

New technology accelerates autism diagnosis and treatment

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According to the Centers for Disease Control and Prevention, nearly one in 68 children have some form of autism – a rate that has increased by more than 120 percent since 2002, when the rate was one in 150 children.

Such a sharp rise might lead to assumptions that the process of diagnosing [autism](#) is a relatively easy one with few obstacles. That is not the case; many children and families wait months or years before receiving a diagnosis. Because early intervention is key to success for children with autism, delays can have long-term consequences for children, families and communities.

In a demonstration of the University of Virginia's dedication to sustained work on autism, the Board of Visitors recently approved \$6.2 million over three years to support transformative autism research.

In the Curry School of Education, Micah Mazurek, an associate professor and clinical psychologist with expertise in autism, is currently working on a project that uses technology to teach and train community-based primary care providers – rapidly improving early access to high-quality care for autism.

She recently fielded a few questions about her research, which began in 2015, and the results to date.

Q. Why is diagnosing autism a critical and sometimes frustrating process?

A. For children with autism, early intervention is critically important. The earlier we can begin working with a child with autism, the better the outcome. Beginning intervention as early as possible capitalizes on important developmental windows and maximizes children's learning potential.

These interventions help children with autism learn the skills they need to communicate, interact with others and manage their behavior. Unfortunately, many children are not able to access these interventions as early as possible because of diagnostic delays.

In many cases, parents are already noticing signs of autism by age 1 and we can make a verifiable diagnosis by the age of 2. Yet the average age of diagnosis is between 4 and 6. This means that we are missing the most important window for intervention.

One of the challenges we are facing is that there are very few health care professionals with training in autism. Autism is a complex disorder and requires specialized training for both diagnosis and treatment. There are large areas of the country, especially rural areas, that do not have access to autism specialists. The growing level of demand, coupled with limited capacity, has resulted in long waitlists at autism centers. Families living in rural areas face even greater barriers and are required to travel long distances to receive autism services. These barriers also mean that many children with autism are not receiving comprehensive health care in their own communities.

My colleague, Dr. Kristin Sohl [of the University of Missouri's Thompson Center for Autism and Neurodevelopmental Disorders], and I

wanted to find a way to address these barriers so that children with autism and their families would have access to high-quality and comprehensive care as early as possible, no matter where they live.

Q. Can you tell us about the idea you had to help reduce the backlog?

A. We were inspired by the work of a physician at the University of New Mexico, Dr. Sanjeev Arora, who designed and developed an innovative virtual training model called "Project ECHO" to train community-based physicians and nurses across the state in effective treatments for hepatitis C. The model dramatically increased access to specialty care in underserved regions.

Our question was, why couldn't we use the same sort of model to improve access to care for autism? Together with colleagues at the University of Missouri, we developed and tested a new "ECHO Autism" program to train community-based doctors and nurses in best-practice care for autism.

ECHO Autism connects local primary care providers to an interdisciplinary team of autism experts, using videoconferencing technology. In developing the model, we wanted to ensure that the expert "hub" team was composed of members with essential types of expertise in autism. We ultimately included a pediatrician specializing in autism, a clinical psychologist, a parent of a child with autism, a social worker, a dietitian and a child/adolescent psychiatrist.

Q. Why did you need all of those perspectives?

A. Each team member brought unique and essential sets of expertise to the table. Because we wanted to train primary care providers in both

identification and medical management of autism symptoms, we needed expertise in diagnosis, assessment, medical treatment and care coordination. Best-practice care for children with autism also requires full partnership with families and incorporation of their perspectives, strengths and values. By including a parent expert on our hub team, we were able to incorporate the lived experience of having a child with autism. This enabled us to teach and model family-centered care and to emphasize the value of family voices and expertise.

Q. Once each of those roles were filed, how did you leverage their expertise?

A. During the initial six-month pilot, our expert hub at the University of Missouri connected virtually for two hours every other week with primary care physicians and nurse practitioners located in rural areas using high-quality, multi-point videoconferencing technology. Each session included a brief lecture and two case presentations, during which primary care providers presented, discussed and received recommendations on their own cases. Through collaborative learning and guided practice, participants learned new skills and began to implement best-practice techniques in their own practices.

Q. Were the results of the six-month pilot promising?

A. The results of the pilot study were especially positive. We saw that providers gained confidence in their ability to effectively screen and identify symptoms of autism and to effectively manage common medical and behavioral challenges. We also saw improvements in their use of recommended autism screening tools and resources. These preliminary results suggest that we were successful in building local primary care expertise in autism and indicate that this model may be helpful for reducing barriers to care for children and families.

Q. What comes next?

A. Our research team has now received funding from the Health Resources and Services Administration through the Autism Intervention Research Network on Physical Health to test the effectiveness of the ECHO Autism model in a large sample, using a more rigorous research design.

In this replication study, we have trained 10 additional expert hub teams in academic medical centers across North America. Each ECHO Autism team will train at least 15 primary care providers.

The reach of this project is especially exciting. In equipping 10 new teams of autism specialists to serve as hubs, we can make an exponential impact in underserved areas by training more than 150 primary care physicians caring for underserved families. The scale of the project also allows us to use a more rigorous research design, including cluster randomization and direct measurement of practice change through chart reviews. This will help us learn whether the model is effective in improving actual care of children with autism.

Q. What constitutes an underserved family?

A. In our project, underserved families are those who are living in federally designated "Health Professional Shortage Areas," or families who face economic, cultural or linguistic barriers to accessing health care (such as low income, homelessness, etc.).

Q. How do you envision the future of this project and what is next for you?

A. We are already testing new ways of extending the scope and reach of

our initial project. For example, we are currently evaluating a more extensive ECHO Autism training model that includes hands-on training and verification of diagnosis for toddlers at high risk for autism.

We also are actively exploring new applications of this model for training others in evidence-based care for autism, including teachers, mental health professionals and other types of health care professionals. By leveraging technology, we are not limited by geographic barriers. This allows us to close the gap between research and real-world practice by spreading knowledge and increasing local capacity for high-quality care in underserved communities.

Provided by University of Virginia

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