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Project team

DIRECTION

Fannie Dagenais

RESEARCH

Audrée Jeanne Beaudoin and Gabrielle Pratte, Université de Sherbrooke

WRITING

Marie-Claude Gélineau and Valérie Perrault

PRODUCTION COORDINATORS

Marilou Denault and Kim Gagnon

LINGUISTIC REVISION (French version)

Jonathan Aubin

ENGLISH TRANSLATION

Cynthia Gates

ILLUSTRATIONS

Jean-Paul Eid

GRAPHIC DESIGN AND LAYOUT

gbdesign-studio.com

COVER PHOTO CREDIT

Jean-Marc Abela, Résonance Créative

ADAPTATION FOR THE INTERNET

Antoine Bergeron, Flora Faullumel, Marie-Claude Gélineau and Tink

DISTRIBUTION

Marilou Denault, Flora Faullumel and Geneviève Joseph

We wish to thank everyone who participated in the revision of this document:

Audrée Jeanne Beaudoin, Institut universitaire de première ligne en santé et services sociaux (IUPLSSS) du Centre intégré universitaire de santé et de services sociaux de l'Estrie – Centre hospitalier universitaire de Sherbrooke et Université de Sherbrooke

Nadia Boudreau and Nathalie Tremblay, Association des haltes-garderies communautaires du Québec (AHGCQ)

Dominique Cousineau, Centre intégré du réseau en neurodéveloppement de l'enfant (CIRENE) et CHU Sainte-Justine

Carmen Dionne, Colombe Lemire and Annie Paquet,

Chaire UNESCO: petite enfance et intervention précoce inclusive et Université du Québec à Trois-Rivières

Isabelle Dubois and **Sylvie Nault**, Association québécoise des centres de la petite enfance (AQCPE)

Béatrice lattoni, Direction régionale de santé publique de Montréal, Centre intégré universitaire de santé et de services sociaux du Centre-Sud-de-l'Île-de-Montréal

Amélie Lavoie and Virginie Nanhou Youkoujouo,

Institut de la statistique du Québec

Véronique Lizotte, Table de concertation pour l'intégration en services de garde des enfants ayant une déficience – région de Montréal (TISGM)

Mathieu Point, Département des sciences de l'éducation, Université du Québec à Trois-Rivières

Gabrielle Pratte, Faculté de médecine et des sciences de la santé, Université de Sherbrooke

Julie Ruel, Institut universitaire en déficience intellectuelle (DI) et en trouble du spectre de l'autisme (TSA) et Université du Québec en Outaouais

Marie-Pier Simard, Centre intégré universitaire de santé et de services sociaux du Centre-Sud-de-l'Île-de-Montréal

Audette Sylvestre, Centre interdisciplinaire de recherche en réadaptation et intégration sociale (Cirris) and Université Laval

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Early Childhood Observatory / Observatoire des tout-petits 2001 McGill College Avenue, Suite 1000 Montréal (Québec) H3A 1G1 Telephone: (514) 380-2001 info@toutpetits.org

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Message from the Director

It is with some emotion that I am drafting this message on a sunny afternoon. First, because it is the last message that I will write as Director of the Observatory and, second, because the subject of children who need special support is one that is particularly close to my heart and those of my entire team.

Some young children need additional support or special interventions in order to develop their full potential. As you read this report, you will encounter Rosa, who has language difficulties, Noah, who has a motor disorder, and Boris, who is autistic. Does our society take these children's difficulties—often invisible to the casual eye—adequately into account? What conditions are we implementing to ensure that these young children can develop, socialize, play, learn and feel included? What is being done to ensure their rights to the best possible health care and quality of education are respected?

The idea is to offer these toddlers the same opportunities as all children, while taking into account their strengths and characteristics. According to their parents, however, obtaining access to educational or health and social services is like navigating an obstacle course.

This report is an invitation to reflect on the nature of difference, on our own prejudices (conscious or unconscious), and on the potential of these children to develop and contribute to society. In this respect, young children are a great inspiration, ready to accept another child just for who they are—they are eager to make friends and will even help them put on their boots if needed! By interacting with these children every day, they develop empathy and an instinct for helping others, while at the same time being a source of encouragement for a friend who needs special support.

We have a lot to learn from the attitudes of young children. We need to adopt an approach that is truly inclusive, to respect every child's right to exist just as they are, to develop their full potential and to make a valuable contribution to society.

I sincerely hope that this report will be a source of inspiration to all who read it.



Lagenais
Fannie Dagenais

Message from the Director

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Summary

Not all children living in Québec have access to the services and support that they need when they need them, which deprives them of opportunities to develop their full potential. This situation is cause for concern: it compromises the fair equality of opportunity for young children and goes against the principles set out in various charters, legislation and agreements regarding children's rights. The benefits of inclusion have been well-documented, both for children who need special support and for those who are not in the same situation. Society as a whole also benefits from inclusion, which fosters positive, compassionate attitudes towards diversity.

Summary !

It is not currently possible to paint a clear picture of children who need special support because no official definition has been adopted yet. For the purposes of this report, therefore, young children needing special support are those between 0 and 5 years of age who present a difficulty in their development or a disability and require support or additional intervention to achieve their full potential.

Regardless of the type of support children require, their parents have many obstacles to overcome. The procedures for obtaining financial aid are complicated, educational childcare services are less inclined to accept their children, the complex nature of the health and social services network and wait times for services are major sources of stress, and the transition from daycare to school is not always smooth. On the other side of the coin, educational childcare services and schools lack the human, material and financial resources they need to facilitate the inclusion of children who need special support.

The present situation is not without consequences. The first five years of life are a critical period in a child's development. **The obstacles these families are confronted with put the development of children who need special support at risk.** The physical and mental health of their parents, obliged to take on additional responsibilities, suffers. Their financial situation is also weakened. Many parents, worried about the repercussions that long wait times for services will have on their child's development, have no choice but to turn to private services. Their many obligations sometimes force them to work part-time or stop working altogether.

Society has the collective levers it needs to promote the inclusion of these children in educational childcare services and schools, and to improve their access to healthcare and services when needed. Certain actions are already underway and others show promise in the fight to remove the barriers that confront parents of children who need special support. These actions are aimed at focusing interventions on the needs of children and their families, providing the personnel of educational childcare facilities and schools with the resources they need, and improving collaboration and continuity of services between the health and social services network, educational childcare services, schools and the community.

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INTRODUCTION

For an inclusive society

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.

Inclusive Early Childhood Care and Education, UNESCO1



For an inclusive society

An inclusive society, in any milieu, encourages full social participation from all its members while valuing diversity. In terms of educational success, it also fosters the learning process of children whose development does not follow the same trajectory as most children in their age group and who need special support. **Genuine inclusion means much more than just admitting a child who needs special support into a given environment;** it involves every child's active participation in daily life in the company of other children. This happens differently for every child, depending on their capacities and their needs.

A young child in an inclusive environment²...

has relationships and interactions with other children and adults.

Inclusive experience

has access, at
different times in
their life, to a variety
of materials and
multi-purpose spaces
that meet their needs
and reflect their
desires and interests.

is engaged in meaningful experiences that mobilize their potential and foster their overall development.

Embracing difference

Early childhood is the best time to learn to embrace difference. Science has shown the positive influence of being exposed to difference at a very young age. **Contact with young children who need special support transforms the attitudes and values of all those who cross their path.** When together in a group, children learn cooperation, mutual assistance and empathy. By offering help, children develop their sense of competence and pride

in themselves. They adopt a more positive attitude, a better understanding and a greater sensitivity to difference³. It is easy to see why inclusion at a very early age is recognized as being one of the best ways to avert negative attitudes towards people who need special support⁴, while fostering their learning process. When children who need special support are in contact with others of their own age, their progress is remarkable. Even if they don't always participate in activities in exactly the same way as their peers, they see, hear, feel and learn⁵.

She never made as much progress as when she tried to keep up with her friends in an environment where other children had abilities that surpassed her own.

It was phenomenal.

— Mother of 4-year-old Olive⁶ (translation)

Unfortunately, conditions that promote inclusion are not always optimal in the spaces frequented by young children who need special support, such as educational early childhood facilities and kindergarten. Many families come up against major barriers in their children's life trajectories. Reports from parents and practitioners have shown that even if children's needs are varied, the challenges faced by their families are the same. **Early childhood is a crucial period in children's development and learning in the short, medium and long term.**

The first few years in a child's life are critical. Since the brain is developing extremely rapidly during that time, it is much more receptive to stimulation. What happens to a child during this period can have significant repercussions on their development, health, educational success and life course. That is why it is so important to create conditions that are favourable to their development in their environments.

She has friends that she adores. It's magical to see them together. There's a little dance that they do in the schoolyard with her walker. The children know how to avoid the wheels and run around her—I had never seen anything like it!



- Mother of 4-year-old Olive⁸ (translation)



Inclusion is based on the principles of equal rights, recognizing that **ALL** children have the right to live their lives by socializing, playing with others and participating in activities, regardless of differences observed in their behaviour, functioning or learning.

Respecting children's rights

The international, Canadian and Québec charters of rights and freedoms remind us of children's right to have access to the conditions that allow them to feel included in society, embark on the different stages in their life with confidence, and become full-fledged citizens.

The United Nations Convention on the Rights of the Child, of which Canada is a signatory, states the following⁹:

- > "All children have all these rights, no matter who they are, where they live, what language they speak, what their religion is, what they think, what they look like, if they are a boy or girl, if they have a disability, if they are rich or poor, and no matter who their parents or families are or what their parents or families believe or do.

 No child should be treated unfairly for any reason."
- > "Governments are responsible for making sure that children's rights are respected. They must help parents protect their children's rights and create an environment where they can grow and **develop** their potential."
- > "Children have the right to the **best health care possible**, clean water to drink, healthy food, a clean and safe environment to live in, and information about how to stay safe and healthy."
- > "Children with disabilities should enjoy a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate their active participation in the community."

This convention also states that governments must make sure that all children have access to the care and services that will allow them to be valued members of society and to lead fulfilling lives.



According to the Québec Charter of Human Rights and Freedoms:

"Every person has a right to full and equal recognition and exercise of his human rights and freedoms, without distinction, exclusion or preference based on race, colour, sex, gender identity or expression, pregnancy, sexual orientation, civil status, age except as provided by law, religion, political convictions, language, ethnic or national origin, social condition, handicap or use of any means to palliate a handicap. Discrimination exists where such a distinction, exclusion or preference has the effect of nullifying or impairing such right¹⁰."



SECTION 1

Who are the children who need special support?

- > DEFINITIONS AND SLIDING SCALES
- > ADOPTED DEFINITION

The portrait of children living in Québec who need special support is incomplete. Since available data primarily represent children who have already been declared eligible for financial assistance from the government, these statistics are not representative of all children needing special support. It is therefore difficult to paint an accurate portrait of children in this group.

Definitions and sliding scales

There is no universal definition for "children who need special support," who present diverse characteristics depending on the context and on the organization defining them. There are many other terms that are also used, including children (living) with a disability, with developmental difficulties/disabilities, with adaptation or learning difficulties, with special needs, etc.

It is therefore not easy to obtain an accurate figure for the number of children needing special support in Québec. Statistics vary widely depending on the definition and criteria used. All the statistics presented below illustrate just one of the many facets of children in Québec who need special support.



Number of young children with a health problem or developmental disorder

In all, approximately 12% of preschool-aged children have at least one health problem or developmental disorder that has been detected by a health professional (some children have more than one), according to the Québec Study on the Accessibility and Use of Childcare Services 2021 (QSAUCS)¹¹.



Note: Some children may have more than one health problem or developmental disorder.

Source: Institut de la statistique du Québec, Québec Study on the Accessibility and Use of Childcare Services 2021 (QSAUCS).

The data presented on the previous page are based on responses provided by parents. Although these figures represent young children with a health problem or developmental disorder that has been detected by a health professional, **this does not necessarily imply that they all need special support**. For example, a child who has been diagnosed with asthma will not require special support in an educational setting.



Number of children who receive the Supplement for Handicapped Children

The Supplement for Handicapped Children (*Supplément pour enfant handicapé* or SEH) is a financial benefit provided by the Québec government to support families with a child whose "physical impairments or mental function disability causes severe and multiple disabilities that prevent [them] from carrying out the life habits of a child of [their] age for at least one year¹²."

6,323 children between the ages of 0 and 5 were receiving the Supplement for Handicapped Children in December 2021.



12.3 out of every 1,000 children in the population of Québec between 0 and 5¹³.

Of these children, slightly fewer than 1 out of 10 (9.4%) were living with more serious disabilities or required complex medical home care and receiving additional financial support in the form of the Supplement for Handicapped Children Requiring Exceptional Care (Supplement pour enfant handicapé nécessitant des soins exceptionnels or SEHNSE)¹⁴.

In order to be eligible for this type of financial assistance, parents must provide a document signed by a healthcare professional confirming their child's diagnosis or difficulty. This means that families who, for various reasons (see page 24), were not able to meet this requirement are not included in this statistic. This is the case for most data based on financing received. However, these families may also require financial support, be it to purchase specialized equipment or to compensate for lost income resulting from accompanying their child to frequent appointments, for example.



Number of young children who benefit from the Allocation pour l'intégration en service de garde (allowance for integration into educational childcare)

The Allocation pour l'intégration en service de garde is a financial support program for subsidized educational childcare services. Integration fosters the child's overall development by helping them to gradually adapt to group life and to participate as much as possible in all daycare activities. This subsidy can be used to purchase equipment, reorganize the physical layout of the facility, provide training and free up staff members, hire new personnel, and manage individual files (to analyze needs, search for resources, develop support plans, etc.)¹⁵. In order for the childcare facility to obtain this allowance, the child must "have a deficiency causing a significant and persistent disability land bel likely to face obstacles in their integration into a childcare centre¹⁶." In this context, a "significant and persistent disability" is defined as a disability that significantly reduces a child's ability to function physically or mentally and is expected to be permanent¹⁷.

11,270 children benefited from the Allocation pour l'intégration d'un enfant handicapé en service de garde (allowance for integrating a disabled child into educational childcare) in a subsidized educational childcare facility in 2019-2020¹⁸.



4% of all young children enrolled in subsidized educational childcare. This proportion doubled between 2008-2009 and 2019-2020, rising from 2% to 4% 19.

Of these children, 6.3% were receiving additional support in the form of the *Mesure exceptionnelle de soutien à l'intégration en service de garde pour les enfants handicapés ayant d'importants besoins* or MES'' (exceptional measure to support integration into educational childcare for disabled children with significant needs) in 2019-2020²⁰.

An application to obtain the *Allocation pour l'intégration en service de garde* requires a report from a professional confirming the child's diagnosis or difficulty. For various reasons, this report is sometimes difficult to obtain (see page 24). Therefore, as is the case with the data based on financing received, **children whose parents were unable to obtain this report are not included in this statistic**.

^{*} The name of this program was changed in 2023 to Allocation pour l'intégration en service de garde. In the interest of consistency, however, we have chosen to respect the original terminology used in the reference consulted.

[&]quot; The name of this program was modified in 2023. In the interest of consistency, however, we opted for the terminology that was used in the reference document we consulted.



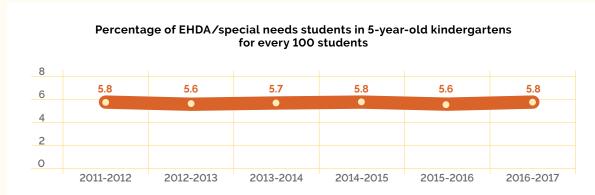
Number of students living with a disability or adaptation difficulties in kindergarten

Some children attending kindergarten are living with a disability or have adaptation difficulties. Within the Québec school system, these students with special needs are called "EHDA" students (*élèves handicapés ou en difficulté d'adaptation**). This administrative classification of children is what determines the amount of financing granted to offer them support services.

4,888 children in 5-year-old kindergartens were considered to be living with a disability or an adaptation difficulty (EHDA or special needs) in 2016-2017.



5.8% of all children in 5-year-old kindergartens in the public system²¹.



Data source : Ministère de l'Éducation et de l'Enseignement supérieur (MEES), Territoires, statistiques et enquêtes (TSE), Direction générale des statistiques, des études et de la géomatique (DGSEG), Direction des indicateurs et des statistiques (DIS), Portail informationnel, Système Charlemagne.

Some children who are not considered to have a disability or adaptation difficulty (EHDA/special needs) still have trouble functioning at school, according to their teachers. These children are not included in the data presented here. The Québec Survey of Child Development in Kindergarten 2017 (QSCDK) indicates that this applied to 1 out of every 10 students (10.8%) in a regular class²². According to school principals, it may be possible that in the absence of any formal recognition of their need for special support, these children are not offered additional resources.

^{*} The acronym seen more frequently is "EHDAA," which stands for "élèves handicapés ou en difficulté d'adaptation ou d'apprentissage." Since children in kindergarten are not assigned a code for learning difficulties (difficultés d'apprentissage), however, we have used the terminology from the reference work consulted.



Number of young children who receive services from a rehabilitation centre

Children with an identified language, motor, hearing or visual disorder may have access to specialized **physical rehabilitation** services.

In 2020-2021, **10,760** between the ages of 0 and 4 received services from a physical rehabilitation centre.



eapproximately 2.5% of children in that age group²³.

Children who have been diagnosed or who are suspected to have, for example, an autism spectrum disorder, developmental delay or intellectual disability may receive specialized services at a **rehabilitation centre for intellectual disability and autism spectrum disorder**.

In 2020-2021, **4,305** children between 0 and 4 received services from a rehabilitation centre for intellectual disability and autism spectrum disorder.



approximately 1% of children in this age group²⁴.

These data represent children who have completed all the steps required to obtain the appropriate specialized resources they need. Children who are waiting for screening or specialized services are therefore not included in these statistics.

Adopted definition

The preceding data show that children who need special, adapted support are often not represented in official statistics. To put the needs of young children at the centre of our considerations, we have included children with and without a diagnosis in the definition used in this report.

On the following pages, children who need special support are those between the ages of 0 and 5 who...



> need additional support or interventions to ensure that they achieve their full potential

AND

have a developmental difficulty, diagnosed or not, or disability for which they might require support

Examples of conditions that could cause a child to need special support:

- > Fairly severe developmental difficulties in the areas of intellectual or cognitive abilities, motricity, language, socialization, emotional regulation, behaviour, etc.
- > Hearing or visual disabilities, cerebral palsy, autism spectrum disorder
- > Chronic health problems, such as cystic fibrosis, heart problems, etc.



SECTION 2

What are the issues that affect children who need special support?

- > DIAGNOSIS-BASED APPROACH
- > ACCESS TO SERVICES
- > FINANCING
- > SUPPORT FOR EDUCATIONAL CHILDCARE SERVICES
- > COLLABORATION BETWEEN ACTORS AND CONTINUITY ACROSS SETTINGS

The years between 0 and 5 are a critical period in early childhood development. Unfortunately, however, there are many barriers that prevent young children who need special support from benefiting from conditions that would foster their overall development.

Diagnosis-based approach

A diagnosis or evaluation of a child's difficulties is currently a critical prerequisite for obtaining financial assistance from the government. It is also the basis for determining which services a child is entitled to, even though those services should depend on the child's needs rather than on their diagnosis²⁵.

Establishing a diagnosis for a child isn't a bad thing *per se*. A diagnosis leads to a better understanding of the situation,

on the child's condition. However, a diagnosis-based

provides benchmarks and shines new light

Sometimes, a child who has been diagnosed with autism spectrum disorder will be perfectly capable of functioning, but will nonetheless be eligible for a whole array of services. On the other side of the coin, there is the child who is much more dysfunctional but, because there is no diagnosis, isn't eligible for anything [...]. It's sad [...] that everything always depends on the diagnosis.

A clinician²⁶ (translation)

approach often reduces the child to their difficulties and what they lack, which risks distorting the way the child is perceived—by their parents, educators or teachers²⁷. It is as if their personality and potential are masked by the diagnosis, with the result being that their abilities and potential are overlooked. This type of approach focuses every intervention on what's "wrong" with the child based on their diagnosis, without taking into account the many needs they may have²⁸. This way of seeing a child can also affect their behaviour as they unconsciously model themselves to reflect everyone's impression of them²⁹.

The child may also be stigmatized and have to deal with prejudice and discrimination.

Even though a diagnosis allows practitioners to identify the causes of the difficulties experienced by the child, it can also create the false impression that everything is understood about their situation. Other aspects that could also influence the child's development and learning may be neglected, such as their relationships with others and their physical, economic and cultural living conditions³⁰.

An increasing body of data, however, supports the position that early childhood health and social services should be offered based on the needs of the young children and their families, not solely on a diagnosis or difficulties documented through a formal evaluation process. A wide range of literature has documented the positive effects of early intervention on young children who are suspected of having an autistic spectrum disorder, before an exact diagnosis has been obtained³¹.

The current financing structure and process for accessing support and health/social services favour a diagnosis-based intervention approach that does not necessarily meet the real needs of children and their families. Even if two children have the same diagnosis, their needs may vary, just like the measures implemented to support their development.

A global approach based on an evaluation of the child's needs and abilities, as well as the facility's capacity for meeting their needs, would maximize their participation and overall development during the first few years of their life³².



Aside from the issues surrounding the diagnosis-based approach, it is important to know that obtaining a diagnosis or having a child's difficulties documented by a healthcare professional is not always possible, for various reasons:

- > The diagnosis or documentation of difficulties can be a **lengthy process** due to delays, wait lists or the need for several appointments to determine the diagnosis, for example.
- > In order to be eligible to the *Allocation pour l'intégration en service* de garde, the persistence of the difficulties must be confirmed, but the evolution can be difficult to predict (in the case of language difficulties, for example).
- > Some disorders require more **prudence** in establishing a diagnosis when children are very young, as in the case of developmental language disorder, autism spectrum disorder or attention deficit disorder³³.
- Children who do not have a family doctor or pediatrician are not able to obtain the medical referral needed to see a health professional who is qualified to provide a diagnosis or attestation³⁴.

In such situations:

- > Children are deprived of the adapted support to which they are entitled but which is essential for their development in early childhood³⁵. Educational childcare facilities intent on including such children need to use various strategies to compensate for this situation and offer them support nonetheless³⁶.
- > Parents under pressure may feel obligated, for the good of their child, to pay hundreds of dollars for appointments with private specialists in order to obtain the necessary documents.

Access to services



Access to educational childcare services

Shortage of spaces and more difficult access to educational childcare services

Attending an educational childcare facility fosters cognitive, language, motor, social and emotional development in young children—including those who need special support³⁷, who learn much more in such an environment than when they stay at home or have contact exclusively with peers living with the same disabilities³⁸. Young children needing special support who do not have access to educational childcare services are deprived of opportunities to socialize with their peers and associate with other children who can serve as models and enhance their motivation to learn³⁹.

33,356 children, including those who need special support, were waiting for a space in an educational daycare on August 31, 2022⁴⁰. Added to those were children attending non-subsidized daycares who are awaiting a space in a subsidized facility⁴¹.

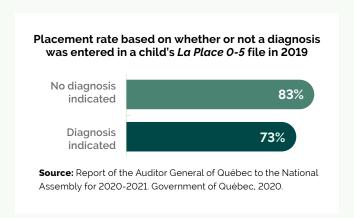
There are no specific data on the number of children needing special support who are waiting for spaces in daycare. However, the Auditor General of Québec has mentioned certain factors that hinder children's access to educational childcare services, one of which is needing special support. The placement rate in educational childcare services was:

The placement rate in educational childcare services was:

73% if the child's parents indicated that their child needed special support in their file on La Place 0-5*, in 2019.

83% for children who did not need special support⁴².

* Dedicated gateway to recognized daycare spaces in Québec.



The proportion of childcare facilities that accept children receiving the *Allocation pour l'intégration d'un enfant handicapé en service de garde** varies depending on the type of facility.

According to a compilation of data from the Ministère de la Famille by the *Office des personnes handicapées du Québec* in 2019-2020:

94% of CPEs welcomed at least one child benefiting from the allowance

83% of subsidized daycares welcomed children benefiting from the allowance

15% of home-based daycares welcomed children benefiting from the allowance 43

These figures have more than doubled since 2008⁴⁴. Since home-based daycares are much smaller, it can be more difficult for them to welcome children who need special support. This could explain the smaller number of children benefiting from the allowance in that type of childcare facility.

Although there is a *Ministère de la Famille* policy that promotes inclusion, **educational childcare services are not legally obligated to accept children who need special support**. The decision is left to management and the board of directors of the establishment⁴⁵.

An educational daycare must have all the necessary resources to ensure the health, safety and well-being of the children it accepts. If any of those conditions are compromised, the daycare may not be able to accept a child needing special support. Although the specific reasons for refusal are not available, it appears that the type and intensiveness of the support required can affect the possibility of a child attending an educational childcare facility or not⁴⁶.

The purpose of the *Educational Childcare Act* is to "enhance the **quality** of the educational services intended for children before their admission to school so as to ensure the health and safety of the children to whom childcare services are provided (particularly **those with special needs** or who live in a precarious socio-economic situation), foster their development, educational success and well-being and provide them with **equality of opportunity**⁴⁷."

^{*} The name of this program was changed in 2023 to *Allocation pour l'intégration en service de garde* (allowance for integration into educational childcare). In the interest of consistency, however, we have chosen to respect the original terminology used in the reference consulted.



The importance of quality in educational childcare services

The Québec government's action plan *Grand chantier pour les familles* was aimed at creating new places in educational childcare. The Auditor General reiterated that the **quality of educational childcare** is **essential** because it "can help avoid downstream expenses in the education system needed to deal with problems associated with adaptation and learning difficulties⁴⁸." (translation) "Quality" refers to personnel training, working conditions of educational personnel, the structure of the educational facility (size of groups, physical layout, etc.), and the implementation conditions of educational services (government financing or non-profit, linked to the community, etc.).



To learn more about the importance of quality, stability and continuity in young children's environments, see our report on <u>The quality of educational childcare services in Québec</u>.

Impact of ineligibility for financing for certain types of daycare

Since non-subsidized daycares are not eligible for the *Allocation pour* l'intégration en service de garde, the number of spaces available for children needing special support is even further reduced. The lack of financial assistance means that certain parents with children in non-subsidized daycare have to provide their own material to improve their children's stimulation or ensure their safety⁴⁹. Some parents must be present at the daycare on a regular basis to provide support for the educational personnel, which can complicate the work-daycare balance and even reduce household income if the parent is forced to take time off or work part-time.



When my son started to go to daycare, I went in almost every lunchtime to help the educators feed him.

Since there was no adapted chair for him, I had to feed him on my lap. He got so used to that arrangement that he wanted to eat on my lap at home as well."

— A parent⁵⁰ (translation)

Because there is a limited number of available spaces in subsidized daycare, many children start by attending a non-subsidized daycare while waiting for a space to open up in the subsidized network. When a space becomes available, the child has to move from one facility to another, which parents of children needing special support find particularly difficult⁵¹. These changes can be challenging for young children, forcing them to adapt quickly, which can create stress during a period of instability. Parents also have to build new relationships with the educational daycare personnel and create new bridges between the health and social services professionals who are following their child and the personnel of the educational childcare service.



To learn more about the importance of quality, stability and continuity in young children's environments, see our report entitled What can we do to foster children's development before they start school?

Non-subsidized daycares accepted **22.6%** of children in childcare, in December 2022⁵².

Converting non-subsidized spaces into subsidized spaces is part of the *Ministère de la Famille's Grand chantier* pour les familles⁵³. As of December 31, 2022, 3,549 spaces had been converted⁵⁴.

Community drop-in daycare centres complement educational childcare services by helping to meet parents' many needs—including parents of children who need special support. However, drop-in daycares are not eligible for the *Allocation pour l'intégration en service de garde* to accompany children who need special support⁵⁵.

86% of community drop-in daycares accepted children needing special support in 2017-2018 in Québec⁵⁶.

Another study done in 2015 showed that drop-in daycares were used as much by families who have a child with an identified health or developmental problem (17.2%) as by families with children who do not have an identified problem (16.2%)⁵⁷.

NOAH

Noah has a form of paralysis that affects his left side and makes it hard for him to move around.



His parents registered Noah on La Place 0-5 ans to find a daycare, indicating that he was a "child with special needs."



They had many refusals from daycares who said they couldn't meet Noah's needs.



Noah's mother had to stay home with him at the end of her parental leave. A year later, Noah's father stopped working and the mother went back to work. Their family income suffered.



Noah was over 3 years old when he got a space in a non-subsidized daycare.



His father often went to the daycare to show the educators there how to apply the recommendations of the speech therapist and occupational therapist.





To be able to take Noah to his many appointments, his father could only return to work part-time.



Access to services in the health and social services network

A complex network

Parents have compared their experiences in attempting to obtain services in the health and social services network to navigating an obstacle course⁵⁸. They feel ill-equipped and left to fend for themselves. They also deplore the lack of information regarding:

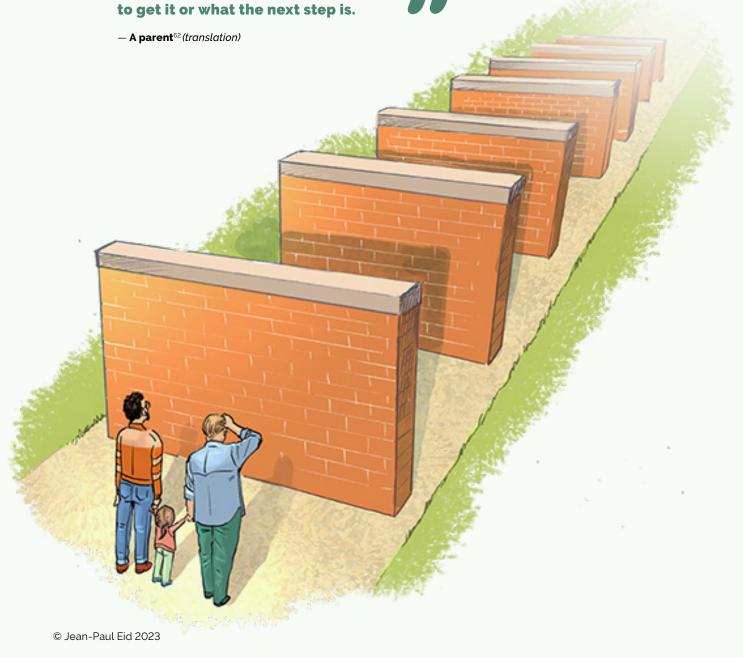
- > next steps
- > where to obtain services
- > which practitioners they need to meet with
- > the procedure to follow to obtain services⁵⁹

The organization of services in Québec is highly variable and the structure of **the health** and social services network is complex. Services are provided at the local, regional or supra-regional level, which can make coordination complicated. Unclear service trajectories can create a "ping-pong effect" for parents, who are constantly transferred from one place to another⁶⁰.

Some parents find it even harder to navigate the network's labyrinth of red tape. These include:

- > parents whose socioeconomic and professional situations are more difficult
- > immigrant families
- families with lower levels of education⁶¹

You've had the follow-up with a specialist.
But that only went so far, and then it stopped. You have no idea what you're supposed to do next. So you have to figure it out for yourself: OK, now that we've seen the OT, what's the next step? What do we do now? It's like a constant battle—you keep telling yourself: [...] I know I have to get help but don't know how I'm supposed



Wait times

There are many steps involved in a child's progress through the health and social services network. Wait times vary depending on several factors, such as the domain of development affected and the child's CISSS/CIUSSS. In certain cases, children must be registered on a new wait list every time they move on to the next step of the process. A child who is on a wait list for screening may subsequently be placed on another list to obtain a diagnosis, and then yet another to receive specialized services, prolonging the wait every time.

In 2020-2021, the longest wait times for an initial specialized appointment were for intellectual disability, autism spectrum disorder and language disorders⁶³. The more complex a child's situation is, the longer the wait times. This applies to children with more than one diagnosis and those whose profile does not entirely correspond with diagnostic criteria or who require the services of a larger number of practitioners with different specialities⁶⁴.

21.3% of young children who presented a significant developmental delay had not received services through programs for physical disability, intellectual disability or autism spectrum disorder within the prescribed timeframe in 2020-2021, according to an estimate by the *Ministère de la Santé et des Services sociaux* (MSSS). The MSSS hoped to reduce that figure to 14% in 2020-2021⁶⁵.

The reasons for these delays are many and complex. The shortage and turnover of personnel is one of the causes, as are the repercussions of the pandemic, which slowed down service delivery because of infection prevention measures and the reassignment of professionals working in those programs to sectors more extensively affected by the pandemice⁶⁶.

The *Institut national d'excellence en santé et en services sociaux* has reported that **it can take several months—even years—before a child receives all the services they need⁶⁷**. Since we know that early intervention is crucial for a child's development, this situation is cause for concern.



Labour shortages

Québec is currently dealing with significant challenges related to labour shortage. Facilities that are frequented by young children who need special support are no exception; their ability to provide services when needed is compromised⁶⁸. In a special report entitled *Putting Students First*, the Québec Ombudsman stated that "school organizations (school service centres and school boards) do not have the necessary staff to respond to the needs of all students. As a result, they must make choices that may hinder access to the right services at the right time⁶⁹."

Several initiatives are underway to respond to this situation. For example, the Québec government's *Opération main-d'œuvre* has been set up to meet current and future workforce requirements in the sectors of health and social services, education and educational childcare services⁷⁰.

Use of the private sector

Some parents, worried about wait times and difficulty obtaining services in the public network, turn to the private sector for professional services.

40% of the parents who participated in the provincial survey of inclusive practices in daycares (Enquête provinciale sur les pratiques inclusives dans les milieux de garde) had turned to the private sector to obtain the report they needed to apply for the Allocation pour l'intégration d'un enfant handicapé en service de garde'71.

42% of the parents of children in school who responded to the Québec Ombudsman's call for testimonials had turned to the private sector to obtain professional services for their child with adaptation or learning difficulties⁷².

A few examples of the cost of certain services in private consultation in 2023:

Service	Approximate cost *
Speech-language assessment	\$500 to \$1,100
Occupational therapy / physiotherapy evaluation	\$700 to \$900
Psychological / neuropsychological assessment	\$1,800 to \$3,100
Therapy / rehabilitation session with a professional** (occupational therapy, special education, speech-language therapy, psycho-education, psychology, etc.)	\$120 to \$140/hour***

Paying for private services can have an impact of families' financial situation⁷³. Coordination between professionals in private practice, partners in the health and social services network and the daycares and schools can also be complicated⁷⁴.

Families that lack the necessary financial resources to pay for private services are doubly penalized: not only can they not access public services in time, they also cannot afford services in the private sector, their only alternative.

^{*} The name of this program was changed in 2023 to Allocation pour l'intégration en service de garde (allowance for integration into educational childcare). In the interest of consistency, however, we have chosen to respect the original terminology used in the reference consulted.

[&]quot;These costs were taken from the websites of specialized clinics, healthcare professionals, associations and professional orders, as well as from consultation with parents, on April 12, 2023.

[&]quot; Since these types of treatment are generally long-term, the unit cost must be multiplied. In certain cases, appointments may be as frequent as twice a week.

ROSA

Rosa is 3 years old. Her parents are concerned because she knows very few words and is unable to speak in full sentences.



Four months later, her evaluations confirm that she has a language disorder.

The wait time for specialized rehabilitation services is several months. By now, Rosa is almost 4.



Services are available for children between the ages of 0 and 5. Rosa would be seen only three times at the rehabilitation centre.

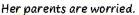


She could be seen sooner by services in the private sector, but her family can't afford it.

Her parents are told that she will be able to obtain services at the school where she is going to go to kindergarten.



The school specialist serves several schools. He won't be able to see Rosa until after Christmas.





Rosa's difficulties make it hard for her to socialize. They're also concerned that she will be held back at school.

Territorial and cultural inequalities

Services offered by CISSS and CIUSSS vary from region to region. In certain regions and in certain CISSS or CIUSSS, young children and their parents have access to a block of 6 to 10 appointments for early intervention in language difficulties. In others, these services are limited to a single information session. Depending on the suspected problem and available resources, some children may also be left without services for several months or years while they wait for a diagnostic evaluation⁷⁵.

Some regions have fewer family doctors, pediatricians and specialists, and some services are concentrated in urban centres. A family living in a remote region might have to travel several hours in order to meet with specialists⁷⁶.

These obstacles sometimes include **linguistic and cultural barriers**⁷⁷. Interpreters are not always available to provide services for clients who do not speak French or English, or even for unilingual English-speakers.

Access to community activities



Families spend time in various places that should be available to everyone. More and more organizations are trying to make their facilities inclusive. Municipalities are making universal accessibility a priority to ensure that services are fully available, whether they be libraries, parks or public swimming pools.



Section 2 – What are the issues that affect children who need special support?

The Agir tôt program

The *Agir tôt* program, aimed at children between the ages of 0 and 5 and their families, was gradually rolled out in CISSSs and CIUSSSs starting in 2019. The objectives of the program are to:

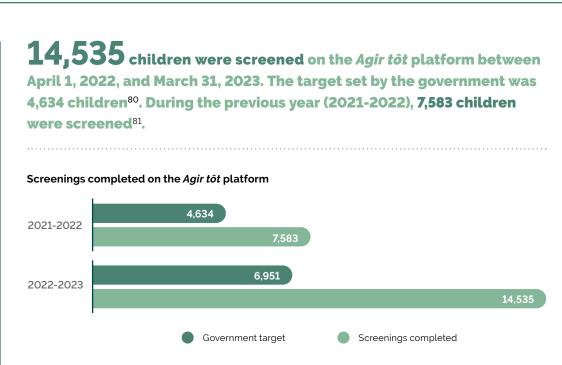
- > **detect as early as possible** any potential developmental gaps between a child and other children in their age group. Detection may be done by parents, educational personnel in an educational childcare facility, community workers or healthcare professionals.
- > **establish a portrait** of the child's overall development that specifies signs of difficulties and refer the child rapidly to the appropriate services.
- > offer services that meet the needs of the child and their family 78.

Process

Once the child's development profile has been established, **various service trajectories are set up to facilitate access to early interventions at the very beginning of early childhood**⁷⁹. At present, access to this type of intervention varies from region to region. It can take the form of development stimulation groups, support for parents and educational personnel, individual and group sessions in speech-language therapy, occupational therapy, psycho-education or specialized education.



One of the strategies used by the *Agir tôt* program is to take advantage of children's 18-months' vaccination to begin tracking their physical health and development. If a concern is raised, the nurse can direct parents to the screening process, if they wish, or to another service that will meet their needs.



Source : MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX. Annual management report 2021-2022, 2022; MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX. *Agir tôt* program, unpublished data, 2023.

The program, which has been positively received, reinforces the importance of early intervention in the lives of children who present developmental difficulties or delays⁸². Although the program is promising, the conditions for its optimal deployment have not yet been set up throughout the entire province.

Management personnel in the health system have warned that an increase in the number of screenings could create a bottleneck in accessing specialized services. They fear that wait times for children's evaluations could grow longer. They also believe that, without a significant injection of resources into the program, it will be difficult to process all requests within a reasonable amount of time⁸³. This delay is already happening in certain regions. For example, the regional PASSAGE study showed that wait times for screening had steadily increased since the launching of the *Agir tôt* program in the region and that, six months and twelve months after screening, many families had not yet received the services to which they had been referred⁸⁴.

From this perspective (and depending on the region), the issues surrounding access to the health and social services network already mentioned in this document could also apply to the *Agir tôt* program. A full evaluation of the program would provide a more accurate picture of where things stand.

Funding



Insufficient funding for educational childcare services

According to the provincial survey of inclusive practices in daycares (*Enquête provinciale* sur les pratiques inclusives dans les milieux de garde), the Allocation pour l'intégration d'un enfant handicapé^{*} is insufficient to cover all of the needs entailed by inclusion.

43% of participating managers consider the amounts they receive insufficient for meeting the needs of young children⁸⁵.

20% of participating managers have reduced the amount of time affected children spend at the facility because of a lack of human resources⁸⁶. That means that some parents have to assist the educational personnel at lunchtime or pick up their child earlier⁸⁷.

Moreover, the amount granted for file management, purchasing equipment and adapting the physical layout (\$2,200) **has not changed in 20 years**⁸⁸, even though costs have increased significantly since then.

A revision of the *Allocation pour l'intégration en service de garde* and the *Mesure exceptionnelle de soutien* is planned as part of the *Ministère de la Famille's Grand chantier pour les familles*. No additional funding has been allocated in the 2023-2024 budget⁸⁹.

The name of this program was changed in 2023 to Allocation pour l'intégration en service de garde (allowance for integration into educational childcare). In the interest of consistency, however, we have chosen to respect the original terminology used in the reference consulted.



For schools



The *Education Act* guarantees access to the complementary educational services that a child's situation requires, including, for example, remedial education, special education, psycho-education, speech-language therapy or psychology⁹⁰.

Complementary services are intended for students who are unable to progress in a normal classroom with the teaching provided in a regular school. The success of complementary educational services in schools depends largely on the school's ability to offer services based on the needs of each student at the right time. These services are currently limited by *Ministère de l'Éducation* funding. The global budget does not reflect real needs or the necessary resources to meet theme⁹¹. Many children with recognized difficulties are therefore left without services, obliging parents who have the means to turn to the private sector for services⁹².

16.6% of children with disabilities or difficulties (EHDA) received no professional services in 5-year-old kindergartens, in 2017⁹³.

The Québec Ombudsman's special report entitled *Putting Students First – For adapted educational services for students with special learning and adjustment needs*⁹⁴ takes a hard look at the lack of complementary educational services funding for children needing special support. Some of the observations made in the report:

- > The Québec Ombudsman sees this as a **failure to respect the students' rights** to the special services they require.
- > This situation worries the Ombudsman greatly. If services are offered based solely on what is possible rather than on what is necessary, **some students** awaiting their turn will not progress the way they otherwise could.
- Consequently, the Ombudsman feels that the way these services are funded must be reviewed, refocused on student needs and rid of the disparities they perpetuate.



The situation for community organizations



Many community organizations play an important role in the lives of parents with children who need special support. Their contributions are manifold: information, respite, activities, support, accompaniment, etc. According to a research report on community organizations that support the well-being of young children, the funding of these organizations does not allow them to do everything they could to foster the welfare of young children, support their parents and prevent parenting problems⁹⁵. Underfunding creates concrete problems for community organizations, resulting in a decrease in activities, poor working conditions, reduced hours, temporary or permanent lay-offs, temporary or definitive closures, etc.⁹⁶.

The government's 2022-2027 Community Action Plan (*Plan d'action gouvernemental en action communautaire*) aims to increase government funding of community organizations' global mission, including that of assisting families with children who need special support⁹⁷. In April 2022, the government also announced an increase in respite services for people living with a disability and their families. Although this input is very welcome, the needs of families are many and community resources are fews⁹⁸.





Administrative complexity (red tape)

The financial assistance application process is cumbersome for both parents and educational childcare services, causing many delays during which children do not receive the support they need⁹⁹. Obtaining funding requires knowledge, determination, skills, time to create a file, and the availability of professionals¹⁰⁰.

Factors that contribute to the administrative burden for parents and/or educational childcare facilities:

- > **Information** on financial assistance available to parents is not centralized. It requires a search on the websites of various government ministries, which makes it harder for parents to find the help they are entitled to.
- > The programs are **not interconnected**. In Québec, for example, parents must complete two separate applications in order to receive the Supplement for Handicapped Children (Subvention pour enfant handicapé) and the Supplement for Handicapped Children Requiring Exceptional Care (Supplément pour enfant handicapé nécessitant des soins exceptionnels)¹⁰¹. The same is true for federal grants. Even if the eligibility criteria are similar, parents have to go through the process at both levels of government.
- > Filling out the **forms** is tedious and complicated. Some are 17 pages long, while other require parents to describe and document all of their child's limitations in daily life for seven "life habits¹⁰²."
- > Many **supporting documents** are required, involving the participation of healthcare professionals who are hard to get hold of and who have little time to devote to this type of administrative task¹⁰³.
- > Some **applications** have to be renewed every year, along with all the same documentation, even if the child's situation has not changed (as could be the case for a child with an intellectual disability, for example).

Some children with extensive special needs could benefit from additional funding in their daycare setting—Mesure exceptionnelle de soutien or MES (financial assistance for the integration of children with disabilities in childcare centres)—but daycare personnel do not necessarily apply for it. Reasons for not submitting applications include:

- > time required to prepare the application (21%)
- > difficulty in accessing outside professionals (17%)
- > extremely complex application (17%)
- > lack of internal resources (6%)104

Moreover, in order to submit an application for the MES, the child must already be attending the educational childcare facility. In some cases, management must take financial risks in order to offer the service while waiting for a response. Because of delays in application processing, parents sometimes have no choice but to withdraw their child from the daycare due to lack of funds—for which they would be eligible¹⁰⁵. In other cases, educational daycares are unable to accept the child without an assurance that they will obtain the MES because they lack the necessary resources to do otherwise.



Support for educational daycares



Insufficient professional support

Most coordinating centres for home daycares and CPEs offer pedagogical support for their educational personnel and home childcare providers in identifying development difficulties and choosing the appropriate intervention for children¹⁰⁷.

In cases where more extensive support is required, other professionals in various areas may be involved (special education, speech-language therapy, psycho-education, etc.). These professionals may be based at a local CISSS or CIUSSS if the child and their family are already receiving services there, or if there is a formal collaboration agreement. Certain educational daycares can also hire professionals, usually special needs educators¹⁰⁸. Parents are often responsible for finding their own support for their child¹⁰⁹, however.

Although the amount and type of support available in Québec varies from region to region, existing professional services are insufficient to meet current needs:

According to a portrait of support services in educational childcare facilities (*Portrait des services de soutien en services de garde éducatifs à l'enfance*):

91% of participating educational daycare managers said they had unmet needs for professionals in their facility¹¹⁰.

57% of participating professionals whose services were listed in the *Portrait* provided under an hour of services every week per facility¹¹¹.

According to a survey on the experience of educators and home childcare providers accepting and accompanying vulnerable children in educational childcare (Enquête sur l'expérience des éducatrices et responsables en milieu familial sur l'accueil et l'accompagnement des enfants vulnérables en service de garde éducatif à l'enfance):

22% of participating educational personnel and

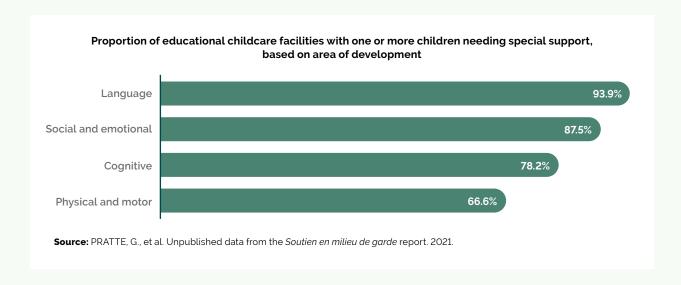
26% of participating home childcare providers said they were able to collaborate with outside professionals when they needed support in connection with a child's development¹¹².

This type of support in daycare settings is generally offered to children with a diagnosis or those who are being followed in the health and social services network, yet who are not necessarily the children for whom the daycare had identified the most needs¹¹³.

Most daycare managers who participated in the *Portrait des services de soutien en services de garde éducatifs à l'enfance* said they would like to have access to at least one stable resource to assist them when they need help for children who require special support¹¹⁴.

Proportion of daycares that accept children who need special support based on the area of development affected

In 2021, managers surveyed for the *Portrait des services de soutien en services de garde éducatifs à l'enfance* had, in their daycare, children with **langage** (93.9%) or **socio-emotional** (87.5%) difficulties. Fewer managers of educational daycares reported having children with **physical** and **motor** difficulties (66.6%)¹¹⁵.



Since educational personnel are in daily contact with young children, they can contribute to the early detection of developmental difficulties. Unfortunately, however, they are not always able to play this important role.

According to the survey on the experience of educators and home childcare providers accepting and accompanying vulnerable children in educational childcare (Enquête sur l'expérience des éducatrices et responsables en milieu familial sur l'accueil et l'accompagnement des enfants vulnérables en service de garde éducatif à l'enfance):

70% of educational personnel in CPEs consider that this task

requires time, energy and planning¹¹⁶. Their work organization does not necessarily allow them to free up enough time to carry out this task.

Just 13% of educational personnel in CPEs consider that they have the necessary conditions to carry out the detection process with children they are concerned about, such as:

- > Having enough quality time to do it properly
- > Using scientifically known and recognized tools
- > Having up-to-date knowledge
- > Obtaining support¹¹⁷.



Insufficient training in the inclusive approach for educational personnel

The initial and ongoing training of educational personnel and teachers has been identified as a key factor in promoting the adoption of an inclusive approach in educational childcare and kindergarten¹¹⁸. It is also one of the cornerstones of high-quality educational daycare. In its consultation workbook on daycare in the spring of 2021, the *Ministère de la Famille* indicated that "competence in the creation of inclusive environments for children with special needs is not included in educators' initial training. Moreover, in the absence of compulsory ongoing training, there is no guarantee that personnel have the necessary resources to support the harmonious overall development and integration of children with special needs¹¹⁹." (*translation*)

Educators' initial and ongoing training allows them to develop skills in providing support, an inclusive attitude and values, and skills in intersectoral collaboration.

52% of educational personnel surveyed consider that their training did not sufficiently prepare them for working with children who need special support¹²⁰.

The college-level training program in *Early Childhood Education* has recently been revised with the addition of a new competence in working with special needs children. The actual effects of this change will not be felt immediately in educational daycares, however.



Collaboration between actors and continuity across settings

The challenges of collaboration and continuity

Since young children who need special support will experience various settings during their lives, collaboration and continuity across those settings and with parents is crucial. Collaboration and continuity improve consistency in interventions within the family, the educational daycare or the school, as well as with professionals in the health and social services network.

The journey of a young child in need of special support poses many challenges in terms of collaboration and continuity within and across environments:

- > **Coordination** between schools, daycares and the health and social services network, as well as with the private sector¹²²
- > Availability of the **resources and time** required to collaborate with partners¹²³
- Poorly defined functioning of establishments in the health and social services network and collaboration mechanisms with insectoral partners (with the exception of reserved spaces [places-protocoles] in educational daycares)¹²⁴
- > Responsibilities for liaising and coordinating services that are often left solely to parents¹²⁵

Even within a single environment, collaboration and continuity can be complicated. This is the case for the health and social services network and schools¹²⁶.

... the conditions for teamwork and for fostering support are not always there, so that genuine collaboration between the members of the school team is often an ideal, rather than a reality.

"

Québec Ombudsman¹²⁷

Including young children who need special support requires **collective management**, a **sharing of responsibilities** and an **appropriate response to children's needs**. It is important that the roles of each of the partners are recognized in order to establish a collaboration framework that includes the sharing of information, knowledge and tools, and intersectoral support mechanisms¹²⁸.

Expanded collaboration



There is also a call for collaboration with resources outside traditional networks. Healthcare professionals point out the necessity of improving and linking the service offerings of various organizations in the community network (such as social pediatrics, organizations for single and immigrant mothers, libraries, speech and language camps, associations) with those offered by establishments in the health and social services network¹²⁹.

Transition to school

The transition to primary school is an important step in the lives of children and their families. If this first transition goes smoothly, it creates a solid base for future transitions¹³⁰. Research study results have shown that a positive transition has repercussions on children's motivation, engagement, perseverance and future success¹³¹. Although the planning of this school transition is important for all children, it is **particularly critical for children who need special support**, who may be more vulnerable to the challenges posed by this change¹³².

Collaboration and continuity across the environments of young children who need special support take on new significance during the transition to school. Some factors create ruptures in services during transitions. Some of the challenges identified in the literature and our surveys include:

- > a lack of **coordination** in planning each child's transition¹³³
- > a lack of **communication** between the educational childcare facility and the school¹³⁴
- > a lack of **communication** between the school and parents¹³⁵
- > an absence of ongoing **funding** which interrupts services¹³⁶
- a lack of information for parents on what the school can offer based on their child's reality¹³⁷

Although all parties are intent on facilitating the transition to school, the planning of the transition still depends largely on the goodwill of individuals or, in many cases, the child's parents.

Written communication

Educational childcare facilities are required to maintain an Education Record, provided by the *Ministère de la Famille*, for every child. This document contains an overview of the child's physical, motor, cognitive, language and social-emotional development, with information based on the observations of educational personnel. With the parents' permission, educational childcare facilities may make use of the Education Record when the child transitions into kindergarten to transfer information to the school¹³⁸. It can be difficult, however, to provide an accurate picture of a child solely through written document. The simple transfer of a physical file is definitely not enough to ensure continuity between the daycare and the school¹³⁹.

Researchers have reported that, in Québec, collaboration practices between a child's various environments (educational daycares, health services, social services, schools, etc.) during a transition are still difficult to establish and poorly adapted to children's complex needs¹⁴⁰.

BOR15

Boris is an autistic child. He has special support at his CPE.



He will be starting kindergarten next year.



In January, his parents call the school service centre for information.



They wanted to arrange a meeting with all Boris's caregivers, the CPE, and the school, so they could exchange their experiences and ideas.







None of the stakeholders had time for such a meeting.



Boris's parents feel powerless. None of the CPE's knowledge will be transferred when Boris starts school.



They feel like they're starting from zero.





SECTION 3

Why is it urgent to take action?

- > CHILDREN'S DEVELOPMENT IS AT RISK
- > PARENTS' PHYSICAL AND MENTAL HEALTH IS COMPROMISED
- > FINANCIAL SITUATIONS OF FAMILIES ARE AFFECTED

The obstacles faced by children who need special support impede access to resources that could maximize their development potential and social participation. As the days go by, these onerous procedures, interminable delays and numerous duties take their toll on parents, whose multiple obligations sometimes oblige them to limit their work to part-time or to stop working altogether, despite their added expenses.

Children's development is at risk

The first years of life are a critical period for **ALL** children's development. It is during this time that the foundations for their future learning are laid¹⁴². **Children who need special support are often deprived of opportunities for development and learning in their early years**, which later emphasizes the inequalities between these children and their "typical" counterparts.

Since we know that early, quality intervention can have a significant impact on the lives of children with developmental difficulties, the current situation is even more worrying¹⁴³. Early intervention can help to **prevent** the onset of more serious difficulties while fostering the child's development and adaptation.

Not being able to access early intervention services can also intensify children's difficulties by creating setbacks in their social and academic development. For example, a child with speech-language difficulties will be at greater risk of developing problems related to behaviour, academic performance and social adaptation, because language development is essential for the acquisition of social skills and school learning¹⁴⁴.

Not being able to benefit from quality educational childcare¹⁴⁵, health services adapted to their needs, optimal coordination between service-providers¹⁴⁶ or support at the right time can have repercussions on young children's development and negatively influence their life course.



After [a child] is put on a waiting list, it can take up to two years before they get any services for a speech or motor impairment or autism spectrum disorder [...]. So, unfortunately, when they start school, they're not ready [...]. It's incredibly sad... I feel terrible about it.

- A clinician¹⁴⁷ (translation)



Parents' physical and mental health is compromised

Organizing their child's daily life, providing the special care they require, navigating the elaborate procedures for obtaining services, going to appointments with specialists, and caring for the other children in their family takes up an enormous amount of parents' time and energy. **Wait times for services** have been described as a particularly agonizing source of stress—and distress¹⁴⁹. A Québec study has pointed to the importance of offering parents support during the period around the diagnostic evaluation, not just once the diagnosis has been established¹⁵⁰. Generally speaking, **parents' psychosocial needs have received little attention amongst the services offered for families with a child who needs special support¹⁵¹.**

Parents who have a child who has a health or development problem are more likely than other parents to perceive their own health as just average or poor.

According to a portrait of the experience of parents with a child living with a health or developmental problem published in 2017:

18.9% of parents who have a child with a health or developmental problem describe their own health as poor or fair, as compared to:

10.4% of parents whose child has no identified problem¹⁵².

There are so many medical appointments, so much organizing of everyone's schedules... you'd think we were managing a small business [...]. It's like we have a parallel existence just for appointments and follow-ups.

- A parent¹⁵³ (translation)

Many studies have shown that the difference in experience between parents whose child has a health or developmental problem and that of other parents lies in the levels and intensity of the stress they live with¹⁵⁴. Parents who have a child with a neurodevelopmental disorder, such as autism spectrum disorder or an intellectual disability, are themselves at the greatest risk of developing **mental health** problems.

30 to 50% of parents of a child with a neurodevelopmental disorder present signs of a mental health disorder (burn-out, depression, etc.)¹⁵⁵.

The **minimal amount of psychological support** offered to these parents, combined with **barriers to obtaining services** for their child's development, exacerbates this problem¹⁵⁶. Respite services are available, but they are insufficient and often expensive¹⁵⁷.

The **lack of communication** between representatives of the school and the health and social services network has been identified as a source of stress by parents, who are often called on to act as an intermediary between the two, which increases their mental workload¹⁵⁸.

Parents who have at least one child with a health or developmental problem have a greater tendency to put a lot of pressure on themselves. They have less feelings of satisfaction and parental effectiveness than other parents¹⁶⁰. Not only can these factors have an impact on their mental health, the accompanying stress levels can negatively affect the parent-child relationship¹⁶¹.

[...] There are discussions that happen among service providers [...] to make sure that everyone has talked to everyone else. But since we're not always included in those discussions, it's up to us to find out if the right people got the message [...]. It's pretty well always the parents' job [...] to keep all the balls in the air... and to make sure nothing falls through the cracks."

- A parent¹⁵⁹ (translation)

The discrepancy between the enormous difficulties these families experience and the few services they are offered increases their vulnerability¹⁶². These parents' lives are strewn with obstacles that require them to wear many hats: they have to be researchers to find the necessary information, service coordinators for their child's caregivers, and advocates to ensure their child's rights are respected, just to name a few. This surfeit of responsibilities takes a toll on their physical and mental health, detracting from their ability to play their most important role: that of parent.



Families' financial situations are affected

The financial situation of families with children needing special support is affected by many factors:

- > Turning to the **private sector for assessments** and other services can cut into the family budget.
- > **Parents' working hours** are often curtailed because of numerous appointments, formalities conducted with various bodies, etc.¹⁶³. Time is also required to attend to the child's basic needs, which can reduce parents' availability.
- > Their child's condition may entail **expenses**, related to purchasing adapted equipment for the home or daycare (such as a positioning chair, stimulation toys, etc.)¹⁶⁴.

According to the 2015 Québec Survey on the Experience of Parents of Children Aged 0 to 5 (*Enquête québécoise sur l'expérience des parents d'enfants de 0 à 5 ans*, or EQEPE), more parents with a child between the ages of 3 and 5 with a health or developmental problem consider that their **income is insufficient to meet their family's basic needs**¹⁶⁵. The extent of financial repercussions depends on the magnitude of the child's needs.

According to the 2015 EQEPE, 30.4% of families with a child who has a severe disorder had financial problems in the year preceding the study, as compared to:

8.6% of families with a child who had fewer needs for support¹⁶⁶.

The decision not to work outside the home because of absences caused by a child's condition and the many appointments and procedures that complicate family-work balance decreases household income. Parents' work is even more affected if their child has major support needs¹⁶⁷.

According to the EQEPE, a proportionally larger number of parents who have at least one child with a physical disability or chronic health problem live in a family where at least one of the parents (or a single parent) works part-time, as compared to parents whose children do not have a similar problem.

According to the 2015 EQEPE, 25.6% of parents with at least one child with a physical disability or chronic health problem live in a family where at least one parent (or a single parent) works part-time, as compared to:

17.9% of parents who do not have any children with a physical disability or chronic health problem¹⁶⁸.

The proportion of families who have at least one parent staying at home is also higher among families with at least one child with a health or developmental problem.

According to the 2015 EQEPE, 14.6% of families with at least one child with a health or developmental problem have at least one parent staying at home by choice, as compared to:

9.8% in the case of families who do not have a child with an identified problem¹⁶⁹.

The increasingly fragile financial situation of families with a child who needs special support is one form of collateral damage caused by the many obstacles encountered during the child's life. **The economic burden for these families is real, contributing to a deterioration in parents' mental health**¹⁷⁰.

SECTION 4

What can we do to better support the inclusion of young children who need special support?

- > ADOPT A NEEDS-BASED APPROACH
- > SUPPORT PARENTS
- > PROVIDE THE NECESSARY RESOURCES
- > IMPROVE INTERSECTORAL PRACTICES

The scientific literature, combined with experience on the ground and surveys of parents and personnel in educational childcare, schools and the health and social services network, identifies courses of action for better assisting young children who need special support. Some of these initiatives are already underway; others are promising. On the following pages, we have provided examples of a few in the hope that they will serve as inspirations. Each of them exemplify the collective levers available to us for taking action to ensure that young children needing special support are able to develop their full potential in the same ways as all other children.

Adopting a needs-centred approach

A needs-based approach means considering the individual needs of every child from the perspective of their overall development, rather than just detecting and focusing on their difficulties. Some children need more support than others to develop their full potential. The support they require should be based on their needs, not their diagnosis or disabilities.

This position represents a paradigm shift from the current diagnosis-based approach, which categorizes and defines children in terms of their diagnosis and what they lack.

Young children needing special support should be able to identify themselves simply as children, not children who are different or "disabled." The needs-centred approach is an invitation to see each child in a positive way, to differentiate the child from their behaviours, and to facilitate their learning process so that they can experience successes¹⁷¹. It also fosters the harmonious inclusion of children who need special support by focusing on their capacities and what they contribute to the group—both in daycares and the classroom.

Developing a **policy of inclusion** can provide an opportunity to focus on the values of respect and kindness that are fundamental to inclusion and a needs-based approach. A policy enables a vision to be shared, thus facilitating the acceptance of children who need special support in educational childcare environments¹⁷².



The Association québécoise des centres de la petite enfance (AQCPE) has developed a <u>writing tool for implementing a policy of inclusion</u> for educational daycares.



The *Enfants Soleil CPE* and coordinating centre for home daycares in the Montréal region has placed the inclusion of **children needing special support at the heart of its mission** and is ensuring that the necessary conditions have been created to achieve that mission.

- > Ongoing training in inclusion is offered to home childcare providers.
- > Help is offered to establish connections between home childcare providers and various partners in the community (CLSC, rehabilitation centres, community organizations).
- Assistance in close collaboration with specialized resources makes it possible to provide children who need special support with the appropriate services.
- Various tools are available through a multimedia library.

Promoting inclusion through public policy



In the country of Georgia, national standards have been established for preschool education. The competency profile for educators includes **values and best practices** in inclusive early childhood education¹⁷³.



In the United States, the federal *Individuals with Disabilities Education Act* guarantees **access to free public education and related services** to all children and youth between 0 to 21 years of age who are living with a disability¹⁷⁴.



Alberta and New Brunswick have education policies that support inclusion¹⁷⁵. In those provinces, all children are accepted in preschools and schools. There are no special classes or schools; **teachers and educators adapt their teaching approaches based on the needs of each child.**

Improving inclusive practices in childcare settings

Inclusive practices recognize that all children are much more alike than they are different—particularly at a young age—regardless of differences observed in their behaviour, functioning or learning processes. These practices assume that all children have a place within the group.



The <u>Guide d'aide à la mise en place efficace de pratiques inclusives en milieu</u> <u>de garde</u> (guide to the effective implementation of inclusive practices in childcare settings) is an easy-to-use tool designed to assist educational childcare personnel in **developing their practice**¹⁷⁶.



The Association québécoise des centres de la petite enfance (AQCPE) has developed <u>Alex – Nature-based early childhood education</u>, based on a close contact with nature. This inclusive pedagogical approach encourages educators to **focus on children's strengths** rather than their difficulties.



Le CPE La Grosse Maison was designed to fully accept children who need special support. In addition to an adapted physical layout (**sensory room, psychomotricity room and accessible outside play area**), educators are trained to value differences.



The *Ministère de la Famille* has developed a pilot project in collaboration with the *Association des haltes-garderies communautaires du Québec*. The aim of the project is to experiment with different strategies for encouraging the participation of children who need special support in selected community drop-in daycare centres, and to evaluate the impact of these strategies over a two-year period.

Saint-Joseph Park

Saint-Joseph Park in the Montréal borough of Rivière-des-Prairies, is the perfect example of a concrete expression of the concept of inclusion. Municipalities have a role to play in the inclusion of young children who need special support by adapting public playgrounds and other facilities. Apart from providing accessible outdoor play modules, the park has been designed to encourage shared play among all children¹⁷⁷.



Saint-Joseph Park (continued)

Saint-Joseph Park is very different from the traditional green spaces with one or two types of adapted amenities, such as swings or a reserved area for people living with a disability. Created in consultation with *L'Étoile de Pacho*, a community organization that provides support for families who have children with a disability, the park was designed to ensure that **ALL children could play together on the same installations**. Every aspect of the park was carefully considered so that all children could fully benefit, regardless of their needs.

- > Access to the park, sanitary facilities and all play modules are completely and universally accessible to both adults and children, with or without functional limitations of any kind.
- > There are no stairs or any other obstacles, ensuring wheelchair access to all areas of the park.
- > The ground covering is colourful to help visually impaired children move about easily.
- > There are different types of swings, adapted merry-go-rounds for wheelchairs and raised sandboxes¹⁷⁸.

The project was the inspiration of a mother of two children, one of whom is Joanie, who has cerebral palsy. When the family used to go to the park, Joanie would cry because she wasn't able to play with the other children. L'Étoile de Pacho, an association of parents of children living with disabilities, collaborated on the project, which helped to ensure that all types of functional limitation were taken into consideration when designing the layout of the park.



 Mother of Joanie, who plays in Saint-Joseph Park.¹⁷⁹ (translation)

Supporting parents

Reducing structural barriers

The barriers faced by parents attempting to obtain services or financial assistance are many and varied, which just adds to their stress and exhaustion. Efforts are under way to reduce the obstacles created by the complex structure of our government institutions, and will continue until 2025-2026.



The *Office des personnes handicapées du Québec* is the force behind the project aimed at **simplifying access** to many of the programs, measures and services intended for people living with a disability, including young children who need special support and their families. Solutions include:

- > improving access to information
- > reducing the number of steps involved
- > improving coordination in accessing services in different networks¹⁸⁰.

Providing parents with better support

Until the many processes and procedures have been simplified, personalized support would help to lighten parents' load. Someone who is well informed, both about the child and their family and the resources available, can provide parents with valuable support¹⁸¹. This **liaison or pivot person** is someone familiar with the various programs that a child is eligible for and can more easily navigate the system. This person could be a healthcare professional or a staff member of an educational daycare, school or community organization.



<u>J'me fais une place en garderie</u> is a community organization that supports Montréal families in their efforts to **integrate a child with a motor disability into a daycare environment**. Counsellors help families find a daycare and then work to create partnerships and promote collaboration among all the actors involved in ensuring the child's inclusion.

Responding to parents' psychosocial needs

There are many ways that parents can obtain support:

- > Engaging with **support groups**, which are often greatly appreciated by parents, as they provide a space for sharing information, help to reduce stress and feelings of guilt, improve self-esteem and break isolation¹⁸²
- > Obtaining a **sponsor** when their child begins the diagnostic evaluation proces¹⁸³



The Agir ensemble en soutien à la santé mentale des familles dont l'enfant présente un trouble neurodéveloppemental : mise à l'essai et évaluation d'un programme pour, par et avec les parents* initiative is aimed at supporting the **mental health of families** with a child between the ages of O and 5 with a neurodevelopmental disorder. Inspired by a project developed in Great Britain, it was translated and adapted for use in Québec¹⁸⁴.



<u>L'Accompagnateur</u> is a **web platform** that lists all available resources for parents and children by region, based on needs¹⁸⁵.

Offering a range of respite services for families

All parents need a break from their children from time to time. This is particularly true of parents of children who need special support, whose daily routine can be much more demanding.

There are different types of services available for families:

- > short- or long-term respite offered through respite homes, summer camps or at home
- > informal caregivers and babysitters for planned needs
- > occasional assistance in the case of an unforeseen temporary event



<u>Portail répit</u> (the respite portal) is an initiative of *Solidarité de parents de personnes handicapées*, funded by the *Office des personnes handicapées du Québec*. This **web platform and mobile application**, which centralizes information on respite organizations and indicates the number of available spaces in real time, is making it easier for families with a member living with a disability to find respite care services¹⁸⁶.

^{*} Acting together to support the mental health of families with a child who has a neurodevelopmental disorder: piloting and evaluation of a program for, by and with parents

Providing the necessary resources

Adequately equipping educational childcare personnel

As part of its *Grand chantier pour les familles* (major project for families) program, the *Ministère de la Famille* plans to offer services adapted to the needs of the most vulnerable children and those with special needs¹⁸⁷. To this end, the scientific literature identifies key factors to ensure that inclusion is a positive experience for young children, their parents and those involved



> pedagogical support

in the learning environment¹⁸⁸:

- > sufficient time for planning and conversation with practitioners and the family
- > access to specialized material and equipment (stimulation material, positioning chair, transition tools, etc.)
- > access to training
- > application of an inclusion policy

Improving support services

The presence of a child needing special support in a daycare or classroom does not necessarily entail professional support. In many cases, environmental adaptations or simple educational interventions are sufficient. Having access to help from professionals with a complementary vision who can analyze the situation from another point of view, however, can be useful in supporting educational facilities in their mission of inclusion.

The majority of daycare managers participating in the Soutien project have expressed the desire to have **access to at least one stable resource to assist their personnel** in caring for children with special needs when necessary¹⁸⁹.



Having access to a **resource person provided by the health and social services network** who would be available to assist educational childcare facilities in a given territory is one path of action that was identified by participants in the Soutien project¹⁹⁰.



The **UnisSon** program is offered at the CIUSSS du Centre-Sud-de-l'Île-de-Montréal. **Specialized practitioners (occupational therapist, specialized educator, etc.) provide support for educational daycare personnel** to include young children with an autism spectrum disorder, a global developmental delay or an intellectual disability. They also work with families throughout their children's early years, from early childhood right up until they enter school.

Support services can also be offered based on a tiered approach, starting with general support services then moving on to more exhaustive services based on the specific needs of families and children. This type of approach raises the awareness of a large number of parents and personnel while offering more intensive services and support to the children who need them.



After providing occupational therapy services for just 137 days during its first year of operation, the **community occupational therapy** program at the CIUSSS de l'Estrie – CHUS achieved the following:

- > raised the awareness of 27 parents and 49 educators on young children's motor development.
- > helped 62 adults (educators and parents) set up strategies to support the development of 396 children.
- > provided one-on-one support to 23 children with developmental issues in close partnership with 70 significant adults (educators and parents)¹⁹¹.



The <u>P4C (Partnering for change)</u> model, based on the Response to Intervention approach (RTI), offers **occupational therapy services** in schools. The model focuses on barriers to learning, with therapists' on-site presence allowing for rapid, early intervention in collaboration with the school team. These services encourage the implementation of universal measures combined with individual adaptations, as needed. This model has been adopted by a research team in Québec¹⁹².

Upgrading initial and ongoing training

The initial training program for educational personnel is currently being revised to enhance its content on inclusion. Until those revisions are implemented, however, it is crucial that managers be made aware of the importance of offering ongoing training to their educational personnel. Proper training will improve educators' confidence by increasing their knowledge and skills in the area of inclusion and maintaining and improving the quality of services offered.



Intégration sociale des enfants en milieu de garde is a provincial organization that supports the inclusion of children needing special support in childcare settings, offering **training and advisory support** that focuses on the needs of individual children and confidence in their own abilities¹⁹³.



The certificate in pedagogical support in educational childcare centres and other daycares <u>certificat en soutien pédagogique</u> offered by the Université du Québec à Trois-Rivières includes a course dedicated to inclusion. This program, developed in response to the demand from educators in the field, focuses on providing **pedagogical support** in childcare settings.

Educational personnel reports learning about inclusive practices primarily from contact with other colleagues¹⁹⁴. Accompaniment with personalized support is one of the most effective ways to help educational personnel feel properly equipped to work with children who need special support¹⁹⁵.

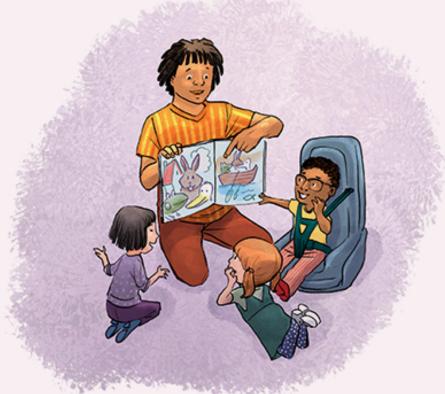


The non-profit organisation CASIOPE, offers accompaniment to managers and **pedagogical support to educational daycare personnel** CASIOPE's mission is to educate educators on childhood development so that they are better able to detect children's needs and act as quickly as possible when necessary. CASIOPE tools are used in 15 cégeps that offer the Early Childhood Education course, where they are appreciated for their reflective approach to children's needs.



The Irish program *Leadership for Inclusion* offers both in-person and virtual accompaniment by **expert tutors**. Results have shown that, prior to the program, 17% of participants did not feel sufficiently competent to implement inclusive practices. Following participation in the program, that figure dropped to a mere 1%, showing that the program significantly improved participants' feeling of competence¹⁹⁶.

The Québec Ombudsman has also underlined the importance of providing teachers with ongoing training in working with children who need special support and their inclusion in the classroom. Access to training should be made easier to ensure the highest rate of participation¹⁹⁷.



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Improving intersectoral practices

Recognizing parents' expertise

Solid **collaboration with parents** and the **recognition of their expertise** as their child's primary educators is crucial. Their knowledge should be put to better use in the health and social services network¹⁹⁸, at school¹⁹⁹ and at daycares²⁰⁰—a desire that has been expressed by many parents with children who need special support. Parents want to be better informed and more involved in meetings. They want their voices to be heard when objectives are being set, and to have more say in making decisions on interventions that concern their child²⁰¹.



The family-partner approach model for children with a neurodevelopmental disorder was developed by Angela Fragasso based on the experiences of parents, healthcare professionals and community workers. The model relies on establishing a **relationship of trust** to create a respectful partnership with families. Not only does this approach improve collaboration with families, it also has a positive effect on the health and well-being of everyone in the household²⁰².

Consolidating intersectoral collaboration

Collaboration among the various networks is essential if children are to have access to all the resources and support they need for healthy development. The literature has identified several concrete ways to facilitate collaboration:

- policies for shared services or agreements for reserved spaces in exchange for professional support, for example²⁰³
- > training in interprofessional collaboration²⁰⁴
- > sufficient human, financial and material resources²⁰⁵
- > **time slots reserved** for collaboration²⁰⁶, access to rooms, material, administrative support²⁰⁷



In Montréal, an early educational intervention program called *Interventions éducatives précoces* (IEP), coordinated by the *Direction régionale de santé publique*, helps to **create connections between educational daycares, community drop-in daycare centres and CLSCs**. In cooperation with educational daycares, IEP workers from the local CLSC facilitate access to educational childcare thanks to spaces reserved for those children being followed by the CIUSSS. IEP workers also offer follow-up assistance to educational personnel who work with young children and provide support for families to ensure each child integrates successfully into their social group²⁰⁸.

At the community level, **collaboration** also promotes cooperation among stakeholders. Several organizations may then become involved, such as educational childcare facilities, school service centres, schools, health and social service centres, community organizations, charitable organizations, local or municipal elected officials, representatives of cultural organizations, and so on²⁰⁹.



The <u>Continuum de services concerté en orthophonie communautaire</u>, (Collaborative continuum of services in community speech-language pathology) developed in the Montérégie region of Québec proposes **innovative strategies** based on all of the practitioners and educators from the health, school and community environments working together²¹⁰. The evaluation of this approach shows that coordinating actors' interventions leads to collective care of families and to earlier interventions adapted to the needs of children who present communication and language difficulties²¹¹.

The **proximity approach** which is effective in establishing and maintaining connections, involves creating a partnership among the various organizations in a given territory to better meet the needs of the population. The proximity approach has been successful in reaching certain clients who are dealing with barriers to services.



Community outreach workers in the Estrie region make it easier for families to connect with the various regional services available. This approach opens up possibilities for referrals and partnerships that are in the best interest of families, creating a social safety net. By improving families' access to services and increasing their trust in the system, community outreach workers also help them improve their feelings of self-efficacy and self-esteem, breaking down their isolation²¹².



The objective of the <u>Carrick</u> project led by the <u>Association québécoise</u> des centres de la petite enfance (AQCPE) is to create **links between the various networks** (educational daycares, the health and social services network, schools, municipalities and family resource centres *lorganismes* communautaires Famille or OCFI) to provide better assistance for children who need special support, including those in vulnerable situations.

Systematizing continuity in the transition to school

A smooth transition from educational childcare to school requires planning, which includes:

- > a structured process
- > release time for school personnel
- > coordination²¹³, with one person appointed to coordinate follow-ups²¹⁴
- > creating an atmosphere of trust among partners²¹⁵

Other strategies have been set up to improve children's transition to school:



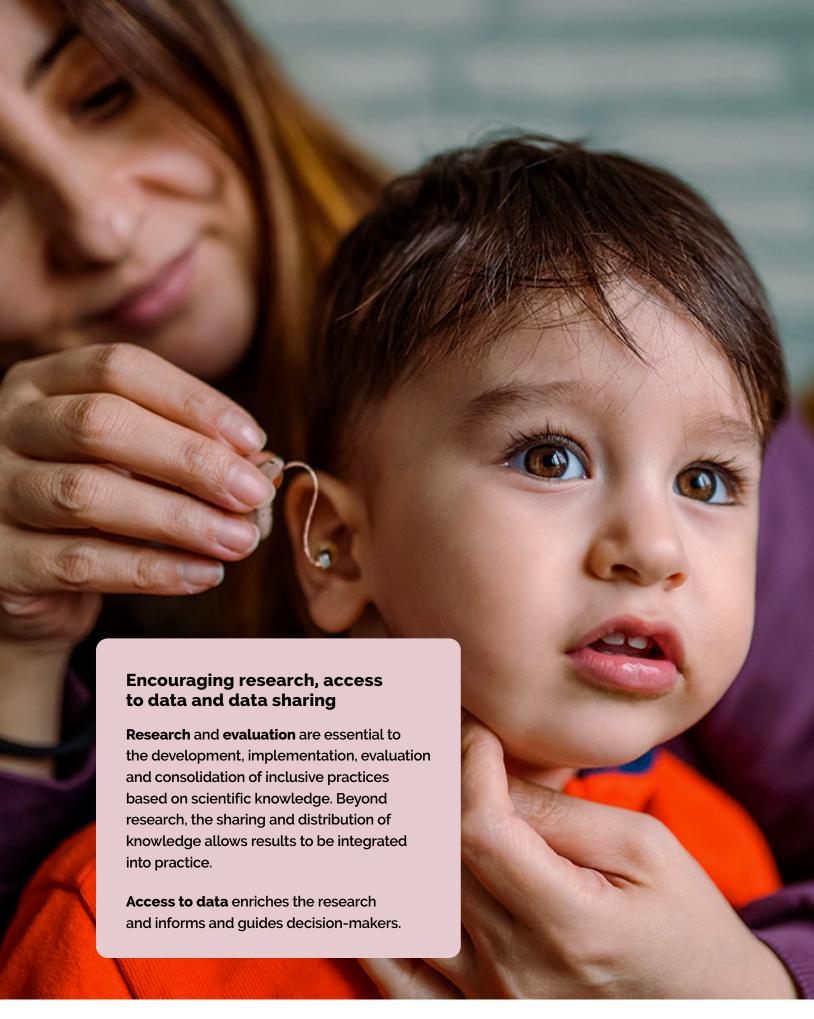
The <u>Transition to Kindergarten guide</u> developed in Québec's Estrie region recommends that a meeting be set up between the family and the various partners (representatives from health and social services, the educational childcare facility or the community) during the month of February and before the child enters kindergarten, offering a **transition plan** for children who need special support²¹⁶.



Moving on to School is a resource tool developed by CASIOPE that promotes **educational continuity** between a child's experience in their childcare environment and starting school. This tool is completed by the child's educator and given to the parents, who can then send it on to the school.



The <u>Place à l'école</u> project was created in November 2020 by the <u>Intégration</u> sociale des enfants en milieu de garde organization to **assist parents** with children who need special support in making the transition to school. The organization guides parents through the many steps involved and provides them with information on available resources.



Conclusion

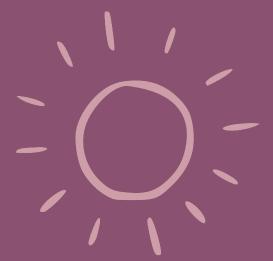
Despite the efforts of their parents and childcare personnel, young children who need special support suffer from inequalities and face barriers that deprive them of opportunities to achieve their full development.

The impacts of this situation are many. First, for the children, who risk not developing their full potential and not being able to play an active role in society, but also for their families, who are affected physically, mentally and financially. Society as a whole suffers both socially and economically from the health costs of failing to take early action, including tangible costs, such as lost income for parents' who have difficulty in staying in the labour force, among others.

More than ever, these issues underline the necessity of mobilizing all stakeholders involved at every level to ensure that these young children are able to take their rightful place in society. Labour shortages mean that innovation will be required: many partners are already working together to make a difference.

UNESCO reminds us that "this vision of inclusion [...] places the responsibility on education and care systems to understand and adapt to the needs of all learners. Inclusion involves accès, access, full participation and availability of all the necessary support for each child [...]²¹⁷".

We need to take collective action to ensure that young children and their families have the support they need, can access educational childcare facilities and schools that are increasingly inclusive, and are able to receive quality health care and social services. We must take action to help ensure that success is possible for everyone, without exception.



Conclusion 78

For your review

The *Observatoire des tout-petits* has produced a comprehensive report on the situation of young children who need special support in Québec.



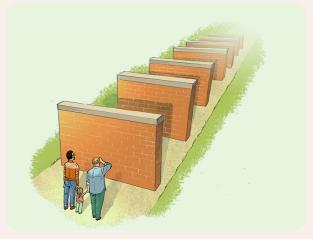
A video for raising awareness



A **brochure** featuring highlights from the report



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tout-petits.org/besoin-soutien-particulier

For your review 79

The information presented in this report was drawn from an analysis prepared by Gabrielle Pratte and Audrée Jeanne Beaudoin.

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The mission of the Early Childhood Observatory, a project of the Lucie and André Chagnon Foundation, is to communicate the current state of knowledge in order to promote informed decision-making on the subject of early childhood in Québec. Our goal is to ensure that every young child living in the province has access to conditions that will enable them to develop their full potential, regardless of where they were born or where they are growing up.

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