



Physicians of Ontario Neurodevelopmental Advocacy

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**Re: Baber Report**

Dear Sir:

We are writing this letter to respond to statements in the report made by Mr. Roman Baber about Autism Services in Ontario. Specifically, we wish to comment on the issues of who should make a diagnosis of Autism Spectrum Disorder (ASD) and how this should be done.

The Physicians of Ontario Neurodevelopmental Advocacy (PONDA) is a volunteer network of physicians and psychologists advocating to optimize the well-being of individuals with neurodevelopmental needs in Ontario by promoting evidence informed policy in the systems of care. Our members include most of those who practice Developmental Paediatrics in Ontario. Developmental Paediatricians are concerned with providing highly specialized health care to children of all ages and developmental levels with respect to their developmental and psychosocial well-being. The diagnosis and treatment of Autism Spectrum Disorder falls in this scope of practice.

On page 9 of his report, Mr. Baber recommends that as a prerequisite to funding, diagnosis of ASD must be made by a Developmental Paediatrician or Clinical Child Psychologist.<sup>i</sup> We believe that to limit the diagnostic capability to this small group of individuals will delay access to appropriate evidence-based treatment services for children with ASD. Long waitlists for the diagnosis will develop. The 2016 Canadian Census data shows 2 207 970 children in Ontario in the Age range of 0-14 years.<sup>ii</sup> The current best estimate of the prevalence of ASD (number of children with ASD) in Canada is 1 in 66 children.<sup>iii</sup> Only for Quebec is there a published incidence (number of new cases in a year), which is 19.1/10 000 in 2015.<sup>iv</sup> There is no reason to expect that in Ontario the incidence would be vastly different. This means that a conservative estimate of the number of children ages 0-14 in Ontario, diagnosed with ASD, in a year would be about 4000.

In Ontario, at the present time, there are less than 40 Developmental Paediatricians who practice in the area of Autism. Many of the physicians have academic, administrative and research roles as well so the number of full time equivalents is much less than 40. Most see children with many types of developmental issues, not just ASD. The cost of an ASD diagnosis performed by a Developmental Paediatrician is billed through OHIP. Child psychology assessments are not a publicly funded service. Most families are not able to afford the cost of child psychology services. So to limit the diagnostic capability to Developmental Paediatricians and child psychologists will create a long waiting list.

We agree that there should be no more “prescription pad diagnosis”, the term Mr. Baber used in his report. However, we believe that there are others with suitable training and expertise who can and should be making diagnoses of ASD. The diagnosis ASD is within the scope of practice and training of Child and Adolescent Psychiatrists. Properly trained General Paediatricians are very capable of making an accurate diagnosis of ASD. This is already occurring in Ontario through the Autism Spectrum Disorder Diagnostic Hubs. A recent review by Zwaigenbaum and Penner, documents the effectiveness of many different diagnostic models in use around the world.<sup>v</sup>

As important as who is able to make a diagnosis of ASD is the issue of how a diagnosis should be made and documented. We believe that input is required from allied health professionals such as Speech and Language Pathologists) and other professional (such as educators) who can provide information about how the child functions outside the environment of the doctor’s office. A multidisciplinary team approach is not always necessary as the review by Zwaigenbaum and Penner documents. For those children with complicated presentations, a multidisciplinary team assessment is invaluable.

ASD is diagnosed by comparing a child’s function and behaviour to a list of diagnostic criteria. There are no laboratory investigations to confirm the diagnosis. Proper documentation of the diagnosis must include reference to the diagnostic criteria. In Canada, the most commonly used criteria are those in the *Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition* (DSM-5). These criteria were developed by an international panel of experts.

We propose that in future, for support from the Ontario Autism Program, a diagnosis of ASD must be made by a Developmental Paediatrician, Clinical Child Psychologist, Child and Adolescent Psychiatrist or General Paediatrician with training in the area of ASD diagnosis. The acceptable documentation of this diagnosis must include reference to the DSM-5 diagnostic criteria and reference to supporting evidence from other professionals.

There are other parts of the report that we agree with, particularly the idea that treatment decisions should be made based on the child’s function and needs and that the treatment must be evidenced based.

Representatives of the PONDA Steering Committee would be pleased to meet with you to discuss these issues and to offer our expertise on the diagnosis and treatment of ASD and all other neurodevelopmental disorders.

Yours sincerely,

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Developmental Paediatrician  
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<sup>i</sup> *Bader Report* page 9

<sup>ii</sup> <https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/details/Page.cfm?Lang=E&Geo1=PR&Code1=35&Geo2=&Code2=&Data=Count&SearchText=Ontario&SearchType=Begins&SearchPR=01&B1=All&GeoLevel=PR&GeoCode=35> (accessed 2019-07-05)

<sup>iii</sup> *Autism spectrum disorder among children and youth in Canada 2018: A report of the national autism spectrum disorder surveillance system*, Public Health Agency of Canada 2018, pg. 1.

<sup>iv</sup> *Autism spectrum disorder among children and youth in Canada 2018: A report of the national autism spectrum disorder surveillance system*, Public Health Agency of Canada 2018, pg. 18.

<sup>v</sup> Zwaigenbaum L , Penner M. Autism spectrum disorder: advances in diagnosis and evaluation. *BMJ* 2018; 361:k1674 doi:10.1136/bmj.k1674.