

Healthcare providers' responses to parental concerns can delay diagnosis of autism spectrum disorders

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Children with autism spectrum disorder (ASD) can develop symptoms before 2 years of age and usually can be diagnosed by 3 years of age; early identification of ASD is associated with improved long-term developmental outcomes. In a new study scheduled for publication in *The Journal of Pediatrics*, researchers assessed how healthcare providers respond to parents' concerns about their child's early development, as well as how that response affected the timeliness of ASD diagnosis.

Katharine Zuckerman, MD, MPH, and colleagues from Doernbecher Children's Hospital Oregon Health & Science University and Oregon State University used data from the 2011 Survey of Pathways to Diagnosis and Services, a nationally-representative, parent-reported survey, to examine the experiences of 1,420 [children](#) with ASD and 2,098 comparison children with nonspecific intellectual disability/developmental delay (ID/DD). According to Dr. Zuckerman, "We know that early identification of ASD is beneficial to children and their families. Unfortunately, many families experience long delays between when they first have concerns and when their child gets diagnosed with ASD." So, the authors recorded the child's age when parents first had concerns about development, the child's age at first discussion with a [healthcare provider](#) about the concerns, the provider's response to the concerns, and, in children with ASD, age at diagnosis.

The researchers found that parents first had concerns about ASD at about 2 years of age, compared with ID/DD at about 3 years of age; they discussed these concerns with healthcare providers at an average age of 2.3 years (for ASD) and 3.2 years (for ID/DD). Children with ASD had 14% fewer proactive provider responses to parents' concerns than children with ID/DD,

meaning that providers were less likely to take steps like conducting developmental tests or referring to a specialist. Children with ASD also were more likely to have their provider reassure parents or tell them that their child will "grow out of it." When the researchers compared children whose providers were more passive and reassuring with children whose providers were more proactive, they found that children whose providers were more passive waited longer, as much as 2 years more, to diagnose ASD. Overall, children were not diagnosed with ASD until approximately 5 years of [age](#), almost 3 years after [parents](#) first voiced their concerns to healthcare providers.

Despite evidence suggesting that parental concerns strongly predict developmental issues, including ASD, there continues to be a long delay between initial conversations with a healthcare provider and diagnosis. "This study implies that the behavior of healthcare [providers](#) is likely a very important factor in delayed autism identification," notes Dr. Zuckerman. Providers may need more education and training to address and react to parental concerns, especially for ASD. Care coordination in the primary care setting may be helpful to ensure that children with ASD receive a timely diagnosis and early therapeutic services.

More information: "Parental Concerns, Provider Response, and Timeliness of Autism Spectrum Disorder Diagnosis," by Katharine Elizabeth Zuckerman, MD, MPH, Olivia Jasmine Lindly, MPH, and Brianna Kathleen Sinche, MPH, appears in *The Journal of Pediatrics*, [DOI: 10.1016/j.jpeds.2015.03.007](#)

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