

PENN STATE MEDICINE



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pathologists
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pastoral care
financial counselors
social workers
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Breaking the cycle

PARTNERSHIP IN CARE CHANGES THE WORLD OF AUTISM

In the wake of an autism diagnosis—one of the most puzzling of human conditions—a family's journey to create order out of chaos begins.

Researchers estimate that as many as 1 in 110 people currently live with what's now known as autism spectrum disorder, a developmental disability that occurs in young children. For reasons that scientists have yet to determine, the incidence of this condition has been rising for decades.

"In part, our ability to identify and diagnose individuals with autism has improved," says Michael J. Murray, M.D., assistant professor of psychiatry and director of the Division of Autism Studies at Penn State College of Medicine.

"Additionally, the diagnostic criteria have been expanded to include higher functioning individuals," adds Susan Mayes, Ph.D., a professor of psychiatry at the College of Medicine. "In the past, children who would not have been identified as having autism because their symptoms are mild and they are bright are now recognized as being on the spectrum."

Does knowing all this affect treatment? "Yes," Murray says. "The population of people with autism is getting older, so the cooperation of different organizations pooling resources and leveraging expertise will create more meaningful answers and produce better outcomes than if each of us tried to do it alone."

A Meeting of the Minds

The path to comprehensive care may be filled with stumbling blocks. But the first step toward better care was creating Autism Central PA, a partnership between the Department of Psychiatry at Penn State College of Medicine, the Center for Autism and Developmental Disabilities at Philhaven, and The Vista School.

Established in 2008 through a grant from the Bureau of Autism Services, Department of Public Welfare, the project joins together autism experts dedicated to increasing awareness about this disorder—often misinterpreted early on—and spreading the word about community resources, screening, and treatment options available to families throughout the region.

"This collaboration allows us to create an interdisciplinary spirit, where we can really look at the spectrum holistically—from all ages, from all functioning levels and from an evidence-based philosophy," says Kirsten Yurich, M.A., clinical director at The Vista School, a day school that uses a common treatment method called Applied Behavior Analysis to teach children with autism.

A Window of Opportunity

Murray says one of the hallmarks of autism is that social skills deficits are what unify the entire spectrum, and

those deficits can show up as early as the first month of life. "These initial social miscues may lead to many other difficulties in language acquisition, communication, and behavior regulation," he says.

Over and over, researchers have found that when children are identified early, and taught intensively and consistently, they are more likely to make significant progress, and in some cases, move off the spectrum. If that intervention is delayed and provided after age four or five, the progress is not as great, Mayes says.

After more than thirty years of research, Mayes, an expert in the field of autism assessment, hopes the thirty-item questionnaire she developed may help alter the outcome of the disorder for some individuals. Formally referred to as the Checklist for Autism Spectrum Disorder, the test summarizes the thirty most prominent symptoms of autism and is one of the tools autism outreach coordinators now use when making contact with physician practices to promote early screening.

What sets this instrument apart from others is that it's simple, reliable, and can be administered in fifteen minutes, Mayes says. "It's one instrument for the entire spectrum covering ages 1 through 17 and all IQ levels."

Reaching Out

On another front, Philhaven created the Autism Resource Center, an information hub whose staff operate a toll-free number, publish a newsletter, provide educational and training materials to health care providers, educators and families, and link parents to summer camp opportunities in the region.

Over the past year, the three staff members have responded to more than 3,000 telephone and e-mail inquiries. Additionally, they began reaching out to even more people by attending health fairs, support groups, and other local events to share autism information and give talks.

"The lesson learned is that by pooling together appropriate resources, here and throughout the community, we can see real progress," says Michael Fueyo, M.D., director, Center for Autism and Development Disabilities, Philhaven

Hospital, clinical assistant professor of psychiatry, Penn State College of Medicine. "For good care to take place, we must begin with a thoughtful and comprehensive understanding of who the child is diagnostically and what his needs are—and that's a big piece of the puzzle that wasn't in place five years ago in the region."

Finding What Works Best

Autism Central PA's work is focused on trying to provide meaningful, "real world" help for families struggling with autism right now, Murray says. "We want to address some of their challenges and struggles and improve the lives of people and their families who are affected with autism."

In light of that goal, Murray and his colleagues at The Vista School are conducting a pilot study to identify what kind of social skills training would be most effective in teenagers with autism. Set to finish in August, the Multi-Media Social Skills Project is using video modeling to teach twenty-four teenagers with autism how to make eye contact, start a conversation, and think critically. Then, they practice their newly acquired social skills on age-equivalent peers who do not have autism—all while taking part in a photography class. Its purpose is to determine how the teenagers with autism feel about themselves before and after the intervention and whether or not these learned social skills are sustained outside the classroom.

"We hope this pilot project evolves into a larger study and eventually into an effective intervention in school systems," Murray says. The second part of the project will enroll adults and is set to begin in August.

Looking Forward

Consistent with its mission, the Autism Central PA network is dedicated to spending time with families and individuals affected by autism as well as health care providers and other supporters in an effort to bring state-of-the-art resources to all twenty-four counties in the region.

"Our goal is that this program will increasingly reflect a broader and more comprehensive approach to care," Fueyo says, "So that over time, it develops into a model of excellence in autism care for the region."

— By Paula Rasich ■

For more information on autism spectrum disorders, call the Autism Resource Center at 877-231-4244 or visit the Web site of Autism Central PA at autismcentralpa.org.

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