Statement from Autism Ontario regarding autism programming in Ontario

There has been a tremendous amount of information circulating about the investment of $333 million by the Government of Ontario over the next five years and their stated goal of children and youth on the autism spectrum receiving critical interventions earlier and services that are better matched to their needs.

Autism Ontario has additional comments and further expansion of views regarding the recent announcement and in response to many ongoing conversations within our autism community.

Our organization continues to advocate for respectful dialogue within our autism community. While we understand at times, our advocacy process doesn’t meet the needs of various groups who want to engage in partisan activities, we do recognize there are many different ways to effect change for loved ones and want all families in Ontario to have access to as much accurate, reliable information as possible.1

The long-time coming report of the Ontario Government’s Clinical Expert Committee resulted in a helpful report with many recommendations that informed the most recent announcement. Although we have provided input along with other community stakeholders and parents on topics related to this announcement, Autism Ontario was not represented on the Committee and the policy decisions on the Ontario Autism Program are the Government of Ontario’s.

A. Autism Ontario’s observations about the MCYS announcement:

1. $333 million over 5 years is the most significant amount of funding announced for ASD supports and services in a very long time.

2. The goal of creating a continuum of ABA services that are timely, effective, and meet the assessed needs of the child in a flexible manner is an important policy and program direction. Despite the proposed short term upheaval for families, every child can benefit from good ABA.

1 Please see our supporting documents: Relevant Resources and Responses to the announcement and Autism Ontario Advocacy FAQs for more information
3. Eliminating a wait list for EIBI for the youngest children means families will have access to important treatment sooner.

4. Families who have been on the waiting list for IBI services for many years are being doubly penalized by not having had access to the best early intervention for their children and by learning they will now not receive this service by being discharged from the waiting list.

5. $8,000 is not enough funding to replace what families would have received through the program, and is far below what many families have already personally invested in their child’s early and ongoing intervention. This devastating news has added to the financial burden borne by families of children and youth with ASD and adds to the stress they experience as caregivers.

6. For some families who would have waited up to 3 or more years on the IBI waitlist, the immediate, short-term funding might come as welcome news, however, what is the $8,000 intended to purchase and will these services be available in local communities? Will the ABA-based services also be geared to the variety of ages (5-18) and the assessed needs of those accessing them?

7. Although the pre-diagnostic pilots for early intervention have varying degrees of evidence supporting them, they are promising practices for community-based intervention. We hope that the children and families involved in these pilots will meet or exceed identified targets associated with the programs. It is also hoped that the evaluation of the pilots will provide further insight into naturalistic ABA models, that the data gathered and reported will inform any future application of these intervention approaches.

8. One of the most significant issues about ABA programming in Ontario is the challenge of access to excellence in ABA-based supports in Ontario’s publicly funded schools. Despite much progress in awareness and understanding in Boards of Education, and even with PPM-140, we know that school issues remain one of the top concerns expressed by parents of students on the autism spectrum. The gap that remains between coordinating ABA services between schools and the community must be resolved if parents are to have confidence that their children will be able to achieve their full potential.

9. Supervision and training of ABA for all professionals in education settings is paramount. This announcement hints at the role of schools, but no further light is shed on what that means.

10. The plan to create a new advisory committee that will include parents and professionals is very important. We recommend that it will also include representation of Board Certified Behaviour Analysts, who were not included in the Clinical Expert Committee.
11. More time between the release of the ASD Clinical Expert Committee Report and the news of the changes to autism programming in Ontario would have been ideal. This might have allowed opportunity for peer-review and public dialogue about the findings to have taken place and further informed the current policy changes.

B. Why is Autism Ontario involved with facilitating the webinars in partnership with MCYS?

1. We are directly connected to more than 15,000 families of children and youth across Ontario through multiple long term relationships through our programs, our website and social media.

2. This new information is important to families in their advocacy journey. Our role in these webinars allows us to hear what families are saying in response to the information so we can support families.

3. Parents and many professionals are familiar with the webinar format we’ve used to host information and training opportunities for many years.

4. Autism Ontario is not in a conflict position since we are not an ABA service provider, which is one of the same reasons we have hosted the ABACUS website for 8 years.

C. Autism Ontario’s views on ASD supports in Ontario.

We support:

1. Seamless, individualized, continually-assessed, evidence-based and effective interventions and supports across the lifespan of all people with ASD.

2. Interventions and supports are provided in a timely and holistic manner with minimal or no waiting to ensure maximum effectiveness and the reduction of family stress.

3. The creation of supportive environments and well-planned transitions for services that provide optimal participation, inclusion and success of the child or adult on the autism spectrum.

4. Parents/caregivers as active, informed partners in the planning, delivery and evaluation of programs supports for their children and families.

5. The need for more ASD-trained and regulated health professionals, educators, behaviour, communication therapists, mental health practitioners and ongoing ASD training to
understand, intervene and support people with ASD at all ages and stages of development and life.

6. Greater public awareness and understanding of the nature of ASD and ways to see the potential in every person on the spectrum.
Autism Ontario Advocacy FAQs

We are being asked many questions regarding Autism Ontario’s advocacy approach during this time of autism program transition. Here are some facts:

Autism Ontario’s advocacy approach is influenced by:

1. The Canadian rules that govern charities and their activities
2. Autism Ontario’s values and Board policies
3. Our strategic directions
4. A desire to speak factually and empathically, highlighting experiences of families across Ontario, discussing the impact of existing public policies and working towards changes that improve systems, policies and which empower families and people on the autism spectrum.
5. Our capacity to respond to various advocacy opportunities with volunteer and staff resources.

How does Autism Ontario come to know what Ontario families of children and adults are saying about anything related to ASD?

- 43 year history of support for families and people with ASD.
- Province-wide Autism Ontario survey conducted in 2014. 1750 people responded, the majority of who were parents/caregivers of children and youth on the spectrum. The results indicated a wide range of themes reflecting family concerns about gaps in services and the need for advocacy, which highlighted transitions to and through adulthood, a lack of confidence in information from health professionals, and the need for improved education, programs and supports for all ages and abilities, including ABA.
- Regular dialogue with parents and caregivers through our Chapters, family participation, scholarship and funding supports feedback and program evaluation of our Potential Programme, March Break and Summer Supports. To access this specific report click here.
- Listening to professionals in the field who work directly with families and to families through Autism Ontario webinars, and through invitations of those and other parents and professionals to speak directly with our elected volunteer leadership and staff.
How and where does Autism Ontario express its views?

Through:

- Regular or specific contact with multiple Ontario ministries including, MCYS, MEDU, MCSS, MTCU, MEDEI, MOHLTC, the Ontario Ombudsman’s office and various standing committees and structures within Ministries such as MACSE, local SEACs, focus groups, partnership tables, etc.

- Formal & informal written responses to requests for our feedback from various Autism Ontario representatives (Chapter leadership, people on the spectrum, Board Members, staff) Recent examples include: Autism Ontario’s Response to From Great to Excellent: Building the Next Phase in Ontario’s Education Strategy.

- Provincial, national, and local alliances, coalitions and committees where we are appointed or are in partnership with other groups. Some examples include our ABACUS Advisory Committee, College Autism and Behaviour Science Advisory Committees, and Ontario Partnership for Adults with Asperger’s and Autism otherwise known as OPAAA.

- Discussions with key Ontario parties. We continue to be a leading source of information for key decision makers who look to our responses regarding policy and programming. Recent work includes speaking out regarding the release of waitlist numbers in 2015 with the NDP; a meeting with the PC leader in March 2016; and with MCYS and MEDU reps at our own provincial gatherings in Toronto of staff, elected Board and Chapter leadership in 2015. To access our position papers, media responses, and reports, please click here.

- Our Public Awareness Campaign: Raise the Flag that is filled with resources and activities created for educators and the general public so that they may be better equipped to understand and meet the needs of people with autism in their communities.

- Our Knowledge Base: A bilingual, searchable database of brief, easy-to-understand documents that are relevant to the lives of youth and adults with ASD their families.

- Our Autism Ontario Publications and our Potential Programme evaluation data regarding our research posters.

- Our magazine, Autism Matters, which contains a wide variety of information on children and adults with ASD, ABA, research, family and personal stories, celebrations, public awareness, advocacy, etc.
What are Autism Ontario Resources and links specific to information about ABA?

Autism Ontario provides supports to thousands of parents through its Potential Programme and has done so for 8 years. We also have Family Support Coordinators and 25 Chapters in all areas of Ontario.

1. Connect to our Family Support Coordinator (FSC) for a local list of autism service providers, support groups, and knowledge about specialized programming. Family Support Coordinators help families navigate to the most effective services.

2. There are several Autism Ontario ABA related resources for families, including:
   a. ABACUS – a listing of ABA service providers serving Ontario including helpful resources for families looking for ABA supports and services.
   b. Everyday ABA with Leslie Cohen – this webinar provides a basic toolbox of positive and effective behavioural strategies for increasing adaptive behaviours that compete with, reduce, and replace challenging behaviours.
   c. ABA in Educational Settings with Tracie Lindblad – this webinar seeks to define applied behaviour analysis (ABA) and clarify how it fits into the Ontario education system through the implementation of Policy and Program Memorandum 140 (PPM-140).
   d. Navigating the system after an autism diagnosis. Dr. Wendy Roberts presents information on how to navigate the sometimes costly, fragmented system that leaves individuals and family members searching for professionals and programs while facing waitlists and gaps in services.
   e. Autism Ontario’s Knowledge Base - a series of brief, easy-to-understand documents that are relevant to the lives of youth and adults on the autism spectrum and their families.
   f. Stay tuned for an upcoming webinar featuring Dr. Leslie Cohen who will be doing 6 face-to-face sessions with families across the province on ABA related practices.

About Autism Ontario: Autism Ontario has a 43 year history of representing thousands of families and people with ASD across Ontario. We are the only organization in Ontario that has formal parent representation in all areas of the province through our 25 Chapters. We advocate on behalf of all people with ASD and their families – at all ages and stages of life, reflecting a wide range of expression and abilities. To connect with us, visit www.autismontario.com

Vision: Acceptance and Opportunities for all people with Autism Spectrum Disorder.
Mission: To ensure that each individual with ASD is provided the means to achieve quality of life as a respected member of society.
Important information for families regarding the recently announced changes to children’s autism services in Ontario:

Relevant resources and responses to the announcement

Government of Ontario & MCYS links

- **Website details:** For information regarding the announced changes to autism programming, and how these changes would impact your child and family, [click here](#).

- **Public On-line Engagement Sessions (April 11-27):** To register for the online engagement sessions about changes to children’s autism services please [click here](#) or visit [www.autismontario.com](http://www.autismontario.com) to learn how to register. **The objective of these sessions is to provide information and address questions that families may have about the changes.**

- **What about your own child’s services?** Contact your [autism service provider](#) directly.

- The **Autism Spectrum Disorder Clinical Expert Committee** had a government mandate to advise the Ministry of Child and Youth Services on up-to-date, evidence-based research on effective clinical practices, services and supports for children and youth with ASD.

- This report **Autism Spectrum Disorder in Ontario 2013** (updated January 27, 2014) contains the basis for many of the government’s recent decisions from a policy perspective. Parents and professionals should take some time to review this document if at all possible. Recommendations may be found on pages 48-55.

Public dialogue on this program and policy changes

The changes to children’s autism services in Ontario have generated ongoing conversation in the media in the past week, with varying degrees of facts, emotion, context and positioning.

The **Ontario Association for Applied Behaviour Analysis (ONTABA)** shared its position statement on their website. [Click here](#) to access it or visit them directly at [http://www.ontaba.org/](http://www.ontaba.org/).

**Baker Law**, who specialize in disability and human rights litigation have posted a response to the changes in autism programming in Ontario. You can [click here](#) to access their statement or visit their website [http://www.bakerlaw.ca/](http://www.bakerlaw.ca/) for more information.
Media: There has been much media attention to these changes – covered by several large media outlets including the Toronto Star, City TV, CBC and CTV. All of these articles have been posted on Autism Ontario’s social media outlets. To access these articles visit our social media channels or please contact us directly at media@autismontario.com

There are some groups who have a presence on social media as a resource and support to families:

1. The Alliance Against the Ontario Autism Program
2. The Ontario Autism Coalition - The OAC released a press release regarding the Ontario Autism Program that can be accessed here.

Both groups are supporting families through formal petitions, organized protests, grassroots action and sharing of information.

Families are also connecting through hashtags on Twitter:

#AutismDoesntEndAt5
#onpoli

As with all information, Autism Ontario endorses the right to information. Autism Ontario strongly believes that it is important to do your own research and make your own informed decisions.