The Inclusive Early Childhood Service System Project (IECSS)

The Inclusive Early Childhood Service System project is a partnership between the County of Wellington and Ryerson University, and a number of academic, municipal and community partners, including Native Child and Family Services of Toronto, Niwasa Aboriginal Education Programs in Hamilton, and the Native Women’s Support Group in the District of Timiskaming. The work presented in this brief is informed by consultation and partnership with these agencies, and by our research.

The purpose of the project is to better understand experiences of disability in early childhood, and to understand how services are delivered in varied geographic and cultural contexts. Our aim is to build theoretical understanding that may inform social policy for the purpose of having more respectful and responsive supports that recognize the value of disability identities, and the need for universally designed services.

The IECSS team meets regularly with the District of Temiskaming Elders Council to share participants’ stories and hear further stories. The Elders share their understandings of child development and difference. In February 2017 the Elders Council hosted a gathering in Toronto with our Indigenous partner agencies, and individual researchers to engage in a discussion of the Indigenous findings of the project and the implications they may have on shaping early years and disability policy.

This is the seventh in a series of policy briefs that are prepared as part of the IECSS Project. To view the other briefs in this series please visit our website.

Indigenous Early Learning and Care

Indigenous children in Canada navigate a variety of early learning and care settings, operating from different ideological frameworks and pedagogical approaches, including both Indigenous specific and general programs (Viruru, 2005). The early learning and care sector includes a broad range of services that may include, early childhood education (Friendly, Grady, Macdonald, & Forster, 2015), childcare (Friendly, 2008), family support programs (Trivette & Dunst, 2007), developmental supports (Greenwood, de Leeuw & Fraser, 2007), and early intervention services (Guralnick, 2011). Children are part of communities, and participate in cultural, social and relational interactions, programs and events (Dunst et al., 2002). Families themselves are also an important setting for early learning and socialization opportunities, as are family focused services even if not specifically directed at children. This has important implications in the development of a multilateral Indigenous ELCC framework, as all programs in which families participate can provide teaching and care that may be of value to Indigenous
families. This brief discusses an Indigenous ELCC framework through the experiences shared with us in research.

**Indigenous Perspectives on Disability**

The IECSS project has 67 family participants who are raising children with disabilities or developmental concerns. We are interviewing these families once per year over three years in Toronto, Hamilton, the County of Wellington, the District of Timiskaming, and Constance Lake First Nation. Of these participants, 21 identify as First Nations or Métis or are caring for a child who is of Indigenous ancestry. These families identify as Ojibway, Oji-Cree, Cree, Métis, Mohawk, Algonquin, Cayuga, Tuscarora, and Onondaga.

The Elders tell us that children are gifts. They are unique and live in a relational world. Children who are identified as having a disability through mainstream diagnostic assessment or placement in early intervention, are knowledgeable in their own ways and teach us how to interact with them if we listen with attunement. Children with disabilities have knowledge to share as well as having the need to learn. Indigenous child rearing requires adults to watch, learn and discern what gifts the child brings with them. This perspective conflicts with western intervention ideologies that are focused on intervening early in order to be effective. This does not mean that Indigenous children do not have the right to early intervention, but it must be balanced with Indigenous knowledge of child development.

**Recommendation**

Intervention for Indigenous children should be provided in a context that is culturally safe and familiar to the child. An Indigenous ELCC Framework must recognize diversity of ability and development of individual children. More work is needed to articulate a theory of Indigenous Disability Culture.

Our study indicates that Indigenous ways of understanding childhood are consistent with many parents’ understanding of disability across cultures. Early intervention that aims to ‘fix’ the child can damage the child’s spirit, usurp parental confidence and relationships, and hinder the development of children’s unique gifts. Elders and service providers tell us that at the core of early learning and care is recognizing and nurturing every child’s spirit within their cultural context.

Those who know the child know best how to support the child’s unique gifts, however they are often not involved in the decisions affecting their child in institutional program settings. Elders tell us that in order to live a good life, you cannot simply practice culture; you must live it every day. When Indigenous families interact with programs and services that conflict with their cultural ways of raising their child, they are impacted on a spiritual level.
What We Are Learning

The IECSS project partnership includes Indigenous service providers and community partners to ensure that Indigenous worldviews and values are respected within the design, analysis, and dissemination of the study’s findings. These partners are Native Child and Family Services of Toronto, Niwasa Aboriginal Education Programs in Hamilton, and the Native Women’s Support Group in the District of Timiskaming. The project is guided by the District of Timiskaming Council of Elders.

Indigenous families interact with a variety of services including early childhood educators, educational assistants, speech and language pathologists, medical professionals, and a wide range of other therapists and professionals. Indigenous families describe developmental concerns as part of a child’s personality, which is not necessarily seen as troublesome in the home environment. Families believe that interventions for children are important within early childhood and school contexts, and developmental success in early years and school environments is a priority for the families in our study. We have heard about some conflict with service providers, when families do not share professionals’ views of their children, or their philosophy. Many families feel that the child they know is not the same as the child being described to them by professionals. For example, medical language used by professionals is sometimes not consistent with family views, and families feel that they are not heard within services that use medical ways of understanding dis/ability. This strains family professional relationships and in some cases leads children being excluded from programs.

Recommendation

ELCC programs should be family oriented and reduce institutional barriers including exclusion of children on the basis of disability. There must be a recognition of the broad range of early years and family services. Indigenous children and families access both Indigenous and disability services.

Geography

Access to services is affected by geography and the institutional structures that are available in the community where a family lives. In northern Ontario, participants in our study access fewer services than families in southern Ontario. Many families have to travel for services, which takes them away from their community to have appointments, treatment or therapy, especially for children getting medical care interventions. Traveling takes time and money and impacts participation in the community for children and family members who travel with the child. While funds may be available to help with costs associated with travel, the processes involved with obtaining financial support are complicated.

In urban communities in southern Ontario, social connections for Indigenous families are often situated in other communities, and they are more transient than other families
in our study. Social conditions of some urban Indigenous families also can lead to frequent moves, and interactions with a large number of institutions, including shelters, and low-cost housing. In urban centres with multiple agencies serving Indigenous communities, there is increased access to culturally safe space. However, some Indigenous agencies do not have disability specific services. In urban centres families have more services available in terms of geography, including a private system of services. However, these services are often not accessible because of cost, and lack of cultural safety meaning that families who do not have economic resources and who do not feel comfortable in non-Indigenous services do not have access to the range of services available in cities.

In both urban and rural environments, families who have children with disabilities have far more institutional interactions often in non-Indigenous agencies, increasing the likelihood that families will interact with professionals who do not have knowledge of or sensitivity to Indigenous child rearing values or practices. Time spent accessing services impacts other members of the family. Parents often have to time off work or make arrangements for the care of their other children. Diagnostic appointments are sometimes offered remotely to families in the north, which impacts the quality of relationships with professionals. Remote service delivery also impacts the intensity of service. For example, speech and language services for northern families are typically delivered through monthly appointments, when families in the south are getting weekly appointments.

Culture and Access

Culture is important to most Indigenous families we spoke with. Some families talk explicitly about their children learning traditions, cultural practices, and Indigenous languages. While parents seek out culturally-based ELCC programs in order for children to have opportunities to learn in cultural ways, these programs are not offered in all communities.

Families accessing a large number of early intervention and medical services, are accessing fewer cultural services. Families are having to choose between early intervention and cultural engagement because they do not have time to do both.

Some of the families in our study do not access culturally specific programs or services. Sometimes this is because the parents, or caregivers are non-Indigenous, and sometimes it is because Indigenous ELCC programs do not have disability specific programs. Many families access services for themselves in addition to early intervention services for their children. Some families in our study, have children who have been apprehended by child welfare agencies. These experiences can lead to further mistrust of institutional agencies that operate from an embedded colonial framework.

Recommendation
Indigenous specific ELCC programs can be important places for children to develop their cultural understandings and self-identities. However, they are not always disability accessible. All programs that serve Indigenous children should be both accessible and culturally safe. Diagnostic assessments should not pathologize children by not recognizing their cultural context.

**Institutional Processes**

Finding services to support a child diagnosed with a disability takes a considerable amount of coordination, self-advocacy, and knowledge of interacting with service systems.

From the family perspective, early learning programs, intervention services, medical supports, cultural programs and other social services comprise a network, or system, of early years services. From an institutional standpoint, these services are compartmentalized into distinct program categories, each with their own processes and criteria for access. Families must continuously adapt to the needs of the system in order to access service. The following are some institutional processes that family’s engaged with as they accessed services and supports for their child.

- **Entry Points:** In order to access a variety of support services, families often have to get a referral by another professional which is not always available or clear to families. Each system of services also has their own processes which means that families must learn the system for every service they access.
- **Diagnosis:** Diagnosis is required to access some services. The diagnostic assessments that are required to access services do not fit with Indigenous ways of understanding diverse childhoods.
- **Documentation:** To access early intervention and accessible early years services, families must attend appointments for assessments, and provide documentation of “needs” and diagnoses. This documentation is needed in order to qualify for service. However, many families found the documents to be unclear, and detached from their own ways of knowing their children. Families have to do a great deal of paperwork in order to access programs or qualify for funding which was difficult for some of them.
- **Coordination of Services:** Families experience wait lists, service gaps, and lost referrals when seeking disability supports for their children. Some support services are offered in blocks of therapy, which are defined by the institution rather than the families’ perception of their needs. In some cases, children receive similar services from multiple agencies. Parents are often the key coordinators between agencies. However, if families are not able to do this coordination, and agencies do not facilitate coordination, there is little communication between agencies.
Successes and Promising Practices

Respectful Relationships: Families in our study have had a variety of experiences in ELCC programs and early intervention services. Families describe positive experiences with professionals when they feel their viewpoint is heard, valued and respected. This is sometimes in the context of Indigenous service agencies who understand families’ cultural interpretations of their child’s characteristics, but it also happens in disability services when the child’s pathology is understood. Families describe feeling supported by non-Indigenous service providers when they listen, and when Indigenous service providers are able to support them to get good early intervention services. Families want to be included in decision-making about their child in a meaningful way. All families value relationships both inside and outside of the service system and feel supported when their relationships are honoured.

Community Partnerships: Building partnerships across agencies helps to provide services for Indigenous children in ways that are culturally appropriate and safe. Parents described Indigenous early years programs that partnered with speech and language services, and occupational therapy services to create a culturally safe hub. This is a model that incorporates culturally appropriate materials into therapeutic relationships. It also provides reciprocal learning opportunities for early intervention and Indigenous early years staff in culturally safe environments.

Acknowledging Family Work: Programs and services that acknowledge the work of families allow parents to focus on the relationship with their child, rather than on securing documentation to qualify for service. However, by default there is always work involved in institutional interactions because parents are engaging in relationships. Agencies that recognize this work, and support families to do this work are more accessible and respectful of the role of parents and family in their children's lives. For example, Indigenous hub-models in which all therapeutic services are available in one place, as well as schools and childcares that have coordinated therapeutic services and transportation are more accessible. Services that limit requests for documentation by developing shared agency protocols are more accessible as are those that value culturally specific viewpoints.

Planning for the future of Early Learning and Child Care

Envisioning an Indigenous framework of ELCC services requires a holistic understanding of children’s lives, in the context of their families and communities. Each family we spoke to is unique; as are the circumstance of each of their communities. Developing a multilateral framework requires consideration of the needs of all children and families, and a flexibility to adapt to their circumstances and their children. Throughout the IECSS project, families, professionals, and Elders have shared their ideas for a supportive early years service network.
Culture and Language at the Core

Elders tell us that language is at the core of the development of children’s identities. Indigenous languages should be incorporated into all early years programs including disability and early intervention services. Children may spend a considerable amount of time accessing therapeutic and disability services and should not be excluded from learning their culture and language as a result. Elders made it clear that cultural knowledge and cultural living are two different things. While some programs teach Indigenous languages or practice cultural activities such as drumming, they should also embody an Indigenous way of life in everything that they do. As Elder Marcia Brown-Martel says “I can put regalia on, but do I live that life outside of the Powwow?” (Personal Communication, 2017). Indigenous children should be provided opportunities for meaningful engagement in cultural life that extends beyond culture-based curriculum, and that does not exclude them from accessing disability specific services.

Inclusive Environments

Indigenous peoples hold the view that everyone has value, has purpose, and belongs within the community (Alberta Education, 2005). This cultural viewpoint honours the uniqueness of each child. An ELCC framework needs to consider all children with their various histories, experiences, gifts and abilities. ELCC environments need to be designed with all learners in mind, which includes children who experience disability. Indigenous ELCC programs should develop relationships with health, early intervention and therapeutic agencies to support families who are engaging with these agencies and develop an ELCC model that is culturally safe and disability inclusive. Non-Indigenous agencies must also be considered in the development of the ELCC Framework because Indigenous children access many services.

References


