



February 13, 2019

Dear Autism Family Advisory Committee:

What a week!

While we had a sense of the direction the government was taking with its new autism strategy, we learned more details, like you, as we watched a live stream of the announcement from Toronto.

It's certainly been a lot of information to digest and CHEO still has much to figure out, but I wanted to reach out to you now as our trusted family advisors. First and foremost, I am full of compassion for the families who are worried over the news and who feel apprehensive about the future. I know many CHEO staff are feeling the same way.

Before discussing the new strategy, I should declare my own biases. I believe services and supports for autism spectrum disorder should be part of our universal healthcare system like they are for concussion, epilepsy, brain cancer and any other health conditions.

When there are resource limitations – as there are in Ontario, not to mention every single healthcare system around the globe – I believe that severity and need should be what influences access to resources. The reality is no Ontario government has ever taken this approach to autism – Liberal, NDP or Progressive Conservative. The bigger reality is that the Ontario Autism Program (OAP) has been in disarray for many, many years, frustrating providers and families alike -- despite the valiant efforts of our staff.

Of all of CHEO's programs, it was the only one where clinical decisions were micromanaged by government – right down to which therapy to provide, for how long and to which child.

The former Children's Minister announced changes in January 2018. There would be unlimited access to treatments, starting with those who sat atop various waitlists at that particular moment in time.

This was excellent news for some families, but the Minister did not in fact provide enough funding for even those families – let alone the ones that were still in the queue. Very early on in its rollout, the program ran out of money. Again, families were frustrated. It's been an unforgiving theme for families for years.

Meanwhile, here in eastern Ontario, by mid-2018 the waitlist was growing at the rate of 54 more kids per month. The former Minister promised there would always be a choice of public or for-profit providers when a child got to the top of the wait list, but there was no mechanism in place to make this happen – so many families were still forced to wait.

I liken it to this: it's as if a child who wasn't breathing arrived in our Emergency Department and was made to wait until the 50 other kids who got there first were seen and treated.

The tragedy therefore was that the youngest kids, who would benefit enormously from early intervention at a very young age (like 2 or 3), were being forced to wait indefinitely for life-changing therapies. Most children currently in CHEO's Autism Program are over the age of 6.

The funding model that Minister Lisa MacLeod has now implemented is one that many autism advocates have been urging for years. It eliminates funding to providers like CHEO and offers families a voucher to purchase service themselves.

It is not what CHEO would recommend to the government but, as a publicly-funded organization, our mandate is to do the best we can for the families we serve. We are no strangers to designing programs with smaller budgets than we would like to have.

We are committed to working with the Ministry of Children, Community and Social Services (MCCSS), as well as families and our talented staff to try to make the new plan work. We are already ramping up our diagnostic hub to continue to drive down waits for diagnosis.

When it comes to delivering behavioural services and supports, we have told our Autism staff to expect the CHEO program to change over the next year and, although we don't know what services we will be able to provide, we are committed to helping families.

There are many elements of the latest autism program reboot that deserve praise. Targeted funding to speed up diagnosis will allow children to enter the program earlier. The regulation of both provider organizations and individual therapists is long overdue.

That's why, when the program was announced, we made this comment: "At CHEO, we've worked hard to cut the wait for an autism diagnosis from well over a year to 24 weeks. With today's announcement, we will be able to further speed up diagnosis. We look forward to working with Minister MacLeod, families and our staff to see how else CHEO can be part of the new provincial autism strategy." Yes, I am very pleased with the extra investment in CHEO's diagnostic hub.

Like all previous changes to the OAP over the years, I expect this one will evolve in coming months and years. The OAP will need to further recognize that children with autism require different intensities of service. And then there's the financial reality that while the Ford Government has increased funding, it is likely not enough to deal with the rapidly-increasing demand.

Changes to our current program will not happen overnight. We have been told 2019-2020 will be a phase-in year – although we do not yet have the details of what that means or how it will work. We have been advocating to the Ministry for high-quality, evidence-based autism services. We are expecting to meet soon with the MCCSS Regional Office to understand what is next for CHEO in particular.

I want to personally thank you for your strong partnership. We will consult with families as we work to figure this all out, and the Autism Family Advisory Committee will have an invaluable role in helping us to do that effectively.

At CHEO, we support children and youth with autism right across our entire organization. To that end, I know CHEO has a unique offering for families. But it's not about us. All the more reason we need to gather input from families about how to reshape our program in the current environment.

Sincerely,



Alex Munter

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