

Diagnostic and Health Care Experiences of Children with Past but Not Current Diagnosis of Autism Spectrum Disorder

Stephen J. Blumberg, Ph.D.
sblumberg@cdc.gov



Centers for Disease Control and Prevention
National Center for Health Statistics

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Prevalence of Autism Spectrum Disorder

(Kogan, Blumberg, et al., *Pediatrics*, November 2009)

- **1.1% of children 3-17 years of age**
- Based on data from the 2007 National Survey of Children's Health
 - Random-digit-dial (RDD) telephone survey of parents
 - 91,642 households with children (0-17 years) participated
 - One child randomly selected from each household
 - Survey focused on the health and well-being of children, their families, and their communities
- Consistent with records-based estimates from CDC's Autism and Developmental Delay Monitoring Network



Prevalence of Autism Spectrum Disorder

(Kogan, Blumberg, et al., *Pediatrics*, November 2009)

- Has a doctor or other health care professional ever told you that your child had autism, Asperger disorder, pervasive developmental delay, or other autism spectrum disorder?
- Does your child currently have autism or autism spectrum disorder?



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- Does your child currently have autism or autism spectrum disorder? **1.10%**



Prevalence of Autism Spectrum Disorder

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- Has a doctor or other health care professional ever told you that your child had autism, Asperger disorder, pervasive developmental delay, or other autism spectrum disorder? **1.78%**
- Does your child currently have autism or autism spectrum disorder? **1.10%**



Prevalence of Autism Spectrum Disorder

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- Does your child currently have autism or autism spectrum disorder? **1.10%**
- **38.2% of children ever diagnosed were reported to not currently have autism/ASD**



Possible Explanations (Kogan, et al., 2009)

- Some children diagnosed at young ages may no longer meet diagnostic criteria at later ages.
- Some children might have been suspected of having an ASD based on screening, but the condition was later ruled out and never truly diagnosed.
- Some children with other developmental conditions might have been intentionally misclassified as having an ASD to facilitate receipt of needed services.
- Some parents might erroneously say their child doesn't have the condition because the child no longer receives special education or other autism-specific services for the condition.



Possible Explanations (Kogan, et al., 2009)

Pathways to Diagnosis

- Some children diagnosed at young ages may no longer meet diagnostic criteria at later ages.
- Some children might have been suspected of having an ASD based on screening, but the condition was later ruled out and never truly diagnosed.

Use of Services

- Some children with other developmental conditions might have been intentionally misclassified as having an ASD to facilitate receipt of needed services.
- Some parents might erroneously say their child doesn't have the condition because the child no longer receives special education or other autism-specific services for the condition.



Survey of Pathways to Diagnosis and Services, 2011

- 1,420 school-aged children with current ASD
 - 187 diagnosed with ASD but not currently
 - 32 diagnosed with ASD whose parents did not know about current status
- *Diagnostic status is based on parent report*



Analysis Plan

- Compared CSHCN with ASD to CSHCN with an ASD diagnosis but not current ASD
- Data were weighted to permit nationally representative estimates
- “Not significant” (ns) means $p\text{-value} > .10$



No Demographic Differences

- CSHCN with ASD did not differ from CSHCN with past but not current ASD on:
 - Age, sex, race/ethnicity
 - Household income relative to poverty
 - Housing tenure (own/rent)
 - Metro/non-metro status, region of the US
 - Parent education, marital status
 - Age of mother when child was born
 - Health insurance coverage or type



Types of Concerns When Parent First Wondered if “There Might Be Something Not Quite Right”

	Ever Diagnosed with ASD		p-value
	Current ASD	Not Current	
	<i>Percent</i>		
Verbal communication	76	59	< .05
Nonverbal communication	77	64	.07
Behavioral difficulties	89	87	ns
Learning and understanding	68	65	ns
Motor skills	66	69	ns
Unusual gestures/movement	54	54	ns
Other medical problems	22	29	ns



Diagnostic History

	Ever Diagnosed with ASD		p-value
	Current ASD	Not Current	
	<i>Percent</i>		
Response to initial concerns			
Referral to specialist	56	58	ns
Developmental testing	47	51	ns
Said too early for concern	42	40	ns
Said behavior was normal	33	16	< .05
ASD was first EBD diagnosis	47	55	ns
ASD diagnosed before age 4	36	40	ns

- No significant differences in types of doctors or health care providers who first told parent that child had ASD.



School-Based Therapy Services Received

	Ever Diagnosed with ASD		p-value
	Current ASD	Not Current	
	<i>Percent</i>		
Services <u>ever</u> received			
Speech/language therapy	82	76	ns
Occupational therapy	74	75	ns
Social skills training	71	70	ns
Services <u>currently</u> received			
Speech/language therapy	54	47	ns
Occupational therapy	38	26	ns
Social skills training	50	22	< .01

- No significant differences in whether child currently has an IEP.



Services Ever Received from Non-School-Based Providers

	Ever Diagnosed with ASD		p-value
	Current ASD	Not Current	
	<i>Percent</i>		
Services <u>ever</u> received			
Behavioral intervention	70	61	ns
Cognitive therapy	55	54	ns
Social skills training	49	40	ns
Sensory integration	58	44	< .05
Alternative therapies	33	24	ns
Speech/language therapy	46	36	ns
Occupational therapy	49	32	.10
Physical therapy	30	29	ns



Services Currently Received from Non-School-Based Providers

	Ever Diagnosed with ASD		p-value
	Current ASD	Not Current	
	<i>Percent</i>		
Services <u>currently</u> received			
Behavioral intervention	40	15	< .01
Cognitive therapy	28	17	ns
Social skills training	24	10	< .01
Sensory integration	20	7	< .01
Alternative therapies	17	11	ns
Speech/language therapy	14	3	< .01
Occupational therapy	11	4	< .01
Physical therapy	5	8	ns

Any Services Received

	Ever Diagnosed with ASD		p-value
	Current ASD	Not Current	
	<i>Percent</i>		
Any school-based services			
Ever received	92	90	ns
Currently received	73	64	ns
Difference	19	26	ns
Any non-school-based services			
Ever received	94	97	.09
Currently received	70	56	.05
Difference	24	40	< .05



CSHCN Reported to Have a Past But Not Current ASD Diagnosis

- **As likely as CSHCN with ASD to:**
 - Have ever received various services
- **Less likely than CSHCN with ASD to:**
 - Currently receive social skills training
 - Currently receive non-school-based services to meet their developmental needs
- **More likely than CSHCN with ASD to:**
 - Have stopped using services



Implications

- **If these children currently have ASD:**
 - Parents may be poor proxies when reporting ASD
 - Prevalence of ASD may be higher than estimated
- **If these children do not currently have ASD:**
 - Suggests that many parents (up to 40%) who learn that their children have ASD can expect that their children will someday no longer have ASD



Children's Social Behavior Questionnaire

	Hartman et al. (2006)		
	Controls	HFA	PDD
	<i>Average Scale Scores</i>		
Behaviors/emotions not tuned to the social situation	4.2	12.1	12.4
Reduced social contact and social interest	1.4	10.2	7.8
Orientation problems in time, place, or activity	1.5	7.7	6.4
Difficulty understanding social information	1.9	8.9	6.1
Stereotyped behavior	0.7	5.2	2.9
Fear of / resistance to change	0.6	3.1	2.3



Children's Social Behavior Questionnaire

	Hartman et al. (2006)			Not Current
	Controls	HFA	PDD	
<i>Average Scale Scores</i>				
Behaviors/emotions not tuned to the social situation	4.2	12.1	12.4	10.3
Reduced social contact and social interest	1.4	10.2	7.8	5.9
Orientation problems in time, place, or activity	1.5	7.7	6.4	6.0
Difficulty understanding social information	1.9	8.9	6.1	6.8
Stereotyped behavior	0.7	5.2	2.9	5.7
Fear of / resistance to change	0.6	3.1	2.3	2.5



Children's Social Behavior Questionnaire

	Ever Diagnosed with ASD		p-value
	Current ASD	Not Current	
	<i>Average Scale Scores</i>		
Behaviors/emotions not tuned to the social situation	11.1	10.3	ns
Reduced social contact and social interest	8.9	5.9	< .01
Orientation problems in time, place, or activity	7.4	6.0	< .01
Difficulty understanding social information	8.3	6.8	< .01
Stereotyped behavior	6.7	5.7	ns
Fear of / resistance to change	3.0	2.5	.04



Limitations in Activities

<i>Percent <u>not</u> able to do activity independently</i>	Ever Diagnosed with ASD		p-value
	Current ASD	Not Current	
Age 6-17	<i>Percent</i>		
Go to bathroom	14	4	< .05
Feed self	7	3	< .05
Ask for things s/he wants	22	9	< .05
Age 12-17			
Cook or prepare meals	68	45	.05
Manage money	81	68	.09
Get around by driving, bus, biking, or walking	52	23	< .01



Asperger's Disorder?

- “Did the doctors, health care providers, or school professionals ever tell you that your child had any of the following autism spectrum disorders?”

	<u>Ever Diagnosed with ASD</u>		p-value
	<u>Current ASD</u>	<u>Not Current</u>	
	<i>Percent</i>		
Asperger's disorder	43	23	.04
Pervasive developmental delay	48	33	ns
Autistic disorder	53	25	.01



Summary

- **CSHCN with past but not current diagnosis of ASD are less likely than CSHCN with ASD to:**
 - Have functional limitations
 - Have symptoms typical of pervasive developmental delays
 - Currently receive social skills training and non-school-based services to meet their developmental needs



Contact Info

- Stephen J. Blumberg, Ph.D.
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 2112
Hyattsville, Maryland 20782
SBlumberg@cdc.gov
- Pathways website:
<http://www.cdc.gov/nchs/slait/spds.htm>

