

EQUITABLE ACCESS TO INCLUSIVE EARLY LEARNING AND CHILDCARE FOR CHILDREN WITH DISABILITIES: THE FAMILY EXPERIENCE

FULL REPORT



“

Access to inclusive early learning and childcare for children with disabilities is critical for the health and well-being of children, families, communities and populations. ”

SHIFT
COLLECTIVE

inclusion for tomorrow

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The Dalhousie University Senate acknowledges that we are in Mi'kma'ki, the ancestral and unceded territory of the Mi'kmaq People and pays respect to the Indigenous knowledges held by the Mi'kmaq People, and to the wisdom of their Elders past and present. The Mi'kmaq People signed Peace and Friendship Treaties with the Crown, and section 35 of the Constitution Act, 1982, recognizes and affirms Aboriginal and Treaty rights.

We are all Treaty people.

We recognize that African Nova Scotians are a distinct people whose histories, legacies and contributions have enriched that part of Mi'kma'ki known as Nova Scotia for over 400 years.

Gratitude

We extend our heartfelt gratitude to all the participants who generously shared their stories and experiences with us. Your insights and perspectives on navigating access to inclusive early learning and childcare for young children with disabilities have been invaluable to our research. Your willingness to share personal journeys has provided a deeper understanding and enriched our study, contributing significantly to the ongoing dialogue and efforts towards creating more inclusive and supportive early learning environments. We would also like to express our sincere appreciation to Sofia So for her exceptional support in the review and graphic design of this report.

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Executive Summary

Introduction

Accessible and inclusive early learning and childcare for children with disabilities is critical to the goal of promoting the full participation of children with disabilities, their parents, and families in social life on a par with others. There is unequivocal evidence showing that high-quality, inclusive early learning and childcare can mitigate the effects of social disadvantage and promote child health and development. Furthermore, accessible and inclusive early learning and childcare is a vital resource for many families with young children, with and without disabilities, enabling them to integrate earning and caregiving activities, adapt to changing and competing demands, and ‘keep their family life running’.

Families of children with disabilities in Canada have experienced a long history of **inequitable access to early learning and childcare**. There is, however, a paucity of data on the experiences of families in Nova Scotia. The purpose of this investigation was to **understand the experiences and challenges for families of children with disabilities in Nova Scotia navigating access**

to inclusive early learning and childcare. One objective was to **explore barriers and facilitators to accessing inclusive early learning and/or childcare**. Another was to **explore how barriers to accessing inclusive early learning and childcare may affect these families** as they strive to keep their family life running, reconciling work, family and caregiving demands.



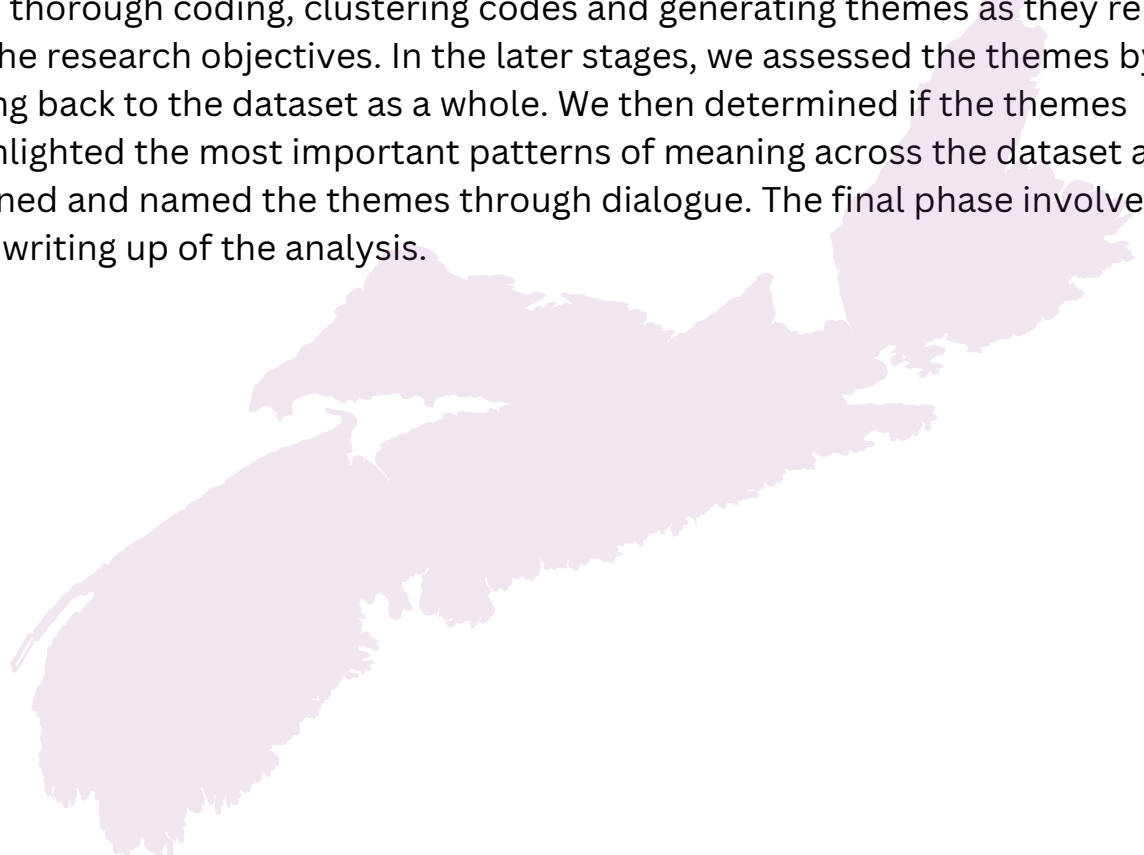
Adopting a critical stance, we take the view that disability is not the outcome of a particular disease or condition but rather an outcome of being a particular person in a particular society at a particular point in time who experiences a particular health-related limitation. Put differently, **disability** can be defined as “**an environmentally contextualized health-related limitation in a child's existing or emergent capacity to perform developmentally appropriate activities and participate, as desired, in society**” (Halfon et. al., 2012, p. 32).

Executive Summary

Methods

An interpretive qualitative study was conducted using semi-structured interviews as the primary data collection method. Semi-structured interviews were conducted with a diverse sample of **17 parents (16 mothers and one father) of preschool-aged (0-5 years) children with disabilities, 3 early learning/childcare centre directors and 1 inclusion coordinator recruited from urban and rural Nova Scotia**. Most of the interviews were conducted by video conferencing or by phone. One parent and the participating inclusion coordinator chose to participate in the interview in person. Interviews ranged from approximately 75 minutes to 120 minutes in length. All interviews were transcribed verbatim. Transcripts were cleaned and de-identified. All participants were given pseudonyms.

Data analysis was supported using Quirkos 2.5.2 qualitative analysis software. Applying Braun and Clarke's (2022) *Six Phases of Thematic Analysis*, we attended to explicit and latent meanings across the interviews. The process involved familiarization and immersion in the data, systematic and thorough coding, clustering codes and generating themes as they relate to the research objectives. In the later stages, we assessed the themes by going back to the dataset as a whole. We then determined if the themes highlighted the most important patterns of meaning across the dataset and refined and named the themes through dialogue. The final phase involved the writing up of the analysis.



Executive Summary

Selected Findings

- Parents spend much time and energy seeking information on early learning and childcare options. Many parents said that they did not realize how difficult of a task it would be: With no available guidance, it was difficult to know where to start. Parents described searching social media and websites for information, posting questions in local social media groups, and talking to other parents to get information and leads on early learning and childcare options.
- Even for families with middle incomes, the costs of childcare could be prohibitive. Families of children with disabilities are more likely than others to experience significant financial hardship. This is due, in part, to the additional costs associated

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Why are we still struggling to provide appropriate places for children with disabilities? It is not like they haven't been around forever.
(Samantha, Parent)

with caring for a child with disabilities, and reduced workforce participation due to inflexible employment conditions, a lack of childcare options, and the sometimes complex care needs of their child with disabilities.

- Many parents are not informed about, and or experience difficulty accessing, available government funding or income support to offset the costs of early learning and childcare. The onerous process of applying for such funding, including qualifying (e.g., obtaining a formal diagnosis from a physician and household income), is a significant barrier, especially for parents who are already marginalized, contributing to growing inequality.



Executive Summary

- Families of children with disabilities are all too often turned away from local early learning and childcare services: Some parents described how their child was denied childcare because the childcare centre did not want to take on more “difficult” or “complicated” cases. As a result, even when families can absorb the costs, many have to travel some distance to access early learning/childcare services. For families who are already experiencing a time crunch, a lengthy ‘commute’ represents a significant barrier to accessing early learning and childcare.
- Parents expressed concern about the capacity of early learning and childcare staff to understand their child’s specific needs [and communicate this understanding to others], actively facilitate their child’s participation in activities, and create a space for relationships and belonging. Several parents described how they trained staff, which could, for example, include showing staff how to

properly care for, change, feed, and communicate with their child and/or relaying information provided by the child’s health care professional.

Parents also identified a number of facilitators of inclusive early learning and childcare.

Such facilitators include:

- higher staff-to-child ratio, with their child receiving (often) one-to-one support
- consistency of staff, meaning their child is supported by someone who ‘knows’ them
- ‘inclusive design,’ i.e., programming for children with varying strengths and learning styles
- effective communication with parents, and between staff, regarding the child’s needs.

Executive Summary

Author Recommendations to Improve Access to Inclusive Early Learning and Childcare

1. Formally **recognize the right** of families of children with disabilities to access inclusive early learning and childcare services in their local community and require childcare providers to create and implement an accessibility and inclusion plan.
2. **Create and maintain a web portal** through which families of children with (and without) disabilities can obtain the information they are seeking, in accessible formats, about inclusive early learning and childcare options in their local community and beyond.
3. To alleviate the administrative burden imposed on families, create a single point of contact for those who may need **assistance navigating systems, including advocacy support and securing any funding available to offset costs.**
4. Consider **eliminating the requirement for families to obtain a formal diagnosis from a physician to qualify for disability funding and services.** Eligibility could also be determined based on allied health professional assessments to reduce wait times.
5. **Establish academic-community partnerships** to build capacity for inclusive early learning and childcare. Consider how, for example, students in occupational therapy, communication sciences, physical therapy, Deaf education, ++, may be able to contribute through field placements.



Situating the Problem

Research Scope & Objectives

Canada has recently committed to improving access to early learning and childcare by implementing a **national universal childcare policy** (Trudeau, 2020; UNICEF, 2019). This has raised many questions for families of children with disabilities in Nova Scotia, where proportionally, more people live with disability than in any other province in Canada (Government of Nova Scotia, 2020). Families of children with disabilities in Canada have experienced a long history of inequitable access to early learning and childcare due to financial, institutional, political, sociocultural, and discriminatory barriers (Eilers, 2020). However, little research is available that attends to families' experiences in the Nova Scotian context (Department of Pediatrics and Healthy Populations Institute, 2022).

As such, **the objectives of this research are to:**

1. Explore barriers and facilitators to accessing inclusive early learning and/or childcare for families of children with disabilities in Nova Scotia.

2. Explore how barriers to access affect parents and families of children with disabilities as they strive to keep their family life running in the face of many changing and competing demands.

The United Nations Conventions on the Rights of the Child (UN General Assembly, 1989) and the Rights of Persons with Disabilities (UN General Assembly, 2006) advocate for children's rights to inclusive play and education. Equitable access to inclusive early learning and childcare necessitates not only the mitigation of barriers (e.g., architectural, economic, social, cultural) but also the active promotion of disability-affirming, inclusive practices and relationships. There are longstanding unmet needs for resources, support, technology, assistive devices, and education-related accommodations for children with disabilities to facilitate inclusive education and social inclusion (Human Resources and Skills Development Canada, 2011; Van Herpt & Fawcett, 2011).

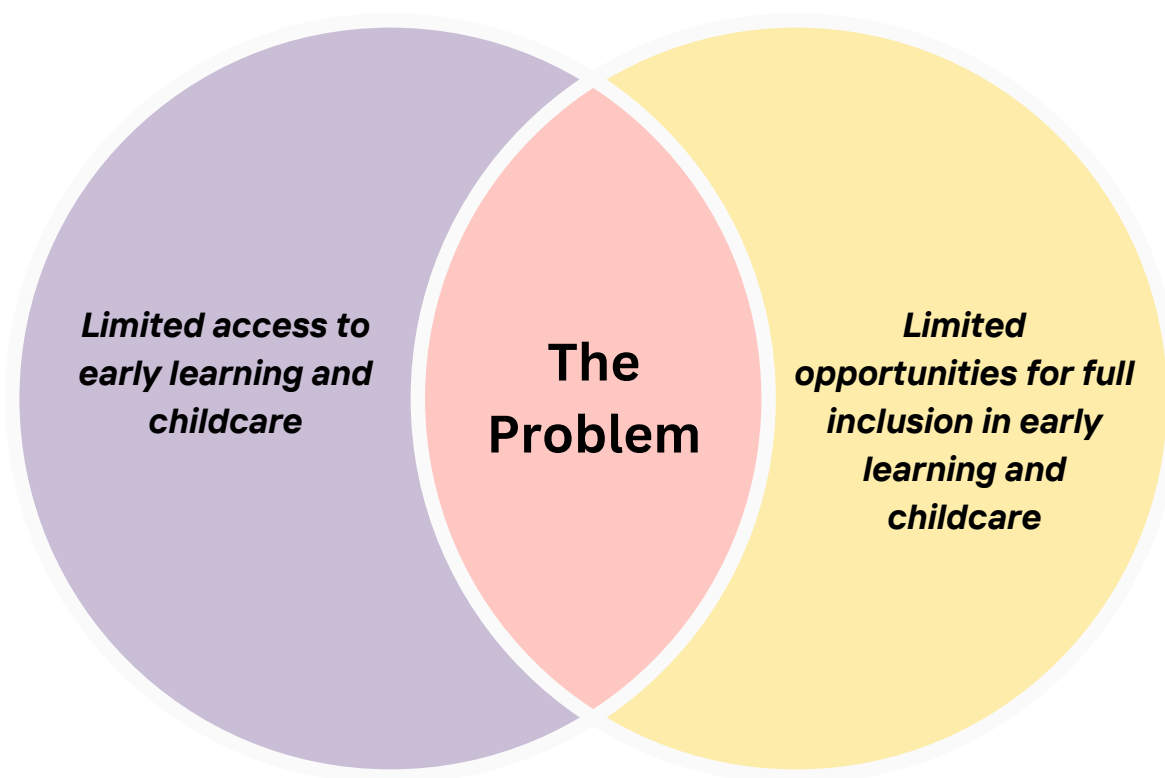
Situating the Problem

Universal access to early learning and childcare is one of our most pressing conversations about culture and community nationally and provincially.

There is a **strong link between high-quality inclusive childcare and better health and developmental outcomes** (Barton & Smith, 2015; Killoran et al., 2007). Quality childcare is determined by the interplay of the overall quality of the setting, the overall culture of inclusion, the degree of inclusion, and the quality of instruction (Knoche et al., 2006).

The problem that frames this study is two-fold:

1. There are systemic gaps that limit families' abilities to **access** and secure early learning and childcare for their preschool-aged children with disabilities.
2. There are systemic gaps that limit opportunities for **full inclusion** in early learning and childcare settings for preschool-aged children with disabilities and their families.



Situating the Problem

Purpose of the Research

*The purpose of this qualitative interpretive study is **to investigate families of preschool-aged children with disabilities' experiences of access to, and inclusion in, formal early learning and childcare settings.***

Access to inclusive early learning and childcare for children with disabilities is critical for the health and wellbeing of children, families, communities, and populations. With a better understanding of families' experiences with access to inclusive early learning and childcare, decision-makers and service providers can **mitigate barriers, facilitate opportunities, and attend to the unique needs** of this priority group. This research has the potential to **directly inform policies and practices** that facilitate equitable access to inclusive early learning and childcare for families with children with disabilities in Nova Scotia.



Situating the Context

Early Learning & Childcare in Canada

The Canadian early learning and childcare system has been based largely on a market model with a patchwork of not-for-profit and profitable services, high fees, and varying degrees of access to childcare dependent on geographic location, among other factors (Prentice & White, 2020). Research indicates there are **not enough spaces for children who need them**. Friendly et al. (2018) found that approximately **only 1 in 5 young children have a regulated childcare space in most provinces**. Other research indicates that almost **one-third of Canadian parents live in what has been labelled a “childcare desert”** (MacDonald, 2018; Young et al., 2020).

A ***Childcare Desert*** is a community where there are **more than 50 young children with less than one early learning and childcare space for every three children of that same age**.

For a number of years, Canada has been working towards a system of universal, affordable, and inclusive

childcare. We are now closer to reaching this goal. Recently, Canada committed to improving equitable access to early learning and childcare by proposing and implementing a national universal childcare policy in which childcare spaces would be available for ten dollars per day (Trudeau, 2020).



Early Learning & Childcare in Nova Scotia

In Nova Scotia, much like many provinces in Canada, the early learning and childcare climate is rapidly shifting. In Nova Scotia, a child can be formally cared for by a licensed childcare centre, a pre-primary program, a home that is approved by a licensed family home childcare agency, a non-regulated childcare provider, or a combination thereof. The Early Years Branch at the provincial

Situating the Context

government's Department of Education and Early Childhood Development is responsible for licensing and monitoring childcare centres, administering childcare subsidies, and administering pre-primary and grade primary programs (Childcare Resource and Research Unit, 2016). As of 2021, there are **334 licensed childcare centres** and **14 licensed Family Home Child Care Agencies** in Nova Scotia (EECD, 2021).



In September 2017, the province began rolling out a free, pre-primary program for children four years of age. In September of the 2020-2021 school year, this pre-primary program was fully implemented across Nova Scotia. Pre-primary is available to all 4-year-old children in their catchment areas, but it is not mandatory (Childcare Resource and Research Unit, 2016). Parents can still choose to enroll their children

in other programs or keep them at home. Pre-primary is stated to be an inclusive program (EECD, 2022b). In 2021, the Report of the Auditor General to the Nova Scotia House of Assembly released a performance report on the *Planning and Implementation of the Pre-Primary Program*. The audit concluded that the initial implementation of the pre-primary program was not adequately planned, and nine recommendations were made. Notably, the audit did not comment on inclusion or children with disabilities.

In the fall of 2022, the province rolled out a pilot early learning program for 3-year-old children in select schools. Priority access to this program is given to children three years of age who identify as equity-seeking and/or from vulnerable families (EECD, 2022b).

In **July 2021**, the Government of Canada and the Province of Nova Scotia jointly signed the **Canada-Nova Scotia Canada-Wide Early Learning and Child Care Agreement**.

Situating the Context

Canada-Nova Scotia Canada-Wide Early Learning & Childcare Agreement

In July 2021, the Government of Canada and the Province of Nova Scotia jointly signed the Canada-Nova Scotia Canada-Wide Early Learning and Child Care Agreement, signalling the start of a shift in Nova Scotia's early learning and childcare environment (EECD, 2021) and establishing early learning and childcare as priorities in Canada and Nova Scotia. Via this agreement, Nova Scotia will receive \$604.9 million in federal funding and invest \$40 million from 2021-2022 to 2025-2026.

Highlights of the Agreement include:

Fee reduction

- The province will significantly reduce costs for families, beginning with a 25 % decrease in April 2022.
- By December 2022, there will be an additional 25% decrease in fees.
- By 2026, families will pay \$10 per day, per child, in all licensed childcare centres that opted to sign the 2022-23 Quality Investment Grant (QIG) Funding Agreement with the Department of Education and Early Childhood Development (EECD). All licensed childcare operators were offered to opt into this funding agreement, with some operators choosing not to do this.
- Government subsidies can still be accessed by families.

Space creation

- In 2022, an additional 1500 early learning and childcare spaces were projected to open in Nova Scotia.
- By March 2026, it is projected that 9500 new spaces will have been created.

Before and After School Care

For 3-5 year-old children, before and after care school options will be improved.

Situating the Context

Wage increases for Early Childhood Educators (ECEs)

- The Nova Scotia Excellence in Early Childhood Education Workforce Strategy is being implemented to increase wages for ECEs, with increases between 14% and 43 % and higher depending on classification level and experience. These wage increases were announced in October 2022 and are retroactive to July 2022.

With the signing of this Agreement,
**Nova Scotia commits to developing
a new provincial organization
responsible for all regulated
childcare in the province**
(Government of Canada, 2022, sect.
5.1.1).



Situating the Context

Inclusive Early Learning & Childcare in Canada

A fundamental right for all children is to **fully engage in inclusive play and learning in their daily lives**, as advocated for by the United Nations Conventions on the Rights of the Child (UN General Assembly, 1989) and the Rights of Persons with Disabilities (UN General Assembly, 2006). Canada has signed both Conventions, thus agreeing to their commitments, including the right to inclusion and the right to access services free from discrimination.

Historically, there has been inequitable access to inclusive early learning and childcare across Canada, including in Nova Scotia, for all children, including children with disabilities (Eilers, 2020; Irwin & Lero, 2021).

Canada has made significant strides in promoting inclusion in primary and secondary education systems across all provinces and territories through legislation and policy. However, there has been little focus on early learning and childcare (Halfon & Friendly, 2013). For Canadian children with disabilities

and their families, there are ongoing critical gaps in relation to inclusion, access to supports and services, and opportunities to fully participate in everyday activities across all provinces and territories (Clark et al., 2009).

A recent study (Irwin & Lero, 2021) evaluated the levels of *program quality* and *inclusion quality* in a sample of inclusive early childcare programs across British Columbia, Ontario, New Brunswick, Manitoba, and Nova Scotia. **Nova Scotia stood out with a significantly lower inclusion quality score compared to the other provinces** in the study, all of which showed much more favourable results (Irwin & Lero, 2021).



Situating the Context

Inclusive Early Learning & Childcare in Nova Scotia

In the Nova Scotia Licensee’s Manual for Regulated Child Care Settings it states that “[i]nclusion supports the right of all children, regardless of their diverse abilities, to participate actively in natural settings within their communities. A natural setting is one in which the child would spend time if [they] did not have a disability (NAEYC/DEC, 2009)” (Government of Nova Scotia, 2021, p. F2). This definition emphasizes inclusion as a right; however, it neglects an emphasis on a felt sense of belonging, a critical component of inclusion as a relational experience (Phelan & Reeves, 2022; Reeves et al., 2023). Alarming, children with disabilities in Nova Scotia are often denied entry to childcare due to a lack of resources to meet their unique needs, and **even if they are accepted, they may not be included** (Irwin & Lero, 2021).

In Nova Scotia, the Early Years Branch at the Department of Education and Early Childhood Development offers the Inclusion Support Grant (ISG) to facilitate the

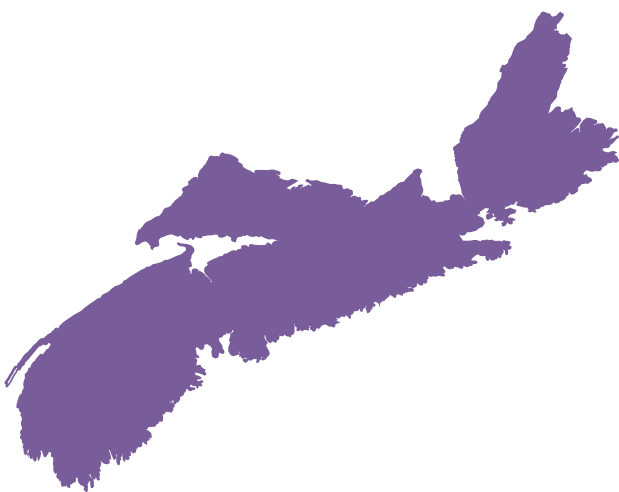
participation of all children in their communities (Nova Scotia Government, n.d.). The Inclusion Support Grant (ISG) aims to assist all regulated childcare centres in creating and sustaining inclusive programs for young children with a focus on diversity, equity, and quality. ISG funding can be used for specialized training and professional development for early childhood educators, hiring additional staff to enhance ratios for the delivery of a facility’s inclusive program, and purchasing educational and resource materials directly related to inclusive programming (Nova Scotia Government, n.d.).

The Canada-Nova Scotia Canada-Wide Early Learning and Child Care Agreement was signed to improve equitable access to childcare by creating more affordable childcare spaces (EECD, 2022).

The provincial government outlined tenant principles in Nova Scotia’s early learning and childcare system. These tenant principles assert that a universal approach to childcare means all children are welcome and belong in early learning and childcare programs in their communities (Government of Canada, 2022).

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Specifically, “Nova Scotia commits to develop and fund a plan to ensure that new space creation ensures diverse and/or vulnerable children and families, including children with disabilities and children needing enhanced or individual supports, Indigenous children, Black and other racialized children, children of newcomers, and official language minorities, have spaces equivalent to or greater than their share of the population in the province or territory” (Government of Canada, 2022, sect. 2.1.1). A new provincial organization will be created to manage childcare and will be responsible for “ensuring that children with disabilities and children needing enhanced or individual supports are welcome, accepted and supported” (Government of Canada, 2022, Annex 2).



In the beginning of the 2023 fiscal year, Nova Scotia will release its Action Plan. The plan will include tracking the progress on the number of children under six years of age with disabilities and/or needing enhanced or individual supports who are in regulated early learning and childcare spaces. Additionally, it will monitor the number or proportion of childcare service providers who offer services adapted to meet the needs of children with disabilities and/or needing enhanced or individual supports (Government of Canada, 2022, sect. 5.1.1).

Finding and securing inclusive early learning and childcare in Nova Scotia has long been an individual family’s responsibility. Children with disabilities and their families have a long-standing history of experiences with inequitable access to inclusive early childcare due to financial, political, social, cultural, and discriminatory barriers (Eilers, 2020). Families want a say in their children’s childcare and early learning. Consideration of the knowledge and viewpoints held by families with children experiencing disabilities are critical to inform an inclusive, universal childcare system designed for all children and their

Situating the Context

families (van Rhijn et al., 2021). Many parents with children with disabilities seek inclusive settings (Barton & Smith, 2015; Odom et al., 2011); “factors that influenced families’ decisions about childcare for their children with disabilities mirror those factors that support inclusion” (Weglarz-Ward & Santos, 2018, p. 140).

As Nova Scotia currently lacks policies or a framework to promote inclusion in early learning and childcare settings, **families often end up taking on the responsibility of promoting inclusion themselves.**



Methodology

Research Methods & Theoretical Approach

Ethical approval was obtained from Dalhousie University on April 26th, 2022 (REB# 2022-6054). An interpretive qualitative study was conducted using semi-structured interviews as the primary data collection method. Critical disability theory (Goodley et al., 2016; Shildrick, 2012) and Ecocultural theory (Gallimore & Goldenberg, 1993; Weisner, 2002) were used to frame the study design, analysis, and interpretation. The combination of theories draws attention to the sociocultural context (including barriers and facilitators), ableism and disablism, work and invisible work, family life and routines, and felt experiences of inclusion, belonging, and well-being. **We asked the following research questions:**

- 1. What are the barriers and facilitators to accessing inclusive early learning and/or childcare for families with preschool-aged (0-5 years) children with disabilities?**
- 2. How does navigating access to inclusive early learning and/or childcare affect family life?**

We interviewed **17 parents** of preschool-aged (0-5 years) children with disabilities and **4 key informants (3 directors and 1 inclusion coordinator)** from early learning and childcare settings.

Recruitment

Maximum variation sampling was used to allow for diverse representation and multiple perspectives to yield rich data (Creswell & Poth, 2018). Maximum variation affords researchers the opportunity to “explore the common and unique manifestations of a target phenomenon across a broad range of phenomenally and/or demographically varied cases” (Sandelowski, 2000, p. 337-338). We outline our strategy for recruitment of both groups in the following pages.

All names of participants, children, and others mentioned in the participants' stories have been replaced with pseudonyms to protect identities.

Methodology

For the purpose of this study, **disability** will be defined as “an environmentally contextualized health-related limitation in a child's existing or emergent capacity to perform developmentally appropriate activities and participate, as desired, in society” (Halfon et. al., 2012, p. 32). A **parent** is defined as a child’s biological or adoptive legal parent or guardian. Additionally, parents of any gender, ethnicity, age, profession, or education level were invited to participate. All participants were compensated \$50 for their time.

Recruitment Strategies for Parent Participants

Members of the research team initially contacted early childcare settings and child and family-related disability organizations in Nova Scotia by email to ask for their support in recruiting parent participants for this study. With consent, study information was shared via our parent recruitment poster/postcard in the following ways:

- Posted on the organization's social media accounts (namely X(Twitter) and Facebook)

- Sent through organization email lists by the organizations themselves

Parent participants were invited to participate in 60–90-minute interviews. Parents were asked about their experiences accessing early learning and childcare for their children with disabilities. In households where there were more than one parent/guardian, both parents were invited to participate (either separately or together). We had two parent partners agree to participate, and both couples completed interviews separately.

Criteria for inclusion for parent participants were as follows:

1. Parent(s) of a child(ren) with a disability(ies) (as identified by parent(s)/guardian(s)) between the ages of 0-5 years who have not started formal schooling (grade primary)
2. Parent participants identify with at least one of the following experiences as they relate to early learning and/or childcare settings (including pre-schools; early education settings; daycares;

Methodology

pre-primary programs; and formalized and regulated home care settings, supervised by a central office, with an early learning curriculum):

- Attempted to access but unable to access early learning and/or childcare for their child(ren) with disabilities
- In the process of trying to access early learning and/or childcare for their child(ren) with disabilities
- Currently accessing early learning and/or childcare for their child(ren) with disabilities
- Was previously accessing early learning and/or childcare for their child(ren) with disabilities but is no longer receiving services

3. Lives in Nova Scotia

4. Parent(s) are comfortable participating in an interview in English

Notably, the number of mothers who responded to be interviewed was far greater than fathers. The sample included 16 mothers and one father. The mothers all identified as female, and the only father identified as male. Diversity was represented across the sample in many respects. Mothers ranged in age from 25-49 years old. Their children with disabilities ranged in age between 18 months and 5 years at the time of the interview.

Children identified with a range of disability diagnoses described as neurodevelopmental, physical, sensory, and genetic/medically complex. Of the 16 mothers, 11 were married, 3 were common-law, and 2 were single. Two married couples participated; one couple were married mothers, and one couple was a married mother and father. Parents were interviewed from across Nova Scotia in mainly large urban, medium, and small population centres and two rural areas (Statistics Canada, 2017), with 7 parents living outside of Halifax Regional Municipality (HRM).



Methodology

Parents from various regions across Shelburne to Glace Bay were interviewed. Parents self-identified in different ethnic and socio-cultural groups, including English, European, American, and French Acadian cultural backgrounds, as well as those who identified as White, Indigenous, and Black. One mother was identified as having a disability, and two mothers (partners) were from the LGBTQ+ community.

In regards to education, 11 mothers graduated from university with a Bachelor's or Master's degree. Two mothers graduated from community college, one mother completed grade 12, and two mothers were current students in community college. Three mothers identified as "stay-at-home" mothers, while 13 mothers were employed in various capacities. Household incomes ranged between \$25,000 and \$175,000 per year, with one participant not knowing their yearly income.

Recruitment of Key Informants

During our initial recruitment, we identified key informants such as directors and inclusion coordinators in early learning and childcare settings. While reaching out to these centres to seek support in recruiting parent participants, we also extended the invitation to key informants to participate. Interested directors or inclusion coordinators were invited to contact us if they wished to take part in an interview. *(Note: Not all early learning and childcare settings have inclusion coordinators.)*

Key informants were invited to participate in 60-minute interviews. Key informants were asked about their perspectives on barriers and facilitators to access and inclusion in early learning and/or childcare settings.



Methodology

Criteria for inclusion for key informants are as follows:

1. Director or Inclusion Coordinator in an early learning and/or childcare setting in Nova Scotia (including pre-schools; early learning settings; daycares; pre-primary programs; and formalized and regulated home care settings, supervised by a central office with an early learning curriculum)
2. Key informants identify with at least one of the following experiences as they relate to early learning and/or childcare settings:
 - Have experience with children with disabilities in their programs at present
 - Have experience with children with disabilities in their programs in the past
 - Have not had any previous experience with children with disabilities in their programs
3. Key informants are comfortable participating in an interview in English

Of the four key informants recruited, two directors were from outside of the Halifax Regional Municipality, and one director and inclusion coordinator were from the Halifax Regional Municipality.

All study participants were given the option to participate in the interviews through videoconferencing (Microsoft Teams), telephone, or in person. Most of the interviews were conducted by videoconferencing or by telephone. One parent and one inclusion coordinator participated in the interview in person. Interviews ranged from approximately 75 minutes to 120 minutes in length. All interviews were transcribed verbatim by a transcriptionist. Transcripts were cleaned and de-identified before being uploaded to Quirkos 2.5.2 qualitative analysis software.

Methodology

Data Analysis

Data analysis was supported using Quirkos 2.5.2 qualitative analysis software. We drew on Braun and Clarke's (2022) **Six Phases of Thematic Analysis** to take both a semantic (inductive) and latent (critical) approach to analyzing the data. All interviews from parents and key informants were included in the data set. The first phase involved deep familiarization and immersion with the content of the dataset. In phase two, we began by coding the text at a semantic level, looking at explicit meanings. Then, we moved on to coding for more implicit meanings, drawing on sensitizing concepts from ecocultural theory and critical disability theory to gain a deeper understanding of the effects on family life. In phase three, we aimed to identify shared patterned meaning across the data set by clustering codes and generating themes as they related to the research questions. In phase four, we assessed the themes by going back to the dataset as a whole. We then determined whether the themes highlighted the most important patterns of meaning

across the dataset and made revisions. In phase five, we refined and named the themes through collaborative writing. The sixth phase involved the writing up of the analysis. Reflexive writing and conversations amongst the research team took place throughout data collection and analysis.



Findings

What are the barriers and facilitators to accessing inclusive early learning and childcare?

Finances:

Money Makes a Difference

Costs for families and available funding were described as important factors for both families and key informants. A main concern for families was the additional costs associated with caring for a child with a disability. These included the costs both related and unrelated to childcare, such as additional health assessments, travel (e.g., driving to appointments), and child-specific needs (e.g., specialized equipment). Childcare itself was described as a significant expense for some families; one parent described how accessible childcare does not come without a price tag:



I do find a lot of the daycares that have the education and the accessibility are much more expensive. And the daycares that I did really like were extortionately priced.
(Teresa, Parent)

Another notable concern was the cost of support when formal childcare was not an option, either due to eligibility criteria (e.g., age) or availability (e.g., space). In these cases, some families described having to hire additional support and assumed the costs:



It is quite expensive. Going the route we are right now until he gets into the daycare - where we have someone coming into our house, it is absolutely ridiculous. We can't afford it in any way, shape, or form, but we are making it work to the best of our abilities.
(Chelsea, Parent)



Findings

Parents in the study frequently reiterated the importance of a high income to alleviate financial struggles:



*So you either have to be really rich or really unable to pay for your own needs and your child's needs, like none of its good.
(Pam, Parent)*

To address this issue, many parents talked about the resources or funding they were able to access. For example, some parents accessed a provincial disability support program that offered a monthly respite allowance. Jordan's Principle was also highlighted, an initiative aimed at helping First Nations children and families access services such as childcare. Parents also named churches, community

members, family members, and friends as important financial resources.

Some families described facing significant barriers to accessing funding support. Notably, household income was a barrier, as it often disqualified families from accessing funding. They stressed that even families with higher incomes faced financial difficulties due to the increased costs associated with caring for a child with a disability. Another common issue was a lack of awareness about available funding opportunities. However, for those who managed to access these opportunities, provincial and federal funding played a crucial role in accessing early learning and childcare, as well as other support services like respite and support workers.



Um, we get a very small amount of disability tax credits. Because he [partner], umm because he earns too much as they say, but to me that is not ok. Like no family plans to have a disabled child, and just because they have a higher income doesn't mean that they have extra money to pay for all these private things the child might need.

(Teresa, Parent)

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The daycare helped me out a lot actually, because they're the ones that put me on the Jordan's Principle Program too. Because they knew I was a single mom at the time, and they knew for single, working, moms that Jordan's Principle will pay for their daycare. So they did that for me. And they also got in touch with Jordan's Principle for [child's name] to have her own educational assistant at daycare. Said to give her more one-on-one and help with her physio exercises that she was supposed to be doing.

(Lena, Parent)

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So, very often, if you're a single mom and you are on income assistance, you're in this cycle that you cannot get out of. If you want to get out of income assistance and start working, typically you're going to start at a minimum wage job and that's not a liveable wage whatsoever. And then, you don't have access to income assistance anymore, which offers only \$400 a month towards childcare and that's only for one kid, I think. So if you have two kids, then you still have to pay full price for one of them, but then also apply for the provincial childcare subsidy, which will make up some of it, but it's still not affordable. So you're stuck. You're stuck at home until all your kids go to the public school system. And then if you find a job, still likely not liveable wages, and have to finagle your work schedule so that it doesn't interfere with after school care. It's not a good situation.

(Joanne, Parent)

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So many folks are unaware of all of what's available, and so not being aware of what's in the community is a problem. My family doctor had no idea about the Disability Support Program. And so, when I shared that with her, and the really wonderful benefits that it brought our family, like we get \$2,400 a month to pay [for support workers] to give us a break, and take the boys out, and work with the boys. And so, because of that, it's been life changing. And my doctor didn't even know about that. Professionals in the community need to be sharing this information with their clients and their patients. [...] And then also, on top of that, there's the Federal Disability Tax Credit, right? So, not everyone knows about that. And, um, I got my boys into that, so that's a little bit extra every month for their costs. And then I also opened them up Disability Savings Accounts and I've been contributing, because I can, you know, for a couple of years now and now they have \$14,000 each. And so, the government contributes, like they match what you contribute, right? So, if folks were aware of that, if they could even afford \$50 a month, the government would match that for them.

(Joanne, Parent)

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Findings

From the perspectives of early learning and childcare service providers, financial barriers also impact the ability to provide inclusive childcare services. They explained that they lacked the resources to offer fair wages to childcare staff, including early childhood educators (ECE). All four key informants mentioned that the pay rates for their staff were too low, but they didn't have sufficient funding to increase the wages. Additionally, parents also expressed concerns about the "unfair" pay for childcare staff.



ECE's are so underpaid. It is like, so so bad. It is, I feel so bad for them. They have really hard jobs, and they love their jobs and work really hard to, you know, mould our kids and they are paid nothing. You know, it is hard for me to say that I want it to be cheap and blah, blah, blah because if it means that the ECE's aren't getting paid a reasonable salary, that is not working. (Jennifer, Parent)

One director also noted that when the recent reduction in childcare fees was announced, there was a promise that early childhood educators (ECEs) would receive wage increases and pensions. However, in subsequent meetings, this director never received any additional information about these promises, leading to anger and frustration among childcare directors and staff.

Similarly, directors also noted that, in addition to unfair wages for staff, they also came across scenarios where they did not have enough funding to have the right number of staff to account for children's needs. For example, two directors expressed the ultimate goal of having an additional teacher or support person in every room of their childcare centre to improve child-staff ratios. Childcare centre directors expressed the importance of having enough funding to hire the right number of qualified staff to provide inclusive, responsive, and accessible childcare.



Findings

Healthcare Teams and Social Supports: It Takes the Right Village

Parents described qualified and professionally trained staff as crucial for accessing and maintaining childcare, navigating health systems, and supporting children with their specific needs (medical, social, physical, etc.). Parents also discussed the importance of staff having a background in childcare development and experience working with children with disabilities. This helped reassure them that the staff were prepared to care for their child. Parents also described experiences where childcare staff were not trained to attend to their child's needs, which caused stress among parents who then needed to train the staff themselves.

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I would like their staff to be prepared better than just relying on a parent because sometimes parents learn things from medical staff under very stressful situations and have limited time to absorb it all. And then now it's my job now to teach someone else how to do it and it feels like, I don't- I don't know if I'm teaching them right. I have no idea.

(Stella, Parent)

Notably, inclusion support provided by inclusion coordinators made a significant difference for children and families who had access to one. For example:

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The inclusion coordinator helps us... she sits in all of our SLP meetings. She facilitates OT and PT coming in. And facilitates goals in the centre. SLP had a picture communication program they were implementing with concrete images and not just the PEC [Picture Exchange Communication] board images but pictures of those things. She helped document them, laminate them, put them on loops. Getting all that going for him in the centre and making sure it was facilitated in the classrooms.

(Sandra, Parent)

Findings

Healthcare team members were identified as supportive of inclusion and key to child development, health, and well-being. These included physiotherapists, occupational therapists, speech-language pathologists, and nurses, to name a few. Parents described how having access to healthcare teams supported physical development, communication, and ongoing assessment needs. Many health professionals visited the children and families at the child's early learning and childcare centre to provide assessment, intervention and/or consultation. This was considered a facilitator because it saved parents valuable time by eliminating the need to travel to appointments at the hospital or clinic. Parents also described several scenarios in which healthcare support became suddenly inaccessible due to various reasons such as the COVID-19 pandemic, transition to school, limited number of sessions, and available funding. This was considered a significant barrier.



Findings

Another frequently reported social support was family, such as the child's grandparents, aunts, uncles, and godparents. Support from family often involved caring for children during the parent's working hours or for extended periods, based on the family's needs. This supported parents' routines, enabling them to fulfill work responsibilities, complete tasks such as grocery shopping, care for other children, and/or rest. However, some parents also described that they could not always rely on family to help, or that they did not trust their family members' abilities to care for their child due to complex needs or necessary training. Family members didn't always live close by, and some described aging parents as not being capable of the responsibility or in need of care themselves. Some families described feeling stretched while caring for both their children and their own parents.

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I've thought, well, what about [their grandmother]? And that again, very inconvenient and I don't really feel comfortable asking for that level of commitment. That's intense. She's retired. She's getting older. I don't even think that she's actually completely capable of that type of responsibility. So, she's not an option either.
(Joanne, Parent)

In addition to specialized staff and family members, another commonly discussed social support was community, more specifically, online communities. Parents noted how their participation and connections within online communities afforded them opportunities to connect with other parents, learn more about diagnosis-specific needs, and learn from other families' successes and challenges. Some parents described how relationships that began within online communities sometimes developed into friendships and supports in daily life.



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Some of my closest friends, now, have children with disabilities because they are the only people that really, truly, get the challenges and exhaustion that comes with the constant fight of advocating for your child with a disability.

(Teresa, Parent)

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Jennifer joined a Facebook community for parents of children with Down syndrome, which facilitated in-person connections, such as attending camps together:

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Every year, except for during the pandemic, we went to the [Camp] for a weekend, a family weekend. Where a bunch of families [of children with Down Syndrome] from Nova Scotia would go. It is great. One of the best parts is when all the kids go to bed, and all the adults hang out in the middle room and talk. It is just nice to be with people who get it, you know. That gets the struggle. Gets the, you know, we get to pick people's brains. We definitely make good relationships through that.

(Jennifer, Parent)

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Findings

In some cases, another important social support was parents' employers. Supports included benefits such as vacation days, personal days and flexible scheduling. These benefits were helpful not only for parents to take care of their children in case of emergencies, appointments, or other health and well-being related issues but also for the parents' physical and mental health and well-being by allowing them to rest and avoid burnout. The best-case scenario, when feasible, was for parents to have the ability to set or adjust their work schedule to meet their family's needs, although this was only possible for some parents. Employer inflexibility impacted parents' career decisions, often limiting earning potential and career advancement.

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I do look for other jobs. Um, but the problem that I find is because of [child's] disability, because of his hospital appointments, umm a lot of companies aren't flexible. Whereas the company I am with right now is extremely flexible and extremely supportive. Um so I know I can take a day off to go to a hospital appointment and it's not an issue.

(Teresa, Parent)



Findings

Disabling Systems and Exclusionary Effects: Muddy Waters

Parents expressed unanimously that inclusion in early learning and childcare for children with disabilities is of utmost importance:



Inclusion is very important. I think every child deserves the right to be included. I don't think it should be a question, or a challenge, or a hurdle, it should just be the norm.
(Teresa, Parent)



Inclusion is very important to me. I don't want my son being excluded because he is a little bit different. He can do everything that everyone else can do, just maybe in a different way. So, it is very important.
(Tiffany, Parent)

Parents expressed that, in their opinions, early learning and childcare centre staff often did not know the meaning of inclusion, misunderstood inclusion, or misrepresented inclusion. For example, one mother described how a childcare centre used the term inclusion interchangeably with diversity, which then led to fewer inclusive practices. Some parents also mentioned that sometimes early learning and childcare staff appeared to base their understanding of disability and inclusion on their past experiences with children with disabilities, as if it were universal. As such, children's unique abilities were not brought into focus and needs remained unmet.

Many parents expressed that a lack of understanding and ineffective implementation of inclusion was a major barrier for children with disabilities to access inclusive early learning and childcare in Nova Scotia long term. Some parents expressed that they felt that Nova Scotia was lagging behind other provinces and countries in the

Findings

provision of inclusive education, especially in the early learning and childcare sector. Parents also described how inclusion is often used as a “buzz word” without implementing disability-affirming and supportive inclusion practices.



That is a heavy word, inclusion, isn't it? It gets bounced around and slapped on everything. Unless you can include my daughter and her little friends, you are not inclusive, you know, and that gets me every time. I know they are an 'inclusive centre', and it's like no. Unless you have a ramp to get kids in and out of the building who would need a ramp, you are not considering the spectrum of people out there. It's unfortunate. I think the word is overused, misunderstood or whatever. It does not always include our kids sadly.

(Samantha, Parent)

When asked to describe inclusion themselves, parents identified the need for their children to be socially included in all activities with peers, make connections, and belong. Some parents also expressed that if their child needed to have different types of support and not always be with their peers, that was fine as long as they were getting the support they needed. Many parents, particularly parents with children with physical disabilities, emphasized the importance of an inclusive physical environment where all children can access the same spaces as their peers. This would include the need for ramps, wider doorways, accessible washrooms, and accessible play equipment indoors and outdoors, etc.

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There's a huge amount of dissonance going on between what I think inclusion should mean, what it is in reality, where the gaps are, and how it's not one size fits all. So at the end of the day, I think what inclusion means for me and my child is whatever is the most conducive environment to help him and support him in reaching the highest capacity of development that's possible. [...] I don't want it to be a one size fits all, and I think at the end of the day, that's what inclusion means to me. That it's based on the needs of the individual and not just some blanket fancy nice-worded policy that says that children with special needs should be included and not separate from their peers 100% of the time.

(Monica, Parent)

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Findings

Some parents shared how their perception of inclusion changed after having a child with a disability and needing to consider their unique needs. For example, one mother expressed that she believed inclusion is a skill that can be learned, and all parents, including those with typically developing children, should understand inclusive practices and how they can support families of children with disabilities. This was also discussed in the context of teaching all children to be mindful of inclusion in their environments.

Some parents shared experiences where their child was denied childcare due to a lack of inclusive practices or the childcare centre's capacity to support the child. For example, several parents described scenarios where their child was turned away because the centre was unwilling to take on more "difficult" or "complicated" cases. One parent, in particular, described how, during a tour of a childcare facility, staff members explicitly noted on their intake form, "using big, bold letters," that their child had Down Syndrome, and later was told they could not be accepted at that location.

Several parents shared instances in which they were initially welcomed into a childcare centre and assured by the staff that their child's needs would be taken care of. However, they were later informed, either on the same day or a few days later, that their child could not return because the centre was unable to support their child's needs. This was often the case if the child had complex health needs (e.g., G-tube) or behaviours that the staff "couldn't handle".

One parent suggested that when childcare centres claim to be inclusive but are not, they should be reported, and accountability is needed.



I'd like to get a list of every place we've talked to that says they are inclusive and report them to the government and say they are not.

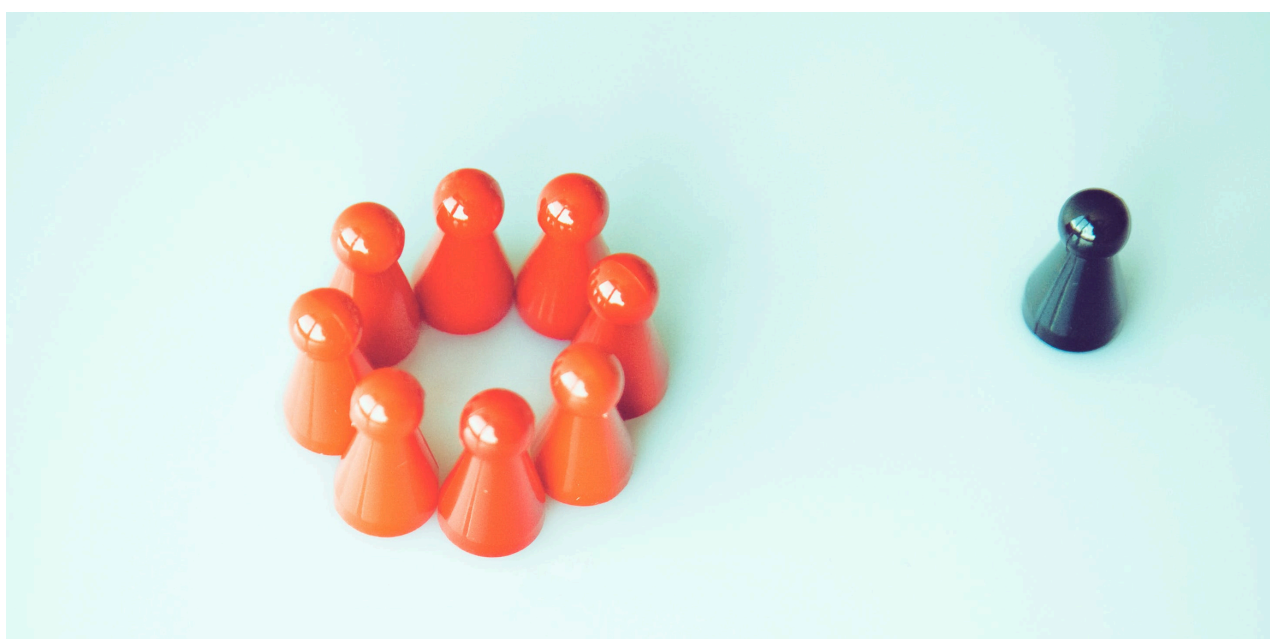
(Andrew, Parent)

Findings

These stories of discrimination stemmed from systemic ableism. For instance, childcare centres often use milestone or norm-driven policies and practices that shape experiences of both access and inclusion. Many parents described how early learning and childcare services, in their current form, had to be adjusted to accommodate their children. Some children with specific diagnoses seemed to receive more support than others. Both parents and key informants expressed that children with disabilities often need extra support, which is not necessarily offered to all children and comes with significant costs under the current system. Notably, inclusion funding is based on the concept of

natural proportions, assuming that only 10% of children would require inclusion support without considering unique differences between communities.

“*The province doesn't step in to support these places or provide any assistance to them. Well, like, any real assistance. We take care of certain segments of society, why are we still struggling to provide appropriate spaces for children with disabilities, it is not like they haven't been around forever. It is heartbreaking.* (Samantha, Parent)



Findings

What are the effects on families?

Limited Options and Necessary Advocacy: Feeling “Stuck”

It is essential to understand what constitutes ideal childcare for parents with children with disabilities in order to provide inclusive and accessible early learning and childcare experiences. According to parents, ideal childcare environments are non-judgmental, equipped with inclusive programming, physically accessible, consistent in staffing, maintain regular communication about children's needs with parents and between staff, have good staff-to-child ratios, provide one-on-one support when needed, and offer access to a systems navigator for information. Additionally, parents mentioned that in an ideal setting, staff are actively involved with the children, are attentive, mindful of the child's well-being, and have the competence to work with children with disabilities, including specialized training. In summary, parents want their children to be welcomed and cared for.

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*My daycare centre, they truly love and care for the kids there and their needs. So, they are more than happy to invite outside community partners and support workers into the classroom to better support the kids. So, whatever the kid needs, they're going to do what they can to be adaptable and flexible.
(Joanne, Parent)*

Key informants stated that early learning and childcare centres generally strive to meet high standards of accessibility and inclusivity. Nevertheless, many parents expressed worries about sending their child to early learning and childcare centres under the current system and available supports.

Findings

Parents' concerns included, but were not limited to, the following:

- Staff members who were educated but lacked experience (e.g., recent graduates)
- Staff members who may not understand the specific needs of their child
- Inaccessible classrooms
- Composition of classrooms (e.g., staff-child ratios, segregation vs. inclusion)
- Availability of one-on-one support for their child

These concerns created feelings of uncertainty for parents. Parents describe having limited options for childcare and **feeling “stuck”**.

Parents also described having to consistently advocate for different outcomes, including but not limited to the following:

- Having their child's needs met, both inside and outside of early learning and childcare settings
- Receiving complete, accurate, and timely information regarding their child
- Being accepted into a disability support program for which they qualified and yet were denied access
- Being granted or assigned a support worker
- Accessing healthcare and associated services and supports

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And we are resourceful, and we're capable, and I know that not every family has the ability to put as much time and effort into advocating for their children. It's a fight, it really is a fight. And I am very passive, quiet, figure things out myself kind of person. Having a child with special needs was a real rupture in me in that I had to get real comfortable, real fast, with making other people uncomfortable, to ensure that [child's name] didn't get special treatment but got what he needed
(Teresa, Parent)

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I actually had to advocate for my kids to even be accepted into the disability support program. They tried to deny us twice. So, I was like, are you kidding me? Like, my boys have an official diagnosis of Autism. They have zero words at 3 years old. And you're saying they don't qualify for this program? So, I did not take no for an answer. And it worked. But like, not everyone has the confidence to do that. So, we almost didn't get that support. And I don't even think my partner would have advocated the way I did. You know what I mean? So, it's like, even their requirements for eligibility needs to be relooked at.

(Joanne, Parent)

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Findings



Impact on Families: The Invisible Work

In this study, all parents—mostly mothers—spent a significant amount of time doing a substantial amount of work to find, access, and maintain inclusive early learning and childcare for their children with disabilities. This work was unpaid and may be considered “invisible work” because, even though it is necessary, it largely goes unnoticed by others. It is also additional work, as it does not replace the other responsibilities, routines, and activities that parents already have. Without the invisible work of parents, mainly mothers, it is questionable whether they would have been able to access inclusive early learning and/or childcare at all.

Parents expressed that taking care of a child with disabilities can be akin to having a full-time job. Many of them have mentioned that these competing demands directly impacted their own work. For example, some parents described having to change jobs or leave the workforce in order to fulfill the necessary caregiving responsibilities.

Seeking out healthcare from specialists and therapists involves a considerable amount of invisible work. Some parents described the significant work required just to find experts to explore a diagnosis for their child so that they could access support. Parents described advocating for referrals to specialized services, organizing referrals and scheduling assessments, and attending subsequent appointments which were not always local. Taking their child to their many appointments often impacted their paid employment.

“*A lot of effort, and homework, and... First of all, trying to identify what services even exist for kids with special needs takes a lot of effort.*
(Monica, Parent)”

Findings

Parents expressed not knowing where to start when they were ready to explore inclusive early learning and childcare options. Navigating the system was a steep and difficult learning curve. One mother shared how it was significantly easier to find childcare for her older child without a disability compared to finding childcare for her younger child with disabilities. One participant discussed that finding childcare involved:

“*[a] lot of talking to people, and emailing, and trying to figure out who to speak to.*
(Lena, Parent)

This circular, invisible work often went on for months.

Parents also spent a lot of time searching for information online. This extra work was seen as necessary because there wasn't enough guidance and resources available. Parents talked about searching social media and websites for information, asking questions in local social media groups to, and talking to other parents or members of their child's healthcare team.

When one mother was asked how she went about finding childcare, she answered:

“*Speaking to friends, also Facebook, you can find anything on there about anything. Google searching, you can find everything, and you can find it negative and positive. So, I actually felt like it was a little mini job trying to figure out where we were going to put our son.*
(Erica, Parent)

Parents interested in specific centres need to contact them to inquire about their availability, the process for getting on the waitlist, the criteria for accepting children, and the centre's approach and philosophy. Parents often must fill out forms and pay fees just to be added to a centre's waitlist. It wasn't uncommon for parents to be on numerous waitlists. Parents described constantly calling centres to follow up with waitlists and although they left messages, many centres never called them back. This would create more work for parents as they would have to continue to reach out to get the information they needed to plan ahead and keep family life running.

Findings

When asked how many childcare places one mother contacted, she stated:

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“I would say between 20-25. That is just the actual facilities, that doesn't even include the in-home daycares that are on Facebook groups.”
(Chelsea, Parent)

Some parents discussed their experiences navigating the disclosure of information related to their child's disability with centers at both the waitlist and intake stages. Disclosure of information took the forms of verbal communication, written communication, or a combination of both. The initial request was often related to the child's diagnoses and particular needs, including medical needs, abilities, and necessary supports required. Sharing detailed personal information with multiple early learning and childcare centres with the hopes that *one* might accept their child demanded significant emotional labour. Once children were accessing early learning and childcare, the invisible work of parents did not end. For example, parents still needed to communicate with staff more often than other

families. Some parents did the work of training childcare staff; teaching staff how to safely care for, change, feed, and communicate with their child. Some parents coordinated getting information from health care professionals to support staff learning. This included health care plans, brochures related to training, or having a health care professional visit in person or meet with staff virtually. One parent described how she spent a significant amount of time facilitating the staff training only to discover that after the training, the centre decided not to accept her child.

When one mother was asked how they would describe their **“work behind the scenes”**, they responded **“exhausting”**.



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Like my kid can't talk, other kids can relay messages on what they ate, but he can't. So, I feel like even getting childcare was a lot of work 'cause I had to call them, and it was exhausting, and then I had to explain everything about him. Like, you know what I mean? Basically, how to care for him, and what he likes, and what he doesn't like. And then I feel like I'm in contact with the daycare way more than any other parents have to be, because I have to ask questions, call and check, and be like, oh wait I forgot to tell you he has occupational therapy at 9 [...] you know what I mean?

(Molly, Parent)

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I got us on every list for the infant spaces around. We finally had one daycare that was 5 minutes from my work. They approved him. They knew when they put him on the waitlist because I only got him on waitlists for daycares that said they would accept the G-tube. They said he was approved. He got the spot. We went in, we paid the deposit. They saw him. We left. I contacted them, and it was about a month before he was supposed to start, a little over a month. But he was going to have surgery in a couple of weeks, so I wanted to go in and do the training before his surgery because I knew that after surgery, he probably wouldn't be in the best mood. So we went in...they arranged for us to go in and do a day of meet and greet, training, that sort of stuff, so they could see exactly what the G-tube was and how it was going to work so we could arrange how much time we would need to be doing the training for. We went in, we talked. I gave them the overview of [child] and his life. We talked about his developmental needs because he is developmentally behind his age group, and then I showed them the G-tube and showed them how to feed him with the G-tube, and it was a really positive meeting. One of the daycare workers actually even held him. She seemed to really like him. They told me at the end of the meeting they needed some time to talk and think about it and make sure they could take him. Two weeks later, I got a call from them telling me that they were not approving him. They couldn't offer him a spot anymore because only one person felt that she could handle him. Everybody else was very afraid of the G-tube and afraid they couldn't handle his requirements.

(Chelsea, Parent)

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Findings

The invisible work of parents also included a vast amount of paperwork. Families often had to complete paperwork related to funding, such as subsidy applications, direct family support applications (respite funding), applications for Jordan's Principle requests, and disability tax credits, to name a few. Sometimes, childcare centres helped parents fill out the applications, alleviating some of the work required of the parent. Sometimes, applications were denied, and families had to do further work to appeal decisions or seek funding elsewhere.

Overall, parents with children with disabilities do an immense amount of work behind the scenes to ensure their child is cared for, supported and included. This invisible work varies depending on the child's needs, available options, and the parent's skills and abilities.



Findings

Parents' Mental and Emotional Well-Being:

"I Was Crying Almost Every Day"

Overall, the stress of navigating access to inclusive early learning and childcare was described as an overwhelming challenge for all parents. In addition to impacts on family life, there were also impacts on individual parents' mental and emotional well-being. Many parents described levels of stress that they had never experienced before or that they never expected. The main stressors reported by parents included having to fund or find funding for appropriate and trained support staff, not knowing what would happen while their child was in childcare or if their child was safe, having a lack of trust in the childcare staff to meet their child's needs, not knowing how to problem solve new or emerging challenges (e.g., new behaviours that parents haven't seen before and how they will train staff to support their child), scheduling and organizing appointments, maintaining employment, and compounding financial stressors.



Yeah. It's stressful. It's definitely- Like it causes me distress as well. Like I'm anxious about it a lot. And, like I said, I don't always trust that when I leave him there he's going to be okay but I don't see another option. That's hard to deal with. And I know it's probably the best place for him in terms of childcare settings, but it still doesn't feel like it's as good as it should be.

(Stella, Parent)

Exhaustion among parents was described as a result of pervasive and overwhelming stress. For example, making large numbers of phone calls and organizing and coordinating schedules were reported as exhausting actions parents do on an ongoing basis to ensure their child is cared for.



Findings

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I think I just assumed that we wouldn't qualify and so- and also again around the systems, it was just another series of hoops to jump through in order to get something that we needed so, like the mental strain and the exhaustion from like, going through another system, 'cause there's just a lot of applications and a lot of paperwork and a lot of "proving" disability [laugh] that can be really exhausting.

(Stella, Parent)

Parents described how their anger, sadness, stress, and exhaustion led to an overarching sense of guilt. Whether it was guilt about not knowing what to do or how to advocate for their child's needs, guilt was described as a common emotion for many parents of children with disabilities. Parents described guilt surrounding their inability to solve or address the challenges they were constantly navigating within the current systems. Some parents also expressed feeling guilty about how their child's need for additional support might be affecting other children in childcare settings.

“

There's a little bit of um [pause], and I'm working real hard on letting this one go, but there's still a little bit of guilt around you know, is having [child's name] in the group going to take away from the other kids' experiences in any way or, is there going to be any negative impact on their experiences because [child's name] is in their group? You know, that's not something I give too much attention or energy to 'cause I know I need to let that one go and not worry about that but it's still there, you know, it still pops up.

(Monica, Parent)

Findings

Overall, **limited options for inclusive early learning and childcare significantly impact families.** Parents of children with disabilities often have to go above and beyond, doing work that goes unnoticed (i.e., invisible work). For example, parents must advocate for their children's needs daily in ways that parents of typically developing children may not need to consider. And finally, the stress, exhaustion, and guilt experienced by parents navigating access to inclusive early learning and childcare can significantly impact their mental and emotional well-being.



Reflections: Insights & Situated Evidence

Inclusive Early Learning and Childcare Settings: The Family Experience

There are longstanding barriers and unmet needs related to resources and supports for children with disabilities in Nova Scotia. Early learning and childcare are no

exception. The stories of parents and key informants interviewed in this study have illuminated key issues that are impacting access to inclusive early learning and childcare for families of preschool-aged children with disabilities across the province. Barriers to access have a cascade of effects on families, resulting in invisible work, mainly performed by mothers, and corresponding feelings of uncertainty, “being stuck”, and overall negative effects on mental health and emotional well-being.

Access and Inclusion

Parents and key informants identified inclusion as a priority.

Despite this, the stories of inclusion and exclusion from parents and key informants created dissonance.

Parents in this study spoke to inclusion being elusive. Despite commitments to inclusion by early

learning and childcare centres, parents described exclusionary experiences that were shaped by systemic constraints and discriminatory attitudes.

Although inclusion is best practice, it is often not implemented in alignment with its theoretical foundations (Barton & Smith, 2015).

Implementation of inclusion is fraught with barriers within and between systems. Barriers include limited awareness of issues within current settings, inconsistent understandings of what inclusion entails in theory and in practice, and a lack of evidence-informed evaluation tools (Irwin & Lero, 2021). Without a formal inclusion policy and practice guidelines, early learning and childcare centres do not have standards to follow and expectations to meet. A formal inclusion policy for early learning and childcare centres could be a first step towards clarity and consistent practices. Inclusion policies and guidelines exist in elementary and secondary education. It is important to note that policies are not enough; even if a setting has inclusion policies in place, it does not mean that children

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with disabilities and their families feel included or that the setting is exempt from discriminatory practices and their effects (Reeves et al., 2022).

Inclusion is not only a practice but a philosophy and a culture. Creating the conditions for inclusive early learning and childcare will require a shift in thinking, moving from inclusion as assimilation to inclusion as belonging for children and families (Phelan & Reeves, 2022; Reeves et al., 2023; Reeves et al., 2022).

Access, Availability, and Affordability

Consistent with existing literature, barriers to access to inclusive early learning and childcare included few available spaces, long waitlists, inaccessible physical environments, and discrimination as it relates to disability (van Rhijn et al., 2021). Children with disabilities have a right to inclusion in all aspects of cultural life. As such, there is a

growing demand for high quality, disability inclusive early learning and childcare. The Canada-Nova Scotia Canada-Wide Early Learning and Child Care Agreement (EECD, 2021) has committed to creating new spaces in early learning and childcare in the province (EECD, 2022). However, it is currently unknown who will qualify for these spots, how qualification will be determined, or if there will be enough space for all children.

This raises several questions for families of preschool-aged children with disabilities.

- ***Will children with disabilities be given priority for acceptance at their local early learning and/or childcare centre?***
- ***Will there be designated spaces for children with disabilities at early learning and childcare centres?***
- ***Will it still be possible for a child with disabilities to be turned away from early learning and childcare centres in Nova Scotia?***

Reflections: Insights & Situated Evidence

As noted by parents in this study, financial barriers exist for families of children with disabilities; a substantial number of families in Nova Scotia live at or below the poverty line (Statistics Canada, 2018). It is important to highlight that many parents were unaware of the funding available, assumed they would not qualify, or attempted to access funding but did not qualify. The Canada-Nova Scotia Canada-Wide Early Learning and Child Care Agreement (EECD, 2021) will reduce costs at childcare centres that signed the agreement. Some parents voiced concerns that with this decrease in cost, more families may seek childcare, increasing the demand for available spaces. This may make it more difficult for families to access spaces for children with disabilities without a formal inclusion policy in place.

Access to childcare is crucial for families when making decisions that significantly impact their family life. Families who have access to childcare that is considered sufficient and satisfactory generally do better managing their day-to-day lives and maintaining a meaningful family routine (McConnell et al.,

2016). Not having access to high-quality childcare can cause stress and conflict when parents want or need to work (Bianchi & Milkie, 2010), thus directly affecting family well-being.

A mother's ability to enter and remain in paid employment depends greatly on access to childcare (Seedat & Rondon, 2021).

In 1976, 40.5% of mothers were in the workforce, whereas in 2021, 76.5% of mothers were employed (Stats Canada, 2022). Therefore, childcare may be considered a crucial resource in organizing a sustainable family routine (Bianchi & Milkie, 2010). **Compared to other parents, mothers of children with disabilities are less likely to be employed in paid work** (Lewis et al., 2000; Statistics Canada, 2022). If mothers are employed, they are more likely to have casual or part-time work due to the challenge of securing appropriate childcare. (Lewis et al., 2000). To manage responsibilities, they often require flexibility and accommodations at work (Breitkreuz et al., 2021).

Reflections: Insights & Situated Evidence

Access, Human Resources, and Specialized Training

There is a shortage of highly qualified early childhood educators in Nova Scotia (Irwin & Lero, 2021).

Both parents and providers discussed issues related to human resources. One center director suggested that if workers were recognized and compensated at a rate commensurate with their value, staffing difficulties might decrease. Irwin and Lero (2021) noted barriers related to childcare staff pay rates and a low incentive for specialized training (Irwin & Lero, 2021). Staff training is frequently optional or unaffordable. This raised many concerns about whether the province has enough staff to fill the needed positions and provide high quality care for children who often have unique and medically complex needs.

Parents and key informants emphasized the need for specialized training to support children with disabilities. The responsibility to train staff is often left to the parent. Early learning and childcare settings may exclude children with disabilities due to

inadequate human, financial, or professional resources to ensure the setting is prepared to include all children (Killoran et al., 2007). This includes a lack of staff confidence and/or training in specialized care. Specialized training focusing on the unique needs of children with disabilities is vital for inclusion (Odom et al., 2011).

Reflecting on the Invisible Work of (mainly) Mothers

Invisible work refers to unpaid and unseen work above and beyond what is expected, often most apparent in caregiving, advocacy, emotional labour, and managing the family routines, finances, and housework. Historically, these tasks



Reflections: Insights & Situated Evidence

have fallen on mothers, whether they are single or partnered, in what is often considered a gender inequity (Seedat & Rondon, 2021). The unseen labour is not frequently recognized or valued in terms of its economic or social contributions (Matthews et al., 2021).

Mothers of young children with disabilities spoke about the practical and procedural work (e.g., researching centres, educating staff, applying for funding, advocating for their child’s right to access and inclusion, etc.) **and the emotional work required** (e.g., managing day-to-day experiences of ableism and discrimination) **behind the scenes.**

Finding and securing early learning and childcare in Nova Scotia has long been the responsibility of individual families, typically mothers (Odom et al., 2011).

Mothers are not just looking for childcare to keep their children with disabilities safe; they are considering the quality of care, inclusion, availability, affordability, and the need for specific interventions (DeVore & Bowers, 2006). Once they have accessed early learning and/or childcare,

mothers then shift their advocacy efforts to cultivating inclusion and belonging for their children.

Invisible work has a negative impact on family life. For instance, the employment of mothers may be hindered by the time they invest in invisible work (Irwin & Lero, 2020). Mothers who can delegate household duties, such as childcare, tend to have higher-paying jobs and more time to spend with their children (Seedat & Rondon, 2021). Research also indicates that compared to mothers with typically developing children, mothers of young children with disabilities tend to experience higher stress levels and have fewer opportunities to engage in recreational and social activities (Grace et al., 2008; Statistics Canada, 2018). This is not surprising given the significant amount of invisible work they take on to address gaps in policies and practices.



Limitations

This study has several limitations. Although the research team made efforts to recruit parents from across the province with diverse backgrounds and experiences, the sample was not diverse enough to make nuanced observations about how intersecting identities shape families' experiences of access and inclusion. Future research is needed to understand the unique needs of priority groups in the province, such as Mi'kmaq and African Nova Scotian communities. Community-based research that actively involves community members and prioritizes their identified needs is necessary to enact change. In addition, most participants were from large or small population centres, with only two from rural areas. Future research exploring diverse geographical regions is also necessary.

Key informants recruited into the study were those who were operating childcare centres that accepted children with disabilities and aspired to inclusion. This inevitably shaped responses, particularly as they related to commitments to inclusion. Follow up studies incorporating more childcare directors, inclusion coordinators, early childhood

educators, and other team members would be useful to better understand barriers and facilitators to accessing inclusive early learning and childcare from a systems and services perspective. It would also be useful to further explore the invisible work of parents and childcare workers to illuminate gaps in processes and identify solutions.



The Ask: Participant Voices

The early learning and childcare landscape in Nova Scotia is rapidly changing. Many changes have been set in motion over the course of the study, and many are yet to come. It will be important to continue to follow the effects of the Canada-Nova Scotia Canada-Wide Early Learning and Child Care Agreement and how these changes will impact families of children with disabilities. It is also important to hear from families before and as changes unfold to inform decisions that will directly affect them.

We asked parents and key informants for recommendations for the future of inclusive early learning and childcare in Nova Scotia. The following recommendations are derived from the data and supported by our analysis.



The Ask: Participant Voices

From Parents

- **That inclusion be trained.** Parents put their trust in early learning and childcare staff, and they want to know their child is in safe and capable hands. Some training is simple, and others more complex. From mobility aids to behavioural supports to feeding tubes, specialized training is needed to support children's diverse needs.
- **That advocacy shouldn't be necessary.** Parents never stop advocating for their children's needs, but the push shouldn't have to be so hard. Allyship is needed with childcare centres so that parents feel they have a teammate who anticipates their needs and goes to bat for their child.
- **That play is part of inclusion.** Parents discussed the importance of play, peer interactions, and the outdoors and how these environments supported early learning and the health and well-being of their children with disabilities. Some parents said that they wished their child had more peers with disabilities, as well as typically developing peers, to play with and to see more kids like them.
- **That the future be clearer.** Parents of children with disabilities do so much on a day-to-day basis to support their kids' needs. They also factor in the 'what's next'. Whether entering school or finding employment, caregivers hope and dream for their children to reach their full potential. Better pathways are necessary to support children and their parents during transitional times across growth and development.



The Ask: Participant Voices

From Directors & Inclusion Coordinators

- **That inclusion be valued.** That children with disabilities experience a sense of belonging. That staff with expertise in supporting inclusion are seen as providing an important, critical service. That inclusion be promoted in centres, and that centres advocate for inclusion in the community. Inclusion is an underlying philosophy that is non-negotiable.
- **That inclusion expertise be recognized.** That we train, recruit, and retain talent through strategies such as fair and competitive wages and compensation packages, including pensions. That the unique skill set of inclusion specialists be respected. That educator-to-child ratios be lowered to meet the needs of each child; it's their right.
- **That if more childcare spaces are created, more specialists must be trained, recruited, and retained.** As more spaces are opened, more staff will be needed. As more children with disabilities are welcomed at centres in their local communities, training for inclusion must be ramped up, and this must start now.
- **That inclusion starts early.** Many infants have unique needs. There are far too few spots available in infant and toddler care and far too few trained personnel to support infants and toddlers with disabilities.
- **That the government be nimble.** Listening is needed. Studies like this are a start. When it comes to making decisions about childcare, people with lived experience must be part of the conversation. Keeping open dialogue and being flexible with families and centres is necessary to gain momentum and traction when it comes to inclusion.

We are in this together...



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