Autism Spectrum Disorders:

What I need to know about my child's care



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For comments on this handbook, please contact the Autism Spectrum Disorders Program at 514-412-4400 ext. 23099

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IMPORTANT: PLEASE READ

This handbook is for information purposes only. It is not meant to take the place of the advice you receive from your treatment team. As every patient is different, different treatments are chosen for each child. We recommend that you speak to a member of your treatment team if you have questions.

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You may be receiving this handbook during a very stressful period in your life.

Your young child may...

- be showing signs of an Autism Spectrum Disorder, or
- have been newly diagnosed with an Autism Spectrum Disorder.

If you are waiting for an appointment or if your child has already been diagnosed, you may have many questions and concerns. You may find it hard to remember all the information given to you about helping your child. This handbook was made to help you.

This handbook is divided into 4 parts:

Part 1: What is an Autism Spectrum Disorder?

The first part of this handbook has information about the different types of Autism Spectrum Disorders. It also addresses common questions or concerns that parents often have.

Part 2: Where can I get help?

The second part of this handbook explains what the specialists at the hospitals, readaptation centers and CSSS-CLSCs can offer you.

Part 3: What treatment options exist?

The third part of this handbook informs you about the different treatment options for children with Autism Spectrum Disorders. This section also gives you a list of questions to ask when you are deciding on a treatment program for your child.

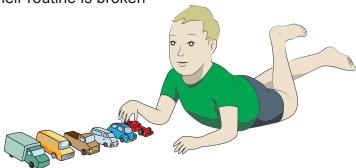
Part 4: What else can I do?

The fourth part of this handbook aims to help you make other important decisions about your child's well-being. Information on daycare, schools, community organizations and private services are given so you know about some of the options offered in your community. Also, websites are given for added information. Lastly, there is a section on the Quebec Ombudsman that will inform you on your rights as you work with government and private institutions in your community.

We encourage you to read this handbook and discuss it with your treatment team if you have any questions. We hope this handbook will be helpful for you. An Autism Spectrum Disorder is a developmental disorder that is often noticed during the first three years of childhood. A developmental disorder is a delay or change in the way a child develops.

Children with Autism Spectrum Disorders may:

- have difficulty interacting with others
- have trouble speaking and playing
- play in a repetitive manner with certain toys
- get unusually upset when their routine is broken



Children with Autism Spectrum Disorders may look quite different from one another. The treatment team evaluating your child may have asked you questions about your child's:

- developmental milestones when your child learned something new, like walking and talking. There are different milestones for each age group.
- level of intelligence how they problem-solve
- language how they speak and understand
- social skills how they get along with others
- motor skills how they move
- daily life skills how they dress, eat, and clean

This information helped the treatment team decide on the Autism Spectrum Disorder diagnosis that fit your child best.

What types of autism spectrum disorders are there?

There are five Autism Spectrum Disorders:

- Autistic Disorder,
- Asperger's Disorder,
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS),
- Rett's Disorder
- Childhood Disintegrative Disorder.

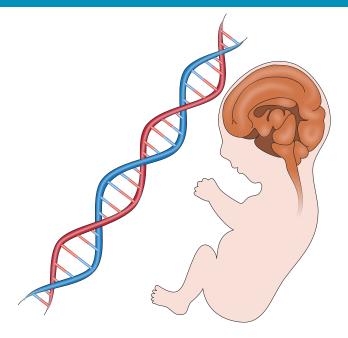
The term "autism" is often used to refer to Autistic Disorder. Some children with autism have good language skills and normal intelligence (problem-solving skills). They are sometimes referred to as having "high functioning autism". While others have severe language and intellectual deficits.

The term "intellectual deficits" or "intellectual disability" means that a person has difficulty problem-solving with and without the use of language and they have trouble with daily living skills that require them to take care of themself. A child with an intellectual disability will learn and develop more slowly than other children his or her age. The terms "cognitive disability" and "mental retardation" are other terms sometimes used to mean "intellectual disability."

The terms "Autism Spectrum Disorder" and "Pervasive Developmental Disorder" mean the same thing. For simplicity, the term "Autism Spectrum Disorder" is used in this handbook to refer to Autistic Disorder, Asperger's Disorder, and PDD-NOS.

Rett's Disorder and Childhood Disintegrative Disorder are very rare conditions. If your child has one of these diagnoses, you should consult with your treatment team to see how the guidelines below apply to you.

Frequently asked questions or concerns



What causes Autism Spectrum Disorders?

Unfortunately, no one knows the exact cause of Autism Spectrum Disorders. Current research suggests that Autism Spectrum Disorders are related to genetic (hereditary) factors that affect brain development very early in life.

Does my child need medical tests to test for other conditions?

Many research studies have shown a relationship between Autism Spectrum Disorders and medical conditions such as seizure disorders, tuberous sclerosis, neurofibromatosis, and Fragile X Syndrome. Your treatment team may recommend medical tests to check for these conditions.

Will my child's language, social and behavioural problems improve with time?

As children grow and change with age, so do their behaviours and abilities. Even though their diagnosis may not change, children with Autism Spectrum Disorders can make a lot of progress as they get older. Depending on your child's strengths and weaknesses and what type of treatment plan you choose, your child's behaviour, language and social skills can improve a lot as he/she gets older. Children who develop good language skills by 5 years old, often show the most progress.

Can my child's language, social and behavioural problems get worse with time?

Some studies show that a small percent of children diagnosed with Autism Spectrum Disorders can lose some skills they have already learned. In the vast majority of cases, loss or "regression" of skills happens very early in childhood. As they get older, it becomes much more unlikely that your child will lose skills.

As they become teenagers, it is more common for children with Autism Spectrum Disorders to develop depression, anxiety, attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, tics and self-injurious behaviour, as compared to children from the general population.



If you observe any of these symptoms in your child, you are advised to speak with your health care professional about treatment options.

Is there a "cure" for Autism Spectrum Disorders?

Although there is no cure for Autism Spectrum Disorders, many symptoms can be treated with early intervention treatment programs or other therapies.

Hospitals

If you suspect something is wrong with the way your child is developing, you need to discuss your concerns with your child's pediatrician or family doctor. He/she may refer your child to a specialized clinic such as one of the four hospitals in Montreal that are specialized in Autism Spectrum Disorders for an evaluation.

Below are a list of Montreal hospitals with Autism Spectrum Disorder diagnostic services where you can call for information on evaluations, treatments and research participation.

There may be a waiting period before your appointment, therefore you may wish to read this handbook to learn about what you can do while you are waiting.

Montreal Children's Hospital-MUHC

Autism Spectrum Disorder Program 4018 Ste. Catherine west K-207, Montreal, (Quebec) H3Z 1P2 Phone: 514-412-4400 ext. 23099 Website: www.thechildren.com

Hôpital Ste-Justine

Centre de développement 3100 Rue Ellendale, Montreal, (Quebec) H3S 1W3 Phone: 514-345-4789 ext. 6634 Website: www.hsj.qc.ca

Douglas Hospital

Autism Spectrum Disorders Program Burland Pavillon 6875 LaSalle Boul., Montreal, (Quebec) H4H 1R3 Phone: 514-761-6131 ext. 3085 Website: www.douglas.qc.ca/

Hôpital Rivière des Prairies

Clinique d'évaluation TED 0-17 7070 Perras Blvd., Montreal, (Quebec) H1E 1A4 Phone : 514-323-7260, ext. 2672 Wesite : www.hrdp.qc.ca/

What can I expect from the evaluation process?

Your child may be referred to a specialist or a team of specialists that will evaluate your child's hearing ability, language skills, motor skills, and intelligence.

Before or after these evaluations, your child may have an appointment with a psychiatrist, developmental pediatrician and/or psychologist at the hospital. They will...

- review your child's developmental history
- observe your child in certain play scenarios.

This evaluation helps outline your child's strengths and weaknesses so they can get the best treatment plan possible.

The treatment team with the Autism Spectrum Disorders program at the hospital will then refer your child to your local readaptation centre.

The hospital may also offer treatment or opportunities for research participation, but most services will be offered outside the hospital, since hospitals mostly specialize in diagnosis.

Sometimes, these type of team evaluations happen outside the hospital, at another community setting. For example, through the Health and Social Service Centres (CSSS)-Local Community Service Centres (CLSC). The team evaluation at the CSSS-CLSC can be done before the hospital or instead of a hospital evaluation.

Who can diagnose my child?

Bill 21 has recently been passed by the government of Quebec and permits psychologists to diagnose Autism Spectrum Disorders.

This was previously reserved to psychiatrists only. Note: This is a recent change and that regulations may be in the process of changing at readaptation centres and at schools.

Why is having a diagnosis necessary?

An official diagnosis is necessary:

- to receive special services from the readaptation centers, which are mandated to provide 20 hours a week of ABA therapy (behavioural interventions) for your child.
- to receive a special code so you can request special school services for your child at the time your child registers for school.

What are readaptation centres?

The Montreal Area has five readaptation centres (or CRDI-TED) that are supported by the government. Readaptation centres are divided by CSSS-CLSC sector.

Readaptation centres provide:

- services to individuals with intellectual impairments and/or Autism Spectrum Disorders throughout their lifespan.
- rehabilitation services (treatment).
- support groups for parents.

Where is the readaptation centre in my sector?

The hospital team members or your CLSC social worker may have already given you the name of the readaptation centre in your sector. If not, contact the Quebec Federation of CRDI-TEDs to find the readaptation centre in your area.

Quebec Federation of CRDIs Telephone: 450-671-5344 Website: www.fqcrdi.qc.ca

The list of readaptation centres in and around the Montreal region is listed below. There may be a waiting period for readaptation centre services, so it is important to continue reading about other services available in your community.

You should be aware that there may be changes to government services over time. The government has advised us that agencies may change names and/or merge in the near future, so the numbers and information below may change after this handbook has been published. Check with the CSSS-CLSC for updates regarding the information on the next page.



List of readaptation centres in the Montreal area

West Montreal Readaptation Centre

8000 Notre Dame, Lachine, (Quebec) H8R 1H2 514-363-3025 www.crom.ca

Miriam Centre

8160 Royden, Montreal, (Quebec) H4P 2T2 514-345-0210 ext. 319 www.centremiriam.ca

Lisette Dupras Readaptation Centre

8000 Notre Dame, Lachine (Quebec) H8R 1H2 514-364-2282 www.lisette-dupras.ca

Gabrielle-Major Readaptation Centre

6455 Jean Talon East, Montreal, (Quebec) H1S 3E8 514-259-2245 www.crgm.qc.ca

L'Intégral Readaptation Centre

75 Port-Royal St. East, Office 110, Montreal, (Quebec) H3L 3T1 514-387-1234 www.integrale.org

List of readaptation centres around the Montreal area

Normand-Laramée Readaptation Centre

304 W. Cartier Blvd., 2nd floor, Laval, (Quebec) H7N 2J2 450-972-2099 www.crdinl.qc.ca

Les Services de Réadaptation du Sud-Ouest et du Renfort

315 MacDonald St., office 105, Saint-Jean-sur-Richelieu, (Quebec) J3B 8J3 450-348-6121 www.santemonteregie.gc.ca

Montérégie-Est Readaptation Centre

1255 rue Beauregard, Longueuil, (Quebec) J4K 2M3 450-679-6511 www.crdime.qc.ca

What can the CSSS-CLSCs offer?

The 28 Local Community Service Centres (CLSC) have been incorporated into Health and Social Service Centres (CSSS). The new names are CSSS-CLSC. Despite the new name, the CLSCs remain at the same locations and provide you with the same services as before.

You can consult with your CLSC at anytime for help and services regarding your child and/or family. To find out which CLSC is in your district, you can call the CLSC Federation telephone number provided below or you can visit the following website and type in your postal code. CLSCs are divided by postal codes.

http://wpp01.msss.gouv.qc.ca/appl/m02/M02RechInfoSante.asp

The CLSC Federation 514-931-1448



What if my child has not been evaluated?

- You can contact the "child and family program" of your CSSS-CLSC.
- A social worker will be appointed to you and evaluate your child and family's needs. The social worker can then help you find the best place in your sector to go for a specialized evaluation for an Autism Spectrum Disorder.

What if my child has already received a diagnosis of an Autism Spectrum Disorder?

• You can contact the Intellectual Disability-Pervasive Developmental Disorder Team (ID-PDD) or (DI-TED) of your CSSS-CLSC and request a social worker. The social worker will evaluate your child and family's needs and help you get what you need.

How can my social worker help me?

The social worker can:

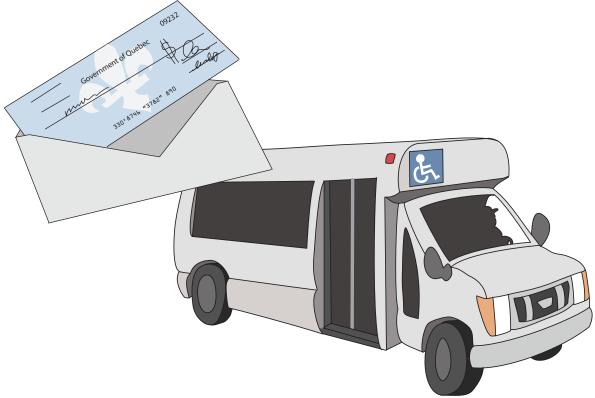
- Recommend different community programs for you and/or your child.
- Inform you about your child's eligibility for services in the readaptation centre in your district.
- Help you complete forms necessary for the readaptation services if they were not completed by the specialized clinic where you got your child's diagnosis.
- Give you information regarding your waitlist status for readaptation services.
- Help you obtain special services and benefits (for example, to receive financial assistance). See the list below regarding special services offered by CSSS-CLSCs.
- Offer emotional support.
- See list below of special services offered by the CSSS-CLSCs.

There may be a waiting time before you see a social worker. If you need immediate help, you may want to contact the treatment team who evaluated your child. You can also contact your family doctor or pediatrician to help you with this process.

You may also want to consult the non-profit organizations in your district to find out about special services offered from the community (see section on non-profit organizations)

Special services offered by CSSS-CLSCs

Below are descriptions of some services that parents may wish to ask their CLSC social worker to investigate for them.



What financial help is available?

- Charitable organizations in your area may give out donations. For example, money or learning/educational materials).
- You may be eligible for Disability Tax Credits and Child Disability Benefits from the federal government.
- You may be eligible for money from the provincial government if your child meets the criteria for having a "severe and prolonged mental or physical im pairment." You may also be eligible for money for having a "handicapped child."

You can ask your CLSC social worker for help completing the forms for provincial and federal financial assistance.

For more information about government subsidies, you are encouraged to call the government agencies or look at the government websites below.

Child Disability Benefit 1-800-387-1193 www.cra-arc.gc.ca Régie des rentes du Québec www.revenu.gouv.qc.ca

What is respite care?

- Respite care is a community service whereby a trained therapist can temporarily take care of your child at their center in order to give you some time to rest.
- Certain community services can send a member of their personnel to care for your child in your home, so you can have some respite.
- Services offered may vary in how much respite time is offered, and whether this can happen during the week or over the weekend. This may be free or cost a small fee. Speak to your social worker for more information.

What support groups are available?

- The CLSC social worker can offer you the possibility of joining a group of parents to share their experience of being a parent of a child with an Autism Spectrum Disorder.
- There are several support groups in and around Montreal.
- A support group may be a good source of both emotional and informational support for parents and children.

What workshops can be helpful?

- Your CLSC may offer special workshops on different parenting issues (for example, feeding or toilet training).
- You may want to participate in a workshop to learn about different parenting techniques that can help your child.

Are there camps available for children with Autism Spectrum Disorders?

• Your CLSC social worker can help you learn more about summer camp programs suitable for your child and find programs offered in your district.

What about adapted transport and special parking permits?

- If your child has physical or behavioural difficulties that make it difficult to use public transportation or taxi services, you may wish to ask for an adapted transportation service.
- Adapted transportation (Paratransit) is a special bus service that can bring you and your child to special appointments, to school or to camp.
- You can also ask about getting a special handicapped parking permit to make transitions easier when you are in a public parking lot with your child.

Your social worker can help you complete the necessary forms for these services.

Once you have a diagnosis you can begin to learn about the many different treatment options that exist for children with Autism Spectrum Disorders. Since there is a lot of variety in children's abilities and because a diagnosis may have been made at different ages, your child's treatment team will help explain the treatment options that should work best for your child.

Together, you can discuss your child's treatment plan. However, it is important to know what treatments have the most success.

What treatments have the most success?

- They begin when children are 5 years and under.
- They last 20 hours or more per week.
- They are unique to each child.
- They focus on language and learning other skills.
- They help with the child's transition to school.
- They involve parents in treatment.

These features may be found in a variety of successful programs including behavioural interventions, speech-language therapy and occupational therapy.

If your child is older, there are still many options available. These may include:

- therapies or support through the school,
- group treatments (like social skills groups)
- medications to treat related symptoms like attention or behaviour problems,
- individual treatments provided by a mental health professional.

For any form of therapy chosen, it is very important to track your child's treatment progress. You can ask the treatment team how they will track your child's progress. You can also ask for written reports and summaries about the treatment they are providing. Many parents find it helpful to keep a binder with all the original reports inside.



In the next section, we will explain some of the different treatment options.

Behavioural Interventions

Behavioural intervention involves teaching a child skills in small steps using repetition and reinforcement. Reinforcement means rewarding positive behaviours, and not rewarding behaviours that you want your child to stop.

Because behavioural interventions, such as Applied Behavioural Analysis (ABA), have received more scientific support than any other treatment for autism, this is the only intensive treatment funded by the Quebec government.

In Quebec, children with Autism Spectrum Disorder diagnoses are entitled to:

- 20 hours of individual ABA treatment per week until 6 years of age.
- receive this treatment by trained therapists at home, at their daycare or in a rehabilitation center.
- have their parents involved and learn the special techniques used.

Unfortunately, there are often long waiting lists for services paid by the government. This may mean that your child will not have immediate access to government funded services following their diagnosis.

Speech-Language Therapy

Speech-Language pathologists help children develop a wider range of communication skills using play and everyday situations.

Speech-Language pathologists encourage:

- the use of words
- manual signs
- picture choice boards
- picture schedules
- specialized communication devices

These methods help to reduce behavioural problems due to communication difficulties. Speech-language pathologists also teach techniques to parents that can be used at home.

Occupational Therapy

Occupational therapists help children learn fine motor (e.g. eating with a spoon) and gross motor skills (e.g. running and jumping) These skills will be necessary for them to carry out activities throughout the day, such as feeding, dressing, playing, and going to school.

Since many children with Autism Spectrum Disorders have a different reaction to sensations around them (for example, being very sensitive to noise), occupational therapists may help children using a sensory integration program. This is a method that helps the child change the way they react to all the information they receive from their different senses. Occupational therapists also teach techniques to parents so you can practise with your child at home.

Social Skills Training

There are a variety of programs that aim to help children with Autism Spectrum Disorders improve their social skills.

Children learn how to:

- make better eye contact
- recognize how others are feeling
- ask questions.

Leaders may use a variety of techniques to teach new skills such as role play and social stories

These programs may be held in a structured environment, like a clinic, at school, at a non-profit organization, at a rehabilitation center, at the hospital or at home.

Medication

There are no medications to cure Autism Spectrum Disorders. However, doctors may prescribe medications to help with certain symptoms or related conditions, such as:

- attention problems or
- severe behaviour problems.

Parents are encouraged to ask their pediatrician for information about side effects of the medication. Children need to be monitored by their doctor as they start a new medication.

You should be aware that there are many unproven "biomedical" and alternative treatments being advertised. These may be expensive and not effective. At worst, these can be dangerous to your child's health and well-being. You should check in with your family doctor or pediatrician before starting any therapies that seem to be outside of the mainstream or have not been directly recommended by your doctor.

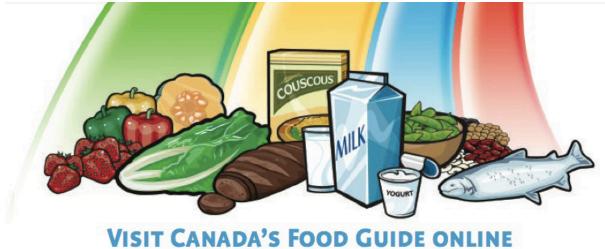
Special Diets

Many parents ask about special diets for Autism Spectrum Disorders. Although some parents have reported that these are helpful, there is little to no scientific support for special diets.

Children with Autism Spectrum Disorders are often picky eaters or may not easily learn toileting skills. This may be related to having gastrointestinal symptoms such as constipation and diarrhea. Proper nutrition in children is essential to healthy development. A dietician or feeding specialist should be consulted to make sure your child is:

- being given adequate nutrition and
- that they have balanced meals.

If your child is having constipation or diarrhea, talk to your family doctor and pediatrician. Be aware of alternative treatments or unlicensed "professionals" who suggest "therapies" that may put your child's health at risk, or that may be costly and get in the way of giving your child more proven treatments.



www.healthcanada.gc.ca/foodguide

A discussion with the **your treatment team** can help guide you in making a choice that is best for you and your family.

You may have a better idea of what treatment program you would like for your child. However, you may also want to know what else you can do to help your child. You may have thought about sending your child to daycare.

Daycares

Daycares provide children 4 years and under a place to go to learn and play with other children.

The Quebec government's daycare program is unique in Canada. The Quebec government:

- subsidizes certain types of daycares, such as "Centre de la petite enfance" (CPE) and certain family daycares.
- pays most of the daycare cost so your child can attend daycare and you only have to pay 7\$/day.
- assures certain standards of quality at these daycares.

What is a CPE?

If you would like to enrol your child in a daycare setting subsidized by the Quebec government, you may consider searching for a "Centre de la petite enfance" (CPE). CPE are:

- government regulated daycares that have subsidized childcare programs that run out of centres.
- all CPE programs are non-profit organizations.



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Other daycare options also exist. For instance, "Garderies" are:

- government regulated daycare centres that are for-profit organizations.
- They are not subsidized, and more expensive.

Also, there are "Drop-in centers" or "Halte-Garderie" which are:

- more casual programs
- some are government regulated and subsidized and others that are not.

Can my child diagnosed with ASD attend a daycare with children that do not have special needs?

Parents should note that as part of an inclusion policy for children with special needs, the government gives extra funding to the daycare to help a child with a diagnosed disability enter daycare.

A child with special needs can receive:

- special services from an integration aide. An integration aide is an educator's assistant who can help your child throughout the entire day or part of the day at the daycare.
- The government also offers daycares a material grant for specialized toys, teaching materials or equipment that can help your child at the daycare.

What questions should I ask when searching for a daycare?

When searching for a daycare it is important that you ask questions such as:

- Is the daycare subsidized by the government?
- Does the daycare make applications to the government for special services for children with disabilities?

Can my CLSC social worker help me find a daycare?

- Your CLSC social worker may help you find a daycare in your district, or you may read the website information below. It is important to note that many daycares have limited spots available. Therefore, it is important to register your child early and place your child on a waiting list at several daycares.
- Your social worker at the CLSC can help you find the forms you need to apply for extra help for your child at daycare. You will need to ask your daycare educator or director to complete these forms in order to obtain the extra funds to help your child. Websites below can help you get more information on day care options, availability and special funds.

Quebec Family and Childcare Services

Ministère de la Famille, des Ainés et de la Condition féminine 600 rue Fullum, 6th floor, Montreal, Quebec) H2K 4S7 www.mfa.gouv.qc.ca

Daycare availabilities in Montreal: www.magarderie.com

Schools

You may have school-related concerns for your child. This next section may answer some of your questions.

It is important to know...

- Your child can attend public school at 5 years of age.
- Some children diagnosed with special needs may get permission to begin pre-kindergarten at 4 years of age.
- Your child must enter school by the time he or she is 6 years old.

The French and English school boards in Montreal have different approaches to educating children with Autism Spectrum Disorders and other special needs. If you can choose between French and English school, you should do some research to find out which system is best suited to your child.

English schools

The English school system in Quebec is offered only to:

- children who have an eligibility certificate or
- children who meet the criteria for an eligibility certificate given his/her disability

There is a law in Quebec that allows only children of parents who themselves went to English school, access to English school (they have an eligibility certificate). However, exceptions may be granted for children with certain disabilities. If you wish to send your child to an English language school, but you did not go to English school, you can contact the English School Board in your district for more information. The numbers are listed below.

The English public school system is an integrated program. Therefore, children with Autism Spectrum Disorders are in classrooms with other children without special needs.

The English public schools have 2 programs:

- a bilingual program which offers 50% English and 50% French throughout the day.
- a French immersion program which offers all French for the first 3 years of primary school and then incorporates English at varying percentages in the higher grades.

More information regarding the different programs can be found on the Montreal School Boards' websites listed on the next page.

English School Boards

English Montreal School Board

6000 Fielding Ave., Montreal, (Quebec) H3X 1T4 514-483-7200 www.emsb.qc.ca

Lester B. Pearson School Board

1925 Brookdale Ave., Dorval, (Quebec) H9P 2Y7 514-422-3000 www.lbpsb.qc.ca

French Schools

You may wish to choose to send your child to a school within the French language school boards. French sector schools in Quebec do not always follow the full integration model.

The French public schools offer:

- specialized classes within regular schools and
- separate schools for children with intellectual disabilities (evaluated by a psychologist).

You may contact the school board in your district for information on policies regarding admission into special classes or special schools in your district. A list of Montreal School Boards is provided below.

French School Boards

Commission Scolaire de Montréal - Special Schools

3737 Sherbrooke est, Montreal, (Quebec) H1X 3B3 514-596-5578 www.csdm.qc.ca

Commission Scolaire de la Pointe-de-l'Île

550 53e Ave., Montreal, (Quebec) H1A 2T7 514-642-9520 www.cspi.qc.ca

Commission Scolaire Marguerite-Bourgeoys - Special Schools

1100 boul. De la Côte-Vertu Saint-Laurent, (Quebec) H4L 4V1 514-855-4500 ext. 4510 www.csmb.qc.ca

School Registration

If you wish to send your child to a government subsidized public school, your next step is to register your school aged child in the public school in your sector.

What do I need to register my child for school?

- You will need to call the school boards listed above for a list of public schools in your neighbourhood.
- Call to find out exact registration dates. Usually school enrolment starts January or February of the calendar year in which the child is beginning school.You can also ask about the services for children with special needs.

What happens after I register my child?

- The school will evaluate your child's needs based on the professional reports you submit to the school.
- If the school decides that they can meet the child's needs, then your child will be accepted to attend that community school.
- The school may agree to find and provide an integration aide for your child if a professional has recommended one.
- The school may make an appointment with you if an Individualized Education Plan (IEP) was requested for your child. An Individualized Education Plan (IEP) describes your child's needs and how best to meet them within the school environment.

Following these steps may help you get the best services available for your child. This way, your child's learning will be monitored and your child can get extra support at school if he/she needs it.

What happens if the school *cannot* meet your child's needs at the school you chose?

If the school in your child's neighbourhood decide that they cannot meet your child's needs, the school will:

- send your child's application to the school board.
- the school board will evaluate your child's file and recommend another public school better suited to your child.

There are a few specialized schools that may be considered. Visiting and speaking to other parents of students already attending these schools may help you make your decision about where to send your child.



Specialized non-profit organizations

After your child has received an Autism Spectrum Disorder diagnosis and your child's name has been placed on a waiting list for the readaptation centre of your district, you may consult with your pediatrician about the services that are best suited for your child. You may have discussed daycare, kindergarten registration or specialized therapy. However, you may still have many questions and wish to obtain more information about Autism Spectrum Disorders and treatments in the Montreal area. You may reach a person at the following non-profit organizations for free information about:

- diagnosis,
- treatment options
- schools
- parent support groups
- conferences on this topic
- where to get materials for treatment

Remember that you should not begin any treatment without first discussing it with your pediatrician or with the treatment team where your child received his/her diagnosis.

Autisme et troubles envahissants du développement Montréal (ATEDM)

4450 rue Saint-Hubert, Local 320, Montreal, (Quebec) H2J 2W9 514-524-6114 www.autisme-montreal.com

Quebec Federation on Autism/La Fédération québécoise de l'autisme

7675 boul. Saint Laurent suite 200, Montreal, (Quebec) H2R 1W9 514-270-7386 www.autisme.gc.ca

Quebec Society for Disabled Children

2300 René-Lévesque Boul. W., Montreal, (Quebec) H3H 2R5 514-937-6171 www.enfantshandicapes.com

West Island Association for the Intellectually Handicapped (WIAH)

111 Donegani Ave., Pointe Claire, (Quebec) H9R 2W3 514-694-7090 www.wiaih.gc.ca

Specialized health professionals

Your child's treatment team will include many specialized health professionals. Your child may also be referred to other specialized health professionals in either the public or private sectors. Either way, you may have questions about the specialized health professional's training and what they will do with your child.

Caution: Some "specialized health professionals" may not be licensed and may not have enough training to know how to help your child.

This section will explain:

- What is a licensed professional?
- What can a professional order help you with?
- What are the differences between public and private services?
- What are some helpful questions to ask the specialized health professional before you commit to working with them?

First, it is important to note that licensed professionals have gone through many years of study/training and had to apply to professional orders, or a governing body, that follow strict rules for their members in order to ensure quality services and protect the general population.

When choosing to work with a specialized health professional, you may wish to make sure that he or she is a certified member of a professional order (for example, the Order of Psychologists). A professional order can be contacted:

- if you wish to work with that type of professional.
- to ask for names of professionals in your area so your child can benefit from their expertise.

Some specialized health professionals who work in the public sector are subsidized by the government, so you just have to present your medicare card and you do not pay for services.

Other specialized health professionals are part of the private sector and provide services that are paid entirely by you or by your private insurance. It is important to ask the specialized health professional if the services that they provide are covered under medicare. If not, and you have private insurance, you can call your insurance company and ask if the service will be partly or fully covered by your plan. Although private services may cost a lot, waiting lists are much shorter, as compared to public services.

A few helpful questions to ask the specialized health professional:

- Are you a member of a professional order? Which one?
- How much experience do you have evaluating and doing therapy with children with Autism Spectrum Disorders?
- How many children have you worked with?
- How many years have you been in practice?
- What kind of therapy approach do you use?
- Is there scientific research that supports the program that you use?
- What is your fee?
- What is the waiting time for your services?
- Do you conduct group sessions?
- Do you come to the home?
- How will you monitor my child's progress?
- Will I get written progress reports?

The next section will explain the role of different specialized health professionals with children diagnosed with Autism Spectrum Disorders. A description of each profession is given with contact information.

Psychiatrists

A child psychiatrist has a degree in medicine and is specialized in mental health.

A child psychiatrist can:

- evaluate a child's mental health.
- evaluate your child and provide a diagnosis valid for obtaining public services in Quebec, if they are specialized in Autism Spectrum Disorders.
- prescribe medication if needed.

For more information on psychiatrist, or if you would like to contact one, you can call the number below.

The Quebec Association of Psychiatrists

514-350-5128 www.ampq.org

Pediatricians

A pediatrician has a degree in medicine and is specialized in children. Some pediatricians have more expertise with Autism Spectrums Disorders than others.

A pediatrician can:

• follow your child's health and development throughout his/her childhood. Regular check-ups are recommended for all children.

Families with multiple children may wish to ask their pediatrician to discuss concerns about sisters and brothers. If there is worry that a sibling may have an Autism Spectrum Disorder, your pediatrician can make a referral to Autism Spectrum Disorder specialists. You may wish to inform the receptionist at the pediatrician's office that your child has an Autism Spectrum Disorder and you may request the first appointment of the day in order to avoid long waiting times.

For more information on pediatricians, or if you would like to contact one, the number is listed below.

The Quebec Association of Pediatricians

514-350-5127 www.pediatres.ca

Neurologists

A neurologist has a degree in medicine and specializes in neurology, the study of the brain. A neurologist with experience in Autism Spectrum Disorders can:

- examine a child's brain functions and structures
- check for other conditions sometimes related to autism, such as epilepsy or seizure disorders.

For more information on neurologists, or if you would like to contact one, the number is listed below.

The Quebec Association of Neurologists

514-350-5122 www.anq.qc.ca

Ophthalmologists

An ophthalmologist has a degree in medicine and specializes in eyes and sight.

An ophthalmologist can:

- evaluate a child's sight
- decide if a child needs glasses or other corrections.

You may ask to see an ophthalmologist who has more experience working with children with special needs. A vision examination is recommended before entering school.

For more information on ophthalmologists, or if you would like to contact one, the number is listed below.

The Quebec Association of Ophthalmologists

514-350-5124 www.amoq.org

Dentists

A dentist has a degree in dentistry. A pediatric dentist is specialized in dental care for children and teenagers.

Regular dental check-ups are recommended for all children to prevent cavities. It may be especially important for children whose sensory issues (for example, sensitive to noise, light or pain) make regular dental hygiene more difficult. If you are concerned about how your child will react to seeing the dentist, you may ask about dentists who work with children with Autism Spectrum Disorders or other special needs. For more information on dentists, or if you would like to contact one, the number is listed below.

The Federation of Dental Specialists of Quebec

514-737-4901 www.fdsq.qc.ca

For more information on medical specialists, you may go to the following website.

Quebec Federation of Medical Specialists

www.fmsq.org

Audiologists

An audiologist has a minimum of a Master's degree and can assess a child's hearing capacities and help determine whether language or social problems may be the result of a hearing impairment.

- A hearing test is recommended for all children suspected of having an Autism Spectrum disorder. Ideally, your child would have received a hearing test before they were diagnosed with an Autism Spectrum Disorder.
- Hearing tests should be done before entry into school.
- For more information on audiologists, or if you would like to contact one, the number is listed below.

The Quebec Order of Speech and Language Pathologists and Audiologists 514-282-9123

www.ooaq.gc.ca

Psychologists

A psychologist has a minimum of a Master's or PhD degree and can evaluate a child's development and intelligence. A psychologist specialized in Autism Spectrum Disorders can evaluate a child for the presence of an Autism Spectrum Disorder.

With the new Bill 21, the psychologist's evaluation can make a child eligible for public services, such as government funded treatments or an integration aide at school.

A psychologist may:

- evaluate your child's intelligence (IQ) and academic skills. Some specialized psychologists, called neuropsychologists, can provide in depth evaluation of skills like learning and memory.
- help parents develop a therapy program that can meet the child's needs at home, at school, and at the daycare.
- help parents manage individual difficulties, couple and family problems.
- have training in behavioural treatment that can be used with children with Autism Spectrum Disorders.
- supervise an ABA treatment program
- offer social skills treatment programs, either individually or in groups.
- help you complete the handicapped allowance form.

For more information on psychologists, or if you would like to contact one, the number is listed below.

The Quebec Order of Psychologists

514-738-1881 www.ordrepsy.qc.ca

Speech and Language Pathologists

A speech and language pathologist has a minimum of a Master's degree and can:

- evaluate a child's speech and language abilities,
- provide therapy that will help a child improve in these areas.
- offer group therapy to provide additional help with social skills.

For more information on speech and language pathologists, or if you would like to contact one, the number is listed below.

The Quebec Order of Speech and Language Pathologists and Audiologists 514-282-9123

www.ooaq.gc.ca

Occupational Therapists

An occupational therapist has a minimum of a Bachelor or Master's degree. They can:

- evaluate a child's gross motor and fine motor abilities (how they move),
- evaluate their perceptual abilities (how they see and deal with different objects in space),
- evaluate their sensory-motor integration (how they adapt to the different sensations in their body).
- provide treatments that can help your child's motor skills and help them learn important basic skills to take care of themselves such as feeding, dressing and learning how to play alone and with others.
- Some occupational therapists can also provide treament for children with sensory needs such as sensitivity to noise or other sensations.

For more information on occupational therapists, or if you would like to contact one, the number is listed below.

The Quebec Order of Occupational Therapists

514-844-5778 www.oeq.org

Dieticians

A dietician has a minimum of a Bachelor or a Master's degree. A dietician can:

- evaluate your child's nutritional needs,
- give you information on what your child needs to eat to stay healthy.

For more information on dieticians, or if you would like to contact one, the number is listed below.

The Quebec Order of Dieticians

514-393-3733 www.opdq.org

Social Workers

A social worker has a minimum of a Bachelor or a Master's degree. A social worker can:

- help determine your child and family's needs.
- help you access services for your child.
- offer counselling for children and their families.

For more information on social workers, or if you would like to contact one, the number is listed below.

The Quebec Order of Social Workers 514-731-3925 www.optsq.org

Psychoeducators

A psychoeducator often has a Bachelor degree, although some may have higher degrees. A psychoeducator can:

- help you set up a home-based treatment program,
- can help your child better cope at daycare or at school.

For more information on psychoeducators, or if you would like to contact one, the number is listed below.

The Quebec Order of Psychoeducators

514-333-6601 www.ordrepsed.qc.ca

Consultants

A consultant (e.g., behaviour consultant) may have a college or university degree, but this is not a title protected by a professional order so you need to be aware that some consultants may have relatively little education, training or experience. There is no required training to use this title. A consultant knowledgeable in Autism Spectrum Disorders can:

- help parents set up a home-based treatment program or supervise therapists working with your child.
- help children cope at daycare or school.
- some consultants can coordinate social skills groups for children and teenagers with Autism Spectrum Disorders.

• others organize parent support groups.

The names of consultants may be obtained by non-profit organizations specialized in Autism Spectrum Disorders.

Integration aide/ "Shadow"

An integration aide or shadow may have a college or university degree. An integration aide or shadow can:

- help your child as he attends daycare or school.
- accompany your child throughout the day and assist the teacher in helping your child learn.

If your child attends a public school, the school may hire an integration aide for your child. Most schools choose the integration aide and provide part-time or full-time help for your child based on the professional's recommendations. It is important to note that integration aides/shadows are not part of a professional order. Therefore, there is no required training. The names of integration aides or shadows may be obtained by non-profit organizations specialized in Autism Spectrum Disorders.

Therapist

A therapist may have a college or university degree. A therapist may:

- help your child practice goals established in therapy from the professional. Therapists are usually supervised from a senior therapist or professional.
- Therapists familiar with Autism Spectrum Disorders may work within a treatment program such as ABA.

Before hiring a therapist, you should be sure that the therapist has experience with children with Autism Spectrum Disorders. It is important to note that therapists are not part of a professional order. Therefore, there is no required training to use this title. The names of therapists may be obtained by non-profit organizations specialized in Autism Spectrum Disorders. ABA therapists who are "Board Certified Behaviour Analysts" have gone through a higher level of training and specialization in treating Autism Spectrum Disorders.

Quebec Ombudsman

If you feel that your rights may have been violated within the public system (for example the CLSC, CRDI, hospital), you may want to file an official complaint within the establishment concerned and/or with the Quebec ombudsman ("Le Protecteur du citoyen"). The role of the ombudsman is to act as a third party regulatory body, to make sure that peoples' rights are respected within all of the government regulated services. If you would like to learn more about your rights, or to file a complaint, you may call or visit the following website.

The Montreal Office of the Quebec Ombudsman

514-873-2032 www.protecteurducitoyen.qc.ca

Books

You may borrow books at no cost from local non-profit organizations, readaptation centres or hospitals. You may visit these organizations and borrow books and videos. A librarian is available to help you find books that can be helpful.

Materials

There are many non-profit organizations in the Montreal area that provide free or low-cost materials for use in home-based treatment programs.

Websites

The internet may serve as a great source of information. However, it is important to note that many websites are unregulated and provide false, misleading or unsupported information. Even though many people mean well, they may post information on websites that may lead you in the wrong direction. The websites listed below have been designed by various national and local organizations that provide information and support to parents of children with Autism Spectrum Disorders.

www.autism.ca

www.nimh.nih.gov/publicat/autism.cfm

www.autismsocietycanada.ca

www.autism.net

www.autismspeaks.org/

French and bilingual websites

www.autismonline.com/languages/french.htm

Free downloads and printable materials for home-based programs

www.abaresources.com/free.htm

www.polyxo.com

Scientific articles

If you wish to learn more about Autism Spectrum Disorders and treatments, you may wish to read the scientific literature. Vast numbers of scientific publications may be obtained on the following websites. You may wish to type in key words (for example for articles related to ABA treatment, parents may type in 'autism and Applied Behaviour Analysis') and the published findings of many related studies will appear.

www.scholar.google.com

www.pubmed.com

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