

Research reduces barriers for doctors treating children with autism

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While autism specialists are crucial in the diagnosis and treatment of children with autism, primary care providers are very often the first to care for children with autism spectrum disorder.



Two new studies reveal a range of barriers these clinicians face in recognizing and treating <u>autism symptoms</u>, as well as evidence that an innovative tele-<u>mentoring program</u>—ECHO Autism—helps reduce these barriers.

The research, led by Micah Mazurek, professor and director of the University of Virginia's Supporting Transformative Autism Research initiative, and Kristin Sohl, associate professor of pediatrics at the University of Missouri, offers promising insight into improving care for children with autism, a population that has increased consistently over the last decade. Key findings are reported in in two journal articles published this spring.

"As the prevalence of autism continues to rise, primary care providers are caring for more and more children with autism in their practices," Mazurek said. "These providers are prepared to diagnose and treat an incredibly wide range of medical issues, yet they receive very little formal training about autism."

Mazurek and her colleagues are working to understand how to better support primary care providers in caring for their patients with autism by learning more about providers' perspectives and by using that knowledge to inform new models for training and mentorship. The providers in the study included pediatricians, family medicine physicians, nurse practitioners and physician assistants.

According to the article published in the *Journal of Pediatrics*, the most common barriers reported by primary care providers related to a lack of knowledge and confidence in providing effective care and resources for children with autism. In fact, 85% of PCPs in the study identified a lack of confidence in managing behavior as a significant barrier to caring for children with autism, and 81% reported limited knowledge about autism resources.



"PCPs in our study reported a strong desire for more knowledge and training on autism, and a dedication to improving their ability to provide best-practice care for these children," Mazurek said.

According to Mazurek, there are not enough autism specialists to meet the needs of most communities. Families seeking access to autism specialists can face months-long waitlists and hundred-mile drives. In fact, 64% of PCPs in the study reported a lack of access to autism specialists as a barrier.

"There is a huge need for improved access to evidence-based care for children with autism across the U.S., especially in more rural and underserved communities," Mazurek said. "These findings highlight the importance of equipping primary care providers with the knowledge and tools they need to provide best-practice care for autism in their own practices and communities."

In the largest and most rigorous study of its kind, Mazurek and her colleagues tested a new model for addressing these needs. In the first large-scale, randomized trial of the tele-mentoring program, ECHO, the research team found the program can effectively equip PCPs with increased knowledge and confidence and reduce barriers to caring for patients with autism.

The Extension for Community Health Outcomes, or ECHO, model was created by Dr. Sanjeev Arora, a physician at the University of New Mexico. The model was originally designed to train community-based physicians and nurses in effective treatments for hepatitis C.

"We were inspired by the way this model leverages technology to equip local providers with the skills they need to care for complex conditions," Mazurek said. "We have been using the ECHO framework to train community-based doctors and nurses in best-practice care for autism



since 2015. With funding from the Health Resources and Services Administration of the U.S. Department of Health and Human Services, we were able to conduct the first large-scale study of the effectiveness this innovative model."

Published in *JAMA Pediatrics*, the world's top pediatric journal, the second paper included 10 ECHO Autism teams at academic medical centers in the U.S. and Canada, who trained a total of 148 PCPs in underserved areas. Through the ECHO Autism program, PCPs connected by videoconference with a team of autism experts, including a physician specializing in autism, a psychologist, a dietician, a parent and an autism resource specialist. The six-month program included 12 two-hour sessions with the interdisciplinary team that included lectures, case presentations, guided practice and discussion.

The researchers found that after participation in the ECHO Autism program, PCPs increased both knowledge and confidence in their ability to provide effective care for children with autism. Providers also reported reduced barriers to caring for children with autism in their primary care practices.

"These results are important because they demonstrate that programs like ECHO Autism may be able to reduce barriers to high-quality care for children with autism," Mazurek said.

However, according to Mazurek, these findings are just the beginning.

In March, the UVA team launched an expanded model of ECHO Autism for PCPs as part of a new program called Virginia Autism LINKS, short for "Leading Innovation through Navigation, Knowledge and Supports." This program will engage primary care providers in underserved areas of Virginia using a more comprehensive 12-month series of ECHO Autism sessions, with an expanded focus on screening, care coordination and



early intervention. PCPs also will join other key stakeholders in a larger "virtual learning community" to work together on improving access to coordinated and integrated care for children with autism in their communities.

"We are hoping that programs like this can help equip community providers with the knowledge and resources they need to support <u>children</u> with <u>autism</u> and their families, no matter where they live," Mazurek said.

More information: Micah O. Mazurek et al. Primary Care Providers' Perceived Barriers and Needs for Support in Caring for Children with Autism, *The Journal of Pediatrics* (2020). DOI: 10.1016/j.jpeds.2020.01.014

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