

The need for increased access to early behavioural intervention programs for autism spectrum disorders

Emilie Poitout



According to the Diagnostic Manual for Mental Disorders, Fifth Edition (DSM-5), autism spectrum disorder (ASD) is a neurodevelopmental disorder affecting ten million people worldwide; it is characterized by pervasive deficits in social communication and interaction, and may be accompanied by language and behaviour disorders, as well as intellectual delays. Moreover, ASD is a new diagnostic category in the DSM-5, as it now includes conditions previously identified as early infantile autism, childhood autism, and Asperger's disorder, among others (1, 2). As a senior medical student doing clinical rotations, I have observed that ASD is indeed a spectrum: patients tend to present with varying levels of functioning—while some complete high school and maintain stable jobs, others have serious language delays and never complete primary school. In spite of these

wide variations in clinical presentation, we are now able to detect and diagnose ASD earlier than ever before. Such early interventions, particularly those prior to six years of age, have demonstrated significant improvements in global level of functioning for these patients (3-5).

The prevalence rates of ASD have drastically increased in the last decade. For instance, while in 2000 one in 150 children had been diagnosed with ASD, this proportion has increased to one in 110 in 2006, and to one in 68 in 2012 (6,7). Some have attributed this rapid increase in prevalence rates to increased capacity in diagnosis as well as to ASD's characterization as a 'spectrum.' Even when these confounding factors are taken into account, however, experts maintain that an increase in the true prevalence rates of ASD cannot be ruled out, suggesting environmental toxins, genetic factors, and advanced maternal age as potential culprits (2). Certain vaccines were also originally incriminated, but the evidence in favour of the vaccination hypothesis has since been refuted (8,9).

In Quebec, a diagnosis of ASD can be made by a psychiatrist or a psychologist, and patients are then usually referred to the Centre de Réadaptation en Déficience Intellectuelle (CRDI) of their local Centre Intégré Universitaire de Santé et Services Sociaux (CIUSSS). Services provided at the CRDI are tailored to each patient's needs and can include accommodation consultation, management, and early childhood intervention (10). The CRDIs are the only publicly-funded organizations delivering services to patients with ASD in Quebec; though certain non-profit organizations also offer services to patients and their families, their funding is usually dependent on philanthropy and hence their sustainability is often uncertain (2). There are, as well, private resources accessible to families who can afford them. Yet, with the recent increase in ASD prevalence in Quebec, all of these resources have experienced a rapid surge in demand. Unfortunately, government funding of CRDIs has not followed the increasing ASD prevalence and patients now have to wait an average of two years before accessing any type of services in the province. Even in the private system, waiting times have been rapidly increasing. In fact, in some jurisdictions, seeing a psychiatrist or psychologist for diagnosis can now take up to twelve months, resulting in a three-year wait for ASD patients and families before interventions can be initiated (11). These delays have not only had detrimental impacts on the quality of life for patients and their families, but they have also negatively affected the potential efficacy of early interventions on social adaptation and functioning level (3-5, 12).

Early Intensive Behavioural Intervention (EIBI), a 20-hour per week program with demonstrated efficacy for children under six years of age with neurodevelopmental disorders, is a key intervention offered by the CRDI system. Recent meta-analyses have reported EIBI and its equivalents can lead to improvements in adaptive behaviour, Intellectual Quotient (IQ), non-verbal IQ, expressive language, receptive language, communication, daily living skills, and socialization (3-5). Such improvements point to the ability of more patients with ASD to function successfully in society, in turn increasing the global quality of life for these patients and their families.

Luckily enough, in March 2017, the Quebec Minister of Health and Social Services announced a \$29 million investment aimed at decreasing waiting times for patients with ASD (13). Given the evidence presented above, I believe that it would be highly beneficial if these sums were invested to improve the availability of early childhood interventions for ASD patients. However, since accessing EIBI services first requires a correct diagnosis, the Ministry should also consider increasing the number of healthcare professionals who can diagnose ASD. Quebec is not alone in enacting these policies: in June 2017, Ontario launched its New Ontario Autism Program, with focus on increasing diagnostic capacity, improving access to resources, and decreasing waiting lists for services. The program also aims to improve the quality of life of patients and families through the aforementioned ways, maximizing the potential and success of patients, increasing active participation in society, and providing the best care in a cost-effective manner (14). It will be essential to closely monitor the impact of these promising initiatives on the populations of patients with ASD, and to ensure that the funds are invested towards evidence-based interventions with established benefits.

References

1. Diagnostic and statistical manual of mental disorders. 5th ed. AP Association. Washington, DC; 2013.
2. L'autisme en chiffres. Fédération Québécoise de l'Autisme [Internet]. 2017. Available from <http://www.autisme.qc.ca/tsa/lautisme-en-chiffres.html>
3. Eldevik S, Hastings RP, Hughes JC, Jahr E, Eikeseth S, Cross S. Meta-analysis of early intensive behavioral intervention for children with autism. *J Clin Adolesc Psychol*. 2009; 38(3):439-50.
4. Makrygianni MK, Reed P. A meta-analytic review of the effectiveness of behavioural early intervention programs for children with autistic spectrum disorders. *Research in Autism Spectrum Disorders*. 2010; 4(4): 577-93.
5. Dawson G, Roger S, Munson J, Smith M, Winter J, et al. Randomized, controlled trial of an intervention for toddlers with Autism: The early start Denver Model. *Pediatrics*. 2010; 127(17): 958.
6. Facts about Autism Spectrum Disorders: CDC; 2017. Available from <https://www.cdc.gov/ncbddd/autism/data.html>
7. Facts About Autism: Autism Speaks Canada; 2017. Available from <http://fr.autismspeaks.ca/about-autism/facts-about-autism>
8. Zerbo O, Qian Y, Yoshida C, Fireman BH, Klein NP, Croen LA. Association between Influenza infection and

The need for early behavioural intervention programs for autism spectrum disorders

- vaccination during pregnancy and risk of Autism Spectrum Disorder. *JAMA Pediatr.* 2017;171(1). Available from doi:10.1001/jamapediatrics.2016.3609
9. Taylor LE, Swerdfeger AL, Eslick, GD. Vaccines are not associated with Autism: An evidence-based meta-analysis of case-control and cohort studies. *Vaccine.* 2014; 32(29):3623–29. Available from (<http://www.sciencedirect.com/science/article/pii/S0264410X14006367>).
 10. Rythme développement lent - déficience sensorielle, rythme développement lent. CRDIQ. 2017. Available from <http://www.crdiq.qc.ca/services-acces.html>
 11. Autisme: les listes d'attente pour les services s'allongent. Radio-Canada.ca. 2014. Available from <http://ici.radio-canada.ca/nouvelle/648335/autisme-quebec-services-dela>
 12. Groux M, Groux, N. Troubles du spectre de l'autisme: l'intervention comportementale intensive, un traitement porteur. *Le Médecin du Québec.* 2012; 47(10), 99-104. Available from <http://www.autisme.qc.ca/assets/files/02-autisme-tsa/Diagnostic-Depistage/TSA-ICI.pdf>
 13. Devoir L. Plan 2012-2022 sur l'autisme: Québec injecte 29 millions. 2016. Available from <http://www.ledevoir.com/politique/quebec/494466/autisme-quebec-injecte-29-millions-pour-reduire-les-listes-d-attente>
 14. Ontario Autism Program: Government of Canada. 2017. Available from <http://www.children.gov.on.ca/htdocs/English/specialneeds/autism/ontario-autism-program.asp>