

Executive Summary¹

Pervasive developmental disorders (PDD)² are characterized by severe and pervasive impairment in several areas of development – reciprocal social interaction skills, communication 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 comprise five specific disorders: Autism, Asperger Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, Rett’s Syndrome and Childhood Disintegrative Disorder.

People with PDD have varying needs for public services. The most commonly expressed ones include access to health and social services based on their needs, a fulfilling education path, a meaningful active life that enables them to achieve self-fulfilment, and a living environment suited to their level of autonomy.

Access to health and social services based on individual needs

For people with PDD, access to services for both physical and mental health problems is often compromised. There is a noted tendency to associate a physical health problem with the PDD, especially if the person is non-verbal.

Mental health services are often limited to medical consultation and medication follow-up and, in some regions, are available solely at health and social services centres (CSSSs). Access to the required services is further complicated when multiple issues are involved: there is confusion over the respective roles and responsibilities of professionals from the different institutions involved, which undermines collaboration and complicates meaningful intervention. Development of expertise in dealing with people who present both a PDD and a mental health problem needs to be stepped up in order to provide professionals with clinical tools to facilitate more effective intervention.

Special attention must also be given to developing expertise in dealing with behavioural disorders, including severe behaviour problems and problematic sexual and emotional behaviour. CSSS teams and other professionals must have valid clinical tools to better prevent disruptive behaviour, especially at school.

Families of people with PDD are particularly vulnerable to burnout and psychological distress due to the heavy parental responsibilities they carry. Caregivers have high needs for support and respite services, needs that are rarely met. Support and respite services are not always accessible and, when they are, they vary widely from one region to the next. The Ministère de la Santé et des Services sociaux (MSSS) must review its support

¹ All of the Québec Ombudsman’s recommendations as well as the related means of follow-up are presented in Appendix 1.

² In this report, the term PDD always refers to pervasive developmental disorders and never to the people living with them. The expression “people with PDD” is used to refer to people with the characteristics of a pervasive developmental disorder. Appendix 2 contains information on each of the disorders on the PDD spectrum.

program for families of people with disabilities as quickly as possible and place emphasis on establishing integrated respite and specialized respite care services.

A fulfilling education path

The education system should help students with PDD develop their full potential, in terms of learning as well as social and communication skills. Adopting an individualized approach, i.e. an approach that addresses the specific needs of each person, and implementing preventive measures and special education services requires effective collaboration between the education and health and social services networks. To that end, use of individualized, intersectoral service plans (IISPs), a recognized tool, should be reinforced. Currently, not all students who should have an IISP have one, or the plan is not implemented properly.

Certain practices involving placing students in classes on the basis that they have the same difficulties raise questions because these practices are not based on a rigorous assessment of each student's ability and needs. Where possible, efforts must be made to find mixed integration solutions, more flexible and often more beneficial for the student.

Management of disruptive behaviour associated with PDD must go beyond immediate crisis intervention. It must also include school-based prevention and follow-up measures so as not to compromise the student's educational success. Support services must be provided outside the classroom as well. In the case of tantrums or crisis situations requiring immediate intervention, it is important that students with PDD be dealt with by the same resource person every time and that a suitable room be available where the student can be taken to calm down. Managing disruptive behaviour also requires effective collaboration between the school and the health and social services network.

Students with PDD are often the victims of abuse and bullying. While it is already mindful of this issue, the Ministère de l'Éducation, du Loisir et du Sport (MELS) must make it a greater priority. The Department is expected to implement direct services to effectively fight harassment, bullying and violence against students in general and the most vulnerable among them in particular.

A meaningful active life providing self-fulfilment

People with PDD continue to have multiple needs when they finish their schooling. Some will be able to enter the workforce, while others will realize their potential through activities promoting social participation. However, the health and social services network generally does not start providing social integration and participation services until a person turns 21, even if the person stopped going to school at age 16. To ensure continuity of services, social integration and participation services should be provided from the time formal schooling ends.

There is deep concern about redefining the role of rehabilitation centres for people with intellectual disabilities and pervasive developmental disorders (CRDITEDs). It is feared that they will stop providing certain services, without CSSSs and community organizations being able to adjust and take over from them. It is also feared that day activity programs or social participation services for people who cannot enter the

workforce will end. The Québec Ombudsman found the provision of these programs and services to be deficient. Consequently, the MSSS must rapidly define, in concert with its partners, the exact nature and content of its planned day activity programs. It must also make sure that the responsible bodies have the resources necessary to adequately deliver these programs.

A living environment suited to the person's level of autonomy

Access to an appropriate living environment for their level of autonomy is crucial for people with PDD. However, not many options are available outside of traditional public housing models, for which there is usually a long waiting list. The shortage of housing for this population group often results in people with different needs living together under the same roof.

The latter finding highlights the need to broaden the range of housing solutions adapted to the special needs of people with PDD. It is also advisable to invest in developing domestic living skills (e.g. learning how to shop for groceries or manage a budget) so that more people with PDD are able to live independently.

A number of adults with PDD live with their parents or another family member. When the caregiver gets too old to look after the person, or dies, it has a tremendous impact. Better planning for these eventualities and the transition from family home to residential resource is required. Possible solutions could be found in local housing initiatives for people with intellectual disabilities.

A COMPREHENSIVE VISION FOR ACTION

In the Québec Ombudsman's opinion, the above needs can be met if all government departments and agencies concerned as well as their respective service networks adopt a comprehensive, collaborative approach. This implies a common vision and clear action plan to which all parties commit. The culture within each organization must evolve accordingly. Efforts must be made on three fronts to successfully make this major shift:

1- Clarify the roles and responsibilities of each government player

Our review revealed that the government's service commitment is spelled out through a number of policies that define a comprehensive, integrated and intersectoral approach. In actual fact, however, the sharing of roles and responsibilities among the various players within the three networks most concerned (health and social services, education and employment) is often problematic.

Health and social services are still organized in such a way that a silo effect is created, with the respective players each reporting to separate institutions. Service continuity is thus not ensured. Significant regional differences in services for people with PDD were also noted. The MSSS must clearly define the roles and responsibilities of each player and insist that the bases of the clinical project be respected in both defining and delivering services. In the education network, school boards' interpretation of a school's mandate varies widely, a situation that MELS must address. As for the Ministère de l'Emploi et de la

Solidarité sociale (MESS), it must set out the role it intends to play to help people who will never enter the job market.

The three departments (MSSS, MELS, MESS) must play a leadership role in concluding effective cooperation agreements involving all of their networks. New incentive measures must be introduced to enhance the development of employability skills following graduation, workplace integration, support and supervision, and social participation, including day services. The improvements made as a result of cooperation agreements should benefit all people with disabilities.

2- Improve performance measurement

In results-based management, aspects not measured in accountability are less likely to be given priority. This is the case with the obligation of intersectoral collaboration contained in various agreements, in particular, through IISPs. Due to the lack of relevant indicators for measuring intersectoral collaboration, there is not enough incentive for public service networks to deem it a priority. Relevant indicators must therefore be established to measure the effectiveness of intersectoral partnerships and their impact on those receiving services.

The tools used to measure performance must ensure that the right worker is made accountable so that intersectoral collaboration becomes imperative. In addition, performance must be measured using the proper indicator to make sure that the public service networks make the most of allocated resources. Each network must strive to improve its own accountability so as to shed greater light on the impact of its action on those receiving its services.

In the health and social services network, management agreements between provincial, regional and local authorities, while pertinent, have too many limits. In the education network, the first generation of partnership agreements has not been fully implemented yet, so not all of the outcomes are known. As for the employment services network, accountability for the provision of services to people with disabilities and, in particular, pervasive developmental disorders, must be more clearly defined.

3- Clarify the provision of public services to vulnerable persons

Currently, the approach taken in addressing the needs of people with PDD differs from one service network to the next. In the Québec Ombudsman's opinion, this is also the case, to varying degrees, for all vulnerable population groups, in particular, people with a physical disability, an intellectual disability or a mental health problem. This situation is primarily due to the lack of a clearly defined service offering for all vulnerable population groups.

We found that access to and the availability of health and social services varied considerably from one region to the next. More meaningful services are needed in the education network for students with disabilities, and in the employment services network for people who are unable to work and would benefit from social participation activities. Thus, each department must clarify and adapt its services to make them more accessible to vulnerable population groups.

THREE IMMEDIATE PRIORITIES FOR ACTION

The Québec Ombudsman's recommendations reflect these findings. They will require a significant, continuous effort on the part of the government departments, networks and institutions concerned, to be carried out in phases. Some of them will require influencing vast networks, a considerable undertaking that demands strong leadership.

Furthermore, our review highlighted the need to prioritize action on three fronts: developing expertise in dealing with people that present a pervasive developmental disorder as well as a mental health problem, improving respite services for parents and family caregivers and enhancing day services for people who are unable to enter the workforce. The Québec Ombudsman expects the departments concerned to promptly implement short-term transitional measures to address these specific needs more effectively.

A solution that matches the needs of youth and adults with PDD could be found if all the departments concerned, their respective networks, the youth and adults concerned and their families pooled their efforts. Those receiving the improved services would also be better informed about the services they are entitled to expect because the government pledged to deliver them.

The Québec Ombudsman made 17 recommendations to that end. The recommendations have been formulated to specify more clearly certain areas of activity that appeared to us to be fundamental. Essentially, the content of the recommendations targets:

- development of clinical expertise in mental health and of tools for preventing disruptive behaviours;
- implementation of support and respite services for parents and families;
- support and assistance for more-vulnerable students, prevention of harassment and bullying and improvement of specialized intervention at school;
- adoption of measures to foster social integration and participation, including day activity programs;
- development of domestic living skills and planning of the transition from family home to a new living environment when families get too old to care for a person with PDD;
- establishment and systematic implementation of individualized service plans and individualized, intersectoral service plans;
- clearly defined roles and responsibilities of each public service network and improvement of intersectoral collaboration and partnership.