



**Autism Ontario
(formerly Autism Society Ontario)**

Pre-Budget Consultation Submission

to

THE HONOURABLE GREG SORBARA

MINISTER OF FINANCE

GOVERNMENT OF ONTARIO

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Autism Spectrum Disorders in Ontario

- **Autism Spectrum Disorders:** Individuals with Autism Spectrum Disorder (ASD) include those with Autism, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified. An individual's position on the spectrum does not equate to their need for support: those who are "high functioning" need support, of a different type, as do those who are lower functioning.
- **Prevalence of ASD:** Recent ASD prevalence rates identify 1/165 individuals being affected by ASD (Fombonne E. The prevalence of autism. JAMA 2003; 289(1):1-3.). Applied to current population rates, that translates to more than 72,000 Ontarians. ASD is affecting the lives of Canadians at alarming rates. Autism affects boys four times more often than girls.
- **All families of individuals with ASD** require seamless, individualized services, treatment, and supports throughout the individual's lifespan, from the time parents begin to seek a diagnosis for their child, right through to the senior years of the person affected by ASD. Services need to be provided by qualified, trained, experienced and competent professionals and para-professionals.
- **The field of ASD is a highly complex one** that requires a deliberate interplay between research, diagnosis, education and treatment and engagement of individuals with ASD and their families. Pro-active inter-ministerial cooperation (for example, including the Ministries of Health, Finance, Education, Community & Social Services and Child and Youth Services) is an essential component for reducing stress on families, addressing service gaps, and building the capacity of Ontario to respond effectively to individuals with ASD.

Getting a Diagnosis

Outcome: Accurate ASD diagnoses are completed in local communities within four to six months or less.

Scope of the problem: Ontario families are not able to apply for or receive publicly funded treatment and supports for their children until they receive a diagnosis of ASD. As importantly, receiving a diagnosis is important for allowing families to understand and move forward in supporting their child. Families are on waiting lists for diagnostic assessments because of a lack of qualified professionals both trained and willing to make

a diagnosis of ASD. Many communities in Ontario must refer families to doctors far from home in order to receive the necessary diagnosis. Children and adults are waiting for years to receive a diagnosis – for example, in-school assessments can take up to two years to be completed. More affluent families seek out private assessments which can cost thousands of dollars, creating in effect, a two-tiered system. Earlier diagnosis leads to earlier treatment and intervention and better long term outcomes for individuals with ASD.

- Autism Ontario recommends that a **minister's working group** be developed and charged with the task of identifying the overwhelmingly persistent barriers to increasing Ontario's capacity for diagnosing ASD and defining steps towards achieving the above outcome. (\$200,000 over two years)

Receiving Ongoing Assessments and Individualized, ASD- specific supports

Outcome: Appropriate assessments are available to individuals with ASD throughout their lifespan.

Scope of the problem: Individuals with ASD face great difficulties receiving publicly funded assessments throughout their lifespan, despite the fact that their needs and abilities change over time. Resources are typically dedicated to diagnostic assessments, often leaving individuals receiving education and other services based on outdated assessments of their skills and abilities. These assessments need to be carried out by trained professionals who can compensate for the limitations of conventional developmental-based assessment tools when applied to individuals with ASD.

- Autism Ontario recommends that parents who pay for private assessments be able to claim the full amount of the deduction on their taxes.

Outcome: The ongoing health & mental health needs of individuals with ASD are addressed by supported and trained professionals across the key Ministry of Health, Children and Youth Services and MCSS.

Scope of the problem: Parents and individuals with ASD do not know where to turn to find trained psychiatrists, family physicians and other health professionals who understand and can respond to the health and mental health needs of this population. Where expertise exists, lengthy and unresponsive waiting lists exist. In addition, individuals with more able levels of autism and Aspergers are excluded from mental health services and supports because of their cognitive abilities.

- Autism Ontario recommends that funds be invested in training for health care professionals in order to be uniquely responsive to the health and mental health needs of all individuals on the autism spectrum, and their families.

Early Intensive Intervention

Outcome:

The current restriction of early intervention programs to those with “moderate to severe” ASD is removed.

All individuals with ASD, regardless of the severity of their ASD, are enrolled in an appropriate intensive early intervention program to provide evidence-based, effective treatment, or treatment where evidence is emerging, for their individual learning needs. “Early” relates not to the age of the individual, but to the time of their diagnosis (that is, the program needs to be accessed soon after diagnosis).

Waiting lists that currently exist in Ontario are eliminated. Treatment programs are equally accessible to English and French speaking families throughout the province. Families on waiting lists are provided consultative model services.

Parents are permitted a choice of either a direct services model or direct funding model without being penalized with lower based funding, or lower quality services, when using the direct funding model.

Clear, impartial, and accessible mechanisms are put in place for families to appeal if they are not accepted into service, or at time of discharge.

Scope of the problem: The present initiative (Autism Intervention Program) is targeted at only the most severely affected children. This means that less than half of diagnosed children will benefit from the program. The expansion of this initiative to include all children affected with ASD will result in savings of millions of dollars, especially since current research indicates that less severely affected children may benefit greatly from this treatment. The provincial auditor’s report indicated significant challenges to the program which must be considered in the continued refinement of this program. The recommendations from this report must be considered in the ongoing development of the AIP.

- Autism Ontario supports the public and ongoing evaluation of the Autism Intervention Program for children with ASD. This is consistent with the government’s support of evidence-based practice for ASD.
- Autism Ontario supports effective evidence-based (and where evidence is lacking, emerging evidence) practices, in teaching individuals of all ages with ASD. Currently, this includes applied behaviour analysis, structured teaching, augmentative communication techniques, and social-communication teaching

strategies, with ongoing research providing evidence to support other practices. Most importantly, the practices are applied in a manner which includes the parents, is based on individualized and continuous assessment, considers clearly defined learning objectives in meaningful environments, and provides measurable outcomes which indicate the effectiveness of applied strategies for the specific individual with ASD. Adaptations are based on objective data from the environments in which the programs take place and in generalized settings.

(additional investment of \$40 million)

Training for Professionals

Outcome:

All professionals and para-professionals providing services to individuals with ASD are trained in evidence-based, and emerging evidence-based practices in ASD services and treatment programs and are able to demonstrate their ability to apply those practices.

Professionals and para-professionals are available to provide services in both official languages.

Ontario Universities and Colleges offer and grant certification, degrees, additional qualification courses and continuing education in evidence-based practices in working effectively with young children, school-aged children, adults with ASD and their families.

Scope of the Problem: There are insufficient numbers of trained professionals to work effectively with individuals with ASD of all ages and abilities. In particular, professionals with expertise in evidence-based practices for working with individuals with ASD in the fields of Applied Behaviour Analysis, Speech Language Pathology, Developmental Disabilities, Early Childhood Education, Social Work, Occupational Therapy, Psychology, particularly at a supervisory and Masters level. Autism Ontario is encouraged by the development of College diploma programs for Autism and Behaviour and also the Masters level program on developmental disabilities at Brock University. More of these programs are needed to increase Ontario's capacity to adequately staff its ASD-focused programs.

- Autism Ontario recommends that **additional funding** be granted to Ontario Colleges and Universities demonstrating excellence and leadership in ASD research, courses of studies in ASD and evidence-based practices for ASD, and partnerships with community ASD treatment and service providers across Ontario

- Autism Ontario recommends that **scholarships** be established to encourage entry into credible programs related to ASD treatment and services for individuals with ASD.
- Autism Ontario recommends that **pre-service and in-service teacher training** require training in special education in general, and ASD in particular; and that training for educational assistants be integrated in a comprehensive staff development plan on evidence-based practices to meet the needs of students with ASD.
- Autism Ontario recommends that students pursuing a course of study that leads to providing services for individuals with ASD be offered education grants in return for providing services in **less-serviced areas**.
- Autism Ontario recommends that a **task force** be formed to develop a multi-year comprehensive and cohesive plan for achieving the above outcomes and recruitment strategies (\$100,000)

Education of Students with ASD

Outcome:

All individuals with ASD have access to transition supports into school through regional programs, whether or not they have participated in the provincial Autism Intervention Program.

All individuals with ASD have access to specialized supports for transitions throughout their educational life, such as transition to senior elementary school, high school, post-secondary education, employment or community living.

Educators develop and apply effective evidence-based, and emerging evidence-based, educational practices in ASD at all grade levels for all students with ASD. They are able to develop educational strategies that are effective for teaching students with Autism and Aspergers Syndrome according to a current and appropriate IEP.

Educational support workers such as Educational Assistants are able to apply effective evidence-based, and emerging evidence-based, educational practices in ASD in the classroom.

Accountability for IEP delivery and use of special education funding be built into the Education Act.

- Autism Ontario recommends that the newly formed **School Support Program – ASD be evaluated** within 6 months of implementation and adjustments be made as required. A survey indicating the current capacity of educators (teachers, educational assistants, educational consultants) to implement evidence-based practices in teaching students with ASD and a report indicating a do-able plan for increasing capacity for each board of education in Ontario be completed. (\$500,000)
- Autism Ontario recommends that educators receive **ongoing professional support** to expand their skills.
- Autism Ontario recommends that **preparation classes** for post-secondary education, currently restricted to the learning disabled, be opened to individuals with ASD.
- Autism Ontario recommends that the **educational funding model be adjusted** to reflect the social complexity and special challenges of high school students.
- Autism Ontario recommends that the **educational funding formula** be based on individualized needs rather than on fixed, and generalized, levels of ability.
- Autism Ontario recommends that all publicly-funded school boards in Ontario (i.e., both public and separate) offer a **full range of placement options** for individuals with ASD, and that all options be accessible to students in their own communities.
- Autism Ontario recommends that existing successful models for **specialized classroom structures** to support students with ASD, such as are offered to students with Asperger's Syndrome in secondary schools, in a supported but integrated environment.
- Autism Ontario recommends that the **elementary and secondary school curriculum** be expanded to include issues related to acceptance of individuals with different needs and abilities.

Supports for Families

Outcome:

The financial burden on families of individuals with ASD is reduced so that they are able to access individualized and meaningful supports in their local communities.

- Autism Ontario supports the recommendations of the *SSAH Provincial Coalition* and that they be implemented so that eligible families of individuals with ASD are not on SSAH waiting lists and have levels of funding consistent with assessed needs.

Parents are able to access evidence-based and community-based learning programs so their individuals may participate in community settings. Examples are social skills and specific skill based groups.

- **Autism Ontario recommends** a central point of access for flexible program supports and to make application process less burdensome on families, as is offered currently through the “Contact Hamilton” program. Information should be available in multiple languages to address multi-cultural needs.

Respite and recreational services have trained staff to support individuals with ASD within local community settings

- **Autism Ontario recommends** that existing excellent models of respite and recreational services for individuals with ASD be replicated in all nine regions of Ontario.

Families can access relevant, factual, supporting information in a variety of languages within their own community.

- **Autism Ontario recommends** that its recently funded Realize Community Potential Program be expanded from six to nine regions to enable Autism Ontario’s provincial chapters to become a key point of contact and referral for families of individuals with ASD.

Government leaders continue to dialogue with Autism Ontario through a central point of contact while formulating service and treatment plans and allow us to proactively assist with communication between parents, clinicians and other Ontario leaders for all stages and aspects of program development.

Supports for Adults with ASD

Outcome:

Services and supports for adults with ASD are mandated with equal access in Ontario as an entitlement. Adults receive support and services regardless of position on the autism spectrum.

- Autism Ontario recommends that the **recommendations of Autism Ontario’s *Transforming Services in Ontario for People who have a Developmental Disability*** submission in November 2004 be implemented. See attached document, and Autism Ontario’s recent presentation to MCSS Minister Meilleur)(\$40 million)
- Autism Ontario recommends that the recommendations of the ombudsman concerning **ODSP funding and processes** be implemented.

Reduce the Financial Burden to Families

Outcome: Families of individuals with ASD have reduced tax burden to minimize the financial burdens they face.

- Autism Ontario recommends **changes to tax policies** to reduce the financial burden on families with children and dependent adults with ASD. For example, privately-obtained assessments be 100% deductible.
- Autism Ontario recommends **tax relief provisions** for tax filers who undertake to fund ASD-related programs from their own financial resources.
- Autism Ontario supports the proposed federal Registered Disability Savings Program. This fund would allow for savings that would provide flexible educational, vocational, and daily living supports for adult children with ASD to enable them to become contributing members of Ontario's workforce. We also recommend allowing greater **flexibility within existing RESPs** for students who are auditing college courses, and to allow greater transferability of such funds.

Support ASD Research in Ontario

To respond to ASD, we must study all areas of human development for persons with ASD, evidence-based intervention, and educational and medical treatment methods across the life span in community settings. This must occur in both large and small-scale qualitative and quantitative research studies. Autism Ontario supports the federal initiative to determine national standards for ASD treatments and programs

Autism Ontario directly supports and promotes ASD research in Ontario through its *Together for Autism* (formerly *Toonies for Autism*) Program.