

Getting quality autism therapy from thousands of miles away

February 25 2020, by Serena Gordon, Healthday Reporter



Mary Crawford and son John Michael

(HealthDay)—By the time he was 7 months old, John Michael Crawford

had been diagnosed with a rare genetic disorder called tuberous sclerosis, associated with a high risk of developmental delays, including autism.

Early intervention programs are believed to help reduce that risk, but these time- and labor-intensive therapies often aren't available in areas of the United States that aren't close to large medical centers.

The Crawfords, from Benton, Ark., live in such an area.

"There are plenty of families who live in places without access to specialists. It's overwhelming when you get the diagnosis, especially when you can't find specialists that can answer questions and teach you," said John Michael's father, Brandon Crawford.

An ongoing trial for a program developed at University of California, Los Angeles seeks to change that with the novel use of technology and developmental intervention therapy for families of children with a high risk of autism that live in rural areas.

Dr. Shafali Jeste, an associate professor at the UCLA Center for Autism Research and Treatment, said, "We're very proficient at making the diagnosis of autism, but families often can't get access to [behavioral interventions](#). But if you can intervene early, you're more likely to change brain development."

Jeste and her research team developed a [telemedicine program](#) to offer these families access to clinical trials of behavioral interventions. The new study uses an intensive behavioral intervention called JASPER (for Joint Attention, Symbolic Play, Engagement and Regulation).

"The intervention targets social and nonverbal communication skills. The intervention is parent-mediated. Parents are taught to deliver some of the key active ingredients of the intervention. We want to make parents part

of the team," Jeste said.

John Michael was enrolled in the study around his first birthday, his father said. The boy and his parents took part in the telemedicine intervention for about two years.

Crawford's wife, Mary, an elementary school teacher, did the behavioral [therapy sessions](#) with their son. Crawford provided the "technical support." He recorded the therapy sessions, and uploaded them to UCLA. Once the sessions were uploaded, they were reviewed by a UCLA therapist who then provided feedback.

"We used play-based strategies and specific toys, like a car. One strategy is to help him reimagine uses of toys. If you have a car and a toy barn, you could show him how to use a toy barn as a garage instead. You use the things you have access to and teach him how to reimagine those things," Crawford said.

Jeste said one aspect of the therapy is to build the skill of "joint attention."

"This is a skill we often take for granted in typically developing children. You might see a bird, point to it and say bird. A typically developing child would likely make eye contact with you and follow your point, but kids with autism struggle with this. They won't make eye contact; they won't follow your point," Jeste explained.

Crawford said that while the strategies in the intervention were pretty straightforward, it was frustrating at times if their son couldn't grasp a concept. He said therapists are better-trained and can adjust their methods faster than parents can.

He said it also felt a bit unnatural to record play sessions at first, but the

[family](#) got used to it.

And, it was great to be able to fit the therapy sessions into their lives rather than have to schedule everything else around a therapist's schedule. He said they even did a therapy session on their vacation.

"Our vacation would have been a session we would have had to skip. This made things easier," Crawford said.

John Michael has aged out of the trial now, but shows no signs of having an autism spectrum disorder now.

"He definitely responded to the strategies. I think it did make a difference. My son is not on the spectrum," Crawford said.

Jeste said the use of telemedicine has enabled the researchers to enroll 30 families of children with tuberous sclerosis in the trial. Without telemedicine, they enrolled just three families in their behavioral [intervention](#) trial, likely because repeat trips to UCLA just wasn't feasible for many families.

"There are many efforts in the [autism research](#) community to deliver more remote delivery models," Jeste said.

Besides including parents in behavioral therapies, telemedicine could be used to bring in other remote providers, like a pediatrician, and train them how to deliver these types of [therapy](#), she noted.

"We need to continue to innovate and develop strategies to improve access to clinical care and research for children and families with neurodevelopmental disabilities," Jeste said.

More information: Learn more about early intervention for autism

from the [U.S. National Institute of Child Health and Human Development](#).

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Citation: Getting quality autism therapy from thousands of miles away (2020, February 25)
retrieved 27 April 2024 from

<https://medicalxpress.com/news/2020-02-quality-autism-therapy-thousands-miles.html>

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