Raising a Child with Early Childhood Dis-ability Supports
Shakonehya:ra's ne shakoyen'okon:'a G'chi-gshkewesiwad
binoonhyag ṣGḍ̃ɬ' r̃Qc;ɬ-ɖ ƛɬQ ɬ ṣGḍ̃ɬ' b:ɬ˨ɬQ ɬ:ɬQ:
Ga-Miinigoowozid Gikendaagoosowin Awaazigish,
Ga-Miinigoowozid Ga-Izhichigetan
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Abstract

The Inclusive Early Childhood Service System Project (IECSS) is a qualitative longitudinal study of families’ experiences of accessing services for their children who have disabilities or developmental delays in early childhood. This article presents findings and analysis of data from Indigenous participants in the IECSS study. The study found that Indigenous families were often very engaged in culturally specific services for their children and families, in addition to accessing mainstream disability support services. Further, the study found that the system operates from a colonial framework that does not align with Indigenous ways of child-rearing and knowledge of human diversity. Consequently, the underlying ideological differences often lead to conflict for Indigenous families as they seek to maintain their cultural understandings of development while accessing supports for their children. These findings suggest that Indigenous concepts of disability and childhood need to be integrated into the current disability support system to increase access and efficacy.

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**About the title:**

Our English title is translated into Mohawk, Ojibway, and Oji-Cree, the languages of our participants because we know from the Elders or Knowledge Keepers that language is key to understanding Indigenous concepts and ideologies. In translation, and then interpretation back to English, we can better understand the cultural practice of raising children, and the cultural construct of disability.

Our Mohawk title is: *Shakonehya:ra's ne shakoyen'okon:'a* (They take care of their children.) or *Yontatehya:ra's ne yontatyen:'a* (One takes care of one's child). We have been told that the Mohawk language is very literal, capturing who is doing what. If they are male or female. It is assumed that when someone has the responsibility to take care of children, that it is in a good way.

Our Ojibway title is: G’chi-gshkewesiwad binoojihiyag Anishnaabe-odiziwin, mnido-odiziwin, miinaa mino bi-maadiziwin

This means that the child is the teacher, teaching us what we do not know through these life stages that are all together. These life stages are to live as native person/people, to live a spiritual life, and to live with spirit within you. In Ojibway/Odawa, Nookimis Bear and Loon Clan tells us that the concept of disability and ability are understood to be there. The children are teaching us what to do and how to be with them.

Our Oji-Cree title is *b柩ۇd^c bۇC^b b cocina* Awaazigish, Ga-Miinigoowozid Gikendaagoosowin Awaazigish, Ga-Miinigoowozid Ga-Izhichigetan

In Anishininiimowin (Oji-Cree), we are told that children each have gifts in their own ways. Children have an inner understanding of themselves and act in ways that reflect that knowledge, even if others do not understand them. This means we need to watch and listen closely to hear what children are trying to tell us.
Introduction

The early intervention service system in Canada is multidisciplinary, with varying approaches to supporting children and families in their development (Underwood, 2012). Although interventions vary in scope, they share the common objective of providing targeted supports for young children with the intention of improving developmental outcomes (Guralnick, 2011). Indigenous children in Canada are often labeled at risk or as having developmental delays within education, health care, social services and other institutional settings (Nguyen, 2011). Indigenous parents access services for their children through mainstream agencies as well as through Indigenous organizations that offer culturally specific programs, such as Aboriginal Head-Start; a culturally based school readiness program premised on Indigenous knowledge and identity development as a precursor to academic achievement (Nguyen, 2011). Indigenous families also sometimes participate in Indigenous programming as part of their own cultural practice and wellbeing, for example going to a Friendship Centre. While those agencies may not offer child-specific programming, they may have the effect of acting as an early intervention program. In spite of that, Indigenous agencies are not recognized by the mainstream as part of the system of disability supports or early intervention. Indigenous children with disabilities may additionally access intervention services such as speech and language programs, behavioural supports, occupational or physical therapies, or medical services, but these services are usually not culturally specific (Niles, Byers, & Krueger, 2007). This article presents findings from a study of Indigenous families’ perspectives of early childhood disability services.

The Inclusive Early Childhood Service System Project (IECSS) is a qualitative longitudinal study of families’ experiences of accessing services for their children who have disabilities or developmental delays in early childhood. Annual family interviews over a three-year period documenting family experiences within the service system aim to uncover institutional responses to children with disabilities and their families. The project has taken place through local partnerships in five geographic areas in Ontario, Canada: The County of Wellington, District of Timiskaming, Constance Lake First Nation, City of Hamilton, and City of Toronto. Geographic diversity enables the project to capture a variety of cultural perspectives with varying approaches to early childhood and disability services in rural, remote, and urban communities. Particular consideration was given to the engagement and involvement of First Nations and Métis partners in the development and implementation of the IECSS project.

Terminology

The term Indigenous is used within this document to refer the descendants of the original inhabitants of North America (also referred to as Turtle Island). This term is inclusive of First Nation, Métis and Inuit communities, both status and non-status. The participants in the study include First Nation and Métis people from urban, rural, and remote areas, both on and off reserve. The participants who identified with specific Indigenous communities are Anishnaabek, Haudenosaunee, and Métis. Not all participants specified with which cultural group they identified therefore, Indigenous is used to refer to these communities collectively. The terms Indigenous and Aboriginal are often used interchangeably in Canada. We use Indigenous as a general term to describe individuals, knowledge and theory from a cultural standpoint, and Aboriginal to describe specific cultural programs or services with that term in their name.
Literature Review

The IECSS project is guided by critical disability theory, with a theoretical perspective grounded in a social model of disability. The social model of disability proposes that disability is the result of interaction between a person with an impairment and the attitudinal and environmental barriers that hinder them from fully participating in the dominant society on an equal basis with others (Oliver, 2013; United Nations, 2007). The conceptualization of disability has been an important point of discussion amongst the Indigenous collaborators in the study. Disability is an ambiguous concept from an Indigenous cultural perspective. The word disability is understood to be a medical and colonial term that situates disability within the individual and their family. While the term disability is, therefore, rejected by Indigenous communities, the values of the social model are somewhat aligned with the Indigenous valuing of individual difference as a community asset.

Disability discourses differ between Indigenous and non-Indigenous perspectives. Traditionally, disabilities have been regarded as gifts by Indigenous communities (Alberta Education, 2005; Lovern & Locust, 2013). Many Indigenous languages have no word for the term disability (Durst, 2006), instead, differences in the pace and trajectory of development are mostly seen as what makes an individual unique. One justification for the lack of Indigenous vocabulary to describe disability may have to do with Indigenous beliefs regarding the power of language. Some Indigenous communities believe that by saying particular words, you are breathing life into them and therefore bringing them into reality (Lovern, & Locust, 2013). According to some Indigenous Peoples, labels, through the power of language, can be limiting to individuals. Medical definitions of disablement generally speak to an inability centred in the individual to support themselves or contribute to society (Durst, 2006). However, these values are rooted in a cultural ideology. What constitutes a disability may depend on the cultural lens of those experiencing impairment or social discrimination on the basis of ability. While there is not always full participation in traditional life for individuals with disabilities, Indigenous communities hold the view that every individual has place and position, and that there is something to be learned by each member of the community (Durst, 2006).

Many Indigenous communities consider children to be gifts from the Creator, sent to the community for a specific reason (Aboriginal Head Start Initiative, 1998; Alberta Education, 2005). Every child therefore has a purpose, has value, and belongs within the community (Aboriginal Head Start Initiative, 1998; Alberta Education, 2005). The concept of gifts also extends to the unique abilities that each child brings to the world; every child has something to offer and is honoured for who they are and how they can contribute to the larger society (Aboriginal Head Start Initiative, 1998; Alberta Education, 2005). However, within the dominant service system, these gifts are not always valued or even recognized. Based on their cultural understanding of the world, Indigenous children engage in the learning process differently than non-Indigenous children (Best Start Resource Centre, 2010), which can be conceived by mainstream service providers as concerning.

Colonization has had significant long-lasting and intergenerational effects on Indigenous populations in Canada. Yet, it is only relatively recent that colonialism has been acknowledged in dominant discourse as a risk factor for optimal development in early childhood (see Truth and Reconciliation Commission of Canada, 2015; and Bombay, Matheson, & Anisman, 2014). Indigenous children are often deemed as disadvantaged in a variety of areas, but services focus on individual impairment rather than on environmental and historical influences that impede their development. The ‘at risk’ discourse further oppresses particular groups and perpetuates negative stereotypes (Swadener, & Lubeck, 1995) which for
Indigenous Peoples can be disabling regardless of impairment. While Indigenous students may face predispositions to a number of negative health outcomes (Bombay, Matheson, & Anisman, 2014; Nagy & Sehdev, 2012), the high rate of diagnosis may have more to do with the early intervention system than the children themselves. Indigenous children are far more likely to be identified as having a learning or behavioural disability than any other diagnostic category (Wright, Hiebert-Murphy, & Gosek, 2005). It is important therefore, for service providers to have an understanding of the colonial histories that condone this cultural separation in order to begin decolonizing their assessment practices and increase support for Indigenous families as a whole (Hollinsworth, 2013).

This study examines the ways that families interact with early childhood services and how they describe the intersections of Indigenous ways of knowing and being, and the institutional practices that are part of the early childhood education, care and intervention system. We are particularly interested in the ways that disability discourses, organizing of services, and Indigenous worldview can lead to a stronger system of support for all children.

Method

This paper has been written through the collaboration of many individuals from differing cultural and academic backgrounds. The authors are Indigenous scholars from Anishinaabek (Nicole Ineese-Nash) and Haudenosaunee (Yvonne Bomberry) communities in Ontario, along with the principal investigator for the IECSS project (Kathryn Underwood) and the IECSS project co-investigator and representative of the Temiskaming Elders’ Council (Arlene Hache). Indigenous analysis of data that is part of the larger IECSS project was guided by the District of Temiskaming Elders’ Council and completed in partnership with several Indigenous community-based members affiliated with the project. Ownership, Control, Access and Possession (OCAP) principles were applied to the project through a Memorandum of Understanding (MOU) with the Temiskaming Native Women’s Support Group and all of the IECSS partner organizations. From the outset, the District of Timiskaming Elders’ Council guided the research, developed partnerships with the research team and community members, and aided in the integration of the Indigenous participant interviews in the analysis of the project.

This article uses data from the first year of the three-year longitudinal study. Participants were recruited through flyers given out at Indigenous service organizations such as Aboriginal Head Start, Aboriginal health services, Native women’s organizations, Indian Friendship Centres, and through mainstream childcare, family support and early intervention agencies. The IECSS project has a total of 67 participants, with 21 of those identifying themselves and/or their children as Indigenous. Of those 21 participants, two were non-Indigenous caregivers of Indigenous children; two were adoptive parents; and two were grandparents. There was one Indigenous father and 16 Indigenous mothers. Indigenous participants identified as Ojibway, Oji-Cree, Cree, Métis, Mohawk, Algonquin, Cayuga, Tuscarora, and Onondaga or they did not specify.

The project was reviewed by the community partners and the ethics boards at Ryerson University, McMaster University and the University of Guelph. The data were collected through semi-structured qualitative interviews as well as service and demographic questionnaires. Interviews took place in a location selected by the participants, usually a coffee shop or public place. Interviews were conducted by research assistants who were hired based on their experience and engagement with Indigenous communities. Participants were offered tobacco to acknowledge the sharing of their stories and a $30 gift certificate. During the interviews, participants were asked to 1) describe their child, 2) describe the
services they access, and 3) discuss their experience of these services from their child and family perspectives. The interviews were transcribed verbatim, then coded on the basis of recurrent topics or concepts, which will be discussed in the following section.

The interviews were first coded by a research assistant. All Indigenous research assistants were then invited to an analysis meeting with the principal investigator and the Indigenous lead co-investigator. The concepts were revised by the first author of this paper and shared with the Elders’ Council and community members in each of the geographic communities. These discussions informed our understanding of the findings. The analysis by Elders was in the form of further stories, that connected the participants’ perspectives to the Elders’ own experiences and to the cultural way in which the Elders understood the experiences of the families. The authors of this paper were present for some or all of the analytical discussions. As authors of this paper, we recognize that our presentation of this research study is informed by the knowledge that has been shared with us, and that this research is a collective process informed by the communities. We have, however, written this article with the intent that the study participants’ stories are at the centre of our analysis. All of the study participants have been asked to participate in follow-up interviews, which will yield longitudinal data about the families and the children in this study.

Findings

Each of the concepts identified in this study are intrinsically interrelated. Organizing human experiences into discreet categories is a Western methodology. We present distinct categories for ease of reading, but acknowledge the intricacies and nuances of lived experiences, and the interrelated ideas which are part of our analysis. Through descriptions of their children, their family, their community, and their interactions with services, participants identified the seven key concepts and concerns that shape their experiences: culture and worldview; historical impacts; access to Indigenous services; geographic accessibility; family support; and transition to school. These concepts are presented along with the interpretation that comes from our partnerships.

Culture and Worldview

Culture is an ambiguous term but we define it as a general worldview that shapes the values and behaviours of the individuals and institutions of a given society. Cultural identity is a personal interpretation of the world that manifests differently in the lives of individuals. Throughout the interviews, cultural identity was described in a variety of ways. Some participants identified as Canadian if they did not participate in traditional ceremonies. ‘Canadian’ was not necessarily seen as a cultural identity, but a neutral way of being. For example, one participant said:

[A]side from my father’s involvement culturally, we haven’t had a lot of specific Aboriginal culture stuff going on. So, I probably wouldn’t specifically seek any of the Aboriginal services. Just because in terms of my upbringing and experiences it is probably more in line with just your average Canadian.

Some participants were very engaged in cultural practices, such as smudging, attending Powwows, and speaking their Indigenous language, while others did not participate in the explicit practice of Indigenous traditions and cultural activities. Cultural practices such as smudging were used by some families in the home; one participant used smudging to help her child regulate his emotions. However, some families only engaged in ceremonial practices within service agencies or programs. These practices are spiritual in nature and participants’ described them as a way of being and knowing. One participant identified
herself as a spiritual conduit and felt that some of what was understood in the service system as a disability in her child could be explained by the child having similar spiritual gifts. One parent identified not being able to attend her home community for ceremonies and felt she had lost a connection to her culture. Cultural identity affected families’ choices regarding services as well as their overall child-rearing philosophies.

Most participants were in contact with an Indigenous support service. Many parents who were regularly involved in Indigenous programs felt that culture was important to them and their children. For instance, one mother said,

Being a mother and a family person, we try to incorporate our cultural beliefs and spiritual values when raising our children. It is very hard to live in a society where those teachings and values aren’t always appreciated. My children have had a very strong understanding since a young age about those cultural values and beliefs.

Several parents made specific reference to learning traditional languages, which led them to culturally specific services and supports. One of the parents expressed regret that although there were programs for children to learn their Indigenous language, there were limited supports for adults to do the same. A few participants felt connected to their Indigenous culture by accessing family support programs that were for their children, but offered cultural activities for the parents such as traditional crafts, storytelling, and dancing. This may have helped to mitigate the conflicting values between Indigenous and non-Indigenous early childhood programs. As one participant said:

You are trying to walk and hold your hand and guide your child with one foot in the western door and one foot in the traditional red road. It’s like two roads you have to walk with your child and help them. I think that is for every First Nations or Indigenous child who are closely connected to Aboriginal culture to have to navigate through both western society and cultural beliefs.

However, not all Indigenous parents were actively engaged in culturally-specific support services. One participant accessed Indigenous services as a programming resource rather than a major support network because her child was involved with many clinical and medical services. Other participants did not engage in Indigenous cultural practices or supports, in part because they were non-Indigenous people raising Indigenous children.

One participant was Métis, but her upbringing was more consistent with that of an “average Canadian” and so she would not necessarily seek out culturally specific services. In this case, the child was accessing several intensive intervention services through multiple agencies, all of which were not available through Indigenous agencies. One mother did not identify her child as Indigenous, but later described her husband as being from a First Nation community and acknowledged accessing Indigenous parenting groups early in her child’s life. Bi-cultural identity was an important consideration in understanding participant perspectives, as it influenced which services were being accessed and whether children had the ability to develop their personal cultural identities and practice cultural traditions as young children. Yet there is little effort to integrate cultural ways of knowing into the general disability support system. As a result, the system can fail to support Indigenous families and label them as requiring special supports if they are not displaying traits that are valued from a Western perspective.

Historical Context
The literature indicates that intergenerational experience has an impact on Indigenous children and their families. This is evident in both the transmission of Indigenous knowledge in which family and familial relations are at the centre of identity and in how inter-generational trauma that is the result of Canadian policies of assimilation and cultural genocide has been transferred. Two of the participants described their own histories and experiences with bullying, discrimination and racism in childhood. These families were sensitive to both the actual and potential for their children to have similar experiences. One mother told her child “I went through the same thing that you’re going through right now, and I don’t remember having feelings like this at your age but… it’s hard and you’re going to be okay.”

One parent described having difficulty talking with service providers about her son. She described feeling nervous, speaking quickly and becoming frustrated and irritated when discussing her son’s behaviour with professionals. She attributed this to the impact of her childhood history of involvement with child welfare services. One non-Indigenous participant did not want to inform her child of his patrilineal Indigenous heritage for fear that the child would seek out information about his father. This mother was incarcerated for the first few months of her child’s life, and when she was released the father discontinued his involvement with the child. This led to her reluctance in applying for Indian Status as she felt she would need to have contact with the father because the child’s Indigenous ancestry was through his family line. Participants’ experiences with the education system varied as well. Some mothers had not completed high school while others were highly educated professionals. It was evident from our documentation of services, that education of the parents and their financial resources created differences in the types of services they accessed for their children.

**Access to Indigenous Services**

Most of the participants were actively engaged in culturally specific programs in their communities and they often described Indigenous services centres as being their central support system. Many parents expressed appreciation towards Indigenous services that incorporated culture into programs for their children. It was important that these services were free and accessible. Many of the parents felt very comfortable in the Indigenous child care services and expressed anxiety regarding their children transitioning into the non-Indigenous school system. One mother said she wished her child could remain at the Indigenous child care program as opposed to going to Elementary School. This desire was linked to both comfort with the program and a feeling that her child may be bullied and have less support within a larger classroom. At the time of the first interviews, Full Day Kindergarten was a new program with larger class sizes than previous half-day programs and many parents in the IECSS project were unclear about what to expect.

Conversely, some participants felt uncomfortable accessing Indigenous services. In some instances this was because the family did not practice Indigenous cultural values at home, or the primary caregiver was non-Indigenous and they did not feel welcome. In some cases, families living in communities with smaller populations felt uncomfortable accessing the Indigenous services due to personal relationships with service providers. These participants sought out support in larger service agencies or other communities. Elders told us that in some communities, the cultural programs for young children were provided by the child protection agency which made many Indigenous families uncomfortable. There remains an inherent fear of child protection agencies, due to the historic and ongoing colonial practice of apprehending Indigenous children and removing them from their homes and communities.
Finally, some families did not access Indigenous services because they were spending their time in disability specific supports. Many Indigenous agencies do not have disability specific supports, in part because the medicalized approaches in disability services are not consistent with Indigenous values of child development. The result is that some families have to choose between disability services and cultural services.

**Geographic Accessibility**

There were differences in the availability of Indigenous service agencies and service providers who had cultural knowledge, depending on where participants lived. There were also significant differences in availability of disability services between rural and urban and northern and southern communities. Several families in the north accessed an Indigenous support service, which was relatively nearby, but for all other developmental services traveled a great distance for appointments. Despite the variation of distances, all parents were willing to travel to access the supports and services their child required. For instance, one mother said:

I was willing to be flexible, I just wanted the service. It had nothing to do with like, that we put barriers in place. We were open and willing to go to […] wherever you want to send us. Traveling to appointments at times hindered children from attending school or early years programs, and in smaller communities, distanced them from their families. Another participant said:

The traveling I’m finding… really hectic. […] When we travel to Ottawa he misses about almost a week. […] Plus, we take his, we take my other son too so they both miss school because of his travel.

Participants from Temiskaming and Constance Lake (in northern Ontario) differed from participants in Hamilton and Toronto in that they did not generally identify distance to services as a barrier. In urban settings, there is better access to public transit as well as a much higher concentration of services. However, families in all communities did have to leave their neighbourhoods or cities to get disability specific health services, or specialized supports.

**Language and Construction of Disability**

Participants ways of describing children’s disabilities and development varied in terms of the vocabulary and detail. Most participants were aware of the developmental differences their child experienced as well as their child’s strengths. However, parents who identified more closely with their Indigenous culture used less detailed descriptions of development and pathology. Elders explained that Indigenous ways of understanding human differences vary significantly from medicalized ways of talking about individuals in Eurocentric societies. In addition, Elders told us that historical and current practices of surveilling Indigenous families and blaming parents for poor developmental environments makes it very high risk for Indigenous parents to talk openly about developmental concerns regarding their children.

Some parents explained that they had uncertainty regarding the services available or had difficulty understanding the language used when discussing developmental concerns with professionals. Participants described feeling dismissed by professionals or not feeling equipped to talk about their child’s disability. One mother repeatedly explained that doctors denied her concerns and because she did not have the specific vocabulary to express them, she had to seek out information herself. Another
explanation could be the way that some medical professionals continue to disregard Indigenous people and their worldview concerning their children. For example, one participant said:

> It is hard as a parent, because it is confusing because you have a western view of what the issues are with your child and then you have a traditional perspective on why your children are experiencing these behavior and health issues and they don’t always match up.

Most of the participants described concerns about their children that related to behaviour or speech development. In trying to understand why participants did not describe their children’s development in detail, we heard from the Elders that from an Indigenous worldview, children are perceived as developing at their own pace. Therefore it may not be that there is limited understanding of developmental concerns, but more so that Indigenous parents are often told by their mothers, aunties, and Elders not to worry if their children are not walking and talking when others think they should. Indigenous teachings are that children will develop those skills when they are ready. Further, when you are raised in a culture that has no word for disability it is difficult to talk with professionals who do not understand your worldview.

**Family support**

All of our participants lived with extended family or very close to the family. Most participants described their family’s involvement in the raising of their children as critical to their overall support. For example, one participant said “[My child] has very involved extended family. He is the only kid in the family right now, so my parents have moved to live like three blocks away so they help”. In many Indigenous cultures, extended families share responsibility for raising children.

Family networks included extended family who helped by picking up children from childcare services, sharing opinions on children’s behaviour, and offering personal, and in some cases professional advice when they worked within social service professions. Further, family relationships were important in terms of sharing cultural practices and emotional support for young children. For example, one mother valued having her children’s cousins in the same classroom, when her child transitioned into public school. Many families described having large extended families who depended on one another. Family support is significantly important for Indigenous parents as it is consistent with traditional methods of child-rearing.

Outside of the Indigenous agencies, few programs are designed to include family networks. Early intervention services, child welfare, child care, and family support can target parents, but exclude other relatives or community members. This means that some of the most important relationships in a child’s life and some of the most critical supports for their parents, are not part of the organization of early childhood and disability services.

**Transition to School**

The final concept that emerged from our interviews was that many parents who had found suitable supports and services in the early years were concerned about the transition to school. One reason for this concern was the class size difference between the Indigenous-specific childcare programs, which had about five to eight children and kindergarten classes that might have up to thirty children. Indigenous programs were also often half-day programming as opposed to full-day school programs. Participants
described concerns that children’s behaviours that were acceptable in Indigenous cultural contexts might be considered inappropriate in schools, which may lead to Indigenous children being bullied. In large kindergartens, parents were also concerned about bullying because of a child’s physical size, or being made fun of on the basis of developmental difference. Participants described feeling stress, anxiety, and hesitation when thinking of the transition to school. One participant explained:

I am just really concerned about my son going into grade one next year. He tries to interact socially with other kids in the park and things like that and they seem to wander off from him or make fun of him and how he talks. It’s difficult for my son, he gets really upset.

A few of the participants described their child’s behaviour varying in different contexts, resulting in behavioural issues within a childcare or school setting. Participants noted that the same behaviours at home were not an issue of concern. One participant explained: “I’m not a hundred percent sure if it’s just the environment here or- or what because he’s different everywhere”. The transition into school can be difficult when the child is coming from an Indigenous program because the underlying pedagogical principles and the settings in which they are offered can differ greatly.

In some cases, children’s conditions limited them from attending early childhood programming altogether. Some participants told us Indigenous childcare centres had refused to enroll a child citing a lack of disability supports as the reason. By contrast, some Indigenous organizations are known to have a more holistic and welcoming atmosphere because of their manifestation of Indigenous principles and ways of knowing in the curriculum. In these cases, some programs are attracting children with disabilities because families feel comfortable with the staff and model of care.

**Discussion**

Early intervention has been widely regarded as essential to promoting optimal developmental outcomes for children with developmental concerns and disabilities in the early years (Guralnick, 2011). At the heart of child development is cultural practice; and for all communities the Elders noted that language is at the heart of cultural practice and attachment. Our study indicates that Indigenous families see language and ceremony as central to cultural identity and to a spiritual way of being and knowing the world. This valuing of Indigenous knowledge is critical to ensuring that children have access to their identity and to valuing Indigenous parenting. However, traditional Indigenous intervention and treatment methods are mostly discounted by the current service system. Indigenous healing practices vary across nations. Many North American Indigenous communities believe that healing intervention is a process that is spread over a prolonged period of time (Portman & Garrett, 2006), a worldview that is in direct contrast to the mainstream message that intervention must be early. Indigenous approaches to treatment require a holistic understanding of the individual within the context of their lives, considering not only their physical well-being, but also their emotional, mental, and spiritual health as pertinent to overall wellness (Portman & Garrett, 2006). Further, disability, wellness, and healing occur in Indigenous cultures through an individual’s relations with the people and non-human world around them (Ross, 2014). In mainstream intervention programs, treatment is prescribed within diagnostic categories for individual children without an understanding of the web of context that contributes to that child’s overall wellbeing. In part, this context includes the historical injustices and ongoing discrimination that Indigenous Peoples face in Canada today.
In addition to the under-valuing of Indigenous ways of understanding, the study found accessibility of services is a problem for many families. Many Indigenous people including participants in the study are forced to make choices between clinical or medical services that are not culturally safe or cultural services that do not offer disability supports (Chapman, 2012). However, Indigenous early childhood programs can aid in children’s development of positive self-identity and promote optimal growth (Greenwood, 2006). Even so, we have found that culturally specific services for Indigenous children with disabilities are relatively non-existent, and as Chapman (2012) notes those that do exist seem to integrate culture only on a superficial level.

Each of the participants offered unique and diverse perspectives that facilitated new ways of understanding how families accessed support. Indigenous families sought support in ways that both differed and aligned with participants in the larger IECSS project. For Indigenous families, supportive services did not always refer to those that incorporated ceremony or traditional beliefs, rather services that integrated an Indigenous worldview and the experiences of their family. Indigenous services were not only supportive for the child, but were also a place for engaging in community where there was a sense of belonging for the entire family, but they did not always include children with disabilities. Rural and remote communities often had fewer options for intervention services, or interventions were offered outside of the community. While some of these families were able to access travel grants and support to aid in getting to a service, there was a lack of consideration of how ongoing disruption would affect children’s ability to participate in their community. The expectation that children leave their community in order to access services also is reminiscent of residential schools and should be understood within that historical context.

Conclusion

Early Intervention is often thrust upon Indigenous children within a colonial structure that may not be compatible with their Indigenous worldview. These interventions may also not be appropriate for all children, because of the underlying values embedded in them, and they can be difficult to access due to long waitlists, cost, location, and number of spaces. The services are often without culturally specific and therefore appropriate approaches. The lack of cultural support in disability services for Indigenous children exposes the need to integrate Indigenous worldviews into the current service system as well as allow for Indigenous services to develop their own models of disability support. This is a challenge because of the inherent differences in disability discourses from Indigenous versus non-Indigenous perspectives (Durst, 2006). Jurisdictional disputes on funding of education and health services for Indigenous children are part of the context in which institutional practices have developed (Blackstock, 2012). Indigenous children are an inseparable entity in early childhood support services; therefore, these environments serve as critical places for decolonizing the support service system as a whole and promoting positive outcomes for Indigenous children and their communities (Greenwood, 2006).

Finally, our study confirms what has been seen in the literature. Even when Indigenous people identify as having a disability, they still face barriers in accessing appropriate services. Many individuals living on reserve are forced to leave their home communities in order to access health and social services pertaining to their impairment (Durst, Bluechardt, Morin, & Rezansoff, 2001). Consequently, they are often isolated from their families and must live in foreign and potentially hostile environments as a result (Durst et al., 2001). Indigenous people with disabilities who live in urban settings are still not fully participating within the dominant culture, due to marginalization, societal attitudes, lack of information, and a shortage of culturally appropriate services (Durst et al., 2001). Mistrust of non-Indigenous social
institutions on the part of First Nations and Mètis communities, rooted in years of colonialism and oppression, has further hindered access to support services for individuals with disabilities (Durst et al., 2001). In order to support Indigenous people with disabilities, integration of their ideologies into the overarching philosophies of disability support services may be necessary. To achieve this however, disability discourse itself may need to undergo a process of decolonization to challenge the current colonial context in which these services are offered.

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