



AUTISM SOCIETY ONTARIO

Pre-Budget Consultation Submission

to

THE HONOURABLE GREG SORBARA

MINISTER OF FINANCE

GOVERNMENT OF ONTARIO

March 4, 2004

**AUTISM SOCIETY ONTARIO
REQUESTS THE FOLLOWING OF THE ONTARIO GOVERNMENT:**

1. **Intensive Early Intervention Funding:** ASO is calling on the Government to expand the intensive early intervention program to provide evidence-based, effective treatment for all children with Autism Spectrum Disorders (ASD) and to eliminate the waiting list that currently exists in Ontario. Services should be equally accessible to English and French speaking families throughout the province.

The present initiative is targeted at only the most severely affected children 6 years of age and under. This means that only one in four 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.

2. **Inter-ministerial Coordination of Autism Services:** ASO calls on the Government to strengthen its inter-ministerial approach to policy development and program delivery where Autism Spectrum Disorders is concerned including charging one Ministry with the lead and enabling that Ministry to establish an AUTISM Secretariat which would provide support and consultation to other Ministries thus guaranteeing a 'seamless' transition and interplay between Ministry programs.

Following on the leadership demonstrated with the early intensive intervention program, it is timely for the Provincial Government to take charge of a process that will develop an integrated and evidence-based diagnostic, training, education and service delivery model for the care and management of those with ASD.

Continue to dialogue with ASO while formulating service and treatment plans and allow us to proactively assist with communication between parents, clinicians and government leaders for all stages and aspects of program development.

Provide \$60 million to provide the following:

- a) **Training:** Provide mandatory training in evidence-based, effective approaches in working with students of all ages with ASD for all professionals (educators, classroom assistants, and educational consultants) working with individuals with ASD in Ontario schools.
- b) **Transition:** Honour the original commitment made for a smooth transition of young children with ASD into Ontario schools. ASO applauds the release of funds to provide regional training for Ontario teachers working with students with ASD. There needs to be an additional commitment to support transition from elementary to secondary school for students with ASD.

- c) **University & College:** There are insufficient trained professionals to work effectively with individuals of all ages with ASD. Thus, education and certification programs at Undergraduate and Graduate levels are essential to systematically train students to become clinicians who are skilled in working with individuals with ASD.
 - d) **Education Standards for Autism:** Education Standards for Autism have been developed, but not yet implemented by the Ministry of Education. We urge the minister to provide the necessary funding to release and implement those standards as they apply to students with ASD. Transition plans for high school students into adult years must be implemented and must be linked to real programs and opportunities for employment or further education.
 - e) **Adults with ASD:** Comprehensive services for adults with ASD must be multi-faceted. The Individualized Funding Coalition presents some of the most flexible way to meet the unique and complex needs of adults with ASD. Models of service delivery for adults with ASD exist in only a few places in Ontario. These successful programs must be replicated for all adults with ASD.
3. **Invest in Services and Supports to Families:** Invest in support to families in their communities through respite care programs, transition funds and training for service providers across Ontario.

Reduce the burden on families to support their adult children with ASD. Provide a range of supported living (including independent living) opportunities for all adults with ASD in their communities.

- a) **Augment Respite Care for parents and caregivers.** ASO is calling on the Government to set aside sufficient funds to ensure that the amount of respite care provided is doubled for all families of children with ASD. These services must be available to families in their own communities. These funds must be carefully allocated so that all families living with ASD have access to the funds.

In the past few years in Canada, ASO has witnessed with profound sadness the choice that a number of families made to take their own life and/or the life of their disabled child. All of these children had developmental challenges diagnosed as, or associated with diagnoses on the autism spectrum. This underscores the tremendous stress and sense of hopelessness experienced by families at all stages of their children's development. No family in Canada should be faced with such challenges because we as a society have failed to provide our most vulnerable citizens with necessary supports. Researchers continue to identify the exceptional stresses of raising a child with autism as greater than those related to other disabilities or illnesses. Recent ASD prevalence rates identify 1/165 individuals being affected by ASD (Fombonne E. The prevalence of autism. JAMA 2003;289(1):1-3.). That translates to as many as 72,000 Ontarians. Autism is affecting the lives of Canadians at alarming rates.

4. **Support Autism Research:** Invest \$ 1 million per year over the next 5 years to Autism specific research projects.
 - a) **Evaluation of IBI Programs:** Conduct research to formally, publicly and prospectively evaluate Ontario's IBI program. Coordinated efforts to evaluate the same types of programs in other Canadian provinces simultaneously are encouraged.
 - b) The field of autism is a highly complex one that requires a deliberate interplay between research, diagnosis, education and treatment.
 - c) There is a scarcity of professionals with training in modern educational and diagnostic approaches. Sufficient funds are required to enable such training. One specific area is the Ministry of Education. It needs to offer additional qualification courses for teachers that focus on ASD and effective teaching methodologies, (currently there is one course) but this requires an investment in qualified trainers.
 - d) Even where intervention programs exist, they are primarily supported by professionals from the United States brought into Canada due to the lack of trained and experienced service providers.
 - e) 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.
5. **Provide \$500,000 in funding to Autism Society Ontario** to enable ASO's provincial chapters to become a key point of contact and referral for families of children with ASD. Expand ASO's current provincial pilot project through the Ontario Trillium Foundation from 3 to 31 chapters in English and French.

ASO is willing to provide ASD awareness training to leaders and clinical service providers in order to inform government and professional groups about the daily experiences of families living with ASD. Within our organization, these opportunities may be provided at cost within local communities. ASO is committed to be a first point of information for parents receiving a diagnosis for their son or daughter. Our recent publications *Children Diagnosed with Autism: What to Expect and Where to Get Help* and *Navigating the Special Education System in Ontario: A Handbook for Parents of Children with ASD* are affordable handbooks and are broadly supported by parents and the professional community in Ontario.

6. **Reduce the Financial Burden to Families:** Through changes to tax policy, reduce the financial burden on families with children and dependent adults with Autism Spectrum Disorders.

ASO calls on the Government to introduce tax relief provisions for tax filers who undertake to provide educational and medical therapies from their own financial resources.

Implement a Trillium Special Care Plan to assist families who cannot assume the costs of treatment to ensure that their children and dependent adults receive services that would otherwise be unavailable without Government assistance.

Investment opportunities: Allow families of children with ASD to establish a registered savings fund (similar to RESP). This fund would allow for savings that would go towards providing other educational supports (e.g. job coaching) for adult children with ASD to enable them to become contributing members of Ontario's workforce.