New program targets toddlers showing symptoms of autism

Parents learn tools to help build communication while awaiting diagnosis or therapy

By: Andrea Gordon Feature Writer, Published on Mon Mar 28 2016

The breakthrough came quietly, during story time.

Ting Chan watched as the trainer for a new autism therapy read to her 3-year-old son during a home visit. Tristan, diagnosed with the neurodevelopmental disorder a year earlier, usually had a different agenda.

But that day on the couch, “he was listening, he was looking at the pictures and following as she read,” recalls the Toronto mother. “I realized this is what she means by getting him to attend to what’s going on. This is the difference.”

It’s the kind of moment taken for granted by most parents. But for Chan, it was a sign of hope after months of uncertainty awaiting an assessment and diagnosis for Tristan, only to be told that he didn’t qualify for intensive autism therapy funded by the province.
It happened thanks to a pediatrician’s referral that got mother and son into a clinical trial for a new intervention called Social ABCs at Holland Bloorview Kids Rehabilitation Hospital in Toronto.

Social ABCs is one of four publicly-funded initiatives the province is expected to announce this week to help babies and toddlers who show signs of autism. It’s also the only one developed in Canada.

“I feel very lucky,” Chan said recently as Tristan, now a 5-year-old kindergarten student at a local public school, leaped into the ball pit in the Holland Bloorview playroom.

In Ontario, there are few options for parents when they suspect autism in a young child, unless they can afford thousands of dollars a year for private therapy.

Evidence is clear that the earlier the treatment, the better the results. Yet wait times for intensive behavioural intervention (IBI) covered by the province can be anywhere from one to four years long, depending on the region. Children also face wait lists for the limited speech and language or occupational therapies they are entitled to.

Social ABCs is among the emerging interventions to address symptoms sooner rather than later — in a child’s home while they wait, and delivered by their own parents or caregivers.

Common red flags for autism include inattention, lack of eye contact and not pointing or trying to speak. So over the course of the six-month program, certified trainers teach parents simple tools to make connections with their toddlers, encourage them to use words and build social skills. Helping children communicate also reduces frustration and in turn, disruptive behaviour.

The idea is to use the one-on-one techniques every day — while eating breakfast, playing with Duplo or at the park — and capitalize on whatever captures the child’s attention.

“A key part of Social ABCs is it builds on a child’s motivation because when they’re motivated, there’s more chance of success,” says psychologist Jessica O’Brien, an autism researcher at Holland Bloorview and co-developer of the program, with psychologist and researcher Susan Bryson of IWK Health Centre in Halifax.

You can see how it works as Chan and Tristan sit on the playroom carpet with a bin of plastic alphabet shapes between them. Tristan reaches for one, but before handing it over, his mom waits for him to focus his gaze and say aloud that he wants “the purple B.”

His reward is not only getting what he wants, but the shared connection with his mother in that moment. That prompts him to ask for one after another until he tells her he wants to look at books instead.

Tristan Chan Wymant, 5, learned new language and social skills when he and his mother participated in a new autism intervention called Social ABCs, which teaches parents strategies to use with their kids at home or in the playground.

The pair was among 60 families in the Social ABCs trial for children ages 12 through 30 months. Half received the intervention as soon as they enrolled. Their outcomes over
the period will be compared with the outcomes of the other 30, who functioned as a control group for six months and then had the option to take the treatment. Tristan and Chan were part of the control group.

Results are expected to be published this year. An earlier pilot study published in December in the journal Autism Research reported language gains among the children and an increase in shared positive connections with their parents.

Social ABCs also has promise as a low-cost model that could be rolled out in child care centres and similar settings. In 2014-15, four ECEs at Humber College Child Care were trained by the researchers to test how effectively it could be delivered in a busy childcare setting. Those results are still being assessed.

Two years after finishing the program, Chan still uses the strategies and says Tristan is continuing to gain ground in his language, attention and social interactions. A big moment came last year when she asked him to turn off a light and he actually stopped and flipped the switch.

To what extent he might have developed skills on his own is hard to know. But she's convinced her training made a difference.

“It was hard at first learning that I had to be quiet and wait,” she says. “My role became different. I had to look for opportunities and take his cues instead of always jumping in and leading.”

Parents of toddlers who show signs of autism will soon have options to help them more quickly when the province rolls out four new treatments for children as young as 12 months old.

The interventions, backed by clinical research, are part of an emerging “naturalistic” approach to treating autism that takes place in the child’s own environment while they play and during the normal course of daily life.

A key part of each program is teaching parents strategies they can use immediately and in the future to help their child engage and communicate.

Pilot programs are to operate for three years through four existing agencies or children’s centres. Details are expected to be announced this week by the Ministry of Children and Youth Services.

The news comes at a time when thousands of Ontario children with symptoms of the neurodevelopmental disorder wait months for an assessment and diagnosis, and then years to get a provincially-funded treatment spot.

Research shows that “providing the right early interventions as soon as the first signs of ASD (autism spectrum disorder) emerge in infants and toddlers can have a significant impact on a child’s development,” the ministry wrote last summer in a statement seeking agencies to deliver the new programs.

The new services are aimed at giving more options to parents who want to help their children immediately instead of feeling they have nowhere to turn while stuck on waitlists. They are easier to implement and much less costly than intensive behavioural intervention (IBI) delivered by therapists.

The number of spots available has yet to be disclosed.

Naturalistic models are based on the principles of applied behaviour analysis (ABA), the most common and tested treatment for autism, which uses repetition and positive reinforcement. But these new approaches add a twist. Instead of instructing, parents follow the child’s lead and learn to harness whatever captures the toddler’s attention as a teaching tool.

The four programs include:

**Social ABCs**: Developed and tested in a clinical trial by autism researchers at Holland Bloorview Kids Rehabilitation Hospital in Toronto and IWK Health Centre in Halifax. It is the only Canadian-made model of the four. The six-month program is aimed at children 12 months to 30 months.

**Early Start Denver Model (ESDM)**: Developed and tested at University of California Davis Mind Institute, a leading facility for autism research. While originally
designed for children up to age 5, the three-month program is considered most beneficial for infants and toddlers. Currently available privately from a handful of certified therapists in the GTA.

**ESI-SCERTS (Early Social Interaction/Social Communication, Emotional Regulation, and Transactional Support):** A nine-month program designed by Amy Wetherby, director of the Autism Institute at Florida State University. Most beneficial for children beginning treatment at ages 12 to 24 months.

**JASPER (Joint Attention, Symbolic Play, Engagement and Regulation):** Developed at University of California Los Angeles and tested in eight clinical trials over 15 years involving 500 children from toddlers to age 8. The approach is taught to parents over a period of two to six months.