



April 15, 2014

The Honourable Laura Albanese, MPP
Chair, Select Committee on Developmental Services
99 Wellesley Street West, Suite 6522
Toronto, ON
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Dear Ms. Albanese,

Re: Interim Report of the Select Committee on Developmental Services

We are writing to thank the Select Committee for the release of their *Interim Report* and for inviting the many hours of testimony from Ontarians living with Intellectual and Developmental Disabilities (IDD) summarized therein. Prominent in the report are the voices of Ontarians and their families affected by developmental disabilities. You heard how dysfunctional and distressing the Developmental Service Ontario (DSO) system is for those who are entering it. You also heard that the current system is bureaucratic and exclusionary of very vulnerable Ontarians, including youth and adults with Autism Spectrum Disorders (ASDs).

It was our honour to present to the Select Committee on December 4th, 2013. As you will recall, the *Ontario Partnership for Adults with Aspergers and Autism (OPAAA)* is a distinct, collective voice of service providers and families advocating for the unique needs of transitional-aged youth and adults living with ASD in Ontario. As OPAAA is focussed on the needs of this group, this response addresses only issues relevant to them. It highlights those areas of the interim report that are germane to youth and adults living with ASD, and identifies problems which require further government examination, considering the unique needs of our community.

1. Autism Spectrum Disorders are Unique Conditions that Require Unique Services and Funding Solutions

We appreciate the emphasis in the report on ASD and FASD as *unique* disorders requiring *unique* solutions. Although some youth and adults with ASDs can benefit from programs and services geared to those with IDD generally, they also require funding and programs which are specific to their needs. Adults with ASD have been labeled an “invisible population”. While features may be more subtle, they can be highly disabling in a society that does not understand them. Without appropriate services, many individuals with ASDs are involved in the criminal justice system,

homeless, undiagnosed and poorly understood. We are also now just starting Canadian research on those who are aging (50+) and living with an ASD.

i) Over-Reliance on IQ to inform programs and funding streams:

Throughout the report, the terms “Intellectual Disability” and “Developmental Disability” are used interchangeably. A clearer understanding and appropriate application of these two terms is of importance to our community and speaks to a core problem which 50% of individuals with ADS encounter: ineligibility for DSO. In Canada, “Intellectual Disability” and “Developmental Disability” are often used interchangeably:

“Developmental disabilities” (DD) is currently the term most commonly used in Canada to refer to lifelong limitations in intellectual and adaptive functioning initially identified in people younger than 18 years. Severity of DD is often correlated with intelligence quotient scores as follows: mild (55-70), moderate (40-55), severe (25-40), and profound (below 25). Intellectual and adaptive functioning of people with DD varies widely and, hence, so does their capacity to function independently. This heterogeneity must be considered when judging the relevance for individuals of general statements about people with DD. Various studies have estimated that such people constitute between 1% and 3% of the general population.” (Sullivan et al., 2006)

Although all individuals with ASDs do have a *developmental disability*, research is beginning to show that *decreasing* numbers of identified individuals with ASDs have an *intellectual disability*, in the truest clinical definition of the word (IQ < 70). In the largest provincial report on individuals with ASDs, less than 15% indicated they had received a diagnosis of Intellectual Disability (Stoddart et al., 2013). Although this is reflective of the higher-functioning group completing the study, it is also suggestive that many individuals with ASDs do not receive a concurrent diagnosis of Intellectual Disability, but are nonetheless in great need of services. All children before the age of 18 across the entire autism spectrum are eligible for funded services. Why does that access to funded services change on their 18th birthday?

It was the hope of our community with the introduction of the new Act that “functional skills” would be taken into equal account as intellectual disability, which can be severely affected despite average or even above average IQ. Unfortunately, the Act sets the bar for functional skills capacity required to access services so low as to be meaningless for those with ASD and in addition, requires that both IQ *and* functional assessment criteria be met. IQ does not translate into the ability to perform “functional skills” for individuals with ASD. People with average or even high IQs can suffer tremendously if they cannot arrive to work on time, for example.

ii) Multiple Medical and Psychological Diagnoses are Common in ASD

We were pleased to see the interim report mention the issue of dual diagnosis. Many individuals with ASD are critically affected by their primary diagnosis of ASD and by chronic mental health disorders. Estimates in the research literature suggest that as many as 84% of individuals with ASDs may also have an anxiety disorder. A recent study of 480 youth and adults with ASDs in

Ontario showed that 70% of individuals had received a mental health diagnosis while 30% believe that they had undiagnosed mental health disorders.

Along with an ASD and mental health issues, youth and adults also suffer from the effects of separately diagnosed learning disabilities, behaviour problems, attention deficit problems and poor functional skills.

A commitment to addressing mental health disorders and IDD has been made in the “Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis” (Ontario, 2008). Unfortunately, our community has seen little to no actual outcomes of this commitment to partnership in addressing the mental health needs of those with autism. We understand that this commitment to cooperation between MCSS and MOHLTC is being re-examined. We welcome being involved in this process.

iii) Social and Communication Deficits are the Core Problems in ASD

As noted in our presentation, the core feature of ASD is social-communication in nature. These social-communication deficits negatively affect every aspect of an individual’s life ranging from managing academic demands, navigating the service sector, developing relationships in the community, reporting on mental health and physical conditions, and living independently. Sometimes, these core features result in academic failure, inability to find and keep a job and criminal involvement. Supports are required in our province that specifically target the core feature of ASDs, which may not be as significant for others living with a developmental disability.

2. Investment of Multiple Ministries in a Coordinated Provincial ASD Strategy is Required

We applaud the mandate of the Select Committee as stated in the report: *“to coordinate the delivery of developmental programs and services across many provincial ministries in addition to the Ministry of Community and Social Services”* (p. 1). Reference is made numerous times throughout the report to the roles of, and need for involvement of, other Ministries. In addition to the complex medical needs which are found in those with IDD and ASD, we believe that mental health assessment and treatment is a medical need and therefore should be included in the MOHLTC response to this crisis. Building capacity in the mental health sector is part of the required response, as is the provision of unique expert services for individuals with a dual diagnosis. In response to this pressing need, we recommend the re-establishment of the Inter-ministerial Committee on Adults with ASDs in order to promote and re-invest in cross-ministerial actions.

We support and reinforce the identified need for a provincial strategy on ASD (p.3). We believe there has been universal ignorance and naiveté about the needs of youth, adults and their families living with ASD. As a province, this has been an artifact of poor knowledge exchange

and dissemination, systems/ministries fragmentation, and piecemeal service provision which is poorly evaluated in the community.

Ontario, and indeed Canada, falls short of the significant financial investment and legislated policies that exist in other developed countries such as the United States and the United Kingdom. Key components of a provincial strategy for youth and adults are articulated in the report, *Diversity in Ontario's Youth and Adults with Autism Spectrum Disorders: Complex Needs in Unprepared Systems* (Stoddart et al., 2013), which we have attached to this submission.

3. Flawed Population Statistics Minimize the Magnitude of the Problem

It is noted in the report that there are approximately 62,000 individuals over the age of 18 with IDD in Ontario. This data was reported by H-CARDD and MCSS and is probably significantly underestimated. The interim report notes that further data needs to be collected and we urge Ministries to do so. It is only with a realistic knowledge of the size of this population that can we determine the true scope of the need.

The latest revelation from the Centres for Disease Control estimates that the prevalence of autism in the United States is now 1 in 68 (March 28, 2014). Although this is American data and assumptions cannot be made as to the applicability of this data to Ontario, emerging Canadian research has shown similar rates.

Considering the population statistics of Ontario from Stats Can¹, the number of Ontarians who were 15 years of age and over in 2013 was estimated to be 11,344,500. Using the conservative range of 1% to 3% living with an IDD—**between 113,455 and 340,355 Ontarians are affected**. It is prudent therefore that we examine population statistics and prevalence rates in the future, not only those who are currently accessing services or have been identified with an IDD.

4. Applying to the DSO: Lack of Transparency and Understanding of ASD

As the committee heard, the experiences of applying for Developmental Services have been described as bureaucratic, stressful and lacking significant outcomes for families and individuals. One service provider in our community noted:

“How does an individual with communication challenges talk about their dreams for their future.....how heart wrenching for families to sit through this and have to answer these questions? My experience directly supporting families through this process has been that resource coordinators from the DSO tend to lead individuals (that can speak) toward answers (don't you want to get married and have kids.....would you want to be an astronaut?)”

¹ Statistics Canada, CANSIM, table [051-0001](#)

A woman with autism has reported her experience of applying to DSO in her on-line blog:

“Due to my communication deficits, I had great difficulty answering some of the questions. Sometimes when I was asked a question, I just sat there trying to figure out what I was being asked. My autism consultant regularly mentioned to the intake worker that autism is a communication disorder and so the intake worker would try to rephrase the question but in actual fact most of time she just repeated what she had already said. My autism consultant ended up having to rephrase the question for me.

There were times that the intake worker would speak to me like I was a baby, making me feel stupid. I know she was trying, but I don't think she understood enough about autism. Autistics do not need to be treated like babies who don't understand. We just need someone to explain things to us in a different way sometimes. It doesn't make us any less intelligent.”

In one region of Ontario, although the DSO application process is reasonably well explained, the expected outcomes of it are not. Parents are provided with a copy of the ADSS and SIS results, but not with a copy of the data extracted from those assessments that will be used to determine access to services. A parent of an individual with ASD who has been through the DSO process reports:

“Having a little knowledge about the developmental services sector, I knew that some other types of data about my son must have been collected so he could be matched up with services. When I requested a copy of that data record, I found substantial errors that would, if not corrected, have meant that my son would have been waiting for services he did not need or desire, and never offered services that he did actually need. This occurred several years ago, when the system was pretty new, but a friend who went through the process a few months ago tells me she didn't receive that type of information and wasn't told it even existed.”

Service providers and DSO staff seem, understandably, reluctant to convey to families the reality that funded services are virtually unattainable for those who are not yet in crisis. This is particularly difficult for those leaving the education system who are not informed adequately about what the future holds. The existence of fee-for-service organizations and agencies is downplayed or not disclosed at all. Such services may not be accessible due to financial barriers, but accessing them allows a parent to maintain employment or to provide respite for an aging caregiver.

A mother of a young man with ASD notes:

“When our son was young, we went into debt to pay for private ABA services (at the time, the age cut-off for such services still existed). Now, in our mid-50s, “retirement planning” means figuring out how long we can put off retirement, and how to balance the need to save for our future as full-time caregivers again face the need to pay for services that will allow our son to capitalize on the astounding gains we have seen throughout his teenage years.”

With the abolition of the concept of a “lead agency” (DSO is being transitioned to take on that role), families are losing a valuable resource. Instead of being able to work with an agency with which they have a personal relationship, families will be handled through a form of call centre, where they might talk to a different person each time they have an inquiry.

5. Ontario’s Two-Tiered System and Capacity for Adults with ASDs

The committee report does not reference the use of private service providers, many of whom are non-profits. Many of these private providers have formed in response to the need in the community that has not been addressed by Ministry-funded programs. As service providers, we know that many in our community have had to pay for services due to long waiting lists, lack of suitable services in their community, or simply the absence of funded services.

Autism Ontario’s SPIRALE & ABACUS databases list hundreds of private service providers of many disciplines. The Redpath Centre for Social and Emotional Development had 650 files open in the last calendar year—the majority of clients were diagnosed with an ASD and a mental illness, and paid for services out-of-pocket. The website, Connectability.ca, lists almost forty service providers in the Toronto region, offering recreation, respite, employment, and community participation support programs. The majority of clinical services are not covered by private insurance plans or government funding. Other services charge a range of fees. Ontario *has* a two-tiered system of services for individuals with ASDs. Putting the funds into the hands of those who are most knowledgeable about their needs, namely affected families and individuals themselves, will ensure that provision of essential medical, mental health and support needs are met.

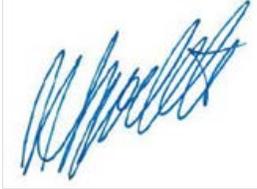
Last week’s announcement from MCSS about the proposed \$810 million investment over three years is welcome news—it will bolster the developmental services sector and significantly reduce the current waiting list for SSAH and Passport funding. Although many adults with ASD will benefit from the investment of these funds, half will not be eligible under the current DSO eligibility criteria. We believe that this is contrary to the intent of the Social Inclusion Act.

As a community, we are in a crisis situation now; however, the crisis will soon worsen. Services for adults with ASDs are so severely underfunded that they are offered exclusively to those facing an imminent crisis, such as loss of housing. In addition, all of the children and youth that have been and are going to be identified with ASDs will be entering the adult system very shortly. Based on American data and our agencies’ experiences there will continue to be more individuals identified with higher functioning forms of ASD, who do not meet DSO criteria.

We are not prepared for what has been called an ASD “*tsunami*”. We must have a longer-term plan that survives the ebb and flow of political parties and their respective fiscal policies. It is incumbent upon us to leave the system in a better state for future generations.

In conclusion, as a collective voice of service providers and families, we look forward to working with multiple ministries to address the inequities, lack of accessibility and massive unmet needs in the current service systems in Ontario. The costs to our province and the personal toll to families will continue to mount if we do not act decisively and effectively to address the poignant and heart-breaking testimonies before us.

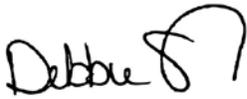
Respectfully submitted,



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Enclosure: "Diversity in Ontario's Youth and Adults with Autism Spectrum Disorders"