

Ontario Autism Coalition

No More Excuses!

MPP Lobbying Kit

April 2016

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General Information

What is lobbying?

Lobbying is a process, which involves writing letters and meeting with politicians about concerns that we have. We lobby because we want the system to improve. We lobby because we live in a democratic society and it is our right to lobby. We are presently lobbying the government to make changes to the Ontario Autism Program that they will be rolling out in May 2016. We are lobbying because we are concerned for the future of our children and all of the children and their families who live with Autism.

Who do we lobby?

Depending on what program we want to implement changes, we lobby either the MP or MPP. The MPs and MPPs are the ones who bring ideas forward, make changes, and vote on the laws that affect our children. In our case, we are lobbying our MPPs who are representatives for the Ontario Government. The MPPs in each riding belong to one of the three parties (PCs, NDPs, or Liberals). We are presently lobbying the Liberal MPPs as we have a majority government in which the Liberals are in power.

How to Lobby

Advocating effectively involves three important components: 1) a strong key message, 2) 1-2 key “asks” or solutions (things that you want to see happen or change) and 3) a personal story. Please use the documents in this kit to help you determine which key messages are important to you, how the decisions that the government is making is affecting your child/family and what “ask” is important to you.

What this lobby kit contains:

1. The main issues of the Ontario Autism Program, including the difference between ABA and IBI. This is a good starting point, which highlights the main issues.
2. The key talking points that you may want to focus on in your meeting. These notes will help guide your discussion. It provides the facts that you need as you ask for what is needed.

3. An MPP Letter/E-mail template, which can be used to contact your MPP to set up a meeting or to connect with your MPP.
4. Lobbying Tip-Sheet with suggestions on how to contact your MPP
5. A follow up letter to your MPP to be sent after your meeting
6. An MPP report back form. After you meet with your MPP, you can complete this form for your own reference. You will want to document the promises that your MPP made. We are also asking you to complete a survey that will enable us to collect and track the responses we are getting as a community

******It is very important that when you have met with your MPP that you complete the survey at:**

<https://www.surveymonkey.com/r/9PRX9Q6>

Main Issues of the Ontario Autism Program

ABA/IBI Explained and the Impact of the Changes in the Ontario Autism Program

prepared by Tim Ingram

ABA the science of behaviour change. IBI is the application of that science to create a program of intensive, comprehensive teaching. The difference between the existing two programs in Ontario is one of COMPREHENSIVENESS and INTENSITY.

A typical IBI program of 25 hours a week would have time to work on: behaviours, receptive language, expressive language, imitation, pre-academics, self-care, gross motor skills, fine motor skills, community access, play, and social skills. Typically, you would see skills gained in all of these domains. The "Ontario ABA program" is a poorly named program where ABA principles are used to teach one skill in a non-intensive way (i.e. one hour per week).

How can you possibly target all of those areas with only a few hours a week? You can't. That's the difference. Here's one way to explain that may make sense: all kids go to school to learn. But instead of going full-time, because you're over age 5, you can only go for half a day, once a week... maybe a little more in some cases, but never all day every day. How likely is it with this level of instruction you will ever learn what you're capable of learning? You can't! And imagine if the government did this, how much money they'd save in the SHORT TERM. But this is exactly what they are doing to the kids with autism.

Meeting with Your Local MPP

1. Find out who your MPP is and get their contact information.

Find out your electoral district by visiting the following website:

<https://www3.elections.on.ca/internetapp/fyed.aspx> . Use your postal code or address to find out your electoral district is.

Once you know what electoral district you live in, find your MPP by visiting the following website:

http://www.ontla.on.ca/web/members/members_current.do?locale=en

2. Send an email or letter asking to set up a meeting (use the template at the end of this document)

3. Set up an appointment to meet with your MPP

- If you have not heard back from your MPP constituency office within 3 days since sending your email or letter, call your MPP's constituency office to set up a meeting. MPPs are usually in their offices on Friday. This is their day to meet with their constituents. If the Legislature isn't sitting, they are available most days.
- Speak with the MPP's assistant or their coordinator. Formally schedule a meeting. Be polite to whomever you are speaking with. They are what is standing in the way between you and your MPP. Being rude results in lost credibility and they will be less likely to want to assist you.
- You may need to call the office more than once. You may need to leave more than one message. Be persistent.

4. Decide who will be coming with you to the meeting.

You may want to bring other people to the meeting such as ABA therapists, teachers, etc., but do not invite more than 2-3 people. Additionally, it is better that those that you invite to the meeting live in the electoral district.

5. Preparing for the meeting

- 3-5 days before the meeting, call the MPPs office to confirm the meeting. If the meeting needs to be rescheduled, be polite.

- Advise the office who will be attending the meeting with you. Enquire about how long your appointment will be. Make sure you can get your message across in 15 minutes as these meetings are generally short.
- Review the most current issues about the Ontario Autism Program and the issues at hand. Review the talking points provided in this kit.
- Bring notes with you that you can refer to during the meeting.
- Arrive to the meeting a few minutes early

6. During the meeting

- Tell your story (refer to the document in this kit).
- Tell your MPP how the Ontario Autism Program has failed your child.
- Refer to the talking points provided in this kit.
- Be assertive. Speak to solutions, rather than problems. Do not get into any arguments. Be friendly. Do not be rude.
- Have a plan of who will speak and when they will speak. Make sure all points are covered.
- Point out what information you have about the MPP's views on the situation that you can support. You want to convey a sense of collaboration.
- Leave time at the end of the meeting to provide the MPP an opportunity to ask questions.
- Ensure that your MPP understands what it is you are asking, and advise them that you will be following up with them.

7. What to ask the MPP to do

This all depends as to what position your MPP has:

- If your MPP is a government *Cabinet Minister*, ask them to bring up the problems/demands in the Cabinet meetings
- If your MPP is a member of the *government party*, ask them to bring up the problems/demands during their caucus meetings
- If your MPP is a member of the *opposition party*, ask them to bring up the problems/issues during Question period in the legislature. Ask your MPP to write a letter to the Ministry of Child and Youth Services to support you and to request a response.

8. Follow-up

- Send a thank you letter to your MPP thanking them for taking the time to meet with you (please refer to the template provided).

- Ensure in your letter, you highlight what you spoke about and what the MPP agreed to do for you.
- Call the MPP at a later date to see if the MPP followed through on any of the promises he/she made.

*****It is very important that when you have met with your MPP that you complete the survey at:**

<https://www.surveymonkey.com/r/9PRX9Q6>

Writing a Letter to Your MPP

General Guidelines: Writing to your MPP about the issue that you have first hand experience can have a positive effect on your MPP. Discuss in your letter your experience with the Ontario Autism Program, how the Ontario Autism Program has failed your child, will prevent your child from reaching their full potential, etc. Tell them what you think a viable solution is. Keep your letter brief. Do not go beyond two pages, otherwise they are less likely to read your letter. Please note, the sample below is just a suggestion. You can modify it as you see fit.

These letters can be mailed, faxed or sent via email.

DATE

Your Name

Your Address

Name of MPP/Party Leader

Street Address

City/ Town, Postal Code

Re: Meeting request from YOUR NAME

Dear MPP **First Name Last Name**,

As a constituent in your riding, I am writing today to express my concerns with respect to the government's recent announcement of the Ontario Autism Program.

As you are aware, Autism is a neurodevelopmental disorder, which affects 1/68 children. Autism affects a child's ability to communicate, and socially interact with their environment. Without appropriate intervention, these children will grow into adults and be unable to become contributing members of society, costing taxpayers upwards of \$2.5 million dollars to support these individuals throughout their lifespan.

We know that Autism is treatable using the principles of Applied Behaviour Analysis. Applied Behaviour Analysis has a long history of effectiveness.

[Insert your personal story here]

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The government's proposed changes to the Ontario Autism Program are devastating to children with Autism in Ontario. **Children with autism need access to the appropriate intervention at the right time and with the appropriate intensity.**

I look forward to meeting with you to discuss these issues and ways in which we can work collaboratively to ensure that children with Autism receive the appropriate customized and intensive intervention they require regardless of age.

Sincerely,

Your Name

Your Personal Story

Your personal story should reflect a concrete real life example of the issue that you are speaking to. Politicians are constantly being bombarded with information that deals with policies, funding etc... We need the politicians to real life examples and how these problems are affecting your family directly. You need to keep the following things in mind:

- Tell them who you are, where you live
- Tell them the challenges you are facing. Example: My son is 5 and has autism.
- Tell them how the challenges have affected your life. Example: My son has severe tantrums. This means that we are unable to go out to public places as he has meltdowns.
- Keep your story simple. We understand that your child's situation may be complex. Try and keep your life story in a simplified version. Example: My son/daughter is currently 5 years old. He/she has been on the waiting list for 2 years and is now being kicked off. My son does not know how to interact with children, or communicate. We started private ABA and we noticed in two weeks that he was able to request his needs etc...)
- Provide very specific examples of how the problems are affecting your life. Example: The fact that you are kicking my son off the waiting list means that we will have to continue providing this therapy to our son at our own cost. We have already refinanced our house and have liquidated all of our assets including our RRSPs).

KEY TALKING POINTS

(can be used during your meeting with your MPP)

Why the Ontario Autism Program is the wrong thing to do

1. The government is misinterpreting the science.

The key to effective treatment of autism is *intensity*. IBI *is* effective for older children, it *does* still work. There are many studies that show this but the government ignores them because the studies don't use the made-in-Ontario term "IBI." The government is punishing children five and over because of the government's failure to shorten waitlists.

2. The government's replacement program isn't ready and won't work.

The studies in the Expert Panel Report show that lower intensity programs don't work. The government has it backwards. They're cutting kids off from a program that is effective and replacing it with one that isn't, while claiming that they're doing the opposite. What's worse is that the ABA program can't handle the sudden influx of kids. Families are already being told their kids will be on a waitlist. Waiting is the most ineffective "program."

3. The government claims that \$8,000 will ease the "transition."

IBI programs cost tens of thousands of dollars per child per year. Anywhere from \$40,000 up. \$8,000 will last about two months. Nobody, not even the government, thinks that kids will only wait two months. We're already getting reports from parents who are being told about a waitlist for the ABA program by their Regional Service Providers.

4. This didn't need to be done.

The Ontario Autism Coalition has recommended that the government focus on a Direct Funding model, similar to those in BC, Alberta and Saskatchewan. The record shows that this method of making money available to families to spend on an approved provider that the family selects can reduce the cost per child to 2/3 of the cost for the same child in the Regional Provider program. The government could get the same service for less money and use the savings to shorten the waitlist.

5. The financial burden that this will shift to families will be devastating.

Several years ago the Ontario Autism Coalition surveyed our membership and we learned that families with children on the spectrum file for bankruptcy at 120% of the rate in the general population. The high cost of IBI services, and all of the other services required for a child with autism are crushing. This move will damage families.

6. The government needs to admit that what they've been trying since 2003 isn't working.

The government has thrown millions of dollars at autism over the last decade. What's needed is three things:

1. Regulation of IBI professionals.

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2. A move away from pouring money into the government run Regional Service providers and towards Direct Funding to help parents find the supports most needed for their child.
3. Meaningful, consistent ABA programs for children and youth with autism in schools.

MPP Follow-up Letter

DATE

Your Name

Your Address

Name of MPP/Party Leader

Street Address

City/ Town, Postal Code

Re: Meeting request from YOUR NAME

Dear MPP **First Name Last Name**,

Thank you for the opportunity to meet with you on _____. I appreciate your interest in the issues identified and your commitment to improve the quality of life for children with Autism.

I commend your recognition that/of **INSERT ISSUES THAT WERE DISCUSSED AT THE MEETING**.

Your commitment to **INSERT WHAT THE MPP PROMISED TO DO** is appreciated.

I look forward to working with you during your term. If you have any questions or require additional information, please do not hesitate to contact _____ at _____.

Sincerely,

Your Name

OAC Media Release

FOR IMMEDIATE RELEASE

April 5, 2016

The Wynne government has given up on children with autism

Families and friends of children with autism are furious after the provincial government's [announcement](#) that Intensive Behavioural Intervention (IBI) therapy will now be cut off for children five and over. Parents of children with autism of all ages and their service providers have begun a campaign to force the government to reverse the decision.

Since coming to power 13 years ago, the government has utterly failed to reduce waitlists for the IBI program. They are trying to disguise their announcement as an attempt to do so, in a press release cruelly timed for release just days before [World Autism Awareness Day](#). What they didn't say is that they plan to do this by denying children over five access to therapy that is intense enough to work for them.

Minister Tracey MacCharles has misinterpreted the report of her hand-picked panel of experts. The government's promise of "more clinically appropriate" 2-4 hours of weekly ABA service for children five and over is not supported by any research, including the work that her panel cited. It is widely accepted that this proposal is sub-therapeutic, and does not result in meaningful outcomes according to the literature review conducted by the government's own [Expert Panel Report](#).

As a consolation prize, the government promised to provide a one-time payout of \$8,000 for families cut off from IBI, saying that they can use it to purchase "other approved services." Families know that a full time ABA program costs between \$50,000 and \$75,000 a year. "This is nothing more than hush money," says Shawna Thornberry of Grimsby, a parent of a 5-year-old boy who has autism. This money is barely enough to get a program up and running. After that, we have no way to maintain it." Far from managing to hush parents, this week's announcement has them howling.

Autism experts, service providers and other advocates have been quick to condemn the government's new "strategy." Dr. James Porter, an expert in ABA, IBI, and Autism, and Past President of the Ontario Association of Behaviour Analysts ([ONTABA](#)), says "with the proposed change in funding, this government has acted in a manner contrary to the values of Ontarians ... the value that Ontarians place on caring, supporting and investing in the most vulnerable members of our community ... this government will be haunted by this shameful legacy."

Other advocates expressed profound disappointment that the new "autism strategy" announcement contained no details whatsoever for either school or adult programs. "As the mother of a teenage boy with ASD and as a teacher myself, I know that programs in schools for our kids are hopelessly

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inconsistent. Despite the heroic efforts of teachers and EAs who work with our kids in the classroom every day, there is simply not enough training and support. They're being asked to teach our kids—who *are* challenging at times—while also struggling with cutbacks and ever-increasing demands on their time. It's not fair to anyone," said Laura Kirby-McIntosh, Vice-President of the Ontario Autism Coalition. "And there wasn't a single word in this announcement about adults with autism. I personally found that shocking."

A letter writing campaign is already underway, and petition signatures are being collected across the province. The petition will be presented to the Legislature later this month by New Democrat MPP [Monique Taylor](#), who will hold a press conference on the issue at Queen's Park on Tuesday, April 12 at 9:15 a.m.

An [online petition](#) started by Ottawa mother Brenna Bloodworth has more than 8,000 signatures and is growing. Parents will meet later this week to plan their strategy to fight the government's changes. Those looking for more information on the controversy are encouraged to visit the [website](#) or the [Facebook](#) page of the Ontario Autism Coalition or the [Alliance Against the Ontario Autism Program](#).

For more information please contact:

Ontario Autism Coalition

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The Ontario Autism Coalition and the Ontario Alliance Against the Ontario Autism Program are planning events in the coming weeks. Follow @OntAutism on Twitter for up to date information.