#### FINAL REPORT

## Children with Disabilities and Access to Recognized Early Childhood Education and Care in Québec

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# **Table of contents**

ACKOWLEDGEMENT	2
LIST OF ABBREVIATIONS AND TRANSLATIONS	3
ABSTRACT	4
EXECUTIVE SUMMARY	5
1. CONTEXT	8
1.1 Initiation of the project	8
1.2 Context in Québec	8
2. AIM	11
3. METHODS	11
3.1 Design	11
3.2 Recruitment and Participants	11
3.2.1 Parents	12
3.2.2 Managers and professionals	12
3.3 Data collection	12
3.4 Data analysis	12
3.5 Conceptual framework	13
4. RESULTS	15
4.1 Participants	15
4.1.1 Parents	15
4.1.2 Managers and professionals	16
4.2 Barriers and facilitators between each stage of access	17
4.2.1 Approachability & Ability to perceive	19
4.2.2 Acceptability & Ability to Seek	20
4.2.3 Availability and Accommodation & Ability to Reach	21
4.2.4 Affordability & Ability to Pay	24
4.2.5 Appropriateness & Ability to Engage	27
5. CONCLUSION AND IMPLICATIONS	33
6. REFERENCES	36
APPENDIX	39
Appendix 1. Parent Interview Guides	39
Appendix 2. Managers and Professionals Interview Guides	40
Appendix 3. Provincial and federal subsidy programs for children with disabilities	42

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# LIST OF ABBREVIATIONS AND TRANSLATIONS

English abbreviation	English term used	French term			
	Terms around early childhood education and care				
	Childcare centres	Centre de la petite enfance (CPE)			
ECEC services ECEC settings	Early Childhood Education and Care services/settings	Services de garde éducatifs à l'enfance (SGÉE)			
	Home childcare provider	Responsable de services de garde éducatif en milieu familial (RSG)			
	Home childcare coordinating office	Bureau coordonnateur (BC)			
	Non-subsidized daycares	Garderies privées non subventionnées			
	Pedagogical support agent	Agent de soutien pédagogique			
	Priority spaces	Places protocoles			
	Subsidized daycares	Garderies privées subventionnées			
Financial terms					
AIDC	Allowance for Integrating a Disabled Child into Educational Childcare	Allocation pour l'intégration d'un enfant handicapé (AIEH)			
	Child Disability Benefit	Allocation pour enfant handicapé			
FICWD	Financial Assistance for the Integration of Children with Disabilities in childcare centres	Mesure exceptionnelle de soutien (MES)			
SHC	Supplement for Handicapped Children	Supplément pour enfants handicapés (SEH)			
SHCREC	Supplement for Handicapped Children Requiring Exceptional Care	Supplément pour enfants handicapés nécessitant des soins exceptionnels (SEHNSE)			

#### **ABSTRACT**

For children with disabilities, access to quality Early Childhood Education and Care (ECEC) is an essential factor in supporting their overall development (Bouchard & Christine, 2010). However, a review of the situation of access to ECEC for children with disabilities, conducted by Scientific Research and Experimental Development Canada in July 2021, identified that parents of children with disabilities are at the mercy of a fragmented system of public and private care options. In this context, Employment and Social Development Canada decided to conduct a comparative project on this issue across three Canadian provinces (i.e., British Columbia, Nova Scotia, and Québec) to gain a deeper understanding of the experiences of parents of children with disabilities trying to access reliable, safe and adequate ECEC for their preschool children with disabilities. This report presents Québec results for this project. Methods: A qualitative study was conducted to identify the barriers to ECEC access for children with disabilities in Québec. Families of children with disabilities and key stakeholders (i.e. individuals involved with managing ECEC and/or supporting children with disabilities in ECEC) were recruited through social media and snowballing. In total, 16 parents of children with disabilities, 3 directors of childcare centres, 1 pedagogical support agent and 1 inclusion coordinator participated in one-hour virtual interview. Qualitative data analysis was based on Archambault et al. (2020) conceptual framework of access to quality ECEC that illustrate the dynamic process of access services based on 6 stages of access: 1- Childcare needs, 2-Perception of need and desire for childcare, 3- Childcare seeking, 4- Childcare reaching, 5-Childcare utilization, and 6- Full inclusion and social participation. Results: Barriers and facilitators were identified in both the supply-side (i.e., ECEC) and demand-side (i.e., family) factors for all stages of access to ECEC for children with disabilities. All participants identified barriers to access ECEC settings for children with disabilities. Depending on children's needs, key barriers emerge at different stages of continuum of access to ECEC. Main barriers for children with severe disabilities were mostly to reach an ECEC setting (e.g. physical barriers, staff apprehension), while children with special needs but without a medical diagnosis, are able to reach ECEC without any particular barrier, but face challenges in ECEC utilization (mainly due to poor access to financial support measures for these children). Finally, neurodevelopmental disorders are often poorly recognized and misunderstood by staff, which limits the quality of services offered and impedes children's full inclusion and social participation. Conclusion: Significant barriers persist in terms of access to ECEC settings for children with disabilities in Québec. It is essential to focus on solutions that have the potential to influence several steps in the process to access ECEC, such as supporting families to navigate access and integration to ECEC, ensuring equitable access between regions, adjusting financial measures to meet the children's needs, and developing the staff skills necessary for the inclusion of all.

#### **EXECUTIVE SUMMARY**

Families of children with disabilities continue to face added obstacles when accessing Early Childhood Education and Care (ECEC) in Québec, and this in spite of renewed commitment by both federal and provincial governments to ensure full social participation of all children and their families. The aim of the present study was to gain a deeper understanding of the experiences of parents of children with disabilities trying to access reliable, safe and adequate ECEC for their preschool-aged children with disabilities in Québec.

METHODS: Families of children with disabilities and key stakeholders (i.e., individuals involved with managing ECEC and/or supporting children with disabilities in ECEC) were recruited through social media and snowballing. In total, 16 parents of children with disabilities, 3 directors of childcare centres, 1 pedagogical support agent and 1 inclusion coordinator participated in a one-hour individual virtual interview. The interview guide explored barriers to and facilitators of access, according to the following 6 stages: 1- Childcare needs, 2- Perception of need and desire for childcare, 3- Childcare seeking, 4- Childcare reaching, 5- Childcare utilization, and 6- Full inclusion and social participation. The conceptual framework illustrates the dynamic process of access to ECEC services, with 10 factors acting on how families navigate from one stage of access to the next. Five of those factors are specific to families, namely their ability to 1- Perceive need, 2- Seek, 3- Reach, 4- Pay, and 5- Engage. The other five factors represent aspects of ECEC: 1- Approachability, 2- Acceptability, 3-Availability & accommodation, 4- Affordability and 5- Appropriateness. In between each stage of access, it is from the dynamic between the factors specific to families and the aspects of ECEC (1- their ability to perceive and approachability, 2 - their ability to seek and acceptability, etc.) that our 5 themes emerged. The interviews were transcribed and coded, to explore how these 10 factors influenced access to ECEC for children with disabilities in Québec.

RESULTS: For each of the themes that emerged from the interaction between family factors and ECEC characteristics, both barriers and facilitators were identified.

Firstly, **approachability** refers to how easily families can find ECEC services for their children with disabilities and information about potential ECEC settings; in other words, to the availability and clarity of the offer of service for inclusive ECEC. Approachability of ECEC for families of children with disabilities in Québec is facilitated by *La place 0-5*, a central access point to ECEC services which was widely known by most participants. Approachability is hindered by the fact that inclusive and adapted ECEC services are poorly and unevenly catalogued, within *La place 0-5* or elsewhere, as reported by both parents and ECEC staff. Families' **ability to perceive** is related to families' recognition of their need for child care. Families' needs and desire for ECEC varied greatly from one family to another. While many families felt the need to access ECEC, particularly for stimulation, respite, or to return to work, others (especially families of children with complex needs) reported an initial desire to keep their child at home longer than peers with typical development.

Secondly, perception of the **acceptability** of ECEC services and settings is influenced by the ECEC provider's positive attitude towards inclusion or by their perceived reluctance to receive children with disabilities. Proactivity boosted families' **ability to seek** ECEC, and so did having the support of a professional or care navigator to help with the search for available and adequate ECEC, as they could assist in overcoming the obstacles of navigating through unknown and informal mechanisms.

Thirdly, **availability** of ECEC services is a significant challenge in a context of a shortage of labour and ECEC spaces. This seems to be exacerbated for families of children with disabilities, insofar as without the means or obligation of prioritizing children with disabilities, ECEC provider may dedicate the limited spaces available to children that do not require specialized support. It is worth noting that many ECEC settings are not able to **accommodate** certain needs because of very real physical constraints, that were found to be alleviated when these settings are designed with the principles of Universal Design in mind. Barriers to the parents' **ability to reach** occurred when the shortage of available and adequate ECEC forced parents to abandon certain criteria for preferred ECEC, including finding ECEC that could accommodate for special needs in the absence of a clear medical diagnosis.

Fourthly, families' **ability to pay** for ECEC is greatly facilitated by the array of low-cost ECEC services in Québec and other financial measures available to pay for non-subsidized daycare or adaptations necessary for the integration of their child with a disability. Similarly, the presence of subsidies specifically intended to support inclusion of children with disabilities was a key facilitator to ensuring ECEC **affordability**. Unfortunately, some of these subsidies are only available to certain ECEC settings, are accessible via burdensome administrative processes or are plainly insufficient. Lack of knowledge about available subsidies was also reported as a barrier to ensuring ECEC affordability in Québec.

Finally, as children with disabilities and their families become users of their ECEC setting, a bond forms between service providers and receivers of care. The appropriateness of the service received by the child with disabilities and their family has a direct impact on their participation, involvement and overall satisfaction, hence on their capacity and motivation to participate in care, or their ability to engage. Effective collaboration between all actors involved in the child's development was brought up by parents, managers and professionals alike as being primordial, both to ensure that ECEC settings are able to provide appropriate childcare and that the child with disabilities and their families are fully engaged and committed to a successful inclusion. The presence of a care navigator was also noted as a facilitator to ECEC appropriateness, insofar as they facilitate collaboration, streamline the sharing of adaptive equipment, and can provide educational staff with support to aid inclusion, as well as training and information about the children and/or their disabilities. Having trained educational staff stands out as a determining factor for ECEC appropriateness, as well as having a dedicated and caring team in place. This is echoed in the various human resources challenges identified as one of the principal barriers to offering appropriate ECEC to children with disabilities, that often result in a lack of understanding of the child and/or their disabilities, and which is in turn linked to unsuitable inclusion strategies being put in place by the ECEC provider, including but not limited to, partial or limited inclusion.

IMPLICATIONS: Study findings point to four courses of action to facilitate access to ECEC for children with disabilities. Although families' experiences in navigating ECEC differ based on a number of factors, including the needs of the child, four cross-cutting themes nevertheless emerge from this study as important levers of action as they have the potential to influence several facets of ECEC access, irrespective of the child's needs:

- 1. Support to navigate access and integration into ECEC should be provided to all families of children with disabilities. This support could be dispensed by resource persons whose mandate would be to support the family, explain the options that are available to them and facilitate the liaison between the family, ECEC staff and the health and social services network, thus streamlining the various stages of accessing quality ECEC (i.e. needing, perceiving, seeking, reaching, utilizing and achieving full inclusion and social participation within ECEC).
- 2. Ensuring inter-regional equity in terms of access to ECEC that is tailored to the needs of children with disabilities is crucial. To this end, it is possible to draw from and extend good practices identified in the Montreal metropolitan region to other regions.
- 3. Ensuring that financial measures are adjusted to the needs of each child with disabilities would have a significant impact on their integration into ECEC. Currently, the criteria do not always correspond to practical realities (e.g., requiring a diagnosis and that the child be already integrated into their ECEC setting before granting specialized funding), the sums available to ECEC providers are insufficient to allow the appropriate support for each child, and the complexity of the administrative processes hinders integration in certain ECEC settings.
- 4. Beyond integration, the ultimate goal of ECEC policies should be that each child be fully included. To this end, it is important to ensure that ECEC reflects and projects an inclusive society. This can be done through public education, by designing ECEC that is universally accessible, and by supporting childcare educators with the inclusion of children with disabilities, both in their initial training and in continuing education.

#### 1. CONTEXT

## 1.1 Initiation of the project

In Canada, 68% of preschool children attend Early Childhood Education and Care (ECEC) (Gouvernement du Canada, 2021). For these children and their families, entering the world of ECEC is a demanding stage in terms of adaptation. This is especially true for families of children with disabilities, for whom the path to ECEC is fraught with additional difficulties (Statistique Canada, 2021; St-Louis et al., 2021). In Canada, 4% of children have a disability (Statistique Canada, 2006). For children with disabilities, access to quality ECEC is an essential factor in supporting their overall development (Bouchard & Christine, 2010). Moreover, the inclusion of children with disabilities in ECEC is not only beneficial for these children, but also for all children, as it can help to foster a culture of respect and understanding for the full spectrum of human ability and can provide the opportunity to learn about and accept individual differences (Équipe « Ensemble pour des milieux de garde inclusifs », 2022).

Measures facilitating inclusion of children with disabilities in ECEC includes: 1) funding for inclusion; 2) qualified staff; and 3) access to professional staff support (Van Herpt & Fawcett, 2011). Even if those measures are well documented, families of children with disabilities continue to have difficulty accessing ECEC (St-Louis et al., 2021).

A review of the situation of access to ECEC for children with disabilities, conducted by Scientific Research and Experimental Development Canada in July 2021, identified that parents of children with disabilities are at the mercy of a fragmented system of public and private care options. Degrees of regulation are inconsistent despite the recent federal commitment to develop and strengthen a childcare system (Emploi et Développement social Canada, 2021; Gouvernement du Canada, 2020). In this context, Employment and Social Development Canada decided to conduct a comparative project on this issue across three Canadian provinces (i.e., British Columbia, Nova Scotia, and Québec) to gain a deeper understanding of the experiences of parents of children with disabilities trying to access reliable, safe and adequate ECEC. This report presents Québec results for this project.

## 1.2 Context in Québec

Québec is known as having innovative and inspiring ECEC since 1997, when low-cost public funded ECEC was developed (Statistique Canada, 2021). There are four main types of recognized ECEC services in Québec (see Figure 1):

- 1. **Childcare centres**: Non-profit organizations that offer subsidized (\$8.70/day) facility-based spaces
- 2. **Subsidized daycares**: generally for-profit private businesses that offer subsidized (\$8.70/day) services in a facility.
- 3. **Non-subsidized daycares**: generally for-profit private businesses that offer non-subsidized services in a facility (price varies).
- 4. **Home-based Childcare**: independent workers (home childcare provider) who offer subsidized (\$8.70/day) or non-subsidized spaces. In order to be recognized, home-based childcare must be regulated by a home childcare coordinating office that is often affiliated with a childcare centre.

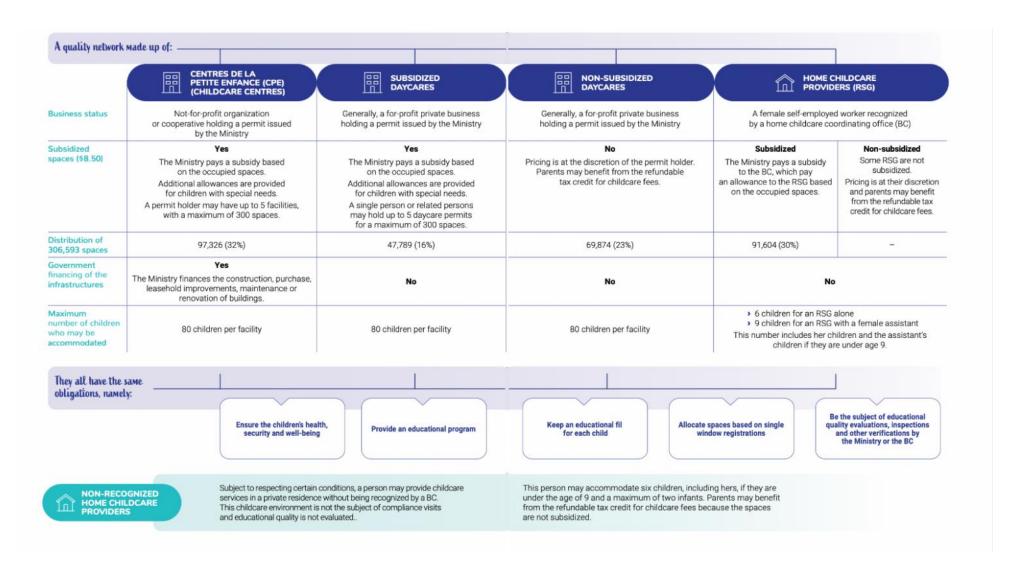


Figure 1. Types of recognized ECEC settings in Québec (<a href="https://www.mfa.gouv.qc.ca/fr/publication/Documents/annexe-cahier-consultation-ang.pdf">https://www.mfa.gouv.qc.ca/fr/publication/Documents/annexe-cahier-consultation-ang.pdf</a>)

Through this diversified system of ECEC services aiming to ensure quality education for preschool aged children, the attendance rate for ECEC is significantly higher in Québec than elsewhere in the country (Statistique Canada, 2021). For example, in 2021, the attendance rate in Québec was 79%, compared to 55% in the rest of Canada. For recognized ECEC settings, the attendance rate was 70% in Québec versus 35% in the rest of Canada (Statistique Canada, 2021).

Although inclusion of children with disabilities in ECEC in Québec is far from perfect, there are several facilitating mechanisms in place. First, it is important to note that the Educational Childcare Act is clear about the objective of ECEC:

Promote the quality of childcare services to ensure the health, safety, development, educational success, well-being, and equal opportunity of children who receive such services, **especially those with special needs** or who live in a context of socioeconomic disadvantage. (Loi sur les services de garde éducatifs à l'enfance, 2020)

Secondly, subsidized ECEC has access to two grants for the inclusion of children with disabilities: Allowance for Integrating a Disabled Child into Educational Childcare (AIDC) and, for greater needs, the Financial Assistance for the Integration of Children with Disabilities in childcare centres (FICWD).

Thirdly, there are also a partnership between the health and social services sector and certain ECEC providers to dedicate priority spaces for children with special needs (e.g., socioeconomically disadvantaged, children with disabilities, etc.) in exchange for support from affiliated professionals. These spaces are called "priority spaces" (in French: *places protocole*). These memorandums of understanding, although useful in some cases to facilitate access to ECEC for children with disabilities, are implemented unevenly across the regions (Saint-Pierre et al., 2008).

Lastly, in the Montreal metropolitan area, there are also two non-profit organizations that promote access to ECEC for children with disabilities: *J'me fais une place en garderie* (Charbonneau & Lalumière-Cloutier, 2022) and *Table de concertation pour l'intégration en services de garde des enfants ayant une déficience - région de Montréal* (Table de concertation pour l'intégration en services de garde des enfants ayant une déficience - région de Montréal, 2022). This support, offered to children with disabilities and their family in Montreal, doesn't have a counterpart outside of the metropolitan area.

Although these mechanisms are in place, recent provincial studies highlight that there are still numerous challenges for ECEC settings that take in children with disabilities. First, in a context of scarcity of places in ECEC and of labour shortage, children with disabilities can be shortchanged, as indicated by a lower placement rate than other children (73% vs. 83%) (St-Louis et al., 2021; Vérificateur général du Québec, 2020). Moreover, ECEC settings that adopt an inclusive approach feel overwhelmed with requests, and express frustrations with the fact that not all settings contribute to the societal inclusion of children with disabilities (Pratte et al., in redaction). Indeed, non-subsidized daycares do not have access to the AIDC and the FICWD (Delisle et al., 2009; Raymond Chabot Grant Thornton, 2021) and among subsidized ECEC, only 48% ECEC settings have an inclusion policy (Équipe « Ensemble pour des milieux de garde inclusifs », 2022). Lastly, studies on the inclusion experience of Early Childhood

Educators (ECE) show that they feel they are not sufficiently prepared to accommodate children with disabilities (Lessard et al., 2021).

Fortunately, the reflection process on how to promote the inclusion of children with disabilities is well underway in Québec. Indeed, the *Ministère de la Famille* conducted a public consultation on ECEC services in 2021. From these consultations came the orientations of the *Grand chantier pour les familles*, which identifies as one of its main objectives to "bring equal opportunity back at the heart of our action [...] by providing adapted services adapted to the most vulnerable children and those with special needs" (Ministère de la famille, 2022, p.8). To this end, the Québec government plans to better support children with disabilities by reviewing the management of the AIDC and by evaluating "opportunities to provide more resources to support children with special needs but without disabilities" (Ministère de la famille, 2022, p.44).

It is in this context of a need for comprehensive data on the accessibility of ECEC for children with disabilities, and of a renewed federal commitment to examining the challenges and barriers parents face in accessing ECEC for their preschool children with disabilities (the 2020-21 Departmental Research Plan of the Commissioner of the Environment and Sustainable Development (CESD)), that we conducted qualitative research on this issue in Québec.

#### **2. AIM**

The main aim of this study is to identify the barriers to access to recognized ECEC for children with disabilities in Québec. Precisely, the research project aims to:

- 1. Examine and understand the parents' experiences about ECEC access or their attempt to register their children with disabilities in ECEC.
- 2. Explore ECEC managers' and professionals' perceptions about the different programs and politics in connection with inclusion services in ECEC.

#### 3. METHODS

## 3.1 Design

This qualitative study used an interpretive description design (Gallagher & Marceau, 2020; Thorne et al., 2004) based on a socio-constructivist approach. This approach acknowledges participants' perspective about ECEC access (or access attempts) for children with disabilities, enabling us to construct a portrait of participants' needs that is representative of the reality of ECEC access difficulties for families of children with disabilities in Québec. Ethical consent was obtained from the ethic committee of the CIUSSS de l'Estrie – CHUS for this project, and all participants completed a consent form.

## 3.2 Recruitment and Participants

Interviews were conducted with two distinct populations: 1) parents of children with disabilities; and 2) managers & professionals

#### 3.2.1 Parents

Parents of children with disabilities enrolled, or wishing to be enrolled in a recognized ECEC setting in Québec were targeted for this study. They were recruited via social media, national and regional organizations for children with disabilities (e.g., Coalition de parents d'enfants à besoins particuliers du Québec, Société de l'autisme et des TED Estrie, l'Étoile de Pacho, etc.) and with the help of targeted childcare centre directors. To be admissible, parents had to: 1) Have a child aged between 0 to 5 years of age with a disability who is receiving (or has received in the last 3 years) recognized ECEC services; OR be currently searching for recognized ECEC services for their child with disability; 2) live in Québec; 3) communicate in English or French; and 4) have access to the internet.

We defined children with disabilities as "a child with a handicap or a functional limitation that requires adaptations" (St-Louis et al., 2021). It is important to note that although the scope of this research focuses on preschool aged children (0-5 years old), four interviews were conducted with parent of children older than 5 years old, in order to get a better insight of the overall experience of families with the ECEC process, including the transition into the educational system. These four children over the age of 5 therefore raise the mean age.

## 3.2.2 Managers and professionals

To be eligible, managers had to be part of the management team of a childcare centre or subsidized daycare (e.g. director, assistant director). Professionals had to have relevant work experience in supporting inclusion of preschool aged children with disabilities in ECEC. They all needed to be able to communicate in English or French. Managers and professionals were recruited via research team contacts and phone call to childcare centres.

#### 3.3 Data collection

Before taking part in the interviews, participants first completed a sociodemographic questionnaire online using the REDCap data collection application (Harris et al., 2019). They were then contacted by the research coordinator to schedule for a virtual semi-structured interview conducted via Microsoft® Teams. Interviews lasted between 25 and 90 minutes. The interview guide was adapted from the questions provided by Employment and Social Development Canada while considering Birkmann and Kvale's establishment and interview conduct (2018). The main themes explored in the parents' interview guide are the need for adaptation and accommodations for their children with disabilities, the trajectory to find ECEC, and the efficiency of support measures in place to ensure inclusion of children with disabilities in ECEC in Québec (see Interview Guides in Appendix 1 and 2). Probing questions were then used to further understand the context of the accommodations and support mentioned by participants. ECEC managers interviews were about provincial policies that facilitate or hinder access to ECEC services for children with disabilities, as well as other relevant experiences.

## 3.4 Data analysis

Sociodemographic data were analysed descriptively for both continuous (mean and standard deviation) and ordinal variables (frequency and percentage). Qualitative analysis took place simultaneously and in parallel with data collection. Data were analysed using deductive and inductive qualitative analysis and following the three main steps proposed by Miles, Huberman et Saladana (2020): extraction, condensation, and interpretation. At the **extraction step**, interviews were transcribed verbatim. Two research team members then coded all interviews

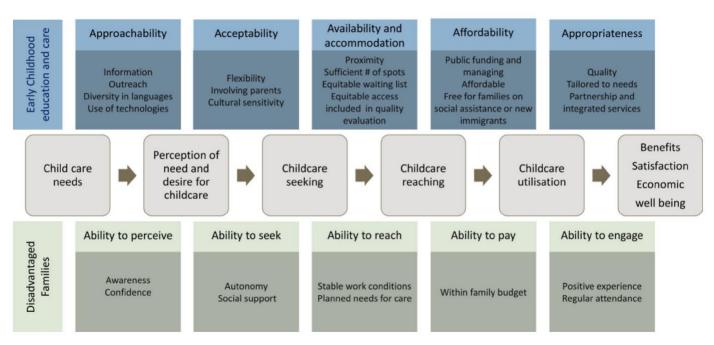
using QDA Miner software. A first draft coding tree was developed using the Archambault and al. (2020) conceptual framework of access to quality ECEC, in order to situate the main categories of barriers and facilitators at each stage of access and the actors involved (see section 3.5 and figure 2). Codes under general categories of the framework were identified inductively and named based on the participants' terms and concepts. After each interview analysis by both evaluators, a discussion was scheduled to reach a consensus. In case of disagreement, a third evaluator was brought into the discussion.

For the **condensation step**, codes and categories were discussed and reorganized by the research team in order to draw out the main results. For the **interpretation step**, after team discussion, the final codes thus created were visually organized according to the Archambault et al. (2020) framework, resulting in the data display in Figure 3.

## 3.5 Conceptual framework

Archambault's conceptual framework (2020), used to organize results in this project, aims at bringing an integrated approach to understanding the barriers to ECEC access for disadvantaged families. It identifies six stages of access: 1- Childcare needs, 2- Perception of need and desire for childcare, 3- Childcare seeking, 4- Childcare reaching, 5- Childcare utilization, and 6- Benefits, satisfaction, economic and well-being. The conceptual model illustrates the dynamic process of access services, with 10 factors influencing how families navigate from one stage of access to the other. Five aspects are specific to the supply side of childcare access (i.e. ECEC services), and five corresponding aspects reflect the reality on the demand side (i.e. families). The supply-side factors of access to ECEC include, for instance, the characteristics of subsidized ECEC providers in Québec (i.e. physical environment, location, education programs, registration processes, etc.), whereas demand-side factors have to do with the characteristics of children with disabilities and their families, including, but not limited to, their cultural, physical and social environments. It is the interaction between these two sets of factors that influences access at each stage of the continuum, starting with the perception of need for ECEC to receiving ECEC.

The results of this project are organized in the section below according to the barriers and facilitators to access identified for both the supply-side (1- ECEC's approachability; 2- ECEC's acceptability; 3- ECEC's availability & accommodation; 4- ECEC's affordability; and 5- ECEC's appropriateness) and demand-side (1- Families' ability to perceive need; 2- Families' ability to seek; 3- Families' ability to reach; 4- Families' ability to pay; and 5- Families' ability to engage).



**Figure 2.** Conceptual framework of access to quality ECEC settings for children from disadvantaged backgrounds (reprinted with permission from Archambault et al. [2020])

#### 4. RESULTS

## 4.1 Participants

Sixteen parents and five managers/professionals were recruited.

## 4.1.1 Parents

Sociodemographic characteristics of the 16 parents interviewed, and their children are detailed in Table 1.

Out of the 17 children discussed in the interviews, 13 were boys (76%) and four were girls (24%). Their age ranged from two to seven years old, with a mean of 49 (+/- 19.4) months. All children were included in the mean age, even though 4 children were older than the scope of this study. Most children (n=14, 82%) had an official diagnosis from a healthcare professional (e.g., pediatrician, neurologist, geneticist). One family was in the process of obtaining a diagnosis for their child with a disability, and another did not want to obtain a diagnosis for fear of their child being labeled, yet the child had clear extra needs for support. Our sample included children with various disabilities such as: genetic-based syndromes or illnesses (n=4), cerebral palsy (n=3), autism spectrum disorder (n=3), intellectual disability (n=2), speech and language delay or disorder (n=2), developmental delay related to a premature birth (n=2), deafness (n=1), Tourette's syndrome (n=1), Down syndrome (n=1), epilepsy (n=1). Each child could present more than one diagnosis.

Type of ECEC and frequentation (i.e., full-time/part-time) was varied among children: seven were registered full-time and three part-time in a childcare centre, two were registered full-time in a non-subsidized daycare, and two were registered full-time and one part-time in a home childcare. One family was never able to find childcare for their child with a disability and this child is now attending kindergarten, at five years of age.

Most of the interviewed families lived in a large population centre (>100,000 inhabitants), with six of the 10 administrative regions of the province represented. Most families (63%) reported a gross family income of >100,000\$/year making our sample a little over national average in terms of gross family income. 47% of families had a single child under the age of 19 living at home (n=7), while the others had two (n=12), three (n=4) or four (n=1) children under the age of 19 living at home. All families were French speaking; for the purpose of this report, parental quotes are translations into English of interview transcripts.

Table 1. Sociodemographic characteristics of parents and their child with disability

<b>Sociodemographic characteristics</b> Children $(n = 17)^b$	$n (\%)^{1,a}$ or mean $(SD)^2$
Sex (boys) <sup>1</sup>	13 (76 %)
Mean age (in months) <sup>2</sup>	49 (19.4)
Age groups <sup>1</sup>	
2 years old (24-35 months)	3 (18%)
3 years old (36-47 months)	6 (35%)
4 years old (48-59 months)	3 (18%)
5 years old (60-71 months)	1 (6%)
6 years old (72-83 months)	2 (12%)
7 years old (84-91 months)	2 (12%)
Diagnosis (yes) <sup>1</sup>	14 (82%)
Type of ECEC settings <sup>1</sup>	
Childcare centre	10 (59 %)
Subsidized daycare	0 (0%)
Non-subsidized daycare	3 (18 %)
Home-based childcare	3 (18 %)
Never found a space for their child	1 (6 %)
Attendance (part time) <sup>1</sup>	4 (24 %)
Parents $(n = 16)$	
Sex (female) <sup>1</sup>	14 (88%)
Age in years <sup>2</sup>	37.9 (4.2)
Marital Status (married or in a relationship) <sup>1</sup>	16 (100%)
Population centre <sup>1</sup>	
< 29, 999 inhabitants	4 (25%)
30, 000 to 99, 999 inhabitants	3 (19%)
> 100, 000 inhabitants	9 (56%)
Participant's work situation (full time) <sup>1</sup>	10 (63 %)
Family income <sup>1</sup>	
25, 000 \$ to 49, 999 \$	1 (6 %)
50, 000 \$ to 69, 999 \$	3 (19 %)
70, 000 \$ to 99, 999 \$	2 (13 %)
> 100, 000 \$	10 (63 %)

<sup>&</sup>lt;sup>a</sup> The total may not add up to 100% due to rounding of results to the nearest unit <sup>b</sup> The sample includes 17 children and 16 parents as one parent has 2 preschool-aged children with disability <sup>1</sup> Ordinal variables: present in frequency and percentage

<sup>&</sup>lt;sup>2</sup> Continuous variables: mean and standard deviation

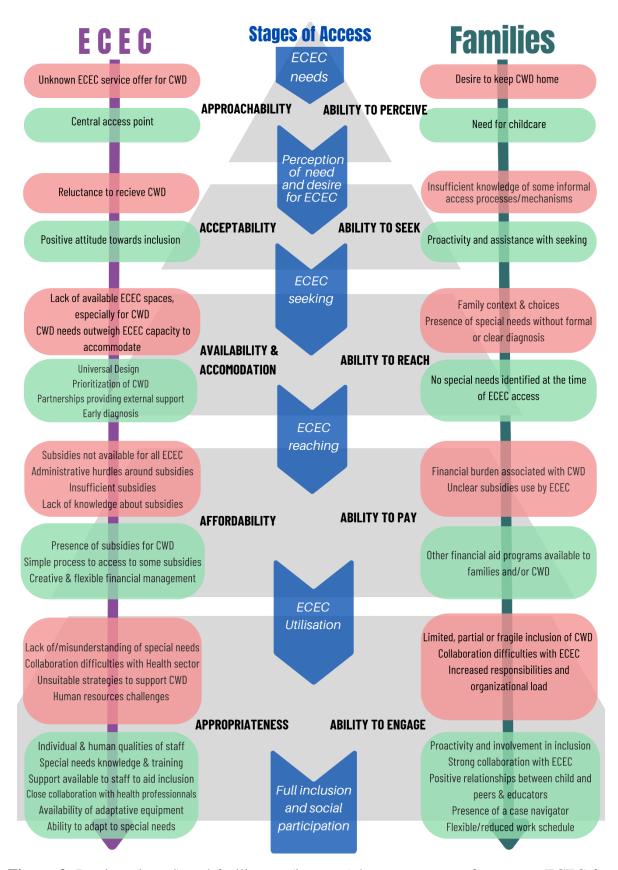
## 4.1.2 Managers and professionals

Three directors of childcare centres whose clientele includes children with disabilities were interviewed. All had over 20 years of experience working in a childcare centre, and all were directors of childcare centres that had partnerships with the health and social services sector to hold priority spaces for children with special needs. Surveyed ECEC settings varied in size, ranging from 80 to 189 places, and included between four and 12 children with disabilities in their installations.

Two professionals were included: 1) a pedagogical support agent (agent de soutien pédagogique) hired by a home childcare coordinating office to facilitate the inclusion of children with disabilities within 67 subsidized home childcare providers; and 2) an inclusion coordinator for a non-profit organization working with families and ECEC providers to ensure the successful inclusion of children with physical disabilities in ECEC.

### 4.2 Barriers and facilitators between each stage of access

Figure 3 presents the barriers to and facilitators of access to ECEC for children with disabilities, as reported by participants and organized according to our conceptual framework. For each stage of access (e.g. need of ECEC), we identified influencing factors on both the supply (ECEC) and demand (families) sides. These influencing factors could either be elements facilitating access (in green) or elements hindering access (in red).



**Figure 3.** Barriers (in red) and facilitators (in green) between stages of access to ECEC for children with disabilities (CWD) in Québec

## 4.2.1 Approachability & Ability to perceive

The majority of participants reported that a central point of access for ECEC is accessible and known to Québec parents. *La Place 0-5* is a well-known digital platform that centralizes the search for spaces in recognized ECEC services in Québec and communicates families' interest to these settings. Several parents reported that they navigated these steps very quickly: "as soon as I found out I was pregnant, I registered him in 0-5" (#20 – parent). Despite this strong **approachability** of ECEC in general, the offer of specific ECEC services for children with disabilities was much less known. As one parent reported, this lack of awareness is a significant barrier to the approachability of ECEC for children with disabilities:

It's that you don't always know what you're entitled to, what's out there. You don't know and you're kind of dependent on what your care navigator knows. Then, if they haven't been in contact with a case exactly like yours, they don't necessarily know. It seems that information doesn't necessarily circulate, and then it varies from one region to another, so then you read things from some parents but it's not the same reality in your region. (#1 - parent)

This lack of awareness of the ECEC available for children with disabilities is shared by parents, their health care providers and some ECEC center directors. In fact, "there are a lot of settings that say: 'Well, send them to specialized daycares anyhow.' So, we get told that too. We have to educate, there's no such thing as specialized daycares, there are only daycares." (#16 – inclusion coordinator).

On the family side, the **ability to perceive** the need for ECEC services varied greatly from one family to another, depending on the course of the child's condition and on various contextual elements. Many families felt the need to access ECEC, particularly for stimulation, respite, or to allow parents to return to work. Other parents reported an initial desire to keep their child at home longer than their typically developing peers. In particular, families of children with complex needs did not consider inclusion in ECEC to be the initial priority, as reported by this parent:

But in the first year, with all the uncertainties, the appointments every week, the first year was very busy, so at the end of the first year, me, it was obvious that I wasn't going back to work right away and that I wasn't looking to bring her to daycare right away either. (#1 - parent)

One inclusion consultant summarised the experiences of several families she accompanied as follows:

Parents who are hyper-vigilant, hyper-traumatized. You know, they had a medical experience and thought their child was going to die. Many hospitalizations. There, they're skin-to-skin with this child. They can't imagine detaching themselves from her. They can't imagine that another adult would be able to take care of her as well as they can. This separation is really difficult for some families. So, at the root of it all, there's already a barrier for parents. (#16 – professional)

Undoubtedly, some families have fears about their child's safety in an ECEC centre. In this regard, one manager mentions that parents wonder:

... if they will be able to. You know, they don't know childcare centres either. They don't know any more than that. And then, they abandoned their children to the childcare centre. That's how they see it. That's not it at all. But hey, they have to learn to trust us too. (#17 - manager)

In addition, contextual elements accentuate some parents' desire to stay home longer with their child such as the presence of social support that allows for some respite, and little constraint regarding a punctual return to work.

## 4.2.2 Acceptability & Ability to Seek

The **acceptability** of ECEC settings for children with disabilities was strongly associated to their positive attitudes towards inclusion. ECEC that were open to receiving children with disabilities were characterized by strong values of inclusion embedded in their mission, previous positive experiences with receiving children with disabilities, and strong support from management. In particular, one parent reported, in relation to the management of a childcare centre, that "there were a lot of children with special needs there, so it was important to her" (#13 – parent). On the other hand, other ECEC settings were reluctant to accept children with disabilities or even refused them. These fears were explained in part by previous negative experiences with inclusion, or by a lack of knowledge about special needs, what they entail, and of the potential positive impact of inclusion on all stakeholders. One parent also emphasized the lack of obligation from ECEC settings in Québec to receive and include children with disabilities.

We really rely on the voluntary nature of each centre's director. And most of the directors, from what I know, are afraid. They don't feel prepared or, they don't say so, but they definitely don't want to tackle the additional procedures that only add to their burden for... that's it, it adds to their burden. (#3 – parent)

Parents' **ability to seek** was hampered by a lack of awareness of certain specific or informal processes for finding an ECEC space for their child with a disability. In fact, despite the central access point where parents can get on the waiting list for various ECEC options (see section 1. Approachability & Ability to Perceive Childcare Need), other informal mechanisms were sometimes mentioned as having been used by Québec parents of children with or without disabilities (e.g. calling the ECEC provider regularly to follow-up on the status of their application). However, these informal processes were reported as not being formalized, listed or harmonized, and therefore, many parents are not aware of them. The results also show that the proactivity of families is a crucial facilitator in the search for ECEC:

At a certain point, I said to myself: "Well, he is developing slower, so it's time. He really needs to start daycare by the end of the year." So, I called several places, including daycare centres. Even though I know that usually, if we're lucky, daycare centres are the ones who call us. I tried anyway. (#10 – parent)

Families of children with disabilities mentioned that other processes can, depending on the context, help in the search for ECEC willing to receive a child with disabilities, such as through primary health care services. However, these processes are again unknown to most parents. One parent reported that he "didn't know that we could be more of a priority" (#7 – parent). Similarly, several participants emphasized that "there is a lack of support for parents" (#8 – parent). In contrast, parents who received help and support in finding ECEC

reported this as an important facilitator. This support for navigating services could take many forms. Some parents received formal support from health and social care providers, or from a community-based organization that supports access to ECEC and inclusion for children with disabilities in Montreal (i.e. *J'me fais une place en garderie*). Other families were referred by an ECEC director to a more accessible or appropriate ECEC for their child. This support was described as "a golden opportunity that is not given to everyone" (#3 – parent).

## 4.2.3 Availability and Accommodation & Ability to Reach

Once families had begun the process of finding ECEC for their child with a disability, they reported facing several obstacles relating to availability and accommodation. In terms of **availability**, it is important to point out that there is a widespread "shortage of childcare services"(#1 – parent) in Québec. Parents reported that "right now, it's really hard to find a childcare setting for all children" (#1 – parent) because "spaces are so rare" (#12 – parent). In fact, many parents with children with or without special needs have difficulty finding a space in ECEC for their child. This shortage of space is even more important for children with disabilities, since ECEC settings are under no obligation to accommodate or prioritize children with disabilities. Quite the opposite, parents felt that because the demand for spaces exceeds the supply of ECEC spaces available, it disadvantages their child with a disability. One parent said that many ECEC settings "are spoilt for choice when it comes to filling their empty spaces. They may well decide to accept the children that are easier." (#8 – parent). Another parent summarized these availability and prioritization issues as follows:

There is no prioritization for children with a diagnosis. They are on the same lists as everyone else and ECEC services can choose to draw, or not, from their waiting lists. It's not first come first served, they choose... So there are barriers. (#1-parent)

However, this is not true for all ECEC settings. Some ECEC prioritize or hold a few spaces for children with disabilities. Moreover, the community-based organization's inclusion coordinator stated that although "parents are often afraid to write down on La place 0-5 that the child is disabled, because they fear they may be discriminated or disadvantaged, [we] encourage them to write it down because there are childcare centres that will prioritize them" (#16 professional). In addition, some ECEC hold spaces named "protocol spaces" to facilitate access to ECEC for children with disabilities or other vulnerabilities. However, to have access to these dedicated priority spaces, the child's disability or need must have been identified at an early age, which allows them to receive services from their local community service centre before attending ECEC. One parent reported that "there were issues finding a space until someone turned to the local community service centre's priority places and then all of a sudden it was fine. He got in and it wasn't difficult." (#12 – parent). Similarly, other ECEC settings have established agreements with community-based organizations or rehabilitation centres. For example, "J'me fais une place en garderie, has [a] little list of some cherished daycares that we've worked with for 25 years. There are even some that will almost, like, reserve spaces for us" (#16 – professional). Similarly, a daycare centre manager who has an arrangement with a rehabilitation centre reported that "we hold [spaces] for this clientele because they have needs, and we are lucky, as I said, to have this suitable facility" (#17 - manager). It is important to note, however, that access to these facilitators varies from one region to another. According to the participants, "There are many things in Montreal, but as soon as you go out of Montreal,

there is a shortage of everything" (#1 - parent). Notably, "the organization *Je me fais une place en garderie* is only available in Montreal" (#2 - parent).

From one region to another, things vary too. You hear that there are priority spaces that can be reserved for children with special needs, but it changes from region to region. Here, when I asked the question, I was told that it was for children from Youth Protection, whereas in other regions, it is for children who are being referred by rehabilitation centres. In other regions, perhaps they have reserved spaces, that there would be easier access, whereas for us, that was not the case. (#1 – parent)

These ECEC space availability issues for children with disabilities significantly limit the choice available to families. Many families reported dropping some of their initial criteria, including type of ECEC setting, attendance time, or distance from home. In fact, more than half of the parents (7/12) spontaneously reported finding an ECEC setting that is farther away than they wish, which involves "a very big detour" (#21 – parent) for the family. One parent explains this trade-off in terms of ECEC proximity as follows: "There was nothing, so finally I managed to find a space. Not in the town where I live. That, I didn't manage. I found one a little farther away. [...] It's a good 25 km from home, so it takes a long time" (#20 – parent). Another parent said that "we came to an agreement, [that the ECEC] would take him two days a week, instead of five" (#11 – parent). It is important to highlight the sense of despondency and rejection that many of these families experience as a result of being denied access to ECEC. One parent reported, "I was worn out from looking, and then I was also emotionally worn out. I was starting to find it hard to be turned down. Everybody was telling me, 'Don't give up, keep going. Maybe you'll find great ECEC. There are daycare centres. Call such and such a place. ' Then I gave up." (#10 – parent)

The limited leeway of ECEC centres to **accommodate** children's special needs was identified as another significant barrier. Despite many settings indicating on *La Place 0-5* that they welcome children with disabilities, parents report that many settings "select the disability they are comfortable working with" (#3 – parent). In fact, many parents report that ECEC centres had refused access to children with disabilities without having even tried.

What really bothered me was the fact that people seemed to think it was so complicated that sometimes they didn't even want to get into it. Like the daycare centres would call me and say, "Oh no, we can't...". Well, why not? Maybe you can. It's not that complicated. (#11-parent)

One parent summarizes her experience in finding an ECEC setting for her child with complex needs as follows:

I called some ECEC settings, and the first thing I would ask was, "Hi. Do you have any spaces right now for a child with special needs?" The answer was yes. That was good news. [...] Then they would ask me, "What are your child's special needs?" Now I would start explaining, for example, my child has Down syndrome, he has pretty severe hypotonia, so he's walking on all fours, but he's not walking yet. He has some health problems. And then I was stopped... "Well, ma'am, your child doesn't walk. Listen, it's not going to be possible." And I

would answer: "Ok. It's not going to be possible, why?" Then they told me, "Because the 4-year-old group is on the second floor." (#10 – parent)

Physical barriers, particularly the presence of stairs in ECEC settings, were also raised as a main barrier, especially for children who do not walk. One parent stated that "even if the reasons are valid, i.e., [the ECEC setting] is on 3 floors and it is dangerous for [my] daughter herself and for the staff, it hurts" (#5 – parent). The inclusion coordinator stated that although ECEC settings often say they cannot accommodate children with physical disabilities because "[they have] stairs", [but for *J'me fais une place en garderie*] it is not a hindrance to send a child to a childcare setting where there are stairs. There are 1,000 strategies to put in place. Then it's often barriers [that they hear] 'ah no the physical environment doesn't allow for it.' " (#16 – professional). Even better, participants noted that having ECEC settings that has been designed with universal access in mind make facilitate access to ECEC for children with disabilities. For example, one director stated that "everything is on the same floor. So, we don't have any stairs, no steps, nothing. Initially, that's very enabling in terms of accessibility for children with reduced mobility, for example." (#18 – manager). Similarly, some ECEC settings were designed with the inclusion of children with disabilities inclusion in mind.

The project [...] was to allow us to welcome this clientele. It was really the primary mission that led to the development of this project. [...] So, it's clear that the design of the building as such, well that was also thought out. That they are all on the same floor and all that. The bathrooms need to be bigger. [It would have] required a lot of work in our other two facilities. It wasn't possible. (#17 – manager)

In addition, collaboration with specialized resources is an important facilitator in understanding each child's needs and the accommodations that need to be made in order to integrate and include them.

Without the support of the rehabilitation centre, you can't welcome a child with special needs like that from one day to the next without having a clear picture and then getting support from the professionals involved. [...] You know, you can't just jump in without really knowing what it entails. So, we have presentations [...] that introduces us to each child with their particularities and all their daily needs, and how their physical or cognitive particularities or whatever. [...] When we were in the planning stage, the occupational therapist came to measure everything. (#17 – manager)

It should be noted that the issues previously raised in this section are most reported by families of children with complex needs identified prior to entering ECEC. In contrast, families with a child who did not yet have identified needs at the time of seeking ECEC had an easier time reaching ECEC. For example, one parent reported finding "an ECEC space at 18 months. We didn't have a diagnosis. A normal child. I don't like saying that, but I'll say it often, a normal child. That means that, basically, you know, he started ECEC like that, without anything." (#9 – parent). Between these two extremes, there are also all the children who have special needs, but who do not yet have a diagnosis or formal follow-ups by health care or social services providers at the time of seeking ECEC. Families reported that the ability to reach ECEC for these children in the grey zone is limited by the lack of access to support mechanisms.

You have to get on *La Place 0-5* like everyone else. You're not special and there's no pass. [My child] didn't have a diagnosis per se, so there were no priority spaces with the Health sector. We didn't have access to that. So we had to look by ourselves, but we had to declare that he had needs. (#6 – parent)

Finally, individual barriers related to the characteristics, choices and values of families can be added to these common barriers. For example, some families moved, which forced them to "refuse [a space] because we were moving" (#1 – parent). Another family (#8) who moved from the Montreal area to a rural area also reported this imbalance of available resources between regions. In addition, some families did not want to give up their criteria for ECEC. For example, some families were offered a place for their child over the age of one "in the nursery group" (#5 – parent). Another family reported that "over the years, I would look and not find, and then I would get a little bit of criticism for not wanting to expand my search radius [...] 30-minute drive from home" (#1 – parent). She further explained her reasoning as follows:

Already, in my mind, in my conception [...] a daycare environment is something close by. And then, having a child with very high needs, it was not at all reassuring to send him to a place that I could not reach quickly if anything happened. I know that I was perceived to be acting in bad faith a little, since it was my fault, by the health network and the professionals. (#1 – parent)

## 4.2.4 Affordability & Ability to Pay

Affordability is primarily influenced by the provincial financial measures available to publicly-funded and subsidized ECEC settings. Indeed, as described in section 1.2 Context in Québec, childcare centres, subsidized daycares and subsidized home childcare providers have access to two financial support measures for inclusion of children with disabilities: Allowance for Integrating a Disabled into Educational Childcare (AIDC) and, for greater needs, the Financial assistance for the integration of children with disabilities in childcare centres (FICWD). As one childcare centre director mentioned, "these children come with financial resources as well; these have to be named" (#17 – manager). It is important to note that knowledge of available subsidies varies greatly from one ECEC to another. Many ECEC settings that have never included children with disabilities are not aware of these subsidies. An inclusion consultant or a health professional often had to explain the available financial measures to these ECEC settings.

Nevertheless, easy access to the AIDC was cited as a significant facilitator: "the basic daycare subsidy, that was granted quite easily" (#20 – parent). In addition, the criteria are generally considered broad enough to allow public and subsidized ECEC settings to access this financial measure. One parent reported that "the childcare centres have a subsidy to accommodate children with disabilities. Frankly, the disability could be anything" (#4 – parent). Only one parent reported that "[his children] is not entitled to any subsidies because they are not recognized as disabled children since they are functional" (#14 – parent), despite suspicions of language disorders, dyspraxia, attention-deficit/hyperactivity disorder and anxiety disorder. In addition, "the Ministry allows a maximum percentage per facility" (#18 – manager) of 15% of children receiving the AIDC. This is a barrier for ECEC settings that are adapted, open and willing to include additional children with disabilities.

As summarized by a pedagogical support agent, the AIDC can be used to either lower the ratio of children per group, provide part-time one-to-one support for the child with disabilities, or pay for adaptative equipment.

[AIDC] is really designed to lower the ratio [of children taken in by home childcare provider]. So instead of, for example, taking in 6 children, taking in 5, to have more time to meet the child's needs. Or it's individualized support for the child. [...] But there is also another component which is an amount that is given for equipment. So, [the home childcare provider] can also buy equipment for, for example, in her bathroom if she needs to have a ramp, something like that, for the child, so that he can get on the toilet. She can pay with that. For example, if she needs a specialized stroller or something. You know, there will be amounts that can be given to pay for those things as well. (#15 – professional)

However, a majority of participants raised issues in terms of the amount offered by the AIDC which was deemed insufficient to meet the needs of children with disabilities. Depending on the salary paid to the person hired through this measure, the directors, educational support agent and inclusion coordinator who participated in the project estimated that the AIDC covers between 3 to 9 hours of support per week for each child with disabilities.

Basically, I would say that the [AIDC] is not huge. It kind of fills in. Basically, if the provider has decided to lower the ratio, well that will make up for the amount she would receive if she had one more child. For one-to-one support, [...] it always depends on the wages of the person who is chosen to provide it. For example, if the person charges \$50 an hour, then at that point, that doesn't allow for much accompaniment per week. (#15 – professional)

The inclusion coordinator reported that often "the [ECEC] will say, 'we need support, let's say 3 or 4 hours a day'. The [AIDC] will only fund an hour or an hour and a half of support from an educator. We [then] ask for the FICWD" (#16 – professional). The FICWD is a second financial aid granted to the ECEC "which is like a grant that they receive to be able to offer additional services" (#11 – parent) "when the child needs more one-to-one support" (#1 – parent). It "can fill up to 8 hours of support for the child per day " (#15 – professional). The majority of participants mention that it is helpful for children with significant support needs. One manger said: "The [FICWD] is helpful [...]. With one-to-one support, we can draw from all the resources and put in place all the adaptations we can to support the child, so that's interesting. (#19 - manager). However, major limitations with the administration of this financial measure were raised by a large number of participants. Indeed, access is largely restricted due inclusion criteria, the process itself and allocated funding. Specifically, the request for the FICWD can only be made twice a year and the child must already be attending the ECEC setting. Parents of children with complex needs identified this as a significant barrier "that you have to [first] get it in, then you file the application." (#11 – parent). Another parent who was unable to access any ECEC for his child with important support needs summarized this paradox:

There is really this question of the [FICWD] [...] which is necessary when you have a child with a severe disability, but it's like the chicken and the egg, because the child must already be registered. [A childcare centre director], what she explained to me, is that usually the child enters the nursery and before having

his diagnosis, there is already more follow-up, more accompaniment and that is when they realize that there are needs and then they make the request. That's the normal process. (#1 - parent)

However, when parents seek a place later on, which is often the case when having a child with complex needs, the current process limits their access to ECEC because many ECEC settings "need to obtain the FICWD in order to be able to accept the child" (#1-parent). They will not accept a child without the assurance of being granted the FICWD, especially since the process is often long and complex. One childcare centre director mentioned that a significant barrier is the delay before getting a response:

The child would enter at the end of August or early September, and we would apply in the fall, in the month of September. Sometimes [...] it wasn't until February that we received the confirmation of admission... What are we supposed to do during that time with this child's needs? (#19 – manager)

Only a few "big" (#17 – manager) ECEC settings have the flexibility to "invest money" (#17 - manager) to accept these children without the extra money up front when they start ECEC. One director illustrates these delays and the financial flexibility required as follows:

By the time the process starts, and for the file to be analysed for the first time, it can take 6 months, so it's huge. At the end of the day, it's obvious that if the childcare centre has a little bit of money, and is certain to have this subsidy, they will say "Oh well, we'll invest", but the reality is that it's still a lot of money to basically pay a salary when we don't know if we're going to get the [FICWD]. (#19 - manager)

Unlike the AIDC, the amount that ECEC settings receive through the FICWD is not predetermined, but rather is assessed by the *Ministère de la famille* depending on the needs of each child. Nevertheless, many participants report that the amount granted was not enough to fully cover the needs of the ECEC setting seeking to adequately support the inclusion of some of the children with complex needs. Participants report having to be flexible and creative. For example, one parent reported that the FICWD "did not cover 100%. We then had to do some gymnastics, and we started picking up our daughter quite early" (#3 – parent). In a similar way, a director mentioned that "the money is really, maximized, used. And I would say that I offer 4 hours of accompaniment and that it's not even what the ministry gives us. [...] So, no, we spend, and I would say that if it's not used for a child, it will be used for another. (#18 – manager).

Some parents report experiencing some discomfort with the use of these subsidies by the ECEC settings. Many parents reported not knowing how the money was being used in the ECEC setting their child attended. In particular, some parents spoke of frustrations, as they felt that their child "never received anything" (#9 – parent). This discomfort was associated with the parents' perception that the money intended for their child was not directly used to support their child's inclusion. One parent reported that they "saw that with the grant there was an extra educator. Her salary was partly extra, but she wasn't necessarily to support the child directly, she was there to support the ECEC setting. So, she was filling in during breaks, during nap time" (#6 – parent). One parent reported the perception that "a lot of the time they don't want to use [the subsidies] because their financial records look better" (#12 – parent).

In terms of families' **ability to pay**, it is important to note that many families report significant financial repercussions, particularly in relation to the costs associated with medical follow-ups, rehabilitation treatments and the purchase of specialized adaptative equipment, as well as the loss of parental earnings due to a delayed return to work. Fortunately, financial support programs (e.g.: Supplement for Handicapped Children, supplement for handicapped children requiring exceptional care, child disability benefit) can limit the financial burden on parents (see appendix 3 for provincial and federal subsidy programs for children with disabilities and their families).

I didn't work for five years. Frankly, in terms of my income I didn't contribute to my savings or my RRSP during those years because I had no income. Fortunately, we had the [Supplement for Handicapped Children Requiring Exceptional Care], which allowed me to survive [...]. Lucky we had it. It allowed me to survive a little bit and take some of the financial stress off. (#1 – parent)

Another family used this grant "to pay the mortgage for the accessible house [they] built 2 years ago [...]. It was a house that cost a lot more because it was adapted." (#3 – parent)

The relative ease with which Québec families are able to pay for ECEC is greatly facilitated by the array of low-cost ECEC services in Québec, including childcare centres, subsidized daycares and home childcare providers, that offer spaces at \$8.70/day (see Figure 1, section 1.2). Other available financial measures may also aid the ability of families to pay for non-subsidized daycare (e.g., provincial tax credit for childcare expenses) or certain adaptations (e.g., private foundation) necessary for the integration of their child in a childcare setting. For example, one parent explain how they manage to pay for a non-subsidized daycare:

A 100% private daycare, so of course the costs were quite high. But we said to ourselves that it's a good environment, it's close by, [the child] is going to be in his or her community too, they're going to be around all their little neighbors. Well, we'll do what we have to do, and with the credit return, it wasn't so bad in terms of money. (#8 – parent)

## 4.2.5 Appropriateness & Ability to Engage

The **appropriateness** of ECEC is directly connected to the ability it has to be fully inclusive of children with disabilities, and to the ability of the staff to adapt their communication and interventions to the individual needs of each child with a disability.

Sometimes, it's the little things. For instance, they gave [my son] permission to play in the fountain to calm himself down, instead of having to drink and come back right away [...] and he stopped having meltdowns. They saw it was a sensory issue and they adapted the rule for him. (#6 – parent)

Having access to the right material was also regarded by many parents as a facilitator to implementing the right strategies, and thus making ECEC more appropriate:

The rehabilitation centre was able to loan a stroller that was adapted for my daughter to be pushed around when [the group] was outside. Even just to be able to eat her snack with the other children when they were in the yard, [...] they were now able to properly sit my daughter so that she is safe and she can eat with her group. [...] They needed a big cushion to support her and prevent her from

toppling over [...] so that was bought, and also had a cube-shaped bench they already had and placed it so she can lean against the wall [...] so she can stay upstairs with them. (#5 – parent)

Access to adaptative equipment was named as a one of the ways to ensure appropriateness. Adaptative equipment was often made available as a result of collaboration and partnerships with the health sector. Same partners offered support to educational staff to aid inclusion. Both families and managers reported that having help to fill in administrative paperwork, to organize harmonized plans of care and interventions as well as to implement day-to-day adaptations and accommodations made an enormous difference with being able to provide appropriate ECEC for children with disabilities. In the words of a director:

We can do it but it takes a lot of our time. Having someone to help [...] also speeds up the process [...]. They also helped to locate the right equipment. Sometimes, we don't really know. We have our expertise, but for the rest we don't necessarily know... We were very well supported, and we can call them anytime we have questions. (#17 – manager)

A close working relationship between the health sector and ECEC was also facilitating appropriateness. ECEC settings which provided, for example, place and time for healthcare professionals to conduct appointments and interventions with the child on site were seen as facilitating inclusion both by families and professionals: "I realized that we were lucky to have a childcare centre that was ok with the physiotherapist and occupational therapist coming in on site, to the childcare centre, to work with my child during the day" (#3 – parent), "When early intervention is available for a child that has, let's say autism, directly in the childcare centre, [resources] need to be opened up and made available so that everything is done for the best interest of the child" (#15 – professional).

A close working relationship between the health sector and ECEC appears to be key key in ensuring care for children with disabilities is fluid, continuous and coherent. "Everyone needs to be aware of what we have in place for this child, and then make sure that it's done." (#14 – parent). Admittedly, most children with disabilities whose families we interviewed had to deal with multiple health care professionals and specialists, and were overwhelmed with the associated organizational burden: "Well, there are a lot of medical appointments, a lot of scheduling, it is clearly like we are running a small business" (#2 – parent).

It was reported that the appropriate strategies – to support both children with disabilities and the development of inclusive ECEC settings – could be better advocated for and implemented more efficiently with the help and collaboration of community-based organizations like J'me fais une place en garderie.

J'me fais une place en garderie come to the childcare centre every week. [...] they come to help with my son, to make sure the specialists' recommendations are put in place, and to offer suggestions to adapt the environment. (#2 – parent)

A problematic collaboration between ECEC and health professionals was also named as a barrier to inclusion. This could be due to long wait times before services could be offered and explained by the fact that health professionals' reality may sometimes be far removed from that of the parents or their ECEC counterparts. Health professionals working with these families often did not know or understand the context of childcare, either because of administrative

constraints (e.g., not allowed to go outside of their district for work) or because they were not certain how they would be received in ECEC settings. The inclusion coordinator we interviewed even noted that: "[...] therapists are shy, sometimes, to go to the ECEC setting. They don't know if they will be welcomed [...]" (#16 – professional). Other times, it was a lack of perceived need or apprehension of judgment on the part of the early childhood educators that hindered beneficial collaboration or fluid communication with health professionals.

It [health sector] works with episodes of service, and you have to name the need for which the intervention is required. And at the childcare centre, they were saying they couldn't name a specific need that required intervention. [...] there was his obsession with cars, but they didn't want to name that to the [health sector]. (#6 – parent)

This was often regarded by parents as an inability on the part of the ECEC centre to cater to the needs of their child, and seemed compounded by a perception of scarce support offered to educational staff in terms of inclusion strategies or about the disabilities themselves, either because of a lack of resources, or of available support professionals. In the words of an ECEC centre director: "The need is there for more support for our educational staff, but we don't have the money to do it" (#17 – manager).

The shortage of qualified early childhood educators in ECEC centres is a theme that came up repeatedly in the interviews. It is mostly ascribed to a societal context of widespread labor shortage in early childhood education and beyond: "There is now such a labor shortage that not all educators are trained. Some are just moms; some are helpers here and there. It changes all the time" (#14 – parent). The shortage of qualified personnel was also explained by organizational and financial constraints making some of the postings unattractive for potential candidates.

What is difficult is that sometimes we have money to hire people but finding them is hard [because] of the labor shortage. Also, we can only post split shifts. Understandably, [...] it is not necessarily something attractive or viable in the long-term for a lot of people (#15 – professional).

Because there are not enough people to cover all the needs, extra work often ends up weighting on the staff that are present, and this in turn begets exhaustion and even burnout, resulting in a higher turnover rate than would be ideal to ensure appropriateness of ECEC. A parent even felt that meeting their child's needs was second to taking care of the staff's wellbeing: "[...] between losing people on staff and prioritizing the needs of a children with disabilities, I have a feeling that the staff comes first" (#14 – parent). Managers echoed the difficulties in finding and keeping competent educational staff, and even reported that they had in effect lost early childhood educators due to the demanding nature of the work:

Because I have lost staff, it's no secret, due to the difficulty of the job, of the group, the synergy and all this [...]. They don't want to penalize the "regular" children who are just there to learn, and they often feel torn between the 2 set of needs. From there emerges a feeling of inadequacy, but it is not that at all... then fatigue and exhaustion settle in. (#18 – manager)

These human resources issues often escalate into internal conflict, as frequent turnover and staff exhaustion exacerbates internal tensions, personnel issues and diverging views on adaptations and interventions. A parent explained that:

A new early childhood educator was hired [...] and we asked for a meeting because we were seeing they didn't have the same way of doing things. Promises were made on one side, but they weren't always feasible on the other side. A squabble erupted around the table, and we realized they had an internal human resources issue. There was a certain stability, but there was a disparity with their personalities, or their perception of interventions. (#6 – parent)

Even when qualified early childhood educators were found to fill in positions to support the inclusion of children with disabilities, there remained concerns regarding the adequacy of their knowledge and/or training (formal or informal), both about the particular needs associated with the disabilities more broadly and about the children specifically: "...a lot, a lot of staff turnover, so we always have to re-explain how it works" (#7 – parent). A manager adds that: "It [is better] for children with disabilities to be welcomed by educators who have solid experience with inclusion" (#18 – manager).

Training is perceived by childcare centre managers as an important means of empowering qualified, competent and confident staff who are better able to adapt to the individual needs of children with disabilities: "We offer formal training, because our educational staff really wanted [to know] how to be inclusive and adapt their interventions for children with disabilities" (#17 – manager). Both families and managers mentioned that ECEC was perceived as warm and welcoming when early childhood educators and ECEC managers possessed the right set of human qualities, background and personality: "When I walk in, my son is always in someone's arms! I'm lucky to be part of such a great childcare centre!" (#12 – parent) and "Human warmth is so important [...] because as a parent, you leave behind what you hold dearest in the world behind [and] it is even worse for parents of children with disabilities" (#5 – parent), and "We were lucky to find an early childhood educator who had someone in her family with the same disability as our daughter. It was such a happy accident to work with someone who already knew how to manipulate the equipment, and [adjust their communication]!" (#7 – parent).

Perceived engagement of the ECEC setting's director had a direct influence on families' appreciation of ECEC appropriateness:

I don't think I can emphasize enough the importance that a director's perception [of inclusion] has on ECEC. Their understanding of the child's needs, their management of the staff's time and allocation; their knowledge of how to obtain and allocate subsidies... It makes all the difference. (#6 – parent)

The first and foremost barrier to appropriateness of ECEC identified in the interviews is the lack of understanding or the misconceptions of the child's special needs by early childhood educators and managers, either because of insufficiencies in formal training, because the complex and ambiguous nature of the child's needs (e.g. invisible disability) or because there was a divergence in opinion about what interventions were most apt for the child. "Sometimes, we don't even know how to deal with our child ourselves. I have no idea how someone without training or basic understanding of my child and their disability, how they could even get

through one day!" (#4 – parent). Others expressed apprehensions about the ability of early childhood educators to properly care for their child without adequate training: "I feel that they don't have all the right tools [to help my child]. It always has to come from me" (#12 – parent).

When an ECEC setting does not have the right tools, strategies and interventions to support children with disabilities, inclusion can be fragile and families tend to be less engaged in the process. Families reported that because of a lack of strategies and limited capacity to adapt to the needs of their child, ECEC settings were often unable to offer full-time childcare, or even excluded their child.

And towards the end, she was exhausted. [My son] would come in and bawl nonstop all day. Then, we started doing half-days. Finally, well, she started to call Grandpa [to come get him] as soon as he started to cry, and so it ended up that he wasn't going at all anymore. [...] And so she ended-up kicking [my son] out because she was exhausted, and she couldn't do it anymore. (#4 – parent)

This partial, or at the very least fragile, inclusion tended to be improved by the proactivity and involvement of the parents in ECEC. In the words of a parent:

I think it has to do with the parent being proactive. You know, often as a parent you have to, like all the time, fuel the mill there, sustain the energy [...] it's like "Okay, well we'll ask a question, or follow-up on a point, then there it goes again, and then everyone is talking, you know and everything, then oops the ball drops, so the parents have to pull everything together again. (#7 – parent)

In the same vein, inclusion was aided by the families' organizational capabilities as well as their ability to react and adapt to changes:

But it's definitely more, it's more demanding. [My son] has physiotherapy and speech-language therapy appointments once a week, and at that time, it can be a little more difficult to organize. It's either me or my spouse who goes, depending on our schedule. When I'm available, I go to his appointments, then I take him to the childcare centre. If his appointments are longer, we have to check with the childcare centre because he can't arrive later than lunchtime, otherwise he won't eat, so we have to keep him at home [...]. But that's because right now it happens to be nap time, and then a child eating while the others are sleeping, it distracts the others. (#13 – parent)

This constant need to adapt and organize around the child's varying needs requires everyone around them to be highly flexible and willing to work in close collaboration. It then follows that the families' **ability to engage** is boosted when collaboration and communication with their ECEC setting is efficient and fluid: "We can stop in the doorway for a 5-10 min chat, and there's no problem. That's really what it's all about: we're bonded close, close" (#6 – parent). The same is true when their expertise about their child is recognized "I don't mind being asked questions in order for them to get to know my child better, and understand what they can do to help us make it work." (#10 – parent) and when they feel that interventions are truly centered around them and their child: "It's like that, it's really that the parent is part of the team, we're like... the parent is really at the center" (#8 – parent). On the other hand, collaboration and communication with the ECEC setting could also be more strenuous:

That's the link with the others, it was never clear. [...] It meant that we didn't have time to talk to the educator because it's so big. [...] it goes fast, they have tight schedules, and at 4:00pm they just up and leave. And then, on top of that, we didn't have the information [and] it started to get stressful because you could see that [my son] was getting really, really tired. (#8 – parent)

When communication or collaboration was seen as problematic, the relationship between families and their ECEC setting could start to erode as parents reported struggling with trust issues "They seem to implement everything I say. But do they implement it all? I have no idea. Since when and for how long? I have no idea. But then again, I have no control over that" (#14 – parent), and even feeling judged "it was a more the attitude of the person [telling me] 'Oh, you're an anxious mom, you have to give the child some time', [but] we knew that [my son's issues] was beyond maternal anxiety." (#8 – parent). Tensions and conflicts could erupt between ECEC providers and families, and the break in trust could devolve to the point where parents reject ECEC observations and recommendations.

The parents didn't believe in medication, and then from there came a bit of frustration when we demanded that [the child] be medicated to come to the childcare centre, because it was dangerous for him and for the other children [...] the parent didn't want to medicate the child at home, so he did whatever he wanted all the time, but [at the childcare] he has to sit at the table. We have rules to follow, and it was more difficult for this child. (#18 – manager)

Collaboration is cited as bolstered and its obstacles somewhat alleviated in the presence of strong and positive relationships with the child within their ECEC setting, both with the early childhood educator "The bond between [my son] and her educator, since he was a baby, she's had him. They share a deep love together, a great, almost fusional bond" (#14 – parent) and with the other children "If there is a special bike day, she brings him out in the stroller. He won't stay inside, he'll follow the group. And his friends know him, you know, they come to see him, they push his stroller." (#11 – parent). An other strong facilitator for collaboration was the presence of a care navigator in the life of the child with disabilities and their family. This care navigator could be a health professional (e.g., "The pivot nurse was also a fantastic resource" (#8 – parent)) or work for a community-based organization:

It's really great, J'me fais une place en garderie are at the centre of it all [inclusion process]. They made [cards] to clearly state what parents want for the child in terms of routine, food, sleep, emergency numbers, the email addresses of the occupational therapist and the physiotherapist, really all of that. (#2 – parent)

The availability of a care navigator was also helpful for families to mitigate the added responsibilities associated with ensuring accommodations were properly communicated to and implemented by everyone. Parents often reported that they were the ones tasked with coordinating inclusion and ensuring that suitable accommodations were put in place: "Like it or not...'It's one more responsibility. I don't mind explaining some of it, but to explain everything... In the end it becomes heavy for us too, as a parent" (#10 – parent), and:

We found ourselves proposing solutions to them. Then we would say to ourselves "you're the ECEC service, not us". We ended up bearing the entire load

of this, and it felt like we were the guardians of the guidelines. It wasn't always straightforward. And we always had to keep at it. (#6 – parent)

Parents reported struggling with managing this coordination with their own schedule and constraints:

My spouse has an atypical work schedule, so he often works variable hours, [...] and in general, his shifts end at 6:30-7:00 p.m., so I can't count on him in the evening [...] and there is one day a week that I have to go to Montreal. So, that too is a little more complicated in terms of managing the daycare. My spouse, in order to be able to pick up my son on time, well he can't work that day. (#8 – parent)

but stated that having a flexible work schedule could contribute to ease this hardship:

I have adjusted my work schedule [...] I am much less tired. No, I'm still as tired as ever, but I'm much more relaxed about scheduling everything and the specialists. The fact that I have a more stable schedule, [...] allows me to book appointments, for example, every other Thursday, that's it, it's settled. (#2 – parent)

#### 5. CONCLUSION AND IMPLICATIONS

This report highlights significant barriers at all stages of ECEC access for children with disabilities in Québec. Specifically, results indicate that families' experiences of accessing ECEC vary greatly according to the type of needs of their child. On the one hand, families of children with complex disorders and/or significant physical disabilities (e.g. that limit the child's ability to walk independently) mainly have difficulty reaching ECEC because of physical barriers, staff's apprehension or administrative constraints that result in uncertainty about obtaining the FICWD, which provides the financial means to offer support tailored to the child's needs. Once these families have reached an ECEC setting that is willing to receive their child with disabilities, subsequent steps are generally streamlined, notably because these settings are often familiar with receiving children with disabilities. On the other hand, the main barriers experienced by children children who have no formal diagnosis but who nevertheless require specialized support are at the stage of ECEC utilization. Indeed, a child not yet recognized as having a disability will not be eligible, via their ECEC provider, for financial support to facilitate inclusion. This category includes children with mild and transient difficulties as well as those in the process of being assessed. Considering the frequently long delays in obtaining diagnoses and assessments, this can have a significant and persistent effect on ECEC funding and, consequently, on the personalized support offered to the child. Finally, children with "invisible" disorders experience difficulties particularly with full inclusion and social participation. In fact, a lack of knowledge of everything that is intellectual disorder, autism spectrum disorder, attention-deficit disorder, attention-deficit/hyperactivity disorder limits the appropriateness of ECEC services for children with these disorders, leading to increases in behavioral issues and a reduction in ECEC attendance, or even full exclusion.

In addition to these issues related to individual children's characteristics, a few cross-cutting themes emerge as important levers for action, since they have the potential to influence several stages in the process of accessing ECEC, regardless of the type of children's needs. Although

there are barriers and facilitators specific to families and ECEC settings, the fact remains that the actions to be undertaken are mostly organizational or societal in nature.

Firstly, the findings presented highlight the importance of providing family of children with disabilities support to navigate access and integration into ECEC. Findings show that when support (formal or informal) is offered to families, it is very helpful. This is largely tied to the cumbersome and unfamiliar administrative processes experienced by families, and in some instances, ECEC providers. Having a social worker, a nurse or a community worker as a care navigator to support the family, explain the possibilities and facilitate the link between the family, ECEC and the Health and Social services facilitates the entire process (Rochon, 2022; St-Louis et al., 2021). Participants noted benefits to having a resource person or care navigator to support their ability to seek, to reach, to pay and to engage in ECEC. Moreover, a care navigator can foster collaboration and commitment among the stakeholders, and the participants reported the benefits of having such a person to support their ability to seek, to reach, to pay and to engage in the process. In addition, a care navigator can foster collaboration and commitment among the stakeholders, which is a condition for success in fostering the overall development of children (Poissant et al., 2014), particularly children with disabilities who are in contact with a multitude of caregivers.

Secondly, it is essential to ensure interregional equity in terms of access to ECEC. The inequities in access to ECEC for children with disabilities reported between the Montreal metropolitan region and the rest of Québec could be resolved by drawing inspiration from good practices and generalizing them to other regions. One parent stressed the importance of ensuring family support and interregional equity, by recommending that the organization *J'me fais une place en garderie* (Charbonneau & Lalumière-Cloutier, 2022) be used as a model:

J'me fais une place en garderie is only available in Montreal. We truly hope that this organization will be replicated in every city because it is really appreciated. It is an organization that helped us. They, through their contacts, already have access and experience in building bridges between families and childcare settings, whether it's in a family setting, a childcare centre or whatever [the type of ECEC], to help integrate children at all levels, and then help parents and educators and management to be inclusive and ensure accessibility as much as possible. (#2-parent)

Thirdly, ensuring that financial measures are adjusted to the needs of each child with disabilities has a significant impact on their integration into ECEC. Of course, the inclusion of children with disabilities requires resources. The issue of funding support for children with disabilities in ECEC settings is central in Québec, since many of the barriers experienced by families and administrators are related to the lack of funding for individualized support that meets the needs of their child. Indeed, despite the fact that the Québec government invests considerable amounts of money in the ECEC network, subsidized ECEC settings and subsidies to support the integration of children with special needs (i.e., AIDC and FICWD) in order to make ECEC affordable and appropriate for children with disabilities, many shortcomings remain. The inclusion criteria for these funds do not always reflect the reality in the field (e.g., the child must be recognized as having a disability, the child must already be integrated into the ECEC setting), which hinders the integration of children into certain ECEC settings. In addition, the amount of money available is often considered insufficient to cover for needs, and

requires ECEC providers to be flexible and creative in the use of their funds, which is not possible for all settings, especially the smallest ones. In this regard, the Association québécoise des centres de la petite enfance (AQCPE) suggests reviewing the funding model to provide both parametric financial support per ECEC and individual financial support to reduce the negative impacts on children and families that are waiting for assessment or a decision on additional financial measures. Finally, many participants questioned the duplication of efforts for families who often receive financial measures from both the provincial government (e.g., supplement for children with disabilities, supplement for children with disabilities requiring exceptional care) and the federal government (e.g., Child Disability Benefit). Greater Interjurisdictional collaboration could potentially avoid some of those unnecessary administrative hoops for parents (Rochon, 2022), for instance, AIDC could be streamlined when the child already has access to SEH. It would be interesting to explore how information could be communicated to avoid multiple steps for families with children with disabilities. For example, could children receiving SEHNSE be eligible for FICWD regardless of the type of ECEC they attend, including non-subsidized settings that do not currently have access to these financial measures?

Fourth, it is important to ensure that ECEC settings are inclusive. Indeed, beyond the mere integration of children with disabilities into ECEC, the ultimate aim should be their full inclusion. UNESCO describes the evolution of the concept of inclusion over time as follows. UNESCO describes the evolution of the concept of inclusion over time as follows:

The concept of inclusive education was initially used to describe the physical and learning adaptations needed to fully include children with disabilities. Over time, there has been a broadening of the meaning of inclusive education to consider the needs of all learners, regardless of their characteristics or the groups to which they belong. It is a shift from accepting difference to valuing diversity. Thus, inclusion has a universal scope. Inclusion embraces a vision of diversity not as a problem to be solved, but as a lever for social justice and equity. It is a recognition of basic human rights and a vehicle for addressing inequalities. (UNESCO, 2021, p. 9)

Working towards more inclusive ECEC means first and foremost working towards a more inclusive society that embraces difference and where everyone has their place. This can be done through popular education, through the design of buildings under the principle of Universal Access, but also through supporting early childhood educators with inclusion of children with disabilities. While this UNESCO report emphasizes that the "responsibility [is] on education and care systems to understand and adapt to the needs of all learners" (UNESCO, 2021, p. 9), the results of our research show a wide variation in terms of the knowledge, prior experience, and sense of competence of ECEC workers and managers in understanding and adjusting to the needs of all young children. The past inclusion of children with disabilities significantly influences feelings of competence and positive attitudes toward the inclusion of other children with disabilities in the future (Yu & Cho, 2022), and Québec educators believe that personalized accompaniment can meet their needs and prepare them to welcome children with disabilities (Chrétien-Vincent et al., 2022; St-Louis et al., 2021).

In sum, significant barriers persist in terms of access to ECEC for children with disabilities in Québec. It appears essential to build on the facilitators documented in this project to facilitate ECEC access for these families.

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#### **APPENDIX**

## **Appendix 1. Parent Interview Guides**

- 1) J'aimerais commencer l'entrevue en vous demandant de me raconter le parcours de votre famille pour trouver une place en garderie pour votre enfant ayant des besoins particuliers et de me parler un peu plus des enjeux financiers reliés à ces besoins.
  - o Quels types de service de garde avez-vous utilisé?
    - ceci pourrait par exemple inclure un membre de la famille, des halte-garderies, du répit offert par des organismes communautaires, des garderies privées, etc.
  - o Pouvez-vous me décrire votre expérience à travers ce parcours? Quelles ont été les plus grandes difficultés et les plus grands succès?
  - o Pouvez-vous me parler de l'impact qu'ont eu les besoins particuliers de votre enfant sur votre vie professionnelle et les finances de votre famille?
- 2) Pouvez-vous maintenant me parler des ressources mises en place pour votre enfant lors de son intégration en garderie?
  - Quelles sont les difficultés rencontrées au quotidien par votre enfant à son service de garde?
  - O Quels accommodements ont dû être mis en place lors de l'accueil votre enfant pour palier à ces difficultés? (ex : recours à des mesures financières spéciales, personnel dédié à votre enfant, formation donnée aux employés, etc.)
  - o Comment ces accommodements répondent (ou pas) aux besoins de votre enfant?
- 3) J'aimerais finalement discuter des pratiques d'inclusion de votre service de garde.
  - Quels autres accommodements répondraient aux besoins de votre enfant & pourquoi ne vous sont-ils pas accessibles?
    - Comment les accommodements offerts à votre enfant se fondent à, et se distinguent de l'ensemble des accommodements offerts au service de garde qu'iel fréquente?
  - o Que connaissez-vous de la formation offerte aux éducateurs de votre enfant?
    - Selon vous, à quel point répond-elle aux besoins de votre enfants, et pourquoi?

## **Appendix 2. Managers and Professionals Interview Guides**

- 1. Pouvez-vous me décrire votre milieu de garde? Éléments de relance :
  - Géographie & démographie, Portrait du personnel (nombre & titres, expérience, diplômes, etc.), Coût aux parents, Horaire, Programme éducatif
- 2. Pouvez-vous me parler des services que vous offrez dans votre milieu de garde à des enfants d'âge préscolaire présentant un handicap?

Questions de relance :

- Pouvez-vous me donner un exemple concret d'intervention que vous offrez aux enfants d'âge préscolaire présentant un handicap dans votre/vos milieux de garde?
- Pouvez-vous me décrire certains des principaux besoins d'accommodements et d'adaptations des enfants d'âge scolaire présentant un handicap dans votre service de garde?
- Parlez-moi de la collaboration des différents agents impliqués dans les dossiers des enfants présentant un handicap (famille, CIUSSS, CRDI, etc.)
- Est-ce que le milieu de garde a une personne dédiée au soutien aux enfants présentant un handicap? Quel est son rôle?
- 3. Quels sont les défis que vous rencontrez pour accueillir des enfants présentant un handicap? Questions de relance :
  - Selon votre expérience, est-ce qu'il y a certains besoins plus difficiles à répondre?
  - D'où émanent les principaux défis que vous rencontrez lors de l'intégration d'un enfant présentant un handicap dans votre milieu de garde?
  - Quelle est la plus grosse difficulté rencontrée lors de l'accueil d'un enfant présentant un handicap dans votre milieu de garde?
- 4. Décrivez-moi les besoins d'accommodements et d'adaptations des enfants présentant un handicap dans votre milieu de garde?

Questions de relance:

- Quelles sont les ressources matérielles et les aménagements physiques requis pour assurer le développement de ces enfants?
- Quels services ou programmes seraient requis au sein de votre service de garde éducatif pour que ces enfants se développent à leur plein potentiel?
- De quoi auriez-vous besoin, en tant que gestionnaire, pour mieux répondre aux besoins des enfants d'âge préscolaire présentant un handicap?
- 5. Au-delà du soutien qui vous est offert actuellement, pouvez-vous me parler de comment les différents services, programmes et politiques gouvernementales pourraient être bonifiés pour mieux répondre à vos besoins en tant que gestionnaire d'un service de garde éducatif au Québec?

### Questions de relance :

- Quels sont les besoins « non répondus » des milieux de garde pour l'accueil d'enfants présentant un handicap (que ce soit dans celui où vous travaillez ou d'autres que vous connaissez)?
- Donnez-moi un exemple concret de ce que devrait accomplir un service/programme/politique pour soutenir l'intégration d'un enfant d'âge préscolaire présentant un handicap à un service de garde éducatif?
- 6. À votre avis, quels sont les éléments-clés à considérer pour qu'une offre de services soit réellement utile aux enfants d'âge préscolaire présentant des handicaps dans les services de garde éducatifs au Québec?

## Questions de relance :

- Quels services ou ressources seraient à prévoir en priorité?
- Quelle fréquence et intensité de service est nécessaire pour que les services soient réellement utiles aux enfants ET au milieu de garde?
- Qu'est-ce que les professionnels devraient faire ou ne pas faire pour assurer le succès des interventions?
- Quels seraient les éléments essentiels à considérer dans l'implantation de programmes ou d'interventions? (Constance du personnel, horaires adaptés, connaissance des dossiers, etc.)
- 7. À votre avis, quels sont les éléments-clés à considérer pour qu'une offre de services soit réellement utile pour les milieux de garde et le développement des enfants?

## Questions de relance :

- Quels services seraient à prévoir en priorité?
- Par qui devraient être engagés les professionnels non-éducateurs?
- Quelle fréquence et intensité de service est nécessaire pour que les services soient réellement utiles pour un milieu?
- Qu'est-ce que les professionnels non-éducateurs devraient faire ou ne pas faire pour s'intégrer au milieu?
- 8. Pouvez-vous me parler des différents services, programmes et politiques du gouvernement qui vous aident au quotidien à l'intégration des enfants présentant un handicap?

Questions de relance : nommer quelques programmes en exemple : ententes avec CLSC, mesure exceptionnelle, AIEH, MES, etc.

## Question de clôture

Est-ce qu'il y a d'autres messages-clés ou d'autres éléments que vous souhaiteriez aborder sur la question de l'intégration des enfants handicapés en services de garde éducatif

Appendix 3. Provincial and federal subsidy programs for children with disabilities (adapted from Beaudoin and Pratte, 2022)

Name	Beneficiary	Admissibility criteria		
Québec				
Supplement for Handicapped Children	Family	Have a dependent child under age 18 who has an impairment or mental function disability that significantly limits him or her in carrying out his or her life habits for a period expected to last at least one year.		
Supplement for Handicapped Children Requiring Exceptional Care	Family	Child has physical impairments or a mental function disability causing severe and multiple disabilities that prevent him or her from carrying out the life habits of a child of his or her age for at least one year, or he or she requires complex medical care at home		
Family Support Program	*this program includes various measures in the form of direct benefits, particularly to pay for respite services, occasional assistance, and support with parenting through assistance with daily activities	Reside with a person who has a disability or autism spectrum disorder (ASD), care for this person on a daily basis and be related to this person (family or extended family); demonstrate a need for support to compensate for the stress and fatigue caused by the special needs associated with the significant disabilities of the person with a disability or ASD.		
Allowance for Integrating a Disabled Child (AIDC)	Subsidized ECEC	This allowance is offered to subsidized childcare providers that wish to provide their services to a child aged 59 months or younger with a disability and is intended to reimburse expenses associated with the child's integration into a group.		

Financial Assistance for the Integration of Children With Disabilities in childcare centres (FAICWD)	Subsidized ECEC	A childcare provider is eligible if the following conditions are met: The provider is an ECEC service provider under the Educational Childcare Act and has subsidized spaces. The provider offers services to a child with a disability aged 59 months or less with a deficiency causing a significant and persistent disability with a major need for additional support due to the significant barriers encountered during the integration process. The provider already receives the Allowance for integrating a disabled child (AIDC) for the child for whom the claim is made. The provider has developed a childcare integration plan for the child. The provider has begun a joint process with partners to meet the child's needs, or has an intervention plan in place that meets the child's needs. Ideally the provider has an intersectorial and individualized service plan (ISP) demonstrating that all the available means available (resources, programs, measures and collaborative efforts) are being used to meet the child's needs and support the child's integration into childcare.		
Transitional Measure for Children Aged 5 with Disabilities	Family	The child is deemed to have a disability. The child attends a subsidized ECEC following the regular schedule. The child does not attend kindergarten. The child is 5 years old as of September 30 of the reference year.		
Canada				
Child Disability Benefit	Family	The child disability benefit is a tax-free monthly payment made to families who care for a child under age 18 with a severe and prolonged impairment in physical or mental functions.		