



# ONTARIO AUTISM COALITION

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January 18, 2020

The Hon. Todd Smith  
Minister of Children, Community and Social Services  
7th Floor, 438 University Ave,  
Toronto, ON  
M5G 2K8  
cc: Sarah Letersky, Jeremy Roberts, Amy Fee, Sarah Hardy

Dear Minister:

I am writing today to express my deep concern over recent developments in the Ontario Autism program and the negative impact that these changes will have on children, families, and service providers in this province. I speak to you from a variety of different perspectives: as the mother of two autistics, as President of the Ontario Autism Coalition, and as a member of the Autism Advisory Panel.

In October 2019, our panel released a Recommendations [Report](#) for a New Needs-Based Ontario Autism Program. You publicly committed to implementing *all* of the Panel's recommendations while responding to a [question](#) in the Legislature on December 10, 2019. However, several things have happened since then that are raising serious concerns in the autism community. In some cases, things are happening that directly contradict the recommendations contained in the Panel's report. When you came into this position, some members of our community cautiously put their trust in you. That trust is evaporating because of the decisions that have been made in recent weeks.

## 1. LACK OF TRANSPARENCY IN THE SELECTION OF THE IMPLEMENTATION WORKING GROUP

On page 47 of the report, the Advisory Panel recommended that the Implementation Committee (now referred to as the Implementation Working Group) should be selected through a "transparent process." While the Working Group includes many well known and highly respected individuals, there was no transparency at all about how they were selected. In addition, the OAC was shocked and disappointed to see that they were not included, despite our nomination of two excellent candidates. Some in the community have expressed concern about how the panel seems weighted heavily in favour of DSO providers. Furthermore, the mandate of the Implementation Working Group says that they were to "begin their work in December 2019 and hold regular meetings as needed." However, there were no meetings in December. In fact, the first meeting did not take place until January 16th.

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# #AutismDoesntEndAtFord

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The Ontario Autism Coalition is a non-profit Ontario corporation dedicated to advocacy and political action on behalf of people with autism.  
[www.ontarioautismcoalition.com](http://www.ontarioautismcoalition.com)

## 2. THE SCHOOL BASED REHABILITATION PROGRAM

On page 39 of the Panel report, we recommended that “any change (in the SBRS [program](#)) should prioritize the minimization of disruption to continuity of care (including disruptions during the school year) and/or any reduction in service levels for children and youth on the autism spectrum.” Instead, the ministry allowed CTCs to [terminate](#) contracts in the middle of the school year. This was the first time the Ministry went against the Panel’s recommendations. It would not be the last.

## 3. DELAY OF THE NEEDS BASED PROGRAM TO 2021

The Dec. 17th announcement was a communications disaster that could have been avoided if the Minister’s office had consulted more directly with key stakeholders. You entered the media studio smiling. You looked excited to announce that you would be accepting “most” of the recommendations of the Advisory Panel. Unfortunately, you left with parents in tears, reporters frustrated and you *never* turned your face to look at the parents in attendance.

Throughout the summer and fall of 2019, you, your Chief of Staff, and MCCSS staff told our Panel repeatedly that April 2020 was a totally realistic deadline for implementation of the new plan. We understood, of course, that not all 23,000 kids on the waitlist would suddenly start needs-based therapy on April 1, but we were assured countless times that it was a realistic date for the launch of the program. What changed, and when?

Families whose lives were turned upside down by the MacLeod plan held on to the promise of April 2020 for dear life, hoping that it would mean at least the *beginning* of access to the need-based therapy they had been fighting for so strenuously. When you announced instead that families will have to wait until 2021, it should not have come as a surprise that parents in the media studio immediately [burst into tears](#). When you admitted that the continuation of the Childhood Budget program might feel like just “more of the same,” you were right. Despite all of the talk about moving towards a “world-class system,” the reality is that the MacLeod plan will be in place for another full year. This is unacceptable.

How is it that it is now suddenly impossible to have Core Services up and running by April 2020 as promised? Please do not try to argue that “these things take time” and “we want to make sure that we get it right.” If your colleague at the Ministry of Education can suddenly create and launch a program to reimburse parents for daycare costs incurred as a result of the one-day teacher strikes, then it is fair for our community to expect that you meet the deadlines that you set for yourself.

## 4. DELAY OF CORE SERVICES

When you said that the only part of the program that might be available as soon as April 2020 was the Foundations program—which involves parent training, support groups and workshops—it sparked confusion and disappointment. Why not ensure that Core Services were the top priority? Don’t you understand that *therapy* is what families have been fighting for? The moment when the press conference completely fell apart, though, was when Jeremy Roberts said that budget cheques are “better than nothing.” Although it may have just been an unfortunate choice of words on his part, his comment was seen as a slap in the face to families who are watching their children lose precious months (and now years) in their child’s development—time that they will never be able to get back.

## 5. THE INTERIM PLAN

The [interim plan](#) that you announced on Dec. 17th (a.k.a. the continuation of the MacLeod Childhood Budget plan) is a horrible idea for reasons which I outlined in my email of Dec. 16th, immediately following a teleconference involving members of the Advisory Panel. Many of my fellow panellists expressed concerns after that meeting that we were simply being *informed* of the plan, not consulted. Clearly, there was no time allotted for input or suggestions, since the following day’s press conference was announced just hours after the meeting. To several of us, it feels as though since our report was released, our advice (as either individuals or as a group) is no longer wanted.

## 6. LACK OF TRANSITION PLANNING FOR FAMILIES

On Page 4 of our report, the Autism Advisory Panel recommended “... that a detailed, family-friendly transition plan [should] be developed to help families understand what the changes to the program will mean for them.” The panel also recommended that transitions into the new OAP should be “seamless” and should not involve interruptions to

service. There were also detailed recommendations about the need for a careful communications strategy (page 49) for all key stakeholders so that everyone in the autism community would have a clear understanding about what was happening and when. As of today's date, there is no evidence of such a plan, and both families and service providers have been left in the dark. Regional service providers are unable to tell frantic parents *any* information about how children currently in service will be brought into the new program. In some cases, they have been sharing false information. With only weeks left to go before some of the current behaviour plans expire, families of the so-called "Legacy kids" find themselves totally alone, unable to plan for their children. Some parents have started [counting down](#) the days until they lose their funding.

For those who have already received childhood budgets, there is no indication as to whether or not they will be able to renew that funding later this year or whether they will have to wait—without any funding or services—until 2021. For those who have never received funding, there is simply no end in sight to their waiting and they have every reason to be sceptical of the Ministry's promise that all families on the waitlist will receive cheques by the end of March.

So many questions remain unanswered for families about what will happen next. The failure to communicate accurate and timely information is having a devastating effect on people's mental health and, in my opinion, amounts to negligence.

## 7. FAILURE TO PROVIDE STABLE FUNDING TO PROVIDERS

In the last few weeks, I have spoken to many individuals who provide autism services in Ontario. Some of them are public providers. I am told that while they have technically received their funding allocations for the next year, those allocations are based only on the provision of "Foundational Services," not therapy. How can this be true? Please, *please* tell me that this is not accurate.

I have also spoken to many private providers, some of whom are literally losing sleep over the uncertainty that lies ahead. Since the announcement that we are still a year away from needs-based therapy, they are scrambling to figure out how to stay in business. How can these businesses plan when it appears that families will not have anywhere near the amount of funding that they need? The failure to provide funding that is based on need is not only hurting families, but it will also likely destroy hundreds of small to medium-sized businesses. How does that fit with the Conservative agenda?

## 8. FAILURE TO RESPOND TO THE PLEA FOR HELP FROM NORTHERN COMMUNITIES

The fact that there was nothing in the December 17 announcement that addressed the crisis in Northern Ontario was a huge oversight, especially given the [press conference](#) and meeting on the issue that had taken place just one week before. The capacity crisis in the north has been well known by this government for months now, and the fact that no action has been taken is inexcusable. Parents and [providers](#) are beyond frustrated. They are in crisis. The North matters and your government is duty-bound to take action *now*.

## 9. A STANDARDIZED ASSESSMENT TOOL

The [mandate](#) for the Implementation Working Group includes a direction that they should operationalize a "standardized clinically informed process to determine each child's level of support needed and applicable OAP funding allocation ... *with no fewer than five levels of need.*" There is no mention in the report of a specific number of "levels of need." Needs-based therapy is predicated on *individual* need; grouping levels is nonsensical. Furthermore, the Advisory Panel specifically *rejected* attempts to introduce such levels. Page 29 of the report states: "Families should receive discipline-specific clinical assessment(s) from *clinicians* of their choosing ... to determine the right approach to treatment." A standardized tool used to measure "level of need" was **not** recommended by the panel (despite *intense* pressure to do so) because such a tool is *not* clinically valid. In fact, our panel was unanimous in saying that a Care Coordinator should NOT be responsible for assessing need—only forecasting.

However, at the December 17th press conference, in response to a question, you said: "It's going to take some time to get the needs-based tool that the Care Coordinators are going to be using up and running as well." This statement indicates that a decision has already been made to go against something that our Panel was absolutely clear about. If so, I am left to feel that a great deal of the time and energy I spent over the summer trying to give you the best recommendations possible was wasted.

The panel recommended that only clinicians should be allowed to assess need. We also clearly insisted that accessing the support of the Care Coordinators should be *optional* for families. (Page 26 of the report states “Families accessing OAP services should be able to choose to access or *opt-out* of service navigation support at any time in their service journey.”)

In 2017, OAC members were surveyed about the Care Coordinator role as we developed recommendations for the Liberal program. Only 38% of our parents said that they would use such a service once they knew that 10% of the program budget had been set aside for the purpose. Government bureaucrats disregarded that information, hired staff based on 100% uptake, and ultimately over 12% of the program budget was spent on staff who provide no therapeutic value. If a single dollar of the program budget is going to be spent on anything other than needs-based therapy for children, there had better be an extraordinarily good justification. Automatically assigning care coordinators does not pass that test.

Many of my fellow panellists share my concern that if an assessment tool is created and then is used by Care Coordinators to determine need, it will be a clear indication that the bureaucratic needs of the autism program are being placed ahead of the needs of children with autism. As Minister, you must *not* allow that to happen.

## 10. CONTRACTS AWARDED WITHOUT COMPETITION

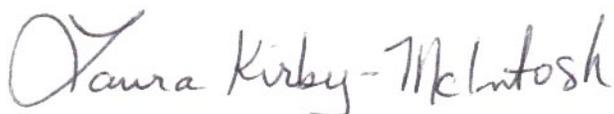
The Advisory Panel received many excellent recommendations about mental health, but they did not make a recommendation as to *which* agency should provide mental health training. Why, then, was [CPRI](#) chosen to do this? Was there an RFP, or an RFI, or was this sole-sourced? Some members of our community (notably autistic self-advocates) have expressed concern about how it is that an agency that is the subject of a [class-action lawsuit](#) for its mistreatment of in-patients has been chosen to do mental health training. We received excellent submissions on mental health from Kinark and from the Hamilton Children’s Hospital. Why not engage them instead, or experts like Dr Jonathan Weiss or Dr Yona Lunsky?

Another concern that has recently emerged is the awarding of an extensive contract to the Hanen Centre for the provision of the “More Than Words” program. We know that a letter has already gone out to several SLP’s inviting them to apply for contracts to provide this program to families on the OAP waitlist. Here, my concern is less about the particular agency that’s been chosen, but more about the process. Again, was this contract sole-sourced? If so, why?

Minister, it’s become abundantly clear to many of us that you and your staff are now limiting contact with your critics. People are saying that you appear to be “battening down the hatches” and cutting yourself off from the autism community, which is a sad contrast to your early months as Minister when you were accessible and had your “listening tour” in full swing. You are in political trouble now not because “this is a difficult file” or because the autism community “can never be satisfied.” Neither of those things is true. You are in trouble because you are ignoring the good advice that has been given to you—and in many cases, you are going directly against it. My members are tired of the delays, desperate for information, and out of patience. As President of the Ontario Autism Coalition, I am right there with them.

We need to meet in person, and soon. I am formally requesting a meeting with everyone copied on this letter, and I’d like to bring along my [Executive](#) Committee. Please trust me when I tell you that I would much rather be spending my time working with you and your staff on solutions than planning another rally. I’m hoping that we can work together once again to rebuild trust between your government and the autism community.

Sincerely,



Laura Kirby-McIntosh  
President  
Ontario Autism Coalition