

FSU leads network to help families respond to autism

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(Photo: Joe Rondone/Democrat)

Florida State University researchers have been awarded a five-year, \$10.2 million Autism Centers of Excellence network grant to test a two-part home intervention designed to bridge the gap between diagnosis and treatment.

Their plan is to coach families and empower them with earlier and widespread access to cost-efficient information, education and support.

"We are honored to receive this grant from the National Institutes of Health," said FSU College of Medicine Distinguished Research Professor Amy Wetherby, director of FSU's Autism Institute and the ACTION Network's

lead principal investigator. "It allows us to collaborate with universities across the country and to develop and train a new workforce of individuals in the community who specialize in helping families understand autism. Our goal is to catch autism early and get underserved children ready for regular kindergarten."

The new ACE ACTION Network brings a unique interdisciplinary team with expertise in early detection, maternal mental health, clinical trials, health disparities, implementation science and policy from FSU, the University of Miami, Boston University, the University of Massachusetts Boston, Kaiser Permanente, the Children's Hospital of Philadelphia and the National Black Church Initiative. It is one of four ACE networks announced this month by the National Institute of Child Health & Human Development.

This autism family project aims to:

- Create a nimble, diverse, low-cost workforce of part-time community health workers called family navigators.
- Study a diverse group of families in Florida, Massachusetts and California, including those from low-income, minority and rural communities.
- Compare the individual and combined effects of two evidence-based interventions and use technology to adjust them along the way.
- Devise a system that can be adapted quickly for any community.

"Right now, early intervention providers are usually experts such as behavior specialists or speech pathologists," Wetherby said. "However, there's a shortage of them, resulting in long wait lists. Our approach is: Can we train people who don't have the specialty degree but have experience with the families?"

These family navigators might be home visitors for Early Head Start, part-time preschool workers or active members of a local church. Ideally, the researchers want people who know the community and can help families transition from learning that their child has autism to learning how to teach their child everyday activities for the child's future.

"We want to look at a broad group of individuals who can increase the opportunities for children and their families to have early intervention," said co-investigator Juliann Woods, professor and associate dean of FSU's College of Communication and Information.

Early intervention is the key for autism spectrum disorder, a condition related to brain development that affects social interaction and communication. The younger the child is when diagnosed, the better the brain can respond to treatment.

Even though a diagnosis is possible as young as 18 months, the median age in the U.S. is still 4 to 5 years. For minority, low-income and rural children, it's more like age 6 — when the opportunity to receive intervention early is no longer possible. That's why Wetherby and her team keep searching for more effective, practical and affordable ways to diagnose and treat young children. They think family navigators could be a game-changer.

"We've built an infrastructure to train professionals and families online," Wetherby said. "We'll invite the families, then measure how they are doing. We're conducting this large randomized trial in Florida and Massachusetts, and then based on what we find out, we'll roll out the adapted intervention in California."

FSU's Autism Institute has spent years developing online tools for everyone from health professionals to families. Chief among those tools is Autism Navigator. Some tools are free to the public. Courses are free to professionals in Florida because the Florida Legislature paid for its development.

"Through Autism Navigator we are now offering a How-to Guide for Families," Wetherby said. "This online course will be part of this project. It will help the family navigators give families access to a lot of information and video examples to speed up their learning. The key is to teach the parent how to do this and do so really efficiently."

“We’re very excited to have the opportunity to show we can do this, one community at a time.”

This is the second ACE project for the Autism Institute. FSU also is a partner in a recently renewed ACE center grant that the National Institutes of Health awarded to Emory University. The FSU team is working on one project to provide interventions — as early as six to 12 months — to teach parents to support their child’s early development.

Additional co-investigators on this project include Heather Flynn, associate professor and vice chair for research, College of Medicine; and Elizabeth Slate, the Duncan McLean and Pearl Levine Fairweather Professor, Department of Statistics.

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