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# 'WE NEED THE DELIVERY OF CORE SERVICES,' AUTISM ADVOCATES SAY

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'We need the delivery of core services,' autism advocates say

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Autism advocates say that while peer mentoring, workshops and coaching sessions announced by the province on Tuesday could help some families, what they really need is the roll out of therapy services for their children.

"What's really difficult is to appreciate the small things that are being given to us when what we've been asking for from the start, and have been very very clear about, is the delivery of core

services," said **Kerry Monaghan**, an Ottawa mother of two children with autism, referring to Applied Behaviour Analysis, occupational and speech therapies.

"We've been promised needs-based therapy with core services, that is the news that we want and until then everything else is going to be lacklustre, because when families are in crisis ... they need reprieve, they need clinicians and professionals involved in their lives in order to achieve real-time relevant goals for their kids in a timely fashion," she said.

Minister of Children, Community and Social Services **Todd Smith** said through a press release on Tuesday that the first phase of "foundational family services" would start Aug. 7. This would include services like family and peer mentoring, caregiver workshops and coaching sessions, and "will be tailored to the unique regional and cultural needs in different communities."

"For example, families may participate in an online group workshop to learn strategies to help toilet train their child and then receive one-on-one clinical follow-up afterward, or they may access coaching sessions to help with managing challenging behaviours," the government added. "The services are based on a family's changing needs over time and their child's needs, strengths and developmental stage."

In December, Smith **outlined** "foundational family services" as one of four main pillars of a new autism program along with core services, early intervention and school readiness services and urgent and complex needs services.

The foundational family services will be free to families and will be hosted through individual, group, virtual and in-person sessions, but the government said the first phase would build on virtual sessions that have been used during COVID-19 and that service providers would expand this to in-person supports depending on safety and public health requirements.

The government said anyone registered in the Ontario Autism Program, including those who fall under an existing behaviour plan or those on the wait-list, can access foundational family services, and that a family can register for multiple services.

"As great as it is in an isolated way to look at foundational services being offered and the program moving forward, we have to look at this big picture," said Monaghan, adding that for many children with autism "every second counts."

"We've been very clear about the need for urgency ... this is a snail's pace," she said. "We need the delivery of core services."

Monaghan said these services are part of a larger program that needs to have core services at its centre.

"They need to start with the body and move outwards, you can't start with the appendages and then hope it comes together, it's not going to be enough in the interim," she said. "Our kids don't have that luxury of time."

Parents of children with autism have pointed to the COVID-19 pandemic, which temporarily halted therapy services for many children leading to regression in some, as another reason for the quick implementation of core services.

"We're sick of waiting, I want to see a program," said **Talitha LeBlanc**, another Ottawa mother of two children with autism – one still under a therapy contract from the previous government and the other with "childhood budget" funding.

While the government had initially planned to implement its new autism program by April 2020, Smith said in December that "reaching full implementation will take us into 2021."

**Laura Kirby-McIntosh**, president of the Ontario Autism Coalition, noted that foundational family services were among the recommendations that the autism advisory panel, which she was part of, made to the government. And while workshops and training programs are helpful for parents, especially those who have received a recent diagnosis for their child, she said the issue is that the whole rollout has been delayed.

"The promise was to have the whole program up and running by April 2020, and here we are in August and we just have only one piece and it's the smallest and the easiest piece," she said. "It's disappointing our families just continue to wait and wait and wait and we have no indication of when any other part of the program or the most important part, which is core services, are going to be available."

Monaghan said many families are experiencing the loss of one-to-one supports right now.

"The message that's being sent via foundational services is this is more work for you; sure it's a support, it's not going to carry any of the load for you," she said. "Parents are not therapists, so this in a lot of ways is downloading more responsibility onto parents when really we need to give up a little bit of that, we need someone to step in and physically help us."

But **Jason Warga**, director of services and supports for Kerry's Place Autism Services, said the feedback the centre has received from families regarding foundational family services during the past 24 hours has been "quite positive."

"We've had many families ask how quickly they can take part in the services and are there opportunities for them to register for a number of them at the same time," said Warga, noting however that he doesn't see the foundational family offerings as a replacement for other services.

"I think it's fair to say that every family is unique, every child, youth and adult that we support is unique, and every family is looking for a slightly different series or menu of services and supports," he said.

Warga said Kerry's Place was already offering various programs that would fall under foundational family services like parent support groups.

"We just had to identify which services would fall under these buckets so families registered with the Ontario Autism Program could continue to access those free of charge," he said, adding that they will be adding some new offerings related to preparing families for participating in virtual services, "the notion of physical distancing, tolerating others wearing and being asked to wear different forms of (personal protective equipment)."

He said the centre will be updating its website in the coming days to show the services it is providing under foundational family services and will be ramping up its existing programs over the next several weeks.

Warga said the existing funding to the centre from the government "is sufficient for what we're intending to do."

CHEO, a pediatric hospital and research centre that also offers autism services, has also been providing foundational family supports.

"CHEO has been providing virtual family foundational services at no cost since the beginning of Covid 19," wrote spokesperson **Paddy Moore** in an email. "Before COVID-19, we have had other iterations of free, in-person foundational services that we have offered families, going back to before the Wynne government."

He said the hospital has expanded its offerings and will continue to do so.

Asked whether the government was providing any additional funding to service providers for offering foundational family services and about previous access to such services, ministry spokesperson **Trell Huether** said "service providers may have previously offered services similar to foundational family services on a fee-for-service basis."

"The new foundational family services include a diverse selection of evidence-informed services delivered by a range of professionals that families can access throughout their OAP service journey at no cost," said Huether.

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