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 children[2-4] 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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Funded by the Medical Research Foundation of Oregon. K.Z. was funded by the National Institute of Mental Health (1K23MH095828). The authors declare no conflicts of interest.

http://dx.doi.org/10.1016/j.jpeds.2015.03.007

conditions, such as DD or intellectual disability (ID), which are more common[30] 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 survey[33] 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,

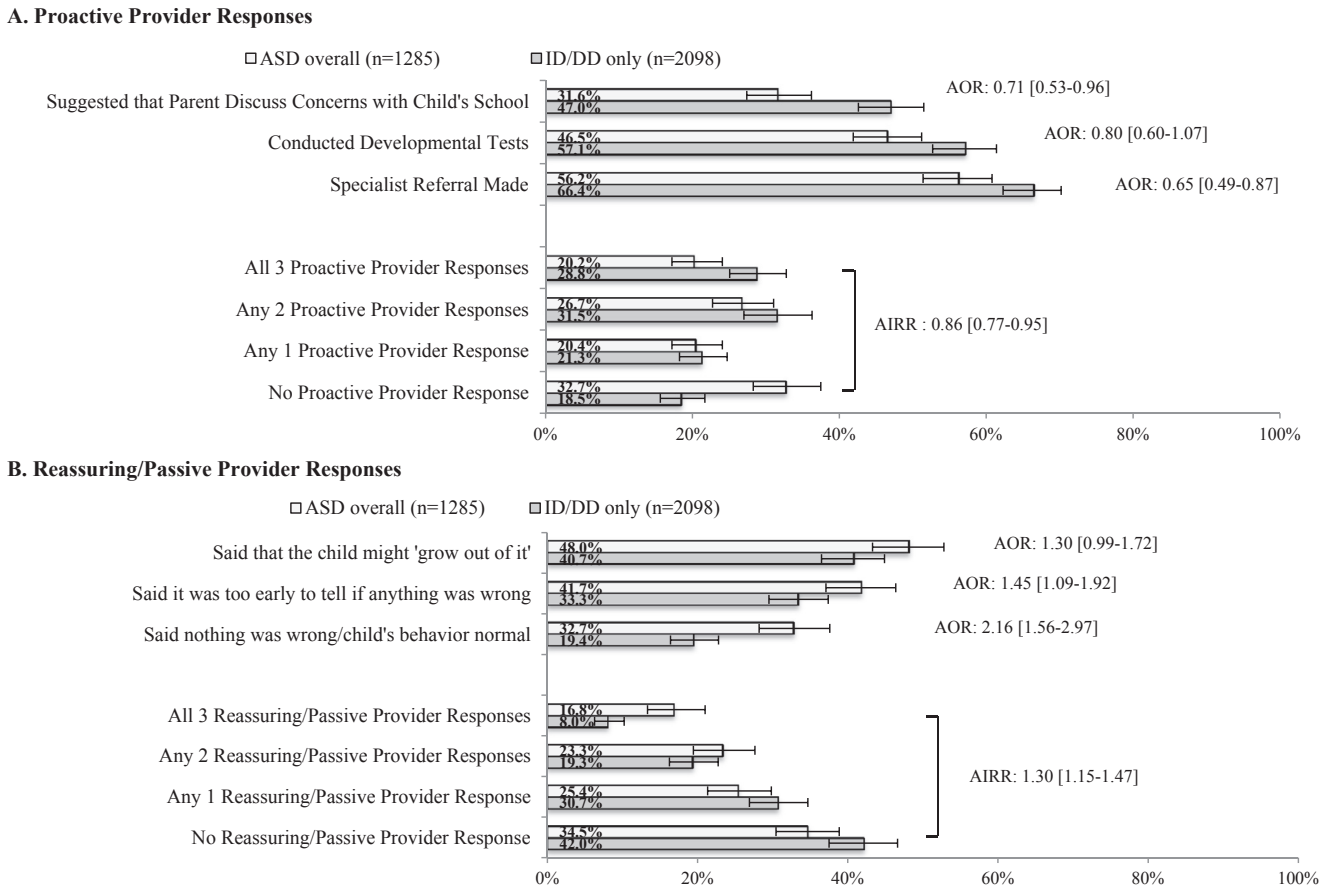

Figure. Weighted proportions, 95% CIs, and aORs of provider responses among US CSHCN aged 6-17 years, by current ASD status. Shown are aORs estimated with multivariable logistic regression, comparing odds of the selected provider response in children with ASD overall and those with ID/DD only. AIRRs, estimated with Poisson regression models, indicate the rate of proactive or reassuring passive provider responses among CSHCN with ASD and those with ID/DD only.

household income, parental educational level, and family structure (Table I).

Data Analyses

Statistical analyses were performed in Stata 13.1 (StataCorp, College Station, Texas). All analyses were adjusted using sampling weights from the NS-CSHCN and the Pathways Survey, which compensate for the probability of being selected for the survey, nonresponse, and incomplete information on ineligibility, among other factors. Weighted results are representative of the US noninstitutionalized population of children aged 6-17 years diagnosed with ASD, ID, and/or DD.[41]

We used descriptive statistics and weighted χ^2 tests to compare sociodemographic characteristics between ASD and ID/DD only, and also among ASD subgroups. We computed mean child age at first parent developmental concerns and mean child age at first parent discussion with a provider, using 2-sample t tests, comparing ASD (both overall and with or without comorbid ID/DD) and ID/DD-only groups. We computed mean age at ASD diagnosis for the ASD groups only (Table II). We then computed two time intervals: (1) time between first parent concerns and first provider conversation (assessed in all groups); and (2) time between first provider conversation and age at ASD diagnosis (assessed in ASD groups only). We used weighted t tests to compare time from concerns to provider conversation in children with ID/DD and children with ASD (with and without comorbid ID/DD) (Table II).

Because ASD can be confidently diagnosed before age 3 years,[5] we created a dichotomous outcome reflecting a diagnostic delay that would be considered long regardless of age: delay between provider conversation and age ≥3 years at ASD diagnosis. We computed the percentage of children with ASD experiencing this delay.

Provider Response to Parent Concerns. We computed the frequency of each proactive and each reassuring/passive provider response in ASD overall and in ID/DD. We then compared proactive and reassuring/passive provider responses in ID/DD to ASD overall using weighted χ^2 tests and multivariable logistic regression. We also compared the

Table I. Sociodemographic characteristics of CSHCN aged 6-17 years, by current ASD, DD, and ID status

Variables	ASD overall (n = 1420)	ASD with coexisting ID/DD (n = 924)	ASD only (n = 496)	ID/DD only (n = 2098)	*P* value ASD overall vs ID/DD only*	*P* value ASD with coexisting ID/DD vs ID/DD only*	*P* value ASD only vs ID/DD only*
Weighted proportion (estimated number of CSHCN aged 6-17 years with current ASD, DD, and/or ID)†	36.2% (653 041)	24.0% (434 000)	12.2% (220 000)	63.8% (1.15 million)			
Child characteristics							
Age, y, %							
6-8 (n = 632)	20.9	19.6	23.6	17.8	.03	.19	.12
9-11 (n = 1089)	33.7	36.0	29.3	30.2			
12-14 (n = 992)	25.6	23.6	29.7	26.5			
15-17 (n = 805)	19.7	20.9	17.3	25.5			
Sex, %							
Male (n = 2436)	82.1	79.0	88.2	62.8	<.001	<.001	<.001
Female (n = 1079)	17.9	21.0	11.8	37.2			
Race/ethnicity, %							
Hispanic (n = 313)	13.0	12.9	13.2	13.5	.05	.06	.06
Black, non-Hispanic (n = 305)	10.7	11.4	9.3	18.5			
Other race, non-Hispanic (n = 358)	10.1	12.5	5.3	8.3			
White, non-Hispanic (n = 2513)	66.2	63.2	72.2	59.7			
Functional limitations, %							
Yes (n = 1994)	64.6	73.0	47.9	51.1	<.001	<.001	.49
No (n = 1524)	35.4	27.0	52.1	48.9			
Health insurance type, %							
Public insurance only (n = 1169)	32.1	37.9	20.9	51.7	<.001	<.001	<.001
Any private insurance (n = 2139)	67.9	62.1	79.1	48.3			
Family characteristics							
Region of residence, %							
West (n = 1014)	20.3	20.2	20.4	21.4	.31	.65	.53
Midwest (n = 810)	24.5	22.1	29.4	24.9			
South (n = 1037)	33.8	36.1	29.4	34.8			
Northeast (n = 657)	21.4	21.6	20.8	18.8			
Household income level, %							
0%-99% FPL (n = 635)	16.9	19.9	11.0	30.9	<.001	.004	<.001
100%-199% FPL (n = 727)	20.5	21.5	18.4	22.1			
200%-399% FPL (n = 1127)	32.7	33.0	32.1	26.5			
≥400% FPL (n = 1029)	29.9	25.6	38.4	20.5			
Highest parental education level, %							
High school or less (n = 699)	23.4	28.2	13.8	51.1	<.001	.02	<.001
More than high school (n = 2819)	76.6	71.8	86.2	48.9			
Family structure, %							
Single mother (n = 677)	22.6	22.0	23.7	30.7	<.001	.003	.02
Other (n = 668)	16.9	17.8	15.1	21.8			
Two-parent biological or adopted (n = 2152)	60.5	60.2	61.2	47.5			

FPL, federal poverty level.
*Omnibus Pearson χ^2 test *P* value considering all groups in the category.
†A total of 3518 CSHCN were reported to currently have ASD, DD, and/or ID during the 2011 Survey of Pathways to Diagnosis and Treatment, representing the noninstitutionalized population of CSHCN aged 6-17 years currently with these 3 conditions. CSHCN who were not reported to currently have any of these 3 conditions (n = 514) were excluded from this analysis.

count and adjusted incidence rate ratio (AIRR) of proactive and reassuring/passive responses for the 2 condition groups, using weighted χ^2 tests and Poisson regression, respectively, with ID/DD as the referent group (**Figure**). Descriptive statistics computed for the proactive and reassuring/passive provider response counts indicated the equidispersion assumption was met. Finally, we compared each of the ASD subgroups (ASD with coexisting ID/DD and ASD only) with ID/DD-only using similar statistical methods (**Table III**; available at www.jpeds.com). Regression models were adjusted for all sociodemographic covariates listed above.

Associations between Provider Response and Diagnostic Delay. In the ASD group only, we tested whether provider response type was associated with diagnostic delay by modeling mean diagnostic delay as well as the dichotomous probability of a ≥3-year diagnostic delay. We used Tobit regression to model mean diagnostic delays according to each provider response, because the sample distribution of diagnostic delays was left-censored at 0 (n = 223), because age values were standardized to years in the entire sample.[42] To fit parsimonious models, we used stepwise regression using backward elimination, in which mean diagnostic delay was regressed on all sociodemographic variables and presence of functional limitations, maintaining variables with coefficients significant at $P < .10$. The variables retained were child age, household income, health insurance type, and region of residence. To assess whether ASD with comorbid ID/DD significantly modified associations between provider response type and diagnostic delay, we

Table II. Diagnostic experiences in CSHCN aged 6-17 years, by current ASD, DD, and ID status

Experiences	Mean (95% CI) time based on child's age in years			
	ASD overall	ASD with coexisting ID/DD	ASD only	ID/DD only
Mean child age, y, of first parent concerns about child's development (n = 3424)*	2.1 (1.9-2.3)	1.9 (1.7-2.2)	2.5 (2.2-2.8)	3.0 (2.6-3.4)
Mean child age, y, of parent's first discussion of concerns with a health care provider (n = 3233)	2.3 (2.2-2.5)	2.0 (1.8-2.2)	3.0 (2.6-3.3)	3.2 (2.9-3.6)
Mean child age, y, when parent was first told the child had ASD (n = 1414)	5.2 (4.9-5.5)	4.8 (4.5-5.1)	6.0 (5.5-6.5)	—
Mean time, y, between first parental concerns about child's development and first discussion of concerns with provider (n = 3158)	0.2 (0.1-0.3)	0.1 (−0.1-0.3)	0.4 (0.2-0.5)	0.3 (0.1-0.4)
Mean time, y, between first discussion of concerns with a provider and age at ASD diagnosis (n = 1282)	2.7 (2.5-3.0)	2.6 (2.3-2.9)	3.0 (2.5-3.5)	—

P values were computed using adjusted Wald tests that compared weighted means between the indicated condition subgroups. — indicates the data are not available.
*Children whose parents indicated that they had concerns about the child's development since birth were coded as having concerns since the child was age 0.

modeled ID/DD status as well as interaction terms between ID/DD status and each provider response, but found them to have no significant effect, and thus eliminated them from the final analyses.

To assess whether provider response type was associated with the probability of a ≥3-year diagnostic delay, we used multivariable logistic regression with the same covariates included in the Tobit regression models. To assess multicollinearity, we calculated variance inflation factors for all models. All variance inflation factors were <10, suggesting that multicollinearity did not substantially bias model estimates.

Results

Of the 4032 CSHCN sampled in the Pathways Survey, 2098 (63.8% of the sample) were identified as having current ID/DD, and 1420 (36.2%) had current ASD. Of those with ASD, 924 (65.1%) had coexisting ID/DD, and 496 (34.9%) had ASD only. Compared with children with ID/DD only, children with ASD overall were more likely to be younger, male, have a higher household income, be privately insured, have more parental education, live in a 2-parent family, and have functional limitations. Among ASD subgroups, compared with children with ID/DD only, children with ASD only had similar rates of functional limitations, whereas those with ASD and coexisting ID/DD had significantly higher rates of functional limitations (Table I).

Initial Concerns and Discussion with Provider

Compared with children with ID/DD only, those with ASD overall had lower ages of initial parental concerns (2.1 vs 3.0 years) and initial discussion of concerns with a provider (2.3 vs 3.2 years). The time between first parental concerns and first discussion of concerns with a provider was similar in the two groups (Table II).

Among the ASD subgroups, children with ASD and coexisting ID/DD had a lower age of first parental concerns (1.9 years) compared with those with ASD only (2.5 years) and those with ID/DD only (3.0 years). Age of discussion with provider was significantly earlier in children with ASD with coexisting ID/DD (2.0 years) compared with those with ID/DD only (3.2 years). The ASD-only group was similar to the ID/DD-only group. Time between first parental concerns and first provider discussion was similar in both ASD subgroups compared with the ID/DD-only group (Table II).

Provider Response to Early Parent Concerns

Bivariate results showed that children with ASD overall were less likely than those with ID/DD only to have each proactive provider response to parent concerns (Figure). They also were significantly less likely than children with ID/DD to have all 3 proactive provider responses. Controlling for covariates, significant differences between the ASD and ID/DD groups persisted for all items except "provider conducted developmental tests," which neared significance (aAOR, 0.80; 95% CI, 0.60-1.07) (Figure). Overall, children with ASD had 14% fewer proactive provider responses than children with ID/DD, after adjusting for covariates (AIRR, 0.86; 95% CI, 0.77-0.95).

Likewise, children with ASD overall were significantly more likely than those with ID/DD only to have each reassuring/passive provider response, and were significantly more likely to have all 3 reassuring/passive responses (Figure). These findings persisted after adjusting for all covariates except "said child might 'grow out of it,'" which neared significance (aOR, 1.30; 95% CI, 0.99-1.72) (Figure). Overall, children with ASD had 30% more reassuring/passive provider responses than children with ID/DD, after controlling for covariates (AIRR, 1.30; 95% CI, 1.15-1.47).

Comparing the ASD subgroups, we found no consistent trend regarding whether provider responses were more proactive in the ASD with coexisting ID/DD group compared with the ASD-only group, and differences between the two groups were slight. Both groups showed trends toward lower rates of proactive provider responses and higher rates of reassuring/passive responses compared with the ID/DD-only group (Table III).

ASD Diagnostic Delays

On average, children with ASD were diagnosed at age 5.2 years. Children with ASD and coexisting ID/DD were

Table IV. Weighted Tobit and logistic regression model results for delay between parent's first conversation with provider and child's initial ASD diagnosis in relationship to provider responses, among all children with ASD

Provider responses	Unadjusted mean years of delay (SE)*	Adjusted mean years of delay (SE)*,†	Weighted proportion with response with ≥3-y delay	aOR of ≥3-y delay (95% CI)†
Proactive provider responses				
Provider conducted developmental tests	−1.3 (0.3)	−1.2 (0.3)	35.8	0.57 (0.38-0.84)
Provider made referral to specialist	−1.6 (0.3)	−1.4 (0.3)	34.4	0.47 (0.31-0.69)
Provider suggested that parent discuss concerns with child's school	−1.3 (0.4)	−1.4 (0.3)	32.0	0.47 (0.30-0.72)
Any 1 proactive provider response	−0.9 (0.4)	−0.8 (0.3)	43.4	0.60 (0.36-0.99)
Any 2 proactive provider responses	−1.6 (0.4)	−1.4 (0.4)	36.8	0.45 (0.26-0.77)
All 3 proactive provider responses	−2.3 (0.4)	−2.2 (0.3)	29.2	0.31 (0.17-0.54)
Reassuring/passive provider responses				
Provider said nothing was wrong/child's behavior was normal	1.4 (0.3)	1.2 (0.3)	54.5	1.79 (1.16-2.77)
Provider said it was too early to tell if anything was wrong	1.1 (0.3)	1.3 (0.3)	49.9	1.66 (1.11-2.47)
Provider said that the child might "grow out of it"	1.3 (0.3)	1.2 (0.3)	53.0	2.02 (1.36-3.01)
Any 1 reassuring/passive provider response	1.7 (0.4)	1.6 (0.4)	50.5	2.44 (1.46-4.07)
Any 2 reassuring/passive provider responses	2.2 (0.4)	2.2 (0.4)	55.3	2.35 (1.39-4.00)
All 3 reassuring/passive provider responses	2.1 (0.4)	2.0 (0.4)	54.2	3.06 (1.63-5.75)

*Partial coefficient P values <.001 for all provider responses in both adjusted and unadjusted models.
†After using a backward stepwise elimination procedure, the following covariates were adjusted for, given their statistically significant partial coefficients at the $P < .10$ level: child age (years), household income level, health insurance type, and region of residence.

diagnosed earlier (4.8 years) than those with ASD only (6.0 years). The mean delay between the first conversation with a provider and diagnosis of ASD was 2.7 years overall, and this did not vary significantly with or without the presence of coexisting ID/DD (Table II). Overall, 44.0% of CSHCN with ASD experienced a ≥3-year delay between first provider conversation and ASD diagnosis.

Relationship of Provider Response to Concerns and Diagnostic Delay

Our bivariate and multivariate analysis results showed that each proactive provider response to parents' concerns was associated with a reduction in the mean delay between first conversation and ASD diagnosis by at least 1 year. Proactive responses appeared to have a cumulative effect, with having more proactive responses associated with greater decreases in mean diagnostic delay. In addition, the odds of a ≥3-year diagnostic delay between first provider conversation and ASD diagnosis were significantly reduced for each proactive response type, and decreased monotonically with the number of proactive responses (Table IV).

Conversely, reassuring/passive provider responses were associated with a ≥1-year increase in the delay between first provider conversation and ASD diagnosis. In addition, having 2 or 3 reassuring/passive responses was associated with longer ASD diagnostic delays compared with having only 1 reassuring/passive response. Likewise, the odds of having a ≥3-year diagnostic delay increased with each reassuring/passive response type, and having all 3 reassuring/passive responses was associated with the highest odds of this delay (Table IV).

Discussion

In this nationally representative sample of children with ASD, we found that despite early parental concerns, ASD diagnosis was delayed by nearly 3 years after the first parental conversation with a provider. In addition, despite evidence suggesting that parental concerns strongly predict child developmental risk both overall and for ASD in particular,[43-45] more than one-half of children with either ASD or ID/DD had passive/reassuring provider responses to parental concerns. Finally, among children with ASD, diagnostic delays were longer when the child's provider had a reassuring/passive response to parental early developmental concerns.

Although the literature suggests that early signs of ASD may be difficult for parents to detect,[5] this analysis shows that compared with parents of children with ID/DD, parents of children with ASD reported concerns earlier and had earlier provider conversations about these concerns, but were more likely than to receive reassuring/passive provider responses to those concerns. This finding suggests that the particular presenting characteristics of ASD may predispose affected children to longer diagnostic delays. Because the longest delay between initial parental concerns and ASD diagnosis occurred after the first provider conversation about parental concerns, the health care system in general and health care providers specifically may play substantial roles in these delays.

Providers may have different reasons for not acting on parents' developmental concerns; for example, they may not elicit these concerns in the first place,[22,23] or may underestimate the importance of concerns that parents raise.[46] Providers also may share parents' concerns but lack screening, referral, or diagnostic resources overall, or may experience significant delays in attempting to access such resources.[28] Although children with ASD were younger than those with ID/DD at the time of initial parental concerns, our analyses controlled for age, and so differential provider responses cannot be solely explained by age differences. However, children with ASD and those with

ID/DD may have differed in content of parental concerns or in provider observations; for instance, some ID/DD-related conditions are apparent at or before birth, allowing providers and parents to enter into early conversations with more information.

A strength of this study is its large, nationally representative sample. The study has several limitations, however. Because the survey assessed children aged 6-17 years, events may have occurred more than 10 years earlier, may be subject to recall bias, and might not reflect current practice. Although parents are generally valid reporters of their child's health care quality and experiences,[47,48] some outcomes may reflect parents' feelings about their child's health care quality overall, rather than specific actions that the provider took or failed to take in response to their concerns. All ID, DD, and ASD diagnoses were parent-reported, so there is no way to assess their validity. Because data were cross-sectional, they do not show any causal relationships among parent concerns, provider response, and diagnostic delays.

Owing to limitations in age reporting in the Pathways Survey (with age recorded in months up to 36 months but in years thereafter), we calculated age in years only. This was the only way to treat the age data consistently, which seemed important as the mean age at ASD diagnosis was >36 months, and many of the diagnostic intervals that we studied spanned the 36-month age time point. Even if age in months had been available for the full age span, it likely would have been unreliable, because many parents of the school-age children in this survey might have had trouble recollecting the exact month of events among children older than 3 years. We recognize that calculating age in years limits the precision of outcomes in this study, and also recognize that there was no way to separate parents who experienced no diagnostic delay from those who experienced very short delays.

Because the study aimed to assess children who ultimately developed chronic conditions, children who did not qualify as CSHCN were not assessed, and children with past but not current ID, DD, or ASD were excluded. ID and DD were analyzed jointly because the conditions present similarly in early childhood, and because the survey contained only 46 children with ID and not DD. Because children with ID or ID/DD likely had more severe symptoms compared with those with DD alone, grouping ID with DD likely biased our findings about age of concerns earlier, or more similar to ASD, suggesting that our findings may underestimate differences. We did not analyze the age of ID/DD diagnosis, because we judged ID/DD-related conditions to be quite heterogeneous in terms of age of presentation. Finally, the sample consisted of parents responding to both the NS-CSHCN and the Pathways Survey and may be subject to nonresponse bias from either survey.[33]

Despite these limitations, however, our data imply that providers' responses to parents' early concerns may be an important contributor to diagnostic delays in ASD, and that children with ASD may be at particular risk of receiving a reassuring or passive response compared with other children with DDs. As a result, providers may need greater education about the validity of early parent developmental concerns in ASD. Payors and policymakers may need to make the next proactive steps more apparent to providers and easier to take. Care coordination in the primary care setting may be particularly important for enabling access to diagnostic and therapeutic services. Programs such as Healthy Steps[49] and the Help Me Grow initiative,[50] which link primary care with community resources, may help providers better identify and refer at-risk children. Incentivizing developmental screening through enhanced payment[51] or requiring it through policy mandate[52] also have been shown to improve screening rates and developmental referrals. Finally, because many children may not be able to access ASD diagnostic services via health care providers, routine developmental evaluation and referral in community[53] or early education settings may be beneficial.

In conclusion, despite early parental concerns, children with ASD receive less proactive provider responses to these concerns than children with ID/DD. Less proactive/more passive provider responses are associated with delays in diagnosing ASD. These findings highlight the need for stakeholders and policyholders to provide more support to front-line healthcare providers, so that children with ASD receive early access to evidence-based care. ■

We acknowledge Benjamin Zablotsky, PhD (Centers for Disease Control and Prevention), for his helpful review of initial findings and drafts of this manuscript. We also acknowledge Julie Robertson, MSW, MPH, and Christina Bethell, PhD, MBA (both, MPH at the Child and Adolescent Health Measurement Initiative), for their assistance with study design and statistical analysis.

Submitted for publication Jun 30, 2014; last revision received Jan 28, 2015; accepted Mar 4, 2015.

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References

1. American Psychological Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington (VA): American Psychiatric Publishing; 2013.
2. Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, Centers for Disease Control and Prevention. Prevalence of autism spectrum disorder among children aged 8 years: Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. MMWR Surveill Summ 2014;63:1-21.
3. Blumberg SJ, Bramlett MD, Kogan M, Schieve LA, Jones JR, Lu MC. Changes in prevalence of parent-reported autism spectrum disorder in school-aged US children: 2007 to 2011-12. National Health Statistics Report 65, March 20, 2013, http://www.cdc.gov/nchs/data/nhsr/nhsr065.pdf. Accessed November 20, 2014.
4. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators, Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders: Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. MMWR Surveill Summ 2012;61:1-19.

5. Johnson CP, Myers SM , American Academy of Pediatrics Council on Children with Disabilities. Identification and evaluation of children with autism spectrum disorders. Pediatrics 2007;120:1183-215.
6. Committee on Children With Disabilities. Technical report: the pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. Pediatrics 2001;107:e85.
7. Landa RJ, Kalb LG. Long-term outcomes of toddlers with autism spectrum disorders exposed to short-term intervention. Pediatrics 2012; 130(Suppl 2):S186-90.
8. Wallace KS, Rogers SJ. Intervening in infancy: implications for autism spectrum disorders. J Child Psychol Psychiatry 2010;51:1300-20.
9. Rogers SJ, Estes A, Lord C, Vismara L, Winter J, Fitzpatrick A, et al. Effects of a brief Early Start Denver Model (ESDM)-based parent intervention on toddlers at risk for autism spectrum disorders: a randomized controlled trial. J Am Acad Child Adolesc Psychiatry 2012;51:1052-65.
10. Kogan MD, Strickland BB, Blumberg SJ, Singh GK, Perrin JM, van Dyck PC. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. Pediatrics 2008;122:e1149-58.
11. Jacobson JW, Mulick JA. System and cost research issues in treatments for people with autistic disorders. J Autism Dev Disord 2000; 30:585-93.
12. Buescher AV, Cidav Z, Knapp M, Mandell DS. Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA Pediatr 2014;168:721-8.
13. Peacock G, Amendah D, Ouyang L, Grosse SD. Autism spectrum disorders and health care expenditures: the effects of co-occurring conditions. J Dev Behav Pediatr 2012;33:2-8.
14. Mandell DS, Morales KH, Xie M, Lawer LJ, Stahmer AC, Marcus SC. Age of diagnosis among Medicaid-enrolled children with autism, 2001-2004. Psychiatr Serv 2010;61:822-9.
15. Mandell DS, Novak MM, Zubritsky CD. Factors associated with age of diagnosis among children with autism spectrum disorders. Pediatrics 2005;116:1480-6.
16. Pinto-Martin J, Levy SE. Early diagnosis of autism spectrum disorders. Curr Treat Options Neurol 2004;6:391-400.
17. Bethell C, Reuland C, Schor E, Abrahms M, Halfon N. Rates of parent-centered developmental screening: disparities and links to services access. Pediatrics 2011;128:146-55.
18. Mandell DS, Wiggins LD, Carpenter LA, Daniels J, DiGuiseppi C, Durkin MS, et al. Racial/ethnic disparities in the identification of children with autism spectrum disorders. Am J Public Health 2009;99: 493-8.
19. Mandell DS, Listerud J, Levy SE, Pinto-Martin JA. Race differences in the age at diagnosis among Medicaid-eligible children with autism. J Am Acad Child Adolesc Psychiatry 2002;41:1447-53.
20. Wiggins LD, Baio J, Rice C. Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. J Dev Behav Pediatr 2006;27:S79-87.
21. Daniels AM, Mandell DS. Explaining differences in age at autism spectrum disorder diagnosis: a critical review. Autism 2013;18: 583-97.
22. Zuckerman KE, Boudreau AA, Lipstein EA, Kuhlthau KA, Perrin JM. Household language, parent developmental concerns, and child risk for developmental disorder. Acad Pediatr 2009;9:97-105.
23. Guerrero AD, Rodriguez MA, Flores G. Disparities in provider elicitation of parents' developmental concerns for US children. Pediatrics 2011;128:901-9.
24. Council on Children With Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. Pediatrics 2006;118:405-20.
25. Radecki L, Sand-Loud N, O'Connor KG, Sharp S, Olson LM. Trends in the use of standardized tools for developmental screening in early childhood: 2002-2009. Pediatrics 2011;128:14-9.
26. Guerrero AD, Garro N, Chang JT, Kuo AA. An update on assessing development in the pediatric office: has anything changed after two policy statements? Acad Pediatr 2010;10:400-4.
27. Daniels AM, Mandell DS. Children's compliance with American Academy of Pediatrics' well-child care visit guidelines and the early detection of autism. J Autism Dev Disord 2013;43:2844-54.
28. Zuckerman KE, Mattox K, Baghaee A, Batbayar O, Donelan K, Bethell C. Pediatrician identification of Latino children at risk for autism spectrum disorder. Pediatrics 2013;132:445-53.
29. Howlin P, Asgharian A. The diagnosis of autism and Asperger syndrome: findings from a survey of 770 families. Dev Med Child Neurol 1999;41: 834-9.
30. Data Resource Center for Child & Adolescent Health. Child and Adolescent Health Measurement Initiative. Exploring health conditions in the 2009/10 NS-CSHCN, http://www.childhealthdata.org/docs/cshcn/conditions-2-pager-final_6-14-12.pdf. Accessed November 20, 2014.
31. Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. Ambul Pediatr 2002;2: 38-48.
32. National Center for Health Statistics. Survey of pathways to diagnosis and services, http://www.cdc.gov/nchs/slaits/spds.htm. Accessed November 20, 2014.
33. National Center for Health Statistics. 2009-10 National Survey of Children with Special Health Care Needs, http://www.cdc.gov/nchs/data/slaits/NS_CSHCN_Questionnaire_09_10.pdf. Accessed November 20, 2014.
34. Autism Services, Education, Resources and Training Collaborative (ASERT). Pennsylvania autism needs assessment: a survey of individuals and families living with autism, http://www.paautism.org/resources/CaregiversorParents/ResourceDetails/tabid/142/language/en-US/Default.aspx?itemid=280. Accessed November 20, 2014.
35. Gadow KD, Devincent C, Schneider J. Predictors of psychiatric symptoms in children with an autism spectrum disorder. J Autism Dev Disord 2008;38:1710-20.
36. Montes G, Halterman JS. White-black disparities in family-centered care among children with autism in the United States: evidence from the NS-CSHCN 2005-2006. Acad Pediatr 2011;11:297-304.
37. King MD, Bearman PS. Socioeconomic status and the increased prevalence of autism in California. Am Sociol Rev 2011;76: 320-46.
38. Fountain C, King MD, Bearman PS. Age of diagnosis for autism: individual and community factors across 10 birth cohorts. J Epidemiol Community Health 2011;65:503-10.
39. Knapp C, Woodworth L, Fernandez-Baca D, Baron-Lee J, Thompson L, Hinojosa M. Factors associated with a patient-centered medical home among children with behavioral health conditions. Matern Child Health J 2013;17:1658-64.
40. Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. J Am Acad Child Adolesc Psychiatry 2008;47:921-9.
41. National Center for Health Statistics. Frequently asked questions: 2011 Survey of Pathways to Diagnosis and Services, http://www.cdc.gov/nchs/data/slaits/PathwaysFAQ.pdf. Accessed November 20, 2014.
42. Long JS. Regression models for categorical and limited dependent variables. Thousand Oaks (CA): Sage; 1997.
43. Glascoe FP. Parents' evaluation of developmental status: how well do parents' concerns identify children with behavioral and emotional problems? Clin Pediatr (Phila) 2003;42:133-8.
44. Ozonoff S, Young GS, Steinfeld MB, Hill MM, Cook I, Hutman T, et al. How early do parent concerns predict later autism diagnosis? J Dev Behav Pediatr 2009;30:367-75.
45. Glascoe FP, Macias MM, Wegner LM, Robertshaw NS. Can a broadband developmental-behavioral screening test identify children likely to have autism spectrum disorder? Clin Pediatr (Phila) 2007;46: 801-5.

46. Bailey DB, Raspa M, Bishop E, Holiday D. No change in the age of diagnosis for fragile X syndrome: findings from a national parent survey. Pediatrics 2009;124:527-33.
47. Garwick AW, Kohrman C, Wolman C, Blum RW. Families' recommendations for improving services for children with chronic conditions. Arch Pediatr Adolesc Med 1998;152:440-8.
48. Homer CJ, Marino B, Cleary PD, Alpert HR, Smith B, Crowley Ganser CM, et al. Quality of care at a children's hospital: the parents' perspective. Arch Pediatr Adolesc Med 1999;153:1123-9.
49. Guyer B, Hughart N, Strobino D, Jones A, Scharfstein D. Assessing the impact of pediatric-based development services on infants, families, and clinicians: challenges to evaluating the Health Steps Program. Pediatrics 2000;105:e33.
50. Children's Trust Fund, a division of the Department of Social Services, State of Connecticut. Help Me Grow, http://www.ct.gov/ctf/cwp/view.asp?a=1786&q=296676. Accessed November 20, 2014.
51. Wegner LM, Macias MM. Services for children and adolescents with autism spectrum disorders: payment issues. Pediatr Ann 2009;38:57-61.
52. Kuhlthau K, Jellinek M, White G, Vancleave J, Simons J, Murphy M. Increases in behavioral health screening in pediatric care for Massachusetts Medicaid patients. Arch Pediatr Adolesc Med 2011;165:660-4.
53. Roux AM, Herrera P, Wold CM, Dunkle MC, Glascoe FP, Shattuck PT. Developmental and autism screening through 2-1-1: reaching underserved families. Am J Prev Med 2012;43:S457-63.

Table III. aORs and AIRRs of proactive or reassuring/passive provider responses by ASD, ID, and DD status

Provider responses	Percentage in category with provider response (95% CI)			aOR or AIRR (95% CI)*		
	ASD with coexisting ID/DD	ASD only	ID/DD only	ASD with coexisting ID/DD	ASD only	ID/DD only
Proactive responses						
Suggested that parent discuss concerns with school	30.1 (25.0-35.7)	35.0 (27.6-43.1)	47.0 (42.7-51.5)	0.69 (0.48-0.98)†	0.77 (0.51-1.17)†	1.00
Conducted developmental tests	49.3 (43.5-55.1)	40.8 (33.3-48.8)	57.1 (52.7-61.4)	0.92 (0.66-01.28)†	0.59 (0.39-0.90)†	1.00
Specialist referral made	57.6 (51.6-63.3)	53.3 (45.2-61.2)	66.4 (62.4-70.2)	0.69 (0.50-0.97)†	0.57 (0.38-0.85)†	1.00
No proactive provider response	31.6 (26.2-37.6)	35.0 (27.6-43.2)	18.5 (15.6-21.7)			
Any 1 proactive provider response	20.6 (16.7-25.1)	20.1 (14.9-26.6)	21.3 (18.2-24.7)	0.88 (0.78-0.98)‡	0.81 (0.69-0.94)‡	1.00
Any 2 proactive provider responses	27.1 (22.4-32.4)	25.8 (19.0-33.9)	31.5 (27.0-36.3)			
All 3 proactive provider responses	20.7 (16.4-25.8)	19.1 (13.9-25.8)	28.8 (25.1-32.8)			
Reassuring/passive responses						
Said the child might "grow out of it"	46.7 (40.9-52.6)	50.7 (42.7-58.7)	40.7 (36.5-44.9)	1.27 (0.93-1.74)†	1.37 (0.93-2.02)†	1.00
Said it was too early to tell if anything was wrong	38.3 (32.8-44.0)	48.8 (40.8-56.9)	33.3 (29.5-37.4)	1.29 (0.94-1.77)†	1.85 (1.25-2.75)†	1.00
Said nothing was wrong/child's behavior normal	31.5 (26.0-37.7)	35.1 (27.7-43.4)	19.4 (16.43-22.8)	2.00 (1.39-2.89)†	2.49 (1.62-3.85)†	1.00
No reassuring/passive provider response	36.5 (31.5-41.9)	30.4 (23.8-38.0)	42.0 (37.5-46.6)			1.00
Any 1 reassuring/passive provider response	26.2 (21.1-32.1)	23.6 (17.9-30.4)	30.7 (26.9-34.7)	1.25 (1.08-1.43)‡	1.41 (1.19-1.66)‡	
Any 2 reassuring/passive provider responses	21.5 (17.0-26.7)	27.0 (20.2-35.2)	19.3 (16.3-22.8)			
All 3 reassuring/passive provider responses	15.8 (11.8-20.9)	19.0 (13.0-27.0)	8.0 (6.3-10.2)			

*All models adjusted for child age, sex, race/ethnicity, household income, insurance type, functional limitations, family structure and highest parental education level.
†aOR from multivariable logistic regression model compares the odds of the selected provider response among CSHCN with ASD + ID/DD or CSHCN + ASD only vs CSHCN with ID/DD only.
‡AIRRs were estimated with Poisson regression models and indicate the rate of proactive or reassuring passive provider responses among CSHCN with ASD + ID/DD or CSHCN with ASD is compared to the rate for CSHCN with ID/DD only.