

February 11, 2020

Honourable Rod Phillips
Minister of Finance
c/o Budget Secretariat
Frost Building North, 3rd floor
95 Grosvenor Street
Toronto ON M7A 1Z1



Submitted by Email: submissions@ontario.ca

Dear Minister Phillips,

Autism Ontario is grateful for the opportunity to have verbally presented key highlights of this submission to you and your team on January 31, 2020.

Now entering our 47th 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 to parents through Autism Ontario through our Service Navigation Program for families accessing OAP funding, Social Learning Opportunities, March Break and Summer 1-1 funding, and funding to develop an OAP Provider list of qualified ABA Program Supervisors. Surveyed families have told us that these supports matter to them. Combined, these programs directly support over 20,000 people in Ontario.

Investments that support people on the autism spectrum and their families make life more affordable, help autistic people prepare for jobs, and encourage the return to work for parents who wish to but who have to remain at home as primary caregivers for their children. This represents an investment in Ontario's tax base and its citizens' well-being.

Top 5 Priorities Rated by Caregivers: In late 2018, Autism Ontario conducted a province-wide survey, resulting in 10 top areas identified by caregivers and autistic adults. 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



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.



#2 Long Waitlists



According to caregivers, long waitlists are the largest barrier to accessing service, with **73.6%** of caregivers identifying waitlists as a large or very large barrier.




#3 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



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.



#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%** .



Investment Recommendations for the 2020-2021 Ontario Budget:

- 1) **Ontario Autism Program:** There is broad community support for the recommendations in the OAP Advisory Panel's report and thousands of families have been waiting to receive the necessary supports for their children. They are tired, worried and yet hopeful about the potential changes to come in a proposed needs-based program. We ask for movement, with haste, to support and implement the recommendations as outlined in the *Ontario Autism Advisory Panel Report* released on October 30, 2019, even while the necessary policy work is being created or realigned with the existing Ontario Autism Program.
 - a. Invest the \$600 million as promised into the OAP
 - b. Implement the recommendations from the OAP Advisory Panel's Report
 - c. Conduct a province-wide capacity assessment of service gaps in order to develop a plan to build professional capacity in a province currently unable to support the current demand for the 4 core services in Applied Behaviour Analysis, Speech Language Pathology, Occupational Therapy and Mental Health intervention and supports.
 - d. Work with the Colleges and Universities, businesses and autism service providers to reverse the current trend of an exit of professionals from the autism field that are needed to keep the very programs being implemented through a needs-based OAP in place and functioning both now and for years to come.
 - e. Collaborate with northern and First Nations leaders to respond to their own culturally informed approaches to supporting indigenous persons on the autism spectrum in their local communities.
 - f. The OAP Implementation Committee should be provided with whatever financial or professional supports are required to roll out the program in a way that allows the needs based approach to be implemented as soon as possible. Families have been waiting and years of helpful and evidence-based intervention are being missed by many children.

- 2) **School years:** Students on the autism spectrum do not receive consistent educational supports across Ontario. It has been about 12 years since the report "Making a Difference for Students with Autism Spectrum Disorders in Ontario Schools, From Evidence to Action" was released. Meanwhile, the

number of Ontario Human Rights cases to address these gaps in learning needs and access to appropriate supports is growing.

In Autism Ontario's recent parent/caregivers survey they indicated that **the #1 concern out of the top ten concerns parents had were Educational Supports**. Although many notable gains have been made in the past 10 years, supports for Special Education are insufficient to meet the assessed need and Individual Education Plans for students with autism, even as currently defined in Ontario legislation and education policy.

- a. Immediately implement a new Autism Education Committee as recommended in the OAP Panel Report in the section with specific recommendations for the Ministry of Education.
- b. Require mandatory Pre-service training in Evidence-Based Practice education practices and Applied Behaviour Analysis for all educators.

3) **Health and Mental Health:**

- a. Implement the Mental Health Committee identified in the OAP Advisory Panel's Report in order to address the many gaps in providing health and mental health supports to people on the autism spectrum and their caregivers.
- b. Continue to financially support the world-class research efforts of the Province of Ontario Neurodevelopmental Disorders Network (POND).
- c. Continue to measure, financially support and aim for earlier and appropriate diagnostic service from health professionals. Programs that train health professionals, such as the ECHO Autism program, are already demonstrating improved professional capacity in this area.
- d. Continue to invest in the health, mental health, recreational and informational/training needs of children and adults and the families who remain the primary caregivers of their loved ones. Programs such as OAP Service Navigation and Social Learning Opportunities have demonstrated benefits for children and families.

4) **Non-siloed Approaches:** As noted in the OAP Panel's report recommendations, key Ministries – Children, Community and Social Services, Education, Health must work together in non-siloed, collaborative approaches with families and autistic people to reduce the coordination and planning burden on caregivers, to avoid unnecessary duplication of services and to provide seamless supports across the life course.

5) **Older Teens and Adults:** 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.**

- a. Invest in high school and transition programs to directly assist students on the autism spectrum with their transition to adult life that include programs that support successful transitions to work, attend college/university, and build adaptive skills needed for adult living.
- b. Implement the recommendations in the Ontario Ombudsman's Report, "No Where to Turn."
- c. Eliminate the waiting lists for Special Services at Home and respite funding.
- d. Conduct a review of Ontario Disability Support Payments and Passport Funding to address ineligibility requirements, insufficient funding levels and unacceptable waiting lists. Claw back penalties for engaging in real work for real pay must not serve as disincentives for attempting varying degrees of employment towards something more sustainable.
- e. Create employer incentives to hire autistic adults capable of a wide range of skilled jobs, not for charitable reasons, but because it makes good business sense.
- f. **Housing:** 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.

Invest in and collaborate with various disability and neurodevelopmental disability groups and all levels of government to make the process of short, medium and long-term planning for the affordable housing needs of adults on the spectrum. The process must be less daunting for their families, create genuine choices based on individualized and changing living requirements throughout adult life.

