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Autism Diagnoses Buried on Pediatricians' Back Burners

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Explain to concerned parents of young children with apparent developmental delays that autism spectrum disorders range from mild to severe, and can be diagnosed accurately with the use of standardized instruments.

BALTIMORE, May 11 — Autism's full spectrum is not often on the radar screen of primary care pediatricians, and even when doctors are thinking autism a proper diagnosis may take a year or more. Those conclusions came from two studies published in the May 11 supplement to the April issue of the *Journal of Developmental and Behavioral Pediatrics*.

In a study of eight-year-old children from the Atlanta area, CDC researchers found that while the children were initially evaluated at a mean age of four, they were not diagnosed with an autism spectrum disorder until a mean of 5.1 years.

Some children were not evaluated or diagnosed until they were almost nine years old, reported Catherine Rice, Ph.D., and colleagues from the CDC and the Emory Autism Center.

The authors of the study did not investigate reasons for the 13-month delay.

But in a separate study, researchers from Johns Hopkins here reported that primary care pediatricians they surveyed said they were not familiar with the screening instruments used, were reluctant to make the diagnosis themselves and deferred instead to specialists, or simply didn't have the time.

José Cordero, M.D., director of the CDC's National Center on Birth Defects and Developmental Disabilities, said that although the Atlanta survey is based on local data, "it serves as an important indicator of the nationwide challenges of diagnosing autism, particularly more mild cases.

"The real public health challenge is to educate doctors on the signs of autism and to encourage use of standardized diagnostic instruments that better identify symptoms relevant to autism spectrum disorder and help distinguish autism spectrum disorder from other developmental delays or disorder," he said. The CDC researchers drew on data from the Metropolitan Atlanta Developmental Disabilities Surveillance Program 2000, a population-based surveillance program.

They identified 115 eight-year-olds who were diagnosed with an autism spectrum disorder, (autistic disorder, pervasive development disorder not otherwise specified, or Asperger's syndrome). They looked at the earliest age of evaluation and the earliest age of diagnosis and type of initial autism spectrum disorder diagnosis, evaluation sources that documented the first diagnosis, and the characteristics of the professionals who assigned the diagnosis, and the tools they used to reach their conclusions.

"We found that children with autism spectrum disorder identified by the surveillance system were initially evaluated at a mean of 48 months but were not diagnosed with autism spectrum disorder until a mean age of 61 months," the authors wrote. "There were no differences in timing of diagnosis based on sex or racial/ethnic classification, although degree of impairment associated with ASD predicted mean age at first evaluation and mean age at first ASD diagnosis."

They also found that most children (76%) were identified as having an autism spectrum disorder in hospitals and clinics, although 24% of the children did not receive a documented diagnosis until they started school, at which time their developmental status was called into question.

Although children with more severe symptoms of autism were evaluated and diagnosed nearly two years earlier than those with mild symptoms, the average age of first evaluation for this subgroup was 3.5 years, and the average age at diagnosis of a severe disorder was 4.5 years. Yet research has shown that most parents of children with an autism spectrum disorder reported concern about their children's development before the children turn two years.

The researchers also found that among the healthcare professionals who made the first diagnosis of an autism spectrum disorder, 70% did not use a standardized diagnostic instrument when they made the call.

The Johns Hopkins researchers, led by Susan dosReis, Ph.D., of the division of child and adolescent psychiatry, surveyed primary care pediatricians in Delaware and Maryland.

They found that among 255 eligible respondents, 82% said they routinely screened for general developmental delays, but only 8% screened for an autism spectrum disorder.

"The main reasons reported for not screening for autism spectrum disorders were lack of familiarity with tools (62%), referred to a specialist (47%), or not enough time (32%)," Dr. dosReis and colleagues wrote. "Most specialist referrals (77%) were to a developmental pediatrician," the Johns Hopkins researchers added. "Most pediatricians (71%) believed that autism spectrum disorder prevalence has increased, and nearly all attributed this to changes in diagnostic criteria and treatment."

The CDC and the American Academy of Pediatrics have a joint campaign called "Learn the Signs/Act Early" that promotes the use of autism spectrum disorder screening tools among general practice pediatricians and other physicians.

Further information is available at (<http://www.firstsigns.org> and <http://www.cdc.gov/ncbddd/autism/actearly/>).

Primary source: Journal of Developmental & Behavioral Pediatrics

Source reference:

Wiggins LD et al. "Examination of the Time Between First Evaluation and First Autism Spectrum Diagnosis in a Population-based Sample." *J Dev Behav Pediatr*. 27(2) Supplement 2:S79-S87, April 2006.

Additional source: Journal of Developmental & Behavioral Pediatrics

Source reference:

dosReis S et al. "Autism Spectrum Disorder Screening and Management Practices Among General Pediatric Providers." *J Dev Behav Pediatr* 27(2) Supplement 2:S88-S94

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