



LE PROTECTEUR DU CITOYEN

Assemblée nationale
Québec

PRESS RELEASE

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**QUÉBEC OMBUDSMAN'S REPORT ON GOVERNMENT SERVICES FOR CHILDREN
WITH PDDs: *LOOKING TOWARD GREATER CONTINUITY IN DELIVERY OF
SERVICES, APPROACHES, AND HUMAN RELATIONS***

Québec City, October 8, 2009 – The Ministère de la Santé et des Services sociaux, the Ministère de la Famille et des Aînés, the Ministère de l'Éducation, du Loisir et du Sport, and the Office des personnes handicapées du Québec have agreed to implement the recommendations issued in the Québec Ombudsman's report on government services for children with pervasive developmental disorders (PDDs) tabled this morning in the Québec National Assembly.

What are pervasive developmental disorders (PDDs)?

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. Although the term PDD encompasses a wide range of manifestations, people suffering from this condition have one thing in common: feelings of considerable distress when faced with change or any kind of new situation.

What was the objective of the study?

The Québec Ombudsman conducted a study on government services for children with a PDD ranging in age from 0 to 7 or having finished their first year of elementary school in order to understand why it continues to receive complaints on this matter despite the expected improvements to ministerial orientations¹ and the sums allocated to implement specialized services.

What are the Québec Ombudsman's conclusions based on?

The findings and recommendations are based on the analysis of the trajectories of parents seeking services for their children. This analysis draws on two surveys: one conducted with

¹ Ministère de la Santé et des Services sociaux document entitled *Un geste porteur d'avenir. Des services aux personnes présentant un trouble envahissant du développement, à leurs familles et à leurs proches.*

150 parents and another with 13 local complaints commissioners from rehabilitation centers for people with intellectual disabilities and pervasive developmental disorders (CRDI-TED) operating in 15 regions of Québec. The Québec Ombudsman also held interviews and panel discussions with 167 parents and stakeholders concerned by the issue.

What can we conclude from the report?

The path children and parents must take through the health and social services, daycare, and education networks is fraught with pitfalls. Problems are often due to excessive compartmentalization. This lack of fluidity has major repercussions on children who have a hard time dealing with the slightest change in their routine. **Greater continuity in service delivery, approaches, and human relationships is therefore needed between the MSSS and its network, the MFA and the educational daycare network, and the MELS and its network.**

The Québec Ombudsman's report concludes that concrete measures must be implemented to address parents' concerns and dissatisfaction. In this regard, the report makes the following observations:

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.

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.

OBSERVATION 3: Parents must fulfill multiple requirements to obtain services.

OBSERVATION 4: Support for families is lacking.

OBSERVATION 5: Ministerial intentions are slow to be fully translated into action in the field, despite the importance of continuity in service delivery. Transitions among networks are difficult.

Based on the five major observations of this study, the Québec Ombudsman, Raymonde Saint-Germain, issued 21 recommendations to the three ministries and their networks as well as the Office des personnes handicapées. A detailed follow-up schedule was issued based on these recommendations in order 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
- **Intervention approaches**, because they must be assessed 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
- **Siblings**, because they can play a critical role in the life of a child with a PDD and the adult he or she will become

- **Steps for seeking financial assistance**, because the numerous formalities imposed by the various networks are notably due to the lack of harmonization between programs
- **Evaluation of children’s needs**, because the quality of the service plan depends on an accurate evaluation of the child’s needs
- **Coordination of services**, because access to the right service at the right time is vital, and transitions between service networks must be seamless
- **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 represents a particularly significant change in the lives of children with a PDD and their parents

What is the expected impact of this report?

The Québec Ombudsman has identified possible short term solutions that can greatly improve the daily life of children and parents themselves. It also recommends pivotal medium term actions to more permanently resolve long-standing problems. The recommendations are realistic and do not involve major costs. 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.

Government services must also meet another challenge: that of adapting to the needs of children and tailoring interventions based on the various stages of their lives as they grow into adulthood. Ms. Saint-Germain has stressed her concerns in this regard, which is why the Québec Ombudsman is currently conducting a special investigation on this issue. Moreover, it should be noted that a number of recommendations in this report can apply to the services provided to people with PDDs in other stages of their lives.

The Québec Ombudsman’s report, the summary of this report, and the results of the study conducted with parents are available on the Québec Ombudsman’s website at www.protecteurducitoyen.qc.ca under “Cases and Documentation.”

- 30 -

Source: The Québec Ombudsman

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