# IECSS

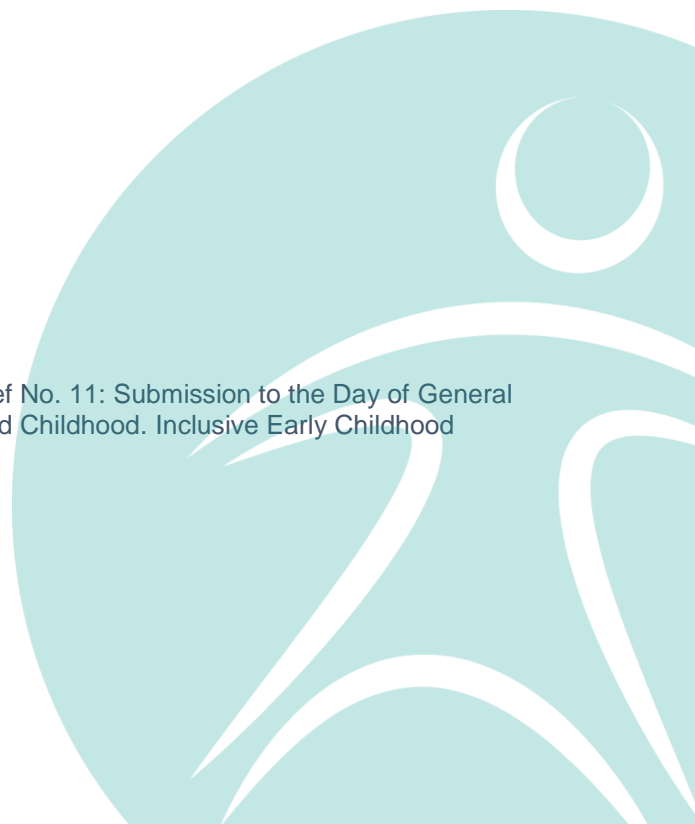**Policy Brief No. 11**
**June 2021**

**Submission to the Day of General Discussion on Children's Rights and Alternative Care: Disability and Childhood**

## IECSS

**The Inclusive Early Childhood Service System Project (IECSS)**

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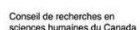
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The IECSS project is a multi-year partnership that seeks to understand how institutions are constituted in our society in order to organize children and their families. The project focuses on disabled childhoods in the context of family, community and society.

## Introduction

This brief is a submission to the Committee on the Rights of the Child, for their Day of General Discussion on Children's Rights and Alternative Care. The brief draws on learnings from the Inclusive Early Childhood Service System project (IECSS), a longitudinal study of family experiences accessing early childhood disability and other services. We have been interviewing families annually in five communities in Ontario, Canada since 2014, and we expanded to the Northwest Territories, Manitoba and British Columbia in 2018.

The IECSS project is interested in understanding how disability is constructed in institutional settings (Underwood et al., 2020). We currently have 137 participants with 35 of those who have interacted with the child welfare system and foster care, adoption processes, family courts or other custodial procedures. Our submission is based on these 35 cases. Many of these families are Indigenous, and many of them are living with low income.

## Disability and alternative care

In our research, we have interviewed families who are birth parents who no longer have custody of their children or who temporarily lost custody, foster parents, and kinship caregivers who include grandparents, aunts, cousins and siblings. In

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our research, we found that disabled[1] children were in alternative care under a variety of circumstances. In some cases, children were in traditional foster care placement; in other cases, children had been in foster care and then adopted. In a number of cases, however, the custodial status was unclear, and this seemed to more often be the case with kinship care, where a birth parent had asked a family member or friend to care for their child, but no legal process had taken place. The custodial status of the relationship had an impact on which funding a family is eligible for, what access they had to specialized services and, and the degree of control the caregiver had in decision-making.

The prevalence of disabled children in alternative care settings in Canada is not definitively known, however, several studies point to the prevalence of disabled children in foster care. Data from the US suggest that disabled children and children with chronic health conditions are more likely in general to experience maltreatment including neglect, physical and sexual abuse (Legano, 2021). One US-based study estimates between 14 and 64% of children in foster care are disabled (Roseneau, 2005). Slayter (2016) found that children with intellectual disabilities were more likely to be in foster care and less likely to have stable care or experience reunification with their birth families. In Canada, Trocmé et al. (2010) determined that approximately 10% of maltreatment investigations involve children who are suspected or identified as being disabled.

For children with chronic health conditions or who are accessing a lot of developmental or

mental health services, it is important that caregivers have the right to make decisions. In some cases, we heard that accessing funding and control over decision-making was much easier with adoption, but we also heard that retaining the fostering relationship versus adoption led to more and continued funding depending on the province or territory in which they lived.

It is also important to know that children may have multiple cultural, racial, linguistic and disability or deaf identities, and they should have access to these identities and communities.

> *Recommendation #1:*
> Given the prevalence of maltreatment and foster care placement for disabled children, it is critical that we listen to and understand the experiences and viewpoints of disabled children, through their own voices.

## Disability and service systems

The early years are a critical time in children's development (Burstein et al., 2021). Advocates for early childhood education and care programs (McCain, 2020), and early intervention researchers (Vargas-Baron et al., 2020) have noted the importance of early access to services, especially for disabled children and their families, as a mechanism to support children's development and participation in schools and other community spaces. Early

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[1] We use the term disabled children here to capture an "identity first" approach. We do, however, recognize that disability is a multifaceted experience and that children and families may not identify with this descriptor.

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years services include childcare and early learning environments, family support and parenting programs, recreation, as well as clinical and therapeutic services. Because disabled children may be accessing a much wider range of services than other children, their viewpoints are important in understanding how these services interact (Davies, Doucet, Atwal & Underwood, 2021).

While many advocates have cited the importance of inclusion in general early childhood and community programs, there are often procedural and structural barriers to the participation of disabled children. Our research team has identified that accessing these services requires a lot of work on the part of families.

That work involves engaging in relationships with professionals, complying with procedures, and seeking medical and psychological services and assessments. Families must also coordinate appointments and professionals across multiple systems including healthcare, early intervention and mainstream early years programs. Some families carry out enormous amounts of work on behalf of this system. Others do not, for many reasons including the fact that families may not have the time, money, literacy, or power to navigate the relationships needed across multiple systems as so they remain marginalized.

The work of families is often disrupted when there are changes in custody. Most processes associated with assessments and applications for services and supports are initiated by parents or guardians. When a child is in foster care, there are many regulations and processes in place to help guardians keep records. However, in kinship custodial relationships there is an expectation that families will keep these records themselves. In our study, we have found that this is difficult for families who have low literacy levels and who have health conditions (including addiction and mental illness). There is an expectation that families of disabled children will be highly organized and compliant with the many procedures involved in accessing special care (Underwood, Church & van Rhijn, 2020). We have also seen some records lost as a result of the death of a parent or guardian. For these reasons, it is important that the services themselves do the work of keeping records and follow up to ensure continuity for the child, particularly when they may be in a fluid custodial situation.

> "Too many children with disabilities get into care, too few get out, and too often they're in the wrong place while there."
> (Rosenau, 2005, p. 2)

**Recommendation #2**
Remove unnecessary bureaucracy and ensure families have the support they need to access services.

**Recommendation #3:**
Ensure that early childhood education, care and intervention systems recognize that children may have fluid custodial relationships. Attach funding to the child, recognizing that changes in custody must not lead to loss of services, or disruptions in communication with caregivers or disruptions in procedural access such as removal from waitlists

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## Disability and parental capacity

McConnell, et al. (2017) note that there is likely bias in child protection responses to parents who have been identified with intellectual disability. In our study, two parents disclosed identifications of intellectual or learning disability, and in both cases they had been closely monitored by child welfare services. These parents also reported active engagement in accessing services for their children. In more than one case, parents or guardians in our study told us they were participating in our research because as part of our research we document and map the work they are doing to access services (see for example Underwood, Frankel, Parekh & Janus, 2019). These maps provided a counter-narrative to official documentation of parental or guardian incapacity, including court records that detailed parent deficits but did not outline the shortcomings of state actors in providing care.

Because of the complexity of the system, when disabled children are placed with foster families, they are often put with foster parents who are considered to have experience with disability and healthcare system navigation. This can facilitate the child's transition into care, but it may also be evidence of the difficulty that birth parents and families face who are not experienced with these systems. This tension is indicative of a system that favours particular parents.

### Recommendation #4:
Create a system where all parents and caregivers are able to participate in early childhood disability services. Ensure that disability is not a reason for parents to be perceived or feel that they do not have capacity to care for their children.

### Recommendation #5:
Create a system where parents are invited into the training environment – erase the false divide between worker expertise and parent expertise and generate a framework that says parents/workers need the same expertise and access to that training

## Racism and ableism in child welfare

Burstein et al. (2021) propose a research informed framework for creating positive early childhood experiences. Their work expressly aims to prevent childhood disability by addressing the systemic causes of adverse childhood experiences including racism, trauma and inequality. Their proposed framework focuses on the need for positive experiences in early childhood so that all children can thrive. However, many early years and child welfare systems construct disability as an individual or adverse event. For example, child welfare along with early childhood and family support systems do not take this approach when using developmental assessments as evidence of parenting capacity and child capabilities.

The Ontario Human Rights Commission (OHRC) has clearly identified over-representation of Indigenous and Black children in the child welfare system. In their report, Childhood Interrupted (2018), the OHRC notes that racial inequality and legacies of colonialism are linked to poorer housing, poverty, poorer mental health, and disability for parents. They call on child welfare systems and governments to avoid

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presuming that these social conditions lead to greater risk for disability or that disability is necessarily evidence of abuse or neglect.

Our research indicates that children's development, which is affected by the same conditions of racial inequality and colonialism, is sometimes used as evidence that parents and family are the cause of developmental delay or disability. Our research is guided by the District of Timiskaming Elders Council who told us that First Nations and Métis families experience surveillance, and deficit views of their children and their parenting, with disregard for the importance of Indigenous children being raised in their communities. Indigenous communities across Turtle Island share the belief that children are gifts and that each one has gifts to share in their communities. This worldview is not well represented in systems that measure normative development through tools and practices that are not culturally relevant.

Through our work mapping how early childhood services, including child welfare, govern the lives of families and children, we have been able to identify the many ways services perpetuate western ways of knowing. This includes assessment, observation in inappropriate settings, and a lack of understanding about how culture, relationships and land-based learning work as both intervention and sites of child development (Lavallee & Lavallee, 2020; Guenette, Sloan, Traynor, & Haché, 2019). We have heard from Indigenous families that they do not have equitable access to disability services, especially when they live in rural and remote communities. We have also heard that some disability services lack cultural relevance, and that some Indigenous services lack disability specific understanding.

Ableism is present in the child welfare system in official judgments about parental capacity to parent. This ableism exists alongside racism. It is important that information about over-representation consider disability, race and poverty as important sites of analysis, program development and decision-making.

**Recommendation #6:**
Disability is higher in communities that have experienced material and other effects of systemic racism and colonialism. Developmental assessments must be considered in this context.

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