Parent Concerns, Provider Response to Concerns, and Diagnostic Delay for Children with Autism and Other Developmental Disorders

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Background

- Autism spectrum disorder (ASD) can be identified before children are two years old.

- Early ASD identification is associated with multiple benefits for children and families.
  - Higher child functioning
  - Lower family stress
  - Cost savings

- Still, many children are not diagnosed with ASD until they are school-aged.

Background

- Health care providers have an important role to play in early ASD identification.
- How providers elicit and respond to parent concerns may impact age of ASD detection.
- ASD may be more difficult for parents and providers to identify than other developmental conditions.

Research Objectives

1. Determine if children with ASD differ from children with intellectual disability and/or developmental delay (ID/DD) in terms of:
    - Age of first parent developmental concerns
    - Age of first discussion of parent concerns with a healthcare provider
    - Provider responses to parent concerns

2. Assess if the type of health care provider response to initial parent concerns is associated with delayed ASD diagnosis

Data Source and Sample

- 2011 Survey of Pathways to Diagnosis and Services (Pathways)
- National, probability telephone survey sponsored by the National Institute of Mental Health
- Follow-back survey to the 2009/10 National Survey of Children with Special Health Care Needs
- 1420 children with ASD and 2098 children with ID/DD aged 6-17 years

Age Measures

- First concern: child's age when parent "first wondered if there might be something not quite right with [the child]'s development"

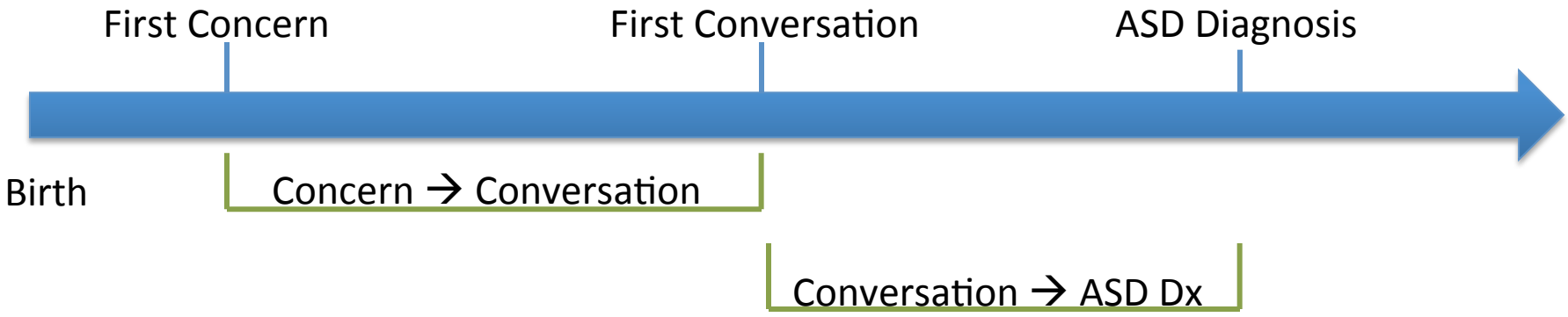
- First conversation: child's age when parent "first talked with a doctor or health care provider about [their] concerns"

- ASD diagnosis: "How old was your child when you were first told [by a health care provider] that [he/she] had autism or autism spectrum disorder?" [ASD only]

Delay Measures

- Delay 1: Time between first concern and first conversation = child's age at first conversation – child's age at first concern

- Delay 2 (Diagnostic Delay): Time between first conversation and ASD diagnosis = child's age at initial ASD diagnosis – child's age at first conversation



Provider Response Measures

"How did that doctor or health care provider respond to your concern?"

- Proactive
  - Conducted developmental tests
  - Made a referral to a specialist
  - Recommended discussing concerns with school
  - Count of proactive responses (range: 0 – 3)
- Reassuring or Passive
  - Said nothing was wrong, child's behavior was normal
  - Said it was too early to tell if anything was wrong
  - Said child might "grow out of it"
  - Count of reassuring/passive responses (range: 0 – 3)

Covariates

- Originally included: child age, gender, race/ethnicity, household income, health insurance status, census region, functional limitation status, highest parent education level, and family structure

- A backwards selection process was used for multivariable models.

- Final multivariable models included:
  - Child age (years)
  - Health insurance status/type
  - Household income level (relative to the federal poverty level in 2011)
  - Census region

Methods: Research Objective 1

- Descriptive statistics

- Two-sample t-tests compared means between children with ASD and children with ID/DD using the following measures:
  - Age of first parent concern
  - Age first discussion of concerns with provider
  - Time between first parent concern and first conversation with provider (Delay 1)

- Adjusted differences in the likelihood and count of provider responses between children with ASD and those with ID/DD assessed with:
  - Multivariable logistic regression models
  - Multivariable Poisson regression models

Methods: Research Objective 2

- Descriptive statistics
- Associations between diagnostic delay and provider responses to parent concerns examined using two analytic approaches:
  - Multivariable logistic regression models
  - Multivariable tobit models
- Plots of residual versus fitted values were obtained to determine gross violations of model assumptions.
- Variance inflation factors were computed to assess bias due to multicollinearity.
  - All mean model VIFs < 2.0
- All analyses were weighted and performed in Stata 13.1.

Sample Characteristics

- Children with ASD = 36.2% of the study sample and represent an estimated 653,041 children

- Children with ID/DD = 63.8% of the study sample and represent an estimated 1,150,000 children

- Relative to children with ID/DD, children with ASD were more likely to be:
  - Male
  - White, non-Hispanic
  - Live in a household with income > federal poverty level
  - Have private health insurance
  - Have two biological or adoptive parents
  - Have a parent with > high school education
  - Have functional limitations

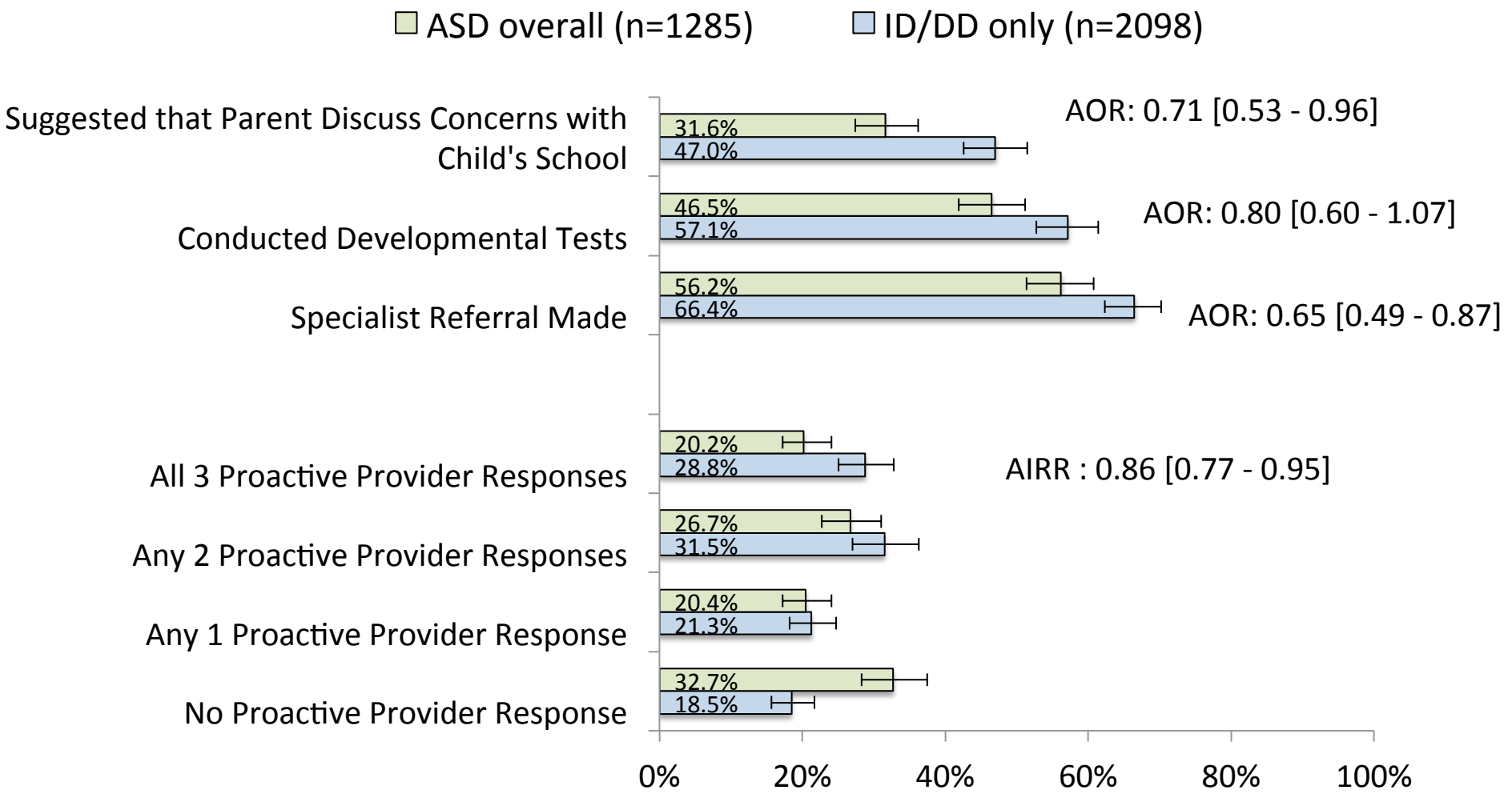
Mean Ages for First Parent Concern and First Discussion with Provider

	Mean Child Age in Years (95% CI)		*P*
	ID/DD	ASD	
First Parent Concern	2.99 (2.63 - 3.35)	2.12 (1.94 - 2.31)	< .001
First Discussion with Provider	3.24 (2.89 - 3.59)	2.33 (2.15 - 2.51)	< .001
Time between First Concern and First Discussion	0.25 (0.12 - 0.38)	0.18 (0.06 - 0.29)	.613

Mean Ages and Diagnostic Delay for Children with ASD

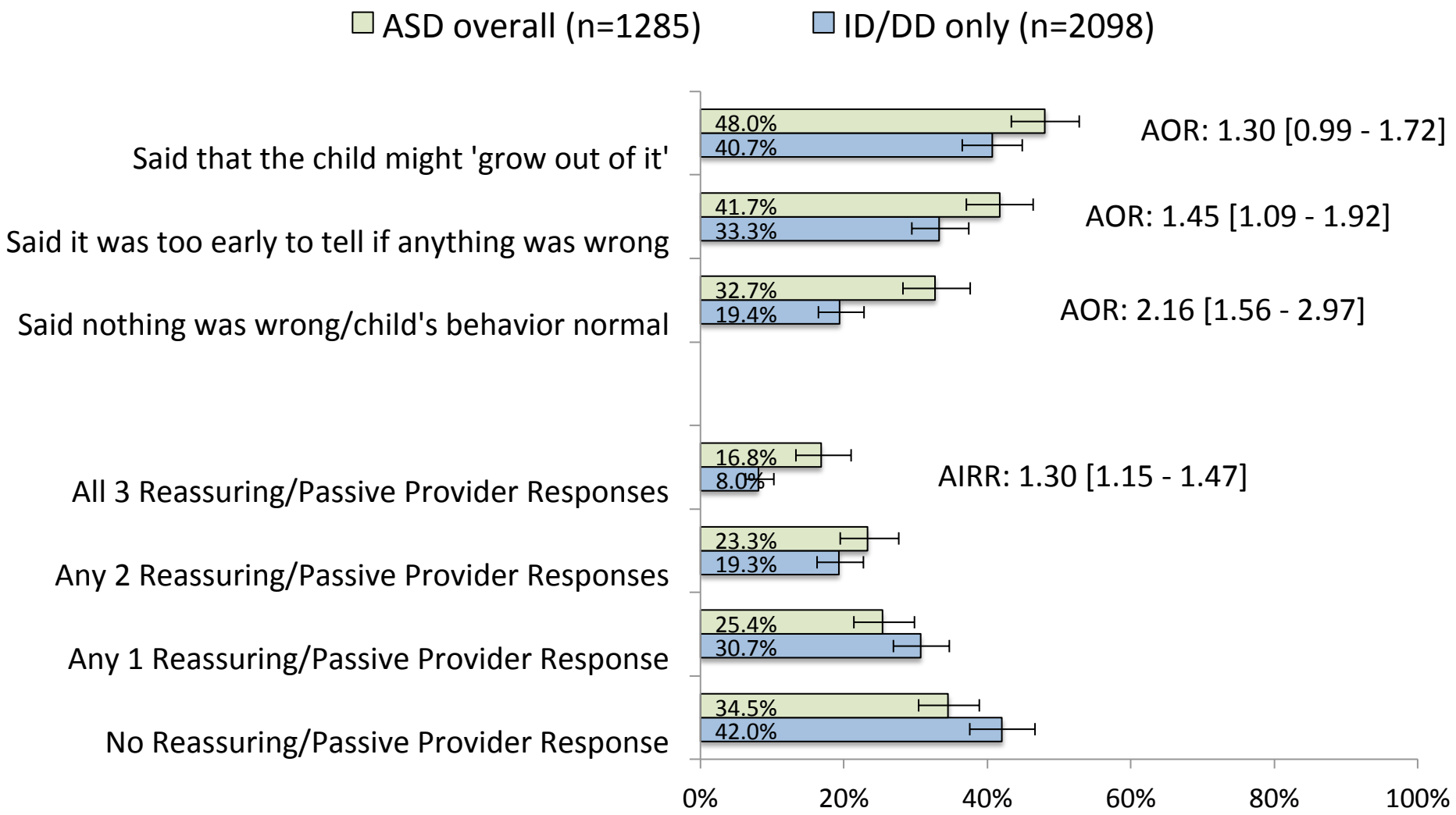
	Mean (95% CI)
Child Age in Years of First Parent Concern	2.12 (1.94 - 2.31)
Child Age in Years of First Discussion with Provider	2.33 (2.15 - 2.51)
Child Age in Years When Parent First Told Child Has ASD	5.18 (4.91 - 5.45)
Time in Years Between Age of First Discussion of Concerns with Provider and Age of ASD diagnosis	2.73 (2.47 - 2.99)

Provider Responses to Parent Concerns: Proactive



Odds ratios and incidence rate ratio adjusted for child age (years), household income level, health insurance type, and region of residence.

Provider Response to Concerns: Passive or Reassuring



Odds ratios and incidence rate ratio adjusted for child age (years), household income level, health insurance type, and region of residence.

Passive/Reassuring Provider Responses and Adjusted Odds of Diagnostic Delay

	Adjusted OR (95% CI) of ≥3 years delay between conversation and ASD diagnosis
Passive/Reassuring Responses	
Said nothing was wrong/child's behavior was normal	1.79 (1.16 - 2.77)
Said too early to tell if anything was wrong	1.66 (1.11 - 2.47)
Said child might 'grow out of it'	2.02 (1.36 – 3.01)

Adjusted for child age (years), household income level, health insurance type, and region of residence.

Passive/Reassuring Provider Response Count and Mean Diagnostic Delay

	Mean ASD Diagnostic Delay in Years Adjusted Coefficients (SE)
Passive/Reassuring Response Count	
Any 1 passive/reassuring response	1.613 (0.378)***
Any 2 passive/reassuring responses	2.167 (0.396)***
All 3 passive/reassuring responses	2.019 (0.405)***

***$P < .001$

Adjusted for child age (years), household income level, health insurance type, and region of residence.

Proactive Provider Responses and Adjusted Odds of Diagnostic Delay

	Adjusted OR (95% CI) of ≥3 years delay between conversation and ASD diagnosis
Proactive Responses	
Conducted Developmental Tests	0.57 (0.38 - 0.84)
Made Referral to Specialist	0.47 (0.31 - 0.69)
Suggested Parent Discuss Concerns with Child's School	0.47 (0.30 - 0.72)

Adjusted for child age (years), household income level, health insurance type, and region of residence.

Proactive Provider Response Count and Mean Diagnostic Delay

	Mean ASD Diagnostic Delay in Years Adjusted Coefficients (SE)
Proactive Response Count	
Any 1 proactive response	−1.188 (0.298)***
Any 2 proactive responses	−1.367 (0.295)***
All 3 proactive responses	−1.437 (0.344)***

***$P < .001$

Adjusted for child age (years), household income level, health insurance type, and region of residence.

Conclusions

- Children with ASD had lower age of initial parent concern and initial discussion with provider than children with ID/DD.
- However, children with ASD were less likely to have a proactive provider response to parent concerns than children with ID/DD.
- Less proactive and more reassuring responses were associated with greater likelihood of diagnostic delay among children with ASD.

Limitations

- Observational study
  - Selection bias
  - Unobserved variables bias
- Measurement error
  - Parent reported data
  - Recall bias: children aged 6-17 years at time of survey
- Precision was lost in the age and delay measures.
- ID/DD groups were combined due to sample size issues.
- Age of ID/DD diagnosis was not examined.

Implications for Practice, Policy, and Future Research

- Encouraging and incentivizing providers to take proactive steps in response to parent concerns may reduce diagnostic delays for children with ASD.

- Understanding other barriers families may encounter accessing diagnostic services is also important in developing future interventions to increase early ASD identification.

Questions or Comments?

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Table 1

	ASD (*n*=1420)	ID/DD (*n*= 2098)	*P*
Weighted Percentage (estimated number of CSHCN age 6-17 years)	36.2% (653,041)	63.8% (1.15 million)	
Age			
6-8 (n=632)	20.9%	17.8%	.03
9-11 (n=1089)	33.7%	30.2%	
12-14 (n= 992)	25.6%	26.5%	
15-17 (n= 805)	19.7%	25.5%	
Sex			
Male (n=2436)	82.1%	62.8%	<.001
Female (n=1079)	17.9%	37.2%	
Race/Ethnicity			
Hispanic (n=313)	13.0%	13.5%	.05
Black, Non-Hispanic (n=305)	10.7%	18.5%	
Other Race, Non-Hispanic (n=358)	10.1%	8.3%	
White, Non-Hispanic (n=2513)	66.2%	59.7%	
Household Income Level			
0%-99% FPL(n=635)	16.9%	30.9%	<.001
100%-199% FPL (n=727)	20.5%	22.1%	
200%-399% FPL (n= 1127)	32.7%	26.5%	
≥400% FPL (n= 1029)	29.9%	20.5%	
Health Insurance Type			
Public Insurance Only (n=1169)	32.1%	51.7%	<.001
Any Private Insurance (n= 2139)	67.9%	48.3%	
Region of Residence			
West (n=1014)	20.3%	21.4%	.31
Midwest (n=810)	24.5%	24.9%	
South (n=1037)	33.8%	34.8%	
Northeast (n=657)	21.4%	18.8%	
Funcional Limitations			
Yes (n=1994)	64.6%	51.1%	<.001
No (n=1524)	35.4%	48.9%	
Highest Parental Education Level			
High school or less (n= 699)	23.4%	51.1%	<.001
>High school (n=2819)	76.6%	48.9%	
Family Structure			
Single mother (n=677)	22.6%	30.7%	<.001
Other (n=668)	16.9%	21.8%	
2 parent biological or adopted (n= 2152)	60.5%	47.5%	

Difference in Ages by Comorbid ID/DD

	ASD overall	ASD+ ID/DD	ASD only
Mean child age in years of first parent concerns about child's development (n= 3424)	2.12 (1.94-2.31)	1.94 (1.72-2.16)	2.50 (2.16-2.83)
Mean child age in years of parent's first discussion of concerns with a health care provider (n= 3233)	2.33 (2.15-2.51)	2.03 (1.84-2.23)	2.95 (2.59-3.30)
Mean child age in years when parent was first told the child had ASD (n=1414)	5.18 (4.91-5.45)	4.77 (4.46-5.07)	6.00 (5.49-6.51)
Mean time in years between first parental concerns about child's development and first discussion of concerns with provider (n=3158)	0.18 (0.06-0.29)	0.10 (-0.06-0.25)	0.35 (0.19-0.50)
Mean time in years between first discussion of concerns with a provider and age of ASD diagnosis (n=1282)	2.73 (2.47- 2.99)	2.60 (2.30-2.91)	3.00 (2.54-3.45)

The Autism Health Care System