li> <li>underdiagnosis of autism among Indigenous children</li> <li>potential explanations for Indigenous underrepresentation in autism prevalence data</li> <li>implications of underdiagnosis and/or underrepresentation</li> </ul>	<ul style="list-style-type: none"> <li>sources of stress &amp; challenge</li> <li>perceived barriers to appropriate support</li> <li>recommendations to improve services</li> </ul>	<ul style="list-style-type: none"> <li>paucity of research &amp; programs addressing these needs</li> </ul>

### 3.2. Overview: Characteristics of the literature

This section provides an overview of the literature based on Research Question #1: *What are the characteristics of this literature and research related to autism and Indigenous peoples in Canada?*

Table 5 summarizes the characteristics (i.e., literature type and methodology, publication date, article aims, population of interest) of the 19 peer-reviewed and eight grey literatures ( $N = 27$ ) included in our review. Our search uncovered both published and unpublished original research ( $n = 17$ ), previous literature reviews ( $n = 6$ ), discussion/opinion papers ( $n = 2$ ) and autobiographical accounts ( $n = 2$ ) exploring a wide

range of topics relevant to autism and Indigeneity in the Canadian context - from the prevalence of autism among kindergarten children in Ontario to parent perspectives on childhood disability services in Manitoba. Just over a third of included articles (40.74% or 11/27) focused specifically on the topic of autism among Indigenous peoples in Canada; five of which were authored by the same researcher as part of her PhD project (Lindblom, 2021, 2017b, 2014a, 2017a, 2014b).

**Table 5. Summary of article type, aims, and population/sample of included articles**

Author(s) and publication date	Publication type (methodology)	Aim(s)	Population/sample
1. Burstyn et al. (2010)	Peer-reviewed journal article (quantitative, retrospective cohort)	To examine the rate of ASD among children aged 6 – 12 years in Alberta, and determine whether certain maternal characteristics are associated with increased risk of ASD in this population.	Population-based birth cohort of children born in Alberta between 1998 – 2004 ( $N = 218,890$ ), 6.6% Indigenous.
2. Clouston (2007)	Doctoral dissertation (mixed qualitative methods, “weaving” narrative research and Indigenous oral research approaches)	To explore the experiences of Indigenous families caring for children with developmental disabilities (including the diagnostic process, areas of stress and challenge, sources of support, perceptions of their child’s disability, and access to resources), in order to inform how clinical practice may better support these families.	Metis and First Nations caregivers ( $N = 20$ ) of youth with developmental disabilities living in Manitoba ( $N = 24$ , age range 4-21 years), 12.5% autistic.
3. Coo et al. (2012)	Peer-reviewed journal article (quantitative, analytical cross-sectional)	To examine the association between child/family characteristics and age of autism diagnosis in 6 Canadian regions between 1997 and 2005.	Children who obtained an autism diagnosis prior to their 15 <sup>th</sup> birthday between 1997 - 2005 in BC, Calgary, Manitoba, Southeastern Ontario, PEI, or Newfoundland & Labrador ( $N = 2180$ ), 3.3% Indigenous*.
4. Di Pietro & Illes (2014)	Peer-reviewed journal article (scoping literature review)	To map the landscape of research on neurodevelopmental disorders among Indigenous children in Canada.	52 academic and grey literature publications involving Indigenous children with ASD, CP, or FASD.
5. Di Pietro & Illes (2016)	Peer-reviewed journal article (qualitative case study)	To obtain the perspectives of Indigenous health researchers on the reasons for and implications of a lack ASD and CP research in Indigenous contexts.	Health professionals who had conducted research with Indigenous communities in Alberta, British Columbia, and Manitoba ( $N = 8$ ), 25% Indigenous.

Author(s) and publication date	Publication type (methodology)	Aim(s)	Population/sample
6. Findlay & Janz (2012)	Peer-reviewed journal article (quantitative, descriptive cross-sectional)	To examine the parent-reported health of Inuit children under 6 years of age, including the prevalence of chronic conditions such as autism, in 2006.	Representative sample of Inuit children under age six residing in the four Inuit land regions across Canada: Nunatsiavut, Nunavik, Nunavut, the Inuvialuit region, and outside Inuit Nunangut (N = 1693).
7. Hadioonzadeh (2012)	Master's thesis (quantitative, analytical cross-sectional)	To examine the association between diagnosis of ASDs and distance to regional intervention centers among pre-school aged children in Ontario. Demographic and socioeconomic variables were also examined to find significant predictors for diagnosis of ASDs.	Population-based cohort of 4- to 6-year-old children attending public senior kindergarten in Ontario between 2009 & 2011, 0.89% Indigenous*.
8. Hiebert-Murphy et al. (2008)	Peer-reviewed journal article (qualitative descriptive)	To explore parents' experiences of accessing community—based services for developmental disabilities, and examine the relationship between patterns of entry and parent-reported needs and priorities for service.	Parents of children with developmental disabilities, including pervasive developmental disorder (n=11, 25%), accessing provincial childhood disability support services in Manitoba (N = 72), 2% Indigenous*.
9. Inman (2019)	Peer-reviewed journal article (opinion article)	To provide a critical commentary on the absence of Indigenous perspectives within autism discourse in Canada.	n/a
10. Lindblom (2014a)	Conference paper (autobiographical account)	To describe the opportunities and challenges one non-Indigenous researcher encountered while conducting research on autism with First Nations communities in British Columbia.	n/a



<b>Author(s) and publication date</b>	<b>Publication type (methodology)</b>	<b>Aim(s)</b>	<b>Population/sample</b>
11. Lindblom, (2014b)	Peer-reviewed journal article (unspecified literature review)	To examine possible explanations for the apparent under-detection of autism among First Nations children in British Columbia.	Academic and grey literature publications addressing autism in an “Aboriginal or ethnic context” (N = 16)
12. Lindblom (2017a)	Peer-reviewed journal article (mixed qualitative methods, ethnography and Indigenous research approaches)	To explore of the use of Indigenous music as a tool to promote a sense of inclusion among First Nations children with autism.	First Nations youth diagnosed with autism (n = 2, 8-year-old boy & 16-year-old girl) and their family members (n = 4) and service providers (n=6) in two regions of British Columbia.  One youth lived off-reserve in an urban centre, the other lived on-reserve in a rural setting.
13. Lindblom (2017b)	Peer-reviewed journal article (mixed qualitative methods, ethnography and Indigenous research approaches)	To explore the meaning, purpose and use of music for First Nations children with ASD.	First Nations youth aged 6 – 15 years diagnosed with autism (n = 5, 80 % male), their family members (n=7), and teachers/support workers (n=12) from several different areas across British Columbia.
14. Lindblom, (2021)	Peer-reviewed journal article (Mixed qualitative methods, qualitative description and Indigenous research approaches)	To explore the use of music as a facilitator of skill development for First Nations youth on the autism spectrum.	First Nations youth diagnosed with autism (n= 3, age range 10-19 years old, 75% male), and their family members (n=5) in three different regions of British Columbia.
15. Ouellette-Kuntz et al. (2009)	Peer-reviewed journal article (quantitative analytical cross-sectional)	To examine the rate of PDD diagnosis among 0 - 14-year-olds living in Manitoba and PEI, and compare the characteristics of diagnosed cases, including ethnocultural identity, between the two regions.	Children aged 0-14 years old with a documented PDD diagnosis living in Manitoba in 2002 (N= 575), 8.3% Indigenous*; and PEI (n = 87), % Indigenous* not reported due to small case counts.

Author(s) and publication date	Publication type (methodology)	Aim(s)	Population/sample
16. Scott et al. (2021)	Editorial in non-refereed journal (discussion paper)	To reflect on the current disparities and barriers to achieving health equity for autistic people in Canada and outline ways to address these challenges in a future National Autism Strategy.	Representatives from autism advocacy organizations, including the British Columbia Aboriginal Network on Disability Society, who spoke on behalf of underserved autistic communities at the Canadian Autism Leadership Summit 2020.
17. Shepherd & Waddell (2015)	Peer-reviewed journal article (qualitative description)	To explore the views and experiences of parents, policymakers and researchers across Canada, in order to understand the current conflicts in autism policy and ascertain if consensus is possible on improving autism services.	Parents of autistic children and young adults (n=15), policymakers (n=13) and researchers (n=11) who had engaged in public forums on autism policy (N = 39) from 8 provinces across Canada, % Indigenous not reported.
18. Shochet et al. (2020)	Peer-reviewed journal article (systematic literature review and resource catalogue)	To identify psychosocial autism programs and resources that have been developed and trialed specifically with Indigenous peoples worldwide.	Peer-reviewed journal articles evaluating programs targeting the psychosocial wellbeing of Indigenous children with ASD and/or other neurodevelopmental conditions situated in Australia (n = 2), Canada (n=3), and Australia (n=2)  Publicly available resources specific to supporting Indigenous peoples with ASD and/or their families. developed in Australia (9), Canada (1), and New Zealand (1)
19. Simpson (2021)	Peer-reviewed journal article (critical integrative literature review)	To explore the intersection of Indigenous and autistic identity and identify culturally responsive interventions aimed at supporting positive identity formation, pride, and resilience for Indigenous autistics	Peer-reviewed journal articles exploring Indigenous and/or autistic identity in Canada (n=4), the United States, Australia, and New Zealand (N = 24).

Author(s) and publication date	Publication type (methodology)	Aim(s)	Population/sample
20. Sterling-Collins (2009)	Book chapter (autobiographical account)	To describe “Aboriginal social work” practices through an experiential example of one Nlaka’pamux social worker’s personal journey supporting her autistic son, and other Indigenous children with special needs in British Columbia.	n/a
21. Stavropoulou-Kampoukou (2019)	NGO report (scoping literature review)	To identify support and service delivery approaches currently being used in Canada that are considered culturally safe for Indigenous children and youth with ASD.	Academic and grey literature focussed on service delivery and access for Indigenous populations with developmental disabilities. Number not specified.
22. Trans PULSE Canada (2021)	NGO report (quantitative descriptive, survey)	To present results from the first Canada wide all ages survey on the health and wellbeing of Indigenous trans, two-spirit, and non-binary people in Canada.	Gender diverse First Nations, Métis, and Inuit youth and adults (age range 14- 64 years) across Canada (N = 252), 20% autistic.
23. Wright et al. (2007)	Book chapter (mixed methods, survey with convergent quantitative & qualitative items)	To identify challenges and “best practices” for addressing the needs of Indigenous children with learning/cognitive and disabilities (including autism) in the care of First Nations child welfare agencies.	Service providers from First Nations child welfare agencies (N=29), providing services to First Nations and Métis children and families in BC (n=8), Alberta (n=3), Saskatchewan (n=3), Manitoba (n=4), Ontario (n=5), Quebec (n=4), & New Brunswick (n=2), both on and off-reserve in urban and rural settings.
24. Woodgate (2013)	NGO report (qualitative description)	To arrive at an increased understanding of the disability trajectory from the perspectives of First Nations families of children with disabilities in Manitoba.	First Nations children with disabilities (n =97, 13.4% autistic), family members (n = 75), and other key stakeholders (n = 28; i.e., service providers, policy makers, Elders) from Winnipeg, Norway House Cree Nation, and other rural and urban areas in Manitoba.

<b>Author(s) and publication date</b>	<b>Publication type (methodology)</b>	<b>Aim(s)</b>	<b>Population/sample</b>
25. Vives & Sinha (2019)	Peer-reviewed journal article (qualitative action research/case-study)	To examine access to services for children with special healthcare needs (including autism) who lived on reserve in Pinaymootang, Manitoba in 2016 and 2017, and assess comparability of services to those available in nearby non-Indigenous communities	Pinaymootang children with special healthcare needs (n = 12, 25% autistic), their family members (n=12), and local service providers & representatives from provincial Indigenous organizations (n=8).
26. Young et al. (2018)	Peer-reviewed journal article (qualitative participatory action research)	To build capacity in treatment and support for individuals and families impacted by autism in remote and rural communities in Canada.	Approximately 200 community stakeholders (leaders, service providers, family members) in 7 communities in rural, remote, and northern regions of Alberta and British Columbia (Fort McMurray, Westlock, Whitecourt, Edson, Williams Lake, 100 Mile House, Tl'esqox (Toosey First Nation)).
27. Zeidan et al. (2019)	Peer-reviewed journal article (comprehensive policy review)	To determine recent advances, challenges and gaps in the planning and delivery of provincial autism services in Quebec.	Autism-related policy documents issued by the Quebec government between 2010 and 2018 (N = 22).

\*Individuals living on-reserve excluded.

ASD = autism spectrum disorder, CP = cerebral palsy, FASD = fetal alcohol spectrum disorder, n/a = not applicable; NGO = non-governmental organization; PDD = pervasive developmental disorder.

Articles spanned a 14-year period from 2007 to 2021, with a median publication date of 2015. Close to half (48.15% of 13/27) were published in the last five years (since 2016), suggesting a slight increase in literature relevant to autism among Indigenous groups in Canada in recent years. Articles focused on a number of geographic locations across Canada. The most frequently reported geographic context was Canada-wide ( $n = 11$ ), followed by British Columbia ( $n = 9$ ), Manitoba ( $n = 8$ ), Alberta ( $n = 5$ ), Ontario ( $n = 3$ ), and Quebec ( $n = 2$ ). Only a handful of articles focused on the eastern provinces of Canada: Prince Edward Island ( $n = 2$ ), New Brunswick ( $n = 1$ ), and Newfoundland and Labrador ( $n = 1$ ). Nova Scotia was the only province that was not represented in any of the publications included in our review. Despite having proportionally higher Indigenous populations than other regions in Canada (Indigenous Services Canada, 2020), only one article was focused on Saskatchewan, and none on the Canadian territories (i.e., Northwest Territories, Nunavut, and the Yukon).

Many articles included a population focus on children ( $n = 12$ ), which is unsurprising given that autism research, as a body of literature, has primarily focused on the early childhood period (Salt, 2021). Many of the publications ( $n = 11$ ) also included the perspectives of parents and/or extended family members. The inclusion of family networks is particularly important in the context of Indigenous autism research, as previous sociological research has shown that the extended family unit is at the heart of the history, culture, and social organization of Indigenous peoples in Canada (Tam et al., 2016), and that extended family ties play a central role in maintaining the health and well-being of Indigenous communities (National Collaborating Centre for Aboriginal Health, 2015). Only one article included autistic Indigenous adult participants (Merasty et al., 2021).

Though the Indigenous population in Canada is comprised of hundreds of distinct groups, over a third of articles (40.74% or 11/27) focused on Indigenous peoples in Canada as a homogeneous group. The remaining 16 articles separated Indigenous identity based on the three Indigenous groups constitutionally recognized by the Canadian government, namely, First Nations ( $n = 11$ ), Métis ( $n = 2$ ), and Inuit ( $n = 2$ ). Promisingly, in recognition of the diverse social, cultural, environmental and linguistic identities of Indigenous groups in Canada, two community-based research articles also focused on the following specific First Nations communities: Pinaymootang First Nation in Manitoba, and Tl'esqox in British Columbia.

Of the 17 empirical studies included in our review, six were quantitative (35.29%), and eleven were qualitative (64.71%). Only one mixed methods study was identified (5.88%). The majority reported on descriptive or observational studies ( $n = 13$ ). Just three intervention studies reporting on the same music-based program were identified (Lindblom, 2021, 2017a, 2017b). We also identified one participatory action research study (Young et al., 2019).

### **3.3. Overview: Quality and cultural rigour of relevant research**

This section provides an overview of the literature based on Research Question 2: *What is the quality and cultural rigour of research on the topic from an Indigenous perspective?*

Empirical studies ( $n = 17$ ) inconsistently reported culturally rigorous research practices based on the CONSIDER appraisal criteria (Table 6). Though most studies included Indigenous peoples or organizations in some capacity as research participants or 'partners' (16/17), fewer studies involved some form of consultation and/or guidance from relevant Indigenous stakeholders during the development, implementation and/or interpretation of the research (11/17). Importantly, no studies provided evidence of meaningful engagement and collaboration with Indigenous perspectives *across all* eight research domains assessed. In terms of research governance, some studies reported shared research leadership with research specific advisory groups representing relevant Indigenous stakeholders and/or the involvement of Indigenous co-investigators as members of the research team (5/17). Other studies described community-university research partnerships (3/17), though the terms of such collaborations were outlined in a formal partnership agreement in only one of these studies. Just two studies involved Indigenous researchers as principal investigators and study report authors. Turning to prioritization, a handful of studies reported that the research aims emerged from priorities identified by Indigenous organizations, governing bodies and/or funding sources (3/17). One study was initiated by community leaders approaching university researchers, which culminated in a community-university partnership. Notably, ownership of Indigenous knowledges and research data was not explicitly described in any of the articles included in our review.

**Table 6. Evidence of culturally rigorous research practice in included empirical studies (n = 17) based on CONSIDER criteria**

	Research domain								
Author/s & Date  (Ref. # from Table 5)	Governance	Prioritization	Relationships	Methodologies	Participation	Capacity	Analysis & Interpretation	Dissemination	Summary
Burstyn et al. (2010)  1									The authors did not acknowledge culturally rigorous research practices.
Clouston (2007)  2	First author of Métis heritage		Researcher provides a statement of positionality.  Consultation with community leaders (Elders and spiritual leaders).  Relied heavily on two key Indigenous informants from the Aboriginal community over a two-year period, throughout the recruitment and interview process, as well as in designing the research methodology and interview questions and turned her attention toward Indigenous research ethics.	Original research methodology modified to prioritize Indigenous oral knowledges systems, and more authentically represent Indigenous voices.  Used the metaphor of weaving as a conceptual framework to synthesize Indigenous ways of knowing with Western academic inquiry  Indigenous informants involved in research design and methods	Researcher described strategies employed to recruit participants in a culturally appropriate manner (i.e., through personal invitation), establish rapport, and reduce barrier to participation (i.e., flexible timeframes, compensation for participation).  Researcher described measures taken to include diversity of views within the community of interest, including more marginalized/vulnerable families (i.e., those on social welfare).  Individual and collective consent process described.	Hiring of two Indigenous research informants over a two-year period.	Method of analysis modified to support critical inquiry and strength-based interpretation, and more authentically depict the stories of Indigenous participants.  Results presented in story form.  Focus on resilience and strengths of Indigenous participants in interpretation of results.  Member checking during analysis/interpretation and prior to the final report to ensure trustworthiness of results..	Researcher ensured results were shared with all participants in a culturally appropriate way (i.e., personal meeting).  Researcher concludes report with recommendations for policy change based on research findings	Author acknowledged relational accountability and respect for traditional customs and knowledge systems. Utilised Indigenous key informants to guide principles of cultural rigour throughout the research process, and consulted with Elders.
Coo et al. (2012)  3									The authors did not report cultural modifications to research practices.
Di Pietro & Illes (2016)  5		Authors reported the research was in response to calls by Indigenous health organizations to improve access to health care and services for Indigenous peoples in Canada; identifying research as a critical first step in addressing this need.			Individual consent process and measures taken to protect the privacy and confidentiality of research participants.		Analysis and interpretation supported critical inquiry. Authors suggested findings regarding diagnostic and service disparities may be attributed to the historical impact of colonization, and highlight the need for strength- and community-based practices to improve engagement and address disparities.		Though the authors reported the research aims emerged from calls from Indigenous health organizations and results were interpreted to support critical inquiry. The research was conducted with healthcare professionals rather than in partnership with Indigenous communities.

	Research domain								
Author/s & Date  (Ref. # from Table 5)	Governance	Prioritization	Relationships	Methodologies	Participation	Capacity	Analysis & Interpretation	Dissemination	Summary
Findlay & Janz (2012)  6		Authors report that they focused on Inuit children because Indigenous leaders have identified the need for de-aggregated Indigenous data.		Survey used to collect data (ACS) was collaboratively developed by Statistics Canada and Indigenous advisors from across Canada.			Interpretation supports critical inquiry. Results contextualized by Indigenous determinants of health.		Some evidence of research responsivity to need identified by Indigenous organization. Method of data collection developed in collaboration with Indigenous leaders.
Hadioonzadeh (2012)  7							Authors reported conducting member checks to ensure reported results reflected participant perspectives and values.		Limited evidence of culturally rigorous research practice. Participants were involved in the interpretation of results.
Hiebert-Murphy et al. (2008)  8									Evidence of culturally rigorous research practices not reported.
Lindblom (2017a)  12			Evidence of researcher reflexivity (author included a statement of positionality).  Author described measures taken to establish rapport and build trust and respect local customs and protocols.		Individual consent process described.		Author reported validating preliminary interpretation of results by conducting follow-up interviews.  Reported results highlight social injustices and positive attributes of Indigenous communities.		Author acknowledged establishing rapport, and respecting the voices of research participants keeping with the principle of relational accountability.
Lindblom (2017b)  13			Authors described measures taken to ensure local community protocols were respected (i.e., taking a course in Indigenist ethics).  Evidence of researcher reflexivity (i.e., describes measures taken to address power imbalance in research).  Author reported Elders and traditional knowledge holders were consulted during the research.	Original research methodology modified from ethnographic approach using interviews, to include story-telling and conversational method of data collection within an Indigenist research paradigm.	Individual consent process described.  The authors Indigenous relatives assisted recruiting participants and establishing trust with relevant communities.		Author describes consulting Indigenous knowledge holders in analysis and interpretation of results.  Interpretation focusses on strengths of Indigenous participants and Indigenous worldviews more generally.		Evidence of culturally rigorous research practices in the following research domains: relationships, methodologies, participation, and analysis and interpretation.



	Research domain								
Author/s & Date  (Ref. # from Table 5)	Governance	Prioritization	Relationships	Methodologies	Participation	Capacity	Analysis & Interpretation	Dissemination	Summary
Lindblom, (2021)  14			<p>Evidence of research reflexivity.</p> <p>Author reports establishing rapport and building relationships over two-year period.</p> <p>Author acknowledges the role of Elders in the research process.</p>	<p>Author reports project conducted within an “Indigenist paradigm”.</p> <p>Included conversation as the main method of data collection.</p> <p>Author reports intervention used was culturally specific, delivered in the specific language, in accordance with traditional protocols and knowledges.</p>	Individual consent process described.		Reported results support a positive perspective of Indigenous worldviews.		Author acknowledged culturally rigorous research methodology, using conversations as a method of data collection and an Indigenous research paradigm, as well as measures taken to develop relationships and trust with participants.
Ouellette-Kuntz et al. (2009)  15							Authors acknowledged the potential influence of systemic racism on results in their interpretation of study findings.		Authors reported measures taken to support critical inquiry.
Shepherd & Waddell (2015)  17									Culturally rigorous research practices not reported.
Trans PULSE Canada (2021)  22	<p>Evidence of Indigenous research leadership</p> <p>(1)All four authors of the research report of Indigenous heritage.</p> <p>(2) Research team included an Indigenous Leadership Group, comprised of Indigenous academic and community researchers, Elders, and other Indigenous gender-diverse peoples who were involved in all aspects of the research process from the outset.</p>		Authors acknowledged the role of Elders in the research process.	Survey questions developed by the sponsoring organization’s Indigenous Leadership Group, who took measures to decolonize the research methodology.	Researchers reported steps taken to ensure they incorporated a diversity of perspectives within the gender diverse Indigenous community (i.e., increasing the accessibility of participation by providing multiple ways to complete the survey, providing translation services).	Hiring of Indigenous research assistant to assist in survey roll-out.	<p>Indigenous researchers analyzed results to ensure strength-based interpretation.</p> <p>Report highlights Indigenous and gender-diverse peoples access to protective factors, supportive of their health and well-being.</p>		Project included Indigenous research leadership and described measures taken to decolonize the research methodology.

	Research domain								
Author/s & Date  (Ref. # from Table 5)	Governance	Prioritization	Relationships	Methodologies	Participation	Capacity	Analysis & Interpretation	Dissemination	Summary
Wright et al. (2007)  23	<p>Project funded by the First Nations Child &amp; Family Caring Society.</p> <p>Project oversight provided by advisory committee, which included Indigenous representatives and experts in childhood disability.</p>		<p>Authors reported measures taken to ensure research was sensitive and respectful of cultural contexts and practices (i.e., including the use of community-based researchers who understand local traditions and customs).</p>	<p>An inductive research methodology was employed in order to represent as accurately as possible the participants' responses with no preconceived hypotheses</p> <p>To ensure cultural appropriateness and relevance of the data collection methods, advisory committee including representatives from relevant Indigenous communities and organizations was involved in developing the research approach and specific data collection methods.</p>		<p>Authors report that the project was designed to maximize opportunities for building research capacity of Indigenous community members. Indigenous individuals were involved as members of the advisory committee, as the project coordinator, and as on-site research assistants.</p>	<p>Interpretation of results highlight the strengths of Indigenous child welfare agencies and Indigenous communities in meeting the needs of Indigenous children and youth with disabilities in care.</p>	<p>Authors conclude the report by providing policy-based recommendations to improve current services.</p>	<p>Authors acknowledged steps taken to respect Indigenous community practices. Included Indigenous research partners to strengthen research capacity and guide culturally appropriate research processes.</p>
Woodgate (2013)  24	<p>Authors report research partnership between University of Manitoba, Assembly of Manitoba Chiefs, &amp; Norway House Cree Nation.</p>		<p>Authors reported consultation with Indigenous “key informants” Elders, Indigenous service providers, and representatives from Indigenous organizations. Though it was unclear how key informants were involved throughout the research process.</p>	<p>Research method guided by a holistic perspective on health and wellbeing.</p> <p>Used multiple culturally appropriate data collection methods (e.g., photo-voice, sharing circles).</p>	<p>Authors described efforts employed to include both urban and rural perspectives, and extended family systems.</p>		<p>Interpretation consistent with critical inquiry and a strength-based approach.</p>	<p>Authors provide “ways forward” (i.e., recommendations for policy change).</p> <p>Authors provide evidence of action-based response to research: research project presented at “First Nations Families of Children with Disabilities Summit” where community members gathered to discuss the best actions, they can take to make a positive difference in the lives of First Nations families and their children.</p>	<p>The authors acknowledged a variety of measures taken to ensure research was inclusive of Indigenous perspectives, values, and strengths.</p>

	Research domain								
Author/s & Date  (Ref. # from Table 5)	Governance	Prioritization	Relationships	Methodologies	Participation	Capacity	Analysis & Interpretation	Dissemination	Summary
Vives & Sinha (2019)  25	<p>Terms of collaboration established in a Research Agreement.</p> <p>Research partnership between Pinaymootang First Nation, McGill University, Université de Montréal, &amp; Nanaandawewigamig: First Nations Health and Social Secretariat of Manitoba.</p> <p>Governing body for the research project was a 15-member advisory committee, comprised in part by members of the Pinaymootang band council and major provincial Indigenous organizations.</p>	Research project initiated by leaders from Pinaymootang First Nation and facilitated by First Nations Health and Social Secretariat of Manitoba.	Authors acknowledge consulting with Elders/community leaders.	Incorporated Indigenous methods of data collection: sharing circles and conversations, that were vetted by the Indigenous advisory committee..			<p>Researchers reported conducted three separate validation sessions with caregivers, service providers, and community leadership prior to the publication of the final report to ensure interpretation of results reflected Indigenous community values.</p> <p>The authors provided evidence that their analysis and interpretation supported critical inquiry, by linking results regarding disparities in service access experienced by participants to structural discrimination within the public service system.</p>	<p>Authors reported that the main goal of the project was to produce a policy report that Pinaymootang First Nation could use in their advocacy efforts.</p> <p>Authors conclude report by providing recommendations for policy change.</p>	The authors report conducting a community initiated research project, with the goal of producing action-based responses to community identified needs. Indigenous data collection methods were utilized and interpretation was validated with all participants and relevant community stakeholders.
Young et al. (2018)  26	<p>Authors described the project as a research partnership between the University of Calgary, University of British Columbia, Thompson River University, Cariboo Chilcotin Child Development Centre and rural Canadian communities.</p> <p>The research team included Indigenous leaders, community activists, and service providers.</p> <p>Authors also reported that participating communities were central in the decision-making process throughout the research planning and implementation.</p>		<p>Authors described measures taken to honour local community protocols and relevant processes for approvals.</p> <p>Researchers reported extensive participatory engagement. For example the project team invited community appraisal, stakeholder engagement, strengths and asset identification, need/priority determination, partnership building and strategy implementation.</p> <p>Authors described involving community leaders throughout the research process.</p>	The authors report that the project was based on principles of participatory action research, which involves active engagement of community stakeholders throughout the research process, including methodological considerations.		Authors acknowledged that a key project aim was to build capacity in treatment and support for individuals and families impacted by autism in rural and remote communities.	<p>Interpretation and analysis conducted collaboratively by research team and community stakeholders, ensuring that results reflected local community values.</p> <p>Results highlight strengths and resources of participating communities.</p>	Authors reported that the research project supported strategies for improved ASD services development, resulting in program development in some communities.	Authors reported culturally rigorous research practices throughout the research process and action-based results that benefitted participating communities, consistent with principles of participatory

In terms of the processes undertaken by researchers to strengthen relationships with Indigenous partners, just over half of the included studies described measures taken to respect Indigenous customs and codes or practice, and/or establish rapport (10/17). Fewer articles reported recognizing and respecting the role of Elders, spiritual leaders and traditional knowledge holders through active engagement (7/10).

With regard to study methodology and participation, a number of studies reported their methodology was informed by Indigenous research frameworks and/or knowledges (5/17). In other instances, data collection tools were reviewed by Indigenous stakeholders to ensure their appropriateness and relevance (3/17). Only one study reported that Indigenous stakeholders were actively involved in designing the study methodology and data collection methods, and two studies reported that community members were involved in ensuring culturally appropriate participant recruitment and/or strategies employed to reduce barriers to Indigenous participation. A handful of studies reported consent procedures and measures taken to protect participant privacy and confidentiality (5/17). Fewer studies described steps taken to ensure the sample of participants represented a diversity of perspectives within the Indigenous population of interest, including socially and geographically isolated groups (3/17).

In terms of capacity-building, three studies reported that the project design purposefully incorporated opportunities to develop research capacity of Indigenous communities through hiring of Indigenous research co-ordinators/assistants and one participatory action study described developing autism service capacity in involved communities. While most studies acknowledged the strengths of Indigenous communities and/or the link between Indigenous health disparities and Indigenous determinants of health (i.e., colonialism, structural racism, systemic marginalization) (11/17) in the study analysis and interpretation, only one (Clouston, 2007) explicitly aimed to identify, learn, and build upon the strengths of Indigenous ways of knowing and being to support Indigenous families and communities impacted by autism. Most studies that involved communities in data analysis and interpretation reported doing so in a way that involved seeking feedback and input into the results, often times to ensure reliability and accuracy of findings (7/17). Beyond analysis, four studies also noted participation of Indigenous stakeholders in the development of policy recommendations resulting from the research.

Finally, with regard to dissemination, beyond sharing findings during the analysis phase, two studies explicitly reported sharing knowledge generated from the research with research participants in community knowledge-exchange gatherings (2/17). Three studies also reported that the research resulted in tangible and beneficial outcomes for Indigenous participants, such as in the development of a policy report that the community could use in their advocacy efforts.

### **3.4. Focal Category 1: Autism diagnosis and prevalence in Indigenous communities**

Eleven of the included articles (40.74%) focused on issues pertaining to autism diagnosis and prevalence in Indigenous communities in Canada. Of these, six epidemiological studies (four peer-reviewed journal articles, a master's thesis, and an NGO report) specifically examined rates of autism diagnosis in Indigenous samples. The remaining five peer-reviewed articles discussed issues related to autism prevalence and diagnosis more generally, exploring potential explanations and impacts of limited epidemiological data on autism among Indigenous communities in Canada. All five of these articles identified that there are no known statistics on the number of Indigenous peoples in Canada living with autism. Three of these were literature reviews, one was an autobiographical account published as a conference paper, and one was a qualitative study exploring the perspectives of health care providers who had conducted research with Indigenous communities in Canada. Recurring findings across the prevalence literature included: lower rates and later age of autism diagnosis among Indigenous children compared to non-Indigenous children in some regions, increased rates of autism among Indigenous boys compared to Indigenous girls, elevated male female ratio among Indigenous autistic samples compared to non-Indigenous autistic samples, underrepresentation of Indigenous populations in Canadian epidemiological data, and under-diagnosis of autism among Indigenous children. Potential explanations for underrepresentation identified in the literature included: barriers to conducting research with Indigenous communities, and inconsistent/unreliable reporting of Indigenous identity in Canadian health data systems. Culturally inappropriate diagnostic processes, limited access to diagnostic services in remote and rural communities, unique beliefs about autism, racial biases of medical professionals, and the impact of long-term colonialism were the most frequently offered explanations for underdiagnosis of autism in

Indigenous communities. Articles also consistently reported concerns regarding implications of the apparent underrepresentation of Indigenous populations both in autism epidemiological research and among individuals diagnosed with autism, such as, a dearth of knowledge on the appropriateness and acceptability of autism-related supports and services in Indigenous communities.

### **3.4.1. Epidemiological studies**

Six epidemiological studies, published between 2006 and 2021 (median publication date = 2011), reported statistics relevant to age at autism diagnosis/autism prevalence among Indigenous samples. Two were grey literature sources. Indigenous sample sizes ranged from 72 (Coo et al., 2015) to 14, 486 (Burstyn et al., 2010b), and comprised between 0.89% and 100% of the total sample under investigation. Individuals living on First Nations reserves were excluded from the sample in half of the studies (Coo et al., 2012; Hadioonzadeh, 2012; H. Ouellette-Kuntz et al., 2006), and most studies (5/6) aggregated data from First Nations, Métis, and Inuit participants. Only one study (Findlay & Janz, 2012) provided results specific to Inuit in Canada. Despite the use of Indigenous identity as a variable for data analysis in all six epidemiological studies, only two studies (Findlay & Janz, 2012; Merasty et al., 2021) reported Indigenous community involvement at any point during the research process (beyond including Indigenous peoples as research participants) and no studies reported obtaining permission for secondary analysis of existing Indigenous data. There was also substantial variability across studies in how autism was operationally defined and assessed, with certain studies examining rates of all pervasive developmental disorders (PDDs; i.e., Autistic disorder, Rett's disorder, childhood disintegrative disorder, Asperger's), while others examined rates of ASDs broken down by diagnostic subgroups. The most common methods used to determine rates of any type of autism diagnosis were parent/self-report survey and file review of provincial health and/or education records. None of the studies confirmed autism diagnoses via clinical assessment using standardized measures (e.g., Autism Diagnostic Interview Schedule). Reported rates of autism among Indigenous samples ranged from 0.23% to 20%. Only one epidemiological study (Burstyn et al., 2010b), conducted in Alberta, explicitly provided a prevalence estimate of ASD in a population-based Indigenous sample (i.e., including Indigenous individuals living both on and off-reserve). Due to variability across

studies in terms of sample and study methods, results regarding prevalence rates of autism in Indigenous communities cannot be reliably compared and should be interpreted with caution.

In a peer-reviewed journal article, Findlay and Janz (2012) used nationally-representative data from the 2006 Aboriginal Children's Survey (ACS; Statistics Canada, 2008) to examine the parent-reported health of Inuit children under age 6 (N = 1698), including the rate of chronic health conditions known to affect young children (e.g., FASD, ADHD, cerebral palsy, ASD). Though the prevalence of reported chronic health conditions was calculated to determine the most frequently occurring chronic health conditions for Inuit children under age six, the authors reported that the proportion of parent-identified autism in their population-based sample of Inuit was less than 5%, and that a specific autism prevalence estimate was "too unreliable to publish" (pg. 9). No clarification was provided on the rationale for this judgement. The authors concluded that the descriptors of chronic conditions used in the ACS may not fully reflect an Inuit approach to child health which may also include physical, mental, emotional and spiritual aspects of life, and study findings regarding the prevalence of chronic health conditions therefore likely underestimated the true prevalence of these conditions among Inuit children. Though the authors discuss the limitations of the survey measures in assessing Inuit views on child health, it is important to note that the ACS was developed collaboratively by Statistics Canada and Indigenous advisors from across Canada. This was the only study to focus specifically on Inuit children, responding to calls from Indigenous health organizations for de-aggregated Indigenous health data.

In another study using national cross-sectional survey data collected as part of the Trans PULSE Canada project, Merasty et al. (2021) examined the self-reported health and well-being of an Indigenous sub-sample of trans, two-spirit, and non-binary youth and adults aged 14 years and older. The authors reported that the national research study was designed with substantial efforts to be inclusive, respectful, and honouring of the truth of Indigenous gender-diverse people's experiences. Indigenous team members were part of the survey development from the outset, and Indigenous and allied community members and researchers were involved in the analysis of responses from people who identified as Indigenous. Of the 252 survey respondents who indicated being First Nations, Métis, or Inuit, 40% identified as neurodivergent and 20% reported having received a diagnosis of autism or Asperger's. These findings are

consistent with findings from previous research that suggests transgender and gender diverse individuals have, on average, higher rates of autism, other neurodevelopmental and psychiatric conditions compared to cisgender individuals (Warrier et al., 2020). However, results were derived from unweighted frequencies and proportions of a convenience sample and, therefore, should be interpreted with caution.

Taking a different approach to examine autism prevalence rates in the general population at a provincial level, Ouellette-Kuntz et al. (2006) used basic diagnostic and demographic data drawn from provincial government social service/education department records and census data to estimate the period prevalence of diagnosed pervasive developmental disorders (PDDs) among children 1-14 years of age living in Manitoba and Prince Edward Island (PEI) in 2002, and compare the observed proportions of diagnosed cases with certain demographic characteristics (e.g., ethnocultural identity, maternal age) to the expected proportion within the same time period. For confidentiality reasons, the ethnic status of children with diagnosed PDDs could not be reported for PEI due to small case counts. Further, though Aboriginal identity (First Nations, Métis, Inuit) was included as a variable in the analysis, children living on First Nations reserves were excluded and permission for the secondary use of Indigenous data was not discussed. Analysis showed that the prevalence of diagnosed PDDs among children 1–14 years of age was 28.4 per 10,000 (95% confidence interval: 26.1–30.8) in Manitoba, and that children of Aboriginal identity with PDDs (8.3%) were significantly underrepresented compared with the general population of aboriginal children living off reserves (15.6%). The authors interpreted this finding as reflecting inequalities in access to diagnostic services for Indigenous children and/or a lack of cultural sensitivity in current assessment tools, rather than a reduced risk of PDDs for Indigenous children.

In a Master's thesis, Hadioonzadeh (2012) also investigated the prevalence of ASDs/PDDs at a provincial level, specifically focusing on regional differences in autism prevalence by Ministry of Child and Youth Services (MCYS) regions in Ontario. Using teacher-reported data drawn from provincial school-board records, diagnostic and sociodemographic information was obtained for all children attending Senior Kindergarten classes in Ontario in school years 2009/10 and 2010/11 (N = 66, 284, <1% Aboriginal) to examine predictors of ASDs in each region. Although the number of Aboriginal children included in the analysis was low (n = 695), findings showed no



significant difference in the proportion of children in diagnosed and non-diagnosed groups by Aboriginal status in the overall sample. Descriptive analyses of demographic characteristics by covariate group did reveal differences between Aboriginal and non-Aboriginal children with ASDs, but the statistical significance of these differences was not examined. For example, the male to female sex ratio was found to be slightly over 5:1 in non-Aboriginal children and 9:1 for Aboriginal children. Compared to non-Aboriginal children with ASDs, Aboriginal children with ASDs also tended to be from neighborhoods with lower levels of income (50% vs. 90%). When sociodemographic predictors were examined within each MCYS region, Aboriginal children were found to be significantly less likely to be in the diagnostic group than non-Aboriginal children, but solely in the Toronto region (OR = 0.15, 95% confidence interval 0.04 – 0.49,  $p < 0.05$ ). The author acknowledged that findings regarding similar ASD prevalence rates among Aboriginal and non-Aboriginal children, both in the overall sample and most MCYS regions, were “encouraging” in light of previous studies demonstrating lower prevalence rates for ethnic minority groups. However, she also suggested that results regarding Aboriginal identity should be interpreted cautiously, as even in this very large population study less than <1% of the sample was identified as Aboriginal and Aboriginal children living on First Nations reserves were excluded from the sample.

In the only other article included in our review to discuss gender differences in ASD diagnosis among Indigenous children, Burstyn et al. (2010) used data drawn from provincial health records to retrospectively analyze rates of ASD diagnosis for all children born in Alberta hospitals between 1998 and 2004 ( $N = 218,890$ , 6.6% Aboriginal). The association between maternal characteristics and ASDs were also examined using relative risk modelling. Analyses showed reduced rates (RR = 0.58, 95% CI = 0.40-0.84) and later age at diagnosis among children born to mothers with treaty Aboriginal status. On average, Aboriginal children were diagnosed almost two years later than the rest of the cohort ( $m = 59.5$  months, IQR 38-74 versus  $m = 36$  months, IQR 47-65). Further, while findings showed a small differential in age at ASD diagnosis between non-Aboriginal boys and girls ( $m = 47$  months, IQR 37-66 versus  $m = 44$  months, IQR 32-62), boys born to Aboriginal mothers were diagnosed at a much older age than girls born to Aboriginal mothers ( $m = 64.5$  months, IQR 40-77 versus  $m = 40$  months, IQR 38-58). The authors interpreted identified disparities in ASD diagnosis by Aboriginal status as suggestive of poor access to diagnostic and treatment facilities in

remote areas, partly on the basis of previous research involving other Indigenous groups, such as Aboriginal children living in Australia (Leonard et al., 2006).

Coo et al. (2012) also investigated issues pertaining to age at autism diagnosis among Aboriginal children. Using data from the National Epidemiological Database for the Study of Autism in Canada (NEDSAC), generalized linear modeling was employed to examine the association between child and family characteristics and the age at which 2180 children (3.3% First Nations, Métis, Inuit) were diagnosed with ASD between 1997 and 2005 in six Canadian regions (British Columbia; Calgary, Alberta; Manitoba; Southeastern Ontario; Prince Edward Island; and Newfoundland and Labrador). Separate regression models were fit to British Columbia ( $n = 1247$ ) and Manitoba ( $n = 493$ ) subsamples to examine whether the effects of family/child characteristics varied between those regions and the overall sample. Results of the analyses found Aboriginal identity to be significantly associated with later age of diagnosis (point estimate = 1.16; 95% CI: 1.01–1.33;  $p = .035$ ), but only in the Manitoba subsample. Further, the effect of Aboriginal identity on age at diagnosis demonstrated within the Manitoba subsample was no longer significant when data was stratified by diagnostic subgroup. Authors concluded that, in their Canadian sample, the influence of Aboriginal identity on age of diagnosis appeared to vary by region, and did not seem to be concentrated at one end of the autism spectrum. Consistent with interpretations of findings regarding lower rates and/or later age of diagnosis among Aboriginal children by authors of included studies from other regions in Canada (e.g., Burstyn et al., 2010; Hadjoonzadeh, 2012; Ouellette-Kuntz et al., 2006), Coo et al. also suggested their findings may reflect inequalities in access to autism diagnostic services in the Manitoba region.

### **3.4.2. Literature reviews**

Di Pietro and Illes (2014) conducted a scoping review of Canadian Indigenous health research on autism, cerebral palsy (CP), and fetal alcohol spectrum disorder (FASD), using a keyword search strategy in electronic databases and Canadian health agency websites to identify both peer-reviewed research and literature from grey sources. This strategy retrieved a total of 52 studies on neurodevelopmental disorders involving Indigenous children in Canada, 51 of which focussed exclusively on FASD. None of the identified studies had to do with autism spectrum disorder. The authors concluded that the absence of ASD research on Indigenous children in Canada is

unjustified in light of prevalence data suggesting higher rates of ASD relative to FASD in the general Canadian population. Further, the authors cautioned against assuming that a lack of relevant epidemiological data signifies that autism is rare among Indigenous peoples in Canada. Instead, they interpreted these findings as an indication that autism is underdiagnosed among Indigenous peoples in Canada, based on previous studies demonstrating: a) disproportionately high rates of disability among Indigenous peoples in Canada (e.g., Rothman & Laurel, 2007), and b) underdiagnosis of autism among Native American/Alaskan children in the United States (e.g., Dyches et al., 2004; Tincani et al., 2009) and Aboriginal children in Australia (e.g., Roy & Balarathnasingam, 2010). The authors speculated that overdiagnosis of FASD, remote location of many Indigenous communities, unique beliefs about disability, language barriers, socioeconomic disadvantage, and the ongoing impacts of colonial oppression have been proposed as contributory factors for disproportionately low rates of autism among Indigenous groups internationally, and may also mitigate or delay diagnosis of autism in Indigenous children in Canada. The authors concluded that culturally relevant diagnostic tools need to be developed before epidemiological assessments on autism in Indigenous communities can be made in Canada.

In another review article published in 2014(b), Lindblom examined both the Canadian and international literature on autism to identify potential explanations for the scarcity of First Nations children with autism, which the author observed while completing her PhD project. Though few details were provided on the review methodology, it was noted that keyword searches were completed in international databases and that inclusion was limited to academic sources. This strategy identified a total of 17 publications (16 journal articles, 1 doctoral dissertation) addressing autism in an “Aboriginal, ethnic, or cultural context” from Canada (n = 4), the USA (n = 7), Australia (n = 3), the Netherlands (n = 1), Korea (n = 1), and Ghana (n = 1). None of the retrieved autism studies included First Nations children in British Columbia and only two studies from other regions in Canada reported results for Aboriginal participants, both of which identified disproportionately low rates of autism in this population. Though the other two included autism studies from Canada collected information on the ethnocultural identity of participants, results were not reported due to small case counts. Results from the 13 international studies suggest that children from minority groups may be underrepresented among children diagnosed with autism. The author interpreted

these findings as an indication that autism is under-detected among First Nations children in British Columbia, corroborating her anecdotal observations while conducting her PhD research. Drawing on the data from international publications the author also identified the following potential explanations for the apparent under detection of autism among First Nations children in Canada: (1) diagnostic substitution/overshadowing, (2) cultural differences in genetic vulnerability and/or perspectives on disability, (3) lack of culturally sensitive diagnostic processes, (4) limited access to ASD assessment services in isolated First Nations communities, (5) racial bias and discrimination among healthcare providers, and (6) the impact of historical oppression and discrimination. The author concluded the review by discussing implications of under-diagnosis for First Nations children with autism at an individual level, such as exclusion from autism funding programs in British Columbia, and posited that Indigenous children are likely lacking access to desired services and supports that are available to non-Indigenous children.

In an opinion article, Inman (2019) also explored potential reasons for and implications of underrepresentation of Indigenous peoples in Canada both among individuals diagnosed with autism, as well as, in autism policy and research. Using a lack of prevalence data on Indigenous individuals with autism in spite of increased monitoring and surveillance of an “autism epidemic in Canada” as a critical starting point, the author drew on the literature from a variety of disciplines (including critical disability studies, medical anthropology, autistic scholarship, Indigenous and critical race studies, medical diagnostic literature) to construct three main arguments. First, that racist health policies and practices have led to the association of FASD with Indigeneity. This association has resulted in the “production of Indigenous FASD epidemic”, which is a fallacy, and simultaneously serves to limit clinical, research, and policy discourse on autism among Indigenous peoples in Canada. Second, overlap in the diagnostic criteria for ASD and FASD, both of which are relational disorders that lack biological markers, have led to the unique subjugation of Indigenous individuals with social difficulties by medical professionals and resulted in the simultaneous overdiagnosis of FASD and underdiagnosis of ASD among Indigenous peoples in Canada. Finally, the so-called FASD epidemic “flattens” Indigenous neurodiversity, by way of silencing Indigenous autistic voices, and also serves to sustain the perception that Indigenous peoples are not fit to govern themselves, thereby justifying the ongoing systematic oppression of

Indigenous peoples within the settler-colonial nation of Canada. The author concluded that diagnostic labels, such as ASD and FASD, are a tool of colonial oppression.

### **3.4.3. Stakeholder perspectives**

In a follow-up study to their 2014 literature review, Di Pietro and Illes (2016) explored the perspective of Indigenous health researchers on the reasons for and implications of the lack of ASD prevalence research in Indigenous contexts identified in their 2014 review. Qualitative interviews were conducted with eight healthcare professionals who had extensive experience in research with First Nations communities in Alberta (n = 5), British Columbia (n = 2), and Manitoba (n = 1). Two of the participating researchers identified as Aboriginal (25% of the total sample). All eight participants reported autism to be relatively common in the First Nations communities they worked in. Consistent with assertions put forth by Di Pietro and Illes (2014), Lindblom (2014b), and Inman (2019), participants viewed the absence of relevant prevalence data as an indication of barriers to autism research and diagnosis in First Nations communities, rather than an indication that autism is actually an absent condition in these communities. All participants indicated that autism remains under-reported, misdiagnosed, or undiagnosed in First Nations communities. Explanations for under-detection offered by participants included: (1) inconsistent and unreliable reporting of Indigenous identity in Canadian health care utilization systems, (2) limited availability of diagnostic services in remote First Nations communities, (3) limited awareness of autism in some communities, (4) lengthy and complex assessment process to diagnosis autism, (5) lack of parental capacity, and (6) mistrust in non-Indigenous health care providers; all of which the authors suggested were linked to the ongoing impacts of colonial oppression on Indigenous peoples in Canada. Corroborating Inman's (2019) opinion, a number of participants (50%) also reported that racial biases of non-Indigenous health care providers commonly results in ASD being misdiagnosed as FASD among First Nations children. All participants perceived that the under-recognition of ASD in First Nations communities (both in research and clinical practice) had negative implications for individuals and communities impacted by the condition. Most importantly, participants stated that Aboriginal children with autism were underserved, especially those in foster care or living on reserve. The authors concluded that community-based epidemiological research to establish ASD prevalence rates among Indigenous populations could serve

as a catalyst for developing public policies and services that address the need for adequate autism care in Indigenous communities, and as such should be a key priority.

Lindblom (2014a) also discussed issues related to autism diagnosis and prevalence in the context of research with Indigenous communities. In an autobiographical account published as a conference paper, the non-Indigenous researcher described the opportunities and challenges she encountered while conducting research on autism with First Nations communities in British Columbia as part of her PhD project. Among identified challenges were the under-detection of autism in First Nations communities, as well as, a lack of relevant prevalence data to justify research endeavours. Based on her personal experience, the author proposed barriers to conducting autism research in Aboriginal communities as a potential reason for the paucity of relevant prevalence data. These barriers included: mistrust of non-Indigenous researchers, and misalignment between the interests and goals of the researcher and the intended participants. The author concluded that autism research conducted in collaboration with Indigenous communities is urgently needed to establish prevalence rates of autism in First Nations communities and, ultimately, give voice to an under-represented and under-served population.

### **3.5. Focal category 2: Descriptive/lived experiences of autism in Indigenous communities**

Four publications included in the review focussed on the lived experiences of Indigenous families, service providers, and other community stakeholders involved in supporting autistic children and youth. One article, published as a book chapter, focussed specifically on a First Nations mother's experience raising her autistic son. The remaining two grey literature reports and a doctoral dissertation described the experiences of family members and service providers involved in supporting children with a range of disabilities, including autism. Though all these articles discussed autism-related supports and services in some capacity, they were categorized as 'descriptive/lived experiences of autism' rather than 'supports and services for autism in Indigenous contexts' because the primary focus of these articles was on Indigenous stakeholders' day-to-day experiences with autism, across a variety of contexts, including but not limited to *how* they experienced autism-related supports and services. Further, these articles concentrated their analyses and discussion on the narratives of

Indigenous individuals with regard to autism and/or contained extensive quotations illustrating Indigenous participants perspectives and lived experiences of autism. While some of the articles categorized under ‘supports and services for autism in Indigenous contexts’ were qualitative research articles that explored Indigenous participants’ perspectives – they did not highlight participant reflections in their analysis or discussion. Recurring topics/issues described by participants in the experiential literature included: Indigenous conceptions of disability (including autism), impacts of autism on community life and family well-being, the importance of community support and traditional cultural practices, views on diagnosis, sources of stress and challenge, perceived barriers to appropriate support, and recommendations to improve supports and services. Examples of participants comments on these topics are included in Appendix D. Of all three categories of article focus, articles included in this category reported the greatest level of Indigenous engagement in research processes and decisions, as measured by the CONSIDER appraisal criteria.

### **3.5.1. Families and service providers of autistic children**

In her book chapter titled “Holistic approaches to supporting children with special needs”, Rona Sterling Collins (Quist’letko), a social worker and mother of a 10-year-old autistic boy from Nlha’7kapmx Nation in British Columbia, utilized the four quadrants of the medicine wheel framework to recount her family’s journey with autism. Beginning her story in her son’s infancy, the author described her son’s development within the physical, emotional, intellectual, and spiritual realms, highlighting his strengths and difficulties, as well as, the challenges and joys her family experienced in these four quadrants at each development. In her narrative, the author also reflected on her family’s experience identifying concerns with her son’s development, obtaining an autism assessment and diagnosis, and seeking and obtaining appropriate support. Woven throughout the chapter, how the author’s understanding, experience of, and approach to supporting her son are intrinsically tied to her Aboriginal worldviews and holistic perspective on health and well-being were also explored. The author identified wait lists, a lack of specialized autism-related services and service providers in rural communities, and service pathway complexity as key challenges in her family’s journey to obtain appropriate supports and services for her son. Community support, connection to traditional spiritual practices, and access to culturally appropriate and family focussed

services were described as important sources of strength and support. The author also discussed the limitations of the medical model of autism, which focusses solely on the physical and intellectual aspects of the condition, for Aboriginal people, and posits that a holistic approach, which also includes the emotional and spiritual realms of human experience, individualised to each family's unique context is required to fully meet the needs of Indigenous children and families with autism. The author concluded the chapter with recommendations for ways social workers can incorporate Aboriginal worldviews to better support Aboriginal children and families with special needs. These included: the incorporation of cultural activities into education programming, inclusion of extended family and community in decision making, celebrating the strengths and progress of the child, offering transportation to access to services, and encouraging diagnosis as a means of accessing financial support.

### **3.5.2. Families and service providers of children with disabilities including autism**

A dissertation by Clouston (2007), "weaved" Indigenous storytelling traditions with narrative interview techniques to explore the lived experiences of First Nations and Métis caregivers of children with developmental disabilities in Manitoba. Three of the 20 participating caregivers (15%) were parents/grandparents (herein referred to as family members) of children with autism, aged 6 to 15 years. Presented in story form, the findings revealed that family members continued to be guided by traditional Aboriginal worldviews, spiritual values, and conceptions of disability in caring for their children with autism within a Western system that (they perceived) pathologizes and de-values developmental differences. All three family members described their autistic children as sacred and having purpose, and considered autism to be a condition associated with challenges, as well as, gifts. They reported it was their "cultural imperative" to take responsibility to provide the best possible care for their vulnerable children, embraced the opportunity to learn from their children's differences, and perceived their own inner growth to be connected with the care and nurturing of their child. Connection to traditional spiritual practices and community, especially extended family, were identified as key sources of strength and support for participants. Concurrently, family members also acknowledged gaps in other community members' awareness and understanding of autism as a substantial stressor and barrier to receiving adequate support. All participants described feeling blamed for their children's 'unusual behaviour', at school,



as well as, in broader community settings. Participants also reported that limited awareness of autism among educators and medical professionals in their First Nations communities contributed to delays in obtaining an autism diagnosis and/or appropriate school supports. Family members' experiences with the diagnostic process itself were varied. One family member reported feeling that a diagnosis of autism did not adequately capture the differences experienced by her child, and expressed dissatisfaction with the diagnostic process ("How can anyone make a diagnosis based on a half hour visit?"). Although the other family members expressed some distrust in medical labels, they also identified autism diagnosis as an important step that helped them understand their child's behaviour and opened new doors in terms of support service eligibility. In addition to limited awareness of autism in First Nations communities, family members' experiences also revealed a total lack of formal autism-related supports and services on First Nations reserves. Faced with an absence of necessary medical, therapeutic, and educational services in their own communities, all three families had made the decision to relocate to urban centres. Moving, however, also presented challenges in that services in urban centres were perceived to lack cultural sensitivity, and family members, removed and disconnected from their communities and cultures, experienced feelings of loss and isolation. In a final summary and reflection on family members' stories, the Métis author highlighted the need to strengthen autism service capacity in First Nations communities and to adapt existing autism supports and services so that they are culturally relevant and responsive to the unique needs of Aboriginal families.

In an executive summary disseminated at the First Nations Families of Children with Disabilities Summit, Woodgate (2013) reported findings from a community-university research partnership project involving families and service providers of First Nations children with disabilities living across Manitoba. Multiple qualitative data collection methods (interviews, photo-voices, sharing circles) were used to elicit participants' attitudes and beliefs about childhood disability, the perceived impact of disability on their lives, their service experiences, support needs, and recommendations for improving service provision. Participants were 75 families of children with a range of disabilities, including 13 with autism, and 28 service providers and other key informants (Elders, policy makers) recruited from Winnipeg, Norway House Cree Nation, and other urban southern and rural northern Manitoba locations. Consistent with participants in

Clouston (2007), family members described their “child(ren) as a gift”, and “special people”, who had much to contribute to their families and society in general. Parents of autistic children in particular, reporting feeling they had learned so much from their children by focussing on the children’s strengths and abilities rather than what they could not do. At the same time, certain parents also reflected on feelings of loss and grief associated with obtaining an official autism diagnosis, recognizing that their children would not be like other children their age and feeling judged or blamed for their children’s behaviour. Turning to the impacts of autism on families’ lives, both family members and service providers acknowledged that raising a child with autism is a lot of work, and that the stress associated with ‘intense parenting’ took a toll on the physical and mental health of families. Families reported that a lack of appropriate social supports and services were important contributors to parents experiencing poor health. Many families reporting struggling to provide a good life for themselves and their children in environments lacking the appropriate supports and services. Parents living on reserve were particularly vulnerable to stress and poor health outcomes due to a complete absence of services in their communities. Even First Nations families living off reserve and in urban centres sometimes experienced ‘missing-out’ on desired services and programs that contribute to them having a good life due to an unnecessarily complex service system. Service providers and other key informants also identified systemic inequalities related to colonialism (e.g., historical trauma, social disruption, external judgement and stigma, poverty) as key barriers to support for Indigenous families. Relatedly, family members endorsed having different “perspectives and problems than mainstream people have” and emphasized the need for supports and services that focus on the strengths and unique social context of First Nations families. Participant recommendations for improving service provision included ensuring non-Indigenous service providers complete training in cultural competency, that providers are flexible around service delivery, and that autism-related supports and services be made available in remote communities.

In another book chapter, Wright and colleagues (2007) reported findings from a multi-phase mixed-methods research project funded by First Nations Child & Family Caring Society, which sought to explore the issues and challenges faced by First Nations communities in meeting the needs of children with disabilities, including autism. The project involved 124 First Nation child and family service agency (FNCFA) staff,

collateral service providers, and community members across Canada. Surveys, semi-structured interviews and focus groups were used to elicit participant experiences with, and perceptions of, childhood disability. Many community members reported holding a traditional view of disabilities, including seeing children with disabilities as a special gift. While this view was perceived as contributing to the valuing and inclusion of people with disabilities in First Nations communities, service providers also expressed that it affected the way needs and services were perceived by communities. Along these lines, service providers identified gaps in community members awareness/understanding of autism and distrust of medical labels as barriers to support in some Indigenous communities. Caution was encouraged regarding the use of the word 'autism' as certain communities expressed concerns regarding the potential stigmatizing effects of a disability label. Agency staff endorsed seeking professional diagnosis only when required to access autism funding programs. Findings from the study also painted a picture of significant unmet needs for First Nations youth with disabilities, particularly those with 'invisible disabilities' like autism. Agency staff and community members reported a number of gaps in services for children with autism in their communities including: a lack of community based-services outside of the school system, lack of early diagnosis and intervention services, lack of access to professionals with specialized training (e.g., psychologists, speech language pathologists, occupational therapists), lack of coordination among existing service providers, and a lack of tangible (e.g., respite, financial assistance) and emotional support (e.g., parent support groups) for affected families. In some communities, participants indicated that only way to access resources to support a child with autism was for that child to be placed in the care of child welfare agencies. Participants reported that this was extremely difficult on the child, the parents, and the child welfare staff. In the face of these challenges, participants described the support of families, which includes extended family members, and their community as key strengths in supporting the needs of children with autism within their communities. The responses of participants in the study also made it clear that is difficult to separate the issue of childhood disability from other social issues within First Nations communities. These issues include, for example, poverty, the effects of residential schools, and lack of economic opportunities. The authors concluded that in order to meet the needs Aboriginal children with disabilities (including autism) and their families, broader social issues within communities must also be addressed.

### **3.6. Focal category 3: Supports and services for autism in Indigenous contexts**

Twelve of the included publications (44.45%) focussed their analyses on some aspect of supports and services for Indigenous autistics and their families. These articles could be further divided into two sub-categories: (a) access and barriers to autism-related service provision, and (b) culturally appropriate autism interventions. In the following section, articles are summarized under the most relevant sub-category.

#### **3.6.1. Access and barriers to accessing to supports and services**

Seven of the eligible articles (25.93%) examined issues concerning access to autism-related supports and services for Indigenous peoples in Canada. One peer-reviewed community-based qualitative study and one grey literature review summary report focussed on service access disparities and barriers for Indigenous children with disabilities, including but not limited to autism. The remaining five articles (three peer-reviewed qualitative studies and two refereed literature reviews), one of which was a participatory action research project, concentrated on challenges to service access and/or support for individuals on the autism spectrum and their families generally, including individuals from Indigenous communities. Recurring issues discussed in the service provision literature included: socioeconomic, racial, and geographic disparities in access to autism-related services; cultural, social, and systemic barriers to support and service utilization specific to Indigenous autistics and their families; and recommendations to address service access disparities and/or barriers.

#### **3.6.2. Access to supports and services for Indigenous children with disabilities**

In a peer-reviewed journal article, Vives and Sinha (2019) summarized findings from a collaborative university-community research project aimed at documenting service access disparities experienced by children with special healthcare needs (SHN) and their families from Pinaymootang First Nation in Manitoba. The project was initiated by and carried out in partnership with Pinaymootang First Nation and a 15-member advisory committee between 2015 and 2017. Information on service access, both on and off-reserve, were drawn from formal and informal interviews with Indigenous, provincial,

and federal service providers; Indigenous leadership; and caregivers of Pinaymootang children with SHN, including autism (though the specific number of caregivers of autistic children included in the project was not reported). Findings revealed that Pinaymootang children living on reserve were routinely denied access to services ordinarily available to other Canadian children with SHN. Of the three service areas (medical, allied, and additional care) considered, Pinaymootang children with autism faced the greatest disparities in access to allied health services. Pinaymootang service providers stated that, as of March 2016, there were no early intervention services available on reserve for children under the age of 5. Older children with SHN were expected to access services through Pinaymootang School, though caregivers and service providers agreed that the range and frequency of allied health services (e.g., physiotherapy, occupational therapy, speech language therapy) provided through the school was vastly insufficient to meet the needs of children with SHN in the community. Conversations with caregivers and service providers off reserve revealed that there was a sharp contrast between allied health services for children living in Pinaymootang and those living in nearby off-reserve communities. In an effort to access allied health services for their children, participating caregivers, such as a mother of a teenage autistic girl, reported having made the difficult decision to relocate her family to Winnipeg. In addition to having access to fewer and less frequent services than were available off reserve, Pinaymootang children living on reserve also experienced delays in accessing allied health services available off reserve. Often these delays were rooted in differential access to diagnostic and assessment services. This was particularly a problem for children with autism in the study, who were typically not diagnosed until years after they started school. One child with verbal communication difficulties, who lived on reserve and was suspected of being on the autism spectrum, remained undiagnosed at the age of 11 despite repeated efforts by his family to obtain an autism assessment that would enable him to receive fundings for speech language therapy. The authors highlighted how this finding is particularly concerning in light of substantial research evidence demonstrating that access to early intervention is essential to support the development of autistic children and improve their social and daily living skills (e.g., Matson & Konst, 2013). They further suggested that denial and delays of allied health services limited the opportunity for Pinaymootang children with autism to thrive and placed additional strain on family well-being. Based on all the information collected, the authors argued that the challenges in accessing services for children Pinaymootang children described by

participants are evidence of a discriminatory service network grounded in colonial history and ideology. They posited that such discrimination against First Nations children with disabilities is actualized through the long-term underfunding of on-reserve services, inconsistent administrative practices, and intentional geographic isolation of Indigenous communities. The article concluded with nine recommendations prepared by the project's advisory committee for future policy to eliminate colonialism as a social determinant for Aboriginal health. Most relevant to autistic children was the recommendation to invest training of local First Nations workers in the allied health profession.

In a research snapshot report (i.e., brief plain language summary of peer-reviewed research for a non-academic audience) published by Research Impact Canada, Stavropoulou-Kampoukou (2019) synopsized findings of a literature review exploring culturally safe service delivery for Indigenous children and youth with autism in Canada. Limited details on the review methodology were provided, however, the author did report using Summon 2.0, Google Scholar and Google search engines to locate journal articles and grey literature published between 2009 and 2019 relevant to the following research question: "What approaches to service delivery currently being used in Canada are considered culturally safe for Indigenous individuals with ASD?" (p.1). The researcher also conducted a search of results from a jurisdictional scan conducted by the British Columbia Ministry of Children and Family Development (MCFD) to identify relevant MCFD research projects. The online database and MCFD jurisdictional scan searches identified only two sources relevant to Indigenous peoples and ASD, and none specifically addressing culturally safe supports and services for this population. Due to the paucity of search results relevant to the initial review question, the researcher decided to broaden the focus of the literature review to explore general issues in service provision for Indigenous populations with developmental disabilities. The researcher did not disclose if a revised search was conducted, nor did he report the number of articles reviewed, or other details of the analysis. The following challenges to service delivery and access for Indigenous families were identified: "lack of safe contexts that support self-identification as Indigenous, lack of cultural competence and safety in workers and institutions, lack of continuity regarding services and funding, assessment and identification difficulties, and foster care as a barrier for service delivery" (p. 2). However, it is important to note that no further explanation of the listed challenges, or from where

they were derived, was provided. The researcher also reported the following six ways services access and delivery could be improved: “involve Indigenous people in service design and delivery, create liaison worker services, develop individualized services, improve communication and cooperation between provincial and federal services, bring special education services to Indigenous communities rather than Indigenous children to services, and adopt strength-based research approaches for ASD and other developmental disabilities” (p. 2). Again, it was unclear the process by which these recommendations were extracted. The author concluded the summary by suggesting that existing approaches to supporting individuals with developmental disabilities and their families are designed through a Western lens, and, therefore, may be poorly aligned with needs and desires of Indigenous families. He also highlighted the need for further research investigating a wide range of neurodevelopmental disabilities, including ASD, with Indigenous communities across Canada, in order to better understand their unique support needs.

### **3.6.3. Access to supports and services for autistic individuals and their families**

Young et al. (2019) conducted a participatory research project aimed at building capacity in treatment and support for individuals and families impacted by autism in rural and remote communities. Seven communities in Alberta and British Columbia were involved as partners in the project, one of which was an on-reserve First Nation community, Tl'esqox (Toosey) of the Tsilhqot'in (Chilcotin First Nation). These communities were selected based on their rurality and willingness to engage in efforts towards improved service delivery in their region. Prior to data collection, the aims and methodology of the project were developed, reviewed and refined with input from community leaders and key stakeholders (community groups, educators, parents, caregivers, siblings, service providers). Fifteen discussion groups, ranging from 10-60 community stakeholders each, were convened across the partnering communities, with approximately 200 stakeholders in total. The number of stakeholders from Tl'esqox were not specified in the article. Discussion groups were focused on how individuals access and navigate services in their community, broader community-level factors that influence service access and uptake, and areas for improvement in resource access and delivery. Collaborative thematic analysis of the data revealed that services are insufficient to meet the needs of families in these communities. Specifically, families identified difficulties in

finding and navigating services (e.g., respite, specialized interventions) and finding support (e.g., emotional, financial). Many also raised concerns about insufficient school resources. Though previous research has identified these concerns to be a common experience for autistic individuals and their families, Young et al. (2019) suggested, based on the findings of this study, that these challenges were amplified for participants residing in rural and remote communities. The identified barriers associated with rurality included: having access to proportionally fewer service providers with specialized autism training relative to urban areas, needing to travel long distances to access specialized autism service providers, and the need to allocate autism funding towards these associated travel costs. Though not the primary focus of this article, the findings also revealed strengths and protective factors of rural and remote communities in supporting and meeting the needs of autistic people and their families. These factors included a sense of mutual responsibility, connectedness and acceptance among community members, demonstrated by informal support of autistic individuals and their families. Overall, this study highlighted barriers to accessing autism-related supports and services in rural communities across Alberta and British Columbia, as well as the ways in which communities come together to support these individuals in the face of an insufficient service landscape. The authors concluded, however, that in order to build capacity in autism supports and services, efforts must take into consideration the unique contexts, culture and priorities of each community. The authors did not reveal or discuss any differences between the First Nations and non-First Nations communities in this study.

Hiebert-Murphy et al. (2008) investigated patterns of entry to community-based services for children with developmental disabilities in a peer-reviewed journal article. Specifically, semi-structured interviews with parents of children with developmental disabilities were conducted to examine the relationship between service access pathways and parent-reported support needs. Seventy-two parents of children with developmental disabilities, including 11 parents of children with pervasive developmental disabilities (PDD; 25% of the total sample), residing in Manitoba participated in the study. Though 15% of Manitoba's population is Indigenous, only one of the participating self-identified as Aboriginal (2% of the overall sample). Thematic analysis of parent interviews identified three key processes that determined family's initial access to community-based services: (1) recognition of delays in a child's development, (2) formal diagnosis of developmental disability, and (3) connection between diagnostic services



and community-based support services. Within each of these processes, complexities of navigating an uncoordinated but centralized service system could result in parent frustration and contribute to delays in accessing services for families. Further analyses of these process factors found four patterns of entry to community-based services related to families' perceived need for services: early, prompt, delayed, and atypical entry. Regardless of parent-perceived need, children with more obvious support needs, such as those with co-occurring PDD and complex medical conditions, were more likely to be recognized by service providers who could facilitate families' navigation to service entry. The authors concluded by expressing caution that though identified typologies may be useful for social workers in the assessment of family needs, they are likely not generalizable to families with diverse cultural backgrounds, such as Aboriginal families. They called for further research with more culturally diverse samples to replicate findings. Specific to Aboriginal families, the authors suggested that this group experience unique sociocultural contexts that may be important to how they access and experience services.

In a peer-reviewed journal article, Shepherd and Waddell (2015) reported findings from interviews with 39 parents, policy makers, and researchers from across Canada who had engaged in public forums on autism policy. The number of Indigenous participants was not reported. While participants had diverse views and experiences of autism, all participants expressed concerns regarding inequities in autism services and funding based on children's level of support needs, and families' geographic location and socioeconomic status. As one participant commented: "I think it's [current funding programs] working fine for some families who can top it up with up with their own funding without having to put a second mortgage on their house and eat macaroni and cheese for the rest of their lives. It's working okay for some families because the kid doesn't need more than a few hours a week or the service provider's really good. But the families with more impaired kids, for them the funding is a drop in the bucket, or for the immigrant families, or poor families, or Aboriginal families" (p. 3561). All participants further agreed on the need to diversify services across the autism spectrum and expanding existing policies and services to reach more disadvantaged children and families, especially immigrant and Aboriginal families.

Zeidan et al. (2019) focused on policy-level barriers to autism services in a peer-refereed literature review of autism-related policies and guidelines issued by the Quebec

government between 2010 and 2018. Specifically, thematic analysis of the 22 identified documents in relation to Canadian model of Social Determinants of Health was conducted to determine recent advances, challenges, and gaps in the planning and delivery of provincial autism services. Analysis revealed that though some social determinants are extensively reflected in autism-related policies in Quebec, others like Aboriginal status, race, education, and unemployment and especially underrepresented. In particular, well-established inequities and barriers affecting service utilization and quality for racialized groups, including Aboriginal peoples, were not addressed in existing autism policies. Further, many autism services were characterized by a 'one size fits all' approach, instead of being tailored on the individual and unique needs, preferences, and social context of each person/family. The authors interpreted these findings as an indication of the inadequacy of existing autism services in meeting the unique needs of Aboriginal autistic children and their families.

In an editorial published in a non-refereed journal, Scott et al. (2021) summarized the key topics that were presented in the equity panel discussion at the Canadian Autism Leadership Summit 2020. Panelists included representatives from four health-related advocacy organizations serving marginalized communities across Canada, including one Aboriginal organization, the British Columbia Aboriginal Network on Disability Society (BCANDS). The panellists discussed current disparities and barriers to accessing timely and appropriate autism assessment, supports and services, and outlined ways to address these issues at a Canada-wide policy level.

Five intersecting determinants of disparities in autistic health and wellbeing were identified: level of support needs, geographical location, cultural/racial diversity, gender, and socioeconomic status. The panel also identified four barriers that interact with the identified disparities, further impacting accessibility of autism-related services. These barriers were: lack of awareness of autism and associated services in underserved communities, lack of research and knowledge about autism in socially and culturally diverse communities, social and cultural factors that limit access to health services, and lack of opportunity for engagement, consultation and advocacy. The panellists further identified factors that uniquely contribute to disparities and barriers faced by Indigenous autistics. With respect to the geographical factors, Indigenous communities often experience geographical isolation in addition to the complexities of navigating and accessing healthcare systems as a result of jurisdictional divisions of healthcare service

delivery. In terms of the cultural/racial diversity-related factors, Indigenous communities are among a number of socially marginalized groups that have an ongoing history of discrimination within the healthcare system, which impedes their access to health services. The pannelists also discussed how this history of discrimination has eroded confidence and trust in the healthcare system among many Indigenous peoples, which can result in a lack of awareness about autism-related services. Four main ideas were presented as solutions to address inequities in autism service access and health outcomes. The first recommendation was to increase funding for community-based initiatives that are responsive to the diverse needs of their community members. Second, the pannelists recommended that the diversity of autistic experiences should be represented in discussions and efforts related to health equity of autistic individuals, and that the connection between healthcare providers and the braoder autistic communities should be prioritized. The third recommendation was for members of the autistic community to strengthen their alliance with the braoder diasbility community in the pursuit of common goals. Finally, the panellists called upon leaders from all levels and sectors of the Canadian government to address the identified inequities in autism services and outcomes. Together, these recommendations are to ensure that autism supports and services are responsive to the unique needs of marginalized individuals within the broader Canadian autistic community, including Indigenous autistics.

#### **3.6.4. Culturally appropriate autism interventions**

Five of the included publications (18.52%) focussed on interventional approaches or strategies to supporting autism amongst Indigenous populations. Two were literature reviews and three were qualitative studies. All five were published in peer reviewed journals. Recurring topics covered in the intervention literature included: cultural needs and values, and a paucity of research and programs specifically addressing the support needs of Indigenous autistics.

##### ***Literature reviews of autism interventions in Indigenous contexts***

Shochet et al. (2020) conducted a review and catalogue of programs designed to support the emotional, psychological and social (psychosocial) wellbeing of Indigenous people with neurodevelopmental disabilities (including autism) and/or their caregivers. Specifically, the study endeavoured to identify which psychosocial supports have been

developed and trialled for this unique populations worldwide by: (1) systematically reviewing relevant intervention research, and (2) collating a list of informal resources promoting psychosocial wellbeing for this group. Key word searches were executed in 28 databases to locate published and unpublished literature on the topic. Additional research articles and resources were identified by contacting experts working in Indigenous health. Articles included in the systematic review were also assessed for methodological quality using the Mixed Methods Assessment Tool (MMAT; Hong et al., 2018). Overall, findings from the systematic review revealed a paucity of evidence-based psychosocial programs designed specifically for Indigenous populations with ASD internationally, as well as in Canada. Of the seven included research articles, only two detailed the implementation of programs to support the wellbeing of Indigenous peoples with autism in Canada (Lindblom, 2017a, 2017b)<sup>1</sup>. As an overview, although the two Canadian articles showed some positive emotional and social outcomes for First Nations children with ASD through the use of culturally adapted music therapies, Shochet et al. (2020) reported that these findings were based on observational reports from the researcher and anecdotal evidence from interviews with a small sample of participants and, therefore, should be interpreted with caution based on low study quality (< 40% on the MMAT). Turning to results from the search of informal supports, 11 psychosocial resources met inclusion criteria, the majority of which were from Australia or New Zealand (10 of 11). The authors identified only one online autism resource from Canada, Four Directions Autism (<http://www.fourdirectionsautism.ca/>). The website was described as providing psychoeducation and support groups for parents of First Nation children with autism and was reportedly developed by a volunteer-run group of Indigenous autism advocates. In their evaluation of the Canadian website, Shochet et al. suggested that though the online resource is no-cost and accessibly formatted, it requires an internet connection to access and therefore, may not be accessible to individuals living in remote communities. Shochet also expressed caution regarding the efficacy of the resource because it has not been empirically evaluated. Based on the dearth of evidence-based programs and publicly available resources specifically developed to support the wellbeing of Indigenous people with ASD they uncovered, the

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<sup>1</sup> Because these articles are already included in our review, a detailed description of these articles is not provided here but in the relevant article synopses below.

authors suggested that Indigenous peoples with ASD may be denied support tailored to their unique needs. Further, they suggested that this population may have no choice but to use mainstream psychosocial supports that lack cultural sensitivity, which may adversely impact their overall psychosocial wellbeing. The authors concluded that collaborative adaptation of existing evidence-based psychosocial programs and resources with Indigenous stakeholders is a critical first step towards meeting the needs of Indigenous peoples with autism and the communities that support them.

Taking a different approach, Simpson (2021) also reviewed and evaluated interventions aimed at supporting the mental health and well-being of Indigenous autistics, this time through the lens of a critical integrative review framework. A key word search of a single online database (Academic Search Complete) using the search terms “Aut\* identity,” “Indig\* identity,” “Abor\* identity,” and “Youth” was conducted to identify peer-reviewed intervention research articles that included Indigenous and/or autistic sample groups. Inclusion was further limited to articles published from 2010 onward. A rationale for date restricting the search was not provided. Details on the article selection process were also not reported. This strategy resulted in the identification of 24 articles exploring the intersection of Indigeneity and autism in settler-colonial nations (e.g., Canada, the United States, Australia, and New Zealand), only five of which specifically investigated culturally appropriate services for Indigenous autistics. Three of the articles described interventions to First Nations children with autism in Canada (Lindblom, 2017a, 2014b, 2017b)<sup>2</sup>. Included articles were summarized in an annotated bibliography and critically evaluated using comparative thematic analysis techniques. These analyses were conducted to identify shared experiences of Indigenous people and autistic people and common components of interventions reporting positive well-being outcome for Indigenous autistics across included studies. Results revealed that the existing research on mental-health supports and services for autistic people and Indigenous people largely exist as two separate bodies of literature. However, both autism research and Indigenous health research demonstrated that autistic people and Indigenous people in settler-colonial nations have a shared experience of historic and ongoing social

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<sup>2</sup> Because these articles are already included in our review, a detailed description of these articles is not provided here but in the relevant article synopses below.

injustices resulting from colonization. These experiences include marginalization, discrimination, exclusion, poverty, and disempowerment. While the intersectional literature reviewed was limited, included studies also demonstrated that both groups face societal challenges and survive ongoing oppression that negatively impacts self-esteem and mental health. Concurrently, positive identity formation was identified as a protective factor associated with resilience and psychosocial well-being in this uniquely marginalized population. Culturally responsive interventions that are self-determined, personalized, and considerate of ongoing forms of discrimination were found to support positive identity formation for Indigenous autistics. Though results suggested that there are few culturally responsive services and interventions to support the unique needs of Indigenous autistics, the author concluded that existing interventions show that incorporating Indigenous knowledges in support programming for Indigenous autistics is a promising means by which to disrupt patterns of social injustices while promoting resilience and well-being among Indigenous autistics.

### ***Qualitative studies of autism interventions for Indigenous peoples***

Three articles by the same author investigated the utility of Indigenous and mainstream music programs in supporting the well-being of First Nations children and youth with autism. The articles are described together, as they report findings from the similar studies, conducted at different time points with slight variations in the research questions and sample sizes. In the first study, Lindblom (2017a) explored the use of Indigenous music as a tool to facilitate social inclusion in two diverse cases of young First Nations people diagnosed with autism in British Columbia – one eight-year old boy residing on reserve in a rural setting and a 16-year old girl living in an urban setting. Multi-sited ethnographic methods were employed to collect outcome data including researcher fieldnotes, filmed observations of Indigenous music interventions, and interviews with family members (n = 4) and service providers (n = 6). Triangulation was used to identify themes associated with social participation across data sources. Findings from the qualitative analyses suggested that individually designed Indigenous music interventions promoted a sense of belonging for participants in their community as demonstrated by increased eye-contact, singing, physical closeness, and playing of instruments with others.

In a follow up study, Lindblom (2017b) explored the therapeutic benefits of music interventions for children and youth with autism through a First Nations lens. Five First Nations children/youth diagnosed with autism (age range 6 - 15 years old), their family members (n = 7) and teachers/support workers (n = 12) participated in the study. This sample included the two children/youth and four family members who had also participated in the earlier study. Participants were recruited from a number of Indigenous communities across BC; the author's First Nations relatives assisted in culturally appropriate recruitment processes and establishing trust with relevant community members. Guided by an "Indigenist research paradigm", data was collected over two six-week community visits in 2013 and 2014 via audio-recorded conversations, filmed observations of music interventions, follow-up conversations, and researcher notes. Data from all sources was merged, analyzed and collated using a combination of Western and Indigenous research methods including mind-maps, thematic coding, triangulation, dreams, feelings, and intuition. The author reported that community knowledge holders and Elders were involved in the analysis and interpretation of results. The interpretation of qualitative data found both mainstream and Indigenous music interventions were associated with positive emotional, cognitive, and social outcomes including improvements in mood, self-regulation, non-verbal communication, and concentration. Further, incorporating Indigenous music into education interventions and support programming was found to have additional benefits for First Nations children with autism such as increased classroom inclusion and participation in community gatherings. In her discussion of study finding, the author highlighted the innate strengths of First Nations communities and traditional worldviews, which she described as supporting the care and inclusion of autistic children. Based on participant reports that traditional music is an important component of First Nations culture, the author concluded that culturally sensitive music interventions and participation in traditional music focussed community activities (e.g., drumming, ceremonies, singing) could play an important role in meeting the needs of First Nations children and youth diagnosed with autism.

In the final article reporting on this series of studies, Lindblom (2021) examined music as a facilitator of skill development for three First Nations youth on the autism spectrum using an Indigenist research framework. Participants in this study were three (2 boys and one girl) of the five original children/youth from the earlier qualitative study

exploring music interventions through a First Nations lens (Lindblom, 2017b), who consented to participate in a follow-up to the original study in 2017. At the time of the follow-up study in 2017, participants were 10-, 18- and 19-years-old respectively. Data was collected through conversations with the three-participating youth, as well as 5 members of their immediate and extended families. The author reported that the term 'conversations' was used in place of 'interviews' to foster a more equitable and respectful relationship between the researcher and individuals participating in the study. Conversations focussed on the functional challenges experienced by the participating autistic youth and how listening to music informally, as well as, participating in music interventions/ music activities had facilitated their development of skills to overcome these challenges. A combination of Indigenous and Western methods was used to deduce themes related to music in daily life, music for therapeutic purposes, self-regulation, and social skills from the transcribed conversations. These methods included: visual mapping, circular coding and critical reflection. Analyses revealed that music played an important role in autistic First Nations youths' daily lives. Participants reported using music to help them communicate and connect with peers and family members, feel safe, self-soothe, make friends, participate in extra-curricular activities, express themselves, and put them in a good mood. Further, participation in Indigenous and mainstream music activities and programs (e.g., school musicals, drumming and singing, cultural events, music class) was reported to have facilitated the youth's development of self-regulation and social skills. The author concluded that findings from this small qualitative study suggest that culturally relevant and sensitive music programming may support the development of functional skills for First Nations individuals on the autism spectrum. In her closing remarks, the author suggested that incorporating Indigenous music activities into autism support services in educational settings may be an opportunity step towards inclusive, equitable, and decolonized education for Indigenous youth with autism, and is a topic that warrants future research attention.



## **Chapter 4.**

### **Discussion**

This study sought to provide an overview of the extent and nature of current literature relevant to autism among Indigenous peoples in Canada in such a way that draws attention to research that is led and informed by Indigenous peoples. Specifically, we conducted searches of the peer-reviewed and grey literature in line with the Joanna Briggs Institute approach for scoping reviews (Peters et al., 2017). We addressed the following research questions: (1) What are the characteristics of the literature related to autism and Indigenous peoples in Canada (e.g., literature type, focal topic, aim, methodology, key messages/findings)? (2) What is the quality and cultural rigour of this research through the lens of an Indigenous framework? Following an extensive systematic search of 29 indexed and non-indexed databases and websites, 27 articles met inclusion criteria. Of these 27 articles, 11 were focused on topics explicitly relevant to autism among Indigenous peoples. The remaining 16 articles included some discussion of autism among Indigenous peoples in Canada as a by-product of their primary examination and analysis. This is higher than the number of articles focused on autism and Indigenous peoples in Canada identified in the previous reviews by Di Pietro and Illes (2014; n = 0) and Lindblom (2014b; n = 4), reflecting both our comprehensive search strategy and an increasing research interest on the topic in recent years. Included articles fell into three broad categories: diagnosis and prevalence of autism among Indigenous peoples; Indigenous perceptions and experiences of autism; and supports and services available for autism (and in some instances other conditions) in Indigenous contexts. Within each of these categories, we then identified recurring issues reported on in the included articles. The following section discusses the practice and research implications of this scoping review related to our two research questions and the identified recurring issues within the abovementioned categories. Strengths and limitations of this review are also subsequently discussed.

#### **4.1. Article characteristics**

The 27 articles included in this scoping review varied considerably in terms of literature type, focus, included populations, contexts, and methodologies. Whilst such

heterogeneity makes comparisons across included publications difficult, several trends can be identified in the characteristics of the literature under review. We included 17 primary research studies, six reviews, and four opinion/reflective pieces. Over half of these (14/ 27) were published in peer-reviewed journals or other academic sources (e.g., theses, conference proceedings) within the last eight years (since 2014), indicating that autism-related research with Indigenous peoples is a relatively recent focus of Canadian academic institutions. Though this finding is encouraging in light of previous research documenting the underrepresentation of individuals from socio-culturally diverse groups in autism research (e.g., Fannin & Fannin, 2017), it is important to emphasize that autism among Indigenous peoples is the primary focus of less than half ( $n = 11$ ) of the 27 articles included on our scoping review. Moreover, the vast majority of recent articles specific to the topic are small, descriptive studies or narrative reviews and have frequently recurring non-Indigenous authors. These qualitative dimensions of the literature base highlight that an apparent increase in research attention towards autism and Indigeneity post-2014 can be attributed to a small cohort of non-Indigenous authors engaging in largely Western-oriented and descriptive-based writing.

It is also worthy to highlight that much of the literature to date relevant to autism among Indigenous peoples in Canada focusses on issues around prevalence and/or access to diagnostic and other support services. There is much less evidence relating to the perspectives, experiences, and needs of Indigenous autistics and the communities that support them – particularly in relation to the interventions or supports these population view as required to fulfill their needs. Though there are very few autism-related articles that centre Indigenous voices in the data, the four highlighted in this review provide a depth and richness of understanding that of which the conventional studies fail to achieve. Hence, there is a strong case to be made for continued support of Indigenous-centered research that gives precedence to Indigenous voices, incorporating Indigenous storytelling and other contextual data that complexifies narratives about autism.

Across all articles, a number of factors outlined the gaps in this emerging area of research. With regards to research populations and contexts, all articles (with the exception of one) focused on children and youth, highlighting the lack of research across other stages of the lifespan. Though this finding is unsurprising given that autism research has historically focussed on the childhood period, there is increasing

recognition of the importance of the lifespan approach to autism research and services (e.g., Graham Holmes et al., 2020; Lai & Weiss, 2017; Turcotte et al., 2016). To ensure an adequate understanding of the perspectives, experiences, and needs of Indigenous autistics across the entire lifespan, research on autism among Indigenous adults is a neglected area of investigation in need of development. Further, most articles described research conducted in Manitoba and British Columbia with First Nations individuals, suggesting that research related to autism among Indigenous peoples is not being conducted Canada-wide and with a variety of Indigenous groups. Given the diversity of Indigenous peoples across Canada, autism-related research with other Indigenous populations (e.g., Inuit, Métis) in other geographic locations is another critical gap in current knowledge in need of research attention. Though much of the qualitative literature on the topic includes the perspectives of parents and extended family members, only one article also considered the perspectives of Indigenous autistics themselves (Lindblom, 2021). Increasingly, autistic researchers and allies have been calling for the recognition of autistic people as experts in their own lives, emphasizing the importance of including members of the autistic community in research endeavours, both as research participants and advisors (Gillespie-Lynch et al., 2017). As such, future autism-related research with Indigenous peoples should prioritize the inclusion/voices of Indigenous autistics in addition to non-autistic members of the communities that support them.

Taken together, these findings suggest that while there have been recent important advances in the field of autism research relevant to Indigenous peoples, there are still significant gaps in the knowledge base, especially with respect to a diversity of Indigenous lived experiences of autism. More research that amplifies and gives precedence to Indigenous wisdoms is required.

## **4.2. Cultural rigour**

Relatedly and irrespective of article focus, we also found minimal evidence of meaningful engagement and/or collaboration with Indigenous stakeholders *throughout all* aspects of relevant research. Research principles and guidelines, such as Chapter 9 of the Tri-Council Policy Statement 2 in Canada and the CONSIDER statement internationally, articulate that any research relevant to Indigenous peoples must be conducted *by* and *with* Indigenous peoples (Canadian Institutes of Health Research et

al., 2018; Huria et al., 2019). These standards are applicable to all forms of original research that could have implications for Indigenous peoples, including research: conducted on Indigenous lands; in which Indigenous identity or membership to an Indigenous community is a criterion for participation and/or is used as a variable for data analysis; in which interpretation of data refers directly to Indigenous persons or groups; or that has the potential to affect the health of Indigenous peoples. Despite the pertinence of these standards to a wide range of research topics and methodologies (as is the case for the disparate research base under review, the 17 primary research articles included in our review inconsistently met criteria for the reporting of culturally rigorous research praxis (Table 6). Though most studies provided some broad and unspecific evidence of community collaboration and engagement (e.g., stated that Elders were consulted during the research process), details demonstrating the mechanics of community collaboration/engagement were often omitted. Across the eight research domains assessed, the criteria for cultural rigour most frequently lacking were: Indigenous driven research aims, the protection of intellectual and cultural property rights; Indigenous data sovereignty, and plans to translate findings into sustainable changes in policy or practice. Further and most strikingly, we identified a near absence of autism-related research in Canada that was led, controlled, and authored by Indigenous researchers *through all phases of the research process*, and/or centred on the knowledges and voices of Indigenous peoples.

Within the three categories that emerged from the articles under review, lack of Indigenous engagement was most evident among primary research articles in the prevalence category. Only one epidemiological study from the grey literature reported on research methods that were developed in collaboration with Indigenous stakeholders (Merasty et al., 2021). Importantly, none of these studies described the consenting process for the secondary use of Indigenous data. Perhaps unsurprisingly, cultural rigour was best exemplified in primary research articles categorized as Indigenous descriptive/lived experiences of autism.

In summary, despite demonstrated efforts towards improving the quality of autism-related research involving Indigenous participants through some form of Indigenous community engagement (and a few strong exemplars of autism-related research conducted in partnership with Indigenous communities), our findings suggest there is a continued tendency to research *on* rather than *with* and *by* Indigenous

communities. While most included articles reported broadly on the presence of Indigenous consultation and/or leadership, specific details on the individual roles, responsibilities, and duration of involvement throughout the different phases of the research project were seldomly reported. Most of these studies .

### **4.3. Prevalence of autism among Indigenous peoples in Canada**

While prevalence rates and public awareness of autism have risen across Canada in recent years (Public Health Agency of Canada, 2021), our findings suggest there is a current lack of accurate data on the prevalence of autism among Indigenous populations in Canada (Di Pietro & Illes, 2014; Inman, 2019; Lindblom, 2014). We identified only a handful of epidemiological studies examining rates of autism diagnoses in Indigenous children, only one of which employed a provincially representative Indigenous sample (Burstyn et al., 2010). Most of these studies excluded individuals residing on reserve lands and were conducted at the provincial level. Although diversity in the sample populations (e.g., age, gender, location of residence, Indigenous status) and differences in the way that autism was ascertained (e.g., teacher report, medical record review) make comparisons across studies difficult (and preclude generalization of results), the available studies offer a snapshot of some issues surrounding autism diagnosis and prevalence in Indigenous communities. Findings from these studies provisionally suggest that Indigenous children are diagnosed at a lower rate and later age than their non-Indigenous peers in some Canadian regions (i.e., Alberta, Manitoba, Toronto; Burstyn et al., 2010a; Coo et al., 2012; Hadioonzadeh, 2012; Ouellette-Kuntz et al., 2006). They also provide emerging evidence that Indigenous boys are diagnosed far more often, but later, than Indigenous girls (Burstyn et al., 2010a). Further, while there is substantial evidence of gender disparities in autism diagnosis among the general Canadian population (e.g., Canadian Academy of Health Sciences, 2022; Loomes et al., 2017), the male-to-female autism ratio appears to be exaggerated among Indigenous samples in some Canadian studies (Burstyn et al., 2010c; Hadioonzadeh, 2012).

However, rather than a true difference in prevalence, these patterns have been interpreted as reflecting inequities in the availability and appropriateness of autism diagnostic services for certain Indigenous populations, especially Indigenous boys (Burstyn et al., 2010; Coo et al., 2012; Hadioonzadeh, 2012; Lindblom, 2014b; Ouellette-

Kuntz et al., 2006). Under-recognition of cultural presentations of autism, reduced access to assessment services in remote communities, mistrust in health care systems, a complex and lengthy diagnostic process, and clinicians' racial biases were all posited as contributing to delayed or missed diagnosis among Indigenous autistics in Canada (Di Pietro & Illes, 2014; Di Pietro & Illes, 2016; Lindblom, 2014b; Ouellette-Kuntz et al., 2006; Shochet et al., 2020). Several included articles also suggested that timely and accurate diagnosis of Indigenous autistics may be impeded by stigmatizing colonial narratives about Indigenous parenting, potentially resulting in Indigenous autistics being misdiagnosed with FASD (Di Pietro & Illes, 2014; Di Pietro & Illes, 2016; Inman, 2019). Though these findings should be interpreted with caution, they are consistent with previous research from other settler-colonial nations. Numerous studies conducted in Australia and the United States have reported that autism is under- and/or misdiagnosed among Indigenous populations in these countries (Bent et al., 2015; Dyches et al., 2004; Graham, 2012; Leonard et al., 2011, 2013; Roy & Balaratnasingam, 2010; Sullivan, 2013; Tincani et al., 2009; Wiggins et al., 2020). More research with First Nations, Métis, and Inuit communities is required to confirm these findings, before definitive conclusions about autism diagnosis and prevalence among Indigenous peoples in Canada can be drawn.

Though limited, the available prevalence data have several implications. First, there is evidence that Indigenous children, on average, receive an autism diagnosis at a later age than their non-Indigenous peers in certain regions in Canada. Based on this pattern, we can infer that Indigenous autistics likely have delayed access relative to their non-Indigenous peers in accessing supports and services, such as school accommodations and funding programs, for which eligibility is conferred by formal diagnosis. For example, in British Columbia a medically-confirmed diagnosis of autism grants families access to up to \$22,000 in annual funding to put towards their child's support needs. This funding program continues up until the age of 6 years, at which time, funding is reduced to \$6,000 per year for out-of-school supports until the child reaches the age of 18 (Ministry of Child and Family Development, n.d.). For school-aged children, an official autism diagnosis (i.e., confirmed via clinical assessment by a psychologist or doctor using standardized tools) allows schools to place the child in one of 10 special needs categories that provides the school access to additional funding for school-based supports (British Columbia Ministry of Education, 2016).

Second, as suggested above, disparities in rates of autism diagnosis by Indigenous status may indicate that Indigenous autistics are not being adequately identified through the current diagnostic system. In other words, autism is under- or mis-diagnosed in this population. If this is the case, Indigenous autistics who remain undetected miss out entirely on the specialized autism funding and other supports/services that are only accessible via formal diagnosis. The benefits of early diagnosis and access to autism-related support programs for autistic individuals and their families are well documented, including but not limited to: reduced family stress; increased school readiness; improved adaptive and psychosocial functioning; and overall quality of life outcomes (Elder et al., 2017; Matson & Konst, 2013; Reichow et al., 2018; Vinen et al., 2018; Vivanti et al., 2014). If Indigenous autistics are indeed diagnosed later than their peers, or not diagnosed at all, this means that they may also be deprived access to supports and services at critical points in development, which may limit their potential for enhanced outcomes (Shochet et al., 2020).

Third, and perhaps most importantly in terms of implications, the available epidemiological literature specifies that there are no known statistics on the number of Indigenous autistics across Canada (Di Pietro & Illes, 2014; Inman, 2019; Lindblom, 2014a). Further, Indigenous individuals appear to be under-represented in the limited provincial prevalence data (Lindblom, 2014b). Various authors have speculated that this phenomenon may be explained by underreporting of Indigenous identity in Canadian health databases/research (e.g. Di Pietro & Illes, 2016; Stavropoulou-Kampoukou, 2019). Prevalence data, or lack thereof, have serious research, policy, and funding implications, such as: informing funding priorities, determining the scale of support services needed and assessing equity of access to services for different groups (Gerlach et al., 2018; Walker et al., 2017). The underrepresentation of Indigenous autistics in national and provincial prevalence data may lead to the assumption that autism is not a concern or does not occur among Indigenous communities; thereby causing government to shift attention and funding away from relevant supports and services for autistic people from Indigenous communities (Di Pietro & Illes, 2014). However, our discussions with members of the Nlaka'pamux Nation in Merritt and Lytton (BC) (Iarocci et al., 2018) and first-hand accounts of First Nations individuals in Manitoba and British Columbia from the experiential literature (e.g., Clouston, 2007; Sterling-Collins, 2009; Vives & Sinha, 2019; Woodgate, 2013) anecdotally suggest that autism is a significant issue in

certain Indigenous communities, and that is not sufficiently captured in the available epidemiological research. Therefore, the systematic collection of autism prevalence data among First Nations, Inuit and Métis peoples should be a priority for future research as it has the potential to draw attention to a currently invisible population and may contribute to ensuring that future autism research, policy and services align with the needs of Indigenous autistics. Ideally, such studies would be driven, controlled, and led by Indigenous researchers and community members, so as to maintain Indigenous voices at the centre of the research.

#### **4.4. Indigenous perceptions and experiences of autism**

Broadly speaking, our findings suggest that Indigenous people living with autism in Canada have some common views and experiences to their non-Indigenous counterparts. On the other hand, Indigenous voices in the reviewed articles also indicate that there are many perceptions and experiences of autism that are uniquely influenced by participants' Indigenous and other overlapping, intersecting identities. Despite some core commonalities among Indigenous participants, it is vital to highlight that Indigenous peoples in Canada are not a monolithic group; there are a variety of factors that affect Indigenous individuals' and communities' experiences with autism, including: geographic location (i.e., urban vs. rural, on-reserve vs. off-reserve), socioeconomic circumstance, family history and structure, spiritual beliefs, and specific cultural values, among others. Keeping this complexity in mind, this section endeavours to describe: a) certain views and experiences of autism that are common to both Indigenous and non-Indigenous autistics and their support communities, and b) views and experiences that are *unique to Indigenous communities*, based on the data from the body of literature reviewed.

Perspectives and experiences that appear to be shared by both Indigenous and non-Indigenous families of autistic children and youth include the following: wanting what is best for their child, harnessing resources and advocating for their child's needs, needing to make sacrifices to meet their child's needs, initial difficulties in coping with an autism diagnosis, feelings of social isolation, fears of external judgement, reduced community participation, high levels of family stress, difficulty in finding and obtaining appropriate supports, inadequate funding for services, negative interactions with service providers, fears about the availability of supports into adulthood, and a desire for more individualized services. There is also a broadly reported challenge of waitlists for formal



diagnosis that impede families' timely access to specialized autism funding and other support services. Many families of autistics also note that the autism service system is complex and disparate, and that its navigation is often a significant source of stress and frustration in accessing autism services for loved ones. Though this list of common views and experiences is likely not exhaustive, these examples from the reviewed literature cumulatively point to an autism service system that many families, *regardless of their sociocultural identity*, perceive as insufficient to meet their needs. In the face of service and funding gaps, many families must rely on a patchwork of informal supports and their own resources (e.g., time, income) to meet the needs of their child, which in turn can have adverse effects on family wellbeing and quality of life. In addition to a shared experience of 'parents/caregivers filling in the service gaps', both Indigenous and non-Indigenous families appear to experience challenges associated with systemic ableism. All families clearly share a desire to provide a good life for their children, and many struggle with high levels of stress, feelings of isolation, and discrimination. Indeed, the critical role of family advocacy in supporting *all* autistic children/youth and the societal exclusion of autistics were themes permeating much of the literature included in our review.

Beyond the universally recognized views and experiences for autistics and their support communities, the articles in this review have highlighted several views and experiences that are unique to Indigenous individuals/communities. Throughout the literature, it is evident that Indigenous views on autism contrast with Western-oriented, deficit-based models of autism, which typically focus on social and intellectual *impairments* associated with the condition. Whereas Western approaches to autism emphasize individual differences and discrete areas of difficulty, our findings suggest that Indigenous cultures tend to be more accepting and inclusive of a broad range of abilities and ways of being. Indigenous communities may also place less importance on the individual difficulties presented in individuals with disabilities, including autistic individuals. For example, there was a broad consensus across included articles that certain Indigenous people in Canada view disability as a special gift from the Creator, and a condition to be celebrated and supported by the broader community, rather than ameliorated. Moreover, evidence suggests that Indigenous communities understand and support autistic children and their families through a holistic strength-based view of wellness and disability; not only are the intellectual and social aspects upheld as

important, but so too are the spiritual, emotional, and extended family/community, and land-based connections. Instead of focussing on what autistic individuals *cannot* do – Indigenous voices in the reviewed studies indicated that they are more likely to focus on existing *strengths and abilities*. It is therefore perhaps unsurprising that certain Indigenous respondents in included articles reported distrust of medical labels, including ‘autism’ (e.g., Clouston, 2007). These contrasting views on autism (i.e., Western vs. Indigenous) appear to stem from communitarian Indigenous worldviews, more generally, and have been observed among Indigenous populations in other settler colonial nations (Bailey & Arciuli, 2020b; Tupou et al., 2021).

Whereas the vital role of community support was communicated by both Indigenous and non-Indigenous participants across many included articles, Indigenous participants, in particular, emphasized the importance of community belonging; highlighting a sense of mutual responsibility among Indigenous communities and traditional collective childrearing practices (especially among extended family) as key protective factors and a source of strength in supporting individuals with autism (e.g., Clouston, 2007; Sterling-Collins, 2009; Woodgate, 2013; Wright et al., 2007). This finding is consistent with previous research demonstrating the central role of the extended family unit and broader kinship networks in maintaining the health and well-being of many Indigenous communities (National Collaborating Centre for Aboriginal Health, 2015; Tam et al., 2016). Further, many Indigenous participants endorsed the benefits of engaging in traditional cultural activities (e.g., ceremony, sweat lodge, going into the bush), seeking guidance from Elders, and embracing spiritual values (e.g., connecting to the mind, body, spirit, nature, and one’s ancestors) as effective means of managing some of the challenges (e.g., stress, isolation) that can come with living with autism (Clouston, 2007; Merasty et al., 2021; Sterling-Collins, 2009; Woodgate, 2013). In the field of Indigenous health research, connection to culture through traditional values and practices are well-recognized as important factors connected to the health and wellness of Indigenous peoples, and have been found to reduce the risk of physical and mental health problems (Barker et al., 2017; Barnabe, 2021; Leeuw & Greenwood, 2007; McIvor et al., 2009; Verbunt et al., 2021). Taken together, Indigenous views and experiences of autism appear to be heavily positively impacted by two factors: spirituality and traditional cultural values; and the role of extended family and kinship networks.

In contrast to the common strengths and sources of support in Indigenous communities, the data also elucidated a few common challenges among Indigenous autistics and support communities. Whereas the reviewed articles suggest that both Indigenous and non-Indigenous autistics and their families face many similar challenges and stressors, our findings broadly suggest that these stressors may be compounded in Indigenous families who also face the confluence of systemic ableism and racism. Perhaps most saliently, historical and ongoing colonial violence and social inequities continue to have unjust and harmful effects on many Indigenous peoples in Canada, particularly Indigenous children/youth (Browne, 2017; Browne et al., 2016; Smylie, 2014). Impacts are well-evidenced in the data on Indigenous health and social outcomes, which are consistently poorer than that of the overall Canadian population on virtually every measure (Greenwood et al., 2015; Kim, 2019a; Public Health Agency of Canada, 2018). For example, Indigenous children are disabled at rates nearly twice that of other Canadian children (Durst, 2006; Statistics Canada, 2019). It follows that Indigenous views and experiences of autism cannot be fully understood without an appreciation of how colonialism and structural oppression have affected and continue to affect the health and wellness of Indigenous communities, families, and children in Canada. Colonial violence against Indigenous peoples has taken several forms including (but not limited to): the creation of reserve lands with insufficient resources and the apprehension of Indigenous children by the Canadian government (initially to residential schools and subsequently to foster homes); the adverse impacts of which extend into the present over multiple generations (e.g., intergenerational trauma).

The vestiges of such colonial violence have daily implications for parents' capacities to support their autistic children; parents are more likely to experience poverty, unstable living conditions, and poor health which can result in greater difficulty accessing and navigating the autism service system (Clouston, 2007; Vives & Sinha, 2019; Woodgate, 2013). Child welfare practices that continue to disproportionately remove Indigenous children from their families, may also shape parents' decision making about accessing autism services (Vives & Sinha, 2019; Woodgate, 2013; Wright et al., 2007). Furthermore, systemic racism in the BC healthcare system, as reported in Turpel-Lafond (2020), directly impacts Indigenous communities' interactions with and motivation to seek assistance from government health and social systems. The understandable avoidance of experiences of systemic racism, beyond the negative

consequences on health broadly, may also lead to negative impacts for Indigenous autistics who often require early intervention and ongoing support from health, education, and social systems.

Taken together, these views and experiences have numerous implications for the supports and services that Indigenous families require in order to successfully advocate and care for, their autistic loved ones. Indigenous peoples in Canada have unique beliefs about disability, family structures, historical experiences, and social contexts that result in distinct experiences of autism, and likely influences the types of support and services they need and desire. Therefore, services for autistic individuals and their families would be most effective if they work toward three goals: 1) design services so that they are sensitive and responsive to the unique Indigenous views and experiences as illustrated in the data, 2) focus on bolstering the existing strengths of Indigenous communities and support systems, and 3) actively resist and redress the colonial violence that continues to negatively impact Indigenous communities.

#### **4.5. Supports and services available for autism in Indigenous contexts**

Access to and barriers to accessing autism-related supports and services for Indigenous autistics and their families appears to vary considerably both between and within Indigenous communities. On the whole, the available literature suggests that Indigenous people have reduced access to autism diagnostic and support services compared to non-Indigenous people in this country. This is consistent with findings regarding disparities in access to autism services for marginalized groups in the United States (e.g., Angell et al., 2018; Aylward et al., 2021; Eilenberg et al., 2019), as well as, in Canada (e.g., Khanlou et al., 2017). For example, a recent qualitative review of the literature found that racial, ethnic, and socioeconomic minority groups in the United States had poorer overall access to early assessment, diagnosis, and therapeutic interventions (Singh & Bunyak, 2018). Our findings regarding autism-related service access disparities also consistent with well-documented inequities in access to primary healthcare experienced by Indigenous peoples in Canada (National Collaborating Centre for Indigenous Health, 2019). Further, though disparities in the accessibility and availability of health and social services for Indigenous peoples are well-established and appear to extend to autism-specific services (e.g., National Collaborating Centre for

Indigenous Health, 2019), they are not addressed in current autism-related policies in certain provinces (Zeidan et al., 2019).

Certain barriers to service access for Indigenous autistics and their families appear to be similar to those experienced by non-Indigenous peoples. For example, both Indigenous and non-Indigenous participants have reported difficulties associated with reduced service availability in rural, remote and northern locations (Young et al., 2019). Indigenous and non-Indigenous families have also raised concerns about service affordability, funding deficiencies, and unnecessary complicated government policies and service pathways (Shepherd & Waddell, 2015b). However, though certain barriers appear to be widespread, Indigenous autistics and their families may be more likely to experience barriers associated with several key determinants of health, such as socioeconomic status and geography, when compared to other Canadians (Scott et al., 2021). According to Statistics Canada, approximately 60% of the First Nations, Métis, and Inuit population live in predominantly rural locations in contrast to 33% of non-Indigenous peoples (Government of Canada, 2018). Further, persistent and large gaps in average income between Indigenous and non-Indigenous peoples are well-documented. Income gaps vary by region across Canada and are largest in the northern territories (Nunavut, the Yukon and the Northwest Territories and in First Nations reserves (OECD, 2020). Distance to autism service hubs, lack of specialized autism service providers, and limited financial resources were noted as particularly salient concerns for Indigenous voices from remote on-reserve communities in the reviewed data (Vives & Sinha, 2019).

Our findings also indicate that Indigenous families may be faced with barriers additional to those reported by non-Indigenous families, including health jurisdiction disputes, involvement in the child welfare system, racism and discrimination, and culturally unsafe care. Though both Indigenous and non-Indigenous people appear to experience barriers to autism service accessibility related to service system complexities, these system-level barriers may be compounded for Indigenous autistics and their families, particularly those living on-reserve. Health and social service delivery in Indigenous communities is complicated by jurisdictional ambiguities such that health services might be the financial responsibility of federal, provincial/territorial, or Indigenous self-governments (Scott et al., 2021). This can result in delays and disruptions in accessing autism-services for Indigenous families due to a lack of

coordination and communication between the different levels of government and agencies that provide services (Woodgate, 2013). Further, the chronic underfunding of First Nations reserves may limit communities' capacities to provide within-community specialized services (i.e., diagnostic, early intervention, and allied health services); thus reducing the likelihood that on-reserve families have access to local supports and services and/or introducing travel-related barriers (e.g., time, cost) to autism services (Vives & Sinha, 2019). Several included articles also raised concerns about an association between involvement in the child welfare system and a lack of autism services in on-reserve communities; noting that Indigenous children with neurodevelopmental disorders, including autism, are often placed and remain in foster care because their communities and families lack access to appropriate supports and services (Clouston, 2007; Di Pietro & Illes, 2016; Vives & Sinha, 2019; Woodgate, 2013). Ironically, however, there is also evidence to suggest that serious and prolonged underfunding of First Nations child welfare agencies established by Canadian Human Rights Tribunal decision (*First Nations Child and Family Caring Society of Canada et al. v. Attorney General of Canada*, 2016 CHRT 2) may limit these organizations' ability to provide staff and foster families with the training/resources necessary to safely care for Indigenous children with neurodevelopmental conditions in their communities (Wright et al., 2007). In order to access timely and appropriate autism support and services, some on-reserve families may make the decision to relocate off-reserve (Clouston, 2007; Vives & Sinha, 2019). However, service relocation may result in a host of additional challenges such as financial hardships, loneliness, loss of community support, emotional stress, and elevated anxiety (Cameron et al., 2014; The Assembly of First Nations, 2017).

Although living in a metropolitan area can provide better access to a range of autism-related services, the reviewed articles suggest that Indigenous peoples may also face multiple intersecting barriers to accessing services in urban centres. Participating parents of Indigenous autistics described instances of racism and perceived disrespect in their interactions with autism service providers, and many reported feelings they were treated with increased scrutiny than non-Indigenous parents (Clouston, 2007; Vives & Sinha, 2019; Woodgate, 2013). Families also reported limited cultural competence and safety among non-Indigenous autism service providers. For example, some Indigenous families perceived non-Indigenous service providers as dismissing their views and

experiences as irrelevant and/or instructing them on how best to support their children with disabilities. This was noted as an issue particularly during the autism assessment process; families felt certain service providers did not take the time necessary to understand their child and often used inappropriate jargonistic language (Clouston, 2007). Further, families' culturally unsafe service experiences may be exacerbated by a paucity of autism supports that have been designed specifically for and with Indigenous peoples (Shochet et al., 2020; Stavropoulou-Kampoukou, 2019). Due to a lack of culturally appropriate autism services, families may be forced to choose between autism expertise and cultural appropriateness when selecting services for their autistic family member(s) (Clouston, 2007; Sterling-Collins, 2009). As highlighted by several included articles, cultural safety training of autism service providers may increase service providers ability to provide culturally appropriate supports; thereby improving Indigenous families autism-service experiences.

The need to adapt autism services to the unique needs and circumstances of Indigenous peoples, so that members of this population have access to services that are both effective (i.e., evidence-based) and culturally appropriate was emphasized across included publications. This appears to be consistent with recommendations for Indigenous public health and early childhood development services more generally (First Nations Centre, 2007; Government Of Canada et al., 2018; Wilmot, 2018). Despite this recognized need, we identified only three primary research articles evaluating culturally adapted autism supports/services. It is important to note that all of these were small ethnographic studies of music interventions for First Nations autistic students in British Columbia, all of which were conducted by the same non-Indigenous researcher. Though these studies provide anecdotal evidence that incorporating cultural activities into existing autism interventions may be beneficial in meeting the needs of some First Nations children/youth, methodological concerns based on *both* Indigenous and Western standards (such as small sample size, lack of control group, lack of Indigenous centered data interpretation, no evidence of Indigenous driven research aims or leadership) and minimal evidence of Indigenous community collaboration/engagement *throughout* the research process severely limit our ability to make inferences based on this data.

Taken together, the reviewed articles broadly suggest that Indigenous peoples may experience disparities in access to autism-related supports compared to the general population in Canada. Service access disparities between Indigenous and non-

Indigenous peoples appear to map onto the Canadian Determinants of Health more generally, of which Indigenous peoples are more likely to experience multiple and intersecting risk factors (e.g., race, gender, socioeconomic status) as a result of historical and ongoing colonial violence. Further, though there is evidence of service access disparities between Indigenous and non-Indigenous people, the included studies also illustrate that certain Indigenous peoples have poorer access to services than others (i.e., there is evidence of disparities within Indigenous populations), also based on several key determinants of health. In particular, Indigenous autistics who are female, live on reserve, and/or have lower socioeconomic status may have reduced access to autism-related diagnostic and support services than other Indigenous autistics (Scott et al., 2021). In addition, Indigenous autistics and their families' access to autism-related supports and services are severely limited by an absence of evidence-based, culturally appropriate autism interventions and other resources. Preliminary research conducted in Canada provisionally demonstrates that existing autism supports and services may be adapted to be more culturally appropriate, however, much further research is required to ascertain *if* and *how* such adaptations are valuable to Indigenous communities.

#### **4.6. Strengths and limitations**

This scoping review extends previous review findings (Di Pietro & Illes, 2014; Lindblom, 2014) by: a) specifically targeting a broad range of sources relevant to autism among Indigenous peoples in Canada, and b) utilising rigorous and transparent search methods consistent with the scoping review framework described in the JBI Manual for Evidence Synthesis (Aromataris & Munn 2020). It follows that a major strength of this review is our thorough search of both published and unpublished, grey literature sources. We systematically searched 10 academic databases, 2 non-indexed literature repositories and 17 Indigenous health/autism websites. The search strategies were developed and refined through the research team and research librarians to ensure the appropriateness, efficacy, and scope of our search. Additional contact with authors revealed no further research in the field (as of 2021), supporting the comprehensiveness of our search strategy. Another strength of our review was our completion of an optional quality appraisal step outlined in the JBI scoping review framework. Although previous reviews have highlighted low levels of Indigenous community engagement in studies on neurodevelopmental disabilities, our assessment and summary of culturally rigorous



research practices using standardized criteria adds weight to these findings. In addition, our decision to appraise the quality of included studies based on Indigenous research standards, rather than conventional critical appraisal tools (e.g., the Critical Appraisal Skills Program), enabled us to conduct our analysis of the reviewed literature in such a way that privileges Indigenous knowledges. Furthermore, the impetus for this scoping review came out of an ongoing autism research initiative within Nlaka'pamux Nation; where research leads from Nzen'man' Child and Family Development Centre articulated the need for a literature review focused on Indigenous approaches to supporting autism in Canada. Finally, this review has compiled a detailed table of the available literature relevant to Indigenous autistics (and their support communities) in Canada, which may be useful to future investigators as a reference guide for this emerging research field. This includes the sole Indigenous-led and publicly-available autism resource we identified in Canada; which may be useful to communities supporting Indigenous autistics.

In light of these strengths, there are several limitations of our review that may limit the interpretation and use of our findings. First and foremost, this review is primarily informed by a search of the indexed literature and government/institutional reports, which systematically prioritizes non-Indigenous perspectives and voices. (Smylie, 2014). Though we endeavoured to identify relevant grey sources through an extensive search of over 15 Indigenous health/disability organizations' websites (the list of which was compiled by the Indigenous Initiatives Librarian at SFU), it is possible that there are Indigenous web-based sources of which we were unaware. Similarly, we may have inadvertently filtered out Indigenous-authored sources via our decision to exclude media sources (i.e., newsletters, magazine articles, blog posts). It is also possible that there is relevant information that is currently being used within Indigenous communities but is unavailable in the public domain and/or is not being shared through conventional sources (such as oral knowledges). Indeed, Indigenous communities in Canada have a long history of using their traditional knowledge systems to find solutions to their own problems (Alexander et al., 2019). It is therefore likely that there is knowledge held within Indigenous communities that was not captured in this review. Second, we conducted a scoping rather than a systematic review of the literature. Although the breadth of our search enabled us to identify and include a wide range of literature (which is particularly important in an emerging field of research), it also renders the integration and

interpretation of included findings challenging. The heterogeneity of included articles precluded our ability to conduct a robust thematic analysis across included articles. Instead, we summarized the key findings/main messages for each of the included articles; however, our synopses are not exhaustive. Therefore, readers should read this review as an overview of the available literature rather than a synthesis from which firm conclusions can be drawn. Readers are also encouraged to read the full texts of included publications. Third, although we made efforts to compile a diverse review team, only one member identifies as Indigenous. Future research endeavours should prioritize the inclusion of Indigenous research leadership, in line with Indigenous rights to self-determination.

## 4.7. Future Directions

Indigenous communities in Canada have called for increased research and policy addressing the unique perspectives, experiences, and needs of Indigenous autistics and their families. However, this review highlights that there are significant gaps remaining in the knowledge base. In particular, there is currently a lack of research on culturally appropriate autism supports and services that is *led* and *informed* by relevant community stakeholders. Indigenous-centred approaches to autism research are critical to ensuring that Indigenous voices are privileged, and that research agendas align with the priorities and values of Indigenous autistics and their communities. Thus, there is a clear need for further research focussed on supporting Indigenous autistics, particularly research that is conducted *by* and *with* Indigenous communities. Further, much of the relevant research has focussed on the perspectives and experiences of family members and/or service providers. Though this has generated a rich pool of information on the barriers to autism research and service utilization in Indigenous communities, the voices of Indigenous autistics were largely absent. This review also highlights a need for research to directly examine autism prevalence rates among First Nations, Métis, and Inuit communities across Canada. In line with this, the future research evaluating the cultural appropriateness of current diagnostic tools may also be of value. This type of research may be particularly valuable in informing equitable public health policy making in Canada, such as the forthcoming [National Autism Strategy](#).

## **4.8. Conclusions**

We conducted a scoping review to identify and describe the literature relevant to autism among Indigenous peoples in Canada. Relevant primary research articles were also evaluated for quality of Indigenous engagement throughout the research process. The results revealed a paucity of published and unpublished literature focused specifically on the topic, especially research that is Indigenous-led, controlled, and authored. Despite significant gaps in Indigenous-centred understandings of autism, there were important exemplars, particularly from the grey literature. Findings suggest that there may be broad differences in Indigenous and Western approaches to autism, which may have important implications for the way autism is defined, assessed, and supported. Findings also illuminate the importance of ensuring that autism diagnostic and support services are both effective and responsive to the historical experiences, strengths and priorities of diverse Indigenous communities. Future research that is grounded in Indigenous knowledges is urgently needed, with specific attention to the intersectional impact of racism and ableism on the support needs of Indigenous autistics. To ensure Indigenous autistics and their communities can achieve optimal wellbeing, autism research, policy, fundings, and service systems need to be more inclusive and equitable.

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## Appendix A.

### Details of Search Strategy

Example search strategy MEDLINE (Ovid)	
1.	exp Indigenous Canadians/ or exp Inuits/
2.	(Athapaskan or Saulteaux or Wakashan or Cree or Dene or Inuit or Inuk or Inuvialuit* or Haida or Ktunaxa or Tsimshian or Gitksan or Gitksan or "Nisga'a" or Haisla or Heiltsuk or Oweenkeno or "Kwakwaka'wakw" or "Nuu chah nulth" or "Tsilhqot'in" or Dakelh or "Wet'suwet'en" or Sekani or Dunne-za or Dene or Tahltan or Kaska or Tagish or Tutchone or Nuxalk or Salish or "St'at'imc" or "Stl'atl'imx" or "Stl'atl'imc" or "Nlaka'pamux" or Okanagan or "Sec wepmc" or Secwepemc or Tlingit or Anishinaabe or Blackfoot or Nakoda or Tasttine or "Tsuu T'ina" or "Tsuut'ina" or "Gwich'in" or Han or Algonquin or Nipissing or Ojibwa or Potawatomi or Innu or Maliseet or "Mi'kmaq" or Micmac or Passamaquoddy or Haudenosaunee or Cayuga or Mohawk or Oneida or Onondaga or Seneca or Tuscarora or Wyandot or Aboriginal* or Indigenous* or Metis or "red road" or "on reserve" or off-reserve or First Nation or First Nations or Amerindian or (urban adj3 (Indian* or Native* or Aboriginal*)).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
3.	exp Child Development Disorders, Pervasive/ or exp Autism Spectrum Disorder/ or exp Asperger Syndrome/ or exp Autistic Disorder/
4.	(autis* or ASD or Asperger* or "Pervasive developmental disorder" or PDD or "PDD-NOS" or "Pervasive developmental disorder not otherwise specified" or "Childhood disintegrative disorder" or "autistic disorder" or "Kanner* Syndrome" or "neuro atypical").mp
5.	1 or 2
6.	3 or 4
7.	5 and 6

#### Databases searched (provider)

- MEDLINE (Ovid)
- PsycINFO (EBSCOhost)
- MEDLINE Epub ahead of print and in-process & other non-indexed citations
- ERIC (EBSCOhost)
- Web of Science (Clarivate)
- Canadian Research Index (ProQuest)
- Academic Search Complete (EBSCOhost)



- Bibliography of Indigenous Peoples in North America (EBSCOhost)
- Scopus (Elsevier)
- Sociological Abstracts (ProQuest)

**Non-indexed databases, online repositories/portals, and websites searched**

- Indigenous Studies Portal Research Tool (iPortal) (available through the University of Saskatchewan Library website)
- Google Scholar\*
- British Columbia Aboriginal Network on Disability Society
- First Peoples Disability Network
- National Aboriginal Document Database
- Autism Community Training
- First Nations Health Council
- National Collaborating Centre for Indigenous Health (NCCIH)
- Indigenous Physicians Association of Canada
- Indigenous Health (Government of Canada)
- First Nations Health Authority
- Canadian Indigenous Nurses Association
- Aboriginal Mental Health Promotion Resources
- Association of Faculties of Medicine in Canada: Indigenous Health
- National Aboriginal Health Organization Archives
- CIHR Institute of Indigenous Peoples' Health
- Aboriginal Ways Tried and True (Public Health Agency of Canada)
- Autism Speaks Canada
- Canadian Autism Research Network

\*In Google Scholar, we scanned the first 100 citations sorted by relevance, as the number of references from other databases was low and therefore we expected to reach saturation of potentially relevant references by this number (Bramer et al., 2017). We also conducted our search of Google Scholar using private browsing mode to prevent our search results being customised based on our previous web-search history.

### **Recordkeeping and approach to website searches**

Websites were searched using the following three staged approach: 1) planning search – identifying websites, 2) executing search – identifying keywords, and 3) screening records and managing results, proposed by Stansfield and colleagues (2016).

Website searches were documented in an excel spreadsheet which included website name, URL, keywords used in the search, search date, and number of resulting records. Keywords were entered into the search field of the website. We conducted title screening of resulting records, and then uploaded promising records into Zotero where we conducted a duplicate check.

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## Appendix B.

### Citation Screening Form

Is the source available in English or French?		
<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Is the source any type of academic or grey literature <b>other than social media, blog posts, fact sheets, news/media articles, oral presentation</b> ? This includes peer-reviewed research of any study design, published and unpublished dissertations and theses, reviews and meta-analysis, conference preceding, editorials, book chapters, theoretical and conceptual papers, position statements, expert opinions, debate/discussion pieces, reports from government agencies and non-profit organizations, and policy documents.		
<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Does the source explicitly include information on autistic individuals (children, adolescents, and/or adults), autism, autism spectrum disorder (ASD), or any other autism spectrum condition listed in previous versions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) III through V, including: infantile autism, autistic disorder, Asperger('s) syndrome/disorder, Rett('s) disorder/syndrome, childhood disintegrative disorder, or pervasive developmental disorder not otherwise specified (PDD-NOS)?		
<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Uncertain
Does the source explicitly include information on an Indigenous population in Canada?		
This includes individuals, communities, or groups in Canada who self-identify as Indigenous, Aboriginal, First Nation(s), Métis, and/or Inuit. See the note below for a more expansive list of Indigenous identities/groups in Canada.		
<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Uncertain
Is a component of the autism information reported specific to/focused on an Indigenous population in Canada? (I.e., Are specific conclusions drawn with regards to autism among Indigenous peoples in Canada and can this information be separated from other results/conclusions)		
Articles which discuss autism and Indigenous peoples separately, but provide no discussion of the intersection of both concepts are excluded.		
<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Uncertain
If information in the document is not sufficient to answer the above questions (you checked "uncertain"), automatically move the publication to the next stage of screening. For example, articles with title and/or abstracts which suggest that nationally representative and/or ethnic minority sample(s) were included, or titles/abstracts which include terms related to demographics, and/or broader umbrella terms associated with autism (e.g., developmental disabilities, pervasive developmental disorders, neurodevelopmental disorders, neurodivergent, neuro atypical).		
Is the article eligible for inclusion?		
<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Uncertain

Note: List of Indigenous groups in Canada

Innu, Inuk, Inuvialuit, Iglulingmiut, Inuinnaït, Athapaskan, Abeneki, Ahousaht, Algonquin, Assiniboine, Anishinaabe, Blackfoot, Cree, Cayuga, Chipewyan, Chilcotin, Dakota, Dene, Denesuline, Dane-zaa, Dunne-za, Dakelh, Dìtìdaht, Ehattesaht, Gitksan, Gitksan, Gwich'in, Haida, Haisla, Han, Haudenosaunee, Heiltsuk, Henaaksiala, Hesquiaht, Hupacasath, Huu-ay-aht, Huron, ȩyârhe Nakodabi, Iroquois, Kainai, Ktunaxa, Kaska, Kwakwaka'wakw, K'asho Got'ine, Kivallirmiut, Ktunaxa, Kootney, Kyuquot, Labradormuit, Lillooet, Lil'wat, Lingit, Maliseet, Mi'kmaq, Micmac, Mohawk, Mowachaht, Muchalaht, Nakoda, Nlaka'pamux, Nuuchah-nulth, Netsilingmiut, Nuchatlaht, Nuxalk, Nisga'a, Nipissing, Nuxalk, Ohiaht, Okanagan, Ojibwa, Oneida, Odawa, Onondaga, Oweenkeno, Pacheedaht, Pacheenaht, Passamaquoddy, Petun, Piikani, Potawatomi, Sauteaux, Sioux, Slavey, Sekani, Salish, Seneca, Sinixt, St'at'imc, Stl'atl'imx, Stl'atl'imc, Shuswap, Secwepmc, Secwepemc, Squamish, Sahtu Got'ine, Squamish, Tionontati, Tagish, Tahltan, Tla-o-qui-aht, Tlicho, Toquaht Tlingit, Tastine, Tsuu, T'ina, Tsimshian, Tsuut'ina, Tuscarora, Tsilhqot'in, Tr'ondëk Hwëch'in, Tsilhqot'in, Tsuut'ina (Sarcee), Tutchone, Shuta Got'ine, Uchucklesaht, Wolastoqiyik, Wet'suwet'en, Wyandot, Wakashan, Yuu-tluth-aht, Yu'lu'il'ath. See <https://native-land.ca> for a more comprehensive list.

Appendix C.

Completed Data Extraction Form

Author(s), author affiliation, & date	Source type (design)	Aim (s)	Focus (autism, Indigenous peoples, or both)  Includes perspectives/voices of Indigenous autistics and/or their family members	Population/sample (e.g., age, sex, number, setting/geographic location)	Methods (data collection & analysis)	Key findings (relevant to our 3 focal categories: F1= autism diagnosis and prevalence, F2 = perspectives and experiences of autism, F3 = supports and services)	Strengths & Limitations
Burstyn et al., (2010)  University of Alberta	Peer-reviewed journal article (quantitative)	To estimate the prevalence of ASD in a population-based birth cohort of residents in Alberta, and to determine whether certain maternal characteristic and obstetric complications are associated with increased risk of ASD in this population.	Autism	Birth cohort of children born in Alberta between 1998 – 2004 (N = 218, 890), 51% male sample.  Sub-sample of children born to Indigenous mothers with “treaty Aboriginal status” (n = 14,486), 6.6% of overall sample.	Secondary use of information on maternal characteristics, obstetric complications, & ASD from provincial health records.  Descriptive statistics used to calculate crude ASD prevalence rate (per 1000) and mean age of diagnosis (months) for strata of each risk factor.  Log-binomial regression used to estimate relative risk (RR) and associated 95% confidence interval (CI) for maternal characteristics and obstetric complications.	F1: Prevalence The most significant and unexpected finding for the authors was that of lower rates of ASD and later age at diagnosis of ASD among children of Indigenous mothers than the rest of the cohort (2.3 per 1000; m age at diagnosis = 59.5 months, IQR 38-74 versus 5.2 per 1000, m = 36 months, IQR 47-65).  Further, relative risk modelling indicated reduced risk of ASD among children of Indigenous mothers (RR = 0.58, 95% CI = 0.40-0.84) compared to children born to mothers without any indications of socio-economic marginalization (RR = 1.00).  Authors concluded that Indigenous genetic factors or “reserve life” may be protective against ASD, or that observed difference may point to factors such as poor access to diagnostic and treatment facilities in remote areas.	Notably, process for the consent to the use of secondary data of Indigenous mothers not reported.  Deficit language used to describe children born to Indigenous mothers. Indigenous identity used as an indicator of socioeconomic nomic disadvantage in the analysis.  No other evidence of culturally rigorous research practices reported.
Clouston, (2007)	Doctoral dissertation (qualitative)	To explore the authentic experiences of Indigenous families caring for children with developmental disabilities, (including caregivers experiences of the diagnostic process, areas of stress and challenge, sources of support, perceptions of their child’s disability, and access to resources) in order to inform and how clinical practice may better support these families.	Indigenous  Extensive inclusion of Indigenous voices	Metis and First Nations caregivers (N = 20) of children with developmental disabilities living in Manitoba (N=24, age range 4-21 years),12.5% autistic.  Subsample of two caregivers providing care to 3 autistic children (12.5% of overall child sample).  Participants recruited through purposeful sampling via mainstream and Indigenous agencies.	Within a qualitative framework, the research integrated Aboriginal ways of knowing with narrative analysis, using the metaphor of weaving, to honour traditional cultural knowledge transmitted in story form.	F2: Perceptions/experiences Families’ cumulative cultural knowledge helps them to advocate for their child (respect, self-growth, purpose, child is gift). Caregivers continue to be guided by values of inclusion rooted in traditional Indigenous societies where all children were considered gifts of the Creator. The lives of children with disabilities had purpose, they were treated with respect, and the self-growth of the caregivers was connected to care of the child.	First author of Indigenous heritage (Métis) Indigenous authorship, Indigenous

		<p>A central focus of the study was to explore the body of knowledge held within individuals, families, and communities, can be used clinically to strengthen families. This knowledge includes how to negotiate transitions between their own cultural understanding and the values of mainstream agencies, as well as how to deal with deep trauma that is the experience of many families and children.</p>			<p>Narrative analytic approach, weaving together common images and meaning in stories by comparing and connecting them to central organizing story of a community elder.</p> <p>Use of large excerpts of narratives to tell participants stories in their own words.</p>	<p>Parenting a child with developmental disabilities brings increased challenges as well as gifts. The hours are long, and the work involved is exhausting. However, families are supported in caring for their children by spiritual values that uphold the life of their child as sacred and having purpose. A part of the meaning for caregivers is that their own growth is enhanced by the presence of the child in their lives because of the opportunity the child provides for inner growth. In order to support children with developmental disabilities parents need to connect to the body, mind, and spirit.</p> <p>Their stories trace how the long shadow of Canadian colonial policies reaches into the heart of family life to the present; their stories also trace enormous resilience and ability to critique mainstream values at a variety of levels as they follow their cultural imperative to "take responsibility."</p> <p>Cultural knowledge informs parenting. Indigenous cultural imperative to "take responsibility" assists families. Many participants negotiate and work with multiple systems in whatever ways necessary to access the very best supports for their children.</p> <p>Spirituality as a source of strength for many, energizing them to advocate for their children with disabilities in a Western society that devalues them.</p> <p><b>Traditional way of life as protective:</b> ruptures to traditional family life have led to reliance by caregivers on medical, social, and educational services based on Euro-Canadian values which are rooted in negative concepts.</p> <p>F3: Support services</p> <p><b>Need for individualized services.</b> Modifying the classroom to the child and not vice versa.</p> <p><b>Importance of diagnosis</b> In helping families understand the needs of their children, in accessing formal supports</p> <p><b>Importance of caregivers as advocates.</b> Many families worry about what will happen for their children once they are gone.</p>	<p>Relied heavily on two key Indigenous informants from the Aboriginal community over a two year period, throughout the recruitment and interview process, as well as in designing the research methodology and interview questions and turned her attention toward Indigenous research ethics.</p> <p>Member checking during narrative analysis and interpretation and prior to the final report.</p> <p>Consultation with community leaders (Elders and spiritual leaders).</p> <p>Met with all participants to disseminate results.</p> <p>Flexible to participant schedules, all participants compensated and provided travel costs.</p>
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						<p><i>Dealing with different worldviews. Participants expressed frustration having to rely on/depend on systems that do not see or value their children in the way they do.</i></p> <p><i>Differences/misalignment in mainstream and Aboriginal values impact services and opportunities to access services</i></p> <p>In Western society, capacity for rational decision making defines whether or not a person is considered a whole and valued member of society. This deficit model of disability has led to the devaluation and exclusion of people with developmental disabilities within mainstream society. Institutions of support based on Western societal values are therefore very different from what Aboriginal people believe they need. Indigenous peoples are conscious that their children are not seen positively in institutions based on Western values. Exclusive values of Western-European based cultures and inclusive values of Aboriginal cultures.</p> <p>Lack of sensitivity to the particular cultural needs and contexts of Indigenous families. They must deal with racism, marginalization, discrimination, negative perceptions. the services for Aboriginal families in urban areas are not culturally appropriate and are not designed to deal with the extreme marginalization many experience, there is nevertheless some support</p> <p><i>Geographic isolation of Indigenous communities.</i></p> <p>Moving as a reality of looking for care in rural communities. Loss of community and culture. One quarter of participants had moved from rural areas specifically to access specialized medical services, social services, and educational opportunities for their children because of lack of adequate access in rural areas.</p>	
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						<p><i>Gaps in services related to jurisdictional disputes between provincial and federal government for children living on reserve. Though education supports are of primary significance to families with children with disabilities, specialized supports for children with disabilities within the education system are not offered in Indigenous communities. Some health services not covered by the Canada health Act, but otherwise covered by the province through the rural health act are not provided to First Nations reserve (e.g., speech language therapists, OTs, PTs)</i></p> <p><i>Lack of access to allied health professional on reserve.</i></p> <p><i>Trade-offs and sacrifices:</i> In order to get culturally appropriate programming and services, Indigenous peoples with disabilities often have to with a lack of disability knowledge among agency staff. In order to have services that deal with disability issues, they often have to forgo the benefits of culturally appropriate services.</p> <p><b>Families' experiences with diagnostic pathways</b> In spite of participants discomfort with the diagnostic process, participants were committed to accessing the best possible care for their children.</p> <p><b>Reliance on formal diagnosis and mainstream medical system to access support</b></p> <p><b>Impacts on carer health and well-being</b></p> <p><b>Strategies to improve services:</b> <b>Cultural values and needs and the provision of culturally appropriate services</b> This study supports the need to build upon Aboriginal traditional values and knowledge to develop interventions to strengthen families and communities. This study also supports the need to utilize and adapt evidence based interventions so that Aboriginal children and families benefit from state of the art knowledge provided for with respect for their culture and awareness of their unique needs.</p>	
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						<i>Clinical practice needs to integrate Indigenous cultural knowledge as well as awareness of the disruptions and marginalization families have experienced when working with children and families</i>	
Coo et al., (2012)  Queen's University	Peer-reviewed journal article (quantitative)	To examine the association between child/family characteristics and age of autism diagnosis in 6 Canadian regions between 1997 and 2005.	Autism	Children who obtained an autism diagnosis prior to their 15 <sup>th</sup> birthday between 1997 - 2005 in BC, Calgary, Manitoba, Southeastern Ontario, PEI, or Newfoundland & Labrador (N=2180), 83% male sample.  Sub-sample of parent-identified autistic Indigenous children (First Nations, Inuit, or Métis) living off-reserve (n=72), 3.3% of overall sample.	Secondary use of basic diagnostic and demographic information recorded in the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC).  Generalized linear modelling and descriptive analysis.	F1: Prevalence  Average age of diagnosis for sub-sample of Indigenous children 67.7 months (SD=36.2), median age at diagnosis = 52.5 months (IQR = 55.5).  Aboriginal identity (imputed models) was significantly associated with later age of diagnosis, but only in a Manitoba sub-sample (not in the overall sample).  Visible minority identity (other than Indigenous identity) associated with earlier age of diagnosis in the overall and Manitoba sub-sample.  Authors suggested that previous research findings regarding underrepresentation of ethnic minorities in terms of referrals to autism assessment centres may partially explain why Indigenous children tended to be diagnosed later than White children in Manitoba.	Consent for the use of secondary data not reported.  No other evidence of culturally rigorous research practices.
Di Pietro & Illes, (2014)	Peer-reviewed journal article (literature review)	To map the landscape of research on autism, cerebral palsy (CP), and fetal alcohol spectrum disorder (FASD) involving Indigenous children, families, and communities in Canada.	Indigenous	52 peer-reviewed journal articles, reviews, and grey literature publications on ASD, CP, and FASD among Indigenous children in Canada	Scoping review using standardized key word search strategy in online databases.  Narrative synthesis of the characteristics of included publications.  Critical analysis of included publications based on level of community engagement and proportion of research on ASD, CP, FASD relative to rates of these disorders in the general population.	F1: Prevalence  Authors found a complete absence of research on autism and among Indigenous children in Canada.  Authors cautioned against assuming that the absence of epidemiological data on autism signified that autism is indeed absent or lower among Indigenous child populations. Given that the rates of disability among Indigenous peoples are nearly twice that of non-Indigenous peoples in Canada, the authors suggest that autism is likely underdiagnosed among Indigenous peoples in Canada.  The authors suggest various factors that might mitigate or delay autism identification among Indigenous peoples in Canada based on evidence from Indigenous populations in other settler-colonial countries, such as: geographic location, unique and distinct beliefs about disability, poverty, and the historical impact of large-scale economic and political oppression.	n/a

						<p>The authors assert the need to develop culturally sensitive diagnostic tools for autism before prevalence estimates can be established.</p> <p>F3: Supports and services Disproportionate focus on FASD in Indigenous neurodevelopmental research perpetuates stigma and excludes Indigenous peoples with other neurodevelopmental disabilities from access to the benefits of research.</p> <p>The authors suggest that the absence of autism research among Indigenous peoples in Canada denies Indigenous children the benefits of research. They conclude that the cultural relevance and appropriateness of any autism intervention and access to services is therefore also lacking.</p> <p>Further research is needed to develop responsively tailored policies and programs that meet the needs of Indigenous children with developmental disabilities.</p>	
Di Pietro & Illes, (2016)	Peer-reviewed journal article (qualitative)	To obtain the perspectives of health researchers working with Indigenous communities in Canada regarding a) reasons for a lack of autism and cerebral palsy research in indigenous contexts, b) potential social and ethical implications of this disparity, and c) recommendations for change.	Indigenous and autism (among other conditions)	<p>Health professionals who had conducted research within Indigenous communities in Canada (N=8), 25% of which identified as Indigenous (n=2).</p> <p>ADULTS</p> <p>All lived or worked in Indigenous communities located within three Canadian provinces Alberta (n = 5), British Columbia (n = 2), and Manitoba (n = 1).</p>	<p>Audio-recorded semi-structured telephone interviews.</p> <p>Thematic analysis of interview transcripts using NVivo.</p>	<p>R1: Prevalence</p> <p>Participants reported neurodevelopmental disabilities in general, including autism, are under-reported, misdiagnosed, or undiagnosed in First Nations communities. And that current prevalence data likely underestimates the true prevalence of conditions like autism.</p> <p>They offered a number of explanations for this phenomenon including: lack of awareness about the significance of NDDs in some communities, diagnostic overshadowing, and Indigenous mistrust in health care providers, which the authors linked to colonialism. (e.g., Trust is always going to be a thing, Children to this day, are still being stolen away from families by government agencies. Look at all the kids who are placed in foster care every year).</p> <p>A number of participants also reported that children with autism or ADHD are frequently misdiagnosed with FASD because of cultural stereotypes and stigma on the part of non-Indigenous health care workers.</p> <p>F2: Understanding</p>	Research largely conducted on rather than in partnership with Indigenous communities.

						<p>Participants described differences in how some communities define and interpret disabilities like autism, suggesting that behaviours that are considered a sign of disability in Western contexts might not be considered a problem in Indigenous contexts.</p> <p>F3: Support services</p> <p>All participants indicated that Indigenous children with NDDs are underserved, especially those in foster care or living on reserve where the availability of health care and specialized services is limited.</p> <p>Disparities in access to diagnostic assessment clinics and tertiary care (e.g., occupational therapy, physiotherapy, psychosocial services) were most frequently cited.</p> <p>Participants reported numerous barriers to service access and utilization for Indigenous peoples including: geographic distance to health care centres, lack of parental supports and resources, and a lengthy and complex diagnostic process.</p> <p>In particular, navigating the complex array of programs and services and government bureaucracy, was often cited as a significant burden to families, making them less likely to seek support.</p> <p>how the complexity involved in accessing autism systems and obtaining a timely diagnosis and funding for services and supports, including early intervention, was a significant deterrent for many Indigenous communities and parents</p> <p>Participants also reported children with NDDs are often placed in foster care because of a lack of resources needed for their care in their home communities.</p> <p>All participants acknowledged the need to improve medical care and practice on reserve, and the development of culturally informed interventions and priorities.</p> <p>The authors called for increased research and funding to support Indigenous families in safely caring for their children at home.</p>	
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Findlay & Janz, (2012)  Statistics Canada	Peer-reviewed journal article (quantitative)	To examine the parent-reported health of Inuit children under 6 years of age using nationally-representative data, including the prevalence of chronic conditions such as autism.	Indigenous peoples	Representative sample of Inuit children under age six residing in the four Inuit land regions across Canada: Nunatsiavut, Nunavik, Nunavut, the Inuvialuit region, and outside Inuit Nunangat.(N = 1693), 51% male sample	Secondary descriptive analysis of parent reported data on chronic health conditions data from 2006 Aboriginal Children's Health (ACS).	Prevalence of autism <5%, however authors determined specific rate was "too unreliable to publish"	<p>Importantly, no information provided on consent process for the use of secondary data.</p> <p>Methodologies: The original tool employed for data collection (ACS) was collaboratively developed by Statistics Canada and Indigenous advisors from across the country.</p> <p>Strength-based analysis and interpretation: Authors contextualize Inuit child health within the social determinants of Indigenous health in Canada.</p> <p>Authors suggest that their measure of health may not have captured Inuit understandings of health.</p> <p>Prioritization: Focus on Inuit children in response to calls by Indigenous authors for de-aggregated health data.</p> <p>No other evidence of cultural rigour.</p>
Hadioonzadeh, (2012)	Master's Thesis (quantitative)	To examine the association between diagnosis of ASDs and distance to regional intervention centers in a population-based cohort of 5-year-olds in Ontario. Demographic and socioeconomic variables were also examined to find significant predictors for diagnosis of ASDs.	<p>Autism</p> <p>No inclusion of indigenous voices</p>	66,284 children attending Senior Kindergarten classes in Ontario in 2009/10 and 2010/11 school year, 0.89% Indigenous.	Secondary analysis of teacher-reported diagnostic and sociodemographic information collected via the Early Development Instrument (EDI) questionnaire.	<p><b>R1: Prevalence</b></p> <p>Aboriginal status was not significantly associated with diagnosis of ASDs in the overall sample.</p> <p>Further, the proportion of children with Aboriginal status in diagnosed (1%) and non-diagnosed groups (1.6%) did not differ significantly and only a small number of children were reported to have Aboriginal status in the overall sample (&lt;1%).</p>	<p>Community engagement not reported.</p> <p>Notably, consent process for the use of secondary data not reported.</p>

		<p>1) To examine regional differences in prevalence of ASDs in Ontario by Ministry of Child and Youth Services (MCYS) regions. 2) To assess the association of ASDs' diagnosis with age, sex, first language spoken at home, English/French as primary languages spoken at home, Aboriginal status, and distance to regional centres where diagnostic and treatment services for children with ASDs are provided.</p>			<p>Descriptive statistics and univariate analysis performed to determine the prevalence rate of ASDs by covariate subgroups and to examine each of the independent variables among diagnosed and non-diagnosed children..</p> <p>Logistic regression used to assess the association between sociodemographic variables and ASD diagnosis.</p> <p>Exploratory analysis of the demographic and socioeconomic characteristics of children with Aboriginal status.</p>	<p>Demographic characteristics of diagnosed children with ASDs show that only 10 of 708 (1.4%) were reported to have Aboriginal status. Sex ratio for boys vs. girls was found to be slightly over 5:1 in non-Aboriginal children and 9:1 for Aboriginal children. None of the diagnosed children with Aboriginal status were reported to have other co-occurring disorders or disabilities.</p> <p>The author concluded that although the number of children with Aboriginal status was low in both diagnosed and non-diagnosed groups, it was encouraging to find the same proportions for diagnosis of ASDs in both groups. This is in contrast to the previous studies that found lower prevalence rates for ethnic minority groups.</p> <p>Regional analysis revealed that children with no Aboriginal status were significantly more likely to be in the diagnostic group in the Toronto region. Possible reasons might be poverty, different clinical presentations, and differences in parental behaviours. However, we should be cautious about this variable as only 10 out of 708 children in the diagnosed group were reported to have aboriginal status. MY OWN INTERPRETATION: It is also possible, based on findings from previous studies (ie., Burystyn), that autism may be detected among Indigenous children at a later age than non-Indigenous children, that Indigenous children in kindergarten may not have yet come to the attention of professionals and have not yet received a diagnosis.</p> <p><b>No significant difference in the prevalence rates of ASD between children with Aboriginal status and non-Aboriginal children.</b></p> <p>Similar prevalence rates of ASD among Indigenous (1%) and non-Indigenous children (1.6%).</p>	<p>Aboriginal status (dichotomous variable) determined based on teacher report "Teachers were instructed to report the child's background as "Aboriginal" if he or she was North American Indian, Métis, or Inuit" (pg. 34). How this was verified was not reported.</p> <p>Large population based sample.</p>
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						<p><b>Strategies to improve service access</b> Having a very small number of diagnosed children with Aboriginal status even in this large population-based study provide further evidence for the need for outreach to these groups of children and clinicians working with them to improve recognition of ASD in this population of children.</p>	
Hiebert-Murphy et al., (2008)	Peer-reviewed journal article (qualitative)	To understand, from parents' perspectives, the process of entry to community-based services for children with developmental disabilities and to explore the relationship between patterns of entry and parent-reported needs and priorities for service.	Developmental disabilities, including autism	Parents of children with developmental disabilities, including pervasive developmental disorder (n=11, 25%) accessing childhood disability support services in Manitoba (N = 72), 1% Indigenous representation.	<p>Audio-recorded semi-structured interviews.</p> <p>Interviewed transcripts analyzed following qualitative analysis procedures using Ethnograph software.</p>	<p>R3: Three process factors are influential in the entry of families to community-based disability support services: recognition of problems in child development, formal diagnosis, and linkage between diagnostic services and community-based supports and services. Though these factors are not necessarily specific to Indigenous families.</p> <p>At each stage, a complex, frustrating, and disparate service system can contribute to delays in service provision for families.</p>	Almost all the participants were White of European decent, and therefore may not be transferable to families of other cultural backgrounds (including Indigenous families).
Inman, (2019)	Peer-reviewed journal article (critical commentary)	To contemplate the absence of Indigenous perspectives within autism discourse in Canada despite increasing concern and surveillance over a growing autism epidemic.	Indigenous and autism	n/a	<p>Critical commentary</p> <p>Unspecified literature review and Interdisciplinary analysis drawing on theories of Indigenous critical race, and disability studies, and foundational intersectional frameworks, medical texts, statistics</p>	<p>F1: prevalence Author argues that the apparent absence of autism among Indigenous populations in Canada is linked to a so-called fetal alcohol spectrum disorder (FASD) 'epidemic' among Indigenous peoples, constructed by the Canadian government as part of a broader biopolitical strategy to limit the reproductive agency of Indigenous women and justify ongoing dispossession of land and resources from Indigenous peoples.</p> <p>Autism and FASD are both diagnoses that lack biological markers, and as such, are particularly at risk of diagnostic bias.</p> <p>Author suggests that the under-diagnosis of autism and simultaneous overdiagnosis of FASD among Indigenous peoples may be linked to an overlap in the diagnostic criteria for autism and FASD, whereas social differences are categorized based on preconceived racial biases of medical professionals and the overarching health system.</p> <p>For example, "disruptive school experiences" and "social difficulties" are often considered as evidence of psychosocial disturbance rather than a manifestation of school and social curricula that is irrelevant, biased and exclusive of Indigenous peoples.</p>	n/a

						<p>F2: Understanding of autism.</p> <p>Autism is privileged diagnosis, associated with economic prosperity and whiteness, whereas FASD is more likely to be diagnosed among populations of lower-socioeconomic status and racialized populations despite the fact that there is no significant data in Canada showing those populations are at greater risk of alcohol consumption during pregnancy.</p> <p>F3: supports and services</p> <p>The intersections of diagnosis, race and class lead to differential access to resources and supports, and differential outcomes in long term wellbeing.</p> <p>Parents of potentially autistic Indigenous children are encouraged to rely on resources provided or FASD, asserting that Indigenous mental health issues are always a result of colonial trauma, and erasing other expressions of neurodiversity.</p> <p>Because FAS is produced as a “catchall category for Aboriginal distress”, disability is the means through which Indigenous self-determination is currently denied.</p>	
Lindblom, (2014a)	Conference paper presentation (narrative account)	To discuss opportunities and challenges encountered while conducting research on the meaning of music for First Nations children in British Columbia, Canada, diagnosed with autism.	Autism and Indigenous	n/a	Narrative account based on personal experience	<p>F1: Prevalence</p> <p>Subtheme: paucity of research (barriers and strategies to address the barriers)</p> <p>One major obstacle to conducting autism research relevant to Indigenous communities, is the scarcity of First Nations children with autism.</p> <p>Though ASD prevalence has risen globally, First Nations children in BC, Canada, are not represented in existing prevalence data.</p>	n/a



						<p>Author speculates that the reason for lack of prevalence data on ASD among Indigenous peoples in Canada, may be substantial barriers to conducting research with Indigenous communities these include: mistrust of non-Indigenous researchers, misalignment between the interests and goals of the researcher and the intended participants.</p> <p>Gatekeepers, and community connections play a key role in gaining access to the field. The researcher was able to use her family connections to various first nations communities to contact potential participants.</p> <p>Research with Indigenous peoples with autism involves developing trust, and ensuring that the researcher accurately conveys the voices of their research participants.</p> <p>In order to conduct autism research with First Nations communities, that is ethically responsible from both Western and Indigenous perspectives, researchers need to learn about and consider Indigenous world views.</p> <p>Researchers must be aware of the reciprocal impact both researcher and participant have on one another.</p>	
Lindblom, (2014b)	Peer-reviewed journal article (unspecified literature review)	To examine possible explanations for the apparent under-detection of autism among Indigenous peoples in Canada.	Autism and Indigenous	16 academic and grey literature publications addressing autism in an "Aboriginal or ethnic context".	<p>Literature review of unspecified design.</p> <p>Keyword search of "international databases".</p> <p>Narrative synthesis.</p>	<p>RQ 1: prevalence</p> <p>First Nations children in Canada are underrepresented in publications regarding autism and the prevalence thereof, and this group appears to be under-detected.</p> <p>Possible reasons for under-detection of autism among First Nations children in Canada, based on the literature on other Indigenous populations, include: diagnostic substitution and differences in symptom presentation, ethnic or cultural differences in perspectives on disability, lack of culturally sensitive diagnostic processes, limited access to ASD assessment services in isolated Indigenous communities, racial bias and discrimination among healthcare providers, and the impact of historical oppression and discrimination.</p> <p>R3:</p>	

						<p>Culturally sensitive diagnostic tools are needed for accurate ASD diagnosis among Indigenous peoples.</p> <p>Cultural sensitivity training is needed among healthcare providers to restore Indigenous trust in the healthcare system.</p> <p>Barriers of ethnic bias, discrimination, and effects of historical oppression need to be eliminated to create equity in ASD care for Indigenous peoples.</p> <p>Potential adverse implications of lack of accurate prevalence data. The author concluded that is autism is indeed under-diagnosed among First Nations children in British Columbia, Canada, they are excluded from eligibility for ASD funding programs and potentially hindered from accessing desired services to reach their full potentials.</p> <p>There is a risk that an autism diagnosis becomes just another label for an already categorized and stigmatized First Nations child. Therefore it is crucial that the process of diagnosis, policy development and research are conducted in collaboration with the First Nations people.</p>	
Lindblom (2017a)	Peer-reviewed journal article (qualitative)	To explore the use of music interventions and activities as facilitators of social inclusion, using two cases of young First Nations people diagnosed with autism in BC.	Indigenous & autism	<p>Two First Nations children diagnosed with autism (8-year-old boy &amp; 16 year old girl), four family members &amp; six service providers residing in British Columbia.</p> <p>One child lived off-reserve in an urban centre. One lived on-reserve in a rural setting.</p>	<p>Multi-sited ethnography: Data collected via fieldnotes, filmed observations of music interactions, interviews in home &amp; school settings.</p> <p>Triangulation used to identify themes across data sources.</p>	<p>F1: Diagnosis &amp; prevalence</p> <p>n/a</p> <p>F2: Understanding</p> <p>“Although Indigenous worldviews are diverse, they are perceived to be more inclusive than Western disability models” (p. 269)</p> <p>F3: Diagnostic &amp; support services</p> <p>One participant had to travel over 300km to access diagnostic services and was initially misdiagnosed with Fetal Alcohol Spectrum Disorder.</p> <p>Neither participant has access to autism funding, so the community members provide financial assistance.</p>	<p>Indigenous Methodologies:</p> <p>Evidence of researcher reflexivity (author included a positionality statement).</p> <p>Author reported incorporating Indigenous research methodologies (i.e., relational accountability).</p> <p>Analysis &amp; Interpretation:</p> <p>Author validated preliminary interpretation of results with Indigenous participants by conducting follow-up interviews.</p>

						<p>“factors such as ethnicity, disability and gender can, separately, pose difficulties” and “when combined . . .” “can develop into insurmountable difficulties” (Lindblom, 2017b, p. 268)</p> <p>Individually designed Indigenous and contemporary music interventions show promise as facilitators of social inclusion for two Indigenous autistic children in their communities. through increased connection with people around them, including increased eye contact, singing, and playing of instruments together</p>	
<p>Lindblom (2017b)</p> <p>Exploring autism and music interventions through a First Nations lens</p>	<p>Peer-reviewed journal article (qualitative)</p> <p>AlterNative</p>	<p>To investigate the meaning of music for First Nations children diagnosed with autism in BC.</p>	<p>Indigenous peoples and autism</p>	<p>First Nations children aged 6 – 15 years diagnosed with autism from several different areas across BC, (n = 5, 80 % males), their family members (n=7), and teachers/support workers (n=12).</p> <p>To protect the confidentiality of research partners, names of the specific First Nations communities involved and their geographic locations were not reported. Research partners lived both on and off reserve.</p>	<p>Author reported the study practices were guided by pan-tribal framework within an Indigenist research paradigm.</p> <p>Data was collected during two 6-week community visits in 2013 and 2014 via audio-recorded interviews, filmed observations of music interventions, follow-up conversations, and researcher notes.</p> <p>Interviews and conversations focused mostly on music, but family members also told stories about the children’s diagnosis and school histories.</p> <p>Data from all sources combined, analyzed, and compared using a combination of Western and Indigenist approaches: mind-maps, thematic-coding, dreams, feelings, intuition.</p> <p>Thematic analysis and triangulation.</p>	<p>F1: prevalence</p> <p>Education professionals reported they have not come across many First Nations students with autism, despite decades of experience teaching on reserve. In school the school setting, participants reported Indigenous students tended to be over reported in some special needs categories (i.e., intellectual disability), but not in categories such as autism or gifted.</p> <p>F2: Understanding</p> <p>Traditional Indigenous values support the care and inclusion of autistic children.</p> <p>Autism diagnosis and intervention are based on a Western, medical, deficit model of disability which poorly aligned with inclusive First Nations worldviews. However, children in the study are all dependent on the dominant systems for health, funding, and support in their home communities and schools. In order for autism diagnosis to be of benefit to First Nations communities, autism interventions and support systems need to be culturally sensitive.</p> <p><b>F3: Diagnostic and support services.</b></p> <p>Even though all five of the First Nations children involved in the study had an autism diagnosis, only one had access to government autism funding.</p>	<p>Evidence of culturally rigorous research practices in the following research domains: relationships, participation, capacity building, analysis, and interpretation.</p>

						<p>Research partners reported that traditional music is an important part of First Nations culture, and that music is used for a variety of purposes such as relaxation, communication, and community gatherings.</p> <p>Culturally sensitive music interventions and participation in Indigenous music activities therefore could play an important part in meeting the needs of First Nations children diagnosed with autism.</p> <p>However, First Nations children in BC have little or no access to Indigenous music used for therapeutic purposes in the school setting.</p> <p>The use of music interventions, especially involving Indigenous music, appears to be underestimated; emphasizing the lack of cultural sensitivity and colonial residue in school-based interventions for First Nations children diagnosed with autism.</p>	
<p>Ouellette-Kuntz et al., (2006)</p> <p>Queen's University</p>	<p>Peer-reviewed journal article (quantitative)</p>	<p>To estimate the prevalence of diagnosed pervasive developmental disorders (PDDs) in Manitoba &amp; PEI compare characteristics of diagnosed cases, including ethnocultural identity, between the two regions.</p>	<p>Autism</p>	<p>Children 0-14 years old with a documented PDD diagnosis who resided in Manitoba (n = 575) or PEI (n = 87) at any time during 2002 (N = 622), 80% male.</p> <p>Sub-sample of Indigenous (First Nations, Inuit, Métis) children living off-reserve in Manitoba (n = 39), 8.3% of the Manitoba sample.</p>	<p>Secondary use diagnostic &amp; demographic information collected from provincial education records.</p> <p>Period prevalence calculated using descriptive statistics (all children identified with diagnosed PDD through record review divided by census counts).</p> <p>Binomial test used to compare observed proportions of diagnosed PDDs with certain characteristics (i.e., ethnicity) to the expected proportion, using children under the age of 15 years in the general population as the comparison group.</p>	<p>For confidentiality reasons, the ethnicity of children with diagnosed PDD could not be reported for PEI due to small case counts.</p> <p>In Manitoba, Indigenous children with PDDs (8.3%) were significantly (<math>p &lt; 0.001</math>) underrepresented compared with the general population of Indigenous children living off native reserves (15.6%).</p> <p>In contrast, visible minorities were significantly (<math>p &lt; 0.03</math>) overrepresented among children identified with PDDs (12.8% compared with 9.8% in the general population).</p> <p>Eight percent of all children with PDDs in Manitoba were Indigenous, whereas this group comprises 16% of the population under the age of 15 years when children living on native reserves are excluded. The reason for this discrepancy is unclear. Future research is needed to determine whether Indigenous children are at decreased risk for PDDs, are underdiagnosed, or are not accessing of receiving services.</p>	<p>Community involvement: Excluded children residing on reserve.</p> <p>Some evidence of strength-based analysis and interpretation: Partial - Indigenous children may be underrepresented because diagnostic tools lack cultural sensitivity.</p>

					Census counts of children living on-reserve were subtracted from denominators used to calculate period prevalence.	If Indigenous children are less likely to be diagnosed with PDDs because their parents are not seeking help or because current diagnostic and assessment tools lack cultural sensitivity, these issues need to be addressed.	
Scott et al., (2021)	Peer-reviewed journal article (commentary)	To reflect on the current disparities and barriers to achieving health equity for autistic people in Canada, and outline ways to address these challenges in a future National Autism Strategy, identified in the equity.	Autism	The panel consisted of representatives from autism advocacy organizations (the South Asian Autism Awareness Centre (SAAAC), Disabled Women's Network of Canada (DAWN Canada), Weeneebayko Area Health Authority (WAHA), and British Columbia Aboriginal Network on Disability Society (BCANDS)), who spoke on behalf of underserved communities in central Toronto, women with disabilities, remote communities in northern Ontario, and Indigenous Peoples in British Columbia.	Critical commentary and reflection based on the equity panel discussion presented at the Canadian Autism Leadership Summit 2020.	<p>R3: Some autistic groups face health inequities stemming from the intersection between several key determinants of health: culture, gender, geography, SES, and level of support needs.</p> <p>In the context of autism, health equity means that each autistic person has access to the resources required to meet their health needs, such as an autism diagnosis/supports/services, regardless of where they live, what they have, or who they are.</p> <p>The panelists identified five factors as major contributors to health inequities within the autism community. These factors extend from the level of support needs at an individual level and its intersection with several key determinants of health. Including: geography, culture, gender, and socioeconomic status. Notably, barriers arise due to a "lack of" theme, including lack of awareness, knowledge, access, and voice within underserved communities.</p> <p>Geography: Small, rural and remote communities do not have the same access to autism-related supports that are available in larger cities. In addition to rurality, Indigenous communities are also faced with jurisdictional issues such that health services might be provided by federal, provincial/territorial, or Indigenous self-governments resulting in a lack of adequate care due to a lack of coordination and communication between the different levels of government, agencies, and stakeholders.</p>	n/a

						<p>Culture and Racialized communities: Black, Indigenous, People of Colour (BIPOC) communities are more likely to experience both interpersonal and systemic racism, rooted in a history of colonialism, which may erode their confidence in the health care system and impede their access to services. Further, various cultural communities (including Indigenous communities), may have specific health beliefs, first languages that are not English or French, and other culturally specific needs that are not considered within current ASD services.</p> <p>Gender: A lack of knowledge about how autism presents itself in girls and women results in disparities in autism diagnosis (with girls more likely to be under—diagnosed or diagnosed later). This in turn impacts the age at which they can qualify for support and therapy services.</p> <p>Socioeconomic Status (SES): Because many autism services are not provided for sufficiently in the public realm (particularly in rural and remote locations), families who can afford to purchase supports privately often do, enabling earlier access and better outcomes for families with higher SES.</p> <p>In order to understand the complexity of ASD care challenges Indigenous peoples face, we must consider each autistic person's overlapping identities and experiences.</p> <p>Indigenous peoples may face numerous barriers to accessing timely and appropriate ASD care. These barriers may be multiplied for Indigenous women and those with lower socio-economic, and/or those living in geographically isolated reserve communities.</p> <p>There may be a lack of awareness of available ASD services in Indigenous communities. This issue can arise for a variety of reasons including intergenerational trauma that can affect trust in health care providers, language barriers, level of education (which can affect health-related conversations when heavy jargon is used), and/or access to the internet.</p>	
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						<p>There is also a lack of culturally diverse knowledge about ASD and how preferred supports may vary based on culture.</p> <p><i>Four reoccurring ideas were identified for how to address inequities in health care for Autistic people. First, allocate resources for regional or in-community endeavours; second, improve Autistic representation and connection with diverse communities; third, establish a community of allies to advocate and collaborate; and fourth, establish leadership within the community and government to make disability a priority for Canada. To achieve equity in health care in a National Autism Strategy, we need to look at the intersectionality of autism with the key determinants of health</i></p>	
Shepherd & Waddell, (2015)	Peer-reviewed journal article (qualitative)	To explore the views and experiences of parents, policymakers and researchers across Canada, in order to understand the current conflicts in autism policy and ascertain if consensus is possible on improving autism services.	Autism	Parents of autistic children and young adults (n=15), policymakers (n=13) and researchers (n=11) from 8 provinces across the country, who had engaged in public forums on autism policy (N = 39), number of Indigenous participants not disclosed.	<p>Qualitative</p> <p>Semi-structured interviews</p> <p>Constant-comparative approach to data triangulation</p>	<p>Participants agreed on the need for more comprehensive services across the spectrum and throughout the lifespan, and on the need to “do more for all” children, especially those from disadvantaged backgrounds.</p> <p>All participants expressed concerns regarding inequities in access to autism services and funding based on geographic location and socioeconomic status, as well as the need for autism policy in Canada to address geographic and socioeconomic disparities.</p> <p>The availability of autism funding may be a particular issue for families who have fewer resources.</p> <p>One researcher commented that: “I think it’s working fine for some families who can top it up with their own funding without having to put a second mortgage on their house and eat macaroni and cheese for the rest of their lives. It’s working okay for some families because the kid doesn’t need more than a few hours a week or the service provider’s really good. But the families with more impaired kids, for them the funding is a drop in the bucket, or for the immigrant families, or poor families, or Aboriginal families.”</p>	Culturally rigorous research practices not reported.

						<p>Publicly available autism supports and services work well for families of autistic children with low support needs, or for families who have the financial resources to 'top up' publicly available funding programs, however procuring the quality and quantity of appropriate autism services is a challenge for low-income and rural families, especially immigrant and Aboriginal families.</p> <p>While participating parents, policy makers, and researchers have diverse views and experiences, they agree on the need to diversify services across the autism spectrum, providing better support during the transition into school and adulthood, and expanding existing services to reach more disadvantaged children and families, especially immigrant and Aboriginal families.</p>	
Shochet et al., (2020)	Peer-reviewed journal article (literature review)	To identify and review existing programs and resources developed worldwide to promote the psychosocial wellbeing of Indigenous peoples with autism and/or other neurodevelopmental disorders.	Indigenous and Neurodevelopmental disorders	Eleven psychosocial resources developed for Indigenous people (e.g., Aboriginal, First Nations, Maori, Native American) with neurodevelopmental disorders (e.g., ASD, Asperger syndrome, intellectual disability), and/or their caregivers developed worldwide, one specifically developed in Canada (9%).	<p>Systematic review and catalogue.</p> <p>Key word searches of online academic and grey literature databases.</p> <p>Quality appraisal of studies included in the systematic review using the Mixed Methods Appraisal Tool (MMAT, Hong et al., 2018)</p> <p>Findings summarized using a narrative approach.</p>	<p>R3: supports and services</p> <p>Paucity of evidence-based programs specifically aimed at enhancing the psychosocial wellbeing of Indigenous peoples with autism.</p> <p>Few publicly available resources specific to supporting Indigenous peoples with neurodevelopmental disabilities and their caregivers. Lack of research suggests that Indigenous people with characteristics or a diagnosis of ASD and/or other neurodevelopmental disorders may be deprived of support at critical points of development or may resort to using psychosocial supports that lack cultural awareness or competency, which may impact on their overall psychosocial wellbeing</p>	<p>Extensive and systematic search of over 40 academic and grey literature databases.</p> <p>Though the importance of Indigenous collaboration in the design and evaluation of autism supports was emphasized by the authors, they did not report on Indigenous engagement in any aspect of the systematic review process.</p>



						<p>Of the seven research articles included in the systematic review, only two described programs to improve the wellbeing of Indigenous peoples with autism in Canada (Lindblom, 2017a, 2017b). <b>Specifics will not be described because these articles are already included in our review.</b> The authors concluded that although the two Canadian articles by the same author reported positive outcomes (e.g., opportunities for social inclusion, improved mood, increased relaxation and concentration) for First Nations children with autism through the use of culturally adapted music interventions, findings are based on observational reports from the researcher and anecdotal evidence gathered from interviews with participants and caregivers, should therefore be interpreted with caution based on low study quality.</p> <p>Eleven psychosocial resources were identified, the majority of which were from Australia. Authors identified only one psychosocial resource developed specifically for Indigenous peoples with autism and/or their caregivers in Canada. (<a href="http://www.fourdirectionsautism.ca/">http://www.fourdirectionsautism.ca/</a>).</p> <p>The Four Directions Autism website is a volunteer-run website providing psychoeducational resources and support (on an individual and group basis) for parents of First Nations children with ASD. Though this is a free and accessibly formatted online resource, it does require an internet connection to access. Further, the efficacy of the program has not been empirically evaluated.</p> <p><b>Strategies to improve the services:</b></p> <p><i>Cultural adaptation of existing programs and resources.</i> The authors concluded that adapted programs showed as much promise as designing new programs.</p> <p>Given the complexities of designing and evaluating new programs, the authors suggest that existing evidence-based psychosocial programs and resources could be adapted collaboratively with Indigenous stakeholders to meet the needs of Indigenous peoples with autism and the communities that support them.</p>	
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Simpson, (2021)	Peer-reviewed journal article (systematic critical integrative literature review)	To explore culturally responsive interventions aimed at supporting positive identity formation, pride and resilience for Indigenous autistics.	Indigenous and Autism	24 peer-reviewed journal articles exploring the intersectionality of Indigeneity and autism in Canada, the United States, Australia, and New Zealand,	<p>Systematic critical integrative literature review</p> <p>Key word search of online databases</p> <p>Critical evaluation of included articles using comparative thematic analysis.</p>	<p>The majority of included articles (88%) found that Indigenous people and autistic people in settler colonial nations have a shared experience of historic and ongoing social injustices such as marginalization, discrimination, poverty, disempowerment, and genocide resulting from colonization.</p> <p>The existing literature on the experiences of Indigenous peoples and autistic people largely exist as separate bodies of knowledge.</p> <p>Indigenous peoples and autistic people both experience categorization and control over identity ascribed to them through colonial systems and structures.</p> <p>Intersection of Indigeneity and autism in settler-colonial nations results in increased exposure to human rights violations.</p> <p>While literature reviewed is not representative of all Indigenous Peoples or autistic people, studies show a clear pattern that both cultural groups face societal challenges and survive ongoing oppression that exacts a toll on self-identity, self-esteem, and overall health</p> <p>Concurrently, literature reveals that positive ethnic and social identity is a protective mechanism for improved health as it is directly correlated to the development of resilience, positive self-image, and healthy coping strategies for Indigenous Peoples and autistic people experiencing injustices</p> <p>Results suggest there is a shortage of culturally responsive services and interventions within the education and disability services space for Indigenous peoples and autistic people promoting health culture-based identity formation.</p> <p>The author concluded that while further research is needed, articles about autism and articles about Indigeneity reveal unique discriminations and considerations found at this intersection, and that positive identity formation can foster resilience in this uniquely marginalized population.</p>	N/A
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						<p>Positive identity formation and social-psychological wellness is bolstered by culturally responsive interventions that are self-determined, contextualized, personalized and account for historical and ongoing forms of discrimination.</p> <p>Indigenous Peoples and autistic people situated in Canada, the United States, Australia, and New Zealand share related historical and ongoing patterns of subjection and oppression as non-normative groups outside the dominant EuroWestern culture resulting in significant negative impacts to self-identity and mental health</p> <p>Incorporating Indigenous knowledges in education and arts programming as a way to disrupt patterns of social injustice, exclusion, and cultural genocide while promote positive identity formation, pride, and resilience for Indigenous autistics</p>	
Sterling-Collins, (2009)	Book chapter (narrative account)	To describe "Aboriginal social work" practices through experiential example.	Indigenous and Autism	Indigenous children with special needs.	One Nlaka'pamux social worker describes her personal journey supporting her autistic son, and other Indigenous children with special needs in British Columbia.	<p>R1: prevalence</p> <p>The author reports that though there are no specific statistics on the number of First Nations children with ASD, through her informal networks she has learned that Indigenous communities are "dramatically affected". In her own community in British Columbia, the author knows of 5 autistic boys.</p> <p>R2: Understanding</p> <p>The medical model of autism is limiting, as it focuses solely on describing the physical and intellectual aspects of the condition. It omits the emotional and spiritual aspects of autism that are central to holistic Indigenous models of health.</p> <p>The Medicine Wheel framework, which incorporates all aspects of the self and their inter- connection to all other beings, is better tool to empower and enhance the lives of Indigenous peoples with autism, and can help family members better understand autistic people's behaviour and needs.</p>	N/A

						<p>To best support Indigenous people with special needs, supports and services need to take a holistic approach, individualized to each person. Building on strengths of the child and their family in emotional, intellectual, physical, and spiritual realms.</p> <p>R3: Programs in rural and remote locations are often inadequate, lack workers with specialized training, and/or cultural sensitivity. As a result, many families of children with special needs have unmet needs and experience feelings of isolation and loneliness.</p> <p>Though families may lack access to needed services, they draw strength from traditional cultural values of inclusion and community responsibility.</p> <p>To support Indigenous families and communities, service planning and delivery needs to incorporate Indigenous worldviews. Social workers play a critical role in bridging cultural relevancy into contemporary services, acting as advocates, and assisting families navigate complexities of the service system.</p>	
Stavropoulou-Kampoukou, (2019)	NGO report (literature review)	To identify support and service delivery approaches currently being used in Canada that are considered culturally safe for Indigenous children and youth with ASD.	Indigenous & Autism	Academic and grey literature focussing on culturally safe services for Indigenous individuals with ASD. Number not specified.	<p>Scoping review of academic and grey literature published from 2009 to 2019, and results from jurisdictional scan conducted by MCFD.</p> <p>Included articles analysed for key themes.</p>	<p>R3: Existing ASD services have been designed through a Western cultural lens, and do not necessarily fit with the types of supports and services families need and want on and off reserve.</p> <p>The literature highlights a number of challenges and barriers in ASD service delivery and access for Indigenous families, including: lack of cultural competence and safety in workers and institutions, lack of continuity in services and funding, difficulties in assessment and identification, foster care as a barrier to service delivery, lack of safe contexts that support self-identification as Indigenous.</p> <p>Service access and delivery could be improved by: involving Indigenous people in service design and delivery, creating liaison worker services, developing individualized services, improving communication and cooperation between provincial and federal services, adopting a strengths-based approach for ASD services, and bringing specialized ASD services to Indigenous communities.</p>	Easy read, short format for knowledge translation.

Trans PULSE Canada (2021)	NGO report (quantitative)	To present results from the first nation- wide all ages survey on the health and wellbeing of Indigenous trans, two-spirit, and non-binary people in Canada.	Indigenous health	Gender diverse First Nations, Métis, and Inuit youth and adults (age range 14- 64 years) in Canada able to access and willing to complete an online survey (N = 252), 20% autistic.	Self-report survey collected information on the health and well-being of Indigenous trans and non-binary people.	<p>R1:</p> <p>Of 252 gender diverse Indigenous survey respondents, many reported lived experience of disability. The most reported disability identities were neurodivergent (40%), and autistic (20%).</p> <p>R3:</p> <p>Results highlighted that community belonging and participation in traditional activities or embracing a traditional identity are important factors connected to the health of Indigenous gender-diverse peoples.</p> <p>Some respondents identified barriers to participating in traditional community ceremonies, such as sweat lodges, due to disability needs.</p>	While Trans PULSE Canada used multiple approaches to make the survey accessible (i.e., online; in-person with the assistance of Peer Research Associates), it was not possible to conduct a random sample of gender-diverse people. As such, this survey captured the experiences of In-digenous gender-diverse people who were able to access this survey. Therefore, the results presented below cannot be assumed to represent true popula-tion demographics, and as such, only represent a proportion of the full Indigenous gender-diverse pop-ulation
Wright et al., (2007)	NGO report published in book chapter (mixed methods)	To identify challenges and “best practices” for addressing the needs of Indigenous children with learning/cognitive and behavioral disabilities (including autism) in the care of Indigenous child welfare agencies.	Indigenous	<p>Phase 1: Service providers from 29 First Nations child welfare agencies (N=29), providing services to First Nations and Métis children and families in in BC (n=8), Alberta (n=3), Saskatchewan (n=3), Manitoba (n=4), Ontario (n=5), Quebec (n=4), &amp; New Brunswick (n=2), both on and off-reserve in urban and rural settings.</p> <p>to supporting on reserve First Nations &amp; Métis children in care in BC (n=8), Alberta (n=3), Saskatchewan (n=3), Manitoba (n=4), Ontario (n=5), Quebec (n=4), &amp; New Brunswick (n=2).</p>	<p>Mixed methods.</p> <p>Data collected in 2 phases.</p> <p>Phase 1: service provider survey with quantitative &amp; open-ended questions</p> <p>Phase 2 “site visits” in five locations across Canada: community focus groups, interviews review of relevant agency policy and financial data, identification of collateral agencies providing supports and services to children with disabilities</p> <p>Descriptive statistical analysis of quantitative data.</p>	<p>R1: prevalence</p> <p>Findings regarding the prevalence of Indigenous children with specific cognitive/learning disabilities in care were inconclusive, although the authors suggest that it is reasonable to estimate that there are a disproportionate number of Indigenous children with disabilities in the care of child welfare children.</p> <p>Barriers to diagnosis: A) lack of agency training/capacity. Many agencies do not collect information on the diagnosis of a child because their primary role is to “protect children from abuse”.</p> <p>B) Concerns about the potential stigmatizing effects of a disability label.</p> <p>Participants noted that, in some cases, parents in the community are fearful of having their children labeled as having a disability. They fear that the label will have negative consequences for the child. Some parents fear being blamed for the disability.</p>	Results non-specific to children with autism.

				<p>Phase 2: Relevant community stakeholders (Elders, agency staff, community service providers, community leaders, foster parents, family members of children with disabilities) from 5 locations across Canada (exact participant numbers and locations not reported)</p> <p>Identified 90 Indigenous children with cognitive/learning disabilities, 2 were specifically identified as autistic (2.22%).</p>	<p>Thematic analysis of qualitative data : coding of the transcripts, written material compiled during site visits, and field notes. Codes were organized into emerging themes.</p>	<p>Agency staff reported that in general, they try not to label children with disabilities. And that professional diagnosis is only sought when required to access funding and support. For children with autism, formal diagnosis is often necessary to access funding and supports.</p> <p>R2: understanding</p> <p>Many participants reported that they hold a traditional view of disability. This view includes seeing children with disabilities as a special gift, and respecting and valuing children with disabilities as important members of the community.</p> <p>R3:</p> <p>Participants reported a number of gaps in services for children with disabilities in their communities including lack of tangible (e.g., respite, financial assistance) and emotional support (e.g., parent support groups) for families caring for children with disabilities, lack of community-based services that extend beyond the education system, lack of specialized training and education for foster parents to meet the needs of children with disabilities, lack of early diagnosis and intervention services, lack of resources to follow through with recommendations that emerge from assessment, lack or access to professionals with specific skills to provide supportive services (e.g., psychologists, speech therapists), lack of services for youth when they reach adulthood, lack of training for professional staff to provide services, lack of coordination among existing service providers, lack of foster homes for children with special needs.</p> <p>Participants also strongly expressed how communities in general, and the child welfare agencies in particular, are seriously limited in how they can respond to the needs of children with disabilities because of their lack of resources.</p>	
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						<p>Participants do not perceive governments and funding bodies to be understanding or, or responsive to the needs of children with disabilities. Most responding agencies (29%) reported they do not receive targeted fundings to support children with cognitive/learning disabilities, and identified the need for additional support to provide care to children with cognitive/learning disabilities. As a result, only 10% of responding agencies reported that their staff receive specialized training in autism.</p> <p>Participants clearly articulated a major dilemma that directly affects the services and supports that they can provide: no one wants to take responsibility for funding supports for children with disabilities. Ongoing jurisdictional arguments around the responsibility for providing disability services are a major impediment to securing resources and providing support to these children and their families.</p> <p>Authors raised concerns about the relationship between autism and the child welfare system, noting that Indigenous children with disabilities, including autism, are often placed and remain in foster care because their communities and/or families lack access to appropriate resources and services.</p> <p>In some communities, the only way to access resources to support a child with disabilities is for that child to come into care. In many communities there are few, if any, voluntary, community-based support services available to children with disabilities and their families. The way in which many child welfare agencies are funded requires the child to be in care before any resources for that child can be secured. Because of the lack of supports, some parents are not able to continue caring for the child. This is extremely difficult for the child, the parents, and child welfare staff.</p> <p>In spite of the challenges that they face, these communities have developed solutions to meet some of the gaps in service. There exists among many of the participants a strong commitment to improving the</p>	
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						lives. Participants described the support of families, which includes extended family members, and their community, as key strengths in supporting children with special needs.	
Woodgate (2013)	NGO report (qualitative)	To arrive at an increase understanding of the disability trajectory from the perspectives of First Nations families of children with disabilities in Manitoba.	Indigenous	<p>First Nations children with disabilities (N=97, 13.4% autistic sample, age and gender not specified), family members (n = 75), and other key stakeholders (n = 28; i.e., service providers, policy makers, Elders).</p> <p>To arrive at a detailed understanding of both the urban southern and rural northern family experience, FN families were recruited Winnipeg, Norway House Cree Nation, and other southern and northern sites in Manitoba, both on and off reserve.</p>	<p>Qualitative research approach guided by the Life Needs Model as situated within the concept of Therapeutic Landscapes (i.e., cultural place-based values affect and main.</p> <p>The concept of therapeutic landscapes brings together the notion of landscape and principles of holistic health, and has been applied to a wide range of contexts to examine how physical, social, mental, and spiritual aspects of an environment interact to affect health and well-being.</p> <p>Multiple data collection methods: interviews, photo-voice, eco-maps, field notes, document review.</p> <p>Four levels of analysis to generate socio-cultural themes and varying profiles of childhood disabilities.</p>	<p>F1: prevalence</p> <p>High prevalence of disabilities, including autism, in First Nations communities.</p> <p>F2: Understanding</p> <p>Child as a Gift. Most parents viewed children with disabilities as “special people” who have lots to contribute to their families and society in general. Stakeholders felt they had so much to learn from children with disabilities.</p> <p>F3: diagnostic and support services</p> <p>Parents struggle to provide a good life for their children in environments that are lacking the appropriate resources and services.</p> <p>Some First Nations parents would appreciate having access to ASD support groups specifically for Indigenous family members.</p> <p>Parents described having to do “intense parenting”, and to having to play multiple roles harnessing their own resources in order to navigate the service system and meet the needs of their child.</p> <p>Parents felt they were judged more harshly in how they raised their child with a disability based on their ethnicity.</p> <p>Family members reported numerous barriers to supporting their child with a disability including structural barriers related to colonialism (e.g., lack of disability awareness, lack of community resources), historical trauma, social disruption, external judgement and stigma, and poverty.</p>	Extensive inclusion of relevant First Nations community members as participants in the research process.



						<p>“It all depends on what side of the road you live on” – participants reported that their access to disability related support and services was largely dependent on their geographic location. The majority of the families in the study who lived on reserves lacked access to many needed resources and programs. Even when services/programs are available, FN families still experience missing-out on services and programs due to the complexities and difficulties in navigating the system.</p> <p>Participant endorsed the need for strengths-based supports and services that focus and build on the strengths of First Nations families and communities (i.e., resilience, collective support).</p> <p>The need for culturally appropriate services and supports. Parents reported having different concerns than non-Indigenous parents, and the need for Indigenous specific services in order to feel heard and feel safe.</p> <p>In order to best serve Indigenous children with families of disabilities and the communities that support them: services need to be tailored to the unique and distinct needs of each family based on collaboration with all relevant family members (included extended family), the needs to be services and programs at each stage of the disability trajectory to ensure a continuous transition of services and programs throughout the lifespan, need for coordinators to navigate the multiple service system, need for sharing circles where family members can talk about their experiences.</p> <p>Need for locally available supports and services to mitigate geographic barriers to service access.</p> <p>Need for cultural competence programs for all service providers.</p>	
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Vives & Sinha, (2019)	Peer-reviewed journal article (qualitative)	To examine access to services for children with special healthcare needs (including autism) who lived on reserve in Pinaymootang, Manitoba in 2016 and 2017, and assess comparability of services to those available in nearby communities off reserve.	Indigenous	<p>Pinaymootang children with special healthcare needs (N=12, including autism although the specific number not reported), family members (n=12), local service providers, &amp; local and provincial representatives of Indigenous organizations (n=8).</p> <p>Children and their families were selected using purposive sampling from a larger group of families enrolled in a program launched by Pinaymootang Health Centre to address the needs of children with SHN in the Community.</p> <p>Service providers and their families were recruited using convenience sampling by the project's advisory committee.</p>	<p>Research collaboration between university researchers, Pinaymootang First Nation leaders, &amp; major provincial Indigenous organizations using a qualitative approach "to produce in-depth, community-based evidence"</p> <p>Multiple data collection methods: participant observation in sharing circles and regional meetings on the implementation of Jordan's principle, focus groups, semi-structured interviews.</p> <p>Specific method of analysis not described. However, research team conducted three separate validation sessions with participants and community leadership prior to the publication of the final report.</p>	<p>F3: Eligibility and coverage for additional care services (respite care, prescription medication, assistive communication devices, and transportation) is dependent on a child's Indian status, and regular place of residence.</p> <p>Pinaymootang children living on reserve experience substantial delays in accessing required supports and services.</p> <p>Indigenous children living on reserve are typically not diagnosed until years after they start school.</p> <p>Challenges in accessing services for Indigenous children on-reserve are the result of a discriminatory public service network grounded in colonial history and ideology.</p> <p>Factors such as long-term underfunding of on-reserve services, inconsistent administrative practices, and intentional geographic isolation of Indigenous communities isolation of First Nations communities interact to perpetuate discrimination against FN children.</p>	<p>Substantial evidence of culturally rigorous research practices</p> <p>Report provides in-depth community-based evidence.</p> <p>Conclusions regarding service disparities may not be generalizable to other Indigenous communities in Canada.</p> <p>Report concludes with 9 recommendations prepared by the project's advisory committee for future policy aiming to eliminate discrimination First Nations children with special healthcare needs experience by way of fully and meaningfully implementing Jordan's Principle in Canada.</p>
Young et al., (2018)	Peer-reviewed journal article (qualitative)	To build capacity in treatment and support for individuals and families impacted by autism in remote and rural communities in Canada.	Autism focus	<p>Approximately 200 autism stakeholders in seven communities in rural, remote, and northern regions of Alberta (Fort McMurray, Westlock, Whitecourt, Edson) and British Columbia (Williams Lake, 100 Mile House, Tl'esqox (Toosey First Nation)).</p> <p>Communities were selected based on their rurality and willingness to engage in change efforts for enhanced service delivery within their region.</p>	<p>Participatory action research approach: prior to data collections, aims and methodology of the project developed, reviewed, and refined with input from community leaders and key stakeholders (service providers, educators, community groups).</p>	<p>F3: supports and services</p> <p>Participants indicated the inadequacy of ASD services in rural regions relative to the needs of affected individuals, their families, and their communities.</p> <p>Specifically, families identified difficulties accessing information, finding and navigating services (e.g., respite, specialized interventions) and finding support (e.g., emotional financial) and many raised concerns about in-sufficient school resources.</p>	<p>The PAR approach to data collection required a time commitment from participants. Some individuals or families may not have been able to participate to the extent described due to conflicting schedules and/or care requirements.</p> <p>Results may not be generalizable outside of the communities involved.</p> <p>Results were non-specific to Indigenous communities involved.</p>

					<p>17 recorded discussion groups with community stakeholders (parents, caregivers, siblings, service providers, etc.) across included communities, including one held in Ti'esqox and ranged from 10 to 60 participants per session.</p> <p>Discussion groups in communities specifically addressed: (1) how individuals with ASD and their families access and navigate services, (2) what elements in the community foster, and conversely limit, resource accessibility and engagement, and (3) what is perceived as needed to improve resources and community experience.</p> <p>Community discussions transcribed and reviewed for emerging themes using thematic analysis. Themes were then distilled through interpretive description, which in turn were presented to community stakeholders for reflection and collective action.</p>	<p>Though these concerns are similar to those heard province-wide, common challenges for families affected by ASD appear to be amplified for rural and remote dwellers. Barriers associated with rurality included: proportionally fewer trained service professionals, long distances to ASD service hubs, and the need to allocate funding for direct ASD services to travel costs. These barriers appear to be similar for both Indigenous and non-Indigenous communities involved.</p> <p>This project also highlighted strengths in rural and remote communities relative to supporting autistic people and their families, such as a sense of "collectivity, community and responsibility for one another". As a result, participants described ingenuity and adaptation, working together to using existing resources to meet the needs of community members with ASD.</p> <p>The authors concluded that decisions about ASD service delivery and support advancement need to reflect the need, uniqueness, and diversity inherent in each community including residents, culture, and priorities.</p> <p>Participants described insufficient services in their rural communities as well as feelings of isolation and distance from resources. However, protective factors such as a "sense of community" and relational engagement with community members were also identified by participants.</p>	<p>Consistent with participatory action research principles, emerging local knowledge was supported with strategies for improved autism spectrum disorder service development.</p>
Zeidan et al., (2019)	Peer-reviewed journal article (comprehensive review and thematic analysis)	To determine recent advances, challenges and gaps in the planning and delivery of provincial autism services in Quebec.	Autism policy	22 autism-related policy documents issued by the Quebec government between 2010 and 2018	<p>Comprehensive search of autism-related policies and guidelines issued by the Quebec government between 2010 and 2018</p> <p>Search strategy not reported.</p>	<p><b>Barriers to person-centred and coordinated care</b></p> <p>Inadequacy of existing services in meeting diverse needs of autistic children and their families.</p> <p>Lack of services tailored to specific subgroups (e.g., autistic people with other co-occurring mental health concerns)</p>	N/A

					<p>Thematic analysis of Quebec autism policy documents in relation to the United Nations Convention on the Rights of Persons with Disabilities and the social determinants of health specific to Canadians using Evidence for Policy and Practice Information and Co-ordinating centre approach</p>	<p>Specific needs of Aboriginal people with autism not addressed in current autism-related policies in Quebec.</p> <p>While some social determinants of Canadian health (i.e., the non-medical factors that influence health outcomes such as education and income), are extensively addressed in public autism policies in Quebec, others like Aboriginal status, race, education, and unemployment are especially underrepresented.</p> <p>Review of autism-related policies in Quebec suggests that many services are still characterized by a 'one size fits all approach', instead of being tailored on individual and unique needs and preferences of each person/family. Further, policies do not consider relevant social determinants of health such as Indigenous status.</p>	
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## Appendix D.

### Examples of family and service provider perspectives

Topic Subtopic/Discussion point	Comments
<b>Beliefs about autism</b>	
Acceptance of differences	<p>"As I've understood it, any child that was born into a First Nations family you just always accept them no matter what, how they come at you. That's just their way and they'll develop into their own person." (Wright et al., 2005, p. 40)</p> <p>"To have been born imperfect is a sign of specialness. Differences are not a terrible thing or a hurtful thing, it means that a child's soul is in touch with the Creator." (Woodgate, 2013, p. 3)</p> <p>"I don't want people to see him as abnormal. I want them just, like, want them to accept him as much as I do, and I know that's the difficulty we really all face. It's like, because what is normal? And like, I think in our communities, I think my ideal First Nation ideation is that we are loving and accepting of our children in that manner, and that we embrace the differences. Because we believe the creator has gifted every child from birth, from the time of creating them in the womb, so, you know, I embrace that." (Wright et al., 2005, p. 40)</p> <p>"It is common in Indigenous communities for folks to be accepting of children with differences. Among our people, [my autistic son] is accepted as part of the whole and for who he is." (Sterling-Collins, 2009, p. 83)</p>
Child as a gift	<p>"Your son has a spiritual gift were the words of a spiritual Elder soon after my son was diagnosed with autism" (Sterling-Collins, 2009, p.66)</p> <p>"He has so much to give, the little guy, I have learned so much from him and his special gift." (Clouston, 2007, p. 183)</p>

Topic Subtopic/Discussion point	Comments
	<p>"We are fortunate that the Creator chose us to have these special kids, because I sure learned lots. I learned to slow down. I learned not to judge people ...We need them. I need them.... These guys changed my life. They changed my life. They 're teachers." (Clouston, 2007, p. 314)</p>
Purpose and learning	<p>"He's just a happy 14-year-old boy who doesn't come across as fourteen but he makes you have a sense of purpose. He makes you feel happy, you just, love him and he's good to be around and he's just...I'm just happy he is in my life and I think he's here to teach everyone patience and just maybe stop and to just give more care and time and...I think he teaches everyone a little more about themselves." (Woodgate, 2013, p. 7)</p> <p>"I understand my responsibility and I'm not bitter about it. Yes, he has extra challenges but those challenges have come to me for a reason. I needed to learn and he helped me with that" (Clouston, 2007,p. 152)1</p>
Holistic view of disability	<p>"I believe that without connection to our heart and emotions, it is far too easy for folks to intellectualize about special needs without fully grasping the impacts of autism on children and families. The philosophy of the medicine wheel has helped me to understand and connect to the spiritual component of [my son's] development." (Sterling-Collins, 2009, p. 71)</p>
Distrust of medical labels	<p>"People have this idea that labeling stigmatizes kids and makes other people look down on them or treat them with contempt or whatever. And that's what they're afraid of when they're labeling. " (Wright et al. p.41)</p> <p>"I know one mom whose son is like thirteen and they were in the process of getting a diagnosis, but they kind of didn't want it. They didn't want to have him labelled." (Woodgate, 2013, p. 13)</p> <p>"Something else that I've come across is in regards to labeling and getting assessment done, is parents' fears around taking the child to have an assessment done and that child being labeled." (Wright et al., 2005, p. 42)</p> <p>"Let's put it this way: special needs is a white term. That's your term. Special needs, if I remember correctly, are taken care of our own way, our own herbal medicines whether they worked fully or not." (Wright et al., 2005, p. 37)</p>
Focus on strengths	<p>"ASD children remember. They 've got this mind. When we go grocery shopping, I don't need to take a list." (Clouston, 2007, p. 321)</p>

Topic Subtopic/Discussion point	Comments
	<p>"They might not seem social but they have a special sensitivity. They have a natural understanding of others; they can be gentle, soothing, and calming." (Clouston, 2007, p. 324)</p> <p>"With respect and encouragement, a child adapts in his/her own way to challenges. The child develops the inner strength to meet the difficulty of others' not seeing his/her value." (Clouston, 2007, p. 330)</p>
<b>Sources of stress/challenge</b>	
Toll of service gaps on family well-being	<p>"The plight of families caring for children with disabilities had to be addressed. And this gap in service provision in this particular area, particularly in First Nations communities has become a major social issue. Most families have been forced to move from their community to urban centers where services are available and accessible. For those families who remain on the reserve they endure a hefty emotional and health toll by caring for their child or children by themselves without any adequate supports." (Wright et al., p. 39)</p> <p>"My child with autism takes up so much energy. You're fighting these different systems that are supposed to be there to help you. You're trying to work all these extra hours to do some type of therapy or intervention. You never go to bed at night, ever, thinking, I did enough today." (Shepherd &amp; Waddell, 2015, 3555)</p>
Caregiver stress/burnout	<p>"There were many times that [my husband and I] - got into heated arguments, fights; we drank because we didn't understand. We didn't know how to cope.... So ... we would drink just to ... hide our problems. It was very hard. It was very emotional ... because of the lack of services on the First Nation reserve. That's what it all boiled down to." (Clouston, 2007, p. 200)</p> <p>"By this time, my son was over four years old and we still didn't have a diagnosis. My husband I were exhausted and deeply stressed. We needed supports and services." (Sterling-Collins, 2009, p. 66)</p>
Blame/Stigma	<p>"When I take my grandson out, he sometimes acts inappropriately; for example, he wants to touch the nylon stockings of women in the street or in malls. H also acts out, like screams, and I feel like people blame me. I sometimes wish I could carry a sign saying 'he has autism' to alert others so I don't have to explain so much to people." (Clouston, 2007, p. 181).</p>
Service relocation	<p>"It was tough but we did what we had to do to get the support we needed, For us, that meant we had to move to Winnipeg." (Vives &amp; Sinha, 2019, p. 7)</p>

Topic Subtopic/Discussion point	Comments
	<p>"The decision to move from a rural community was hard. I was fighting with the decision to for a long time. It was getting so heavy, and I know the services in the city were well-equipped to care for children with developmental disabilities like hers. You cannot imagine how painful this decision was to make. I had a lot of positive feedback from doctors, service providers and other caregivers, so we moved to Winnipeg. I also took into consideration the needs of my other children. I didn't want them to think that living on Income Security (welfare) was the way of life." (Clouston, 2007, p. 201)</p> <p>"If you were in city or are living in the city then you would get the resources right away in place, so it's veery hard for a lot of families, they have to relocate because it's not available in their own communities." (Woodgate, 2013, p. 13)</p>
Social exclusion/ isolation	<p>"I have one little boy who he has Asperger's and he played hockey all his life until now and he's, he's thirteen and he just couldn't take the social part of it anymore and getting ostracized all the time. A lot of the kids won't go near him." (Woodgate, 2013, p. 15)</p> <p>"There are many in this community who are affected by ASD but who are not here [at a capacity building meeting] because of social isolation, physical isolation, or difficulties finding childcare or inability to get off of work?" (Young et al., 2019, 1148)</p>
Intense parenting	<p>"I have someone that I have to look after and give my attention to all the time....If she were normal like maybe things would have been different. I wouldn't have to worry about somebody looking after her." (Woodgate, 2013, p. 7)</p> <p>"That's the tiring part. You have to keep repeating your story. To make others understand. Over and over again. And you just want to choke them! 'You [teachers] went to University! You 're the one who should know.'" (Clouston, 2007, p. 321)</p> <p>"And you know having somebody that needs a child to be looked after 24 hours is a lot of work, and like there's emotionally, mentally, physically, you know all the, spiritually, all these areas get affected because there's no time that you can put into your own self when you live with a child, when you have a child that has a disability like autism. It's like that child has to have all the attention. " (Woodgate, 2013, p. 14)</p>



Topic Subtopic/Discussion point	Comments
Perceived judgement	"I feel like I am always being judged. They always say that 'you are not being judged or not judging you, we're just trying to help you understand how your daughter learns and what, how she'... Maybe if they would say 'we're concerned or do you know that your daughter has some disabilities...' It makes me feel like they think I abused [my daughter], like I hit her and I beat her up and all that and I haven't." (Woodgate, 2013, p. 8)
Missing out on valued activities (reduced community participation)	"We enjoy boating and camping but to date we haven't taken my son in the boat. I don't know that he would be able to sit and be comfortable and not agitated for any period of time, and to think about taking him out on the boat and then have him become agitated. That would be, it would be too much, he'd put everyone else at risk." (Woodgate, 2013, p. 9)
Feeling like an outsider	<p>"When I look at this picture [of my childhood hockey team] I think you know this is where I wish my son was right now. This is what I, I wanted for him. You know to have that, that camaraderie. And to have a team, to have friends, to be a part of something. And I don't think he feels that". (Woodgate, 2013, p. 11)</p> <p>"You know sometimes I say to them [the teachers] maybe my kid is getting upset because she has to get taken out of the room to get extra help and it does make her upset right, like she wants to play and be with her friends and her other friends don't have to do it." (Woodgate, 2013, p. 11)</p>
Intersection with child welfare system	<p>"What happens is systemically when the parents aren't getting the support they need, it gets worse for the children and then it gets worse for them. We get the cycle going. Very often kids are put into voluntary placement simply to access services and that's really sad, you know." (Wright et al., 2005, p. 45)</p> <p>"I felt like we had to take kids into care to provide services for. Not just for people who are disabled, medically complex needs but also social needs, like, uh, for treatment for autism and all that. "(Wright et al., 2005, p. 54)</p> <p>"I think also the parents are disempowered, huge to think you have a special needs child, and you want the best for that child and yet are incapable. Yes, we are incapable because the funding isn't there and so you have to give a child to somebody else to look after... The parent feels inadequate. The child is taken out of the home. The child doesn't feel good. The whole family's affected because they have a failure, right, and that permeates the whole community." (Wright et al., 2005, p. 55)</p>

Topic Subtopic/Discussion point	Comments
	<p>"Some parents with severely affected children need to give them up to foster care so the kids can attend school in Calgary. If you have very complex children and the family is not able to move into the city, for a variety of reasons, the children need to be placed in foster care. Over the years I've seen several children from reserve who needed to be placed here in ongoing care so they have access to special needs school, physio, occupational therapy, and better care." (Di Pietro &amp; Illes, 2016, p. 248)</p>
Intergenerational trauma	<p>"My husband was damaged by the residential schools. He has to deal with the memories on a regular basis. Add that to caring for our son. It can be a lot". (Clouston, 331, p. 331)</p> <p>"If us parents aren't using services or following through well you have to think what's the barrier that's keeping them from getting there. There are things mainstreams take for granted that you know parents can be self-sufficient and independent and do all these things but you know for our people it's not that easy, it's just not, its life skills that a lot of us just don't have [because of our historical experiences]". (Woodgate, 2013, p. 12)</p>
<b>Diagnostic pathways/experiences</b>	
Recognizing atypical development	<p>"The people at the babysitting service at the [childcare program] noticed that he was behaving strange . . . well, not strangely, but he would just go and play with toys, and that's all he would do, never interact although she wanted to. " (Hiebert-Murphy et al., 2008, p. 426)</p> <p>"Well I did think something might be different, but everyone like [her husband's] mom kept saying 'oh well it'll come.' [Her husband] took a while before he would [agree with me] and I keep thinking if there's something I can do, I want to do it now." (Hiebert-Murphy et al., 2008, p. 426)</p>
Wait times	<p>"Even though we knew something was different about him it was difficult to get a referral to a specialist because a psychologist would only come to the school, maybe, once a year..... Once we got a referral we had to wait six months to get an appointment, and then travel five hours to an appointment in the city " (Clouston. p. 197)</p>
Seeing multiple professionals	<p>"We had to see 2 or 3, maybe 4 professionals until someone finally listened to our concerns." (Clouston, 2007, p. 198)</p>

Topic Subtopic/Discussion point	Comments
	<p>"It's kinda frustrating when you know you're right, you figure you're right, and it turns out you're right, and nobody's gonna listen to you. But unfortunately that's . . . I don't blame [the doctor] directly, and I don't blame anybody in the hospital. Um, that's their job; they know it, and if someone tried to tell me my job in that same mannerism, I would be upset, too. But most of the time, I have to admit, I was right, and I guess that's what made it frustrating." (Hiebert-Murphy et al., 2008, p. 426)</p>
Rushed consultations	<p>"How can they know that he has autism after only 30 minutes?" (Clouston, 2007, p. 221)</p>
Coping with a diagnosis	<p>"This diagnosis was hurtful because we believed that his capacity to learn was greater than was suggested by the diagnosis of autism." (Clouston, 2007, p. 198)</p> <p>"I felt a certain relief to finally get a diagnosis, but at the same time, I was also devastated. I had no idea the level of grief that a parent could feel when their child is confirmed to have autism by a medical specialist. It took me months to process my grief. I cried a lot. I tried to negotiate with the creator. I blamed myself. I was angry and hurt. Despite my grief, I made an agreement with myself that I would not let my grief consume me and that I would continue to fight for services for [my son]." (Sterling-Collins, 2009, p. 69)</p>
Benefits of diagnosis	<p>"Funding was available for the services we needed because he had an autism diagnosis." (Clouston, 2007, p. 196)</p> <p>"We finally had an answer. It really helped us understand what was happening for him." (Lindblom, 2021, p. 82)</p>
Limited knowledge of autism	<p>"They had to send him to a specialist. And that's when a bunch lot of doctors sitting around, and the ... social workers. And that's when they told me [he had] autism. I didn't ask them "what is that - what is autism?" I just ... I couldn't even understand.... I couldn't understand then; I just heard ... I saw lips moving; I just sat in shock, I guess. But, I finally knew; I didn't know why he was screaming like that." (Clouston, 2007, 179)</p> <p>"Getting the diagnosis meant absolutely nothing to me, I didn't know what autism even meant, but that began my quest to understand as much as I could to help him." (Shepherd &amp; Waddell, 2015, p. 3554)</p>
<b>Sources of support</b>	
Community connection/commitment	<p>"The strongest things about Aboriginal people is our support systems. I don't think we could cope without them." (Woodgate, 2013, p. 12)</p>

Topic Subtopic/Discussion point	Comments
	<p>"We need to lean on each other; we have all been there or will be there. "(Young et al., 2019, p. 1149)</p> <p>"The role of Elders you know . . . it's the backbone of the community. The traditional knowledge holders and the um respect and the deference that is given to them, and the kids learn all of this stuff just by being in the community." (Linblom, 2017a, p. 206)</p>
Strength and resiliency of Indigenous communities	<p>"They're our kids and we're going to support them, find a way to meet their needs one way or another. I've worked in group treatment centres and in prisons, and who do you think end up there?... We know these children [with developmental disabilities] will be disproportionately represented in the institutions. If we can intervene with some private programs, and I feel that we can, Aboriginal agencies can. Aboriginal communities can and have got a really rich history of including special children. I think that can happen. There's also a lot of hope, and I see hope growing. I'm really, I want us not to lose sight of that. Yes there's a huge issue and yes there's a whole bunch of things that need to be done, but we're doing a lot." (Wright et al., 2005, p. 58)</p> <p>"Despite the challenges, I am amazed at the strength and resiliency of families and communities. Families, service providers, and communities do their best to work with children with special needs (including autism) being inclusive and supportive to children and families as much as possible. This is often done with little funding and resources. The reality is that in many Aboriginal communities, the staff of community service programs provide the primary support system for families because of the lack of specialized resources." (Sterling-Collins, 2009, p. 83)</p>
Connection to the autism community	<p>"It was comforting and enlightening to listen to other parents who were experiencing the same struggle as us. There were times when I felt completely alone and isolated. Learning that other parents shared the same struggles helped me to keep moving forward." (Sterling-Collins, 2009, p. 68)</p>
Extended family	<p>"We got so much help from our own family. They understood. They understood. They helped us. We could not have raised him for all these years without them. They'd babysit for us. They knew how [my son] was and they'd come and keep him. I'd never say enough thanks to my nephews ... my daughter.... It was very hard" (Clouston, 2007, p. 198)</p>

Topic Subtopic/Discussion point	Comments
	<p>“So that example is um primarily in our communities because of the way we were raised. And how we look after one another. And when we define, or when we see a disability, no matter what the area, whether it be a limb, speech, um deaf, autism, whatever, we don't label that person in the community. They're just known to have what they have and we accept it and help them as much as we can. When you mention three or four generations being involved, it's because um they've been taught to look after their family members, you know, first. Nurturing, caring and remember what our parents told us and how they raised us too.” (Linblom, 2017a, p. 206)</p> <p>“We were in 'survival'. We had immediate family to help us. Those are the ones we followed We followed them and they followed us. I have a lot of my family here now. Many 'relocated' here. There's such a lot of us.” (Clouston, 2007, p. 320)</p> <p>“We (my family) all make the main caregiver . . . Chip in, take turns.” (Lindblom, 2017b, p. 275)</p>
Traditional/spiritual practices and beliefs	<p>“I am grateful for the Creator for putting me in touch with spiritual side. Practicing my faith was a lifeline in the early years. I was reminded I had a special son and I needed to do what was best for him, despite the challenges he would face.” (Sterling-Collins, 2009, p. 69)</p> <p>“When [autistic daughter] participates in our ceremonies, well it gives her a place to be proud.” (Lindblom, 2017b, p. 278)</p> <p>“She likes going out in the bush with her dad sometimes, she just really likes going up there, it helps her calm down I guess.” (Woodgate, 2013, p. 11)</p> <p>“I know there are spirits around us and they help us, they guide us. I've dreamt of [adopted children 's] grandmother. I believe in dreams. The Creator wants the best for us. I love my boys. I respect all children I respect all people because I got to know myself. How I feel is how you all feel. Life is a journey. We 're here on a journey, we 're here to learn, we 're here to meet one another. To enjoy our lives together as best we can.” (Clouston, 2007, p. 315)</p> <p>“And I've noticed what mainly makes him normal is the native drums...Cause every time he hears them</p>

Topic Subtopic/Discussion point	Comments
	<p>he normally just sits and he's just quite normal actually...because there's quite a few songs from the native ones that he likes...And I've noticed this one called Hello mother that he seems to know very well because he could drum it himself...A song like that from the natives takes years to learn and my uncle who is an Elder with a big name, he sang it to [autistic son] before and he learnt it in one session." (Lindblom, 2021, p. 14)</p> <p>"Native spirituality is powerful. Don't mess with it. Spirit They tried to take it away. They tried... Spirit is number one. Connect with your spirit and you can get through anything." (Clouston, 2007, p. 316)</p>
Indigenous values and worldviews	<p>"Caregivers respect their own values and worldview. In attempting to deal with the many challenges of their children who suffered from developmental disabilities (including autism), caregivers were deeply conscious of their own commitment, and recognized their own strengths and commitment. Within their value system, not caring for children was not an option." (Clouston, 2007, p. 330)</p>
Parents as advocates	<p>"We knocked on a lot of doors back home. Just to get the help we needed". (Clouston, 2007, p. 198)</p> <p>"We have to be the voices of our children. If we don't fight for them, no one will." (Clouston, 2007, p. 75)</p> <p>"I told my husband, 'To hell with them. We don't need them. We've lasted this long with [my son].... They're not apprehending my son - he's not an animal ...So that was it! Forget about that! So I started advocating on his behalf to Indian Affairs because I knew there was funding available there.... I know there is.... I made a presentation to [education authorities] ... it hurt us so emotionally because we ... felt like we were inside something but we couldn't get out. We didn't know what to do...." (Clouston, 2007, p. 198)</p> <p>"My phone bill was high. When the computers came in, I started looking for information on the internet. I got some from that. That's the thing. You try to find as many resources as you can on your own. You have to do the 'walking'. Nobody's going to do it for you. Their doors are open from 9:00 o'clock to 3:30 (on the reserve) and that's it. The education system... on both sides of the community they had services like speech and language, but we couldn't access that. People living only a mile away, and they had all the services that we had to fight for." (Clouston, 2007, p. 318)</p>

Topic Subtopic/Discussion point	Comments
	"Advocacy is important. I give permission to people not to 'like' me. A parent needs to be strong to advocate for the child." (Clouston, 2007, p. 320)
Holistic approach	<p>"A holistic perspective supports [my son's] overall development; his strengths can be utilized to assist in the areas that need support. Using an Indigenous perspective (mind, body, spirit) feels like the most fitting and respectful way to meet [my son's] needs". (Sterling-Collins, 2009, p. 72)</p> <p>"To fully help us, to give the support, we need, supports and services need to take into consideration all aspects of the person with the disability. Their mind, body, spirit, their connection to the land. The health of their family and their community." (Woodgate, 2013, p. 17)</p>
Parent resilience	<p>"I've always been the sole provider of my family. I was Mother and Father to all my children. I have always tried to provide a safe and loving home. I could not see myself planning them in jeopardy [moving in with their father for extra support]. I was too used to being a single parent and caring for my daughter on my own. I was self-reliant, and that's the only way I knew how to get things done. Sharing a household was out of the question. Even though it meant [my daughter] would have both parents to love and care for her. I have faced many hardships in my life. I was in [residential school] also, and that put a lot of loneliness in my younger years. But, I found that with each hardship that I faced, it made me stronger for the next one. I may have been preparing myself for caring for my daughter." (Clouston, 2007, p. 203)</p> <p>"Forget about racism. Or hatred Or whatever. We 're strong. We are [Cree word, I think Anishnabe] or whatever you want to call us. We 're home; we 're God's people. We 've seen it all. They 've brought it right here. Right in front of our faces. Sometimes I do have to sit up at night and cry a lot." (Clouston, 2007, p. 317)</p>
Sense of family & community responsibility	"I have met parents of children with special needs (including autism) who don't have access to specialized services or therapists, have no respite services and don't have a full understanding of their child's disability or disorder. However, what they do have is a sense of family and community responsibility, cultural and traditional values and unconditional love for their children." (Sterling-Collins, 2009, p. 83)
Access to intervention	"I'm hoping that with my oldest boy, intervention is going to provide him with the ability to eventually live independently and support himself, and if he can do that, we'll be delighted. Now my youngest son, no, he's going to need supervised, supported care all of his life. He has a 40-hour-a-week

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	intensive program, he's making huge gains, but he still has no cognitive understanding of danger, he has a lot of echolalic language, most people don't understand what he's saying. But he can dress himself, he ties his shoes, he can use the toilet. That's what intervention has done for him. Without intervention, he'd still be in a diaper." (Shepherd & Waddell, 2015, p. 3555)
Hope for the future	"I don't know I guess my wish for her is to live a healthy life and not be ashamed of who she is." (Woodgate et al., 2013, p. 15)
<b>Barriers to diagnosis and support services</b>	
Differences in how Indigenous communities define and interpret disabilities	<p>"And then you have to define what you consider a significant disability...or is this just normal for our community here? Because if the kid is not reading at grade 6, in our society that would be a major disability, learning disability, while there it is not a big deal...if you go to the schools, they are totally overwhelmed with some of the needs there and they don't get enough funding for the interventions. There is a total lack of awareness." (Di Pietro &amp; Illes, 2016, p. 245)</p> <p>"We didn't know what to compare him to. We thought he was the most wonderful kid and everything like that. We sensed something was off, but we just thought he was wonderful. Our pediatrician sent us to a developmental clinic and they decided he was special needs [autistic], we didn't decide that." (Hiebert-Murphy et al., 2008, p. 426)</p> <p>"In the terms of you know traditional First Nations, um is, a lot of times communities wasn't built on a deficit model . . . There's a view of people who are a part of the community everyone has a role and education happens organically within a family. Uh, you go hunting, fishing, trapping. All the traditional activities were done with the people you had." (Lindblom, 2017, p. 206)</p>
Jurisdictional issues	"I asked for information [from local Regional Health Authority] .... They send you to ... different agencies ... they don't want to do [anything] for you. And, as soon as they hear that you're from a First Nation reserve [they say], 'No, can't help you. Sorry. We can't help you because you're living on a reserve.' That's where the boundary cuts off a lot of the services." (Clouston, 2007, p. 200)



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	<p>"I am not really ok with it. We have to go into our [community] monies to provide services that government agencies should be responsible for... Why do we have to go to our resources to provide a program [for children with disabilities] like that? It should be there from governments to provide that service. They could build and provide it like in an urban centre... Because we're federal, responsibility would be federal. But then again, the province as well should take into account... but they always have a jurisdictional BS, the boundary line, you know. Somebody else is responsible... And it shouldn't occur because we're supposed to be helping the people in our community but what we see is these jurisdictional issues instead of providing what the people require. (Wright et al., 2005, p. 52-53)</p> <p>"The biggest challenge is the jurisdictional issue. I think that there are many organizations and governments...forget that there is a provincial, territorial and federal jurisdictions here. Equal access to services is a great idea but it isn't really a reality here." (Scott et al., 2021, 64)</p>
Deficit approach of service providers	<p>"Parents try so hard to be positive, but when you talk to professionals, I feel everything is negative, like your dreams go down the toilet every time you go to the doctor's office." (Young et al., 2019, p. 1148)</p> <p>"For once it would be nice if we didn't just talk about all the things he can't do. Why can't they focus on his strengths?" (Wright et al., 2005, p. 57)</p> <p>"Are you really saying you'd like to eradicate autism? What does 'cure' mean? Is that the end of the quirky wonderful gifts that autistic individuals have given to society?" (Shepherd &amp; Waddell, 2015, p. 3555)</p>
Mistrust of Western systems	<p>"They are so reluctant to speak up. This is the problem. You need somebody who is courageous enough, to stand out as an advocate and say 'I'm a parent of an autistic child and I'm living on reserve and that is the situation here'..." (Di Pietro &amp; Illes, 2016, p. 246)</p> <p>"They do not have trust and why should they? I think that there is a need to make sure that whatever we do brings Aboriginal People along with us, which is a very hard thing because of trust and colonialism." (Di Pietro &amp; Illes, 2016, p. 246)</p>
Largely non-Indigenous service providers	<p>"When I'm talking to a non-Aboriginal medical professional, I'm afraid I might ask the wrong questions and not receive the proper help." (Clouston, 2007, p. 205)</p>

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	<p>“Trust is always going to be an issue, especially when you are asking families to hand over their children to non-Indigenous service providers. Children, to this day, are still being stolen away from families by government agencies. Look at all the kids who are placed in foster care every year.” (Di Pietro &amp; Illes, 2016, p. 246)</p>
Lack of services on reserve	<p>“She is able to access programs over there that she can’t on the reserve . . . After finding out from the school on the reserve that they wouldn’t be able to offer her any kind of special programming because of funding right I said, Okay. So I put her in school off reserve and then they had all kinds of programming for her . . . They have different levels of funding for different levels of disabilities with kids, and my daughter was a level 3, which is the highest needs. So she was fully funded, her [educational assistant] was fully funded just for her and her programming. You don’t get that on reserve.” (Vives &amp; Sinha, 2019, p. 8)</p> <p>“The government needs to step up! When are they going to bring the resources we need to our reserves, to improve the lives of our children? When is the funding going to come our ways? When will the resources come to my community? When am I going stop leaving my reserve for better services?” (Woodgate, 2013, p. 11)</p>
Culturally inappropriate services	<p>“The Supported Child Development Program (universal provincial program for special needs children) is not culturally relevant or family-focused, which posed a challenge to us and other Aboriginal families.” (Sterling-Collins, 2009, p. 67)</p> <p>“And that’s kind of what I mean by culturally appropriate for service delivery because I know for a lot of our people, there are circles out there, there are support services for children like mine, but um most people won’t access them because they come into a room and they are the only brown face they don’t know how to cope with that, so they don’t come back.” (Woodgate, 2013, p. 12)</p> <p>“It is very difficult to get respite; my child has specific needs and you have to be able to trust the person coming into your home. And we face big challenges with conflicts of interest because qualified respite providers are limited; the people with skills to care for [my child] are my family as well so it’s considered a conflict of interest if they were to provide respite and therefore they cannot help.” (Young et al., 2019, p. 1147)</p>

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Parental capacity	<p>"I think there's a gap in supports that way and yes, we want mothers and children and fathers even to become involved in the assessment, diagnosis, and care of a child with a disability. But if you think about the capacity of perhaps a single mother to do that or the capacity of a family to navigate those challenges or just deal with day to day life enough ... that a person has to cope with that anything added on top of that, it's just too much." (Di Pietro &amp; Illes, 2016, p. 247)</p>
Geographic remoteness	<p>"You're isolated by miles, but you're also isolated in other ways ... you don't have resources outside the four walls of your living situation ..." (Young et al., 2019, p. 1147)</p> <p>"The population is small here so there are less children with ASD, so the parent has to be expert because (the) school is not expert. It also means there is a big gap in the classrooms since the last time expertise was needed for a child with ASD, there may be a few years since the last child with ASD was in that grade." (Young et al., 2019, p. 1147)</p>
Insufficient government funding for Indigenous organizations	<p>"This is why we are using community funds - government has cut these services for the north. Communities have had to pick up the costs for children with special needs". (Wright et al., 2005, p. 27)</p> <p>"It's easy for Health Canada to say, well we don't have a problem. We don't have that many children. It's cause it's never been identified. But they conclude we don't need the funding cause there's no numbers. Well if you don't generate the numbers cause you don't put any assessments in the communities, it's pretty easy to justify the expenditures... But it is that kind of thinking that is a big frustration for the parents and caregivers of these children." (Wright et al., 2005, p. 52)</p> <p>"As far as autism and cerebral palsy, I haven't seen any evidence that would say there is from a health policy perspective a need to get involved. " (Di Pietro &amp; Illes, 2016, p. 248)</p> <p>"I feel I'm playing with people's livelihoods here. If the funding is not renewed, how will my [Indigenous allied health worker] provide for her family? Where is she going to go? And what am I going to tell her?" (Vives &amp; Sinha, 2019, p. 17)</p>

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Inadequate school resources	<p>"There are a high number of children with identified developmental issues who need one on one support. Our schools in area not equipped to successfully work with these children. Instead, they (my impression) is that they continue "passing" them into next grade. End result: Student graduates but is not ready for University. They need to go back to upgrade or get discouraged and do not try to further education." (Wright et al., 2005, p. 31)</p> <p>"We don't have any special places for [autistic child with cognitive impairments] to go or any specialized person to help him. You have a child that comes in and you tell them "Okay, don't go there, don't do that." The next minute he forgets. They're just put in the classroom, we were told, inclusion, not to separate them . . . and that's a challenge for the teacher at our community school." (Vives &amp; Sinha, 2019, p. 8)</p>
Influence of racism	<p>"There is racism in the north, and a lot of families can't speak up for themselves when they receive shabby treatment. Services are contracted out, people who provide these services don't treat Aboriginal families right. Racism is a factor." (Wright et al., 2005, p. 33)</p> <p>"[In Ashern] they didn't want nothing to do with [my son]. They used to make us wait in the waiting room and then finally said, "Okay, now you have to go to Winnipeg." So why waste two, three hours when we can be in Winnipeg in two or three hours? (Vives &amp; Sinha, 2019, p. 7)</p>
Limited access to early diagnosis and intervention services	<p>"There's a struggle just around the availability of services starting with assessments being able to, the children being able to access appropriate assessment, you know, to diagnose what the issue is. I mean that's a challenge. There's, once it's identified, to be able to offer regular and frequent services, whether it's OT, speech, psychology. I think the community relative to other communities does fairly well, but as you can see, there's huge gaps in terms of frequency and intensity of service." (Wright et al., 2005, p. 48)</p>
Lack of service continuity	<p>"That whole area of once a child leaves school, whether they're sixteen or eighteen or twenty-one, there has to be something in the community that takes over the role of the school in making sure that kids with handicaps and disabilities are able to participate in the community still." (Wright et al., 2005, p. 49)</p> <p>"When I die, what happens to my child, especially if services are not available in our community?" (Young et al., 2019, p. 1148)</p>

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Overly medically focused support	<p>"Why should he be on drugs because others treat him badly? Who has the problem?" (Clouston, 2007, p. 250)</p> <p>"The school keeps pushing medication. So does the psychiatrist. He doesn't need medication at home. They probably want him to have it so that he is easier to manage". (Clouston, 2007, p. 331)</p>
Inadequate individual level funding	<p>"We're told we need to do something, we need to do it very intensively, and we need to do it soon. So parents are left with a real vulnerability. Maybe they've been told that, say, ABA is the way to go, because that one's got the most science behind it. So there's this incredible burden. Here's this diagnosis. I'm not going to get government help. I'm told this is what I ought to do. It's 40 to 60 to 80 thousand dollars a year. But if I don't do it, I'm somehow depriving my child." (Shepherd &amp; Waddell, 2015, p. 3554)</p>
Service pathway complexity	<p>"In my journey with [autistic son], I have learned to navigate the system to access services and supports although there have been many hurdles and limitations. I have found the process very frustrating and time-consuming," (Sterling-Collins, 2009, p. 84)</p> <p>"We are relatively close to a big center and I try to send any kids for diagnosis at [name withheld] Hospital. Even to get the diagnosis there are so many barriers about bureaucratic forms that have to be filled out and, and stuff like that. It's very, very hard and a lot of developmental services are stretched as it is, so parents don't show up or fill in the forms.... Quite often the government says: 'Oh, but we need that speech assessment, an OT [occupational therapist] assessment,' and all this kind of stuff –otherwise we don't give the funding because it's not a complete assessment. Right, so we are waiting for over a year and then the parents forget about it or appointments and they have to fill in some very complex questionnaires. Sometimes, they don't even know the language. You know? They don't understand what all the questions are. And so they would need somebody to help them to fill in the questionnaires and send them in. In the meantime, they've moved a couple of times and their phone is disconnected...! So there are some very practical barriers to get a diagnosis. (Di Pietro &amp; Illes, 2016, p. 248)</p>

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	<p>“There are lots of kids in those communities that are not diagnosed and the parents don’t have the resources to get them a diagnosis and the care that they need. ... So there is a referral clinic that they can go to, which is about an hour away, and will provide some services for assessment. So the next step would be now they got their child to see the pediatrician, who only comes once every two weeks, and hopefully they can get to that clinic –somebody can give them a ride on that day- now when they see me, I fill in a form that goes to the clinic. [The clinic] will then mail this big package back to the caregiver. It’s huge this package! Like 30 pages long. Plus the school has to do an individual assessment of their IQ and their academic achievement. When they get the package back in [the clinic], then they will give the parents an appointment. So that is a huge hurdle for access to care and diagnosis. I would say that about in 5% of cases they get the information back that they need.” (Di Pietro &amp; Illes, 2016, p. 247)</p> <p>“There are so many [professionals]. Like if you look at his list from his assessment for school . . . and the list of people I think it’s a page and a half of doctors, psychologists, you know social workers . . . Half of them I don’t even know.” (Hiebert-Murphy et al., 2008, p. 429)</p> <p>“We’re tired, we’re battered, but it’s easier to do it by yourself, because battling the system, you’re done.” (Shepherd &amp; Waddell, 2015, p. 3556)</p>
Policy gaps	<p>“The policy changes and the programs (e.g., Jordan’s Principle) that have developed to meet our needs [Indigenous children with autism] were primarily the result of litigation and that’s not a really good way of developing policy. A lot of the problems we’ve had are because this wasn’t developed through policymakers sitting down and thinking about how they could work out a good program. This was the result of litigation.” (Shepherd &amp; Waddell, 2015, p. 3553)</p>
<b>Strategies to improve services</b>	
Indigenous support groups	<p>“So for us, we need our own support circles to feel safe in order for our voice to be heard and our own unique perspectives and issues because we don’t have the same problems and the same perspectives that mainstream people have, you know and that’s something that needs to be addressed.” (Woodgate., 2013, p. 12)</p>

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Incorporating traditional support systems	<p>"We need to encourage parents to utilize traditional and cultural support systems. If it is appropriate and the family is willing you could assist the family by setting up visits with Elders, spiritual leaders, cultural and traditional resource people and attending ceremonies or other cultural activities. Consider how cultural activities might be included directly into the child's programming and ask the family what they might like to see." (Sterling-Collins, 2009, p. 87)</p>
Address barriers to service utilization	<p>"It is essential that barriers of ethnic bias, discrimination and the impact of historical oppression are eliminated to ensure that First Nations and other aboriginal children with autism have the possibilities to reach their full potential and that their rights are recognized and respected." (Lindblom, 2017a, p. 203)</p> <p>"Assist families in accessing services and resources. The parents may not know how to begin to access services so assist them in the process by making phone calls and appointments, paperwork if they request, asking pertinent questions at medical appointments. You might attend the first sessions with a family until they are underway and feel comfortable in the system. Remember that it takes time to build trust and respect. " (Sterling-Collins, 2009, p. 85)</p>
Consider community contexts	<p>"What we must take into consideration in a lot of, uh, reserve communities is that unemployment is very high. The cost of living is high too. Something like buying pampers [for a child with a disability] could mean not eating for a week. That's what some people have to decide. So that's another reality that has to be taken into consideration is, uh, a lot of these families are on social assistance. And they just cannot make ends meet, you know." (Wright et al., 2005, p. 43)</p> <p>"And you can factor in also the housing situations and the poverty and the lack of jobs. Kind of the overall health of the community in a way and the mental well-being of the community. There's a long way to go cause if you have, uh, your adults in the community that are unhealthy and not doing well and, uh, there's, you know, sad stories for the kids, right?" (Wright et al., 2005, p. 43)</p> <p>"Every community, even parts of the community, is very different. You have to learn really fast. Have to be respectful. How to respond. And, uh, you have to know your resources, whatever's in that community. (Wright et al., 2005, p. 45)</p>
Hiring Indigenous service providers	<p>"Culturally based services are being provided as we are utilizing service providers that know the culture of the family". (Wright et al., 2005, p. 28)</p>

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	<p>“Aboriginal people, we understand each other. We don’t have to explain where we come from or all that. It’s just easier to have people who have the expertise to support you and also understand your culture.” (Clouston, 2007, p. 331)</p> <p>“I Asked for an Aboriginal worker because I feel more comfortable. I don’t have to worry.” (Clouston, 2007, p. 231)</p>
Holistic approach to services	<p>“We work from a holistic perspective, so it’s always families/communities driven.” (Wright et al., 2005, p. 28)</p> <p>“Work to develop the mind body, and spirit of the autistic child, their connection to the land and our family. That’s the only way they can thrive.” (Clouston, 2007, p. 87)</p> <p>“Assist the family in developing a holistic plan for child and family. This should include services in the four quadrants of the physical, emotional, intellectual, spiritual, and cultural. Involve other service providers who can provide services and supports for a coordinated approach. Ensure the services best meet the needs of the child and the family. For example, consider an outreach or home visiting approach to for services.” (Sterling-Collins, 2009, p. 85)</p>
Developing local community level supports & initiatives	<p>“We cannot expect families to leave their communities to go with the services. We need professionals who are licensed to medically diagnose (i.e., ASD) our children in our area and we need more community resources instead of having someone come in from out of town i.e., occupational therapist, child development counselor, etc.” (Wright et al., 2005, p. 30)</p> <p>“In community programming supports which could include things like respite services, even local events to allow children with autism to have some fun, local support, groups for parents, caregivers, and educational workshop opportunities that you know others in more urban destinations would have access to...” (Scott et al., 2021, p. 68)</p>
Supporting parents and extended family & community	<p>“We need to help parents deal with day-to-day issues. We need to address issues around employment, housing, mental health so that families have the capacity to care for their children safely at home.” (Wright et al., 2005, p. 31)</p>



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	<p>"I think it's important that while the child with the special needs is the focus, that you can't forget about the family members or community members that are supporting the family and the child. I think it's important that they have a safe place to go to where they feel it's not judgmental, where they feel welcome to come and be honest about the things that are happening at home." (Wright et al., 2005, p. 45)</p> <p>"Remember that there can be incredible stress places on parents, siblings, grandparents, and other extended family members. Everyone will be impacted by an autism diagnosis. Recognize that they may be overwhelmed, stressed, or grief-stricken. Assist in setting up a professional support system for the entire family. This may include counselling services." (Sterling-Collins, 2009, p. 84)</p>
Need for action	<p>"It seems like there's like research on Aboriginal communities and Aboriginal people. There like... we've been researched to the max probably. It's time to do something other than research. Like what do we do with our research, our findings? Like we know that there's kids out there... things need to happen. More action than reaction I guess." (Wright et al., 2005, p. 60)</p> <p>"As a civil society, we have a responsibility to care for children with disabilities and to watch out for them. Somebody has to start taking up the banner and fight. ... These kids are voiceless." (Di Pietro &amp; Illes, 2016, p. 249)</p> <p>"Most important to anything ... the conversations need to turn into action. And they need ...to turn into implementation plans ... It's not only to talk about it, but to also have a coordinated strategy of how to make it happen ... no matter how many of these conversations we have, if there's no movement towards getting this towards implementation you know we're going to be lost." (Scott et al., 2021, p. 70)</p>
Increase representation and connection	<p>"To improve services we need to be working with community organizations and specifically cultural liaison[s] to ensure that strategies that are being developed are actually culturally responsive ... [and] dedicating resources to create materials in different languages would help with awareness and outreach into these communities." (Scott et al., 2021, p. 68)</p>
Strength-based support	<p>"Services for disabilities in Indigenous communities needs to be more strength-based rather than deficit-based. Let's do this program that has the potential to really highlight what they can do, that has the potential to ensure that children have the best possible opportunities." (Di Pietro &amp; Illes, 2016, p. 248)</p>

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	<p>"Families need to be supported in celebrating the progress of the child no matter how small. Point out their strengths and be sure to share your joy in these strengths with the people who love you and him. These strengths can be used to support areas that need improving, and help the family realize their strength as a whole." (Sterling-Collins, 2009, p. 85)</p>
Government investment	<p>"But we have to understand ... anything we do is going to cost money ... autism is expensive and we need to have supportive governments. [T]he federal government is great but the provincial and territorial government is where things are going to happen. They have to be at the table, they have to be prepared to step up and that comes back again to who do we have in leadership positions and what is their priority of disability." (Scott et al., 2021, p. 69)</p>
Centering community priorities	<p>"Aboriginal communities are striving for self determination at all levels of community development. Aboriginal families with special needs (including autism) are not a new concept. We have always revered our "gifted ones" through time. Today, we are incorporating the traditional and cultural ways with contemporary services." (Sterling-Collins, 2009, p. 83)</p> <p>"What is the best support to put in place in terms of the educational system? ... what supports are needed for transitions to adulthood, and what works best and what is successful?... that evaluative piece I think is neglected .... I talked about needing research on sort of what interventions work. We want to make sure those interventions are also culturally appropriate and informed." (Di Pietro &amp; Illes, 2016, p. 248)</p> <p>"What do they want, not us deciding what they want... let's have a conversation and start with the person who we're thinking [about]... equity means all of us working together." (Scott et al., 2021, p. 69)</p>
Community-based research	<p>"It [disability] has to be recognized before it actually gets investigated .... I think the prevalence data would be important because that helps us to kind of tailor responses and interventions. There's quite a high percentage of Aboriginal kids with cerebral palsy and autism, but the research doesn't cover it. This is what's needed for change." (Di Pietro &amp; Illes, 2016, p. 248)</p> <p>"The lack of attention at least says there has to be some basic prevalence data collected and that we are falling short in that minimum area." (Di Pietro &amp; Illes, 2016, p. 248)</p>

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	<p>"Keep listening to the people and what we need for healing -instead of holding so tightly to protocols that were brought over here and enforced through colonization. Stop ignoring the needs of the people." (Merasty et al., 2021, p. 6)</p>