SPECIAL OMBUDSMAN'S REPORT

on Government Services for Children with Pervasive Developmental Disorders

LOOKING TOWARDS GREATER CONTINUITY IN SERVICE DELIVERY, APPROACHES AND HUMAN RELATIONS

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Developmental Disorders

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ACRONYMS

ADHD	Attention deficit and hyperactivity disorder
CDPDJ	Commission des droits de la personne et des droits de la jeunesse
CHSLD	Long-term residential care centre
CPE	Early childhood centre
DSM-IV	Diagnostic and Manual of Mental Disorders, Version IV
IBI	Intensive behavioural intervention
MELS	Ministère de l’Éducation, du Loisir et du Sport
MFA	Ministère de la Famille et des Aînés (encore cette appellation sur Internet)
MSSS	Ministère de la Santé et des Services sociaux
OPHQ	Office des personnes handicapées du Québec
PDD	Pervasive developmental disorder
RCID-PDD	Rehabilitation centre for intellectual disabilities and pervasive developmental disorders
RCPD	Rehabilitation centre for physical disabilities
RRQ	Régie des rentes du Québec
TEACCH	Treatment and Education of Autistic and Related Communication Handicapped Children

MESSAGE FROM THE OMBUDSMAN

In 2003, the Minister of Health and Social Services tabled an orientation document[1] on the provision of services for children with pervasive developmental disorders (PDDs), their families and their entourage.

In its 2005-2006 Annual Report, the Health and Social Services Ombudsman[2] observed that children with PDDs received public services from a number of sources including rehabilitation centres for intellectual disabilities and pervasive developmental disorders (RCID-PDD), on the basis of their age rather than their level of ability. As a selection criterion, it was concluded that age is not necessarily appropriate to the children's real needs. This observation, along with the habilitation problems identified in the Québec Ombudsman's own investigations, led the Ombudsman to look carefully at the true impacts of ministerial orientations.

The Québec Ombudsman wanted to understand why complaints were still being received despite the service organization improvements announced in the orientations, and despite the significant sums of money allocated for the introduction of specialist services. It was for this reason that a study of the principal service networks for children with PDDs was undertaken.

The study focuses on children throughout Québec with PDDs, aged 0 to 7 years or having completed Elementary Cycle One. Its aim was to document access to and relevance of the government services available to these children. Are service delivery methods able to provide a timely response to the needs of the children and their parents? The study identified a number of strengths, but also some significant deficiencies that form the basis of the observations and recommendations presented in this report.

The in-depth analysis of the paths taken by children and their parents in seeking services revealed some viable solutions that are realistic in today's context. These solutions depend on the gains obtained from an improved service structure, removal of duplications and the innovative capacities of the institutions that provide the services in question. The services given to these children constitute an investment in their capacities and in their future participation as citizens, and need to be designed to play this role.

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[1] MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX, *Un geste porteur d'avenir. Des services aux personnes présentant un trouble envahissant du développement, à leurs familles et à leurs proches*, Québec, Bibliothèque nationale du Québec, 2003, 68 p.

[2] On April 1, 2006, the duties formerly entrusted to the Health and Social Services Ombudsman were transferred to the Québec Ombudsman, in accordance with the amendments to the Act respecting the Health and Social Services Ombudsman.

I therefore hope that this report and its recommendations, when implemented, will help ensure that children with PDDs will have all the opportunities they need to achieve their full potential, and that their parents will have the support they require to fulfill their role in that process. If this is to be possible, it will be necessary to change the services themselves, the physical environment in which they are provided, and the level of social acceptance. This challenge can only be met through a combined, ongoing effort on the part of those concerned.

The Government services also face another challenge, that of adjusting to the needs of the children as they become adults, and regulating their interventions according to the different periods of the children's lives. I must reiterate my concern about this aspect. Indeed, it is for this reason that the Québec Ombudsman is currently engaged in a special investigation of the issue. It should also be noted that many of the recommendations made in this report may also apply to the services provided at other periods of the lives of people with PDDs.

Raymonde Saint-Germain
Québec Ombudsman

INTRODUCTION

1.1 What are PDDs?

Pervasive developmental disorders (PDDs)[3] *are characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests and activities. The qualitative impairments that define these conditions are distinctly deviant relative to the individual's developmental level or mental age*[4]. PDDs comprise five specific disorders: Autism, Rett's syndrome, Childhood Disintegrative Disorder, Asperger syndrome and PDDs Not Otherwise Specified (PDD-NOS). Information on these various disorders can be found in Appendix 2.

1.2 What is the Québec Ombudsman's mission?

The Québec Ombudsman is particularly concerned by the relationship between citizens and the public authorities. The institution's mission is to ensure that human rights are upheld, and to intervene with Québec government departments and agencies, and with the various health and social services network authorities, to remedy situations that are prejudicial to individuals or groups of citizens. The Québec Ombudsman is appointed by elected members from all the political parties, and reports to the National Assembly. He or she is required to act independently and impartially, regardless of whether an intervention is undertaken on the institution's own initiative or as a result of complaints from citizens.

1.3 What new elements does the Ombudsman's report contribute?

In recent years, a number of opinions and studies have examined the problems faced by children with PDDs, and their parents, when seeking proper resources and follow-up from practitioners. The Québec Ombudsman has examined the actual situation faced by the people concerned, in order to assess the appropriateness of the services available to them in principle, from a multi-organizational standpoint. Three government departments and their networks[5] are involved, namely the health and social services network, the educational childcare network and the education network. To simplify the text, references in this report to "the three government departments" will encompass all three organizations.

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[3] The term PDD is always used in this report to refer to invasive developmental disorders, and never to the people who suffer from them. In the Québec Ombudsman's opinion, it goes without saying that children are not "PDDs". They are people, citizens in their own right, living with PDDs. The term "children with PDDs" is used to refer to them.

[4] AMERICAN PSYCHIATRIC ASSOCIATION IV, *Diagnostic and Statistical Manual of Mental Disorders,* 4th Edition. Washington DC, 2000.

[5] It should be noted that in the case of educational childcare services, this is not a public service network in the general sense, like the educational and health and social services networks. However, the term "network" has nevertheless been used to refer to the childcare services provided under the auspices of the Ministère de la Famille et des Aînés, in order to simplify the text.

In recent years, these three networks have undergone some extensive changes as a result of legislation that has required some major restructuring. The observations and recommendations made in this report have taken account of this aspect, and of the difficulty of building bridges between the networks as they undergo those changes[6].

The Ombudsman has:

- examined the duties stipulated in the legislation and regulations, and identified the administrative basis, mandates and resources concerned;
- documented the fit between the original principles and current everyday practice; and
- assessed the cohesion between needs, methods in the field and the results obtained for the children, as described by their parents.

The study produced by the Ombudsman is descriptive in nature. It examines and documents the paths taken by parents seeking services for their children, from the time the first symptoms are observed until the child reaches 7 years of age or completes the first grade of elementary school. Two surveys were carried out, one involving 150 parents of children with PDDs, and the other involving 13 local complaints commissioners from rehabilitation centres for intellectual disabilities and pervasive developmental disorders. The Québec Ombudsman also met with 167 individuals (parents, practitioners in different areas, and service managers) for a series of interviews and focus groups.

In addition, the Ombudsman examined the parents' descriptions of the paths they had taken, in an effort to understand the children's situation before and after the division of responsibility, i.e. when the child starts school (for those who do in fact attend school).

Based on the dissatisfaction expressed by the parents, the Ombudsman focused mainly on the following elements:

- Access to services;
- Service intensity;
- The continuity and consistency of services available from the three networks;
- The administrative formalities undertaken by parents in order to obtain funding.

The study was made possible thanks to the contributions of the parents and the resources directly concerned, primarily the practitioners from the community organizations that support parents, as well as public service planners and providers at every level throughout Québec. Their stories

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[6] Following the adoption, in November 2005, of the *Act to amend the Act respecting health services and social services*, the Ministère de la Santé et des Services sociaux continued the service reform begun in 2004 when the *Act respecting local health and social services network development agencies*. These two Acts lay the foundations for the new service structure.
The *Educational Childcare Act* replaced the *Act respecting childcare centres and childcare services*, changing the service structure by introducing coordination offices and fostering the harmonious development of childcare supplies.
The *Act to amend the Education Act and various legislative provisions* was adopted in December 1997. It restructures the powers and responsibilities of, and the relationships between, the educational institutions, school boards, the Ministère de l'Éducation and the Government.

highlighted the considerable effort being made to help these children to achieve their full potential.

SUMMARY

In accordance with its power of initiative and its strategic directions, the Québec Ombudsman uses a comprehensive approach to conduct studies that give insight to highly complex issues due to the multiple government stakeholders involved. In this context, the Québec Ombudsman conducted a study on government services for children with pervasive developmental disorders (PDDs),[7] entitled *Looking towards greater continuity in delivery of services, approaches, and human relations.*

Access to public services for children with a PDD and their parents: a path fraught with pitfalls

A pervasive developmental disorder is a condition that people must live with their entire lives. The term encompasses a wide range of manifestations. However, one thing that people with this condition have in common is a feeling of considerable distress when faced with change or any kind of new situation.

The Québec Ombudsman's study targeted children with a PDD ranging in age from 0 to 7 or having finished their first year of elementary school and examined their paths through the public services networks designed to help them. For these children, dealing with transitions in the way government services are delivered is a source of change that causes them distress. The ministries at issue here are the Ministère de la Santé et des Services sociaux, the Ministère de la Famille et des Aînés, and the Ministère de l'Éducation, du Loisir et du Sport. Ministerial policies and service networks must better take into account the trauma these children endure in situations of transition, which is the case when they must switch from one service network to another based on their age and needs.

Legitimate grounds for dissatisfaction

Pursuant to complaints by parents of children with a pervasive developmental disorder, the Québec Ombudsman conducted a study documenting the discrepancies between

- What government authorities say about how services for children with a pervasive developmental disorder (PDD) are organized
- How things actually are in the field

Upon completion of the study, the Québec Ombudsman confirmed that the dissatisfaction many parents expressed was generally very well founded. The study revealed that problems are often due to excessive compartmentalization and a lack of fluidity from one tier to another, both within organizations and between organizations.

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[7] Pervasive developmental disorders (PDDs) include a spectrum of behavioral problems commonly associated with autism such as Asperger's syndrome, Rett's syndrome, childhood disintegration, autism and pervasive developmental disorders not otherwise specified under the spectrum of PDD.

As a result, concrete measures must be implemented to address parents' concerns and dissatisfaction with regard to:

- **Information**, because it is important to give them straightforward answers about the issue of PDDs and effective interventions and raise stakeholder and public awareness in order to ensure appropriate care and eliminate prejudices
- **Intervention approaches**, because there are many questions surrounding the intensive behavioural intervention (IBI) approach recommended by the health and social services network such as the school network's *Treatment and Education of Autistic and Related Communication Handicapped Children* (TEACCH) approach, and we must assess them with a view to guaranteeing their effectiveness
- **Identification** of PDDs, because if a PDD is detected at the right time and in accordance with ethical practices, the child's chances of development are maximized
- **Diagnoses**, because they are crucial for identifying the appropriate services and must be made at the right time and based on more consistent procedures in order to meet the requirements of the three service networks
- **Siblings**, because they can play a critical role in the life of the child with a PDD and the adult he or she will become
- **Steps** parents must take to seek financial assistance, because the numerous formalities imposed by the various networks are due in part to the lack of harmonization between programs
- **Evaluation** of children's needs, because the care taken in this analysis has a direct bearing on the quality of the service plan, which makes it possible to identify how to improve the child's chances of integration and development
- **Coordination of** services, because access to the right service at the right time is vital, and transitions among service networks must be easy going
- **Education for** all children who are old enough, because parents need support to ensure their children are educated
- **Facilitating the child's introduction into the school system,** because this step signifies a particularly significant change in the lives of children with a PDD and their parents

The Québec Ombudsman has found that, as in many other public or private organizations, communications and relations between the three ministries often fall short due to rigid structures, "silo" budgeting, resistance to change, individual attitudes, and even polarized schools of thought. The impediments caused by the lack of smooth transitions between the services offered are likely to be harmful to the children and their families.

However, these ministries' missions are complementary and interrelated based on the underlying logic that habilitation is an asset for children throughout their personal trajectories, that their time in educational daycare prepares them for community life and starting school, and that it is in the schools' best interest to know the children's background. In fact,

- The health and social services network has a primary responsibility in providing diagnoses, habilitation/rehabilitation, and interventions, whether specific or specialized.
- Daycare services are responsible for providing quality educational services and ensuring the health, safety, development, well-being, and equal opportunity of the children receiving these services, notably those who have special needs or who are socioeconomically disadvantaged.
- Based on the children's capabilities and needs, the school network must provide opportunities for them to develop the knowledge and skills needed to succeed in school, to explore their potential, and integrate into society. It must act in keeping with the three components of the school's mission, which are to instruct, socialize, and qualify its students.

Furthermore, the Ministère de la Santé et des Services sociaux orientation document and action plan, entitled *Un geste porteur d'avenir. Des services aux personnes présentant un trouble envahissant du développement, à leurs familles et à leurs proches,*[8] expressly stipulates that intra- and inter-sectoral collaboration must be central to the actions taken, a crucial factor in providing comprehensive and appropriate services.

Greater continuity in service delivery, approaches and human relationships means encouraging cooperation and collaboration among the Ministère de la Santé et des Services sociaux and its network, the Ministère de la Famille et des Aînés and the educational daycare services network, and the Ministère de l'Éducation, du Loisir et du Sport and its network.

Main observations of the Québec Ombudsman's study, possible solutions, and recommendations

The following observations and recommendations are based on a detailed analysis of the path children must take in search of services that meet their needs. This analysis revealed a path fraught with pitfalls throughout the three networks.

OBSERVATION 1

When a child is suspected of having developmental issues: the necessary information, awareness, detection capability, and ability to refer the child to the right resources are not always available.

Health and social services centers should normally be the gateway to services. They should put parents in contact with practitioners who are familiar with PDDs and can provide them with the support, understanding, information, and guidance they need. The role of daycare services should be to provide information about the general condition of the child suspected of having a PDD and about the resources available in the public service network. Subsequent information about the child must flow in both directions in order to facilitate follow-ups by the daycare service in collaboration with the health and social services center.

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[8]. Ministère de la Santé et des Services sociaux, *op. cit.*, see Note 1.

The study revealed that the role of the health and social services center must be reinforced and that daycare services do not have all the information or the necessary support of specialists in the health and social services network to fully carry out their role. Schools have the same gaps in terms of the information provided to parents.

As a result, none of the three networks takes full responsibility for informing parents seeking services and explanations. In the Québec Ombudsman's view, this situation is mainly due to the lack of information that network stakeholders themselves have on PDDs, their manifestations, and the sequence of services most recommended in this field. In concrete terms, although each of these stakeholders could act to support parents and direct them to sources with more information, they are not carrying out their role as they should, leaving parents to go back and forth from one institution to the other.

Moreover, technological tools facilitating information distribution and sharing are not optimally used, both within and between networks and with the public. A visit to the websites of these ministries and their respective networks illustrates this: relevant information on this topic is hard to find and inconsistent.

Recommendations

The Québec Ombudsman has two recommendations to the three ministries urging them to work together to ensure that network personnel called on to provide assistance have access to information on the nature of PDDs and the resources available within the three networks.

OBSERVATION 2

Parents are quickly faced with scientific controversies and the polarization of schools of thought on the nature of PDDs and the types of interventions that should be used.

For researchers, stakeholders, and parents, there is no consensus on the profile of children with the same PDD diagnosis. Although many agree on the multiplicity of genetic causes with a neurological component, others believe that environmental factors combined with biological factors are responsible for the appearance of PDDs. Questions also remain about related manifestations and the best treatment approaches. Another pitfall is the difference between disorders grouped under the PDD umbrella and the wide variety of symptoms. In the face of such varied conditions, certain scientists maintain that a single intervention strategy is not enough, while others feel that the major similarities between the conditions justify similar services for each.

Given the scientific uncertainties, new mechanisms for sharing experiences and best practices are promising ways to support practitioners and reduce prejudices between sectors. At the same time, the scope of the resources deployed and the investments in interventions—both within the health and social services network and the education network—largely justifies the need to evaluate the effectiveness of these interventions.

Recommendations

The Québec Ombudsman has two recommendations. First, it recommends that the three ministries implement consistent continuing education and knowledge-transfer programs. Second, it recommends that the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport have their interventions evaluated.

OBSERVATION 3

Parents must fulfill multiple requirements to obtain services.

Even though ministerial orientations for the health and social services network in *Orientations ministérielles 2003* specify that "it is critical that services for people with PDDs must be **based on meeting peoples' needs rather than on the presence or absence of a diagnosis**," the Québec Ombudsman's study shows that the diagnosis is the only real trigger for habilitation/rehabilitation services. Pending diagnosis, health and social services centers should provide "specific" services. However, the study revealed that these services are not always available and, more importantly, that they are not provided in a timely manner.

To gain access to the services provided by rehabilitation centers specialized in intellectual disabilities and pervasive developmental disorders, a diagnosis is mandatory. The study also found that if the diagnosis was made by a doctor acting without a multidisciplinary team, the centers sometimes conduct another evaluation of the child.

At the same time, educational daycare services ask parents to produce a confirmation of the child's disability or impairment in order to submit an application for additional financial support from the Ministère de la Famille et des Aînés. Upon request by the school board, parents must provide confirmation of the PDD diagnostic evaluation before the child's first year of school if it was carried out more than 12 months before the child's school admission application. The school board also imposes strict requirements on the type of doctor qualified to confirm the diagnostic evaluation.

Mired in all the intricacies of diagnostic and evaluation requirements, parents are often caught off guard at each new step, which delays their access to services and forces them to pay certain fees to satisfy the requirements.

Recommendations

The Québec Ombudsman has three specific recommendations for the three ministries to facilitate access to their services. It also has an overall recommendation that all of the ministries harmonize their diagnostic requirements or other conditions.

OBSERVATION 4

Lack of family support

The study revealed that for some parents, caring for a child with a PDD can result in them leaving their jobs in order to have the time they need to navigate through each step of the process or to avoid irritating coworkers due to their higher-than-average levels of absenteeism (medical appointments, treatments, incidents at daycare or in school, etc.). In other cases, the considerable pressure involved can even break up the couple.

Although it is possible to access various financial assistance programs, whether directly (for example through the Régie des rentes) or indirectly (support that helps families receive services administered by government ministries), the criteria are multiple and inconsistent. Furthermore, there are considerable variations in the support provided by each health and social services center.

Moreover, siblings of children with a PDD have to come to terms with the amount of time, energy, and resources a family spends on a child with a PDD. Experts and parents maintain that brothers and sisters make an indispensable and very valuable contribution to the lives of children with a PDD. Special consideration must also be given to the specific difficulties they face. Also, siblings should be involved in the development of individualized service plans, when appropriate. Mechanisms for taking families' needs into account are already in place in the form of intervention plans and individualized service plans. It is therefore important to ensure that these mechanisms are actually put to use.

The Québec Ombudsman's study found that a number of families have a second child with a PDD. The presence of this second child (whether or not a twin) is likely to generate special needs. However, ministerial policies are not explicit about how to meet the needs of these families. The Québec Ombudsman is of the opinion that the Ministère de la Santé et des Services sociaux must more carefully examine the repercussions such a situation can have on a family in order to plan services and support tailored to their situation.

Recommendations

The Québec Ombudsman has one recommendation for the Ministère de la Santé et des Services sociaux: that it provide guidelines for network professionals on how to support families. It also has two recommendations for the Ministère de la Santé et des Services sociaux and the Ministère de la Famille et des Aînés to the effect that they harmonize their procedures for accessing financial support.

OBSERVATION 5

The achievement of ministerial intentions are not fully translated into action in the field, despite the importance of continuity in service delivery. Transitions among networks are difficult.

Individuals with PDDs become disorganised when the smallest change is made to their routine. Any changes (e.g., new clothing, new route, new decor, new voices, new instructions, etc.) may cause distress and exterior manifestations of their disorientation. This is why continuity in the delivery of services, the flow of information, and the actions between the various stakeholders is so important.

The Québec Ombudsman's study found that parents navigating the system face shortcomings with regard to the connections within and among the networks involved in helping children with PDDs. It also identified a series of problems—mainly inconsistencies in services and difficult transitions when switching from one service to another—that arise as children get older. Despite the ministries' intentions, all three networks operate with something of silo mentality. This is particularly true when children transition from a family or educational daycare setting to a school environment. The size and diversity of the regions served also complicates service delivery considering how much situations can differ depending on the environment (urban and highly populated areas, urban to less populated areas, semi-urban areas, and rural areas).

In fact, the measures to ensure continuity and facilitate transitions are well known—and have been for over 15 years. They are based on the availability of an evaluation tool—the service plan[9]— which is used to clearly identify an individual's needs and determine the services and resources best suited to meet those needs. In order to implement this plan, services must be provided by the right resource at the right time and at the right intensity. To that end, a person most commonly referred to as the case manager in service settings must coordinate the plan's implementation.

The study showed that each network has adopted its own definition of the service plan (plan names vary from network to network) and that the development of these plans can impose

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[9] In the health and social services network, these are referred to as intervention plans and individualized service plans. In the daycare services network, they are called integration plans, and in the school network, they are called individualized and intersectoral service plans.

redundant and inconsistent requirements on parents. Moreover, parents are often left on their own to ensure that these plans are coordinated, which is a heavy burden indeed. Although the three networks have a shared responsibility due to the intersectoral nature of the PDD challenge, the coordination role is often disputed and is not legitimately incorporated into the process.

For educational daycare services in particular, integrating children with PDDs involves specific challenges that can only be overcome with the joint support of professionals from the health and social services network. In addition, the Ministère de la Famille et des Aînés is not sufficiently aware of the impact that its policies have on facilitating the integration of children with PDDs and does not provide clear enough guidance about exclusion policies from daycare.

In schools, information sharing between daycare and health and social services stakeholders is not effective enough to facilitate smooth transitions. The study also revealed that certain children do not have access to education.

Recommendations

The Québec Ombudsman has three recommendations (one for the Ministère de la Famille et des Aînés, one for the Ministère de l'Éducation, du Loisir et du Sport, and one for all three ministries) regarding the harmonization and effective implementation of service plans. It also recommends that the three ministries work together to redefine the coordination role and establish conditions for success.

It has three specific recommendations for the Ministère de la Famille et des Aînés: limit the negative impacts of exclusion policies, establish links to ensure the required professional support is provided, and evaluate the impacts of incentive integration policies.

It has three recommendations for the Ministère de l'Éducation, du Loisir et du Sport: ensure that memoranda of understanding signed with the Ministère de la Famille et des Aînés and the Ministère de la Santé et des Services sociaux facilitate knowledge- and expertise-sharing. It also recommends that the Ministère de l'Éducation, du Loisir et du Sport take the necessary steps to identify children who are removed from school in order to ensure that they have access to education in their best interest.

Possible solutions suggested in the report

The Québec Ombudsman would like to stress how important it is for the public bodies concerned to

- Increase information and awareness-raising efforts
- Better define the problematic of PDDs
- Evaluate the intervention approaches used in Québec
- Facilitate access to a PDD diagnosis and appropriate services
- Reaffirm the role of health and social service centers as a gateway to services for children with PDDs
- Better take into account families (including siblings) of children with a PDD
- Strengthen recognition of the role community organizations play in supporting parents
- Simplify the process for parents seeking financial assistance
- Create links between service networks
- Improve the needs assessment process for children with a PDD within service plans
- Improve service coordination
- Guarantee access to education for all children

Desired outcome of this report

Based on the issues parents face, the Québec Ombudsman has identified possible short term solutions that can greatly improve the daily life of children and parents themselves. The recommendations directed toward harmonizing requirements are an example of this. It also recommends pivotal medium term actions to more permanently resolve long-standing problems. Implementing coordination mechanisms and tools is a perpetual challenge that requires a sustained effort. Even though the need to have one stakeholder implement and coordinate intersectoral service plans has been acknowledged since the 1990s, results to this effect have been mitigated. The recommendations are realistic and do not involve major costs. In fact, the benefits of improved information and responsibility sharing could well generate the savings needed to follow up on the recommendations on improving services. By closely monitoring the implementation of these recommendations, the Québec Ombudsman will make sure that consistent efforts are made to ensure that short term concerns do not push back fulfillment of service continuity objectives. The Québec Ombudsman believes that not only will children with PDDs benefit, but also the adults who have just as pressing a need for a humane approach, easy access to services, and an appropriate assessment of how their needs are being met.

1. THE STORY OF ANDRÉ-TIM, A CHILD WITH PDD, AND HIS PARENT: THE GAP BETWEEN "WHAT ACTUALLY HAPPENS" AND "WHAT SHOULD HAPPEN"

The following story illustrates the requirements relating to assessment, diagnosis, confirmation of handicap, confirmation of disability or confirmation of impairment and confirmation of the PDD diagnosis[10] that parents are likely to encounter when approaching the three networks to obtain services for their children. To illustrate this process, we will present the fictional case of André-Tim, whose path through the public system began when he was 16 months old, in a local educational childcare centre.

What should happen…

André-Tim's childcare provider would tell the parent that, in her opinion, the child has some developmental difficulties.

According to the *2003 Ministerial Orientations*, the parent and child would then go to their local health and social services centre, which is the central reference institution in the process. They would then be referred to a resource able to assess and diagnose the child. In the case in question, the parent would therefore be advised by the childcare provider to begin the process by contacting the health and social services centre.

What actually happens …

In reality, this automatic response does not occur in every childcare centre, or in society in general. In many cases parents are left on their own when it comes to finding a gateway to the services they need, perhaps via their existing resources, or on the recommendation of family and friends. The resources in question may be a family doctor, pediatrician, specialist, health network practitioner (a public or private clinic, hospital or child psychiatric clinic, etc.). Given the lack of known standards or protocols for diagnostic procedures, parents who feel the initial assessment is incomplete will tend to seek a second opinion as to whether the diagnosis truly reflects the child's problem. Doubt is usually accompanied by a desire to confirm the initial diagnosis, a process that obviously causes additional delays.

What should happen…

The health and social services centre would refer André-Tim to a doctor able to assess his condition and make a diagnosis. When his name reaches the top of the region's waiting list, he would meet with the doctor.

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[10] Parents are required to present diagnosis confirmations or assessments (the terminology changes depending on the government department and network) in order to obtain access to services. For example, a parent wishing to obtain childcare services must provide confirmation of the child's impairment or deficiency.

What actually happens …

In reality, for most children, the initial resource is not the correct one, and parents must often knock on several doors before meeting with the appropriate person. This often results in the accumulation of delays of six months or more.

What should happen …

The doctor who observed André-Tim's behaviour would refer him for examination by a multidisciplinary team at the designated regional hospital, so that a diagnosis of PDD could be given where appropriate.

What actually happens …

In reality, the availability of multidisciplinary teams able to assess children and make this type of diagnosis varies from region to region. In many cases, parents and children who live in remote areas must go to Quebec City or Montreal and deal with the ensuing delays and expenses.

What should happen …

Once a diagnosis of PDD is made, André-Tim's parent would be referred to the regional rehabilitation centre for intellectual impairment and PDD by the health and social services centre providing specialist front-line services. The rehabilitation centre is the institution responsible for providing specialist intensive behavioural intervention (IBI) and other habilitation and rehabilitation services. The parent would also be referred to other institutions able to provide appropriate services not available through the health and social services centre.

What actually happens …

In reality, André-Tim is placed on the health and social services centre and rehabilitation centre waiting lists. He is entitled to the services available from the health and social services centre, and to specialist services from the rehabilitation centre. However, in cases where the diagnosis is made by a doctor who is not part of a multidisciplinary team, the rehabilitation centre will often assess the child again, to confirm his or her condition and needs.

Given the children's special needs, it is not rare for educational childcare centres to ask parents for confirmation of the impairment or disability, so that it can request additional financial support from the Ministère de la Famille et des Aînés. Some early childhood centres have signed agreements to this effect with private sector specialists including speech therapists, and in such cases they are able to proceed more quickly. However, once confirmation of the disability has been obtained, the child must be referred to the health and social services centre for assessment and a specific diagnosis. However, even if André-Tim clearly needs to be referred to the health and social services centre, the early childhood centre may not be aware of all the steps in what is a very complex process, and may not tell the parent what to do. In addition, once the speech therapist issues confirmation of the impairment, the parent may wrongly consider it to be a diagnosis and believe that the process is complete. Misunderstandings are common, and can slow down the process of obtaining services.

What should happen …

Once he is old enough, André-Tim would prepare to attend a school that could provide the professional resources he needs.

What actually happens …

In reality, the school board will ask the parents to produce confirmation of the PDD diagnosis if it was made more than 12 months prior to the school admission application. The school boards have strict requirements concerning the type of doctor who is qualified to diagnose PDDs. The following citation clearly illustrates the problems parents may encounter in obtaining the necessary appointments and certifications within a reasonable time

Excerpt from *The Organization of Educational Services for At-Risk Students and Students with Handicaps, Social Maladjustments or Learning Difficulties*, Ministère de l'Éducation, du Loisir et du Sport, 2006, p. 21 (boldface text as in the original document):

> "Students are deemed to have a pervasive developmental disorder when:
>
> - They have been diagnosed by a **psychiatrist or a child psychiatrist working with a multidisciplinary team**
>   or
>   by a **physician** (general practitioner or a pediatrician) **working with a multidisciplinary team** and whose expertise in evaluating pervasive developmental disorders is recognized by the health and social services network
>
> - Their overall functional evaluation on the basis of systematic observation techniques and standardized tests results in one of the following diagnoses:
>   - autism;
>   - Rett's syndrome;
>   - childhood disintegrative disorder;
>   - Asperger's syndrome;
>   - nonspecific pervasive developmental disorder."

Parents, unable to navigate their way through all the diagnosis requirements, are often caught off-guard by this new step, which can also generate long delays. In the case of André-Tim, a diagnosis had already been made when he applied for habilitation services, and given the nature of PDD, that diagnosis is final.

From the school board's point of view, the request for confirmation of the diagnosis is nevertheless justified because it allows the board to assign a "difficulty code" that reflects the student's specific needs, and it is this code that allows the board to receive an additional budget from the Ministère de l'Éducation, du Loisir et du Sport, for the services required. In addition, the school boards also receive funding for the organization of services for students at risk or with learning disorders. These amounts are paid into a general budget for all students requiring special services. This means that the amount paid to the school board for André-Tim is not assigned to him personally, but is used to manage a set of resources for him and for other students with similar special needs. Regardless of the purpose of the confirmation of diagnosis – whether individual or collective – it involves further action, delays and sometimes additional costs for the parent concerned.

André-Tim's story shows what happens to a child with PDD, and illustrates the obstacles facing families as they negotiate a path through the three networks that provide the services they need.

2. PDD – SOME FUNDAMENTAL DIFFERENCES

It is difficult, at the present time, to find data on the prevalence and number of people with PDDs. Depending on the sources consulted, there are anywhere between 15 and 70 cases per 10,000 inhabitants, and between 200 and nearly 800 new cases per year. What is the reason for such huge disparities? There are a number of potential reasons, the principal one being an increase in the prevalence and number of cases as a result of better detection methods, new specialist clinical practices, and pressure to influence diagnoses in order to obtain services or financial benefits. According to some people, the lower figures are due to the fact that doctors are asked to be careful because a PDD diagnosis can cause children to be ostracized, or the fact that some practitioners do not acknowledge this kind of disorder. For others, the uncertain numbers make it difficult to provide proper services[11]. In any case, it is clear that the reasons for the wide variation deserve to be better documented.

Among other things, specialists do not agree on the following aspects:

- Is the steady increase in the number of cases from year to year due to an epidemic, to greater awareness or to more sophisticated detection methods?
- Can a PDD be detected by a child's parents or daycare providers, or only by medical professionals?
- Can a diagnosis be made and interventions implemented in the first few months of a child's life, or is it absolutely necessary to wait until the child is two years of age?
- Does the age at which diagnosis is possible depend on which of the five PDD sub-groups is involved, or on the child's symptoms?
- Is a PDD a specific state, a developmental impairment or a mental illness that should be listed as such in the directory of mental diseases (DSM IV)[12]?
- Does a PDD necessarily involve intellectual impairment?
- Is it necessary to wait until the child is at least seven years old before making a final decision as to whether or not he or she is intellectually impaired, or can this be confirmed at an earlier age?
- Are behavioural disorders generalized or are they present only in approximately 20% of cases?
- Where behavioural disorders are exhibited, is it accurate to say that they may, in some cases, have been caused by the child's environment or by an intervention, or are such disorders simply a component of the PDD?
- Is the diagnosis of "nonspecific PDD" that is applied to more than 30% of newly-diagnosed children a true diagnosis, or a default diagnosis, or a diagnosis that is given simply to ensure that the child is able to receive services?

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[11] A more detailed discussion of the utility of prevalence and occurrence data for resource allocation can be found in the section on financing.

[12] *Ibid.,* See Note 4.

- Is an intensive behavioural intervention the best type of intervention for children with PDDs, or is it more useful when the child starts school?
- Must an intensive behavioural intervention take the form of a one-on-one relationship between child and practitioner, with the child being withdrawn from his or her reference group, or would it be just as effective if the child were kept in the reference group?
- What type of childcare service is most appropriate? Would it be an early childhood centre or a daycare centre in which the child is part of a group, or a family-type service involving less stress and a more personal relationship with an adult?
- In schools, should children with PDDs be placed in regular classrooms or in special classes?

The above antagonisms exist within a context where there is no formal mechanism to resolve scientific controversies. There is therefore a need for some kind of mechanism that would allow practitioners from the health and social services network, the education network and the childcare network to upgrade their knowledge of PDDs on a regular basis, and to share the latest knowledge in their possession.

The question of applying the latest knowledge deserves further attention, given the extent of the controversy in the field. One the one hand, scientific knowledge is applied in more traditional training activities[13]. At the same time, however, it can be disseminated through guidelines and practice guides issued by organizations responsible for overseeing practices – for example, the professional orders and associations.

In recent years the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport have set up a number of joint initiatives, including a national PDD network known by its French acronym RNETED[14]. The network has organized a number of training sessions on different topics, and disseminates research into the development of best Canadian practices in the detection, assessment and diagnosis of autism spectrum disorders[15]. As part of this process, the needs of doctors and parents were identified. The network has its own website with limited access (code-protected) discussion boards.

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[13] The Office des personnes handicapées du Québec (OPHQ) has asked the professional orders to consider the possibility of improving their members' ability to meet the needs and uphold the rights of disabled people.

[14] The Ministère de la Famille et des Aînés, the health and social services agencies, the rehabilitation institutions, hospitals, parents and the Office des personnes handicapées du Québec are also members of the network.

[15] NACHSHEN, J., GARCIN, N., MOXNESS, K., TREMBLAY, Y., HUTCHINSON, P., LACHANCE A., BEAURIVAGE, M., NREITENBACH, M., BRYSON, S., BURACK, J., CARON, C., CONDILLAC, R.A., CORNICK, A., OUELLETTE-KUNTZ, H., JOSEPH, S., RISHIKOF, E., SLADECZEK, I.E., STELMAN, M., TIDMARSH, l., ZWALGENBAUM, L., FOMBONNE E., SZATMARI, E., MARTIN-STOREY, A., & RUTTLE, P.L. (2008). *Screening, Assessment and Diagnosis of Autism Spectrum Disorders in Young Children: Canadian Best Practice Guidelines.* Miriam Foundation, Montreal, Québec.

Although these practices, which are based on convincing data, have been available since 2008, there still remains the considerable challenge of incorporating them into the system. If the professional orders were to play an active role in this process, among other things by issuing guidelines, it would clearly be much easier to transfer research findings into practice.

It would therefore be important for the Ministère de la Santé et des Services sociaux to obtain the support of the Collège des médecins du Québec, asking it to work with the other professional orders concerned in order to prepare PDD guidelines in general, and nonspecific PDD diagnosis guidelines in particular, as well as any other processes stipulated in the *2003 Ministerial Orientations*.

This entire process could also be based on the guidelines already produced by the Collège des médecins and the Ordre des psychologues du Québec on children with attention deficit hyperactivity disorder (ADHD). One of the goals of these guidelines was to facilitate access to a diagnosis. They are well-known in the both the health and social services network and the educational network, and many people believe they have helped improve access to information and proper diagnoses for the children concerned[16].

Nevertheless, the fact remains that training and guidelines alone will not be sufficient. Given the deficiencies in scientific PDD data, the development of knowledge and silo practices, differences in the level of basic training received by practitioners, differences in organizational cultures and the many prejudices regarding other peoples' skill levels, there is a clear need for new methods of approaching both knowledge and dissemination vehicles. Innovative procedures require shared knowledge. They present knowledge as a dynamic process in which experiential know-how is a major component. The success of the communities of practice is a good example of this. A community of practice is a group that interacts, learns together, builds contacts and develops a sense of belonging and mutual commitment. The added value of this type of approach, which combines the goals of practice improvement and the creation of collaborative mechanisms aimed at reducing prejudice and controversy, is obvious, provided of course that the communities include all practitioners regardless of their institution or sector[17].

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16. Bill 21, amending the Professional Code in the field of mental health and human relations, was adopted on June 18, 2009. As a result, psychologies are now able to make assessments that provide access to services.
17. The RNETED, on its page entitled *Travailler en réseau*, makes reference to the community of practice guide produced by the Centre francophone d'informatisation des organisations (CEFRIO).

RECOMMENDATION CONCERNING A BETTER DEFINITION OF THE PROBLEM OF PERVASIVE DEVELOPMENTAL DISORDERS (PDD)

WHEREAS elements of the cause, manifestation, diagnosis, treatment and prevalence of PDDs are still unknown, and the advancement of knowledge in the field is insufficient to settle the resulting controversies;

WHEREAS the clearer scientific research into PDDs becomes, the easier it will be to plan and implement services;

WHEREAS, until progress is achieved in the field of scientific knowledge, a mechanism is required that will enable parents and practitioners to distinguish between tested scientific knowledge on the value of certain interventions and simple opinions regarding interventions that have been insufficiently assessed;

WHEREAS, as a result of scientific uncertainty, mechanisms designed to share experience and best practices, such as the communities of practice, are useful in supporting practitioners and reducing inter-sector prejudices.

RECOMMENDATION 1

The Québec Ombudsman recommends that the three Government ministries responsible for providing care and services to children with PDDs – namely the Ministère de la Santé et des Services sociaux, the Ministère de la Famille et des Aînés, and the Ministère de l'Éducation, du Loisir et du Sport, along with their respective networks, including the network of educational childcare services – should ensure that knowledge sharing programs on PDDs that are consistent with basic and continuous training programs are made available to practitioners by their respective networks, along with shared notions that will provide everyone with a similar level of basic knowledge and a common language to describe this particular condition.

FOLLOW-UP:

The respondents for each of the three Government departments shall inform the Québec Ombudsman of the mechanism selected, no later than March 31, 2011. In addition, they shall inform the Québec Ombudsman every year of the programs and actions implemented, and shall, after five years, submit an assessment of the relevance of these various elements for practitioners.

3. THE APPLICABLE LEGISLATION AND ITS IMPACTS ON SERVICE NETWORKS

3.1. Legislation

Before examining the supply of services for children with PDDs, it is first necessary to see how the legislation describes the fundamental rights of these children. The Québec Ombudsman therefore made an in-depth study of the applicable conventions and legislation, a summary of which appears below.

- The **Convention on the Rights of the Child,** to which Canada adhered in 1991. The Convention aims to ensure that children receive the services they need to integrate society and reach their full potential. It is up to the signatory countries to enforce these rights through their own legislation. In Canada, this falls under provincial jurisdiction. Québec law meets the standards of international law.

- The recent **Convention on the Rights of Persons with Disabilities** (2006). This Convention invites signatory countries to do what they can to ensure that children with disabilities, like all other children, are able to enjoy fundamental rights and freedoms. In the field of education, it rejects the exclusion of disabled children on the grounds of their disability, and reasserts the principle of mandatory free access to elementary and secondary education. It also recommends the introduction of reasonable accommodation measures.

- The **Canadian Charter of Rights and Freedoms**. It stipulates that the law applies equally to everyone, and that everyone is entitled to the same protection and advantages under the law, without discrimination based on mental or physical impairment.

- The **Québec Charter of Human Rights and Freedoms**. It guarantees fundamental rights and freedoms in relationships between individuals and prohibits all forms of discrimination, including discrimination based on handicap.

- The **Civil Code of Québec**. The Code is a core document for children's rights, and in combination with the Québec Charter and the general principles of law, it governs relationships between individuals, as well as property. It gives children:
    - the right to the protection, security and attention that their parents or the persons acting in their stead are able to give;
    - the right to know that every decision concerning a child is taken in light of the child's interests and respect for his or her rights;
    - the right to consideration of the child's age, health, personality and family environment, as well as the other aspects of his or her situation, in addition to his or her moral, intellectual, emotional and material needs.

- The **Act respecting health services and social services**. It expressly acknowledges that everyone is entitled to receive proper health and social services. However, this right is exercised in light of organizational and functional limitations and institutional resources.

- The **Educational Childcare Act.** Its purpose is to promote the quality of educational childcare services dispensed by childcare providers "so as to ensure the health and safety of the children to whom childcare services are provided, particularly those with special needs". Although conditional on organizational and resource limitations, the Act acknowledges that all children have a right to personalized educational childcare.

- The **Education Act**. The Act covers students with handicaps, and in addition to the general provisions for all children, occasionally provides for special arrangements in order to achieve the goals relating to the provision of preschool, elementary and secondary education set out in the basic school regulations. It contains special provisions to ensure that children with disabilities have the best possible chance of adapting to, integrating and developing within society. The school boards are responsible for adjusting their educational services to meet the needs of handicapped children, based on an assessment of their abilities.

If we look at how these various acts and conventions apply to children with PDDs, we note that they contain progressive, inclusive provisions. In addition to general provisions covering all individuals, children and adults alike, they also make special provisions for children with disabilities, guaranteeing the best possible chance of adapting to, integrating and developing within society. The regulations made under the various acts also reflect this concern.

3.2 The courts

The following cases all helped to clarify aspects of the services available for children with PDDs.

With regard to health services, the Supreme Court of Canada, in the Auton case (2004)[18], pointed out that the Canada Health Act and relevant provincial provisions – in Québec, this principally meant the Health Insurance Act[19] and the Hospital Insurance Act– do not guarantee financing for every treatment medically required by every citizen. The only financing provided for by law is the financing of services described as "essential" by the Court, namely those delivered by a physician within the meaning of the Canada Health Act, and other services described as "non-essential", which may be financed in whole or in part, at the discretion of the province.

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[18] *Auton (Guardian ad litem of) v. British Columbia (Attorney General)* [2004] 3 S.C.R. 657, 2004 SCC 78.

[19] Act corresponding to British Columbia's *Medicare Protection Act [R.S.B.C. 1996] Chapter 286:* although their provisions are different, Québec's legislation is identical in terms of coverage.

In Québec, the definition of "insured services" given in the Health Insurance Act[20], does not necessarily cover PDD-related services, except for "all services rendered by physicians that are medically required". PDD-related services are therefore not expressly "insured", although they may be made available through and financed under certain government programs.

With regard to educational childcare services, Québec's human rights and children's rights tribunal, in the Garderie du Couvent Inc. case (1997)[21], reminded educational childcare providers that they cannot refuse to take a child who exhibits behavioural problems, in spite of certain standards, without first attempting, within reason, to adapt their services to the child's condition and needs, unless this would place an excessive constraint on their organization or operations. Since this ruling, every situation has been assessed on a case-by-case basis.

With regard to educational services, the main legal issue for many years has been the integration of handicapped children and children with PDDs into regular classrooms. The Québec Court of Appeal, in the Potvin case (2006)[22], reviewed its own previous decisions in 1994[23], as well as the Supreme Court of Canada's decision in the Eaton case (1997)[24].

According to the Court of Appeal, the applicable sections of the law are consistent with the lessons drawn by the Supreme Court in the Eaton ruling. Integration of handicapped children into regular classrooms is a generally applicable standard but does not establish a legal presumption. The decision as to whether or not to integrate a child into a regular classroom should be made in light of the child's best interests, following an assessment of his or her needs and abilities. In addition, the decision should not result in unreasonable or excessive constraints for either the school or the other students.

3.3 The recourses available to dissatisfied parents

If parents are dissatisfied with the services rendered by any of the three networks (health and social services, educational childcare, education), they have access to a certain number of recourses.

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[20] *Health Insurance Act,* R.S.Q., c.A-29.

[21] *Commission des droits de la personne et des droits de la jeunesse*. v. *Garderie du Couvent Inc. et coll.*, Tribunal des droits de la personne et de la jeunesse, Laval, 1997 CanLII59 (QC T.D.P.).

[22] *Commission scolaire des Phares v. Commission des droits de la personne et des droits de la jeunesse et Joël Potvin et coll.*, 2006 CanLII QCCA 82.

[23] The Marcil case: *Commission scolaire St-Jean-sur-Richelieu v. Commission des droits de la personne du Québec et Daniel Marcil et coll.* [1994] R.J.Q. 1227 (C.A) and the Rouette case: *Commission scolaire régionale Chauveau v. Commission des droits de la personne* [1994] R.J.Q. 1196. (C.A.).

[24] *Eaton v. Brant County Board of Education* [1997] 1 S.C.R. 241.

The health and social services network

Under the Act respecting health services and social services[25], the parents of a child with a PDD (or their representative) may, if they are dissatisfied with a service received or requested from an institution, make a written or verbal complaint to the local complaints and service quality commissioner at the health and social services network institution concerned. The commissioner reports to the institution's board of directors and is responsible for ensuring that users' rights are upheld and their complaints are addressed quickly. The commissioner must apply the complaints examination procedure adopted by the institution, study users' complaints with due regard for their rights, submit conclusions to the user or user's representative, with reasons, and where applicable, make recommendations to the authorities concerned. If the parent or representative is dissatisfied with the conclusions, or does not receive a response within 45 days of making the complaint, he or she may contact the Québec Ombudsman directly. The Ombudsman then examines the case in accordance with the Act respecting the Health and Social Services Ombudsman[26] and the Public Protector Act[27]. In an emergency, the Ombudsman may intervene of its own initiative, even before the local complaints and service quality commissioner becomes involved.

This procedure addresses the need for complaints to be considered first by the institution providing the service, and then, where applicable, by the Québec Ombudsman, which offers a guarantee of impartiality and independence in keeping with its mission.

Educational childcare services

The Educational Childcare Act outlines the rights and obligations relating to service access and quality. If the parents of a child with a PDD are dissatisfied with a service received or requested from an educational childcare provider (for example, refusal to admit the child or to provide all the special services required by his or her condition), they can complain only to the childcare provider itself, which considers the complaint via its board of directors, composed mainly of parents. The Act is not very explicit in this respect, and its provisions do not impose any obligations. If the parents are dissatisfied with the way the complaint is handled, the law does not provide for any independent recourse. Generally speaking, the educational childcare network does not have any kind of complaints forum that is sufficiently distanced from the actual service providers.

In 2002, the Ministère de la Famille et des Aînés adopted a policy and administrative procedure for the processing of complaints concerning the quality of educational childcare services. The policy provides that parents who are dissatisfied with a service received may complain to the Complaints Office of the Ministère de la Famille et des Aînés. Depending on the reason for the complaint, they will be advised to approach the service provider first. If they are still dissatisfied with the response from the service provider, the Complaints Office will consider the complaint itself. In the case of a

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[25] *Act respecting health services and social services,* R.S.Q., c. S-4.2, ss. 47 to 76.14.

[26] *Act respecting the Health and Social Services Ombudsman*, R.S.Q., c P-31.1.

[27] *Public Protector Act*, R.S.Q., c. P-32.

child with special needs, the MFA's action plan for disabled people provides that the complaint will automatically be referred to the regional branch concerned, so that it can provide the support needed for the child to be admitted to or remain at the childcare service[28]. The complainant can also request a review if he or she is dissatisfied with the way the complaint was handled, and in addition, recourse to the Québec Ombudsman is always possible[29].

The education network

A request for a review by the school board's board of commissioners may be made in respect of any decision concerning a student that is made by the board of commissioners itself, the executive committee, the school council or a member of the school board staff. There is also a disciplinary complaints mechanism for gross misconduct or serious offences by teachers. Bill 88, the Act to amend the Education Act and other legislative provisions, adopted on October 28, 2008, provides that all school boards must adopt a formal complaints mechanism, including a Student Ombudsman [30].

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[28] The complainant must be notified of the outcome of his or her complaint within 45 days.

[29] The letter sent by the Ministère de la Famille et des Aînés concerning the outcome of the complaint review procedure stipulates that the complainant may have recourse to the Québec Ombudsman.

[30] Although the Québec Ombudsman acknowledges the relevance of this mechanism, she has expressed reservations concerning some sections of the Act, in particular those concerning the powers of the Student Ombudsman, the complaints examination procedure and the reporting procedure.

4. INTERDEPENDENCY OF THE THREE NETWORKS

It is not only the legislation, regulations and court rulings that determine the supply of services, but also the structure of the service networks themselves.

4.1 The health and social services network: a recent but unevenly applied reform

The health and social services network is incontestably the primary provider of services for children with PDDs and their families, since interventions by the network's clinical specialists are the triggers that lead to the provision of specific (health and social services centre) and specialized (RCID-PDD) services.

The Ministère de la Santé et des Services sociaux, in its 2003 Ministerial Orientations and action plan, clearly expressed its intention to meet the needs of children with PDDs, in thirteen different areas, namely information and awareness, detection and diagnosis, "case manager" (or navigator), access to services, overall needs assessment, specialized habilitation/rehabilitation services, intensive behavioural intervention (IBI), support for families, home support and residential services, inter-sector collaboration, training, supra-regional services and the national specialist network.

Some major changes have been made to the health and social services network since the 2003 orientations and action plan were tabled. These changes can be divided into two types: structural and clinical. The structural changes include the creation of 95 health and social services centres as a result of merging all the local community service centres (CLSCs), long-term residential care centres (CHSLDs) and general and specialist hospitals in a given area. The clinical changes include the adoption of two principles underlying the division of roles and responsibilities and service organization methods. These principles are the population-based approach, and the service hierarchy. Under the population-based approach, the service supply must be tailored to the needs of the population in the territory covered by the health and social services centre, while under the service hierarchy, the gateway to service is the front line institution, which, where necessary, oversees the provision of specialist services through agreements with network and non-network partners. The ultimate goal is to provide easier access to the services required by the general public, and to ensure the continuity of the services offered by the different authorities. After six years, however, this major restructuring has still not been completed, and the progress made in implementing the principles of the reform varies considerably from centre to centre. The anticipated benefits of the new service structure have not yet been achieved in many places.

The Québec Ombudsman's study reveals that, while the 2003 Ministerial Orientations identified the needs and proposed appropriate solutions, the various authorities have not always taken the steps required to forge contacts either within their own network, or with partners in other networks.

Although, generally speaking, the reconfiguration of the health and social services network provides a better guarantee of service continuity, inter-service and inter-program fluidity problems continue to exist. The people most affected by these problems – parents, practitioners and managers – have expressed concern, and are worried that the current reform will impose even more changes that will not only prevent it from being implemented, but will also reduce the scope of the anticipated benefits.

4.2 Educational childcare services: Under development and undergoing consolidation following amendments to the Act

Educational child care services are currently being developed and consolidated as a result of recent amendments to their structure. They are governed by the new *Educational Childcare Act*[31], and their mission is:

- to foster the well-being, health and safety of the children;
- to provide children with an environment conducive to their overall development.

Educational childcare services are independently responsible for selecting the children they receive, provided they comply with the terms of their permit (in the case of early childhood centres and daycare centres) or of the authorization granted by a coordinators' office certified by the Ministère de la Famille et des Aînés. Currently, it is up to the permit holders to devise their own policy for admission and expulsion of children[32]. The Québec Ombudsman notes that some children are either refused admission or expelled after admission simply because they have a PDD. Some daycare providers are unable to offer the services required by these children, and in such cases parents have no other choice but to seek a new resource or keep the child at home. Admission and expulsion policies, when they exist[33], tend to be fairly general and do not address the issue of handicapped children or children with PDDs. The courts have stipulated that all daycare centres must make a considerable effort to receive these children[34]; however, centres may also find that the fact of taking on a child with a PDD would place excessive constraints on their resources.

According to the information received during the study, some educational childcare centres do not feel able to receive children with PDDs because they do not, at the present time, have the expertise they need to enrich their knowledge in order to admit and maintain atypical children. Others freely admit that as a result of having already taken on a child with a PDD, with considerable support from the health and social services network, they now know that it is possible. It is important to remember that all these initiatives are voluntary. The question of financial support from the Ministère de la Famille et des Aînés to facilitate the integration of

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[31] *Educational Childcare Act*, R.S.Q., c. S-4.1.1.

[32] As mentioned in the *Educational Childcare Regulation* (2005), c.47, s. 10.8' "A permit applicant must send an application in writing to the Minister together with the following information and documents, as applicable: the general orientations and the policies governing the admission and expelling of children".

[33] Although not obliged to do so, many daycare services have their own policies for the integration of handicapped children, including children with PDDs.

[34] Commission des droits de la personne et des droits de la jeunesse v. Garderie du Couvent Inc., cited in Note 21.

handicapped children with significant special needs has been raised and deserves attention, since many people believe that the lack of financial resources acts as a barrier to the admission of these children. The extent of the funding required and the terms of access to it need to be examined from the standpoint of facilitating the integration of children with PDDs.

The Ministère de la Famille et des Aînés, in its 2007-2008 Plan of Action, presented a number of awareness measures to improve access to daycare services for handicapped children. The educational childcare program's objectives expressly cover children with special needs. In addition, the Ministère de la Famille et des Aînés, in collaboration with the Office des personnes handicapées du Québec, sits on a number of regional issues tables that have, in many cases, demonstrated their ability to improve access to daycare services for handicapped children.

Nevertheless, the Québec Ombudsman draws the attention of the Ministère de la Famille et des Aînés to the need for guidelines that clearly define the scope of policies governing the admission and expulsion of children with special needs, and for a requirement to the effect that educational childcare permit holders must submit these policies to the MFA as part of the reporting process, thereby informing it of their admission criteria[35]. Similarly, educational childcare centres should also be required to inform parents of these criteria, and to explain why children are refused admission or expelled[36].

In recent years, the Ministère de la Famille et des Aînés has prepared a framework agreement defining the supply of basic health and social services for children attending early childhood centres, and ensuring access to those services for which the CLSC branch of the health and social services centre is responsible[37]. The results of the agreement have been assessed, and an evaluation document was published in 2008. It revealed that the outcome has been generally positive, with 74% of the local community service centres (CLSCs) having entered into agreements, and a satisfaction rate of 90% among early childhood centres for the support received from the CLSCs. The Ombudsman believes the agreement mechanism should be maintained. However, the study concurs with the evaluation findings to the effect that the supply of specialist support services from the health and social services network is somewhat uneven.

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[35] The Ministère de la Famille et des Aînés has a certain number of levers at its disposal. For example, it is able to establish rules, including rules of occupation, that childcare services must apply, and it has the power to check the accuracy of the information it is given. Childcare services are also required to submit an annual activity report, which provides the MFA with extensive information on the availability and quality of the services rendered.

[36] This recommendation is in addition to the objectives of the 2007-2008 *Plan of Action* of the Ministère de la Famille et des Aînés concerning the analysis of complaints in order to develop a better knowledge of the need for access to the MFA's documentation and services, and to reduce the number of expulsions and refusals.

[37] MINISTÈRE DE LA FAMILLE ET DE L'ENFANCE et al., *Protocole CLSC-CPE. Guide d'implantation, entente-cadre et protocole type*, Québec, Bibliothèque nationale du Québec, March 2002. (amended in 2004 to replace "CLSC" by "health and social services centre").

In addition, the evaluation revealed that the agreements have not really, or not at all, helped vulnerable children under the care of rehabilitation centres, because the centres themselves are not parties to the agreements. As a result, childcare providers do not have formal access to assistance from health and social services network specialists.

It is important to note that the role of the childcare providers is to prepare children for school. However, when these children eventually apply for school and their needs are assessed, the childcare provider only rarely passes on the information they have collected to the school concerned. Although formal links between the educational childcare centres and the education community are practically non-existent, the Québec Ombudsman believes that close collaboration is required if a clearly defined, tangible and effective relationship is to be forged [38].

4.3 The education network: Successful integration is possible

Children must be five years old in order to start preschool education, but handicapped children may be admitted at four years of age. At the same time, a transitional measure allows five-year-olds to remain in daycare for an additional year. However, they must attend school from the time they attain six years of age.

The situation described below is interesting within the context of this report, and highly revelatory as well. Some parents of children with PDDs who are old enough to start kindergarten sometimes decide to keep them at home or in daycare for an additional year. They base their decision on the fact that they believe the child is not ready to enter a system they consider to be less well adapted in terms of general supervision and physical safety, and where the child would no longer receive intensive behavioural interventions (IBIs), where the learning methods will require more of the child, where the child will be in a much larger group, and where the child's condition is more likely to result in marginalization. These parents often find it is easier for their children to integrate school after this additional year in daycare. This may be due among other things to the fact that:

- the derogation could not be given until the school authorities had agreed to the requested extension;
- tripartite contacts (daycare, school and parents) had to be forged;
- the child was know to the school before he or she started attending;
- the information forwarded from one network to the next was useful in ensuring the child's integration.

Clearly, a combination of coordination, circulation of information and involvement of the school before the child actually starts attending appear to make the transition easier. These can

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[38] Some interesting tools have been developed at the request of childcare services, to ensure that relevant information is forwarded to schools. For example, the "Passerelle" tool developed in Montérégie is often cited as a reference. However, there is very little information on the schools' interest in using the data provided by these tools.

therefore be regarded as conditions for success that should be applied consistently so that all handicapped children are able to benefit from them.

Parents often find that schools encourage their children to become more independent of their families, thereby helping them to acquire the kind of personal skills that require distance from the mother and father. However, from the standpoint of parents who have had to work hard to ensure that their children receive the services they need, schools can seem like closed environments, rather than open environments. The transition to school practitioners with the skills needed to organize the everyday lives of handicapped children in their new environment can be difficult if the teachers fail to recognize the parents' own competencies. Parents find it hard to deal with this new separation, particularly when their child comes home from school upset about something that happened during the day but unable to explain what it was. Daycare providers often give daily feedback; schools do not. In addition, parents may feel that their child has regressed because he or she is not getting the necessary support in the classroom. The school, for its part, is not getting valuable information that would help it to understand the true nature of the child. This is just one of the consequences of failing to share information.

The lack of communication between schools and childcare providers can also complicate the integration of children with PDDs. The first few days at school are key in determining what the Ministère de l'Éducation, du Loisir et du Sport describes as the "adventure" of life at school. This is true for all children, and particularly for children with PDDs.

Lastly, it should be noted that the intensive behavioural intervention (IBI) services offered by the Ministère de la Santé et des Services sociaux are intended for children who are between two and five years of age. Subsequently, the health and social services network assesses the needs of each child and his or her family, and provides the appropriate services. These services are different from the intensive behavioural intervention services provided in the past, and both the child and the family must adjust to this change.

The result of this is that, during the first few days of school, children with PDDs must not only adjust to losing the type of relationship they had with their daycare provider and the type of services they received from the health and social services network, but they must also change their relationship with their parents. Schools, for their part, while responsible for all the children, do not necessarily have the resources they need to welcome special needs children into their classrooms. On the other hand, special schools, while appropriate for some children, result in needless segregation for others.

From the standpoint of children whose condition is characterized by a profound aversion to change and considerable difficulty in accepting change, starting school becomes all the more disruptive when it involves major upsets in their lives.

We reiterate the urgent need for the three networks to remove inter-network barriers and provide easier access to services and information, despite uncertainties concerning intensive behavioural interventions (IBIs) and the integration of children receiving IBIs. These uncertainties, and the relevance of a gradual and planned transition between the approaches used by the health and educational networks, are being discussed at national level by issues tables, but at the local level, where the transitions actually take place, the change can be sudden. In an uncertain context such as this, the priority should be to maintain a close relationship with the children's parents.

The education network in particular must think up and foster new ways of including parents in their children's educational process for as long as is necessary, based on conditions derived from a combination of educational effectiveness and parental competencies. Clearly, children with PDDs should be able to benefit from a combined effort designed to improve their chances of participating in society. The complementarity agreements between the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport – excluding the Ministère de Famille et des Aînés – are designed to ensure coordination, complementarity and continuity of action. So far, however, they have not produced the anticipated benefits. Although provided for in the agreements, the sharing of expertise and of human and financial resources has not been achieved in the field.

Generally speaking, it is much easier to establish a coherent continuum of services when the division of roles and accountability is clear. The use of agreements has become the most popular way of achieving this goal. For example, the principle of service hierarchy to facilitate transfers from front-line services to specialist services in the health and social services network has more chance of being introduced quickly if targets are included in management and accountability agreements. With regard to cooperation, experience over the years has already shown that the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport are capable of dealing with shared challenges, and there is nothing to suggest that they would not be capable of doing exactly the same thing with the Ministère de la Famille et des Aînés as an additional partner.

When this report was written, the framework agreement production guide, which also covers service agreements between the health and social services network and the education network, was under review. At the same time, there were plans for the systematic introduction of an inter-sector individualized service plan to structure the transition from daycare to school.

RECOMMENDATIONS TO CREATE LINKS BETWEEN THE SERVICE NETWORKS

WHEREAS the health and social services network, through its health and social services centres and the RCID-PDDs, is an important PDD specialist within the government apparatus;

WHEREAS the educational childcare community fulfils a primary mission in the areas of integration, referral to other networks and preparation for life at school;

WHEREAS the educational childcare community must be able to rely on timely support from health and social services centre professionals when it takes on children with PDDs – while awaiting a RCID-PDD intervention – in order to avoid a situation where a child is refused by a daycare provider or expelled due to a lack of understanding of the child's condition and the steps required to address it;

WHEREAS the educational childcare community does not have a mechanism that would formalize the support from and collaboration with specialists from the health and social services network;

WHEREAS the Ministère de la Famille et des Aînés must be aware of the true benefits of its policies for the children and their parents;

WHEREAS the Ministère de la Famille et des Aînés has sufficient levers in its educational program, its partnerships and its reporting mechanisms to enable it to obtain a profile of service availability and quality;

WHEREAS parents must be properly informed of the conditions for access to daycare services.

RECOMMENDATION 2

The Québec Ombudsman recommends that the Ministère de la Famille et des Aînés should establish and monitor the implementation of guides for educational childcare services, focusing in particular on:

- **The content of policies governing the admission and expulsion of children with special needs;**
- **A method that will enable every educational childcare service permit holder to submit a specific admission and expulsion policy, so that the Ministère de la Famille et des Aînés can follow up and understand the grounds for exclusion;**
- **A method to inform parents clearly about the criteria used to accept children in educational childcare services;**
- **A requirement that every refusal or expulsion should be in compliance with the policy, be made in writing, with reasons, and be sent to the parents concerned.**

FOLLOW-UP:
The Québec Ombudsman shall be informed, by March 31, 2011, of the process that will be used to produce the proposed guide and follow-up mechanism, and a copy of the guide and follow-up procedure shall be submitted to the Québec Ombudsman by March 31, 2013.

RECOMMENDATION 3

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux and the Ministère de la Famille et des Aînés should take the steps required to ensure links between their respective networks by providing tools such as framework agreements, so that the educational childcare providers that accept children with PDDs are able to obtain the professional support they require from the health and social services centres (CLSC mission) and the RCID-PDDs, in order to provide continuity of service to the children.

FOLLOW-UP:
The Québec Ombudsman shall be informed by the representatives of each government department, no later than March 31, 2011, of the process introduced to institute these links, and copies of the draft agreements and other tools shall be submitted to the Ombudsman as soon as they are available.

RECOMMENDATION 4

The Québec Ombudsman recommends that the Ministère de la Famille et des Aînés should assess the effectiveness of its measures to integrate children with PDDs, in particular by:

- **Reviewing the relevance of the methods used to allocate its subsidies for daycare services and the subsidies composed of amounts allocated jointly with the Ministère de la Santé et des Services sociaux, in order to respond more effectively to the real needs of children with PDDs;**
- **Adjusting organizational methods by including the necessary additional resources to improve the integration process;**
- **Making the necessary corrections to future allocations and organizational methods in order to facilitate integration.**

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2012, of the results of this assessment and of the plan to implement any ensuing remedial measures.

WHEREAS the health and social services network, through its health and social services centres and the RCID-PDDs, is an important PDD specialist within the government apparatus;

WHEREAS, to be effective, the Ministère de l'Éducation, du Loisir et du Sport must have information on the prior path of children with PDDs, with due respect for the legal requirements concerning confidentiality and the protection of personal information.

RECOMMENDATION 5

The Québec Ombudsman recommends that the Ministère de l'Éducation, du Loisir et du Sport should work with the Ministère de la Famille et des Aînés in order to prepare a guide or reference framework leading to the introduction of a framework agreement to ensure that the school boards and educational childcare providers within their territories can agree on formal collaborative measures that would allow for the transfer of information and expertise regarding children with PDDs, and to allow schools to prepare for the arrival of such children at least one term in advance.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2010, of the process introduced to produce the guide or reference framework, and a copy of the guide or reference framework, along with the implementation follow-up procedure, shall be submitted to the Québec Ombudsman by March 31, 2011.

RECOMMENDATION 6

The Québec Ombudsman recommends that the Ministère de l'Éducation, du Loisir et du Sport and the Ministère de la Santé et des Services sociaux, when renewing their framework agreements, should introduce methods that will facilitate the transfer of information on the child's situation when one or other of the networks takes charge of the child, with due respect for the rules relating to confidentiality.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2011, of the process introduced to produce the agreements, and copies of the draft agreements shall be submitted to the Québec Ombudsman by March 31, 2012.

5. PARENTS AND RELATIVES WHO FACE A MAJOR UPSET IN THEIR LIVES

5.1. Understanding the situation of parents, families and relatives of people with PDDs as they negotiate the service networks, with due consideration for the emotional and psychological aspects

Receiving the diagnosis: shock, grief, and finally, acceptance and action

As mentioned, the Québec Ombudsman's study of the government services available to children with PDDs began by examining the parents' path through the network of services offered by the three government departments. It is, of course, relevant to ask why this report focuses on the situation of the parents rather than of the children? First, it goes without saying that for all children from 0 to 7 years of age, or who have finished their first year of elementary school, the parents are the primary caregivers. It is therefore the parents who interact with the service agencies that can help to ensure the child's well-being. In the case of children with PDDs, the complex interactions involved place such a heavy burden on parents that it is essential for them to feel supported, well-equipped, and prepared to accompany their child along the path that provides the best chance for development. However, it should also be remembered that during this process, the parents are carrying a considerable emotional and psychological burden that appears the moment they first suspect their child has developmental issues. **The emotional journey taken by parents generally leads them to a full acceptance of the situation. However, between these two points, they will have been severely tested as they go through the traditional stages of mourning:**

- Shock at the news of the diagnosis
- Denial of the diagnosis
- The emergence of emotionally stressful feelings, including despair, guilt, shame, rage, undermining of self-esteem, or even questioning the meaning of life
- The emergence of ambivalent feelings, such as refusing to believe the truth even while searching for a cure
- Feelings of detachment or the need to review one's priorities to be able to offer the child every possible chance for improvement
- Acceptance of the child's developmental issues, followed by action to consult available resources and defend the rights of the child

For some parents, this last stage of acceptance and action may involve resigning from their jobs, either to gain the time they need to navigate through the process, or to avoid the reactions of coworkers who are irritated by frequent absences (medical appointments, treatments, incidents at daycare or at school, and so on). In other cases, stress can even lead to the break-up of the couple.

In the case of grandparents, once the initial shock is over, some will be able to help the parents in welcoming and caring for their child, while others will not.

Siblings of children with PDDs often find it hard to come to terms with the amount of time, energy, and resources the family spends on their brother or sister. Fear, shame, and feelings of helplessness are mixed with feelings of deep attachment. However, most experts and parents maintain that brothers and sisters make a vital and extremely valuable contribution to the lives of children with PDDs. Once they understand the nature and manifestations of PDDs, brothers and sisters can play a crucial role throughout the life of their sibling. For this reason, it is essential to provide the support and information these young people will need to fulfil this significant role. Special consideration must also be given to the specific difficulties faced by the child's siblings. For example, they should be involved in the development of individualized service plans, where appropriate.

The Québec Ombudsman's study found that a large percentage of families also have a second child with a PDD. Whether or not this second child is a twin, his or her presence in the family is likely to generate special needs. However, government policies do not specify how the needs of these families are to be met. The Québec Ombudsman is of the opinion that the Ministère de la Santé et des Services sociaux must carefully examine the repercussions this situation can have for families, in order to provide appropriate services and support.

Mechanisms for taking families' needs into account are already in place in the form of intervention plans and individualized service plans. It is therefore important to ensure that these mechanisms are actually used.

RECOMMENDATION TO GIVE MORE CONSIDERATION TO THE BROTHERS AND SISTERS OF A CHILD WITH A PDD

WHEREAS siblings play a crucial role in the life of a child with a PDD and the support needed to assume this role is not specifically provided;

WHEREAS brothers and sisters often act in the place of the parents of a child with a PDD once the parents are no longer around;

WHEREAS the specific needs of families that HAVE a second child with a PDD deserve to be better understood;

WHEREAS the Ministère de la Santé et des Services sociaux is planning to define a supply of services for families.

RECOMMENDATION 7

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux should establish guidelines for professionals in its service network on how to support families and siblings of children with PDDs, as well as families that include more than one child with a PDD.

FOLLOW-UP:
A copy of these guidelines shall be deposited with the Québec Ombudsman before March 31, 2013.

A perception that often involves rejection

An additional challenge for parents is to overcome the many persistent myths and prejudices in their regard, which are due among other things to a lack of knowledge about PDDs in many service networks and in society in general. Although scientific research has disproved these beliefs, they continue to be held against parents, even today. For example:

- Parents are incapable of recognizing their child's developmental issues, causing them either to over-dramatize the situation or underestimate its importance.
- Parents are responsible for the child having a PDD, because of their attitudes and methods.
- The child will never improve and has no potential.
- The child is a considerable financial burden for the State even though he or she has no future, and deprives other children of the benefits of those funds. If the child is in a regular classroom, he or she slows down the entire group.

A lack of support can be resolved using community resources

Every stage of the parent's journey, from the time the child's developmental issues first become apparent, throughout the ensuing period of doubt, while travelling back and forth between healthcare professionals to try and learn about the condition, or when the diagnosis is first made, can be painful, distressing, and lonely. Waiting times are an additional source of concern. Lonely, overwhelmed by their problems and in need of support, parents find little comfort in the public services, at least not in the short term. However, the Québec Ombudsman's study found that community organizations can provide parents with new and valuable help. By bringing together people in similar situations, within a flexible structure, these organizations are able to respond to requests for help in the weeks or days immediately following their first contact with a parent in distress. If necessary, they can also adjust to non-standard working hours.

The Québec Ombudsman observed that these organizations were able to provide immediate, supportive assistance on the following issues:

- Information on existing resources and how to access them
- Improvement of parental skills
- Recurrent and occasional support
- Referrals
- Assistance with procedural aspects (especially for obtaining subsidies and allowances) and exercising their rights
- Suggestions for intervening with the child
- Support during times of discouragement or crisis
- Relief of loneliness
- Access to respite and daycare services, day camps, summer camps and other leisure activities
- Help with homework
- Support during the stages of mourning

Practitioners in these community organizations must be able to count on contacts with professionals from the three networks—the Ministère de la Santé et des Services sociaux, the Ministère de la Famille et des Aînés, and the Ministère de l'Éducation, du Loisir et du Sport—in order to:

- Act effectively and within their particular role in the lives of the parents and child
- Benefit, where appropriate, from the networks' information about the children and families that either come to them or are referred to them, in order to provide the help they need as quickly as possible
- Have access to the same opportunities as public network practitioners for increasing their understanding of PDDs

With this in mind, the Ministère de la Santé et des Services sociaux, as it restructures its network, must recognize the role played by community organizations in the lives of children with PDDs and their families, and must ensure that bidirectional links are forged between these organizations and its own professionals.

5.2. Funding of services and budget allocations

Some of the participants in our study commented on the financial assistance granted by the various government authorities to people with PDDs. Some of their comments suggested that the client group composed of children with PDDs receives significant sums of money, while others suggested that the sums granted are insufficient.

With the help of a specialist[39], the Québec Ombudsman was able to gather data on financing and budget allocation methods. The data in question are published by the government departments concerned, usually on their websites. In Québec, four departments are directly or indirectly involved in granting funds to children with PDDs. They are the Ministère de l'Éducation, du Loisir et du Sport, the Ministère de la Famille et des Aînés, the Ministère des Finances through the Régie des rentes du Québec, and lastly, the Ministère de la Santé et des Services sociaux.

First observation: The amounts are granted out of a budget envelope intended for several different client groups.

Second observation: Within these shared envelopes, it is impossible to identify the portion allocated to people with PDDs[40]. In addition, while it is possible to monitor the rate of increase in the amounts granted, it is not possible to judge the relevance of the initial allocation for each department. Information is not available on the precise nature or amount of the resources required to achieve any given program or to dispense any particular service.

In other words, the departments do not provide data on the connection between the needs of the children and families that they wish to meet and:

- the resources needed to meet those needs, or
- the cost of those resources.

The precise cost of the various services is not known, and it is therefore impossible to establish how much each child or each family should receive, on average, according to the promises made in the Government's programs. As a result, increases in the amounts granted could be either top-up payments compensating for an initial investment that was insufficient, or real investments of new money.

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[39] Mr. Jean-Noël Thériault of JNT Conseils.

[40] Even the Ministère de l'Éducation, du Loisir et du Sport is unable to identify the amounts allocated to people with PDDs. However, the school boards are able to identify the type of direct services instituted for each individual handicapped student.

Third observation: The reference period for budgets is not conducive to continuous service. Budgets are granted annually, with the resulting uncertainty, particularly for community organizations, as to whether they will actually be renewed the following year. This can cause some services to be discontinued, and make it difficult to retain experienced staff. In 2008, in a brief on homelessness[41], the Québec Ombudsman favoured a review of budget periods, proposing that they should ideally be extended to three years, in order to consolidate the supply of services.

Fourth observation: The complex formalities surrounding the financing process, as described by parents, is clearly confirmed. This is due to the fact that parents must not only comply with administrative requirements in order to obtain direct funding, but must also complete certain other finalities for indirect funding with amounts paid to the authorities providing the services. The table below summarizes the most important components of funding for parents, along with the associated requirements.

Government departments and type of allocation (universal or specific)	**Direct funding paid to parents (subsidies or credits)**	**Indirect funding paid to authorities**
Ministère des Finances du Québec and Canadian Department of Finance: tax credits	Parents must be familiar with and understand the exemptions to which they are entitled and provide attestations, including an assessment by a health professional.	
Ministère des Finances du Québec: Child Support (Régie des rentes du Québec)	Universal measure available to all parents; eligibility is established from the income tax return.	
Ministère des Finances du Québec: Handicapped Children's Supplement (Régie des rentes du Québec)	Parents must submit a form, part of which must be completed by a professional in order to prove the child's condition.	
Ministère de la Santé et des Services sociaux: Family Support Program via the health and social services centres	Parents must comply with the access conditions established by the health and social services centres (forms, needs assessment, accounting for amounts granted).	
Ministère de la Santé et des Services sociaux: Home Maintenance Program via the health and social services centres	Parents must comply with the access conditions established by the health and social services centres (forms, needs assessment, accounting for amounts granted).	

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[41] PROTECTEUR DU CITOYEN, *Phénomène de l'itinérance au Québec.* Mémoire présenté à la Commission des affaires sociales, octobre 2008.

Government departments and type of allocation (universal or specific)	Direct funding paid to parents (subsidies or credits)	Indirect funding paid to authorities
Ministère de la Famille et des Aînés: Allowances paid to daycare providers for integration of handicapped children		Parents must provide an attestation from the Régie des rentes du Québec or a report from a professional, confirming the child's impairments or handicaps[42].
Ministère de l'Éducation, du Loisir et du Sport: Allowance paid to school boards		Parents must provide confirmation of the diagnosis

Given the large number of forms to be completed in order to enable children with PDDs, and their parents, to obtain all the credits, subsidies and services available to them, there is a clear case for a single wicket approach to program access, at least for allowances of a similar nature.

However, it is difficult to comment on or make recommendations concerning service funding levels. In short, in the case of the Ministère de l'Éducation, du Loisir et du Sport, the available funds are intended for all children with handicaps or learning or adaptation disorders (referred to by the French acronym EHDAA), to cover operating expenses. It is up to the school boards to assign the amounts received. In the case of the Ministère de la Famille et des Aînés, an allowance for the integration of handicapped children is paid to daycare providers[43] in order to cover the additional expenses incurred during the process. Some children also receive additional financial assistance due to the severity of their handicaps. These payments are made under the *Exceptional Assistance Measure for the Integration of Disabled Children with Major Needs into Childcare Services,* financed jointly by the Ministère de la Santé et des Services sociaux and the Ministère de la Famille et des Aînés. In the case of the Ministère des Finances, the Régie des rentes du Québec manages the *Supplement for Handicapped Children.* In the case of the Ministère de la Santé et des Services sociaux, the available monies are taken from a budget intended for the *Intellectual Disability and PDD* program. The following table shows the amounts available from the various government departments.

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[42] Parents must also work with the daycare provider to draw up an integration plan for their children.

[43] Early childhood centres, subsidized daycare providers and coordinating offices for family daycare units.

Measure and fiscal year	**MELS**	**MFA**	**MF/RRQ**	**MSSS**
EHDAA: 2006-2007 operating expenses, based on original budgets	$1 530 000 000			
Allowance paid to 2006-2007 daycare services for 3 500 children		$22 900 000		
Exceptional joint integration support measure in 2006-2007 for 98 children		$180 000		$180 000
Supplement for Handicapped Children program: Cost of measure in 2007-2008			$3 400 000	
Intellectual Disability and PDD Program in 2004-2005				$590 300 000
Intellectual Disability and PDD Program in 2006-2007				$689 000 000

The budget granted by the Ministère de la Santé et des Services sociaux is divided among the community organizations, health and social services centres and other categories of institutions, including rehabilitation centres, for the provision of first-line and second-line services. According to the Ministère de la Santé et des Services sociaux, the budgets intended for home services, including support for the families of people with PDDs, are financed from the portion of the budget assigned to front-line services. Intensive behavioural interventions (IBI) are treated as second-line services, under the "social integration support" heading. It is important to remember that children with PDDs also receive general services, the cost of which is paid out of other budgets. For example, the medical services required to obtain a diagnosis are funded out of the budget of the Régie de l'assurance maladie du Québec. The following table shows the breakdown of the *Intellectual Disability and PDD* Program budget.

Allowance and fiscal year/budget share	Community organizations	Health and social services centres	Other institutions
(Approximate) allowance for service providers in 2005-2006	2 %	10 %	88 %
Allowance and fiscal year/budget share	General and specialized services		Specialized IBI service
First-line services including home services for the entire program	6 %		
Second-line services in 2005-2006 for the entire program			21 %
(Approximate) portion allocated specifically to children with PDDs in 2006-2007			3 %

The budget allocation method used by the Ministère de la Santé et des Services sociaux deserves special attention, given that a number of questions have been raised since the restructuring of the health and social services network undertaken in June 2004 concerning the impact of the principle of population responsibility on budget allocations.

Under the principle of population responsibility, all the stakeholders offering services to the population of a given area are deemed to share responsibility for that population, by providing as complete a set of services as possible. If this principle were to be applied strictly, then the local authorities would need an accurate profile of the population with PDDs in order to decide how much money should be allocated to them. Clearly, the number of people with PDDs, along with prevalence (i.e. the total number of people at a given time), would be a significant element in this profile. The regional authorities granting funds to local institutions would then need to receive sufficient budgets to cover these local profiles.

In reality, however, budgets are not allocated in the way described above. A new budget allocation method was introduced on April 1, 2004, and has gradually replaced the former method based on budget history. Under this latter method, the budget for a given year is established for the most part on the basis of the budget for the previous year, leaving very little room for adjustments to reflect changes in service volume and intensity. The new method is intended to ensure that budgets are distributed fairly between the regions. It takes a certain number of features into account, such as remoteness and dispersion, as well as the presence of institutions providing special services, such as the university hospitals and clinics. The budget allocation also includes amounts for special activities, along with centrally-administered amounts.

The process of change is therefore still in its initial stages, and inter-regional inequities will gradually be corrected. However, the correction process is slow, because the Ministère de la Santé et des Services sociaux has elected to cover differences in budgets out of the development portion of its allowances.

Given the ongoing changes to the budget allocation methods, we were unable to find the expense-related information we needed to calculate the relative share given to each type of program client group. The Ministère de la Santé et des Services sociaux itself does not have full information on this aspect. However, reliable information on the various client categories is not necessarily required, or needed, because budgets are established on the basis of other criteria. It would therefore be premature to suggest that data from a study of prevalence would be needed as a basis for the resource allocation process. Similarly, it is beyond the scope of this study to give an opinion on the epidemiological interest and complex technical issues of this type of study.

Nevertheless, it is important for the government departments that provide funding to identify the number of new PDD diagnoses made each year in Québec, so as to be aware of how the situation is evolving over time. With this information, they would be in a position to ensure that budget increases were in line with the increase in the percentage of the population with PDDs.

The burden of financial worries and the never-ending formalities

The parents of children with PDDs are faced with some significant financial costs, not only to meet their children's special needs, but also to address the additional demands placed on their own time. Among other things, they need:

- respite;
- support in emergencies;
- babysitters;
- help around the house;
- assistance with hygiene.

These types of needs are acknowledged by the Ministère de la Santé et des Services sociaux, which relies on the community agencies to provide a large proportion of the related services. However, many community agencies do not think the Government gives them sufficient financial support for this task.

As far as the parents are concerned, there are two principal sources of financial assistance for support services:

- The Family Support Program and the Home Maintenance Program, administered by the CLSC-branch of the health and social services centres;
- The Child Support and Supplement for Handicapped Children programs, administered by the Régie des rentes du Québec.

In the case of the health and social services centres' subsidies, we were told that parents often do not know of their existence (agencies, formalities, conditions, amounts available). When they are eventually told about them, they apply but must generally face long delays before learning whether or not they are eligible. If they do qualify, they may have to wait even longer if the annual budget has been exhausted, in which case benefit payments are postponed. Once they have received the assistance, they often find that it is insufficient to meet their needs, and must still pay a significant percentage of the cost out of their own pockets, as was previously the case at earlier phases of the process. Moreover, the amount of support and the way it is allocated varies from region to region.

The health and social services centres do not all have banks of respite care resources, due to the special skills required to work with children with PDDs. It also takes time to obtain the initial needs assessment appointment, and the only factor that appears to shorten the wait is clear evidence to the effect that the parents are exhausted and the child will have to be placed if help is not forthcoming quickly.

With regard to the programs offered by the Régie des rentes du Québec, the Québec Ombudsman was told that the Régie is working closely with the Ministère de la Famille et des Aînés on the terms of access to parental support measures. The problem here is due to the fact that the allocation rules are outdated. They were introduced the early 1980s, when PDDs were poorly defined and often associated with mental disorders and intellectual handicaps. Institutionalization was still common practice at the time. As a result of this, children must be severely handicapped to qualify for support. However, this approach is unsuited to the problems specific to PDDs, which are related more to the range of disabling factors, which are extremely demanding for parents, than to the severity of the child's limitations. Support from the Régie des rentes should also be in addition to the other subsidies paid to parents, so that the allocation formalities can be simplified.

In 2007, the Office des personnes handicapées du Québec[44] issued a number of observations to the effect that it was necessary to set up a single window concept for access to information on the various support measures available to handicapped people and their families, and that an effort should be made to standardize and simplify the access rules.

It is therefore clear that a single window concept would do much to simplify matters for parents.

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[44] The mission of the Office des personnes handicapées du Québec is to enforce the principles and rules set out in the Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration, and to ensure, within the scope of its powers, that government departments and their networks, municipalities, and public and private agencies, continue their efforts to improve the potential for handicapped people to integrate and participate fully in life in society. With regard to relationships with Québec authorities, the Office has the power to oversee local, regional and national implementation of the inter-sector actions required to integrate handicapped individuals or groups of individuals, and in particular, upon request, to help coordinate these actions. The Office also carries out promotional initiatives, makes recommendations and performs evaluations.

RECOMMENDATIONS AIMED AT SIMPLIFYING THE STEPS TAKEN BY PARENTS TO OBTAIN FINANCIAL ASSISTANCE

WHEREAS the parents of children with PDDs are eligible for special financial assistance and, to obtain that assistance, must contact the entities responsible for a broad range of programs with an equally broad range of administrative formalities;

WHEREAS these parents must, among other things, repeatedly satisfy requests for justifications and attestations from subsidizing organizations;

WHEREAS the Office des personnes handicapées du Québec has already worked with numerous partners to produce an in-depth reflection on the question of financial support for handicapped people and their families;

WHEREAS the Ministère de la Famille et des Aînés is concerned with the harmonization of family support programs.

RECOMMENDATION 8

The Québec Ombudsman recommends that the health and social services network and the Ministère de la Famille et des Aînés should inform it of the steps currently being taken to harmonize family support programs with a view to meeting the needs of parents more effectively, including a review of the allocation rules and access procedures of financial support programs for the parents of children with PDDs, in order to avoid duplication of processes, the imposition of different requirements, unjustified exclusions and generally cumbersome administrative requirements.

FOLLOW-UP:
A person shall be formally appointed by each of the government departments, by December 31, 2009, to provide the Québec Ombudsman with annual reports on the steps taken to harmonize current programs or new programs.

RECOMMENDATION 9

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux should harmonize the family support practices of the health and social services centres, and that the Office des personnes handicapées du Québec, in conjunction with all the other authorities involved in the allocation of financial assistance to the parents of children with PDDs, should assess the relevance of a single wicket or other mechanism as a means of facilitating parental access to the information and monies they need.

FOLLOW-UP:
A person shall be formally appointed by the Ministère de la Santé et des Services sociaux, no later than December 31, 2009, to provide the Québec Ombudsman with annual reports on the steps taken to harmonize the practices of the health and social services centres, and a person from the Office des personnes handicapées du Québec shall be appointed to provide the Québec Ombudsman, no later than March 31, 2012, with the outcome of the evaluation concerning the relevance of the single wicket or other mechanism, in order to agree upon follow-up to this recommendation.

6. THE JOURNEY ACROSS THREE SERVICE NETWORKS: OBSTACLES FOR PARENTS, IMPACTS FOR CHILDREN

6.1. Required information and awareness among practitioners and the public

We have noted that information flows awkwardly and unevenly at the local level[45] within networks and from one network to another, resulting in ruptures of service and obstacles for children with PDD and their families. What about the information given to the people who are most concerned – in other words, the children's parents, the practitioners who work with them, and the groups most directly affected by the situation faced by children with PDD? And what about the other parents whose children attend childcare establishments or schools where a child with PDD is integrated, not to mention children from First Nations communities, immigrant families or cultural communities, whose integration poses additional challenges?

The complexity of ensuring the availability of appropriate, up-to-date information always relates back to the same issues, namely the nature of PDDs themselves – and the lingering inaccuracies in our knowledge of them – plus the lack of connectivity within and between the networks.

The 2003 Ministerial Orientations sought to improve access to services for children with PDDs. At the same time, the principles behind the restructuring of the health and social services network were also shifting in the same direction. Every health and social services centre should be serving as a gateway to services for all the residents in its territory, and particularly for children with PDDs. But this is not the case in many areas: even since the adoption of these policies, parents are still invariably forced – both before and after diagnosis – to undertake arduous research in order to obtain appropriate information and services, arrange appointments with front-line practitioners and specialists who can provide them with appropriate services, and find the resources that will give their child the best chances of development. And they must do all this at a time when they themselves are struggling to accept a difficult situation. The health and social services centres need to speed up the implementation of the reform and take steps to create service corridors with their partners. They must be familiar with the means available, identify the stakeholders, refer people appropriately and then ensure that the service continuum is effectively in place. In the long run, parents should be able to recognize the health and social services centres as the places where:

- their journey begins;
- they are referred to practitioners who thoroughly understand PDD issues;

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[45] At the provincial level, the Office des personnes handicapées du Québec offers an reception, information and referral service and provides a variety of documentation on all issues of relevance to disabled people. This chapter is concerned with the lack of local information at the service points.

- they obtain the support they need to feel understood, be informed, and be guided by the practitioners;
- they are referred to services designed specifically for them;
- they obtain complementary services before, during and after the provision of specialized services, if necessary, or useful referrals.

The Québec Ombudsman fully supports these objectives, but notes that they have not yet all been achieved.

Childcare providers do not currently receive the information and cooperation they need from health and social services network specialists to fulfil their role with the parents of children with PDDs. In principle, this role would be to provide valid information about the status of a child suspected of having a PDD; that is, to refer the child to the right place in the public service network. Subsequently, the information about the child should be shared in both directions to allow for follow-up by the childcare provider in cooperation with the health and social services centre.

Both the health and social services network (health and social services centres, physicians' offices) and educational childcare providers have problems when it comes to informing parents about the role of the rehabilitation centres for intellectual disabilities and pervasive developmental disorders (RCID-PDDs), which are responsible for arranging intensive behavioural interventions (IBI) and other forms of habilitation/rehabilitation services for children with PDDs. While every practitioner from every network need not be conversant with the details of the rehabilitation centre service supply, they should at least be able to tell parents where to obtain the relevant information quickly.

Schools suffer from the same shortfalls in terms of the information they give to parents, with the result that parents often receive no indication of potential avenues for intervention, preferred pedagogical approaches for the child, or specialized professional services available through the school network.

The result is that none of the three networks assumes full responsibility for informing the parents in their quest for services and explanations. In the opinion of the Québec Ombudsman, this situation is due mainly to a lack of information in the three networks concerning PDDs, their clinical features, and the most widely recommended sequence of services in the field. In concrete terms, while each of these stakeholders could in theory provide constructive support for parents on PDD issues or existing resources, or direct them to sources with more information, they are not carrying out their role as they should, causing parents to go back and forth from one institution to another.

In general, children are subjected to a variety of health checks, routine examinations and vaccinations. These evaluations should allow for more useful discussions between the various practitioners and should guarantee rapid admission to other health and social services programs, and to specialized services if required. If the practitioners know what PDDs are and are familiar with the best responses to them, based on current knowledge of diagnostic support, parental support and management by the educational childcare provider or school, then they should put that knowledge to use. In reality, however, practitioners do not necessarily have the resources, tools and information they need to play this supporting and guiding role. Furthermore, there are some ethical issues to consider if they suspect a child has a PDD. If they are not certain that the child will be admitted quickly to the required follow-up services, they find themselves facing a dilemma. If staff shortages and waiting times will, in any case, delay the child's acceptance for treatment for several months – and often more than a year – the practitioners may see no urgency to act or share their concerns with the parents. Since they cannot make the diagnosis and do not have information on the best way to proceed from an ethical point of view, many are likely to hesitate before revealing observations that will have such a serious impact. As mentioned earlier, it is not easy to separate the clinical features of a PDD from the range of other possibilities, and mistakes can have serious consequences.

At the same time, public awareness of PDDs can defuse fears and misunderstandings. While such awareness is desirable in any group, it is absolutely vital for the parents who are directly affected, including those whose children are exposed to children with PDDs. Awareness can help change the group dynamics in daycares and classrooms. The rejections so often experienced by children with PDDs and their parents are frequently due to ignorance on the part of other parents and children, who feel uncomfortable around children whose behaviour can sometimes be disconcerting.

Information is key to resolving these concerns, and yet little use is made of technology as a means of circulating and sharing information both among the networks and with the public. An analysis of the websites of government departments and their networks reveals that relevant information is hard to find and that the discourse is disjointed, for both the public and practitioners alike.

On June 4, 2009, the Conseil des ministres adopted a policy called *À part entière : pour un véritable exercice du droit à l'égalité.* This policy was adopted because the Act to amend the Act to secure the handicapped in the exercise of their rights and other legislative provisions required the Office des personnes handicapées du Québec to update its corporate policy *À part... égale,* which dated back to 1984. The new policy seeks to increase the social participation of handicapped people over a ten-year period. Along with the Act, it provides a solid foundation to guide government actions with respect to handicapped people and their families. In addition, it serves as a valuable asset for the government departments, agencies and municipalities that must, under the Act, produce annual plans of action aimed at removing obstacles to participation for handicapped people.

RECOMMENDATIONS TO IMPROVE ACCESS TO INFORMATION, AWARENESS AND PDD IDENTIFICATION

WHEREAS the *Orientations ministérielles 2003 – Un geste porteur d'avenir. Des services aux personnes présentant un trouble envahissant du développement, à leurs familles et à leurs proches* contains provisions that recognize the importance of information for all practitioners and parents;

WHEREAS practitioners in the three networks – health and social services, educational childcare and education – have a major role to play in providing information and raising awareness about PDDs;

WHEREAS there are currently some significant gaps in terms of parental access to information and PDD identification, and parents must undertake complex procedures, the length of which is likely to hinder the child's development and upset the family's balance;

WHEREAS practitioners in all three networks should act as conduits of knowledge concerning the most appropriate approaches and services, in order to lessen the burden on parents, increase the effectiveness of the sources, and foster concerted action among the three networks;

RECOMMENDATION 10

The Québec Ombudsman recommends that the health and social services network, the childcare network and the Ministère de l'Éducation, du Loisir et du Sport should ensure that the personnel responsible for providing assistance to parents and children have proper access to information on the nature of PDDs and on the resources available within the three networks, in order to provide better service to the parents and children, on a continuous basis. In other words, they should:

- **be able to tell parents what do to (steps, contacts, services);**
- **be able to guide parents appropriately within a reasonable timeframe;**
- **facilitate intake of children and parents by the appropriate services**

FOLLOW-UP:
The Québec Ombudsman shall be informed by a designated representative of each government department, no later than March 31, 2011, of the mechanism proposed to follow through on this recommendation.

RECOMMENDATION 11

The Québec Ombudsman recommends that the Ministère de la Famille et des Aînés should participate in inter-sector round tables involving the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport and in all types of government discussions where any decisions and actions will affect children with PDDs.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2011, of the means implemented to arrange the participation of the Ministère de la Famille et des Aînés.

6.2. *Case manager*:[46] Role and current place

To simplify access to services for children with PDDs, the Ministère de la Santé et des Services sociaux relies on professionals who serve as navigators, to ensure that parents do not find themselves alone and unguided in their search for services. The 2003 MSSS guidelines connect the navigators to the health and social services centres, but also seem to suggest that they might work out of rehabilitation centres, thereby creating some confusion. For navigators to fulfil their role:

- They must be allowed to oversee the complementarity of interventions in all three service networks (information, coordination, communication and liaison roles);
- Their role must be known;
- Their connection to the health and social services centre (port of entry) must be clear;
- Their interventions must be accepted by all the partners in the three networks.

However, the Québec Ombudsman has found that the navigators are not widely accepted as the people in charge of coordinating these services.

Part of the problem derives from the definition of the navigator's task. According to the 2003 Ministerial Orientations, navigators are responsible for coordinating services and clinical interventions in their field of professional expertise.[47] The navigators themselves deem this dual task almost impossible to fulfil. The other problems noted by the Québec Ombudsman in the field were as follows:

- The "service coordination" aspect is often perceived by other practitioners as an intrusion on their work.
- The coordination task is further complicated by the fact that the navigator has no power conferring authority over other practitioners. The sequence of services that navigators may suggest is subject to the goodwill of the people who provide them. Overall, practitioners are generally in favour of the navigator's mission … as long as he or she does not encroach on their territory.
- The fact that the navigator is anchored to a specific area of expertise and continues to work in it, for example as a social worker for individuals and families, causes confusion for parents who have trouble grasping the navigator's role and limitations (they are more likely to view the navigator as a clinician rather than a coordinator).
- Clarification of the division between the navigator's role and the role of the individual service plan (ISP) coordinator would help resolve some of the confusion.
- Practitioners in all three networks are often unaware of the existence of the navigator, or when they are aware, they consider the navigator to have little expertise in the area of PDDs.
- The navigators often have no specific expertise in PDDs. When they do, that expertise is questioned if it turns out that their understanding of PDD issues is not compatible with that of more specialized practitioners, such as rehabilitation centre staff.

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[46] *Case manager*, or navigator, is a dedicated expression used by the Ministère de la Santé et des Services sociaux.

[47] MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX, *op.cit*., note 1.

From the parents' point of view, it would be useful to be able to count on a reliable source of reference and service coordination, but in reality they encounter a variety of problems with navigators. For example:

- There is no navigator.
- There is a navigator, but one who has little experience with the realities of PDDs.
- The navigator cannot really facilitate access to services or transitions between service levels.

In light of this, parents and practitioners alike are more inclined to deal directly with resources at the rehabilitation centre, school or elsewhere, in order to reduce delays between requests for service and service delivery. This is obviously contrary to the scenario suggested under the reform, which involves using the health and social services centre as the port of entry to the network.

Another phenomenon concerning the role of navigator is that, currently, the role combines so many different tasks:

- Organizer of assistance and relief care;
- Supporter for families facing long waiting times;
- Coordinator of individual service plans;
- Clinician assigned to specific habilitation services;
- Specialized rehabilitation centre educator;
- Defender of the rights and interests of children with PDDs;
- Stakeholder of some importance as a service navigator at the beginning of the parents' journey but who eventually cedes this place to rehabilitation centre practitioners or school personnel;
- Resource for children in crisis and requiring third-line services (superspecialized services provided by hospitals);
- Overworked resource, since new cases are identified every year and the irreversible diagnosis demands ongoing intervention adjusted to the individual's changing needs throughout his or her lifetime.

We can therefore conclude that the navigator's mission is amorphous, subject to widely varied interpretations, and not very realistic.

In June 2008, the Ministère de la Santé et des Services sociaux published a service access plan for people with physical or intellectual disabilities or PDDs.[48] In this document, it used the term "*case manager*" to designate the person responsible for coordinating services for children and families. It also says, however, that there should be one *case manager* (or institutional navigator) for institutional services and another (network navigator) to coordinate the individual service plan. The network navigator maintains ties with the institutional navigators to coordinate the interventions under their responsibility. The logic behind this "superimposition" of navigators is not explained, and the document does not clearly identify the impact for parents attempting to coordinate all the various services.

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[48] MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX, *Afin de mieux faire ensemble – Plan d'accès aux services pour les personnes ayant une déficience*, Quebec City, Bibliothèque nationale du Québec, June 2008, 75 p.

In fact, for the last few years, the focus has been more on mechanisms that promote continuity, such as intervention plans or individual service plans, than on the people in charge of implementing those mechanisms. For example, in 2009-2010, training on the plans has been arranged, but discussions of the competencies required to coordinate those plans have only just begun, in both the health and social services network and the education network. Furthermore, the matter of leadership does not seem to have been considered. Current documentation invites partners to participate, but does not specify who is in charge. The uneven application may result in a lack of clear direction.

As part of the follow-up to the complementarity agreement between the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport, an evaluation is currently underway and the results should be available soon. The results of this evaluation should be used to support the work required to reinforce the role of the navigator.

RECOMMENDATION TO ESTABLISH THE ROLE OF THE NAVIGATOR IN THE SERVICE STRUCTURE

WHEREAS the service coordination needs of people with PDDs and their parents are not being met, especially due to the numerous practitioners appointed to fulfil this role;

WHEREAS the role of navigator is not well known in the health and social services, educational childcare and education networks, is not properly incorporated into the trajectory of parents of children with PDDs, and is a shared responsibility, due to the inter-sector nature of the role;

WHEREAS beyond the provincial leadership role played by the Office des personnes handicapées du Québec on the notion of individualized and coordinated service planning, involved practitioners who support children and their parents in their trajectory, primarily by coordinating and implementing the service plan, are not widely available;

RECOMMENDATION 12

The Québec Ombudsman recommends that the three government departments – the Ministère de la Santé et des Services sociaux, the Ministère de la Famille et des Aînés, and the Ministère de l'Éducation, du Loisir et du Sport – working in conjunction with the Office des personnes handicapées du Québec, should redefine the inter-sector function of the navigator by undertaking an evaluation to identify the conditions for success that will reinforce the navigators' true role as major players with parents and with other practitioners working in various service areas.

FOLLOW-UP:
Respondents from each of the three government ministries shall report to the Québec Ombudsman, no later than March 31, 2011, on the objectives of the evaluation, the division of responsibility and their respective department's contribution to the inter-sector effort, and, in 2013-2014, shall meet with the Québec Ombudsman to share the information acquired during the evaluation and agree on future actions.

6.3. Habilitation/rehabilitation services: The importance of diagnosis for accessing services

Although the 2003 Ministerial Orientations stipulate that the service structure for people with PDDs must be based on meeting people's needs, rather than on the presence or absence of a diagnosis,[49] the Québec Ombudsman's study shows that the diagnosis is the only real trigger for habilitation/rehabilitation services. This highlights the critical importance of diagnosis and the absolute need for parents to know where to go to obtain one. There is also lingering confusion for parents between two very different notions:

- Diagnostic evaluation: It can be made by a multidisciplinary team of trained clinicians that may include a doctor, but the result must, in all cases, be confirmed by the doctor.
- Doctor's diagnosis: The responsibility lies entirely with the doctor. The doctor may be assisted by a multidisciplinary team and may take the diagnostic evaluation into account.

The result is that:

- A diagnosis can only be made by a doctor, and obtaining a diagnosis is usually a complex task for parents (Where to go? What type of doctor to consult?) that involves long wait times of up to two years.
- In the meantime, parents may also be asked to obtain an assessment of the child's handicap or impairment, so that the childcare establishment can apply for financial support from the Ministère de la Famille et des Aînés. Given that the assessment report can be provided by someone other than a doctor, it is not considered to be a medical diagnosis. But parents often mistake it for the magical medical diagnosis that will finally open some doors for them, by providing access to specialized habilitation/rehabilitation services.
- In addition, confirmation of the diagnostic evaluation is sometimes required by the Ministère de l'Éducation, du Loisir et du Sport once the child reaches school age.

If we go back to the journey of André-Tim described earlier in this report, we see that the requirements of the three networks:

- are different;
- are a source of confusion and require the parents to engage in several different processes;
- lengthen and increase the burden of the search for services

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[49] MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX, *op.cit.*, note 1.

In addition, the health and social services centre's vocation as the gateway to services is not widely understood.

The Ministère de la Santé et des Services sociaux should ensure that the health and social services centres immediately embrace their gateway role, managing access to services and especially access to diagnosis, so that the general public and the service providers turn to them for the help and resources they need, or for referrals to appropriate services.

In June 2008, the Ministère de la Santé et des Services sociaux published a service access plan for people with physical and intellectual disabilities and PDDs. The plan establishes a standard of 30 days as the maximum wait time for access to specific services when the request is classified as a high priority level.[50]

In spite of discussions between the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport concerning the different diagnosis confirmation requirements to gain access to services, no solution has yet been found and there is no apparent reason for the delay.

RECOMMENDATIONS TO FACILITATE ACCESS TO THE PDD DIAGNOSIS AND APPROPRIATE SERVICES

WHEREAS access to specific front-line habilitation/rehabilitation services should not depend solely on obtaining a PDD diagnosis and may begin before the diagnostic evaluation has been completed;

WHEREAS parents are obliged to undertake numerous procedures to obtain or confirm a PDD diagnosis for their child;

WHEREAS it is important, given the shortage of health care professionals, not to increase the number of interventions required.

RECOMMENDATION 13

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux should ensure that children awaiting a PDD diagnosis receive specific services based on their condition and needs, in accordance with the conditions and timelines set out in the 2008 service access plan.

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[50] It should be remembered that the specific services offered by health and social services centres do not include diagnostic evaluation. Depending on the regional service structure, diagnostic evaluation may be provided by hospitals or professionals in rehabilitation centres.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2011, of the way in which the Ministère de la Santé et des Services sociaux plans to ensure that the health and social services centres are offering these services when required, and the Ministère shall report annually to the Québec Ombudsman on the results of the health and social services centres' accountability with regard to this recommendation.

RECOMMENDATION 14

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux, the Ministère de la Famille et des Aînés and the Ministère de l'Éducation, du Loisir et du Sport should ensure that their respective networks, including childcare services, harmonize their diagnosis and confirmation requirements to save parents from an avoidable increase in procedures.

FOLLOW-UP:
The respondent from each of the three government departments shall report annually to the Québec Ombudsman on the follow-up to this recommendation until the requirements have been properly harmonized.

RECOMMENDATION 15

The Québec Ombudsman recommends that the Ministère de la Famille et des Aînés should take the necessary steps to ensure that the educational childcare services, once they have been informed that a parent has obtained a report from a professional confirming the child's disability or impairment for the purpose of a childcare subsidy, immediately refer the parent to the area's health and social services centre so that the process of obtaining a medical diagnosis can begin.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2011, of the means offered to the childcare services and the initiatives planned as follow-up to this recommendation, such as information provided directly to parents by the Ministère de la Famille et des Aînés when the childcare subsidy is granted, and a report on these means shall be submitted to the Québec Ombudsman by March 31, 2013.

RECOMMENDATION 16

The Québec Ombudsman recommends that the Ministère de l'Éducation, du Loisir et du Sport should examine the financing conditions for handicapped student services in order to simplify the process and facilitate the allocation of assistance, particularly when a child has already obtained a medical diagnosis for a lifetime condition such as a PDD. The requirement for the parent to produce a confirmation of the child's diagnostic evaluation on entering school should be abolished.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2011, of the steps taken in response to this recommendation.

6.4. Wait times

The journey taken by André-Tim and his parent was not only replete with formalities, especially surrounding the diagnosis, but also involved unreasonable delays that became a serious problem. The Québec Ombudsman believes that, while it is understandable for delays and waiting lists to exist, steps must nevertheless be taken to reduce delays that are unreasonable and that may damage the person's health and security. The Québec Ombudsman's study revealed that André-Tim and his parent were likely to encounter delays throughout their journey:

- Before obtaining confirmation of the child's handicap, disability or impairment;
- Before obtaining a diagnosis or confirmation;
- Before the first evaluation at the CLSC-branch of the health and social services centre;
- Before the file is assigned to a professional at the CLSC-branch of the health and social services centre;
- Before an intervention plan is developed by the health and social services centre;
- Before the first evaluation at the rehabilitation centre;
- Before the file is assigned to a professional at the rehabilitation centre;
- Before preparation of the rehabilitation centre intervention plan or the individual service plan[51] involving contributions from professionals at the health and social services centre and the rehabilitation centre;
- Before obtaining specialized habilitation/rehabilitation services;
- Before obtaining services in the community (day camps, vacation camps, transportation, sports activities, artistic or recreational activities);
- Before obtaining specific services other than specialized adaptation services, before, during and after episodes of service adaptation, etc.;
- Before being given a place at school in a classroom appropriate for the child;
- Before being given a place in the school daycare service;
- Before the appointment of a new practitioner, when the practitioner assigned to the child is absent for a long period of time.

The Québec Ombudsman's study did not attempt to establish an "acceptable" waiting time, nor did it try to specifically establish waiting times for each step, as these may vary considerably from one person to another or from one time to another, and may overlap (the child is on several waiting lists at the same time for different services). Nevertheless, the Québec Ombudsman found that the service structure for a child with a PDD quickly becomes overwhelming for the parent, who encounters delays at all or nearly all the stages listed above, each of which can only be negotiated with a good dose of vigilance, patience and determination. Once again, a lack of fluidity in service access and the failure to share information within and between the networks slows the journey and hinders the outcome.

According to the 2003 Ministerial Orientations, the health and social services network should strive to ensure that children with PDDs can obtain all the services they need within their own

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[51] These concepts are explained later on in this report.

community, in a timely manner. But in the opinion of the taskforce of PDD practitioners created by the Ministère de la Santé et des Services sociaux in 2006-2007[52] to determine the outcomes of 2003 orientations, significant improvements are needed and strategies must be implemented for:

- Identification of children with PDD;
- Evaluation of their needs by front-line specialist teams;
- Referral to a specialized PDD diagnostic evaluation team;
- Development of an individualized service plan (ISP);
- Referral of the child to a rehabilitation centre;
- Referral of the child and family to appropriate community organizations;
- Sharing of specialized resources in each region: rehabilitation centre for intellectual disabilities(RCID-PDD) and physical disability rehabilitation centre.

In other words, the Ministère de la Santé et des Services sociaux is aware that problems persist. In fact, it recently submitted a service access plan for the disabled entitled *Afin de mieux faire ensemble*[53] which proposes criteria and standards to set guidelines for access to complementary, ongoing services.

The Québec Ombudsman can therefore only reiterate one of the aims of this report, which suggests that the Department's intentions must be implemented in the field and that the service partners must work together in order to provide the right resources at the right time.

In June 2008, in response to the need for all handicapped people to have access to ongoing services, the Ministère de la Santé et des Services sociaux published its *Plan d'accès aux services pour les personnes ayant une déficience*. The Québec Ombudsman is aware that the task of implementing the access plan is complex, and is anxious for the plan to provide a practical response to the problems experienced in the field. It has therefore decided to monitor compliance with the timeframe, the implementation of the planned measures, and the impact on waiting lists and continuity of service between the rehabilitation centres and the health and social services centres. Furthermore, the Québec Ombudsman will ensure that the client groups targeted by the access plan are treated fairly regardless of the type of disability they have or the region in which they live in. By monitoring the access plan, the Québec Ombudsman will be aware of access and continuity problems encountered by various client groups, especially teen and adult PDD clients and, if necessary, will be able to make recommendations to the institutions concerned.

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[52] GROUPE DE TRAVAIL SUR LES SERVICES OFFERTS EN TROUBLES ENVAHISSANTS DU DÉVELOPPEMENT, *Les services offerts en troubles envahissants du développement*, Quebec City, Ministère de la Santé et des Services sociaux, December 2007, 20 p.

[53] MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX, *Afin de mieux faire ensemble – Plan d'accès aux services pour les personnes ayant une déficience*, Quebec City, Bibliothèque nationale du Québec, June 2008, 75 p.

6.5. The challenge for parents: Successive evaluations of their child's needs

The Québec Ombudsman's study reveals that a PDD diagnosis provides few indications of the extent of the child's impairment, since every case is different. An evaluation of the specific condition of each child is required to determine their needs and identify the interventions required. After the clinicians have assessed the child's needs, conferred with other experts and achieved a consensus, the information is brought together in the form of an intervention plan. It is then shared and an individualized service plan is prepared. The purpose of the ISP is to plan and coordinate all the interventions required from professionals working in different institutions. The child's needs and the steps required to respond to those needs must be reassessed as the child changes and grows towards adulthood. In this sense, the study reveals that the major challenge consists in ensuring that services are adapted to needs, not vice-versa. The parents' involvement is required at every step in the process, and there must also be continuity:

- Diagnostic evaluation, attestation of disabilities;
- Evaluation of needs;
- Development of:

    - A health and social services intervention plan (IP): which generally includes a description of the child's needs, the intervention goals, the methods to be used, the anticipated duration of services and reference to a periodic review.
    - The educational childcare service integration plan: prepared by the childcare service in collaboration with the parent. The purpose is to determine the child's abilities and specific needs and to propose ways of facilitating their integration into the childcare environment.
    - The school network intervention plan (IP): which must be completed for children with handicaps or adaptation or learning disabilities and adapted to the their needs by the school principal, with the help of the parents, the service staff d and the child himself or herself if possible, to determine not only the problems but also the skills and capacities of the people involved. Once the situation is clear, an assessment is performed to identify what can be done to help the student overcome problems, draw on his or her strengths, and achieve progress.
    - The individualized service plan (ISP): required when a child will receive services from more than one practitioner working in more than one institution.[54] This involves a group planning exercise under the direction of a coordinator who will be responsible for its implementation.
    - The inter-sector individualized service plan (IISP): required when a child needs services from the education and health and social services networks in complex situations that exceed the mandate of a single institution and require contributions from several practitioners, coordination of interventions, decisions that will affect the child's various

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[54] The idea of institution includes daycare services, which are sometimes involved in preparing the individualized service plan.

developmental spheres, and coordination to prepare for the child's entry into school or to prevent a deterioration of the child's situation.

The above list refers to a specific, logical scenario for configuring and offering services based on the child's real needs and development as he or she grows and moves from one network to another. For the parent, however, this process represents:

- A confusing array of steps;
- A silo-type resource structure;
- A series of delays;
- A difficult and sometimes unreasonable journey in terms of requirements and additional appointments;
- An exhausting time commitment;
- A possible source of conflict and confusion due to the conflicting opinions of different practitioners;
- Eternally starting over.

Proper management of a child with PDD can only be achieved through a dynamic understanding of the various assessment plans:

- The intervention plan as a process and not simply as a tool. It allows the professional, after assessing the child's strengths and weaknesses, to determine the interventions and methods required to achieve the goals and meet the child's specific needs, based on the professional's own expertise and the institution's mission

- The individualized service plan or the inter-sector individualized service plan as a process and pooling of expertise, and not simply as a collection of intervention plans. The ISP brings together all the partners able to help the child to progress by responding to his or her needs. It assumes that these people are working together in a true partnership, towards goals established through an approach designed to seek solutions by targeting the services able to provide them. The terms of the individualized service plan stipulate that a coordinator must be appointed to plan the process, monitor its progress, assess the achievement of goals, review the goals as necessary, provide access to services, and inform and support the parents by ensuring that they play an active role in the process.

Obviously, all these plans share the same goal. Even so, it has been impossible to give them a single name so that they can become part of the service process, or to combine them in a single technology-based tool that would facilitate the transfer of information.

When the child's diagnosis is first announced, most parents are likely to enter into contact with a health and social services centre, a rehabilitation centre, an educational childcare provider and a school. A separate intervention must be prepared in each of these institutions. In addition, an individualized service plan must probably also be prepared by the professionals from these various institutions, depending on the path taken by the child. Within this framework, the child is served by the following organizations, simultaneously or sequentially:

- A health and social services centre and an educational childcare service;
- A health and social services centre and a rehabilitation centre;
- A health and social services centre and one or more schools;
- A rehabilitation centre and an educational childcare service;
- A rehabilitation centre and one or more schools;
- A health and social services centre, an educational childcare service, a rehabilitation centre and a school;
- A rehabilitation centre for intellectual disabilities (RCID-PDD) and a rehabilitation centre for physical disabilities (RCPD).

The Québec Ombudsman also notes that, due to a lack of connectivity between individuals, services and networks, parents are often obliged to repeat the child's history at different meetings with practitioners to establish the intervention plan or individualized service plan. The fairness of the needs assessment may also be adversely affected by these perpetual repetitions and lack of continuity.

With regard to the intervention plans and individualized service plans, which the Québec Ombudsman acknowledges to be the cornerstones of the child's case management, problems exist in all three networks.

In the health and social services network, the applicable regulation – the Organization and Management of Institutions Regulation (c.S-5, r.3.01) – provides for the development of an intervention plan for different categories of clients, including users admitted to or registered in rehabilitation centres (section 42) or receiving services from a CLSC (section 56).[55]

The educational childcare service is not required to prepare an intervention plan for the child. On the other hand, under the budget rules of the Ministère de la Famille et des Aînés,[56] an "integration plan" must be prepared by the childcare provider in cooperation with the parents. This is mandatory if the childcare provider wants to receive the disabled child's allowance. Given the importance of having a detailed profile of the child and his or her development at the time of entering school, however, and given the childcare provider's knowledge of the child, it is critical for the childcare provider to forward the information it has gathered over time, among other things to facilitate the child's entry to a regular or special school.

The education network has no legal obligation to establish an intervention plan or an individualized service plan, except for children recognized as "students with handicaps, social

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[55] Although this regulation does not specify all the categories of clients for whom a plan must be prepared, the *Act respecting health services and social services* stipulates that an individualized service plan must be prepared when a user in a category defined by regulation must receive health and social services over a prolonged period that require the participation of practitioners outside the primary institution. The individualized service plan must be prepared by the institution that dispenses most of the services or by the institution of the designated practitioners, after consultation among themselves.

[56] According to the Ministère de la Famille et des Aînés, most childcare services apply for the subsidy to accommodate a handicapped child.

maladjustments or learning difficulties." For a variety of reasons often related to behaviour, the child may not necessarily be deemed to have a handicap, social maladjustment or learning difficulty, in the sense that he or she does not need special assistance in the classroom. In this case, the child will not always have an intervention plan or individualized service plan and, when such a plan appears to be necessary, it is often prepared late. This is due to a variety of reasons, one being the fact that the professionals involved want to observe the child's reactions. The plan may therefore not be prepared until classes resume in January, or even in the spring. In the meantime, access to special services is compromised.

In general, in all three networks, there are a number of factors that impede cooperation and continuity in the application of individualized service plans involving more than one network:

- Mistrust in assessments made by another group of professionals (leading to a tendency to "reinvent the wheel," go back to square one and redo the entire assessment);
- Resistance to the pooling of expertise (silo operations, apparently irreconcilable professional cultures, barriers between institutions, hierarchical divisions, differences of opinion between schools of thought);
- Failure to understand the need to change tactics as the child grows, and to reflect the missions of the institutions from which the child is receiving services – and this, in spite of shared goals;
- Differences in language, concepts and intervention tools (e.g., intensive behavioural intervention (IBI) and *Treatment and Education of Autistic and Related Communication Handicapped Children* (TEACCH);
- Lack of a designated leader who is accepted by practitioners from all three networks.

While the Québec Ombudsman is well aware of the joint efforts of the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport, which have made the harmonization of intervention plans and service plans between the two networks a priority under their complementarity agreement,[57] it notes that the anticipated results have yet to be achieved and that the Ministère de la Famille et des Aînés was supposed to have been included in the discussions.

The reports on the agreement identify additional contextual factors explaining the problems that have yet to be overcome:

- Poor knowledge of the agreement among practitioners in both networks;
- Low rate of parental participation;
- Sporadic participation by some rehabilitation centres;
- Failure of some regional authorities to play their decision-making role.

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[57] MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX, and MINISTÈRE DE L'ÉDUCATION, DU LOISIR ET DU SPORT. *Deux réseaux, un objectif : le développement des jeunes. Le plan de services individualisé et intersectoriel. Rapport déposé au Comité national de concertation sur l'Entente de complémentarité des services entre le réseau de la santé et des services sociaux et le réseau de l'éducation*, Quebec City, Bibliothèque nationale du Québec, November 30, 2005, 19 p.

At the same time, other studies have clarified the notions of information sharing with due respect for confidentiality and the importance of ensuring that parents and children are aware of the notion of consent to share information.

The experience of some regions has been analyzed to identify conditions for the successful implementation of **inter-sector individualized service plans (IISP)**. Basically, the analysis showed that events leading to the completion of the plans must be clearly established so that they can be applied systematically to all children. Transitions must be targeted from the outset, and the institution that initiates the process must be clearly identified.

In its 2008 access plan, the Ministère de la Santé et des Services sociaux notes that service continuity is adversely affected during the transition to daycare, at entry to elementary school, during the transition from elementary to secondary school, and during the transition to adult life. The Department's preferred means of dealing with this is the individualized service plan. The standard for continuity is to develop and implement an individualized service plan when the person and his or her family are in transition. No mention is made of agreements with partners to update the procedure at the appropriate time, or to coordinate with the other networks' plans. The 2008 access plan was well received, however, and the authorities responsible for monitoring the complementarity agreement at both the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport see the plan as part of the solution to the problem outlined above.

RECOMMENDATIONS TO IMPROVE THE NEEDS ASSESSMENT PROCESS FOR CHILDREN WITH PDD

GIVEN THE IMPORTANCE of ensuring that, in keeping with the new situation arising from the restructuring of the network of the Ministère de la Santé et des Services sociaux, institutions continue to apply intervention plans (IP) and individualized service plans (ISP) regardless of age or place of residence for all clients with complex needs, especially people with PDDs;

GIVEN THE IMPORTANCE of developing and coordinating intervention plans, integration plans and individualized service plans for children with PDDs;

GIVEN that, pursuant to the Education Act, the school principal, with the help of the parents of a student with a handicap, social maladjustment or learning difficulty, the staff that provide services to that student and the student himself or herself, unless he or she is incapable of doing so, shall establish an intervention plan;

GIVEN THE IMPORTANCE of always pursuing the most diligent and most appropriate action for a child with a PDD, and the need to act at the right time;

GIVEN THE IMPORTANCE of ensuring that children with PDDs have an intervention plan (IP) at every stage of their development, regardless of the network to which the institution providing the services belongs.

RECOMMENDATION 17

The Québec Ombudsman recommends that the Ministère de la Famille et des Aînés should provide childcare services with the tools they need and foster their commitment to establish a detailed profile and progress report for the child, in order to provide the school with this information and facilitate the child's transition.

FOLLOW-UP:
THE Ministère de la Famille et des Aînés shall inform the Québec Ombudsman, no later than March 31, 2011, of the tools chosen to prepare these profiles, and shall also, no later than March 31, 2013, submit a report analyzing the profiles and their impacts on the transition process.

RECOMMENDATION 18

The Québec Ombudsman recommends that the Ministère de l'Éducation, du Loisir et du Sport should take steps to encourage the school network to become involved in the development of an intervention plan (IP) or individualized service plan (ISP) before a child with a PDD enters school, whether or not the child is deemed by the school board to be a student with a handicap, social maladjustment or learning difficulty.

FOLLOW-UP:
THE Québec Ombudsman shall be informed of the outcome of this recommendation by March 31, 2011.

RECOMMENDATION 19

The Québec Ombudsman recommends that, in pursuit of their efforts to harmonize intervention plans (IP) and individualized service plans (ISP), the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport should include the Ministère de la Famille et des Aînés in the process and ensure that these plans provide for the effective participation of parents and key stakeholders in order to maximize the child's chance of successful integration into the school environment.

FOLLOW-UP:
The Québec Ombudsman shall be informed of the follow-up to this recommendation by March 31, 2011.

6.6. Effective access to habilitation/rehabilitation programs

The ultimate goal of all the factors examined so far is access to good quality special and specialized habilitation/rehabilitation services that reflect the latest best practices. The Ministère de la Santé et des Services sociaux has focused its effort on intensive behavioural intervention (IBI),[58] and it is this method that the Québec Ombudsman has examined. In keeping with the choice of the Ministère de la Santé et des Services sociaux, the rehabilitation centres use intensive behavioural intervention except in a handful of rare cases where the integrated intervention model is used instead.

Health services and social services

- The health and social services centres were supposed to be responsible for offering early stimulation[59]. However, very little has been done to make this service available to children with PDDs, and the health and social services centres generally refer the children directly to the RCID-PDDs.
- A considerable effort has been made to expand the formula: financing of training for professionals/supervisors and technicians so that they can provide intensive behavioural intervention (IBI), and allocation of human and financial resources to the RCID-PDDs to serve the target clientele.

Educational childcare services

- The educational childcare services consider intervention, habilitation and rehabilitation goals when adjusting their activities and daycare interventions to the child's situation.
- They give the health and social services centres and rehabilitation centres access to their premises to provide specific and specialized services for children with PDD.
- They participate in the development of the intervention plan or individualized service plan when the health and social services centre or rehabilitation centre develops a plan and asks for their input.[60]

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[58] Intensive Behavioural Intervention (IBI) is a generic term for the therapeutic approaches that have evolved from the work of Dr. O. I. Lovaas over the last 35 years. This method teaches small, measurable units of behaviour systematically. Every skill the child does not demonstrate is broken down into small steps. Each step is taught by presenting an instruction. A prompt is added if necessary. Appropriate responses are followed by consequences that have been found to function effectively as reinforcers. Upon repeated trials, as learning takes place, prompts and reinforcers are faded. Simple responses are built systematically into complex and fluid combinations of typical, age-appropriate responses. There is a gradual progression from one-to-one to small group to large group instruction. In Quebec, the treatment may cost between $15,000 and $55,000 per year for staff alone, depending on the intensity of the program and the hourly remuneration of the professionals (psychologists, speech therapists, EIBI technicians, specialized educators). CHILDHOOD AUTISM IN CANADA: SOME ISSUES RELATING TO BEHAVIOURAL INTERVENTION. Prepared by Sonya Norris, Science and technology division, Jean-Rodrigue Paré, Political and social affairs division, Sheena Starky, Economics division, January 26, 2006. A detailed description of the various behaviour approaches can be found in C. Maurice, G. Green & S.C. Luce (dir.), *Behavioral Intervention for Young Children with Autism*, Austin (Texas), Pro-Ed, 1996.

[59] MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX, *op. cit*., p. 1.

[60] As mentioned earlier, one of the challenges for childcare services is to obtain the support and cooperation they need from health and social services network practitioners, in order to integrate handicapped children.

School network services

- The Quebec Education Program is mandatory for most students, including those with PDDs but with no intellectual impairment.
- There is no preferred approach. Depending on the needs of the student, a number of different approaches are used, including the *Treatment and Education of Autistic and Related Communication Handicapped Children* (TEACCH) method, the *Picture Exchange Communication System* (PECS) and behaviour modification approaches.
- School network institutions offer complementary educational services (psychology, specialized education, speech therapy, etc.).
- School network services include regional support and consulting services for students with PDD.
- They sign very few collaborative agreements with rehabilitation centres for intensive behavioural intervention (IBI) if the children are of school age.
- They sometimes make arrangements for the rehabilitation centre to advise the teacher when a child with a PDD enters the school, but the centre is not in direct contact with the child.

6.7. Essential links yet to be developed

Between the health and social services centres and the rehabilitation centres

When the child finally obtains access to habilitation/rehabilitation services, the Québec Ombudsman notes that, in general:

- The health and social services centre does not play the clear front-line role assigned to it; in other words, it does not specific early stimulation services (as opposed to intensive behavioural intervention (IBI), a specialized service offered by the rehabilitation centres).
- The health and social services centre and the rehabilitation centre do not generally enter into the type of partnership stipulated in the 2003 Ministerial Orientations[61], in order to:
  - Clarify their respective offers of service;
  - Agree on shared service access procedures;
  - Reduce waiting times;
  - Facilitate collaborative initiatives that will allow the health and social services centre to access rehabilitation centre expertise for its own programs;
  - Work together (health and social services centre and rehabilitation centre) to offer personalized intermediary services so that neither the child nor the family is left stranded without service;

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[61] MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX, *op. cit.*, note 1.

- Work together (health and social services centre and rehabilitation centre) to ensure service continuity and complementarity, and to provide real support at each step and in every situation

The Québec Ombudsman's study reveals that much still remains to be done for these commitments to be implemented, and for children and parents to enjoy concrete benefits. For example, even though they are the front-line stakeholders, not all the health and social services centres have resources in their workforce with the necessary skills and experience to handle PDDs. As a result, cases are not always properly managed while people are waiting for second-line services from a rehabilitation centre or after the rehabilitation centre has finished its specialized interventions. There may also be problems in returning to specific front-line services.

It is important for the Ministère de la Santé et des Services sociaux to ensure that the information given to front-line practitioners who work with people with PDDs includes guidance on directing children with PDDs and their parents to the appropriate resources. The Department should also set up links that would allow for coordinated action by the health and social services centres and rehabilitation centres, including the use of navigators and the development of intervention plans and individualized service plans. This would ensure that children and parents are supported more effectively.

Between educational childcare services, health and social services centres, rehabilitation centres and schools

The educational childcare program seeks to achieve the following objectives:

- Provide children with quality child care services;
- Serve as a reference tool for anyone working in the daycare sector;
- Promote better consistency between these various environments;
- Foster continuity of all family and early childhood interventions[62].

With regard to habilitation, the main role of educational childcare providers is to ensure continuity of interventions with the child and the family. To do this, they need support from the health and social services centre and the rehabilitation centre, whether or not intensive behavioural intervention (IBI) is carried out at the daycare premises. The childcare providers must also share information and help achieve the goals of the intervention plan or individualized service plan.

In recent years, a framework agreement has been developed to define the basic supply of health and social services for children who attend early childhood centres, and to ensure that children who have a file with the CLSC-branch of the health and social services centre have access to an early childhood centre.[63] In theory, the agreement provides for the sharing of expertise between the early childhood centres and the health and social services centres. However, the Québec

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[62] MINISTÈRE DE LA FAMILLE ET DES AÎNÉS, *Accueillir la petite enfance. Le programme éducatif des services de garde du Québec. Mise à jour*, Quebec City, Bibliothèque nationale du Québec, 2007, p. 7.

[63] MINISTÈRE DE LA FAMILLE ET DE L'ENFANCE *et al.*, *Protocole CLSC-CPE. Guide d'implantation, entente-cadre et protocole type*, Quebec City, Bibliothèque nationale du Québec, March 2002, p.5. (modified in 2004 to change CLSC to CSSS)

Ombudsman notes that very few of the educational childcare providers that receive children with PDDs have adhered to the agreement, which they seem to regard as being too restrictive.[64] The agreement does not suggest concrete, realistic means of arranging the cooperation. The result is that the sharing of expertise between the early childhood centres and the health and social services centres, and the support that should be given by health and social services centres to help integrate children with PDDs into daycare environments, are irregular.

As for the education network, the turbulence that children and parents experience when the children first arrive in the network has already been described in this report. Lack of knowledge about the effects of switching from intensive behaviour intervention (IBI) to other intervention approaches, including *Treatment and Education of Autistic and Related Communication Handicapped Children* (TEACCH), and the uncertainty generated by the transfer, are just two of the factors that lead some parents to decide not to send their child to school. Decisions such as this are not common, but they do exist, and are of great concern to the Québec Ombudsman.

6.8. Intensive behavioural intervention (IBI) across Quebec

In the 2003 Ministerial Orientations, the Ministère de la Santé et des Services sociaux states that it is difficult, based on current knowledge, to be certain of the most appropriate behavioural approaches for children with PDDs. The Department has chosen intensive behavioural intervention (IBI) as the approach offered in the rehabilitation centres. While described as "intensive", the level of intensity of the treatment can vary. Based on the most convincing current data, the Department has chosen:

- Intensive behavioural intervention (IBI);
- At a rate of 20 hours a week;
- For children aged 2 to 5.

In the field, the Québec Ombudsman has noted that since the 2003 Ministerial Orientations were issued, the availability of IBI services has increased considerably.

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[64] This result contrasts with the data in the evaluation report for the CLSC-CPE framework agreement and protocols published in fall 2007. The report estimates that 49% of early childhood centres had signed the framework agreement and 40% declared that they had no trouble with the application. Early childhood centres that did not sign the agreement indicated that collaboration with the CLSC was already satisfactory and that they did not believe a protocol would improve their access to CLSC services. One explanation for this difference lies in the findings of the evaluation report, which suggest that one of the restrictions in the agreement is the level of assistance that can be offered to certain client groups. It mentions that because the children's hospitals and rehabilitation centres are not parties to the agreements, the early childhood centres might have difficulty accessing their services. Since most children with PDDs receive services from rehabilitation centres, it is possible that these agreements with the front line are perceived as demanding too much effort for the benefits obtained in terms of support. After this evaluation, the Ministère de la Famille et des Aînés worked with the Ministère de la Santé et des Services sociaux and the association involved to review the framework agreement and protocols, taking the restructuring of the two networks into account. Their intention was to improve service reciprocity and access to services by expanding the signature of the agreement protocols to daycares and coordinators' offices.

It is not the role of the Québec Ombudsman to judge the relevance of intensive behavioural intervention, nor to comment on the way it is provided. Throughout the study, however, it was clear that one of the major problems relating to IBI is due to inaccuracies in its definition and application. The following factors speak volumes in this regard:

- When the Québec Ombudsman asked for a definition of intensive behavioural intervention, there were almost as many definitions given as there were professionals asked.
- IBI cannot be offered other than on a one-to-one, child/professional basis in a closed room, although isolation of the child from the group is contrary to the inclusion philosophies embraced by both the educational childcare network and the schools.
- As soon as they are admitted to the school network, children with PDDs no longer receive IBI, although according to many clinicians in the health and social services network, they could continue to do so. These people feel that the decision not to offer IBI was based on administrative and financial constraints, as well as silo budgeting, and not on the child's needs. To date, there has been no scientific research on the consequences of moving from IBI to TEACCH, which is the approach normally used in Québec's schools.
- IBI may be dispensed differently both within the same rehabilitation centre and in centres within the same region, often by practitioners with differing levels of training.
- Supervision of technicians by professionals varies considerably, and is irregular.
- Sometimes people whose only claim to competency is their interest in PDD practise the habilitation method selected by the rehabilitation centre, with no immediate supervision.
- When a child is deemed to need 20 hours of IBI a week, these hours almost always include the practitioner's transportation and preparation time, leading to significant disparities from one case to the next.
- The presence of the parent is not always requested, even when the parent asks to be involved in applying the IBI.
- IBI is not the only habilitation method used in Quebec.

Researchers and health and social services network professionals believe it is crucial to explore other issues related to IBI and the TEACCH method, including:

- The efficiency of IBI as it is currently administered in the health and social services network;
- The need to administer IBI solely on a one-to-one basis (child-practitioner) outside the child's group;
- The compatibility of this one-to-one relationship with the child's integration in the group, since integration is one of the major objectives of both daycare providers and schools;
- The question of implementing IBI in schools and daycare providers because of the nature of the goals;
- The efficiency of TEACCH and how it is administered in the schools;

- The links between these two intervention methods and how continuity can be achieved between them;
- The contribution of educational childcare services to continuity with IBI administered in their premises, and ways of improving complementarity with the health and social services network and the education network;
- The effect of the quantity and intensity of the IBI received by the child on his or her integration or non-integration into regular classes;
- The effect on so-called "regular" children of including children with PDDs in their group
- The difficulties encountered by teachers when children with PDDs enter the school environment; it would be appropriate to identify the PDD training and professional assistance they need when they come into contact with these children;
- The obstacles to complementarity between the health and social services network and the education network, in terms of sharing human and financial resources and possible solutions.

Bearing in mind that every child is unique, it may seem odd to choose approaches that are applied in a standardized way. Furthermore, considering the small amount of convincing data on the impact of the interventions, the ensuing debates and disparities in the application of these approaches come as no surprise. Research funds are scarce, and allow only for partial assessments that do not show how effective the application methods are. Longitudinal evaluative studies by neutral researchers, free from any influence, should be undertaken to measure the improvements in living conditions and integration for the people concerned.

RECOMMENDATION TO ENSURE QUALITY INTERVENTIONS

GIVEN the expected impact of intensive behavioural intervention (IBI) used with children with PDDs at a period of their lives when the effects of early intervention are likely to be the most promising;

GIVEN the legitimate hope of parents for access to the best treatment for their child;

GIVEN the methods used and the financial investments made by the Ministère de la Santé et des Services sociaux for IBI, and the uncertainties that arise during transitions to other approaches;

GIVEN that the Ministère de l'Éducation, du Loisir et du Sport does not recommend any single approach, even though the TEACCH method is widely used;

GIVEN the incomplete nature of scientific knowledge on the causes of and approaches to PDDs.

RECOMMENDATION 20

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport should agree to an assessment of their respective approaches in order to measure the efficiency and effectiveness of their rehabilitation interventions in terms of:

- **Early application or starting age for IBI**
- **Intensity, duration or end of IBI**
- **Location of intervention**
- **One-to-one method of administering IBI**
- **The people authorized to administer IBI**
- **Supervision mechanisms for practitioners administering IBI**
- **Role of parents in the IBI framework**
- **Efficiency of the methods used in schools and how they are administered**
- **Impacts of transitioning from IBI to other methods upon starting school**

- **Effect on so-called regular children of the inclusion of children with PDD in their group**

And that, at the same time, the Ministère de la Santé et des Services sociaux should ensure that its officers monitor advances in the most effective intervention methods for children with PDDs and quickly transfer this knowledge to all practitioners.

And that the Ministère de l'Éducation, du Loisir et du Sport should contribute to the development of research into the transition to pre-school education, foster the introduction of educational practices based on sound scientific data, assert its leadership in research support and promote inter-network sharing of expertise.

FOLLOW-UP:
A representative appointed by the Ministère de la Santé et des Services sociaux for intensive behavioural intervention (IBI), and a representative appointed by the Ministère de l'Éducation, du Loisir et du Sport for the methods used in the schools, shall report to the Québec Ombudsman by March 31, 2011, on the objectives and methods used to evaluate and transfer knowledge, including the involvement of partners, and in 2013-2014, they shall meet with the Québec Ombudsman to share their results and agree on future actions.

6.9. In Quebec, some children with PDDs are not educated

With regard to the school network, the Québec Ombudsman observed during the study that some school-age children with PDDs are kept at home even though the parents have not come to any agreement with the school board concerning home schooling. In these specific instances, the Québec Ombudsman notes that the parent's choice was based primarily on the following reasons:

- The child's PDD was detected late and the child therefore did not have access to intensive behavioural intervention (IBI) or received it for only a short time. The child was therefore not ready to attend school.
- The parent was not aware of the availability of services that would have allowed the child to attend school.
- After a trial period at school, the parent felt the child was not being given the assistance required to advance academically.
- Regular school, designed primarily for "regular" children, with its methods, challenges and restrictions, caused the child to regress, since he or she was either kept in a state of passive tranquility so as not to disrupt the class, or pushed into crisis due to an overload of external stimuli.
- The school insisted that the child be given behaviour-modifying medication, despite objections by the diagnosing doctor and the parent's refusal to agree to the school's demand.
- The lack of appropriate childcare services at lunch and after school to meet the needs of a child who cannot cope with the activity and disturbance levels of regular school care

environments. The atmosphere in these environments usually triggers a profound sense of disorganization for the child or cancels out all the teacher's efforts to integrate the child.

- The absence of hygiene support for the child (diaper changing, in particular). School management does not feel teachers should be responsible for this task, and the schools have no resource to take it on, so children are often sent to special schools even when they have the capacity to function in a regular classroom.

Some of the children in this situation were planning to enter school late, after additional time in kindergarten to reinforce their skills. In other cases, the parents could simply not find an appropriate place of learning for their special-needs child in the regular school environment. As for special schools, where the child would potentially be with children suffering from severe impairments, they also seemed to provide an environment in which the child would regress rather than make progress. The Québec Ombudsman noted that in many cases, neither the school authorities nor the Youth Protection Directorate seemed to be aware of the situation, and that even if they were, neither had the means to enforce the provisions of the law stating that parents must ensure that their children are educated, since education is mandatory in Quebec from age 6 onwards.[65]

This phenomenon, although rare, is worrying. A better understanding is needed, and parents must fully grasp the idea of schooling. It is also important for parents to know about possible alternatives if, for one reason or another, home schooling is felt to be preferable to regular school, since children must not be deprived of the opportunity to develop their full potential.

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[65] *Education Act*, R.S.Q., c.I—13.3, art. 1, par.3.

RECOMMENDATION TO GUARANTEE ACCESS TO EDUCATION FOR ALL CHILDREN IN QUESTION

WHEREAS attending school is mandatory from the age of six and certain parents choose not to enrol their children in school, largely due to a lack of information or inability to find the anticipated resources at a school;

WHEREAS this choice is contrary to the Education Act and may be harmful to the children in terms of learning, autonomy and socialization;

WHEREAS the identification of these children depends on the sharing of information from other networks, including the educational childcare services, that these children may frequent.

RECOMMENDATION 21

The Québec Ombudsman recommends that the Ministère de l'Éducation, du Loisir et du Sport should take the necessary steps to identify children who are not attending school and that, in a joint framework agreement with the Ministère de la Santé et des Services sociaux and the Ministère de la Famille et des Aînés, it should agree on mechanisms to ensure that all school-age children receive an education in their own best interests.

FOLLOW-UP:
The Quebec Ombudsman shall be informed of the outcome of this recommendation by March 31, 2011.

7. Conclusion

In the course of the study on government services for children with PDDs, the Québec Ombudsman met with parents throughout Québec who are determined to improve their children's prospects. She also met with practitioners who are interested in and want to help these children, and who are better informed than ever before about their condition. The Québec Ombudsman was able to appreciate the effort made by a great many people to help children and families who live with a difference, and will continue to do so throughout their lives. It is a difference that weighs all the more heavily because of the endless search for services, as well as the changes that must be made to their lives and their environment. Doors remain closed to these children, but their parents are determined to open as many as possible. Practitioners and professionals have proved themselves to be competent in providing assistance and guidance, and in giving the children the best chance of integrating everyday life and society.

The 2003 Ministerial Orientations published by the Ministère de la Santé et des Services sociaux were established to identify and offer services for children with PDDs and their families. As for the impact of these orientations, the Québec Ombudsman's initial response is that in some respects they have in fact changed the world. Previously, there were no services specifically for children with PDDs, and the Ministerial Orientations provided knowledge, methods and guidance to fill the gap and offer resources. For parents, the measures were a source of hope. However, while the orientations made a significant public sector contribution to the lives of people with PDDs, creating services specifically for them, six years later there are still some major problems in the three service networks concerned. These problems must now be identified, understood and resolved. Otherwise, there is a risk that the gains made in interventions and development opportunities for children with PDDs will be lost.

The study on which this report is based examined the situation of children with PDDs who were between 0 and seven years of age or having completed the first year of elementary school. This group was chosen because it has been targeted by government efforts in recent years, and the Québec Ombudsman, in keeping with its mandate, decided to analyse the services available to this client group. But what happens when the children are older? Do they stop having specific needs? Are they necessarily capable of integrating regular school, training and work environments? Many people told the Québec Ombudsman that serious problems arise in subsequent years, including marginalization, segregation, isolation and exclusion. A PDD diagnosis is definitive and remains with the person throughout his or her lifetime. Government services must adjust to the needs of children with PDDs as they grow, and must adapt their interventions as the children become adults, as well as providing more support for their parents.

The Québec Ombudsman is convinced that the recommendations for change described in this study are based on realistic findings and will generate much-needed improvements that will help enhance the future prospects of children with PDDs. The lack of resources cannot be used as an excuse for inaction. On the contrary, it is up to decision-makers and practitioners to adopt an open attitude to change, so that they are able to share, work together and achieve a better organization of work. Clearly, resources must be available for this purpose.

After completing the study, the Québec Ombudsman believes it is critical to ensure that knowledge is shared between the networks, and to develop joint, interdisciplinary, inter-sector intervention plans that extend beyond the networks' respective areas of practice and personal convictions. Outweighing all these considerations are the interests of the child, whose future may be transformed by the skills, open-mindedness, determination and empathy of practitioners who provide professional and human support while listening to the parents and including them in the process.

Appendices

Appendix 1 – Recommendations and Follow-up by ministry

RECOMMENDATIONS TO MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX AND RÉSEAU DE LA SANTÉ ET DES SERVICES SOCIAUX

RECOMMENDATION TO GIVE MORE CONSIDERATION TO THE BROTHERS AND SISTERS OF A CHILD WITH A PDD

WHEREAS siblings play a crucial role in the life of a child with a PDD and the support needed to assume this role is not specifically provided;

WHEREAS brothers and sisters often act in the place of the parents of a child with a PDD once the parents are no longer around;

WHEREAS the specific needs of families that HAVE a second child with a PDD deserve to be better understood;

WHEREAS the Ministère de la Santé et des Services sociaux is planning to define a supply of services for families.

RECOMMENDATION 7

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux should establish guidelines for professionals in its service network on how to support families and siblings of children with PDDs, as well as families that include more than one child with a PDD.

FOLLOW-UP:
A copy of these guidelines shall be deposited with the Québec Ombudsman before March 31, 2013.

RECOMMENDATIONS AIMED AT SIMPLIFYING THE STEPS TAKEN BY PARENTS TO OBTAIN FINANCIAL ASSISTANCE

WHEREAS the parents of children with PDDs are eligible for special financial assistance and, to obtain that assistance, must contact the entities responsible for a broad range of programs with an equally broad range of administrative formalities;

WHEREAS these parents must, among other things, repeatedly satisfy requests for justifications and attestations from subsidizing organizations;

WHEREAS the Office des personnes handicapées du Québec has already worked with numerous partners to produce an in-depth reflection on the question of financial support for handicapped people and their families;

WHEREAS the Ministère de la Famille et des Aînés is concerned with the harmonization of family support programs.

RECOMMENDATION 9

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux should harmonize the family support practices of the health and social services centres, and that the Office des personnes handicapées du Québec, in conjunction with all the other authorities involved in the allocation of financial assistance to the parents of children with PDDs, should assess the relevance of a single wicket or other mechanism as a means of facilitating parental access to the information and monies they need.

FOLLOW-UP:
A person shall be formally appointed by the Ministère de la Santé et des Services sociaux, no later than December 31, 2009, to provide the Québec Ombudsman with annual reports on the steps taken to harmonize the practices of the health and social services centres, and a person from the Office des personnes handicapées du Québec shall be appointed to provide the Québec Ombudsman, no later than March 31, 2012, with the outcome of the evaluation concerning the relevance of the single wicket or other mechanism, in order to agree upon follow-up to this recommendation.

RECOMMENDATIONS TO MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX ET AU RÉSEAU DE LA SANTÉ ET DES SERVICES SOCIAUX (Continued)

RECOMMENDATIONS TO FACILITATE ACCESS TO THE PDD DIAGNOSIS AND APPROPRIATE SERVICES

WHEREAS access to specific front-line habilitation/rehabilitation services should not depend solely on obtaining a PDD diagnosis and may begin before the diagnostic evaluation has been completed.

RECOMMENDATION 13

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux should ensure that children awaiting a PDD diagnosis receive specific services based on their condition and needs, in accordance with the conditions and timelines set out in the 2008 service access plan.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2011, of the way in which the Ministère de la Santé et des Services sociaux plans to ensure that the health and social services centres are offering these services when required, and the Ministère shall report annually to the Québec Ombudsman on the results of the health and social services centres' accountability with regard to this recommendation.

RECOMMENDATIONS TO MINISTÈRE DE LA FAMILLE ET DES AÎNÉS

RECOMMENDATIONS TO CREATE LINKS BETWEEN THE SERVICE NETWORKS

WHEREAS the health and social services network, through its health and social services centres and the RCID-PDDs, is an important PDD specialist within the government apparatus;

WHEREAS the educational childcare community must be able to rely on timely support from health and social services centre professionals when it takes on children with PDDs – while awaiting a RCID-PDD intervention – in order to avoid a situation where a child is refused by a daycare provider or expelled due to a lack of understanding of the child's condition and the steps required to address it;

WHEREAS the educational childcare community does not have a mechanism that would formalize the support from and collaboration with specialists from the health and social services network;

WHEREAS the Ministère de la Famille et des Aînés must be aware of the true benefits of its policies for the children and their parents;

WHEREAS the Ministère de la Famille et des Aînés has sufficient levers in its educational program, its partnerships and its reporting mechanisms to enable it to obtain a profile of service availability and quality;

WHEREAS parents must be properly informed of the conditions for access to daycare services.

RECOMMENDATION 2

The Québec Ombudsman recommends that the Ministère de la Famille et des Aînés should establish and monitor the implementation of guides for educational childcare services, focusing in particular on:

- **The content of policies governing the admission and expulsion of children with special needs;**
- **A method that will enable every educational childcare service permit holder to submit a specific admission and expulsion policy, so that the Ministère de la Famille et des Aînés can follow up and understand the grounds for exclusion;**
- **A method to inform parents clearly about the criteria used to accept children in educational childcare services;**
- **A requirement that every refusal or expulsion should be in compliance with the policy, be made in writing, with reasons, and be sent to the parents concerned.**

FOLLOW-UP:
The Québec Ombudsman shall be informed, by March 31, 2011, of the process that will be used to produce the proposed guide and follow-up mechanism, and a copy of the guide and follow-up procedure shall be submitted to the Québec Ombudsman by March 31, 2013.

RECOMMENDATION 4

The Québec Ombudsman recommends that the Ministère de la Famille et des Aînés should assess the effectiveness of its measures to integrate children with PDDs, in particular by:

- **Reviewing the relevance of the methods used to allocate its subsidies for daycare services and the subsidies composed of amounts allocated jointly with the Ministère de la Santé et des Services sociaux, in order to respond more effectively to the real needs of children with PDDs;**
- **Adjusting organizational methods by including the necessary additional resources to improve the integration process;**
- **Making the necessary corrections to future allocations and organizational methods in order to facilitate integration.**

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2012, of the results of this assessment and of the plan to implement any ensuing remedial measures.

RECOMMENDATIONS TO IMPROVE ACCESS TO INFORMATION, AWARENESS AND PDD IDENTIFICATION

WHEREAS the *Orientations ministérielles 2003 – Un geste porteur d'avenir. Des services aux personnes présentant un trouble envahissant du développement, à leurs familles et à leurs proches* contains provisions that recognize the importance of information for all practitioners and parents;

WHEREAS practitioners in the three networks – health and social services, educational childcare and education – have a major role to play in providing information and raising awareness about PDDs;

WHEREAS there are currently some significant gaps in terms of parental access to information and PDD identification, and parents must undertake complex procedures, the length of which is likely to hinder the child's development and upset the family's balance;

WHEREAS practitioners in all three networks should act as conduits of knowledge concerning the most appropriate approaches and services, in order to lessen the burden on parents, increase the effectiveness of the sources, and foster concerted action among the three networks;

RECOMMENDATION 11

The Québec Ombudsman recommends that the Ministère de la Famille et des Aînés should participate in inter-sector round tables involving the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport and in all types of government discussions where any decisions and actions will affect children with PDDs.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2011, of the means implemented to arrange the participation of the Ministère de la Famille et des Aînés.

RECOMMENDATIONS TO FACILITATE ACCESS TO THE PDD DIAGNOSIS AND APPROPRIATE SERVICES

WHEREAS parents are obliged to undertake numerous procedures to obtain or confirm a PDD diagnosis for their child.

RECOMMENDATION 15

The Québec Ombudsman recommends that the Ministère de la Famille et des Aînés should take the necessary steps to ensure that the educational childcare services, once they have been informed that a parent has obtained a report from a professional confirming the child's disability or impairment for the purpose of a childcare subsidy, immediately refer the parent to the area's health and social services centre so that the process of obtaining a medical diagnosis can begin.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2011, of the means offered to the childcare services and the initiatives planned as follow-up to this recommendation, such as information provided directly to parents by the Ministère de la Famille et des Aînés when the childcare subsidy is granted, and a report on these means shall be submitted to the Québec Ombudsman by March 31, 2013.

RECOMMENDATIONS TO IMPROVE THE NEEDS ASSESSMENT PROCESS FOR CHILDREN WITH PDD

GIVEN THE IMPORTANCE of developing and coordinating intervention plans, integration plans and individualized service plans for children with PDDs;

GIVEN THE IMPORTANCE of always pursuing the most diligent and most appropriate action for a child with a PDD, and the need to act at the right time;

GIVEN THE IMPORTANCE of ensuring that children with PDDs have an intervention plan (IP) at every stage of their development, regardless of the network to which the institution providing the services belongs.

RECOMMENDATION 17

The Québec Ombudsman recommends that the Ministère de la Famille et des Aînés should provide childcare services with the tools they need and foster their commitment to establish a detailed profile and progress report for the child, in order to provide the school with this information and facilitate the child's transition.

FOLLOW-UP:
THE Ministère de la Famille et des Aînés shall inform the Québec Ombudsman, no later than March 31, 2011, of the tools chosen to prepare these profiles, and shall also, no later than March 31, 2013, submit a report analyzing the profiles and their impacts on the transition process.

RECOMMENDATIONS TO THE MINISTÈRE DE L'ÉDUCATION, DU LOISIR ET DU SPORT

RECOMMENDATIONS TO CREATE LINKS BETWEEN THE SERVICE NETWORKS

WHEREAS, to be effective, the Ministère de l'Éducation, du Loisir et du Sport must have information on the prior path of children with PDDs, with due respect for the legal requirements concerning confidentiality and the protection of personal information.

RECOMMENDATION 5

The Québec Ombudsman recommends that the Ministère de l'Éducation, du Loisir et du Sport should work with the Ministère de la Famille et des Aînés in order to prepare a guide or reference framework leading to the introduction of a framework agreement to ensure that the school boards and educational childcare providers within their territories can agree on formal collaborative measures that would allow for the transfer of information and expertise regarding children with PDDs, and to allow schools to prepare for the arrival of such children at least one term in advance.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2010, of the process introduced to produce the guide or reference framework, and a copy of the guide or reference framework, along with the implementation follow-up procedure, shall be submitted to the Québec Ombudsman by March 31, 2011.

RECOMMENDATIONS TO FACILITATE ACCESS TO THE PDD DIAGNOSIS AND APPROPRIATE SERVICES

WHEREAS parents are obliged to undertake numerous procedures to obtain or confirm a PDD diagnosis for their child;

WHEREAS it is important, given the shortage of health care professionals, not to increase the number of interventions required.

RECOMMENDATION 16

The Québec Ombudsman recommends that the Ministère de l'Éducation, du Loisir et du Sport should examine the financing conditions for handicapped student services in order to simplify the process and facilitate the allocation of assistance, particularly when a child has already obtained a medical diagnosis for a lifetime condition such as a PDD. The requirement for the parent to produce a confirmation of the child's diagnostic evaluation on entering school should be abolished.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2011, of the steps taken in response to this recommendation.

RECOMMANDATION VISANT À AMÉLIORER LE PROCESSUS D'ÉVALUATION DES BESOINS DES ENFANTS PRÉSENTANT UN TED

GIVEN THE IMPORTANCE of developing and coordinating intervention plans, integration plans and individualized service plans for children with PDDs;

GIVEN that, pursuant to the Education Act, the school principal, with the help of the parents of a student with a handicap, social maladjustment or learning difficulty, the staff that provide services to that student and the student himself or herself, unless he or she is incapable of doing so, shall establish an intervention plan;

GIVEN THE IMPORTANCE of always pursuing the most diligent and most appropriate action for a child with a PDD, and the need to act at the right time;

GIVEN THE IMPORTANCE of ensuring that children with PDDs have an intervention plan (IP) at every stage of their development, regardless of the network to which the institution providing the services belongs.

RECOMMENDATION 18

The Québec Ombudsman recommends that the Ministère de l'Éducation, du Loisir et du Sport should take steps to encourage the school network to become involved in the development of an intervention plan (IP) or individualized service plan (ISP) before a child with a PDD enters school, whether or not the child is deemed by the school board to be a student with a handicap, social maladjustment or learning difficulty.

FOLLOW-UP:
THE Québec Ombudsman shall be informed of the outcome of this recommendation by March 31, 2011.

RECOMMENDATION TO GUARANTEE ACCESS TO EDUCATION FOR ALL CHILDREN IN QUESTION

WHEREAS attending school is mandatory from the age of six and certain parents choose not to enrol their children in school, largely due to a lack of information or inability to find the anticipated resources at a school;

WHEREAS this choice is contrary to the Education Act and may be harmful to the children in terms of learning, autonomy and socialization;

WHEREAS the identification of these children depends on the sharing of information from other networks, including the educational childcare services, that these children may frequent.

RECOMMENDATION 21

The Québec Ombudsman recommends that the Ministère de l'Éducation, du Loisir et du Sport should take the necessary steps to identify children who are not attending school and that, in a joint framework agreement with the Ministère de la Santé et des Services sociaux and the Ministère de la Famille et des Aînés, it should agree on mechanisms to ensure that all school-age children receive an education in their own best interests.

FOLLOW-UP:
The Quebec Ombudsman shall be informed of the outcome of this recommendation by March 31, 2011.

RECOMMENDATIONS TO THE MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX AND THE RÉSEAU DE LA SANTÉ ET DES SERVICES SOCIAUX AND THE MINISTÈRE DE LA FAMILLE ET DES AÎNÉS

RECOMMENDATIONS AIMED AT SIMPLIFYING THE STEPS TAKEN BY PARENTS TO OBTAIN FINANCIAL ASSISTANCE

WHEREAS the parents of children with PDDs are eligible for special financial assistance and, to obtain that assistance, must contact the entities responsible for a broad range of programs with an equally broad range of administrative formalities;

WHEREAS these parents must, among other things, repeatedly satisfy requests for justifications and attestations from subsidizing organizations;

WHEREAS the Office des personnes handicapées du Québec has already worked with numerous partners to produce an in-depth reflection on the question of financial support for handicapped people and their families;

WHEREAS the Ministère de la Famille et des Aînés is concerned with the harmonization of family support programs.

RECOMMENDATION 8

The Québec Ombudsman recommends that the health and social services network and the Ministère de la Famille et des Aînés should inform it of the steps currently being taken to harmonize family support programs with a view to meeting the needs of parents more effectively, including a review of the allocation rules and access procedures of financial support programs for the parents of children with PDDs, in order to avoid duplication of processes, the imposition of different requirements, unjustified exclusions and generally cumbersome administrative requirements.

FOLLOW-UP:
A person shall be formally appointed by each of the government departments, by December 31, 2009, to provide the Québec Ombudsman with annual reports on the steps taken to harmonize current programs or new programs.

RECOMMENDATIONS TO CREATE LINKS BETWEEN THE SERVICE NETWORKS

WHEREAS the health and social services network, through its health and social services centres and the RCID-PDDs, is an important PDD specialist within the government apparatus;

WHEREAS the educational childcare community fulfils a primary mission in the areas of integration, referral to other networks and preparation for life at school;

WHEREAS the educational childcare community must be able to rely on timely support from health and social services centre professionals when it takes on children with PDDs – while awaiting a RCID-PDD intervention – in order to avoid a situation where a child is refused by a daycare provider or expelled due to a lack of understanding of the child’s condition and the steps required to address it;

WHEREAS the educational childcare community does not have a mechanism that would formalize the support from and collaboration with specialists from the health and social services network;

WHEREAS the Ministère de la Famille et des Aînés must be aware of the true benefits of its policies for the children and their parents;

WHEREAS the Ministère de la Famille et des Aînés has sufficient levers in its educational program, its partnerships and its reporting mechanisms to enable it to obtain a profile of service availability and quality;

WHEREAS parents must be properly informed of the conditions for access to daycare services.

RECOMMENDATION 3

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux and the Ministère de la Famille et des Aînés should take the steps required to ensure links between their respective networks by providing tools such as framework agreements, so that the educational childcare providers that accept children with PDDs are able to obtain the professional support they require from the health and social services centres (CLSC mission) and the RCID-PDDs, in order to provide continuity of service to the children.

FOLLOW-UP:
The Québec Ombudsman shall be informed by the representatives of each government department, no later than March 31, 2011, of the process introduced to institute these links, and copies of the draft agreements and other tools shall be submitted to the Ombudsman as soon as they are available.

RECOMMENDATIONS TO THE MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX AND THE MINISTÈRE DE L'ÉDUCATION, DU LOISIR ET DU SPORT

RECOMMENDATIONS TO CREATE LINKS BETWEEN THE SERVICE NETWORKS

WHEREAS the health and social services network, through its health and social services centres and the RCID-PDDs, is an important PDD specialist within the government apparatus;

WHEREAS, to be effective, the Ministère de l'Éducation, du Loisir et du Sport must have information on the prior path of children with PDDs, with due respect for the legal requirements concerning confidentiality and the protection of personal information.

RECOMMENDATION 6

The Québec Ombudsman recommends that the Ministère de l'Éducation, du Loisir et du Sport and the Ministère de la Santé et des Services sociaux, when renewing their framework agreements, should introduce methods that will facilitate the transfer of information on the child's situation when one or other of the networks takes charge of the child, with due respect for the rules relating to confidentiality.

FOLLOW-UP:
The Québec Ombudsman shall be informed, no later than March 31, 2011, of the process introduced to produce the agreements, and copies of the draft agreements shall be submitted to the Québec Ombudsman by March 31, 2012.

RECOMMENDATIONS TO IMPROVE THE NEEDS ASSESSMENT PROCESS FOR CHILDREN WITH PDD

GIVEN THE IMPORTANCE of ensuring that, in keeping with the new situation arising from the restructuring of the network of the Ministère de la Santé et des Services sociaux, institutions continue to apply intervention plans (IP) and individualized service plans (ISP) regardless of age or place of residence for all clients with complex needs, especially people with PDDs;

GIVEN THE IMPORTANCE of developing and coordinating intervention plans, integration plans and individualized service plans for children with PDDs;

GIVEN that, pursuant to the Education Act, the school principal, with the help of the parents of a student with a handicap, social maladjustment or learning difficulty, the staff that provide services to that student and the student himself or herself, unless he or she is incapable of doing so, shall establish an intervention plan;

GIVEN THE IMPORTANCE of always pursuing the most diligent and most appropriate action for a child with a PDD, and the need to act at the right time;

GIVEN THE IMPORTANCE of ensuring that children with PDDs have an intervention plan (IP) at every stage of their development, regardless of the network to which the institution providing the services belongs.

RECOMMENDATION 19

The Québec Ombudsman recommends that, in pursuit of their efforts to harmonize intervention plans (IP) and individualized service plans (ISP), the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport should include the Ministère de la Famille et des Aînés in the process and ensure that these plans provide for the effective participation of parents and key stakeholders in order to maximize the child's chance of successful integration into the school environment.

FOLLOW-UP:
The Québec Ombudsman shall be informed of the follow-up to this recommendation by March 31, 2011.

RECOMMENDATION TO ENSURE QUALITY INTERVENTIONS

GIVEN the expected impact of intensive behavioural intervention (IBI) used with children with PDDs at a period of their lives when the effects of early intervention are likely to be the most promising;

GIVEN the legitimate hope of parents for access to the best treatment for their child;

GIVEN the methods used and the financial investments made by the Ministère de la Santé et des Services sociaux for IBI, and the uncertainties that arise during transitions to other approaches;

GIVEN that the Ministère de l'Éducation, du Loisir et du Sport does not recommend any single approach, even though the TEACCH method is widely used;

GIVEN the incomplete nature of scientific knowledge on the causes of and approaches to PDDs.

RECOMMENDATION 20

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux and the Ministère de l'Éducation, du Loisir et du Sport should agree to an assessment of their respective approaches in order to measure the efficiency and effectiveness of their rehabilitation interventions in terms of:

- **Early application or starting age for IBI**
- **Intensity, duration or end of IBI**
- **Location of intervention**
- **One-to-one method of administering IBI**
- **The people authorized to administer IBI**
- **Supervision mechanisms for practitioners administering IBI**
- **Role of parents in the IBI framework**
- **Efficiency of the methods used in schools and how they are administered**
- **Impacts of transitioning from IBI to other methods upon starting school**
- **Effect on so-called regular children of the inclusion of children with PDD in their group**

And that, at the same time, the Ministère de la Santé et des Services sociaux should ensure that its officers monitor advances in the most effective intervention methods for children with PDDs and quickly transfer this knowledge to all practitioners.

And that the Ministère de l'Éducation, du Loisir et du Sport should contribute to the development of research into the transition to pre-school education, foster the introduction of educational practices based on sound scientific data, assert its leadership in research support and promote inter-network sharing of expertise.

FOLLOW-UP:
A representative appointed by the Ministère de la Santé et des Services sociaux for intensive behavioural intervention (IBI), and a representative appointed by the Ministère de l'Éducation, du Loisir et du Sport for the methods used in the schools, shall report to the Québec Ombudsman by March 31, 2011, on the objectives and methods used to evaluate and transfer knowledge, including the involvement of partners, and in 2013-2014, they shall meet with the Québec Ombudsman to share their results and agree on future actions.

RECOMMENDATIONS TO THE MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX AND THE RÉSEAU DE LA SANTÉ ET DES SERVICES SOCIAUX, THE MINISTÈRE DE LA FAMILLE ET DES AÎNÉS AND THE MINISTÈRE DE L'ÉDUCATION, DU LOISIR ET DU SPORT

RECOMMENDATION CONCERNING A BETTER DEFINITION OF THE PROBLEM OF PERVASIVE DEVELOPMENTAL DISORDERS (PDD)

WHEREAS elements of the cause, manifestation, diagnosis, treatment and prevalence of PDDs are still unknown, and the advancement of knowledge in the field is insufficient to settle the resulting controversies;

WHEREAS the clearer scientific research into PDDs becomes, the easier it will be to plan and implement services;

WHEREAS, until progress is achieved in the field of scientific knowledge, a mechanism is required that will enable parents and practitioners to distinguish between tested scientific knowledge on the value of certain interventions and simple opinions regarding interventions that have been insufficiently assessed;

WHEREAS, as a result of scientific uncertainty, mechanisms designed to share experience and best practices, such as the communities of practice, are useful in supporting practitioners and reducing inter-sector prejudices.

RECOMMENDATION 1

The Québec Ombudsman recommends that the three Government ministries responsible for providing care and services to children with PDDs – namely the Ministère de la Santé et des Services sociaux, the Ministère de la Famille et des Aînés, and the Ministère de l'Éducation, du Loisir et du Sport, along with their respective networks, including the network of educational childcare services – should ensure that knowledge sharing programs on PDDs that are consistent with basic and continuous training programs are made available to practitioners by their respective networks, along with shared notions that will provide everyone with a similar level of basic knowledge and a common language to describe this particular condition.

FOLLOW-UP:
The respondents for each of the three Government departments shall inform the Québec Ombudsman of the mechanism selected, no later than March 31, 2011. In addition, they shall inform the Québec Ombudsman every year of the programs and actions implemented, and shall, after five years, submit an assessment of the relevance of these various elements for practitioners.

RECOMMENDATIONS TO THE MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX AND THE RÉSEAU DE LA SANTÉ ET DES SERVICES SOCIAUX, THE MINISTÈRE DE LA FAMILLE ET DES AÎNÉS AND THE MINISTÈRE DE L'ÉDUCATION, DU LOISIR ET DU SPORT (Continued)

RECOMMENDATIONS TO IMPROVE ACCESS TO INFORMATION, AWARENESS AND PDD IDENTIFICATION

WHEREAS the *Orientations ministérielles 2003 – Un geste porteur d'avenir. Des services aux personnes présentant un trouble envahissant du développement, à leurs familles et à leurs proches* contains provisions that recognize the importance of information for all practitioners and parents;

WHEREAS practitioners in the three networks – health and social services, educational childcare and education – have a major role to play in providing information and raising awareness about PDDs;

WHEREAS there are currently some significant gaps in terms of parental access to information and PDD identification, and parents must undertake complex procedures, the length of which is likely to hinder the child's development and upset the family's balance;

WHEREAS practitioners in all three networks should act as conduits of knowledge concerning the most appropriate approaches and services, in order to lessen the burden on parents, increase the effectiveness of the sources, and foster concerted action among the three networks;

RECOMMENDATION 10

The Québec Ombudsman recommends that the health and social services network, the childcare network and the Ministère de l'Éducation, du Loisir et du Sport should ensure that the personnel responsible for providing assistance to parents and children have proper access to information on the nature of PDDs and on the resources available within the three networks, in order to provide better service to the parents and children, on a continuous basis. In other words, they should:

- **be able to tell parents what do to (steps, contacts, services);**
- **be able to guide parents appropriately within a reasonable timeframe;**
- **facilitate intake of children and parents by the appropriate services**

FOLLOW-UP:
The Québec Ombudsman shall be informed by a designated representative of each government department, no later than March 31, 2011, of the mechanism proposed to follow through on this recommendation.

RECOMMENDATION TO ESTABLISH THE ROLE OF THE NAVIGATOR IN THE SERVICE STRUCTURE

WHEREAS the service coordination needs of people with PDDs and their parents are not being met, especially due to the numerous practitioners appointed to fulfil this role;

WHEREAS the role of navigator is not well known in the health and social services, educational childcare and education networks, is not properly incorporated into the trajectory of parents of children with PDDs, and is a shared responsibility, due to the inter-sector nature of the role;

WHEREAS beyond the provincial leadership role played by the Office des personnes handicapées du Québec on the notion of individualized and coordinated service planning, involved practitioners who support children and their parents in their trajectory, primarily by coordinating and implementing the service plan, are not widely available;

RECOMMENDATION 12

The Québec Ombudsman recommends that the three government departments – the Ministère de la Santé et des Services sociaux, the Ministère de la Famille et des Aînés, and the Ministère de l'Éducation, du Loisir et du Sport – working in conjunction with the Office des personnes handicapées du Québec, should redefine the inter-sector function of the navigator by undertaking an evaluation to identify the conditions for success that will reinforce the navigators' true role as major players with parents and with other practitioners working in various service areas.

FOLLOW-UP:
Respondents from each of the three government ministries shall report to the Québec Ombudsman, no later than March 31, 2011, on the objectives of the evaluation, the division of responsibility and their respective department's contribution to the inter-sector effort, and, in 2013-2014, shall meet with the Québec Ombudsman to share the information acquired during the evaluation and agree on future actions.

RECOMMENDATIONS TO THE MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX AND THE RÉSEAU DE LA SANTÉ ET DES SERVICES SOCIAUX, THE MINISTÈRE DE LA FAMILLE ET DES AÎNÉS AND THE MINISTÈRE DE L'ÉDUCATION, DU LOISIR ET DU SPORT (Continued)

RECOMMENDATIONS TO FACILITATE ACCESS TO THE PDD DIAGNOSIS AND APPROPRIATE SERVICES

WHEREAS access to specific front-line habilitation/rehabilitation services should not depend solely on obtaining a PDD diagnosis and may begin before the diagnostic evaluation has been completed;

WHEREAS parents are obliged to undertake numerous procedures to obtain or confirm a PDD diagnosis for their child;

WHEREAS it is important, given the shortage of health care professionals, not to increase the number of interventions required.

RECOMMENDATION 14

The Québec Ombudsman recommends that the Ministère de la Santé et des Services sociaux, the Ministère de la Famille et des Aînés and the Ministère de l'Éducation, du Loisir et du Sport should ensure that their respective networks, including childcare services, harmonize their diagnosis and confirmation requirements to save parents from an avoidable increase in procedures.

FOLLOW-UP:
The respondent from each of the three government departments shall report annually to the Québec Ombudsman on the follow-up to this recommendation until the requirements have been properly harmonized.

Appendix 2 – Useful concepts for understanding PDDs

What are pervasive developmental disorders (PDDs)?

The Diagnostic and Statistical Manual of Mental Disorders, known as DSM IV, was developed by the American Psychiatric Association. This clinicians' guide sets out the official nomenclature for diagnoses. In this manual, PDDs *are characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communications skills, or the presence of stereotyped behaviour, interests, and activities. The qualitative impairments that define these conditions are distinctly deviant relative to the individual's developmental level or mental age.*
PDDs include five disorders: autism, childhood disintegrative disorder, Asperger's syndrome, Rett's syndrome, and pervasive developmental disorders—not otherwise specified (PDD-NOS). The reader will find a complete definition of these disorders in the DSM IV. The excerpts presented here are reproduced directly from the descriptions in the manual.

Autism is probably the best known of these disorders. The DSM-IV definition of autism is the most widely used. Its essential characteristics are *a markedly abnormal or impaired development in social interaction and communication, and a markedly restricted repertoire of activity and interests. Manifestations of the disorder vary greatly depending on the developmental level and chronological age of the individual.*

For example, a qualitative impairment of social interaction may be demonstrated by an inability to establish peer relationships appropriate to the child's level of development, or a failure to spontaneously share personal pleasures, interests or successes with others. A communication impairment may be demonstrated by a delay in or total lack of spoken language development, or a marked inability to engage in or sustain a conversation with others. Impairments may also be evidenced by restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities, such as apparently inflexible adherence to specific, non-functional routines or rituals, or persistent preoccupation with parts of objects.

With **childhood disintegrative disorder**, development appears normal for the first two years of life. It is defined as *a clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas: 1) expressive or receptive language; 2) social skills or adaptive behaviour; 3) bowel or bladder control; 4) play; or 5) motor skills. Abnormalities of functioning in at least two of the following areas: 1) qualitative impairment in social interaction (e.g., impairment in nonverbal behaviours, failure to develop peer relationships, lack of social or emotional reciprocity); 2) qualitative impairment in communication (e.g., delay or lack of spoken language, inability to initiative or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play); 3) restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities, including motor stereotypies and mannerisms. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.* (Other diagnostic possibilities must be ruled out for this diagnosis to be confirmed.)

With **Asperger's syndrome**, there is no significant clinical delay in cognitive development or the development of age-appropriate autonomy, adaptive behaviour (except in terms of social interaction) and curiosity in the environment. It is defined by *the qualitative impairment in social interactions, as manifested by at least two of the following: 1) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction; 2) failure to develop peer relationships appropriate to developmental level; 3) a lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g., by a lack of showing, bringing or pointing out objects of interest to other people); 4) lack of social or emotional reciprocity. Restricted repetitive and stereotyped patterns of behaviour, interests and activities. The disturbance causes clinically significant impairment in social, occupational, or other importance areas of functioning. There is no clinically significant general delay in language. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.*

Rett's syndrome is defined as *the presence of all of the following: 1) apparently normal prenatal and perinatal development; 2) apparently normal psychomotor development throughout the first 5 months after birth; 3) normal head circumference at birth. Onset of all of the following after the period of normal development: 1) deceleration of head growth between ages 5 and 48 months; 2) loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing); 3) loss of social engagement early in the course (although often social interaction develops later); 4) appearance of poorly coordinated gait or trunk movements; 5) severely impaired expressive and receptive language development with severe psychomotor retardation.*

The last category is **non-specific PDD, or PDD–not otherwise specified**, which is defined as *the presence of either a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communications skills, or stereotyped behaviour, interests and activities. The criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder.* For example, this category, under the term "atypical autism", includes presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, subthreshold symptomatology, or all of these.

These definitions clearly illustrate the complexity of presentations and the difficulty, for non-experts, of distinguishing the features of these five disorders and their differences with disorders that do not qualify as PDDs, such as attention-deficit hyperactivity disorder (ADHD), reading disorder (dyslexia) or dysphasia.

According to the DSM-IV, ADHD is defined by *at least six of the following symptoms of inattention, hyperactivity or impulsivity which occur before age 7 years and persist for at least 6 months to a degree that is maladaptive and inconsistent with developmental level: Inattention: the child often fails to give close attention to details or makes careless mistakes in schoolwork, work or other activities and/or often has difficulty sustaining attention in tasks or play activities and/or often does not seem to listen when spoken to directly and/or often does not follow through on instructions and* *fails to finish schoolwork, chores, or duties in the workplace and/or often has difficulty organizing tasks and activities and/or often avoids, dislikes or is reluctant to engage in tasks that required sustained mental effort and/or often loses things necessary for tasks or activities and/or is often easily distracted by extraneous stimuli; Hyperactivity: the child often fidgets with hands or feet or squirms in seat and/or often leaves seat in classroom or in other situations in which remaining seated is expected and/or often runs about or climbs excessively in situations in which it is inappropriate and/or often has difficulty playing or engaging in leisure activities quietly and/or is often "on the go" or acts as if "driven by a motor" and/or often talks excessively; Impulsivity: the child often blurts out answers before questions have been completed and/or often has difficulty awaiting turn and/or often interrupts or intrudes on others.*

Reading disorder is defined as *reading achievement (accuracy, speed or comprehension) that falls substantially (at least two years) below that expected given the individual's chronological age, measured intelligence and age-appropriate education and that significantly interferes with academic achievement or activities of daily living that require reading skills.* This specific reading disorder cannot be explained by intellectual impairment, psychoaffective disorders, sensory deficit (visual or audio), lack of educational opportunity or lack of motivation and interest.

Dysphasia, also called expressive or receptive language disorder, is associated with *symptoms such as: limited range of vocabulary, difficulty acquiring new words, word-finding or vocabulary errors, shortened sentences and simplified grammatical structures* below the level expected given the individual's developmental stage. *The language difficulties interfere with academic or occupational achievement, or with social communication. The symptoms do not meet criteria for a Pervasive Developmental Disorder. If mental retardation, a speech-motor or sensory deficit or environmental deprivation is present, the language difficulties are in excess of those usually associated with those problems.*

Appendix 3: Background to the Québec Ombudsman's study

The Québec Ombudsman studied a specific group of children with PDDs

The Québec Ombudsman elected to limit the study to children aged 0 to 7, or those not having completed the first year of primary school, since the health and social services network is responsible for administering special rehabilitation services directly to children until they enter school. Subsequently, under the Education Act, the children also become the responsibility of the education network.

Methodological issues[66]

The following clarifications are for readers who may not be familiar with the terminology and methods of scientific research. Our goal is to describe the methodological bases of the study as simply as possible. This is a descriptive study. Its objective is to describe the trajectory taken by parents in their search for services for children with PDDs. The study does not seek to test hypotheses in order to establish cause-and-effect relationships, explain what is described, or assess the effectiveness or efficiency of the services offered; other research methods would be required for this.

The study is retrospective in the sense that the people interviewed were explaining facts and situations that had already occurred. It is based on the following elements:

- The principles of qualitative methodologies: the results are described without the use of statistical tools to quantify differences.
- A well-planned sample of parents and other people was selected to reflect a variety of approaches, schools of thought and geographical situations: these people were therefore not selected strictly at random, as is often the case with a random sample

The strengths of the qualitative methodology used for this study are as follows:

- In-depth analysis of information gathered from several sources: surveys, interviews, focus groups, documentary analysis.
- Plausibility of the reported data thanks, in part, to the fact that several different sources and data collection methods produce similar conclusions and corroborate the information obtained.
- Detailed description of situations witnessed in the field, so that readers can determine whether the study results apply to cases of specific interest to them.

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[66] This study used a qualitative approach. Consequently, the sample was carefully planned to include contrast based on the principle of diversification. Its validity relies on the usual strategies of detailed description to help the reader understand the scope of the study. The in-depth analysis was used to produce a classic trajectory or indicator case, the probability of which is based largely on the triangulation of data collection methods and the triangulation of different information sources to corroborate the data.

The methodology was used to produce a "classic trajectory", referred to as the "André-Tim case."

The main limitation of the method is that it does not allow for generalization, that is, the use of the findings to draw conclusions about groups of people or contexts other than those in the study.

Data collection

The data were collected between February and October 2007 throughout the territory of Quebec. They reflect the prevailing situation during those months and are based on government documents tabled during that time.

An initial survey[67] for parents was prepared in collaboration with SOM – Recherches et sondages. A sample was then built, based on the demographic weighting of Québec's regions. The response rate was 88.8%, for a total of 150 parents who completed the telephone interview. It is important to note that there were not enough children from immigrant and cultural communities in the sample. The Québec Ombudsman did, however, question practitioners on this specific topic, and was informed of certain difficulties experienced by these children and their families. Despite efforts to this end, it was not possible to examine the situation of children living with their families in First Nations communities. Due to the lack of specific data, this report therefore does not include recommendations on the subject of these families, even though the Québec Ombudsman is sensitive to their situation and feels that the three government departments concerned should be able to provide practitioners in their respective networks with appropriate tools to address this cultural variable.

A second survey was carried out with the 13 local complaints and service quality commissioners at rehabilitation centres for intellectual disabilities and pervasive developmental disorders (RCID-PDD) in Québec's 15 administrative regions. The survey was concerned with complaints received by their respective services and, where applicable, the solutions offered in response. The responses to this second survey were not significantly different from the comments made by service planners and providers, and were not processed separately.

Meetings were held across Quebec with 167 people, including parents, representatives of community organizations, government departments, administrators and managers of services at all levels, clinicians, other professionals, teachers, technicians, volunteers and researchers. Some of these meetings took the form of individual interviews and others were group discussions.

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67. The results of this survey can be seen on the Québec Ombudsman's website at www.protecteurducitoyen.qc.ca.

A careful examination of the complaints received by the Québec Ombudsman from parents of intellectually impaired or PDD children helped in the identification nof certain problems.[68] These individual complaints clearly echoed the testimony gathered over the course of this study.

The Québec Ombudsman upheld the strictest confidentiality for the people who took part in the surveys and meetings. As a result, the data are collated in compliance with its commitment to protect the identities of the individuals and organizations that took part.

The relevant texts provide additional clarification

The study took into account the applicable legislation and regulations,[69] as well as the related government policies[70] and relevant court decisions. The courts have interpreted the legislation to see whether government departments complied with them in the development and provision of their services.[71]

The Québec Ombudsman documented its knowledge of PDDs by reviewing analyses of the situation of handicapped children in Quebec.

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[68] The analysis focused on the period between April 1, 2005, and January 20, 2009. Over this period, 176 complaints were filed with the Québec Ombudsman by people with PDDs.

[69] The legislation includes the *Canadian Charter of Rights and Freedoms,* the *Quebec Charter of Human Rights and Freedoms,* the *Quebec Civil Code*, the *Act respecting health services and social services*, the *Educational Childcare Act* and the *Education Act*.

[70] The main documents are as follows: The government action plan: *Un geste porteur d'avenir. Des services aux personnes présentant un trouble envahissant du développement, à leurs familles et à leurs proches; Le Cadre de référence national pour la conclusion d'ententes de services entre les CSSS et les centres de réadaptation en déficience intellectuelle*; The academic adaptation policy set out in the document entitled: *Une école adaptée à tous ses élèves; L'organisation des services éducatifs aux élèves à risque et aux élèves handicapés ou en difficulté d'adaptation ou d'apprentissage;* The guidelines issued by the Ministère de l'Éducation, du Loisir et du Sport as set out in the document entitled: *Les services éducatifs complémentaires : essentiels à la réussite;* The update of the educational program: *Accueillir la petite enfance, le programme éducatif des services de garde du Québec;* The reference framework: *Mesure exceptionnelle de soutien à l'intégration dans les services de garde pour les enfants handicapés ayant d'importants besoins. Cadre de référence 2004 – 2007; Le Plan d'action du ministère de la Famille, des Aînés et de la Condition féminine à l'égard des personnes handicapées. Une responsabilité dans le cadre de la Loi assurant l'exercice des droits des personnes handicapées en vue de leur intégration professionnelle et sociale*.

[71] Concerning the right of children with PDDs to receive services from the health and social services network: the Auton and Barclay cases. Concerning access to educational childcare services for children with PDDs: *Commission des droits de la personne et des droits de la jeunesse v. Garderie du Couvent Inc.* et al. Concerning the recourses exercised by parents against the educational community: the Marcil, Rouette, Eaton and Potvin cases.

Appendix 4: Credits and acknowledgements

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Think tank
For the completion of special projects, a think tank is set up to examine the report independently and critically. The think tank members are chosen for their expertise and ability to take a broader view. The members of this think tank were:
Luc Malo, former Deputy Minister at the Ministère de la Santé et des Services sociaux and President of the Conseil d'administration de l'Association des établissements de réadaptation en déficience physique du Québec (AERDPQ)
Irma Clapperton, Doctor and Public Health Specialist
Nathalie Bigras, Professor/Researcher in the Department of Education and Pedagogy at the Université du Québec à Montréal (UQAM)

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