



Parental Concerns, Provider Response, and Timeliness of Autism Spectrum Disorder Diagnosis

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Objectives To assess differences between child age at first parental concern and age at first parental discussion of concerns with a health care provider among children with autism spectrum disorder (ASD) vs those with intellectual disability/developmental delay (ID/DD), and to assess whether provider response to parental concerns is associated with delays in ASD diagnosis.

Study design Using nationally representative data from the 2011 Survey of Pathways to Diagnosis and Treatment, we compared child age at parent's first developmental concern with age at first discussion of concerns with a provider, and categorized provider response as proactive or reassuring/passive, among 1420 children with ASD and 2098 children with ID/DD. In the children with ASD, we tested the association between provider response type and years of diagnostic delay.

Results Compared with children with ID/DD, children with ASD were younger when parents first had concerns and first discussed those concerns with a provider. Compared with parents of children with ID/DD, parents of children with ASD were less likely to receive proactive responses to their concerns and more likely to receive reassuring/passive responses. Among children with ASD, those with more proactive provider responses to concerns had shorter delays in ASD diagnosis compared with those with passive/reassuring provider responses.

Conclusion Although parents of children with ASD have early concerns, delays in diagnosis are common, particularly when providers' responses are reassuring or passive, highlighting the need for targeted improvements in primary care. (*J Pediatr* 2015;166:1431-9).

Autism spectrum disorder (ASD) is a common neurodevelopmental condition of early childhood associated with atypical social communication and interaction, as well as restricted and repetitive behaviors.¹ ASD affects between 1% and 2% of US children²⁻⁴ and is becoming more prevalent,^{2,3} making early identification an important public health consideration. Early signs of ASD can be recognized by a trained professional before age 2 years,⁵ and early identification is associated with improved long-term developmental and family outcomes.⁶⁻¹⁰ Because the lifetime cost of treating an individual with ASD exceeds \$1 million in the US, efforts to identify promptly and treat ASD symptoms and comorbidities also may affect long-term costs.¹¹⁻¹³ Unfortunately, however, many children with ASD are not diagnosed until school age,¹⁴⁻¹⁷ and poor, minority, and less-severely impaired children are often diagnosed even later.^{15,18-21}

How health care providers elicit and respond to early parent developmental concerns may influence the age at ASD detection. Parents are likely to mention developmental concerns first to pediatric health care providers, who have frequent early contact with families; however, some studies suggest that many providers do not effectively elicit parents' developmental concerns,^{22,23} even when a child is at risk for developmental delay (DD).²² To bolster early identification of ASD and other delays, the American Academy of Pediatrics recommends standardized primary care-based screening for ASD and other developmental problems.^{5,24} Nonetheless, many primary care providers do not follow screening guidelines,²⁵⁻²⁷ and even when they do follow these guidelines, many do not feel comfortable identifying children at risk for ASD.²⁸

In addition, because obtaining an ASD diagnosis typically requires specialty referral,⁵ health care providers may serve as gatekeepers for access to diagnostic and treatment services. Previous research shows that parents experience long delays between initial evaluation and ASD diagnosis,²⁰ and that providers often inappropriately reassure families who need ASD specialty consultation.²⁹ However, to date no studies have examined how provider responses to parental developmental concerns relates to the age at ASD diagnosis.

Furthermore, no studies have examined whether provider responses differ among children with ASD compared with children with other early developmental

AIRR	Adjusted incidence rate ratio
ASD	Autism spectrum disorder
CSHCN	Children with special health care needs
DD	Developmental delay
ID	Intellectual disability
NS-CSHCN	National Survey of Children with Special Health Care Needs

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conditions, such as DD or intellectual disability (ID), which are more common³⁰ and may have similar presenting symptoms.

Therefore, this study aimed to assess, how health care providers responded to parents' early developmental concerns, whether responses differed between children who developed ASD and those with other developmental conditions, and whether the quality of the provider response was associated with timeliness of ASD diagnosis, in a nationally-representative dataset. Our specific research questions were: (1) Did child age at first parental concern and first parental conversation with provider differ among children eventually diagnosed with ASD compared with those diagnosed with DD or ID?; (2) Did provider response to concerns differ among these conditions?; and (3) Among children with ASD, was a more proactive/less reassuring provider response to parental concerns associated with earlier ASD diagnosis?

Methods

Data came from the 2011 Survey of Pathways to Diagnosis and Services ("Pathways Survey"), a nationally representative, parent-reported survey of children ever diagnosed with ASD, ID, and/or DD and who also qualified as children with special health care needs (CSHCN) as assessed by the CSHCN Screener, a non-condition-specific measure.³¹ This study was deemed exempt from review by the Oregon Health & Sciences University Institutional Review Board. The Pathways Survey was a follow-up to the 2009/10 National Survey of CSHCN (NS-CSHCN). The following parents or guardians who completed the NS-CSHCN were recontacted to participate in the Pathways Survey, those who reported that their child was ever diagnosed with ASD, ID, and/or DD; and those whose child was aged 6-17 years in 2011. Of these, 71% were successfully recontacted, and 87% of those recontacted agreed to participate (n = 4032).³² In the survey, a parent or guardian was interviewed about a randomly selected CSHCN with ASD, ID, and/or DD per household.

We compared CSHCN with ASD with CSHCN with ID and/or DD. Children with ASD were defined as CSHCN whose parent reported a medical diagnosis of "autism, Asperger disorder, pervasive developmental disorder, or other autism spectrum disorder"³³ which was present at the time of the NS-CSHCN survey and again when recontacted for the Pathways Survey.³²

Children with ID were defined as CSHCN with a parental report of medical diagnosis of "intellectual disability or mental retardation" present at the time of the NS-CSHCN survey and again when recontacted for the Pathways Survey. Children with DD were defined as CSHCN with a parental report of a diagnosis of "a developmental delay that affects [his/her] ability to learn" present at the time of the NS-CSHCN survey³³ and again when recontacted for the Pathways Survey.³² Children with ID and/or DD were grouped for analytic purposes.

To assess comorbidity between ASD and ID/DD, we analyzed children with ASD overall (regardless of ID/DD comorbidity; called "ASD overall") and subgroups of children with both conditions ("ASD with coexisting ID/DD") and those with ASD without ID/DD ("ASD only"). Children who had ASD, ID, and/or DD in the past but not presently were excluded (12.7%; n = 514).

Measures

We studied 3 time points in a child's diagnostic history. The first time point was age of first parental concerns, defined as the child's age when the parent "first wondered if there might be something not quite right with [the child]'s development." If parental concerns were present since birth, then age was coded as 0 years. Another time point was the age when the parent "first talked with a doctor or health care provider about [his/her] concerns." The third time point, assessed only in children with ASD, was age of ASD diagnosis. This was assessed by asking: "How old was your child when you were first told that [he/she] had autism or autism spectrum disorder [by a health care provider]?"

For all age-related variables that we assessed in the Pathways Survey, parents provided age in years and months up to age 36 months and in years after 36 months. To standardize findings across younger and older age ranges, and because many of the ages and age-related intervals studied spanned the 36-month time point, we rounded down months to whole completed years (eg, 6 months or 11 months = 0 years, 15 months or 23 months = 1 year), so that measures would be comparable across the entire age span.

We also assessed providers' responses to parents' first concerns via yes/no report of 6 provider actions. These actions, which were developed for the Pathways Survey from the Pennsylvania Autism Needs Assessment,³⁴ were classified into two domains. Proactive provider responses included 3 possible actions: "conducting developmental tests"; "making a referral to a specialist; such as a developmental pediatrician, child psychologist, occupational, or speech therapist"; and "discussing concerns with the child's school." Reassuring/passive provider responses also included 3 possible actions: saying "nothing was wrong, the behavior was normal"; that "it was too early to tell if anything was wrong"; or that "the child might 'grow out of it.'" We also enumerated cumulative proactive and reassuring/passive responses to see whether multiple proactive or reassuring/passive responses had an additive effect (Figure).

Because child and family factors could confound the relationships among parent concerns, provider responses, and delays in ASD diagnosis, we measured child and family sociodemographic factors previously associated with differences in health status,³⁵ health care quality and access,³⁶⁻³⁹ or severity of developmental disorders.^{37,40} Child-level covariates included child age, sex, race/ethnicity, presence of functional limitations, and health insurance type. Family-level covariates included US region of residence,

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