

ADHD

ATTENTION-DEFICIT/HYPERACTIVITY DISORDER

Working Together to Provide Better

SUPPORT

for Young People



Plan of Action

Québec



together provide young Support



Working Together to Provide Better **SUPPORT** for Young People

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Plan of Action



MESSAGE FROM THE MINISTER OF STATE FOR EDUCATION AND YOUTH AND THE MINISTER OF STATE FOR HEALTH AND SOCIAL SERVICES AND MINISTER OF CHILD AND FAMILY WELFARE

In the past few years, much has been made of young people with “attention-deficit/hyperactivity disorder”¹ and their problems, as well as those of their parents and of the personnel who work with them on a daily basis. A great deal of information, often contradictory, has been disseminated by the media on this topic, often causing confusion among parents and professionals, who have clearly expressed their need for assistance in understanding the situation and dealing with it.

We are therefore particularly pleased to announce this plan of action, the purpose of which, as its title indicates, is to encourage all those involved *to work together to provide better support for young people*.

This disorder affects various aspects of students’ lives and calls for the intervention of a number of professionals. It is thus essential that these professionals work together to achieve a comprehensive overview of the situation and of the methods of dealing with ADHD, and the measures proposed in this plan of action were devised in just such a spirit of partnership. We would like to emphasize the exceptional contribution made by the members of the advisory committee that was set up to counsel the Ministère de l’Éducation (MEQ) and the Ministère de la Santé et des Services sociaux (MSSS) on this topic. They have clearly shown their concern for

1. In the literature, various terms and acronyms are used to designate this disorder. In this document, we have chosen to use “attention-deficit/hyperactivity disorder” and its abbreviation “ADHD”.

young people and their commitment to achieving consensus on the measures designed to assist them and their parents. Our sincere thanks go to them as well as to the individuals and organizations that were consulted with a view to the publication of this plan of action.

We would also like to praise the efforts of the various professionals and parents who, over the past years, have developed an expertise which guided the choice of the measures contained in this plan of action. It is with the strength of their conviction that these people devoted their experience and creativity to serving the young people affected by this disorder in the hope of offering them a brighter future. We continue to rely on their commitment in seeing to the implementation of the proposed measures.

This plan of action addresses the major concerns currently dominating the health and education sectors, namely, joint action and prevention. Indeed, it is important that we intervene together as early as possible in order to prevent problems and mitigate their impacts. Other measures currently being developed should contribute to creating a context favourable to the plan's successful implementation. For example, those announced by the MEQ as part of the plan of action for special education include reducing the number of students per class in kindergarten and in

Cycle One of elementary school, and increasing professional resources in the schools. The MSSS has also adopted a number of assistance measures, including a support program for vulnerable young families, the objective of which is to help children and their parents. Other measures of the MSSS aim at increasing the availability of medical services offered by general practitioners for more complex tasks, as set out in the agreement signed recently by the Fédération des médecins omnipraticiens du Québec. The establishment of a joint frame of reference for the organization of health and social services for school-age children is yet another important step forward.

The plan of action calls for improved knowledge of ADHD and the methods of dealing with it, a clearer definition of everyone's roles and responsibilities and an invitation to work as a team at all levels. In our opinion, this plan constitutes a concrete step in the right direction. However, as always, its success will depend on everyone's cooperation.

We are convinced that this initiative will contribute to the development of greater solidarity between parents and professionals in both the health and education sectors, for the greater good of all children with difficulties. Ultimately, we all share the same goal: to help young people to grow and live life to the fullest under the best possible conditions.

INTRODUCTION

Contextual elements

Young persons with attention-deficit/hyperactivity disorder (ADHD) display persistent patterns of inattention and/or hyperactivity that are more frequent and severe than those generally observed among other young people at similar levels of development. It should be noted that, proportionally speaking, this disorder affects more boys than girls. The manifestations of this disorder can in turn cause other problems that impact on the child's ability to function at school, in social contexts, and in the family environment. These children find it difficult to remain attentive in class and to follow instructions; conflict often defines their relationships with their peers; and their parents must devote a great deal of effort to maintaining a harmonious family atmosphere. In short, these young people require services and supervision aimed at fostering full development of their potential and their well-being.

According to recent research, the causes of this disorder would appear to be biological or genetic. However, social factors can aggravate the symptoms or contribute to their persistence. Moreover, other problems, such as behavioural or anxiety-related disorders, are often present. Screening and diagnosis thus often require a careful assessment by professionals from various fields in order to pinpoint the disorder and related problems, and to determine the needs of the child and his or her parents.

Treatment of these young people is a complex issue that sparks heated debate from both a scientific and human perspective. A therapeutic approach that

is often prescribed, but that remains highly controversial, is the use of central nervous system (CNS) stimulants. Over the past few years, the number of prescriptions for CNS stimulants has risen considerably. However, it is difficult to determine whether this is due to widespread abuse of the medication or whether the number of cases treated has increased thanks to heightened awareness of the problem, early detection of ADHD, or prolongation of stimulant therapy into adulthood. This medication has a short-term effect on symptoms of impulsiveness and inattention, but does not cure the disorder permanently. For this reason, numerous clinicians and researchers have acknowledged the importance of devising measures to equip young people to deal with their problems themselves. Thus, a multimodal approach—one that takes into account all the needs of the child and his or her family, and that may include modifications to the classroom environment, family information sessions to demystify the disorder, cognitive and behavioural treatment and training in social skills—should accompany the medication where prescribed.

A plan deriving from joint action with the principal partners

Given the complexity of the situation and public controversy over the use of CNS stimulants, the Ministère de l'Éducation and the Ministère de la Santé et des Services sociaux decided to set up an advisory committee in order to take stock of the current situation, recommend effective action to assist these young people and their parents, and support the

measures taken. This committee was composed of representatives of the principal partners involved in the intervention process for young people with ADHD. The opinions and comments of practitioners who dispense treatment to these young people, as well as those of the other partners, were also noted as part of an information-gathering process and during committee meetings.

The main difficulties highlighted by parents and professionals can be divided into four broad categories: the general lack of knowledge of the subject and the need to keep this knowledge up to date; the need for information on ADHD and training on how to deal with it; the lack of access to intervention resources and the need for better coordination among them; and the challenge of providing support for the parents of these young people. The actions proposed stem directly from the difficulties mentioned.

Position of the government departments

Certain basic principles, which influenced the choice of the measures set out herein, reflect the spirit in which the young people concerned should be dealt with. Thus, the two government departments (MEQ and MSSS), along with the advisory committee, consider that children with ADHD or who display the symptoms thereof are first and foremost children with many qualities and resources that adults must take into account and put to good use. The primary concern of all professionals must be to fulfill the needs of these young people. Various measures must be

envisaged as soon as the first symptoms of ADHD are identified and even before a formal diagnosis has been made. If the symptoms are severe and it is suspected that the child may have ADHD, a multidisciplinary assessment must be conducted so as to rule out any other possible diagnosis and take into account all factors that might contribute to the emergence of the symptoms observed. Use of medication should be envisaged solely in the context of this multidisciplinary assessment, once it has been determined that, without this aid, the young person's academic, emotional and social development could be jeopardized. Furthermore, consistent with a multimodal approach, the intervention methods must include various pedagogical, psychosocial, behavioural and family-oriented measures, rather than being limited solely to medical treatment. Finally, joint action by professionals and parents is vital to ensuring that the intervention is coherent, complementary and continuous.

The following plan of action proposes measures to support the approach taken with young people with ADHD or who display symptoms of this disorder. These measures will be implemented gradually over the next three years. This plan of action is the government's way of acknowledging both the efforts made by parents and professionals to assist these young people and the importance of supporting the actions taken, in the best interests of the children and their families.

PLAN OF ACTION

MONITOR THE DEVELOPMENT OF KNOWLEDGE AND ENSURE ITS DISSEMINATION

New information on ADHD and appropriate ways of dealing with it is constantly coming to light. Scientists are studying several aspects of this disorder: some focus on the nature, causes, and everyday symptoms, while others concentrate on determining the most effective measures for helping young people and their parents. The information disseminated by the media, which is often contradictory, can trigger prejudice against persons with ADHD and their families.

The abundance of available literature complicates the task of those who work with this disorder. Their challenge is to constantly adapt their methods to reflect the most recent scientific findings, which requires a great deal of time and effort and can make their work considerably more complex. In several areas, highly relevant expertise has been developed. Professionals could save valuable time if they had access to the latest information on the subject.

The sizable upswing in the consumption of CNS stimulants (especially methylphenidate, better known as Ritalin) observed in recent years raises numerous questions. Several people insist on the importance of obtaining reliable data on the consumption of this medication in order to analyze, understand and explain the factors responsible for this increase. In Québec, there is no directory that provides a profile of those who take CNS stimulants or of the context in which they are prescribed. Such

information would allow the evolution of the situation to be monitored and the necessary measures to be taken.

In this context, the Ministère de l'Éducation and the Ministère de la Santé et des Services sociaux agree to:

- Provide the public with information on attention-deficit/hyperactivity disorder and its impacts on the young people affected and their parents
- Ensure that personnel working in the education and health and social services sectors are kept abreast of new developments concerning this disorder and the appropriate measures for dealing with it
- Closely monitor variations in the consumption levels of the medication prescribed to treat this disorder, and take action where necessary

Means

- The Ministère de l'Éducation (MEQ) and the Ministère de la Santé et des Services sociaux (MSSS) will publish an information brochure intended for parents, professionals, and the public at large. The purpose of this brochure will be to make citizens aware of the disorder by providing information on ADHD and its impacts on the child and his or her entourage, and on the appropriate measures and resources for dealing with it.
- The MEQ and the MSSS will publish this plan of action and distribute it to parents and personnel working in the education and health and social services sectors in order to inform them of the

measures to support the action taken with young people with ADHD or who display the symptoms thereof.

- The MEQ and the MSSS will ensure that the latest findings on this disorder and on the appropriate measures for dealing with it are published on a Web site and made accessible to all those interested.

The site will be maintained and updated based on documentary research and references provided by recognized partners. In addition, links will be established with other existing sites—in both French and English—in the fields of health care and education, so as to reach all professionals concerned.

This site will also supply information on projects or initiatives launched by the school and health and social services networks for those who wish to draw inspiration therefrom in order to enhance their intervention methods.

Moreover, it will provide those interested in learning more about ADHD with a forum for interaction and discussion on the topic.

- The Ministère de la Santé et des Services sociaux will develop a quebec-wide monitoring system aimed at obtaining accurate data on the consumption of CNS stimulants prescribed for ADHD, especially methylphenidate. A committee composed of representatives of the MSSS, the Collège des médecins, the Ordre des pharmaciens du Québec and the Régie de l'assurance-maladie du Québec (RAMQ) will be mandated to implement and develop this system. Other partners may also contribute, as needed.

- The MEQ and the MSSS, in cooperation with organizations involved in research (universities, research funds, etc.), will propose research topics aimed at improving knowledge on ADHD and developing more effective measures for dealing with it.
- The Ministère de la Santé et des Services sociaux will ask the RAMQ to use the means at its disposal to analyze the information in its possession on the use of CNS stimulants and, where applicable, to submit recommendations.

SUPPORT PERSONNEL WORKING IN THE AREAS OF ASSESSMENT, DIAGNOSIS, INTERVENTION AND TREATMENT

Assessment of and intervention with children who display symptoms of ADHD constitute a particular challenge for personnel working in the education and health and social services sectors, because there is no diagnostic tool designed specifically for ADHD.

Diagnosis of the disorder must be based on the observation of behaviour patterns that occur mainly at school, but also in the home and other environments; unfortunately, the mechanisms of communication between the school and health-care networks are often deficient. Often, the information physicians need to make a diagnosis is not available, and they must rely on a brief observation of the child and information reported by the parents.

School personnel also have a difficult task. Indeed, the teaching staff must adapt their instructional methods to take into account the specific

characteristics of each student in a group context, and the needs expressed are varied: they may be medical, psychological or social in nature and have sizable pedagogical impacts. This is especially true for children with ADHD. It can be difficult for a teacher to recognize the exact signs of the disorder at an early stage, adopt the appropriate teaching and classroom management strategies and, where necessary, refer the affected student to the relevant aid services.

The duty of school principals is to support the teaching staff, even in difficult situations. Unfamiliarity with the disorder and its symptoms can make their task arduous and even, at times, impossible. Professionals in the education system are also called upon to work with students with ADHD, whether for assessment or to determine intervention strategies. They must therefore keep abreast of the latest developments in order to be capable of helping the students and providing the teaching staff with support.

Analysis of the situation clearly points to the need for basic information that is felt by the personnel of both the education and health-care networks, information that fosters joint, coherent treatment.

In this context, the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation agree to:

- Promote the harmonization of the medical and psychological treatment of young people with ADHD
- Promote ADHD-related training for personnel working in the education and health and social services sectors

Means

- The Ministère de la Santé et des Services sociaux will grant financial assistance to the Collège des médecins and the Ordre des psychologues du Québec for work aimed at formulating guidelines for treatment by their professionals. Representatives of these two professional associations will devise criteria for the assessment, diagnosis, treatment and monitoring of young people with ADHD. These guidelines will be distributed to all members concerned.
- The MEQ and the MSSS will support the development and implementation of a training program on ADHD. This program will provide a common knowledge base that will foster joint action and the coordination of professional practices. It will deal with various aspects of the question, such as the normal development of attention, symptoms of the disorder, problems that can crop up during the learning process, "ADHD-friendly" pedagogical approaches, classroom management, assessment conditions (including observation tools), the most pertinent measures to be taken, and the importance of the individualized education plan and of cooperation with parents and other professionals.

The training program will be offered jointly to designated professionals working in the health and education sectors in all regions, in order to promote joint action. These persons will then train others in their respective regions, in particular, school personnel and those working in the field of health and social services.

Parents could be invited to take part in these training sessions as well. Once training is completed, support services will be offered to ensure that the program content has been clearly understood and assimilated. For the school system, regional support resources will be called upon. For the health and social services sector, staff in charge of training under the responsibility of the regional health and social services boards will be recruited to train personnel. A representative of the English-language sector will also be appointed.

- The Ministère de l'Éducation will contact Québec universities and colleges to encourage them to offer ADHD training to the fledgling teachers, technicians and professionals who will have to deal with the problem in future.

FACILITATE ACCESS TO RESOURCES AND PROMOTE JOINT ACTION

The lack of resources available to treat young people with ADHD is often decried by the media and professionals alike. Despite the efforts made in recent years in both the health and education sectors, the accessibility of services remains limited. Persons who are qualified to recognize ADHD in young people and deal with it effectively are few and far between. Many of them are too busy to fulfill all requests because of the scope of their task, and long waiting periods can result, which can jeopardize the implementation of assistance measures adapted to the needs of the

child and his or her parents. However, the solution does not lie solely in increasing the number of professionals, but also in training personnel so as to ensure that there are more people equipped to deal with it. Moreover, the planning and distribution of specialized resources and, more specifically, ways of organizing services so that the use of existing resources is optimized, can also contribute to broader accessibility. It is important to continue the efforts made in recent years, in both the health and education sectors, to facilitate access to services.

ADHD is a complex problem requiring a differential diagnosis resulting from a multidisciplinary assessment. In order to ensure that the student develops to his or her full potential, the professionals concerned must achieve consensus on the specific methods to be used for each child. Educators are in the ideal position to observe the student's behaviour and the impacts of the measures taken, given that they work with him or her on a daily basis, and professionals working in the health and social services sector should therefore seek out their cooperation.

The challenge of these people is to work together and coordinate their interventions in order to offer services that are adapted to the needs of young people with ADHD or who display the symptoms. Such an approach allows professionals to pool their expertise and share available information, determine the child's overall needs, and make the decisions called for; it also requires that the roles and responsibilities of each person be clearly defined.

In this context, the Ministère de l'Éducation and the Ministère de la Santé et des Services sociaux agree to:

- Rally the professionals from both the health and education sectors in order to foster a better understanding of the problem, the intervention methods and the ways of working together
- Encourage regional authorities to adopt a collective approach aimed at facilitating access to resources and promoting joint action
- Promote the coordination of interventions at the local and regional levels

Means

- The Ministère de l'Éducation and the Ministère de la Santé et des Services sociaux will see to the organization of a province-wide symposium bringing together parents and personnel working in the sectors concerned in order to update their knowledge, make them aware of the importance of cooperation and joint action, and motivate them to take action.
- The MEQ and the MSSS will ensure that the province-wide frame of reference for the organization of health and social services offered to school-age youngsters, which is currently being developed, results in services that are more accessible and better coordinated between the two sectors of intervention.
- The MEQ and the MSSS will encourage the regional health and social services boards and the regional offices of the MEQ to undertake or continue a collective approach geared

to a comprehensive planning of services, improved access to resources for young people with ADHD in their respective regions, and better coordination of interventions. The situation of young people from disadvantaged environments will have to be studied in order to determine whether more specific assistance measures should be adopted in their regard.

- The MEQ and the MSSS will publicize regional approaches to organizing services and joint action mechanisms that promote access to resources. These initiatives may be used as a reference by professionals from other regions. The two government departments will also promote existing joint action mechanisms. Indeed, in several areas, a guide or a procedure that sets out the roles and responsibilities of each partner at the local level (the family, the school, the physician, etc.), and suggests mandating an individual to coordinate interventions and action among professionals, has already been developed. The Web site, which will serve to update knowledge, will act as a medium for publicizing tools or interesting projects.
- The Ministère de la Santé et des Services sociaux will invite the main associations or federations representing physicians to study the constraints linked to the implementation of the measures proposed with regard to treating young people with ADHD, and to suggest possible solutions.
- The Ministère de l'Éducation has already announced, in the plan of

action accompanying the new policy on special education, various measures to support the action taken with young people with ADHD or who display its symptoms. These measures include a reduction in class size in kindergarten and Cycle One of elementary school, increased professional and pedagogical support resources, consolidation of regional support resources, and the development of research into preventive intervention with at-risk students. These, as well as other measures set out in the plan of action on special education, should ensure that the young people in question receive enhanced support.

SUPPORT PARENTS

In addition to problems at school, ADHD can cause several major upheavals in the child's living environment (at school, in daycare centres, within the family, etc.). The parents must negotiate, often on a daily basis, with those in charge of these environments in order to ensure that their child is integrated, by suggesting supervision and support strategies. They must also attempt to maintain a harmonious family atmosphere. Their task is demanding and requires unflagging determination. They need to be informed, supported, encouraged and guided. It is also important that they be able to dialogue with other parents experiencing similar difficulties.

Several parents have joined forces to set up associations or groups that can provide the services they need, although certain organizational difficulties often crop up. These

associations do not exist in all regions and often have difficulty making their presence known.

On the other hand, certain parents whose children have ADHD are faced with very demanding situations, which can cause them a great deal of distress. They require periods of rest or respite as a result, so that they can analyze the situation and better help their child to face day-to-day problems. However, such respite and relief resources are not always accessible to these parents.

In this context, the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation agree to:

- Offer parents information on ADHD and the existing resources adapted to their needs
- Promote the creation of parent groups and support existing associations
- Offer parents the possibility of benefiting from respite and relief services

Means

- The MEQ and the MSSS will work together to disseminate information on ADHD, measures to deal with it and available resources. Moreover, they will notify parents once the Web site is up and running, so that they can monitor new developments on the subject.
- The Ministère de la Santé et des Services sociaux, via the regional health and social services boards and a number of other establishments, will support the setting up and continued existence of associations or groups intended to assist parents of children with ADHD.

- The Ministère de la Santé et des Services sociaux, in cooperation with the regional health and social services boards, will ensure that respite and relief resources are made available to parents of children with ADHD.

MONITOR THE IMPLEMENTATION OF THE PLAN OF ACTION

The Ministère de l'Éducation and the Ministère de la Santé et des Services sociaux intend to ensure that the measures proposed in this document are implemented effectively.

Means

- The Ministère de l'Éducation and the Ministère de la Santé et des Services sociaux will set up a follow-up and evaluation committee formed of the principal partners, to monitor the implementation of this plan of action, which will be carried out over a three-year period.



ATTENTION-DEFICIT/HYPERACTIVITY DISORDER



Ministère de l'Éducation
Ministère de la Santé et
des Services sociaux