

**Report by the Québec Ombudsman**

Service access, continuity and complementarity for young people (0-18 years old) with an intellectual disability or an autism spectrum disorder

March 24, 2015

## Summary

- 1 On October 27, 2014, the Québec Ombudsman presented its brief within the context of the special consultations on Bill 10 – *An Act to modify the organization and governance of the health and social services network, in particular by abolishing the regional agencies*. On February 9, 2015, the Bill was passed with several amendments. Given these particular circumstances, this report therefore draws connections between the results of our systemic intervention and the overhaul of the health and social services network presently underway.
- 2 The systemic intervention concerns the services provided to young people aged 0 to 18 years old with an intellectual disability or an autism spectrum disorder,<sup>1</sup> confirmed or unconfirmed and with or without physical disability. When parents turn to health and social services institutions, their main expectation is that their children will be given stimulation to develop their autonomy. As a rule, these services are delivered by rehabilitation professionals<sup>2</sup> who work in public network institutions.<sup>3</sup>
- 3 Currently, these services are provided by institutions with dovetailing missions that work together to ensure an adequate response to public needs. However, the Québec Ombudsman has found that what is really available is different from what the service organization model provides on paper. The result is that children with more than one disability often need services from more than one institution. When they are required to shuttle between institutions, they regularly encounter a break in service continuity. Sometimes the problem is the fact the services provided by institutions with different missions are not complementary.
- 4 Lack of access to the right service at the right time may be detrimental to these children. At a key stage in their development, access to these services is a pressing matter. **In the Québec Ombudsman's opinion, these children should be able to count on public resources being available to them, resources based on their needs, regardless of the type of disability.**<sup>4</sup>
- 5 This report documents the three following problem areas:
  - ▶ service **continuity** for people referred by rehabilitation centres for physical disabilities (CRDPs) to rehabilitation centres for intellectual disabilities and pervasive developmental disorders (CRDITEDs) further to a confirmed diagnosis of intellectual disability or autism spectrum disorder;
  - ▶ **access to professional rehabilitation services** in CRDITEDs;

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1 Published in May 2013, the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), subsumes pervasive developmental disorders (PDDs) under autism spectrum disorders (ASDs). Henceforth, clinicians will have to establish the severity of the clinical symptoms of ASDs (mild, moderate, severe) and, consequently, the level of support required. After analyzing these changes and the critiques of this new diagnostic approach, from now on the Québec Ombudsman will use the term "autism spectrum disorder" (ASD) to designate the diagnosis of this client population, while being very watchful as to the potentially adverse effects of the new classification on service access.

2 For the purpose at hand, we are referring in particular to speech therapy, occupational therapy and physiotherapy.

3 For example, as at March 31, 2015, there are 95 health and social services centres (CSSSs), some 20 rehabilitation centres for intellectual disabilities and pervasive developmental disorders (CRDITEDs) and as many rehabilitation centres for physical disabilities (CRDPs). Further to the reform that will take effect on April 1, 2015, the number of public institutions will decrease from 182 to 51.

4 That is to say, three broad disability categories: physical, intellectual and autism spectrum disorders.

- ▶ **complementarity of services** between CRDPs and CRDITEDs for people requiring services from both types of institutions.
- 6 It bears pointing out that this report differs in three respects from two previous reports<sup>5</sup> by the Québec Ombudsman, which concerned services to people with an autism spectrum disorder. First, **it is more broadly based** to include people with an intellectual disability. It goes on to examine service access, continuity and complementarity problems **from a more specific angle—that of rehabilitation services**. Lastly, it is part of the movement created by the network reform underway to **integrate health services and social services**.
  - 7 In short, the Québec Ombudsman's report documents the most widespread difficulties young people and their families face as they make their way through the system and seeks to find the causes. Ways of preventing the recurrence of these problems are identified and described in recommendations to the Ministère de la Santé et des Services sociaux.
  - 8 These recommendations are aimed at supporting the integration of health services and social services, which is crucial to service access, continuity and complementarity for these young people and their families. The recommendations can be summarized as follows:
    - ▶ The first two recommendations call for the designation of a front-line navigator (pivotal resource) as soon as a user enters the system and continuous use of the individualized service plan for any transition through the system.
    - ▶ The third and fourth recommendations urge the Department to determine a standard reference date (system entry date) for fair positioning of users on any waiting list constituted within the context of a disability care pathway.
    - ▶ The fifth recommendation reiterates the importance of using an individualized service plan for all users who require services from more than one provider and coordination of this plan by the navigator (pivotal resource).
    - ▶ The sixth and seventh recommendations introduce the need for a template for an integrated service network for people with disabilities that will define the service offering, service pathways, operational practices and model partnership framework agreements between service programs for the client populations they share.
    - ▶ The eighth and final recommendation requests examination of the usefulness of grouping disability service programs, including the pooling of program resources.

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<sup>5</sup> Special report by the Québec Ombudsman on *Services provided to young people and adults with a pervasive developmental disorder*, 2009; Special report by the Québec Ombudsman on *Services provided to young people and adults with a pervasive developmental disorder: From government commitment to cold hard facts*, 2012.