

# EXPLORING SOCIALLY-RESPONSIVE APPROACHES TO CHILDREN'S REHABILITATION WITH INDIGENOUS COMMUNITIES, FAMILIES, AND CHILDREN

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# CONTENTS



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1.0 INTRODUCTION	5
2.0 DIS/ABILITY AND REHABILITATION IN THE CONTEXT OF INDIGENOUS CHILDREN IN CANADA	7
2.1 The Diversity of Indigenous Families	7
2.2 The Invisibility of Indigenous Children with Disabilities	8
2.3 Different Perspectives on 'Dis/ability' & Rehabilitation	9
2.4 The Disabling Impacts of Colonization	11
3.0 EMERGING THEMES IN CHILDREN'S REHABILITATION WITH INDIGENOUS COMMUNITIES, FAMILIES, AND CHILDREN IN CANADA	15
3.1 Responding to Communities' Rights to Self-Determination	16
3.2 Learning from 'Community'	17
3.3 Focusing on Strengths and Well-being	18
3.4 Investing in Relationships	19
3.5 Making Space for Indigenous Knowledges and Languages	20
3.6 Using Assessments Cautiously	22
3.7 Reaching Rural and Northern Communities	23
4.0 CONCLUSION	26
4.1 Resources: Information ON, PT, and SLP in Canada	27
REFERENCES	28



*Working towards ensuring that Indigenous children have the opportunities, developmental and health trajectories, and quality of life and well-being across their life course equitable to children in the wider population in Canada requires a critical examination of children's rehabilitation.*

# 1.0 INTRODUCTION



Jordan River Anderson was a First Nations little boy from Norway House Cree Nation in northern Manitoba who was born with a rare muscular disorder that resulted in complex medical needs. After spending the first two years of his life in hospital, doctors decided that he could go home. However, the provincial and federal governments argued over who should pay for the care and resources Jordan needed to live at home. In 2005, Jordan passed away in hospital, having never spent a day of his life in his family home or community. In 2007, the House of Commons unanimously endorsed ‘Jordan’s Principle’ – a child first principle aimed at ending the racial discrimination of First Nations children by holding all levels of government accountable for the equitable treatment of all Indigenous<sup>1</sup> children, regardless of where they live (Canadian Human Rights Tribunal, 2016; Jordan’s Principle Working Group, 2015).

As a result of chronic underfunding and potentially remediable

administrative and jurisdictional funding confusions and disputes, many Indigenous children continue to be denied timely access to critical healthcare and social services equitable to the wider child population in Canada. The ongoing work by Indigenous leaders, organizations, and communities in Canada to ensure that the full intent of Jordan’s Principle is implemented for all Indigenous children, regardless of where they live, has drawn national and international attention to addressing Indigenous communities’ and families’ rights to equitable access to essential child health, rehabilitation, and social programs and services (Canadian Human Rights Tribunal, 2016; Canadian UNICEF Committee, 2009).

Working towards ensuring that Indigenous children have the opportunities, developmental and health trajectories, and quality of life and well-being across their life course equitable to children in the wider population in Canada requires

a critical examination of children’s rehabilitation.<sup>2</sup> Across Canada, the delivery of community-based children’s rehabilitation is primarily the domain of three distinct disciplines:<sup>3</sup> occupational therapy, speech-language pathology, and physiotherapy. A central premise of children’s rehabilitation is that due to the neural plasticity of infants’ brains, the earlier interventions for young children can start, the more beneficial they will be (Hadders-Algra, 2004; Hebbeler et al., 2007). In the wider population, children’s rehabilitation has been shown to be highly beneficial for optimizing the growth and development of children from birth to school-entry, who have, or are at risk for, developmental delays and disabilities (Landa, Holman, O’Neill, & Stuart, 2011; National Early Childhood Technical Assistance Center, 2011). Currently, there is a lack of literature on children’s rehabilitation with Indigenous communities, families and children in Canada.

<sup>1</sup> In this publication Indigenous is a broad and inclusive term that refers collectively to the original peoples of Canada and their descendants, including First Nations, Inuit and Métis peoples. Wherever possible, specific Indigenous groups are cited.

<sup>2</sup> In some parts of Canada, children’s rehabilitation is also called ‘early intervention therapy.’

<sup>3</sup> A definition of, and information on, these distinct disciplines is provided in section 5.1 Resources.

This publication is written for Indigenous communities and organizations, and children's rehabilitation stakeholders, including government funding agencies, who are questioning how to support the health and well-being of Indigenous children who have developmental challenges, disabilities,<sup>4</sup> and complex health conditions through the provision of community-based children's rehabilitation services and programs. The specific purpose of this publication is to:

- 1) explore the relevancy of the concepts of 'disability' and 'rehabilitation' within the settler-colonial context of Canada;
- 2) highlight emerging themes in the literature on rehabilitation with Indigenous children in Canada, and
- 3) identify current gaps in knowledge and areas for future research.

In order to augment the relative lack of literature currently published on this topic, the author<sup>5</sup> received ethical approval from the Research Ethics Board at the University of Northern British Columbia to undertake a small number of semi-structured interviews. In the Fall of 2016, the author circulated an email

with information about participating in a phone-call interview to various national organizations including the: National Association of Friendship Centres, First Nations Health Managers Association, First Nations Child & Family Caring Society of Canada (FNCFCFS), the Canadian Pediatric Society, and the three national associations that represent speech and language pathologists (SLPs), occupational therapists (OTs) and physiotherapists (PTs) in Canada. The National Collaborating Centre for Aboriginal Health and the FNCFCFS also posted this information on their Facebook pages. This recruitment strategy did not garner any response from national Indigenous organizations and, unfortunately, it was beyond the scope of the project to pursue further recruitment strategies.

This strategy was successful in recruiting a small group of interdisciplinary rehabilitation therapists as key informants: SLPs (n=5), OTs (n=5), and PTs (n=2), located in eight different provinces and territories across Canada.<sup>6</sup> The majority of therapists self-identified as Euro- or French Canadian. Only one therapist self-identified as having Indigenous ancestry.<sup>7</sup> Therapists had wide age ranges and varying years of experience, (ranging from 1½ to over

20 years), working with Indigenous families and children in diverse rural and urban communities. Therapists were employed by, and located in, various Indigenous and mainstream organizations.

Following signed consent, all interviews were audio-recorded and an anonymized summary emailed to each participant in order to verify and/or extend the content. The narrative data, which represents the views of predominately Euro-Canadian rehabilitation therapists, are used in this publication to help contextualize the themes identified in the literature.



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<sup>4</sup> As discussed in this publication, the relationship between health conditions and 'disabilities' is complicated and determined by multifaceted contextual factors (World Health Organization, 2015).

<sup>5</sup> The author of this publication is a Euro-Canadian occupational therapist and researcher who has had the privilege of working with and learning from Indigenous communities, families, and early childhood organizations, primarily in BC, for the past 18 years.

<sup>6</sup> Therapists were located in: New Brunswick, North West Territories, British Columbia, Newfoundland & Labrador, Manitoba, Quebec, Ontario, and the Yukon.

<sup>7</sup> It is not known how many rehabilitation therapists in Canada self-identify as having Indigenous ancestry because this information is currently not collected. Anecdotal evidence suggests it is a small percentage. The majority of rehabilitation therapists in Canada have varied European ancestry and may have limited knowledge of Canada's colonial history and experience of working with Indigenous communities and families.



## 2.0 DIS/ABILITY AND REHABILITATION IN THE CONTEXT OF INDIGENOUS CHILDREN IN CANADA



### 2.1 The Diversity of Indigenous Families

Indigenous children in Canada grow up in extremely diverse geographical and socio-cultural families, neighbourhoods, and communities. The 2016 Census reports an estimated 1.67 million Indigenous peoples in Canada who self-identify as First Nations, Inuit and Métis, comprising approximately 4.9% of the population (Statistics Canada, 2017). There are more than 600 First Nations and over 70 Indigenous languages across Canada. Métis have their own unique history, culture, and nationhood, and live in all parts of Canada but predominately in the western provinces or Ontario. Inuit in Canada also have a unique culture and knowledge system, and approximately 73% of Inuit families live in Inuit Nunangat<sup>8</sup> (Statistics Canada, 2017). Although many Indigenous families live in urban centres, there is a great deal of mobility both within and between cities, and back and forth between urban municipalities and rural Nations or communities (Browne, McDonald, & Elliott, 2009a). The demography of Indigenous families differs significantly from non-Indigenous families in Canada, with a fast growing and youthful population, and with larger families and younger parents (Statistics Canada, 2013, 2017).

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<sup>8</sup> Approximately 65,025 Inuit in Canada live in the four Inuit regions (Inuit Nunangat), which includes: Nunavik (northern Quebec), Nunatsiavut (northern Labrador), Nunavut, and the Inuvialuit Region of the Northwest Territories, as well as other locations across Canada (Statistics Canada, 2017).



*The absence of reliable data and research on disabilities in the context of Indigenous children in Canada has been identified as a serious concern for many years*

*(Ball, 2008b; Leitch, 2007).*

## 2.2 The Invisibility of Indigenous Children with Disabilities

Currently, there is a worrying absence of useful and reliable population level data on childhood disabilities and health conditions in Indigenous populations in Canada. The three most common neurodevelopmental disorders amongst all children in Canada are autism spectrum disorder, cerebral palsy, and Fetal Alcohol Syndrome Disorders (FASD). However, there are no known statistics on the number of Indigenous children in Canada with autism or cerebral palsy, and virtually no relevant research on these disorders within this population (Di Pietro & Illes, 2013; Lindblom, 2014). The absence of reliable data and research on disabilities in the context of Indigenous children in Canada has been identified as a serious

concern for many years (Ball, 2008b; Leitch, 2007). This dearth of data and research results in a lack of evidence to advocate for, and inform the, provision of effective and culturally safe rehabilitation services with Indigenous children.

National data<sup>9</sup> is available on unintentional childhood injuries. This data shows that First Nations and Inuit children and youth have the same types of injuries as the wider population but at rates three to four times the national average (Banerji, Canadian Paediatric Society, & First Nations Inuit and Métis Health Committee, 2012). Available data from the 2008-2010 First Nations Regional Health Survey (RHS) reveals that 7% of First Nations children living in on-reserve and northern communities have been diagnosed with ‘a health condition’ that was likely to negatively impact their learning. The most prevalent health conditions

identified were: speech or language difficulties (58%), learning disability (58%), attention deficit disorder/attention deficit hyperactive disorder (57%), visual impairment (54%), ‘cognitive or mental disability’ (54%), hearing impairment (54%), and FASD (24%) (First Nations Information Governance Centre, 2012). Similar data for Inuit, Métis, or off-reserve First Nations children is not available.

It is commonly assumed that FASD is more prevalent among Indigenous populations in Canada. Indigenous communities are concerned about FASD; however, reliable data for First Nations, Inuit and Métis populations is not available (Pauktuutit Inuit Women of Canada, 2010; Werk, Cui, & Tough, 2013), and there is no conclusive evidence that FASD rates in Indigenous children in Canada are higher than the general population (Pacey, 2009). The Regional Health

<sup>9</sup> Due to the limitations of available data and the tendency for decontextualized health statistics to perpetuate deficit-orientated stereotypes, population level data on Indigenous children’s health and well-being needs to be used extremely cautiously.

Survey reports that 1.8% of First Nations children have FASD (First Nations Information Governance Centre, 2012). Earlier data from the 2006 Aboriginal Children's Survey indicates that First Nations children in Western Canada and the Territories are more likely than Métis children to have been diagnosed with FASD (Werk et al., 2013). As well, rates of diagnosis are reportedly slightly higher among children living in families who had a low income and experienced food insecurity, and much higher among children in the foster care system. This survey also reports that only 50% of First Nations children diagnosed with FASD have received any intervention.

Current and reliable information about the prevalence of speech-language and hearing disorders

among young Indigenous children is also lacking. However, there is evidence that compared to the wider child population in Canada, First Nations and Inuit children have a higher overall prevalence of chronic otitis media (middle ear inflammation) and concomitant hearing loss that may negatively affect speech and language development (Ayukawa, Bruneau, Proulx, Macarthur, & Baxter, 2004; Bowd, 2005). Similarly, data from the 2006 Aboriginal Children's Survey shows that approximately 13% of First Nation children aged 2-5 years living off-reserve were reported by their parents as having a speech and language delay, compared to a national average of 4% among all children in Canada (Findlay & Kohen, 2013).

### 2.3 Different Perspectives on 'Dis/ability' & Rehabilitation

How 'disability' and 'rehabilitation' are understood influences how services are designed and delivered and their potential relevancy and cultural safety for Indigenous populations. In recent years, two predominant and interconnected models of disability – the individual/biomedical model<sup>10</sup> and the social model<sup>11</sup> have influenced children's rehabilitation. Individualistic and biomedical perspectives of disability are reinforced by, and reproduced through, research, education, funding, organizational, and professional policies and structures, and therapeutic interventions that are primarily focused at the level of an individual child and family unit (Gerlach, Teachman, Laliberte Rudman, Huot, & Aldrich, 2017b).

*How 'disability' and 'rehabilitation' are understood influences how services are designed and delivered and their potential relevancy and cultural safety for Indigenous populations.*



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<sup>10</sup> Individualized biomedical perspectives “firstly, locates the ‘problem’ of disability within the individual and secondly it sees the causes of the problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability” (Oliver, 1996, p. 32).

<sup>11</sup> A social model locates impairment in the physical body but emphasizes how individual and institutional prejudices and discrimination, exclusionary policies, and inaccessible environments influence individuals’ lived experiences of disability and an oppressive process of ‘disablement’ (Kulnik & Nikolettou, 2017)

In many jurisdictions across Canada, accessing specific funding and/or specific services or resources is dependent on an individualized and biomedical process of identifying and assigning a diagnostic label or condition to a child. This structure maintains the focus on ‘children’s bodies’ regardless of how their families’ daily lives are differentially shaped by social and structural determinants (Miller & Rosenbaum, 2016). For Indigenous children, the assigning of specific disorders/delays/disabilities can represent another deficit-oriented label for a population who have experienced being historically categorized and stigmatized as the ‘inferior Other’ (Ellison, 2008).

Resistance to the individualization and medicalization of disability by people with lived experiences of disabilities led to the emergence of a social model in the United Kingdom in the late 1980’s (Oliver, 1996). Rather than focusing on ‘treating’ a disability, rehabilitation from this perspective focuses on promoting social inclusion, equal rights, and addressing underlying socio-economic and political structural inequities (Gilroy, Donnelly, Colmar, & Parmenter, 2013). In an attempt to merge individual and social approaches to disability and create an accepted international conceptual framework, the World Health Organization (WHO) launched the International Classification of Functioning, Disability and Health<sup>12</sup> (ICF) in 2001. The capacity of the ICF framework to shift rehabilitation research, education,



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and practice in Canada beyond individualized, deficit-oriented, and decontextualized perspectives continues to be debated (Leplege, Barral, & McPherson, 2015; Miller & Rosenbaum, 2016).

In global settler-colonial contexts, individual and social models and human rights disability discourses have been critiqued for privileging Western Eurocentric, individualistic, and deficit-oriented language and concepts, and failing to be inclusive or representative of the enormous diversity of Indigenous perspectives and experiences of disability (Elder, 2015; Gilroy et al., 2013; Hollinsworth, 2014; Meekosha, 2011; Phillips & Higgins, 2013). In the Canadian context,

rather than critiquing or focusing on illness or disability language and concepts, First Nations, Inuit and Métis communities and health organizations have advocated for distinct perspectives of health that often share a focus on well-being, balance, harmony, and healing (Graham & Leeseberg Stamler, 2010; Métis National Council, 2017; National Collaborating Centre for Aboriginal Health, 2013; Tagalik, 2015). Well-being often involves a balance in the mental, physical, spiritual, and emotional aspects at the level of the individual, family, and community or Nation. Achieving and maintaining balance and well-being is frequently a relational process achieved through

<sup>12</sup> In the ICF framework, “disability is understood as a dynamic continuum, influenced by biology, social factors, environmental conditions, health services, and personal preferences” (Halfon, Houtrow, Larson, & Newacheck, 2012, p. 16).

connections to and between the land, the spirit world, and community (Greenwood, de Leeuw, Lindsay, & Reading, 2015).

A human rights-oriented framing of childhood disability is being used by the Assembly of First Nations and the First Nations Child and Family Caring Society to hold the federal government accountable for providing equitable health and social care programs for all Indigenous children regardless of where they live, and implementing the full intent of Jordan's Principle (Canadian Human Rights Tribunal, 2016). The United Nations Committee on the Rights of the Child provides a framework for children's civil, political, economic, social and cultural rights, and was the first core human right treaty to make specific references to Indigenous children in a number of provisions in recognition that they require 'special measures' through legislation and policies in order to ensure their individual and collective rights (United Nations Committee on the Rights of the Child, 2009). In particular, Article 30 holds the Government of Canada accountable for ensuring that "every Indigenous child has the opportunity to live, learn, and enjoy their language, culture, and religion" (Greenwood, 2016, p. 20). These rights are interdependent with the United Nations Declaration on the Rights of Indigenous Peoples (2007), which were fully endorsed by the Government of Canada in 2016. This Declaration makes reference to the 'special needs' of Indigenous children and its full implementation is a key recommendation of the 2015 Truth and Reconciliation Commission of Canada (TRC).

## 2.4 The Disabling Impacts of Colonization

There is robust evidence that children's early relationships, experiences, and environments have a huge impact on their health and well-being across their life course and the prevalence and extent of developmental delays, disabilities, and health conditions (Shonkoff & Phillips, 2000). However, prevailing perspectives on disability largely fail to recognize the multifaceted disabling impacts of colonization on the health and well-being of Indigenous families and children (Gilroy et al., 2013). Also, although the provision of children's rehabilitation often takes into account the immediate context of families' lives, rehabilitation practices and organizational structures tend to be preoccupied with interventions at the level of individual families and children, and have yet to fully consider how to be responsive to the historical and ongoing effects of colonization on Indigenous communities, families, and children's everyday lives. The following section highlights the inseparability between the multifaceted impacts of colonization on Indigenous communities and families' lives and their children's access to equitable outcomes in their health, well-being, and developmental trajectory.

Prior to colonization, many First Nations and Inuit communities and families raised, cared for, and educated their children within an extended and interdependent system of relationships which helped to ensure children's safety and well-being (Inuit Tapiriit Kanatami, 2014; Irvine, 2009).

Colonization has been described "as the broadest and most fundamental determinant of Indigenous health and well-being in countries where settler-colonial power continues to dominate" (de Leeuw, Lindsay, & Greenwood, 2015, p. xii). The 'single most devastating factor' in the breakdown of Indigenous cultures and communities was the residential school system (Armstrong, 1996). For over 100 years, multiple generations of young children were removed, often by force, from their families and home communities, to spend their childhoods in church-run residential schools. Many were physically punished, emotionally traumatized, sexually abused, and denied the opportunity of having healthy and loving relationships with their siblings, parents, and extended family. Consequently, as adults, many struggled to care for themselves or their children (Fournier & Crey, 1997; Royal Commission on Aboriginal Peoples, 1996; TRC, 2015). The last residential school closed in 1996.

*Achieving and maintaining balance and well-being is frequently a relational process achieved through connections to and between the land, the spirit world, and community*

*(Greenwood, de Leeuw, Lindsay, & Reading, 2015).*

*Compounding the over-representation of Indigenous children in the child welfare system are enduring patriarchal and racialized discourses that portray Indigenous women as 'unfit' mothers and their children as 'at risk'*

*(Cull, 2006; de Leeuw, 2009, 2014).*



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In the second half of the 20th century, the government instituted a new approach to the assimilation of Indigenous children that is commonly referred to as the 'Sixties Scoop.'<sup>13</sup> Between 1960 and 1990, it is estimated that over 11,000 children were adopted by non-Indigenous families who often lived in a different province or sometimes a different country (Trocmé, Knoke, & Blackstock, 2004). Government intervention in Indigenous families and children's lives continues today through provincial/territorial child welfare authorities, with more children being removed from their homes than at the peak of the residential school system (McKenzie, Varcoe, Browne, & Day, 2016). There is also evidence of families living in rural First Nations communities having to 'voluntarily'

place their children in the child welfare system in order to access health and rehabilitation services (Nishnawbe Aski Nation, 2016).

Compounding the over-representation of Indigenous children in the child welfare system are enduring patriarchal and racialized<sup>14</sup> discourses that portray Indigenous women as 'unfit' mothers and their children as 'at risk' (Cull, 2006; de Leeuw, 2009, 2014). Indigenous mothers' experiences and/or expectations of being racialized in their interactions within mainstream institutions influences their access to, and utilization of, health and early intervention programs for their children (Gerlach, Browne, & Greenwood, 2017a; Health Council of Canada, 2011). Thus, Indigenous children's

health is not only compromised by racialized legislation that limits their equitable access to essential social and health care services comparable to other children in Canada (Canadian Human Rights Tribunal, 2016), but also by racialized and stigmatizing discourses within mainstream institutions and the broader society (Loppie, Reading, & de Leeuw, 2014).

The socio-economic status of Indigenous families in Canada varies greatly (Place, 2012). Approximately 43% of First Nations households have to survive on less than \$20,000 a year (First Nations Information Governance Centre, 2012). For Inuit in Nunavut, the annual average total income ranges from \$21,000 to \$47,000 (Statistics Canada, 2016). International

<sup>13</sup> In 1959, 1% of children who were legal wards of the state were Indigenous. By the end of the 1960s, this number had risen to 30-40% (Fournier & Crey, 1997).

<sup>14</sup> Racialization may be conscious and deliberate, an act of racism that openly discriminates, or unconscious and unintended. Racialization results in the marginalization of individuals and population groups on the basis of presumed biological, physical, or genetic differences (Browne, 2005).

evidence is strengthening the link between growing up in poverty with an increased incidence and severity of early developmental delays and disabilities, and poor physical, mental health, and early learning outcomes (Blackburn, Spencer, & Read, 2013; McPherson & McGibbon, 2010; Raphael, 2011). The health statistics available for Indigenous children that show high rates of infant mortality, respiratory problems, childhood obesity and diabetes, and accidental injury and death, have all been linked to the multifaceted effects of growing up in impoverished conditions (Office of the Provincial Health Officer, 2009; Public Health Agency of Canada, 2001, 2011; Saylor, 2004; Smylie, Fell, & Ohlsson, 2010).

Indigenous children's health and developmental trajectory can also be profoundly impacted by structural inequities that are beyond the immediate control of their communities or families. Specifically, the historically entrenched and under-resourced funding and organizational structure of children's health and rehabilitation services for Indigenous communities in Canada continues to create inequitable access to services in urban and rural areas, adversely impacting the health, well-being, and developmental potential of Indigenous children with developmental challenges and disabilities and violating their human rights (Canadian Human Rights Tribunal, 2016). There has also been a lack of investment in Canada and internationally on understanding how children's rehabilitation policies, practices, and service delivery models can expand beyond a predominately biomedical and individualistic orientation and

be inclusive of, and responsive to, the historical realities, current socio-economic and community contexts, and the strengths and priorities of Indigenous communities and families (Ball & Lewis, 2014; DiGiacomo, Davidson, & Abbott, 2013).

In the following section, recurring themes in the available literature on the provision of children's rehabilitation with Indigenous communities, families, and children in the Canadian context provide a starting point for exploring transformative practices and models of service delivery. All of the themes are aligned with the underlying principles and motives of cultural safety. These themes provide talking points for further dialogue and research, and generalizations must be taken cautiously. The themes are augmented with narratives from interviews with key informants.

*Indigenous children's health and developmental trajectory can also be profoundly impacted by structural inequities that are beyond the immediate control of their communities or families.*





*A context of mistrust that has been shaped by families' experiences of historical and ongoing government-sanctioned over-surveillance and intervention, and systemic racism and discrimination can result in Indigenous parents being reluctant to access programs with their children*

*(Gerlach et al., 2017a; Health Council of Canada, 2011).*

# 3.0 EMERGING THEMES IN CHILDREN'S REHABILITATION WITH INDIGENOUS COMMUNITIES, FAMILIES, AND CHILDREN IN CANADA



A context of mistrust that has been shaped by families' experiences of historical and ongoing government-sanctioned over-surveillance and intervention, and systemic racism and discrimination can result in Indigenous parents being reluctant to access programs with their children (Gerlach et al., 2017a; Health Council of Canada, 2011). According to Ball (2008a), indications that Indigenous families do not feel safe in accessing services for their children include: low utilization rates of available services; 'denial' of suggestions that there is a problem, and reticence in interactions with practitioners.

Cultural safety was originally conceptualized in Aotearoa/New Zealand by Māori nurse-leaders, in order to counteract culturalist discourses in healthcare policies and practices that resulted in people delaying or avoiding accessing care as a result of feeling unsafe. Respectful, trusting, and ethical healthcare relationships and broad, relational perspectives of health that include the historical and ongoing effects of colonization on Indigenous peoples' access to equitable health and healthcare are at the core of cultural safety (Papps & Ramsden, 1996; Ramsden, 1993).

*I think one of the barriers is that families don't trust outside people or early intervention therapists because they feel they are going to be judged for their parenting and they wonder if being labelled might be harmful for their child - that they will be stigmatized or child protection may take their child away because it's a reflection of their parenting skill.... I think there are a lot of barriers around trust. I don't see a lot of outside agencies taking enough opportunities to build trust – they don't come and spend time in the First Nation communities, and share information about their programs in a low-key way (OT, Ontario).*

In early childhood programs, when parents do not engage with rehabilitation programs or conform to program expectations, they can become labelled as disinterested or noncompliant. Describing parents in this way tends to imply a deficit in relation to the parents rather than focusing on barriers within programs (Day, 2013). An important implication of cultural safety is that rather than implying there is a 'problem' with a family, organizational leaders and providers

understand how taken for granted policies and practices can present as barriers to program access and engagement when they fail to take into account the social contexts and complexities of Indigenous families' everyday lives (Gerlach et al., 2017a). For example, Peltier (2011), an Speech-Language Pathologist (SLP) from the Mnjikaning First Nation in Ontario, states:

*A service delivery model that presents more than one chance for assessment and offers multiple visits and appointments in the home and clinic can also facilitate engagement and support the development of an assessment and intervention approach that best meets the needs of the client. This is especially relevant to members of the Aboriginal population who seasonally move back to their traditional territory for hunting, ceremonial purposes or visits with family since these communities are often a long distance away. (p. 133)*

In a national survey with SLPs working with First Nations and Inuit communities, Ball and Lewis (2011) conclude that if program engagement is a problem, it is the therapists' responsibility to problem-solve with families and adapt their model of service delivery accordingly. However, it

is also increasingly recognized that cultural safety needs to be practiced and supported at funding and organizational levels (Greenwood, Lindsay, King, & Loewen, 2017).

*We have a discharge policy of three no-shows and you are supposed to be discharged but I am flexible with that and if it is a family that I know has difficult circumstances, such as unemployment or no transportation, I will be a lot more lenient with reminder calls and rescheduling.*

*Staff need to understand that they need to adapt (rather than the families). We need to adapt to families and ask for peoples' feedback. (SLPs, Northwest Territories).*

Currently in Canada, cultural safety is being woven through some healthcare institutional mandates, policies, and professional practice guidelines for care involving Indigenous peoples (Aboriginal Nurses Association of Canada, 2009; Greenwood et al., 2017; Indigenous Physicians Association of Canada & the Royal College of Physicians and Surgeons of Canada, 2009). Also, various rehabilitation university programs and national and regional associations are exploring how to respond to the Calls to Action of the TRC, particularly in relation to recruiting more Indigenous students and providing effective education about Indigenous history and rights, cultural safety, and anti-racism skills in university curricula and continuing education (Canadian Association of Speech- Language Pathologists and Audiologists



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[CASLPA], 2010; Gasparelli et al., 2016; Restall, Gerlach, Valavaara, & Phenix, 2016). There is increasing recognition in the international, interdisciplinary rehabilitation literature that cultural safety is an important aspect of effective rehabilitation with Indigenous populations (Gerlach, 2007, 2012; Gray & McPherson, 2005; Kendall & Marshall, 2004; Main, McCallin, & Smith, 2006; Stedman & Thomas, 2011). However, there remains a lack of empirical evidence on the provision of culturally safe rehabilitation with Indigenous communities and families in Canada and internationally.

In the following section, many of the key principles of cultural safety are woven through the interdependent themes identified in the literature. For further readings on cultural safety see Browne et al. (2009b), Gerlach (2012), Greenwood et al. (2017), Health Council of Canada (2012), and the National Collaborating Centre for Aboriginal Health (2013).

### 3.1 Responding to Communities' Rights to Self-Determination

Pertinent to the design and delivery of children's rehabilitation with Indigenous families and communities are the Articles in the United Nations Declaration on the Rights of Indigenous Peoples (2007) that affirm their fundamental rights to self-determination and self-governance, and to being actively involved in 'developing and determining' health and social programs which, as far as possible, need to be administered through Indigenous organizations. This Declaration is consistent with the 'Calls to Action' of the TRC (2015), and with repeated calls from Indigenous communities, organizations, and leadership for community self-determination of healthcare programs so that they are informed by, and responsive to, a community's history, current resources, and self-identified concerns, priorities, and aspirations

(Canadian Human Rights Tribunal, 2016; Inuit Tapiriit Kanatami, 2014; Nishnawbe Aski Nation, 2016; Vives et al., 2017).

*Communities need to identify training needs. ... I plan to spend time in the day cares so that I can make specific recommendations based on their environmental setup and ways of doing things. It has been well received and they seem to be excited about it. The need for this type of training was identified by the day care manager during the [community] focus group discussions and I'm following up on it (OT, Ontario).*

Self-determination is inseparable from community-driven program planning and the well-being of the community, neighbourhood, or Nation as a whole (National Collaborating Centre for Aboriginal Health, 2016; Nishnawbe Aski Nation, 2016; Tagalik, 2010). Community ownership and decision-making are also central to effective health promotion programs with Indigenous infants and children (Smylie et al., 2015). Moreover, in identifying promising practices in strengthening Indigenous families living in urban centres across Canada, Scott (2012) highlights that “community engagement, empowerment and ownership lead to long-term solutions, maximize vicarious learning,

and guarantee that services are relevant and effective” (p. 7).

A community-led and driven approach to service delivery reflects the key principles of ‘community-based rehabilitation’ as proposed by the World Health Organization, which aim to implement the United Nations Convention on the Rights of Persons with Disabilities (World Health Organization, 2010). Currently, the potential of a human rights perspective to inform and possibly shift and broaden the scope of rehabilitation programs with Indigenous families and children remains inadequately explored. However, it is anticipated that transforming and tailoring rehabilitation programs from a human rights perspective will involve dismantling and redistributing power relations as community self-determination becomes central to the provision of services (Gibson, Butler, Henaway, Dudgeon, & Curtin, 2015).

### 3.2 Learning from ‘Community’

A recent report on improving children’s rehabilitation services for First Nations in northern and north-western Ontario notes, “First Nations parents and service providers’ voices [need to be] at all levels of planning for [children with] special needs” (Nishnawbe Aski Nation, 2016, p. 10). Rather than viewing community members as recipients of services, engaging in a process of community

self-determination values the perspectives and experiences of local families, Elders,<sup>15</sup> healthcare, early childhood and social service providers as being a rich source of knowledge that is key to the co-development of effective and sustainable rehabilitation with Indigenous communities and families (Ball & Lewis, 2014; Ball & Pence, 2006; Raining-Bird, 2014).

Importing a predetermined approach or model of rehabilitation into a community risks that the services/programs will fail to be respectful of/responsive to, and build on the existing knowledge, resources, and programs that currently exist within each community. There is no ‘one size fits all’ approach; rather, effective rehabilitation programs are tailored in response to each community and/or family context (Zeidler, 2011). When therapists come into a community for the first time, before they see any families, they need to ask ‘what do I need to know about your community and who do I need to talk to?’ By being present and spending time in communities, including in ways that go beyond a professional role, therapists are more able to form relationships with and learn from community members, including Elders, health managers, nurses, teachers or early childhood educators, about their culture and protocols, and the history, events, places, families and relationships that have shaped the community (Raining-Bird, 2014).

<sup>15</sup> Elders are “those who have shown wisdom and leadership in cultural, spiritual and historical matters within their communities, and might not necessarily be old. Elders represent an essential connection with the past; they are keepers of the community knowledge and supporters of its collective spirit” (King & Gracey, 2009, p. 82).

Learning from communities requires that therapists are comfortable moving away from an expert-driven model, positioning themselves as learners, and taking part over time in community activities, gatherings, and celebrations (Peltier, 2011; Zeidler, 2011). Partnerships with knowledgeable Elders, families, and community members that are grounded in a shared vision also foster the co-creation of socially responsive rehabilitation programs. For example, by having a shared vision, parents, First Nations communities and rehabilitation service providers in Manitoba are working together to address the stigma associated with FASD through education and research initiatives (Manitoba FASD Coalition, 2017).

Partnering with local community organizations also supports the provision of children's rehabilitation services in places where families feel welcome, accepted, and a sense of belonging, and where they may be already accessing a range of programs and resources (Ball, 2005; Hughes, 2013; Lynam, Scott, Loock, & Wong, 2011). Examples include urban Friendship Centres, First Nations or Inuit health centres, or on- and off-reserve Aboriginal Head Start Programs. Through partnerships with Indigenous communities and organizations, rehabilitation therapists can also more effectively share their knowledge and skills with community-based frontline workers, paraprofessionals, and therapy assistants.<sup>16</sup> For example,

SLPs in Canada have reported how they are supporting community-wide initiatives around language development with infant and children in early childhood and school settings by partnering with First Nations and Inuit community programs and stakeholders (Ball & Lewis, 2011; CASLPA, 2010; Gardener & McCrick, 2010).

*I started doing meetings with Aboriginal Head Start staff every other month to go over the children's goals and where I am seeing improvements in individual children and what are some of the tips and tricks that I am seeing working and what they [staff] are doing that is working... This approach also increased open communication between staff and myself directly... Helps to build on staff's existing skills and knowledge about speech and language and add to what they are already doing rather than change it (SLP, British Columbia).*

### 3.3 Focusing on Strengths and Well-being

*I have worked with many people who feel that they know so much; 'you need to listen to us' - instead of being open and working together with families, and focusing on a strengths-based approach rather than a disability approach (OT, Manitoba).*

There is a tendency for the language and foci of rehabilitation to be deficit and problem-oriented, and focused on identifying what an individual child cannot (King, 2009). This singular focus can divert therapists' attention away from exploring other possibilities, needs, and hopes with families that can support their children's well-being. Deficit-oriented discourses also contrast sharply with Indigenous values and perspectives that foreground strengths-based approaches that centre on individual and collective health and wellness (First Nations Health Authority, 2015a; Irvine, 2009; Stout, 2012). Scott (2012) highlights how this approach allows for a fundamental shift "in the discourse about the inherent strengths that can be found in Aboriginal families and communities in Canada where the focus is on finding solutions and celebrating innovation" (p. 7). Focusing on strengths allows for early success to be achieved, readiness for change to be acknowledged, and the process of healing to be driven by parents (Scott, 2012).

*I like to think about 'what is important for you as a family and how are we going to work on that together?' It comes down to the health of the whole family. What are the concerns, hopes and dreams from the family's perspective and working with families so that they can recognize that they do have the answers and capacity to provide what their child needs and the rest of the team is there for support (PT, Yukon Territory).*

<sup>16</sup> Designated therapy assistants may receive 'on the job training' in communities through ongoing training with, and supervision from, a rehabilitation therapist. Currently in Canada, there appears to be a need for generalist therapy assistant programs that specialize in working with Indigenous communities.

Collective or community well-being is fundamental to many Indigenous cultures (Greenwood et al., 2015). Focusing on well-being at the level of the community is well aligned with emerging calls within the rehabilitation literature for a radical shift beyond an individualized ‘pull-out model’<sup>17</sup> of service delivery to community level and population health approaches and interventions (Ball & Lewis, 2011; CASLPA, 2010; Gerlach et al., 2017b). This may include, for example, working with communities to: apply for a grant to improve outdoor play opportunities for young children; collaborating on enhancing language stimulation or early literacy skills with local day care and preschool programs, or creating greater opportunities for physical activities.

*There will be children who need very specialized physiotherapy support - but it also makes perfect sense that in partnership with First Nations, a physiotherapist becomes involved in creating greater opportunities for physical activities or participation in communities for all children and youth (PT, Yukon).*

Rather than focusing on dis/abilities, effective and culturally safe children’s rehabilitation seeks to build on communities and families’ existing strengths and capabilities (Gerlach, 2007; Peltier, 2011; Zeidler, 2011). In relation to SLP, Zeidler (2011) comments:

*Aboriginal people are frequently confronted with negative statistics and information about their well-being and their ability to parent and to live healthy lives. Professionals need to be sensitive to the effect that diagnostic labels, such as those that speech-language therapists<sup>18</sup> would apply to describe children’s language skills, can have on family members (p. 141).*

Moreover, in blending Western and Anishinaabe perspectives, First Nations SLP Peltier (2011) in Ontario notes:

*I choose to frame it [speech therapy] within an educational framework more so than as a deficit-based clinical approach. This is more in line with the Aboriginal worldview as I know it, which appreciates the strengths that each of us possesses and nurtures children to best enhance their gifts. This approach has proven to be rewarding and empowering for the children and parents (p. 130).*

*Children need food, housing, more sleep, and sometimes therapy is not a priority. ... I have thought about advocating for housing – sometimes in writing a report for my manager I will add that we didn’t see so many kids because they didn’t eat or were too tired – so just letting them know that this is the reality. Sometimes in our homes and with our full bellies we forget (SLP, Northwest Territories).*

Taking into account parental/maternal well-being, family support networks, and home circumstances expands the scope of children’s rehabilitation programs in response to families’ self-identified strengths, concerns, and priorities so that the needs of families as a whole are addressed (Head & Abbeduto, 2007). Emerging research with urban-based Indigenous early childhood intervention programs in British Columbia highlight how a focus on family well-being shifts attention to providing supports for families to have greater access to basic determinants of health, such as food and housing security, prior to focusing on individual children’s development (Gerlach, Browne, & Suto, 2016).

### 3.4 Investing in Relationships

*[There] needs to be a broadening and recognition that how we interact with a person likely has a greater impact on them than anything else we are doing. Your technical knowledge is a small piece compared to your ability to develop trust and relationships with families (PT, Yukon Territory).*

Investing time in building non-judgmental, mutually respectful, equitable, and long-term relationships are fundamental to cultural safety and pivotal to the success of rehabilitation with Indigenous communities and

<sup>17</sup> This approach recognizes that a small number of children may still need specific 1:1 support.

<sup>18</sup> It is standard practice in Canada and elsewhere to refer to professionals trained in speech and language as ‘Speech-Language Pathologists.’ However, Zeidler (2011) prefers the title of ‘Speech and Language Therapist,’ recognizing that an emphasis on ‘pathology’ can create a barrier to engaging with families and communities.

families. Rehabilitation models of service delivery that are fast-paced and compress time make it difficult to build trusting relationships. Rather than focusing on ‘the work to be done’, therapists need to be open to slowing down and deferring their professional agendas - making time and space to develop relationships with community stakeholders, Elders, and extended family members. During early interactions with communities and families, sharing, learning, food, and humour are key elements of building positive relationships; also, spending time in staff rooms, offices and shared community spaces in order to become a known and trusted face (Ball & Lewis, 2011; CASLPA, 2010; Zeidler, 2011).

*You need to be willing to really put yourself out there and build relationships – our resource worker took me to the community kitchen and to all the different events to get me out there and meet families and that has made a huge difference – I don’t know whether I would have the same parent involvement that I do if I didn’t have that (SLP, British Columbia).*

Supporting community and family well-being also requires that rehabilitation organizations and therapists have close working relationships with local Indigenous early childhood programs, such as Aboriginal Head Start programs, as well as with a continuum of local and regional intersectoral services, programs, and resources (Peltier, 2011). Providing programs and services as part of a collaborative community team has been identified

as a core element of promising practices in promoting Indigenous children’s health (First Nations Health Authority, 2015a). Shifting the focus to community and family well-being may also impact the composition of community-based teams beyond child-focused service providers; for example, the inclusion of adult mental health specialists and community stakeholders involved in diverse health and social programs.

*We are known in the community. We have attended a powwow and try to be as much of the community as possible. Word of mouth and the trust we have – resulted in expanding services to other communities (SLP & OT, Quebec).*

A focus on building relationships also requires that rehabilitation managers and therapists recognize the importance of, and spend time reflecting on, how their relationships with Indigenous communities and families are irretrievably shaped by the broader colonial and paternalistic nature of the relationship between Indigenous peoples and the Government of Canada. Aligned with cultural safety and the ‘Calls to Action’ in the TRC, everyone involved in the provision of rehabilitation services need to be supported to ‘turn their gaze inward’; reflecting on their position of power and privilege within Canadian society and how their assumptions, biases, and judgements influence their interactions and relationships with Indigenous communities and families (Gerlach, 2012; Gerlach, Sullivan, Valavaara, & McNeil, 2014).

*Something I struggle with when working with families is remembering my own biases, privileges, upbringing, and life experiences. Everyone is different, but in some communities those differences are more pronounced and trying to keep that actively in mind when I am building relationships and giving recommendations. Remembering that what I think is important is not the be all and end all of what is important (SLP, Northwest Territories).*

### 3.5 Making Space for Indigenous Knowledges and Languages

Elders and traditional knowledge holders are the only ones who can use Indigenous healing knowledges and practices. Indigenous knowledges are tribal, land- and language-based, extremely diverse, and cannot be generalized (Greenwood et al., 2017). At their core, many Indigenous knowledges and values reflect a relational worldview. The dynamic and relational nature of Indigenous knowledges is conveyed by Greenwood (2005) as follows:

*The foundations of Indigeneity, then, are comprised, in part, of values that privilege interrelationships among the spiritual, the natural and the self; reflect a sacred orientation to place and space; encompass a fluidity of knowledge exchanged between past, present and future, thereby allowing for constant and dynamic knowledge growth and change; and honour language and orality as an important means of knowledge transmission (p. 554).*

The inclusion of Indigenous knowledges and practices in all programs with Indigenous families and children is increasingly recognized as being essential to improving children's health and well-being across their life course and the future collective health and well-being of their communities and Nations (Greenwood & Jones, 2015; Reading & Wien, 2013). In Alberta, for example, research with youth from the Yellowknives Dene First Nation identified a wellness and strengths-based approach to physical activity that extends beyond soccer and running to include traditional games and activities, being out on the land, and actively contributing to their community (Tang & Jardine, 2016).

In many urban, First Nations, Inuit, and Métis communities, local Elders, family members, and early childhood workers

contribute towards an intricate system of knowledge transmission in order to nurture children's identities, ancestral knowledges and languages, and their relationships to the spirit and natural worlds (McIvor, Napoleon, & Dickie, 2009; Smylie et al., 2009; Tagalik, 2015). Early childhood practices and systems that recognize and reinforce Indigenous cultures and languages are highly valued by many Indigenous parents and form the foundation for a growing number of Indigenous-specific early childhood programs across Canada (Gray Smith, 2015; Greenwood, 2006).

Developing relationships over time and partnering with, and learning from, Elders and knowledge keepers within a community can support the inclusion of Indigenous knowledges, languages, and practices related to health and healing, family life and child rearing. This knowledge is

foundational to transforming the design and delivery of children's rehabilitation programs and services so that they are respectful, meaningful, and experienced as culturally safe by Indigenous communities and families (Ball & Lewis, 2011; Peltier, 2011). For example, through her long-term relationships as an SLP with the Lil'wat Nation in south-western BC, Zeidler collaborated with the community's cultural centre staff and local parents on a shared vision of developing parents' awareness of their children's development, building on the positive ways in which they are interacting with their children. This collaboration led to the co-creation of 'Talk, Learn and Grow Together' or 'Ri7p', a strengths-based program that incorporates drumming and dance, local traditional stories, the ancestral language, and celebrations (CASLPA, 2010).

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*Early childhood practices and systems that recognize and reinforce Indigenous cultures and languages are highly valued by many Indigenous parents and form the foundation for a growing number of Indigenous-specific early childhood programs across Canada*

*(Gray Smith, 2015; Greenwood, 2006).*

### 3.6 Using Assessments Cautiously

In the early stages of the rehabilitative process, therapists routinely use standardized assessment tools and procedures, based on universal assumptions of ‘normal development’, in order to help inform and plan their interventions and recommendations (McLaughlin, Goodley, Clavering, & Fisher, 2008). Understanding disability in the context of the inequitable power relations that persist in a settler-colonial society such as Canada is central to understanding how the taken for granted rehabilitation practice of using normative developmental assessments can be complicit, albeit inadvertently, in perpetuating colonial discourses that marginalize and inferiorize Indigenous parenting and children.

Focusing on children’s strengths and capabilities is a key factor in ensuring that assessments are undertaken in ways that are culturally safe (British Columbia Aboriginal Child Care Society, 2013a). There is also emerging evidence that ‘milestone achievement’ for Indigenous children may differ. For example, data on developmental domains collected from the 2006 Aboriginal Children’s Survey, suggest that Inuit, Métis and off-reserve First Nation children achieve gross motor and self-help skills earlier and language skills later compared to the wider child population (Findlay, Kohen, & Miller, 2014).

*Some of the families have said ‘I’m ok with you working with them [their children] but I don’t want them to undergo any testing’ (SLP, British Columbia).*

First Nations and Inuit communities have expressed concerns about the use of normative developmental assessments, and identified the need for culturally appropriate early childhood screening and assessment tools (British Columbia Aboriginal Child Care Society, 2013; Inuit Tapiriit Kanatami, 2014; Nishnawbe Aski Nation, 2016).

*I don’t think we are assessing children on things that are important and functional. [There are also] challenges in terms of differences in dialect and lack of assessment tools. For example for a vocabulary test when you look at the items and it has a tree branch but they have no trees (SLP, Northwest Territories).*

The very concept of testing and ranking a child’s development may be offensive to parents who value and accept their children’s differences and prefer to focus on their abilities and wait until they are older before making attributions about them (Gerlach, 2007; Greenwood & de Leeuw, 2007). Also, perceptions of normative developmental assessments as ‘a test, pass or fail’ highlight parental concerns

that a child’s inability to reach certain developmental milestones is implicitly tied to judgements about their parenting and used to justify heightened surveillance and intervention by child welfare authorities (de Leeuw, 2014).

SLPs<sup>19</sup> across Canada are also questioning the culturally biased and ‘unfitting’ nature of the content and structure of their screening and assessment tools and the ‘often impersonal, authoritarian process’ in which they are used with First Nations and Inuit children (Dench, Cleave, Tagak, & Beddard, 2011; Peltier, 2011). SLPs are also concerned about the validity and reliability of Western speech and language assessment tools, which do not have Indigenous children in their standardization samples and do not account for cultural differences in speech patterns or the use of non-standard English/French. Their use can result in language differences being misdiagnosed as language disorders among Indigenous children, and the under- or over-identification of communication disorders (Ball & Berhardt, 2008; Gould, 2008; Peltier, 2009).

*At the preschool I do assessments with staff who speak the ancestral language – I won’t do a pull out 1:1 assessment – and if the child wants to label something in either language then I would give them credit for that. I would like to see some standardized measures of assessing different dialects of English – so more functional ways of measuring dialects used in the communities would be helpful (SLP, Northwest Territories).*

<sup>19</sup> While much of the current literature on the use of assessments with Indigenous children in Canada draws on the SLP literature, the concerns and strategies raised by this profession are considered to be highly relevant for the OT and PT professions, and for assessments focused on other domains of development.

The usefulness of assessments is dependent in large part on how the information is shared and discussed with parents, extended family members, and involved community stakeholders. As discussed earlier, the provision of effective rehabilitation takes place in the context of relationships; this includes the assessment process, which needs to be supportive, safe, and non-judgmental for all involved; using plain, positive, and strengths-based language (Gerlach, 2007; Goelman et al., 2011; Zeidler, 2011). The perspectives and input of a child's parents, family and others involved in their life is an essential part of the assessment and their involvement is critical before, during, and after any assessments take place (British Columbia Aboriginal Child Care Society, 2013; Goelman et al., 2011).

*I think therapists need to spend more time listening to parents and finding out what their priorities are in an open-ended way. Otherwise, I think there is a high probability that they won't find out about activities that are meaningful to a family, such as participating in ceremonies.... I think therapists need to keep the dialogue open without specific structured questions and the perception that they need to get through all this on my first meeting (OT, Ontario).*

Increasing the relevancy and usefulness of assessments also requires that the assessment process and findings engage and build capacity with educational and community stakeholders and programs with whom families and/or children are involved (Pei, Job, Poth, & Atkinson, 2013). Additional recommendations for undertaking standardized assessment with Indigenous children include: having a parent and siblings present, involving extended family and/or early childhood workers who know the family and child, engaging in and observing a child during free play activities, actively listening, and involving activities and topics with which a child is already familiar. Alternatively, therapists may omit or defer formal initial interviews and developmental assessments, preferring to focus on building relationships and learning about a family and child through informal observations and conversations (Ball & Lewis, 2011; Gould, 2008; Peltier, 2011).

### 3.7 Reaching Rural and Northern Communities

*Back in the 1990's I was working in fly-in communities and I was getting really frustrated about going up there and setting up these lovely treatment plans and bringing in equipment, only to come back on the next visit and nothing had been addressed and the equipment was collecting rust in the backyard. And I was thinking there has to be a better way here (OT, Manitoba).*

As previously discussed, for many rural Inuit and First Nations, timely and equitable access to children's rehabilitation is at best delayed and most often non-existent (Inuit Tapiriit Kanatami, 2014; Jordan's Principle Working Group, 2015). Many Inuit and First Nations families living in rural communities have to drive or fly long distances to access a children's rehabilitation program based in an



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urban centre. Rehabilitation services are also provided to some rural communities by a fly- or drive-in model of service delivery. In this context, equitable relationships and reciprocal knowledge sharing between rehabilitation therapists and local early childhood or child health personnel and community and family members are central to providing early intervention that is respectful and meaningful (Zeidler, 2011).

*What worked well in Inuvik was being a generalist PT and seeing all ages – requires being a PT that is comfortable in their overall skills and then accessing specialist PT and knowing when to consult (PT, Yukon Territory).*

Providing services in rural locations may also require therapists to become generalists with a broad and intergenerational scope of practice (Roots, Brown, Bainbridge, & Li, 2014). Addressing the particular strengths and priorities of rural First Nations and Inuit communities also warrants a greater national dialogue on, and investment in, allied Indigenous health or therapy assistants<sup>20</sup> in Canada. Recent research undertaken in collaboration with the Pinaymootang First Nation and Nanaandawewigamig, and the First Nations Health and Social Secretariat of Manitoba recommends that:

Investments in capacity building need to be made immediately. These investments should support both short-term (e.g., additional training on speech and language basics for case workers already working in communities) and long-term (e.g., funding the training of local First Nations workers in the allied health professions) capacity development. (Vives et al., 2017, p. 15)

Information and communication technologies are increasingly being used by a growing number of rural and northern First Nations and Inuit communities in Canada in order to help address the travel and financial barriers involved in healthcare delivery and support community development activities that foster community wellness (Canada's Health Informatics Association, 2013; Molyneaux & O'Donnell, 2009). As rural and northern communities have increased Internet capacity, there are increasing opportunities for rehabilitation programs to use telerehabilitation<sup>21</sup> to extend their reach to geographically isolated communities and families. In rural and northern Canada, tablet computers, such as an iPad®, are being used as a platform for audiology testing for children (Rourke, Kong, & Bromwich, 2016).

In BC, the First Nations Health Authority (2015b), in a partnership with the BC Early Hearing Program, is using telehealth equipment to connect families in rural First Nations with hearing assessments

and speech and language services for their infants. This service allows families to access time sensitive infant diagnostic hearing and speech therapy assessments and intervention without having to travel long distances and leave their home communities.

*Sometimes the whole internet system in a community will be shut down because we take up the whole broadband width. You need the structural supports (SLP, Northwest Territories).*

Key informants also identified a range of communication technologies that they are currently using to provide telerehabilitation with Indigenous communities, including: FaceTime® and Skype®, portable tablets that can be used in families' homes and community settings, and more static telehealth equipment that is often based in local health centres or hospitals. While internet access in rural Indigenous communities is improving (Canada's Health Informatics Association, 2013), several key informants from different regions of Canada reported that the band width of internet service remains a huge factor in many communities.



<sup>20</sup> In Canada, there has been a shift from therapy assistants having on the job training to accredited diploma level rehabilitation assistant programs, and a limited number of profession specific programs, for example, speech and language pathology assistants.

<sup>21</sup> Telerehabilitation refers to information, communication and related technologies that can enhance the capacity and accessibility of rehabilitation by providing interventions remotely (Seelman & Hartman, 2009).



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The provision of telehealth with Indigenous communities is grounded in the principles of community self-determination and partnership previously discussed. Rather than a separate form of intervention, spending time in community and having relationships in place is a key factor in the success of using the available technology as a complement to existing services (Eriks-Brophy, Quittenbaum, Anderson, & Nelson, 2008).

*Having a relationship in place before using telehealth makes a big difference in order for the process to work effectively (SLP, Northwest Territories).*

A national survey of SLPs working with First Nations communities concluded that assessments are best done in person once a relationship has been established rather than remotely using technology (CASLPA, 2010). However research by the FASD Network in Manitoba involving health, social service, educational professionals, and parents/guardians of children

diagnosed with FASD indicates that diagnostic assessments and follow-up can be undertaken remotely in partnership with community stakeholders as part of an integrated model of service delivery (Ens, Hanlon-Dearman, Cox Millar, & Longstaffe, 2010; Hanlon-Dearman, Edwards, Schwab, Cox Millar, & Langstaffe, 2014).

*People said they really appreciated not having to come down to [the city] to get the assessment and follow up; that they can stay in their communities.... My follow-up is all by telehealth now – it’s becoming the new way. People were at first a bit sceptical... [but] they are telling us that they do really appreciate this service (OT, Manitoba).*

Once relationships are in place, telerehabilitation can add value in between visits, particularly when it is provided through portable technology that allows therapists to provide consultation and training in community settings, and engages with involved community stakeholders (Ens et al., 2010;

Molyneaux & O’Donnell, 2009). Telerehabilitation can also be used to support and enhance education and professional development for community stakeholders and coaching for family members (CASLPA, 2010; Eriks-Brophy et al., 2008). However, further research is needed to fully explore the potential of telerehabilitation from the perspectives of Indigenous family members, youth and children in different regions of Canada.

*A 10 year old Inuit girl was seen first at our major children’s hospital and came back to us for follow-up care, so we had her started on a post-op exercise program. I had seen her here before she went back to the coast, and then we could check in on her progress every couple of weeks [using telehealth].... I could observe her walking and doing the different leg movements for me and then we could progress the exercises based on what I could see. It was a check in for us and a motivator for her too (PT, Labrador & Newfoundland).*

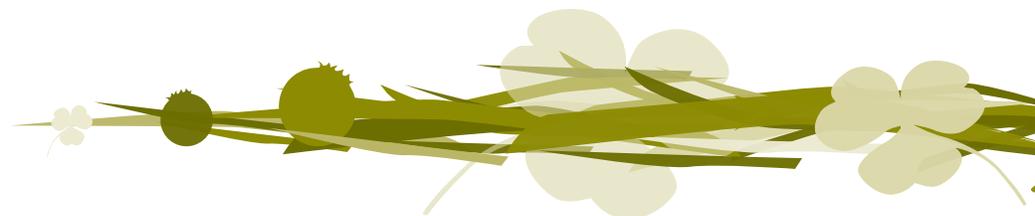


## 4.0 CONCLUSION



For children's rehabilitation to be responsive to the lived realities of Indigenous communities and families, service delivery models, policies, and practices need to be informed by an understanding of dis/ability in relation to the multifaceted, historical, and ongoing effects of colonization. The available evidence, as discussed in this publication, points to a radical shift in service delivery that is grounded in Indigenous self-determination and human rights and characterized by: a primacy to building relationships and community partnerships; respect for and inclusion of Indigenous knowledges, languages, and practices; and responsiveness to the particular needs of rural communities that includes building capacity with allied health paraprofessionals and telerehabilitation. The current literature also emphasizes a foci on strengths, capabilities, and well-being, and the cautious use of developmental assessments and screening tools. There is no pan-Indigenous approach, as children's rehabilitation programs are tailored for each distinct community and family context.

It is hoped that this publication contributes to a greater dialogue between Indigenous organizations, community leaders and stakeholders, and government funding agencies and rehabilitation organizations and therapists on the design, and delivery of community-driven, socially responsive, and culturally safe children's rehabilitation services and programs. Currently, the literature on children's rehabilitation with Indigenous communities and families, and the perspectives and experiences of the rehabilitation therapists who participated in interviews for this publication, represent predominately Euro-Western worldviews. Further research centred on the perspectives, experiences, values, and concerns of Indigenous stakeholders, parents, Elders, children, and youth is foundational to meaningful, and long-lasting, transformation of children's rehabilitation.



## 4.1 Resources: Information ON, PT, and SLP in Canada

### Occupational Therapy

‘Occupational therapy is a type of health care that helps to solve the problems that interfere with a person’s ability to do the things that are important to them – everyday things like: self-care - getting dressed, eating, moving around the house; being productive - going to work or school, participating in the community; and leisure activities - sports, gardening, social activities. Occupational therapy can also prevent a problem or minimize its effects’ (<https://www.caot.ca/site/aboutot/whatisot?nav=sidebar>).

#### National Association

Canadian Association of Occupational Therapy (CAOT)  
<https://www.caot.ca>  
Phone: 613-523-2268  
Toll-Free: 1-800-434-2268

#### Relevant Position Statement

*Occupational therapy and Aboriginal health (2011)* <http://caot.in1touch.org/document/3700/O%20%20OT%20and%20Aboriginal%20Health.pdf>

For more CAOT position statements: [http://caot.ca/site/pt/caot\\_posn\\_stmt](http://caot.ca/site/pt/caot_posn_stmt)

### Physiotherapy

‘Physiotherapists are primary health care professionals with a significant role in health promotion and treatment of injury and disease. They combine their in-depth knowledge of the body and how it works with specialized hands-on clinical skills to assess, diagnose and treat symptoms of illness, injury or disability’ (<https://physiotherapy.ca/about-physiotherapy>).

#### National Association

Canadian Physiotherapy Association  
<https://physiotherapy.ca>  
Phone: 613-564-5454  
Toll-Free: 1-800-387-8679  
Email: [information@physiotherapy.ca](mailto:information@physiotherapy.ca)

#### Relevant Position Statements

*The role of Physiotherapy in Aboriginal Health Care*  
<https://physiotherapy.ca/sites/default/files/positionstatements/role-of-physiotherapy-in-aboriginal-health-care-2014.pdf>

#### *Population Health*

[https://physiotherapy.ca/sites/default/files/positionstatements/population-health\\_en.pdf](https://physiotherapy.ca/sites/default/files/positionstatements/population-health_en.pdf)

#### *Physical Activity for Children and Youth*

[https://physiotherapy.ca/sites/default/files/positionstatements/physical-activity-for-children-and-youth\\_en\\_2.pdf](https://physiotherapy.ca/sites/default/files/positionstatements/physical-activity-for-children-and-youth_en_2.pdf)

### Speech Language Pathologists and Audiologists

Speech Language Pathologists (SLPs) screen, assess, identify and treat speech, language, voice, fluency (stuttering), swallowing and feeding problems for all age groups in addition to advocating for the prevention of these disorders.

Audiologists screen, assess, identify and treat hearing loss, auditory processing disorders, tinnitus and other auditory disorders, as well as balance problems for people of all ages. Audiologists also advocate for the prevention of these disorders. Communication health assistants play an important and valued role by working in a supportive capacity with audiologists and SLPs.

#### National Association

Speech-Language and Audiology Canada (SAC)  
<http://www.sac-oac.ca>  
Phone: 613-567-9968  
Toll-Free: 1-800-259-8519  
Email: [info@sac-oac.ca](mailto:info@sac-oac.ca)

#### Provincial Associations

<http://www.sac-oac.ca/professional-resources/provincialterritorial-associations>

#### Relevant Position Statements

*Speech, Language and Hearing Services for First Nations, Métis and Inuit Children in Canada with a Focus on Children 0-6 years of Age.*  
<http://www.sac-oac.ca/sites/default/files/resources/Complete%20report%20-%20English.pdf>

#### *Use of Telepractice for SAC SLPs and Audiologists (2006)*

[http://www.sac-oac.ca/sites/default/files/resources/sac\\_telepractice\\_position\\_paper\\_english.pdf](http://www.sac-oac.ca/sites/default/files/resources/sac_telepractice_position_paper_english.pdf)

For more SAC position statements, papers and guidelines, see: <http://www.sac-oac.ca/sac-work/position-papers-and-guidelines>



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