

January 15, 2019



**To: Standing Committee on Finance and Economic Affairs
regarding Pre-Budget Consultations 2019, Government of Ontario**

Autism Ontario Presenters:

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Dear Committee Members,

Now entering our 46th year, Autism Ontario has envisioned *acceptance and opportunities for people on the autism spectrum*. The families who formed Autism Ontario in 1973 would never have imagined the prevalence rates for autism to grow to 1 in 66 children in Canada. In Ontario that represents 135,000 citizens.

Autism Ontario continues to envision a Province that offers seamless supports across the lifespan that reflect the wide range of expression in autism, the constantly changing needs of this able, yet vulnerable population and which addresses the needs of caregivers and families who bear both the joys and the substantial weight of care and advocacy for their children from infancy to and throughout adulthood.

Thank you for the support that is provided in support of families through our Potential Programme and with March Break and Summer funding. Surveyed families have told us over and over that these funds matter to them. Combined, these programs directly support over 20,000 people in Ontario.

In 2018, Autism Ontario conducted a province-wide survey, resulting in 10 top areas identified by caregivers and autistic adults. Those non-prioritized top 10 are the following:



Service barriers for adults – According to autistic adults, the largest barrier to accessing services is the lack of trained professionals who understand autism.

Education support – According to caregivers, the top area of need for a child with autism in their communities is support within the education system.

School transitions – The majority of caregivers of high school aged children do not feel well supported and ready to transition their child out of school and into adulthood.

Societal attitudes and perceptions – Autistic adults and caregivers both report that societal attitudes and perceptions about ASD have been a large or very large source of stress in the past year.

Financial hardship – A majority of caregivers say that finances have been a large or very large source of stress in the past year.

Waitlists – The majority of caregivers find long waitlists to be a large or very large barrier to accessing services.

Service needs for young children – According to caregivers, the top service needs for children aged 4 and under, are behavioural intervention and speech language pathology.

Crisis status – Most caregivers are between a three and a five out of ten, in terms of crisis level.

Mentorship and support – There is large scale interest in receiving peer support via a parent to parent mentorship program.

Mental Health – Autistic adults identified their top service need as psychological or psychiatric support.

In November 2018 we asked our survey respondents to rate these top ten items in order of priority and these top 5 emerged:

1. Education Support

About ten years ago the Ministry of Education reported that there were about 7,000 students with ASD in Ontario's schools. Today that number has tripled to over 20,000 students. Educational supports that were implemented for students with autism years ago are now insufficient in scope and effectiveness. Part of the current challenges with ABA implementation and parent satisfaction will not be addressed without a focus on improved school supports and transition planning that has meaning and achievable outcomes and opportunities for adult life.

#1 Education Support

According to caregivers, the **#1 area** of need for a child with autism is support within the education system, even though **77.8%** of caregivers of high school aged children feel listened to by their child's school.

Thank you for the additional investment into OAP services in this current year's budget.

However, the over 20,000 children and youth on the waiting lists for OAP services are currently not able to be served in timely and equitable fashion. Additionally, unless increased evidence-based supports and implementation supervision by qualified professionals are available in all Ontario schools, it will be impossible to meet the educational needs of students with ASD. The Ministry of Health is also noticeably absent in providing necessary health supports for people with autism across the lifespan.

We recommend:

- Creating an employment category in schools of Registered Behaviour Technician, supervised by Board employed BCBAs or Behaviour trained Psychologists;
- Increased ABA supervision in schools,
- Collaboration across Ministries with the emphasis on the child's learning and mental health needs over silo-ed systems,
- Mandatory Pre-service training in Evidence-Based Practice and Applied Behaviour Analysis for all educators.

2. Long Wait Lists



Families are waiting for everything. Waiting for:

- A diagnosis/diagnoses that determines eligibility/access to services
- the Ontario Autism Program,
- an educational assistant,
- informed school personnel,
- health and mental health supports,
- adaptive program supports and Passport Funding
- job opportunities, and
- housing.

We are concerned about rumours that this government is considering substantive changes to the Ontario Autism Program. Our survey in 2017 indicated that one third of parents are single caregivers and that one third favoured the option of Direct Service provision while 2/3rds preferred Direct Funding. We urge the government to consider offering *choice* to families based on assessed needs of both the child and the family's needs. Children should also receive these services where they spend the majority of their day, which is in school during school-aged years.

3. Financial Hardship

We know that **the burden of care on families is both stressful and costly.**

We have attached a 2014 research paper entitled “The Value of Caregiver Time: Costs of Support and Care for Individuals Living with Autism Spectrum Disorder”, by Carolyn Dudley and J.C. Herbert Emery†. In it they describe what costs are attributed to families who raise children with autism in Canada, including Ontario data sources. The numbers are both startling and sobering. But there are solutions. Autism Ontario welcomes the opportunity to be part of the dialogue and shaping new opportunities for people with ASD and their families.



Financial Hardship

Finances has been a large or very large source of stress in the last year for **50.7%** of autistic adults and **56.3%** for caregivers. According to caregivers, finances are the **2nd largest** barrier to accessing services.

4. School Transitions



School Transitions

87.4% of caregivers of high school aged children say that it is stressful to plan for their child's transition out of high school. **59.2%** are not confident their child will have a smooth transition out of high school.

Autism’s prevalence rates are not only an alarming statistic for children and youth, but we are now seeing these numbers grow along with the children as they become teens and adults. More importantly, **these students are now beginning to exit high school unprepared and unsupported for life as adults in higher numbers than ever.**

The majority of these graduates are sitting at their parents’ homes doing little, are under or unemployed and over half are or will be struggling

with additional mental health challenges such as anxiety and depression. With approximately 15,000 people with Developmental Disabilities (including autism) waiting for Passport Funding, we know that those families have few options to assist their now young adult children towards a promising future. Having those young adults at home means that at least one care-giver is also at home and not earning through employment or investing in their own retirement, while their children with ASD, who could also be working, participating in meaningful day-time activities or attending post-secondary education, are not.

Many of these adults could have **meaningful employment** if employers saw that hiring people with autism is good for business rather than a charitable act. Autism Ontario has been involved in several projects (e.g. Specialisterne Canada's employment program and Integrated Autism Consulting's "Transition to Life" program) over the past few years that directly support the successful employment of adults on the autism spectrum. Investing in these types of programs and others would have an impact on the Ontario economy and the lives of adults with autism and their families.

5. Adult Services

Eligibility: At least half of adults on the autism spectrum are deemed ineligible for Passport funding. This must change to eligibility based on assessed needs and not paid for out of the pockets of caregivers.

We encourage the continued implementation of recommendations identified by the Ontario Ombudsman's office in its "No Where to Turn" report.

Housing: Autism Ontario is gratified to have seen a second round of funding for unique housing proposals through the former MCSS' Housing Task Force. This must be the first in many future steps that will assist people with Developmental Disabilities, including ASD, to create or find affordable housing options.

In the absence of increasing supportive housing options, the number of adults with autism who are in crisis will continue to grow. And supporting a model that is primarily crisis driven is a far more costly proposition than focusing on prevention of the circumstances that result in more restrictive responses. We also worry about a new trend of seeing children with disabilities, including autism, in long-term care facilities, effectively replicating an institutional model of care which is neither appropriate nor necessary.

In a recent TVO "Agenda" program, a parent and her autistic adult son remarked that they are not looking for pity, but for respect and opportunities as caregivers and as citizens who have much to offer society. Autism Ontario strongly supports this notion in its vision of "acceptance and opportunities for all people on the autism spectrum".



#5 Adult Services

According to adults, the largest barriers to service are: 1) A lack of necessary services, **63.4%**. 2) A lack of professionals who understand autism, **63.1%**.

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