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How many doctors does it take to diagnose an autism spectrum disorder (ASD)? This is a question that many parents continue to ask in response to their frustration with the diagnostic process. For example, a survey of more than 1,200 families in the United Kingdom found that only 8 percent of families received a diagnosis for their children upon their first clinical visit; 40 percent received a diagnosis by the second clinical visit; and 63 percent finally received a firm diagnosis by their third clinical visit. In many instances, parents waited more than 5 years before a diagnosis was confirmed.

A recent survey of parents of school-age children with ASD across five countries (including the US) found an average diagnosis age of 7.5 years for higher functioning ASD such as Asperger syndrome and a consistent concern with the timeliness of identification and frustration with the delay in accessing services. Parents reported visiting, on average, between four and five clinicians en route to an ASD diagnosis. The number of professionals visited did not differ significantly based on child's gender, race, or type of ASD diagnosis. Child diagnostic age was positively correlated with the number of professionals seen during the process of obtaining a diagnosis. In effect, the more professionals that families saw on their journey to a diagnosis, the older he or she was when finally receiving a diagnosis. Despite the fact that the diagnostic age is decreasing, just over 40 percent of parents reported that they were not satisfied with the diagnostic process. In fact, the more professionals that families saw on their journey to a diagnosis, the more negatively parents viewed the experience. Parents were more satisfied with the diagnostic process when they saw fewer professionals to get the diagnosis and when the children received diagnoses at younger ages.

What are the implications? A late diagnosis postpones the timely implementation of intervention services and may contribute to parental distress in coping with an ASD. It is well established that early interventions for children with developmental disabilities are important in increasing cognitive, linguistic, social, and self-help skills. Assisting parents to develop effective management techniques is also likely to avoid or minimize the potential for secondary behavioral and emotional problems. Importantly, because more capable children with ASD are likely to be educated in general education classrooms, delayed recognition of their problems can result in the implementation of ineffective or inappropriate teaching methods that fail to address the core social-communication deficits of ASD. Delays in diagnosis and identification also have wide implications for families. It is now accepted that autism is most likely among the most heritable of all childhood disorders and that for any family with a child with ASD, there is considerable risk that other children in the family may have social, language, or other neurocognitive problems. Family histories of autism or autistic-like behavior or having an older sibling with autism are known risk factors. A delay in identification may result in siblings with the 'broader phenotype' being overlooked and as a result, not receive the help needed to address their problems.

Although further research is necessary to identify what additional factors make the diagnostic experience a negative one for so many families, it is clear that better screening and identification practices are needed. Parents are frequently faced with a slow and frustrating period of uncertainty and worry and find themselves in the position of trying to convince their children's doctors that there is a need for a specialist assessment. Unfortunately, many pediatricians, clinicians, and educators take a “wait-and-watch” approach and may not recognize the early red flags. Several studies that have qualitatively examined parents' views on the diagnostic process have noted a tendency for some physicians to minimize or dismiss parents' concerns about their children's development and, instead, to encourage them to wait for their children to “out grow” their problems. Thus, it is critically important that health care providers be well-informed about autism in both their initial training and continuing education programs. This includes the practice parameter of routine developmental surveillance and screening for children who are at-risk for autism.

Although no two children are alike in terms of their development and behavior, best practice requires that a standardized screening tool be administered at any point when concerns (red flags) about ASD are raised by a parent or teacher or as a result of school observations or questions about developmentally appropriate social, communicative, and play behaviors, or where there is a family history of autism or related disabilities. Parents should also continue to be vigilant and keep an ongoing record of behavior that appears atypical or concerning. This information can be very useful in any future assessments.

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