

24 April, 2019

Dear CHEO Autism Program families and staff,

For many families, it feels a bit like the world got tipped upside down since the new Ontario Autism Program (OAP) was announced and there's been non-stop raging debate from all sides. At CHEO, we've been engaging with families and the government about the OAP for years, now more than ever before, and I want to share our next steps with you.

At the core of it, it's clear that everyone wants what's best for children and youth with autism.

Like almost all parents, those with autistic kids love their children and will do anything and everything for them. Unlike most parents though, parents of kids with developmental disabilities confront a world that is not designed for their children. They are forced to relentlessly advocate for resources their kids need to be able to live their best life. I have so much admiration and respect for these families.

Minister Lisa MacLeod is right to try to fix a program that was serving far too few of the families that need it. We would not likely be having this conversation if she had inherited a well-functioning, financially-sustainable program with which families were satisfied. The OAP has been in disarray, failing to help the majority of families and frustrating providers for many, many years. 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, when and to which child.

By mid-2018, our region's waitlist was growing at the rate of 65 kids per month. Families had been promised a choice of public or private provider when a child got to the top of the list but there wasn't any mechanism in place to make that happen. So they continued to wait. It took about 90 days for the old OAP to run out of money last year. These are the problems that needed to be fixed. Families were very frustrated and I can assure you providers were too.

My own view is that evidence-based therapies for children and youth with disabilities like autism should be part of our universal healthcare system like treatment for any other condition. When there are resource limitations – as there are in every single health and social services system around the globe – access should be triaged on the basis of need and acuity.

But the reality is that no Ontario government has ever taken this approach to autism services – Liberal, NDP or Progressive Conservative. And for years, many autism advocates have called for a direct-funding model instead.

The government has announced there will be consultation on key aspects of the new program, including the important question of how to help kids who need a greater intensity of service and how to connect behavioural services for autistic kids with health care, social services and education more broadly. CHEO has been advocating for this for years and will continue to do so.

In the meantime, [the new OAP is starting to roll out](#) and will mark a departure from how CHEO usually delivers care.

We are in a transition period right now. Kids currently receiving autism services under the OAP have been extended through to summer and fall. Those coming off the waitlist will soon start receiving payments from the government, which they can use to purchase autism services. By April 1, 2020, the Ministry's goal is for all children to obtain service in this way.

So, for the first time at CHEO, we've had to develop [a fee schedule for clinical services](#) and will be offering a variety of programs to those who have received direct funding from the government or who opt to pay out of their own pocket. We are not trying to make money, this is about covering our costs so we can maintain these crucial services. We will trial our approach through spring and summer to see how we can best serve families and ensure the broadest possible access. Charging for services raises clinical, ethical and financial issues and we look forward to the guidance of our community as we work through those. We've also never done this before. So we'll probably make some mistakes and not get it entirely right on first attempt. We ask for your patience as we learn to work in this new way.

We also expect that, by fall, the OAP will be different than it is right now. These next few months give us a chance to try out this new way of delivering service and we will make every effort to make it work.

Here's why. Autistic kids are part of every single program at CHEO – whether it's our specialized dental clinic, our development and rehabilitation program or mental health counselling. They come to our Emergency Department, are seen in our clinics and sometimes need to be hospitalized. We want to connect our services and work together as a team of 3,000 child health professionals to help autistic kids live their best life. Key to all of that: the behavioural interventions in the OAP, they are a crucial part of the comprehensive care we offer.

I would like to express my gratitude to CHEO's dedicated, hard-working Autism Program staff. They have faced more change more frequently than any other part of CHEO over the past several years. Despite uncertainty about the future, they have

demonstrated character, professionalism and dedication, focusing on what matters most: kids and families.

I have learned so much from parents who have children with autism. In fact, one of my very first family meetings after joining CHEO in 2011 was about their frustration with the OAP. These extraordinary families have been saddled with such a dysfunctional service system for years so they have developed considerable expertise. They deserve to be respected, listened to and we look forward to working with them to co-design our future services.

The government has promised to listen to them too.

No matter what the new OAP will look like or which provider you choose, kids with autism are counting on all of us to work better together. Let's get it right, finally.

A handwritten signature in blue ink that reads "Alex Munter". The signature is written in a cursive, flowing style.

Alex Munter  
President and CEO, CHEO