

BRIEFING NOTE: Recommendations for changes to the [Ontario Autism Program](#)

For:

The Ministry of Children, Community, and Social Services



Delivered by:

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TABLE OF CONTENTS

1. Introduction to the OAC
2. Some key numbers
3. ASD, ABA and ABCs: Autism Acronyms in Ontario
4. Priority: How to Reduce the Waitlist
5. What the Liberals left Unfinished
6. Pitfalls: What the Government Should *NOT* do
7. Appendices: (withheld from the public document for confidentiality reasons)
 - a. THE DSO REGIONAL PROGRAMS ARE VIOLATING THEIR OWN [GUIDELINES](#)
 - b. THE DSO REGIONAL PROVIDERS ARE NOT HELD TO THE SAME STANDARDS AS DFO PROVIDERS
 - c. THE DSO REGIONAL PROVIDERS ARE MISLEADING AND CONFUSING PARENTS
 - d. OVERVIEW of MEDICAID MANAGEMENT SERVICES IN FLORIDA
 - e. SAMPLE FEE SCHEDULE FOR ABA SERVICES FROM THE U.S.A. (BLUE CROSS)

1. INTRODUCTION TO THE OAC

The Ontario Autism Coalition (OAC) is a grassroots political advocacy group that was formed in 2005 and has grown into a province-wide organization with over 4,000 members. The OAC organized over 25 rallies between 2005 and 2011 to draw public attention to the need for publicly funded programs that effectively meet the needs of individuals in the Autism community. During our “No More Excuses” campaign, we also met with countless government policy advisors, senior provincial Cabinet Ministers and MPPs to make our case. In 2010, we issued a detailed recommendations report to the government, outlining strategies to address the needs of individuals with autism from preschool to adulthood. In 2011, the OAC became an Ontario not-for-profit corporation. We receive no government funding, we have no paid staff and we have no office.

The OAC experienced unprecedented growth in the spring of 2016 as a result of the Wynne Government's announcement that they were re-introducing age cutoffs for IBI therapy. Following a successful campaign to end the age cutoff, ([#AutismDoesntEndAt5](#)) and to persuade the government to move to a model based on direct funding, the OAC assisted in the development of the new Ontario Autism Program. Today, the OAC continues to advocate for improvements to the program. In 2017, we launched our third campaign ([#AutismDoesntEndAtSchool](#)) to ensure that the quality of ABA delivered in classrooms is the same as the ABA that can be accessed in the Ontario Autism Program.

For more information about the history of the Ontario Autism Coalition, please visit our website:

<https://ontarioautismcoalition.com/history/>



2. SOME KEY NUMBERS

NUMBERS WE *DO* HAVE:

- Number of children with autism in Ontario: [prevalence rate](#) = 1 in 66
- Approximate number of children with ASD in Ontario: 40,000
- Number of children on the waitlist: 20,000
- Hourly rate for DFO providers is \$55
- Current budget for the Ontario Autism Program: \$194,558,234 + \$62 million added from the Liberal's spring budget

NUMBERS THE MINISTRY *DOESN'T* HAVE:

- Cost per child in DSO programs
- Hourly rate for DSO
- Hours being prescribed for each level, average and duration
- Average BCBA/Psych caseload and "duration" (We know what they *should* be according to the BACB [guidelines](#), See pages 34 and 35)
- The number of families that wanted DFO, couldn't get it, and either waited or went DSO.

NUMBERS YOU CAN ACCESS THAT WE CAN'T:

- Number of children currently receiving service from the OAP
- Number of children on the waitlist at level 1, 2, or 3 severity (we know these numbers were provided to the OAP Implementation Committee)
- Results from the [Provider Survey](#) sent out earlier this year. This survey was put out to the behaviour analytic workforce "to understand how the autism behavioural services workforce in Ontario (including publicly funded, private, and non-profit providers) can be developed" (taken directly from the document)
- What data was gathered in relation to the diagnostic hubs that have been developed across Ontario? This may help to determine the usefulness of varying ways the diagnosis is received.
- How much money has been spent so far on the "Family Support Workers" created under the new OAP? What role are the Family Support Workers actually providing (i.e., what are families getting out of it).

3. THE ABCs OF ASD & ABA: IMPORTANT AUTISM ACRONYMS

Acronym	Meaning
<u>ABA</u>	Applied Behaviour Analysis <ul style="list-style-type: none"> • Focused interventions: Target a specific skill deficit and/or one or more behavioural excesses; interventions are usually time-limited and implemented until goal is achieved (<u>OSETT-ASD</u>, 2017). • Comprehensive interventions: Include essential practice elements of ABA and typically implemented in a very intensive and comprehensive manner (<u>OSETT-ASD</u>, 2017).
<u>ABC</u>	Antecedent-Behaviour-Consequence
<u>ABLLS-R</u>	Assessment of Basic Language and Learning Skills Revised
<u>ACSD</u>	Assistance for Children with Severe Disabilities
<u>ADOS</u>	Autism Diagnostic Observation Schedule (there is a first and 2nd edition to this)
AG	Auditor-General (sometimes used to indicate the Attorney General)
<u>AIP</u>	Autism Intervention Program (the pre-2017 program)
<u>AO</u>	Autism Ontario
<u>AODA</u>	Accessibility for Ontarians with Disabilities Act
<u>AODA Alliance</u>	The Accessibility for Ontarians with Disabilities Act Alliance
<u>AS</u>	Autism Speaks (There is also <u>Autism Speaks Canada</u>)
<u>ASAN</u>	Autism Self Advocacy Network
ASC	Autism Society of Canada - now called <u>Autism Canada</u>
BACB	<u>Behavior Analyst Certification Board</u>
<u>BCBA</u>	Board Certified Behaviour Analyst
<u>BCBA-D</u>	Board Certified Behaviour Analyst Doctoral
<u>BCaBA</u>	Board-Certified Assistant Behaviour Analyst
BIP	Behaviour Intervention Plan/Program (may also be <u>BSP</u>)
BSP	<u>Behaviour Support Plan</u> /Program
<u>CASDA</u>	Canadian Autism Spectrum Disorder Association

<u>CFS</u>	Connections For Students
CIC	Clinician-in-Charge (Also known as Clinical Supervisor)
<u>DFO</u>	Direct Funding Option (under the OAP)
<u>DSO</u>	Direct Service Option (under the OAP) but can also mean Developmental Services Ontario
<u>DTC</u>	Disability Tax Credit
<u>EA</u>	Educational Assistant (in some boards may be called ERW or TA)
EDU	Short for for the Ministry of Education
ERW	Education Resource Worker (in some boards may be called EA or TA)
<u>FA</u>	Functional Analysis
<u>FBA</u>	Functional Behaviour Assessment
FSP	Family Service Plan—an optional plan for integrating OAP services with other services that the family needs. Regional providers are making it a requirement
IBI	Intensive Behavioural Intervention (Ontario term previously used to describe services in the AIP - also known as comprehensive ABA)
<u>IEP</u>	Individual Education Plan
<u>IPRC</u>	Identification, Placement and Review Committee
ISP	Individual Service Plan/Individual Support Plan - under the OAP, this may be the Behaviour Plan and it outlines the goals to be achieved and the interventions to be used to attain those goals (a new one should be developed minimally every 6 months)
IT	Instructor Therapist (works directly with the client and must be supervised by a Senior Therapist and/or Clinical Supervisor - also known as an ABA Therapist)
NT	Neuro-Typical
<u>OAC</u>	Ontario Autism Coalition
<u>OAP</u>	Ontario Autism Program
<u>ODSP</u>	Ontario Disability Support Program
<u>OHRC</u>	Ontario Human Rights Commission
<u>OHRT</u>	Ontario Human Rights Tribunal
<u>ONTABA</u>	Ontario Association for Behaviour Analysis

<u>OSETT</u>	Ontario Scientific Expert Taskforce for the Treatment of Autism Spectrum Disorder
OT	Occupational Therapy /Occupational Therapist
PPM	Policy/Program Memorandum (i.e. PPM 140 , PPM 156 , etc)
<u>RBT</u>	Registered Behaviour Therapist
<u>RDSP</u>	Registered Disability Savings Plan
SEA	Special Equipment Amount (sometimes; Special Ed Assistant)
SEG	Special Education Grant
SEPPA	Special Education per Pupil Amount (calculated on basis of total enrollment of students, not just students with Spec Ed needs)
SIP	Special Incidence Portion (funding for additional staff to ensure health & safety of students who have extraordinarily high needs)
<u>SLP</u>	Speech Language Pathologist
SNA	Special Needs Assistant (TDSB)
<u>SSAH</u>	Special Services at Home
SST	School Support Team (TDSB)
ST	Senior Therapist (supervises & trains ITs - must be supervised by a Clinical Supervisor)
TA	Teaching Assistant (in some boards may be ERW or EA)

4. YOUR PRIORITY: HOW TO REDUCE THE WAITLIST

Build more capacity into the system

- A 2017 OAC survey of ABA providers in the autism field showed a critical shortage of practitioners
- A [labour market survey](#) put out by the government earlier this year will reflect these results; although it's worth noting that there were some concerns with the wording of some of the questions
- A better definition of focused ABA and the use of programs such as Project Impact will leverage existing capacity more effectively, but the longer-range need requires more practitioners
- You can't throw money at the program if you don't have enough professionals to meet the need
- There is a huge need to build more capacity in rural and northern Ontario
- Easy wins:
 - Open the Grant Assistance Program (GAP) to non-DSO staff
 - Encourage ABA providers from U.S. to come to Ontario because we're "open for business"
 - Fund more ABA training programs in Ontario's colleges and universities

Define diagnosis

- End "prescription pad diagnosis"
- Red flags are an indicator that assessment should be done, but could be something other than autism
- Family doctors and psychologists can certainly identify the "red flags" of autism, but should then refer the individual for a more comprehensive evaluation
- A comprehensive evaluation would include the use of standardized assessment tools province wide--either the ADOS-2: Autism Diagnostic Observation Schedule and the ADI-R: Autism Diagnostic Interview-Revised (This is [required](#) in B.C.)
- Screening tools include—Early Screening for Autism and Communication Disorders (ESAC) and the Systematic Observation of Red Flags of ASD in Young Children (SORF-22)

Define 'Focused' ABA

- Nearly half of the kids on the waitlist often do not need comprehensive ABA
- Some would benefit from existing programs that combine therapy for the child with parent training, and include group therapy targeting certain areas such as social skills (speak with ONTABA for more specific recommendations)

Eliminate the conflict of interest between the Regional Programs and the Private Providers

- DSO providers must **not** handle the money. The evidence of their fiscal mismanagement and unethical behaviour is overwhelming. The OAC has been begging for an end to this conflict for over a decade. The Liberals did nothing.
 - For samples of evidence from two different DFO providers, see Appendix A & B
 - For samples of evidence from the OAC membership, see Appendix C

Establish a more responsible, transparent method to flow the funding

- The Passport online direct-billing system addresses parent concerns *and* it's cheaper
 - No second bank accounts, no payment delays / late fees due to slow reconciliation
 - Parents do NOT want to take on the role of accountants
 - For an example of how the system works in Florida, see Appendix D

(*Note: the OAC does **not** recommend the use of an private corporation to function as the “management company” as in the Florida model. We believe that the function of administering OAP funding must be brought back to the offices of the Ministry of Children, Community, and Social Services, using online technology that is *already in place**)

Eliminate the incentive to over-prescribe hours (Laura)

- The \$55/hr “all-in” rate does not over all costs when there are <15 hours/week
- Break out “big ticket” costs that are not direct instruction:
 - Assessments
 - Supervision
 - Rural area travel
- Establish a standard fee rate card that *all* providers must abide by, *including DSO providers* (we’ve brought a sample from the USA—Blue Cross)
- ONTABA has provided its members with a guideline to ethical billing and provided a copy to the previous government

THINGS THE LIBERALS LEFT UNFINISHED

Regulate private providers

- [SEG Report](#)
 - Completed for the MCYS in 2014
 - Included a labour market scan, inter-jurisdictional scan, and extensive consultation
 - Provided recommendation for regulation of behaviour analysts in Ontario, specifically Title Protection with Scope of Practice, with full function regulatory approach in the end state
- Title protection versus full regulation
 - [ONTABA Town Hall October 2016 on Professional Regulation](#)
 - Pursuing title protection at this time through Private Bill, with the goal of full autonomous regulation
- [HPRAC](#) report to the previous ministry
 - Provided advice on activities specific to ABA that pose a significant and inherent risk of harm
 - Report submitted to the minister on January 31, 2018
- [ONTABA's Position on the Autonomy of Behaviour Analysts in Clinical Practice](#)
 - The BCBA/BCBA-D credential is the necessary and sufficient qualification for the supervision of ABA programming in the treatment of Autism
- [BACB Model Act for Licensing/Regulating Behavior Analysts](#)

Protect the system, in addition to the families

- Implement the System Review Committee (SRC) for practitioners
 - Local Review Committee (LRC) that addresses disputes and provides peer review
 - Systems Review Committee (SRC) that addresses disputes that cannot be resolved at the LRC level and provides systems level direction on ABA best practice standards
 - [Independent Clinical Review Process Guidelines](#)
- Set trigger values for weekly hours and overall budgets that would result in review
- [Ensuring Quality Service Provision: A Statement on the Importance of Regulation, Accreditation and the Appropriate Clinical Oversight of Behaviour Analytic Programs for Children and Youth with ASD in Ontario](#)

Reduce the number of Family Support Workers

- Make the use of family support workers optional, not mandatory
- Although they have stated it is mandatory, TPAS for example reached out to families and then never actually saw them. In January at the clinician's meeting, we were told that our families must do this meeting if they were to be brought into the new OAP. It never happened.
- A 2017 straw poll found that 80% of OAC respondents thought they would make use of an FSW, but when told that the cost was 10% of the program budget, only 30% thought they would
- For many families, these workers are a duplication of service they already received elsewhere

Implement meaningful ABA in Classrooms

- Now that eligibility for the OAP goes up to the age of 18, ABA services simply **MUST** be provided in schools. (Want to clear the waitlist? This is the best way...)
- The Ministry of Education has been dragging their heels on this—get them to the table
- In 2017, the OAC released a full [report](#) of recommendations for education; ONTABA is preparing an ABA in schools document as well
- The [Pilot Project](#) announced last year is a start, but there's much, much more to be done.
- There is an important human rights case currently before the OHRT on this issue--best that the government act before the courts order them to:
 - Visit [this link](#) to visit the website of Baker Law, the firm bringing the case
 - Read this article from the [Toronto Star](#)



#AutismDoesntEndAtSchool

6. PITFALLS TO AVOID: WHAT THE GOVERNMENT SHOULD ABSOLUTELY NOT DO:

- Restricting service on the basis of age has been tried twice and has led to province-wide protests. More importantly, it is unsupported by evidence.
- Hard caps in either hours or dollars do not address need, and would not reflect best clinical practice.
- Hard caps in duration of service do not address need, and would not reflect best clinical practice.
- Opening up the program to interventions that are not evidence-based.
- Sacrificing the quality of treatment in order to shorten the waitlist.
 - i.e. omitting the supervision requirements
- Opening up an unrestricted free market in ABA without regulation.