

PRESS RELEASE

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THE QUÉBEC OMBUDSMAN RELEASES A SPECIAL REPORT ON SERVICES FOR YOUTH AND ADULTS WITH A PERVASIVE DEVELOPMENTAL DISORDER

Québec City, May 23, 2012 – The Québec Ombudsman today released a special report entitled *Services Provided to Young People and Adults with a Pervasive Developmental Disorder: From Government Commitment to Cold Hard Facts*. The report, submitted to the National Assembly, follows a first report released in October 2009 on services for children aged 0 to 7 years with pervasive developmental disorders (PDDs).

What are PDDs?

PDDs are characterized by severe and pervasive impairment in several areas of an individual's development – reciprocal social interaction skills, communication skills – or the presence of stereotyped behaviours, interests and activities. PDDs comprise five specific disorders: Autism, Asperger Syndrome, PDD Not Otherwise Specified, Rett's Syndrome and Childhood Disintegrative Disorder.

The Québec Ombudsman's review procedure

The Québec Ombudsman relied on a number of information sources to arrive at the findings in this special report and make appropriate recommendations. In addition to studying all of the complaints received from 2005 to 2012, it thoroughly examined various policies, action plans and other government documents, conducted a critical analysis of scientific studies on the organization of services for people with PDD and conducted individual and group interviews with experts and professionals in the field. Lastly, it assembled focus groups to fully understand the needs of people with PDD.

Major findings of the Québec Ombudsman

First and foremost, the Québec Ombudsman found that services for youth and adults with PDD, as presented in several policies, action plans and other government documents, are **theoretically** wide-ranging, comprehensive and provided collaboratively by the health and social services, education and employment networks. The government's current service commitment is essentially to meet the primary needs of people with PDD and their families.

According to the Ombudsperson, Raymonde Saint-Germain, “the difficulty for those concerned is that the service offering remains theoretical; in reality, the promised services are relatively inaccessible. Significant gaps between the stated services and the services actually available were observed in each of the networks. In addition, service delivery varies considerably from one region to the next, particularly in the health and social services network.” This situation led the Québec Ombudsman to conclude that each government department and network needs to clarify and adapt the services that are actually available. In other words, they must inform citizens of the services they are actually entitled to expect.

The needs of people with PDD and their families vary and are often complex, so addressing them poses major challenges for all of the public service networks concerned.

In the health and social services sector, people with PDD often have a harder time obtaining the medical services they need, especially when there is a dual diagnosis of PDD and mental health problems. Behavioural disorders, including severe behaviour problems and behaviours of a sexual nature, need to be addressed more effectively. The heavy burden of caring for a person with PDD generally renders parents and other caregivers particularly vulnerable to burnout and psychological distress. They have major needs in terms of respite, general and specialized services, and those needs are often not met.

In the education sector, better support is needed for students with PDD, especially outside the classroom. Managing disruptive behaviour is a significant challenge. In the case of tantrums or crisis situations, it is important that the same resource person deal with the child every time and that a suitable room be available where the child can be taken to calm down. Because children with PDD can easily become victims of abuse and bullying, more-concrete action must be taken to protect them at school. Specific prevention and monitoring measures must be adopted to allow students with PDD to develop their full potential.

Once they have finished their schooling, people with PDD who are unable to enter the workforce have significant needs. Social participation services that meet those needs, such as day activity programs, are required; however, it is not clear who is responsible for delivering these services. Rehabilitation centres for people with intellectual disabilities and pervasive developmental disorders (CRDITEDs) are gradually withdrawing from this area of activity, despite the fact that no other body has the resources to take over under the proper conditions. In addition, social participation services are generally not offered until the age of 21, even though a number of young people stop going to school at age 16, creating a five-year gap during which they do not have access to services.

Obtaining a suitable place to live is also complicated. There are often long waiting lists for traditional public housing models and the shortage of housing for this client group results in people with different needs living together under the same roof. A wider range of housing solutions is needed and focus should be placed on developing the domestic living skills of people with PDD to help increase their autonomy and make them eligible for residential resources with less supervision (and therefore also less costly). In addition, better planning of the transition from family home to residential resource when aging parents are no longer able to care for their children with PDD is required.

A comprehensive vision for working collaboratively

In the Québec Ombudsman’s opinion, the government departments and agencies concerned can overcome these challenges provided that a comprehensive, collaborative vision is developed for all players from the public service networks concerned. We conclude from our review that effective collaboration between the various players can be strengthened on the condition that their respective roles and responsibilities in different situations described in this special report are clearly defined. A comprehensive, collaborative vision also requires greater transparency in departmental and network accountability so as to be better able to determine how far we have left to go in guaranteeing people with PDD and their families the services pledged to them by the government.

To that end, the Québec Ombudsman made 17 recommendations aimed at:

- developing clinical expertise in mental health and tools for preventing disruptive behaviours;
- implementing support and respite services for parents and families;
- supporting and assisting more-vulnerable students, preventing harassment and bullying and improving specialized intervention at school;
- adopting measures to foster social inclusion and participation, including day activity programs;
- developing domestic living skills and planning the transition from family home to a new living environment when family members get too old to care for a person with PDD;
- establishing and systematically implementing individualized service plans and individualized, intersectoral service plans;
- clearly defining the roles and responsibilities of each public service network and improving intersectoral collaboration and partnership.

“A number of these recommendations are primarily targeted at decision makers, administrators and professionals in the public service networks. Despite their specialized nature, we believe that these recommendations could concretely improve access to government services for people with PDD and their families,” Raymonde Saint-Germain concluded.

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Source and information:

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