

Autism Early Detection Program Expands

Developed at UC San Diego, effort seeks to identify at-risk toddlers by first birthday

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Autism spectrum disorder (ASD) is now estimated to impact one in every 68 children born in the United States. Yet despite its rising prevalence and the known benefits of early detection and treatment, toddlers in much of the United States are routinely not identified as possibly having ASD until well after their third birthday.



Karen Pierce, PhD

“By that time, much precious brain development has already occurred,” said Karen Pierce, PhD, associate professor of neurosciences at the University of California, San Diego School of Medicine and assistant director of the UC San Diego Autism Center of Excellence.

A new 5-year, \$5.1 million grant from the National Institute of Mental Health (NIMH) seeks to remedy that by expanding a program developed by Pierce and colleagues to reduce the mean age of ASD diagnosis in multiple cities across the U.S.

The program, called Get SET Early, is based upon a one-year well-baby check that Pierce first described in a paper published in 2011. In those findings, Pierce and colleagues reported that San Diego toddlers who were systematically assessed for ASD around their first birthday typically began receiving treatment

within a few months, years before children in many other cities.

With NIMH funding, the Get SET Early program expands upon Pierce’s original model, adding new features and technologies, such as an iPad-based automatic referral system.

The improved model consists of three stages: In the Screening stage, a network of pediatricians conduct repeat evaluations of toddlers at multiple ages – 12, 18 and 24 months – using

standardized testing and scoring. "Since the symptoms of autism can come on slowly between 12 and 24 months, if we screen three times we are almost guaranteed to detect the overwhelming majority of children with this disorder," Pierce said.

In the second Evaluation stage, toddlers who may have ASD are immediately referred to local clinics that specialize in ASD for more detailed evaluation.

In the final stage, Treatment, toddlers showing clear signs of ASD are referred to an established network of healthcare specialists for rapid treatment. "There is evidence that early therapy can have a positive impact on the developing brain," Pierce said. "The opportunity to diagnose and thus begin treatment for autism around a child's first birthday has enormous potential to change outcomes for children affected with the disorder."

The Get SET Early program will expand first to Phoenix, which has one of the oldest average ages of ASD detection in the country. A recent survey conducted by the U.S. Centers for Disease Control found that children with autism living in Phoenix were typically not identified until they were almost five years old.

In her 2011 study, published in the *Journal of Pediatrics*, Pierce and colleagues created a network of 137 pediatricians in the San Diego region and asked them to include a brief assessment at the toddlers' traditional one-year health checkup. The assessment consisted of parents or caregivers answering a questionnaire called the Communication and Symbolic Behavior Scales Developmental Profile Infant-Toddler Checklist that queried about a child's use of eye contact, sounds, words, gestures, object recognition and other forms of age-appropriate communication. Any infant who failed the screening was referred to the UC San Diego Autism Center of Excellence for further testing and re-evaluation every six months until age three.

While the NIMH grant will initially test the feasibility of establishing the Get SET Early model in Phoenix, research and testing will also continue in San Diego to assess the efficacy of new improvements, such as repeat triple screenings and Internet-based tracking of referrals and treatment.

"By creating a simple screening, evaluation and treatment initiation and tracking model, we hope to establish national standards so that one day ASD detection and treatment between the first and second birthday will happen for all children," said Pierce.

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