

Prevalence and Trends of Developmental Disabilities among Children in the United States: 2009–2017

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abstract

OBJECTIVES: To study the national prevalence of 10 developmental disabilities in US children aged 3 to 17 years and explore changes over time by associated demographic and socioeconomic characteristics, using the National Health Interview Survey.

METHODS: Data come from the 2009 to 2017 National Health Interview Survey, a nationally representative survey of the civilian noninstitutionalized population. Parents reported physician or other health care professional diagnoses of attention-deficit/hyperactivity disorder; autism spectrum disorder; blindness; cerebral palsy; moderate to profound hearing loss; learning disability; intellectual disability; seizures; stuttering or stammering; and other developmental delays. Weighted percentages for each of the selected developmental disabilities and any developmental disability were calculated and stratified by demographic and socioeconomic characteristics.

RESULTS: From 2009 to 2011 and 2015 to 2017, there were overall significant increases in the prevalence of any developmental disability (16.2%–17.8%, $P < .001$), attention-deficit/hyperactivity disorder (8.5%–9.5%, $P < .01$), autism spectrum disorder (1.1%–2.5%, $P < .001$), and intellectual disability (0.9%–1.2%, $P < .05$), but a significant decrease for any other developmental delay (4.7%–4.1%, $P < .05$). The prevalence of any developmental disability increased among boys, older children, non-Hispanic white and Hispanic children, children with private insurance only, children with birth weight ≥ 2500 g, and children living in urban areas and with less-educated mothers.

CONCLUSIONS: The prevalence of developmental disability among US children aged 3 to 17 years increased between 2009 and 2017. Changes by demographic and socioeconomic subgroups may be related to improvements in awareness and access to health care.



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Dr Zablotzky and Mrs Black conceptualized and designed the initial study and conducted the data analysis; Dr Maenner conceptualized and designed the initial study; Drs Schieve, Bitsko, Blumberg, Kogan, and Boyle and Ms Danielson aided in interpreting the data analysis; and all authors contributed to the initial manuscript, provided critical reviews on all manuscript drafts, and approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

WHAT'S KNOWN ON THIS SUBJECT: Previously, researchers found health disparities in diagnosed developmental disabilities by demographic and socioeconomic characteristics among US children. Changes in awareness, knowledge, health care services access, and improved measurement make it important to continue to monitor prevalence changes in the population.

WHAT THIS STUDY ADDS: With this study, we present new nationally representative data on the prevalence of developmental disability, recent demographic trends, and estimates by urban or rural residence.

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Developmental disabilities are a group of lifelong conditions due to an impairment in physical, learning, language, or behavior areas. Children diagnosed with developmental disabilities typically require services to address behavioral and developmental challenges.¹ Measuring the prevalence of developmental disabilities in the population helps gauge the adequacy of available services and interventions.

Timely data are essential to capturing changes to the prevalence of developmental disabilities and provide an opportunity to address challenges in estimating prevalence, including changing definitions and labeling practices. Up-to-date estimates can also be used to shed light on the role that increased awareness, improved diagnosis, changes in diagnostic criteria, and increased availability of services may play in the measured prevalence of identified developmental disabilities.² They can also be used to provide insight into potential demographic groups who may be underdiagnosed and socioeconomic characteristics that may serve as barriers to receiving a diagnosis, such as living in a rural area without access to specialized health services.^{3,4}

Large national surveys such as the National Health Interview Survey (NHIS) were designed to provide up-to-date population-based estimates of health in the United States. Since 1997, the NHIS has included questions (with minimal changes in question text year to year) on a comprehensive group of 10 developmental disabilities. However, few articles have been published in which authors detail the prevalence for the full set of conditions, and, instead, they focus on one or a small group of these conditions.⁵⁻¹⁰ The most recent NHIS-based estimate on all 10 conditions covered 1997 to 2008,¹¹ examining changes in prevalence over the time period. The prevalence was found to be 13.9% among children ages 3 to 17 for 1997 to 2008.

In this article, we update this estimate of developmental disabilities (using data from the 2009 to 2017 NHIS), with the goal of better understanding the major demographic and socioeconomic characteristics that are related to prevalence, along with an investigation to changes in the prevalence of developmental disabilities during this time period.

METHODS

Data are from the 2009 to 2017 NHIS, conducted by the National Center for Health Statistics (NCHS). NHIS is a nationally representative survey of the civilian noninstitutionalized population.* Households are sampled and selected to be interviewed in person by trained Census Bureau interviewers. Within each household, families are identified and complete a brief questionnaire on selected demographic and broad health measures. Next, one adult and one child are randomly selected to be the subject of a more-detailed health questionnaire. The child interview is conducted with a parent or guardian. Between 2009 and 2017, the family completion rate ranged from 65.7% to 81.6%; among households with children, the completion rate for the child questionnaire ranged from 89.8% to 92.3%, yielding an overall response rate of 60.6% to 74.6%.†

Children aged 3 to 17 years were included in the analytic sample (total 2009–2017 unweighted sample size: $n = 88\,530$). The developmental disabilities questions included in the NHIS child questionnaire are provided in Table 1. Parents were asked whether their child had 10 specific developmental disabilities,

including attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), blindness, cerebral palsy (CP), moderate to profound hearing loss, learning disability (LD), intellectual disability (ID), seizures in the past 12 months, stuttering or stammering in the past 12 months, or any other developmental delay. Children whose parents answered in the affirmative to any of these conditions were classified as having the global “any developmental disability” outcome no matter how many conditions they endorsed their child having. Question wording and format for most developmental disabilities were consistent over the study period; exceptions include ASD, ID, and other developmental delay. The definition of autism was expanded to include “autism spectrum disorder” in 2011 and again in 2014 to include “autism, Asperger’s disorder, pervasive developmental disorder, or autism spectrum disorder.” In 2014, the question on autism also became a specific standalone question, rather than being included in a checklist of conditions to select, and the position of the question was moved within the survey (now coming before the question on any other developmental delay). Up until 2011, ID was ascertained by using the phrase “mental retardation”; in 2011, the item phrasing was changed to “intellectual disability, also known as mental retardation.” This condition has been described as ID throughout, regardless of year.

Selected demographic and socioeconomic characteristics included age, sex, urbanicity of residence (dichotomized as urban or rural‡), race and ethnicity, current

* For more information about the NHIS, please visit https://www.cdc.gov/nchs/nhis/about_nhis.htm.

† For more information about the response rate of the NHIS during this time frame, please visit ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHIS/2017/srvydesc.pdf.

‡ Urban was defined as areas consisting of urbanized areas of 50 000 or more people and urban clusters of 2500 to 49 999 persons; rural was defined as all other areas not included within the urban definition; see <https://www.census.gov/programs-surveys/geography/guidance/geo-areas/urban-rural.html>.

TABLE 1 The NHIS Questions on Developmental Disabilities, 2009–2017

Condition	Survey Question
Attention-deficit/hyperactivity disorder (ADHD)	“Has a doctor or health professional ever told you that [survey child] had attention-deficit/hyperactivity disorder (ADHD) or attention deficit disorder (ADD)?”
Autism spectrum disorder	2009–2010: “Has a doctor or health professional ever told you that [survey child] had autism?” ^a 2011–2013: “Has a doctor or health professional ever told you that [survey child] had autism or autism spectrum disorder?” ^a 2014–2017: “Has a doctor or health professional ever told you that [survey child] had autism, Asperger’s disorder, pervasive developmental disorder, or autism spectrum disorder?”
Blindness	“Is [survey child] blind or unable to see at all?”
Cerebral palsy	“Has a doctor or health professional ever told you that [survey child] had cerebral palsy?” ^a
Intellectual disability	2009–2010: “Has a doctor or health professional ever told you that [survey child] had mental retardation?” 2011–2017: “Has a doctor or health professional ever told you that [survey child] had an intellectual disability, also known as mental retardation?”
Learning disability	“Has a representative from the school or a health professional ever told you that [survey child] has a learning disability?”
Moderate to profound hearing loss	“Which statement best describes [survey child]’s hearing without a hearing aid: Excellent, good, a little trouble hearing, moderate trouble, a lot of trouble, or is [survey child] deaf?” ^b
Other developmental delay	“Has a doctor or health professional ever told you that [survey child] had any other developmental delay?”
Seizures	“During the past 12 months, has [survey child] had seizures?”
Stuttering or stammering	“During the past 12 months, has [survey child] had stuttering or stammering?”

Questions about intellectual disability, blindness, cerebral palsy, hearing loss, intellectual disability, seizures, and any other development delay are asked of children of all ages (0–17). Questions about ADHD, autism spectrum disorder, stuttering and/or stammering are asked of children 2–17 years of age.

^a Condition listed as part of a checklist with several conditions included. Respondents were asked whether their child had any of the conditions, and if so, which specifically.

^b In 2014, respondents were given the instruction to consider their child’s hearing without the use of hearing aids or other listening devices before being asked “Which statement best describes your child’s hearing?” In all years, moderate to profound hearing loss included the categories of deaf, a lot of trouble [hearing], or moderate trouble [hearing].

insurance status (categorized as private only, any public coverage [Medicaid, other public, State Children’s Health Insurance Program, Medicare, military coverage or other government], or no coverage), maternal education level (categorized as less than high school, high school or some college, and college degree or greater), family federal poverty ratio (categorized as income <200% federal poverty level [FPL] or ≥200% FPL; imputed when missing), and low birth weight (defined as <2500 g).

Weighted percentages of children who had each of the selected developmental disabilities and any developmental disability were calculated for the overall time period of 2009 to 2017 and stratified by the selected demographic and socioeconomic characteristics. Differences between percentages of developmental disabilities by selected demographic and socioeconomic characteristics were first evaluated by using χ^2 tests at the $P < .05$ level. Significant differences within groups were then evaluated by using pairwise comparisons. Three-year

pooled estimates of each of the selected developmental disabilities and any developmental disability were calculated for 2009 to 2011, 2012 to 2014, and 2015 to 2017 overall and by selected demographic and socioeconomic characteristics. Linear and quadratic trends over time were tested by using linear regression. The significance of the percentage change over time was assessed via t test. All analyses incorporated complex sample design variables and weights to allow for the calculation of nationally representative estimates by using SUDAAN version 11.0. Joinpoint was used to test for inflection points in the prevalence of any developmental disability over the time period of 1997 to 2017, which includes estimates published previously on the same composite indicator of any developmental disability.¹¹

RESULTS

Prevalence

Between 2009 and 2017, the overall prevalence of any developmental

disability among children aged 3 to 17 years in the United States was 16.93%, ranging from 0.16% for blindness to 9.04% for ADHD (Tables 2, 3, and 4).

Child-Level Characteristics

Overall, children in the oldest age group (ages 12–17 years) were the most likely to be diagnosed with any developmental disability and specifically with ADHD, LD, and ID; however, they were least likely to be diagnosed with stuttering or stammering or any other developmental delay and less likely to be diagnosed with seizures than children aged 3 to 5 years. Boys were more likely than girls to be diagnosed with any developmental disability, specifically with ADHD, ASD, CP, LD, ID, stuttering or stammering, and any other developmental delay.

Non-Hispanic white children were most likely to be diagnosed with ADHD and more likely to be diagnosed with ASD than non-Hispanic black or Hispanic children. Non-Hispanic black children were most likely to be diagnosed with LD

TABLE 2 Prevalence of Developmental Disabilities in Children Aged 3 to 17 Years by Age Group, Sex, and Race and Ethnicity

Condition	Total, %	Age Group, %			Sex, %		Race and Ethnicity, %			
		3–5 y	6–11 y	12–17 y	Boys	Girls	Non-Hispanic White	Non-Hispanic Black	Non-Hispanic Other	Hispanic
Any developmental disability	16.93	10.55	17.35 ^a	19.73 ^{a,b}	21.55	12.11 ^c	18.47	19.02	12.67 ^{d,e}	13.88 ^{d,e,f}
ADHD	9.04	2.13	9.26 ^a	12.30 ^{a,b}	12.44	5.48 ^c	10.74	9.85 ^d	6.59 ^{d,e}	5.66 ^{d,e,f}
ASD	1.74	1.68	1.75	1.75	2.66	0.78 ^c	1.95	1.54 ^d	1.77	1.34 ^{d,f}
Blind or unable to see at all	0.16	0.10	0.19	0.16	0.15	0.17	0.14	0.17	0.14	0.20
CP	0.31	0.28	0.28	0.35	0.40	0.21 ^c	0.32	0.42	0.32	0.22
Moderate to profound hearing loss	0.63	0.45	0.73 ^a	0.62	0.69	0.56	0.68	0.63	0.68	0.50
LD	7.74	3.30	8.02 ^a	9.71 ^{a,b}	9.56	5.85 ^c	8.03	9.10 ^d	5.79 ^{d,e}	7.07 ^{d,e,f}
ID	1.10	0.63	1.03 ^a	1.41 ^{a,b}	1.41	0.78 ^c	1.05	1.35	0.90	1.14
Seizures, past 12 mo	0.77	1.07	0.68 ^a	0.71 ^a	0.81	0.73	0.72	0.91	0.55 ^e	0.89 ^f
Stuttered or stammered, past 12 mo	2.02	2.73	2.26 ^a	1.43 ^{a,b}	2.75	1.27 ^c	1.55	3.40 ^d	1.41 ^e	2.53 ^{d,e,f}
Other developmental delay	4.38	4.67	4.70	3.92 ^{a,b}	5.49	3.22 ^c	4.90	4.44	3.81 ^d	3.39 ^{d,e}

^a Significantly different from children ages 3–5 ($P < .05$).

^b Significantly different from children ages 6–11 ($P < .05$).

^c Significantly different from boys ($P < .05$).

^d Significantly different from Non-Hispanic white children ($P < .05$).

^e Significantly different from Non-Hispanic black children ($P < .05$).

^f Significantly different from Non-Hispanic other children ($P < .05$).

or stuttering or stammering. Hispanic children were least likely to be diagnosed with ADHD. Overall, non-Hispanic white and non-Hispanic black children were more likely to be diagnosed with any developmental disability when compared with either non-Hispanic other children or Hispanic children.

Children receiving any form of public health insurance were more likely to be diagnosed with any and each of the individual developmental disabilities when compared with children receiving only private health insurance and uninsured children, with the exception of blindness in the

latter group. Children with only private health insurance were more likely to be diagnosed with ADHD, ASD, and any other developmental delay when compared with uninsured children but were less likely to be diagnosed with LD. Children with low birth weight (<2500 g) were more likely to be diagnosed with any and each of the specific developmental disabilities when compared with children of normal birth weight.

Family-Level Characteristics

Children with mothers who had a college or greater education level were least likely to be diagnosed with any developmental disability and

specifically least likely to be diagnosed with LD, ID, seizures, and stuttering or stammering. Children with mothers with less than a high school education were more likely to be diagnosed with blindness, LD, ID, or stuttering or stammering but were less likely to be diagnosed with ADHD or any other developmental delay when compared with children with mothers who had only completed high school or some college.

Children in families living at <200% of the FPL were more likely to have been diagnosed with each developmental disability, except ASD. Children with a rural residence

TABLE 3 Prevalence of Developmental Disabilities in Children Aged 3 to 17 Years by Health Insurance Status and Birth Weight

Condition	Health Insurance Status, %			Birth Weight, %	
	Private Only	Any Public	No Coverage	<2500 g	≥2500 g
Any developmental disability	13.75	21.82 ^a	13.37 ^b	23.96	16.06 ^c
ADHD	7.50	11.68 ^a	5.54 ^{a,b}	10.77	8.68 ^c
ASD	1.45	2.23 ^a	0.96 ^{a,b}	2.18	1.73 ^c
Blind or unable to see at all	0.07	0.28 ^a	0.16	0.52	0.12 ^c
CP	0.17	0.53 ^a	0.12 ^b	1.65	0.17 ^c
Moderate to profound hearing loss	0.42	0.94 ^a	0.49 ^b	1.06	0.60 ^c
LD	5.43	11.12 ^a	6.26 ^{a,b}	11.58	7.27 ^c
ID	0.59	1.86 ^a	0.64 ^b	2.23	0.94 ^c
Seizures, past 12 mo	0.52	1.13 ^a	0.67 ^b	1.61	0.69 ^c
Stuttered or stammered, past 12 mo	1.22	3.19 ^a	1.52 ^b	3.14	1.93 ^c
Other developmental delay	3.50	5.84 ^a	2.80 ^{a,b}	9.23	3.90 ^c

^a Significantly different from children with only private health insurance ($P < .05$).

^b Significantly different from children with any public health insurance ($P < .05$).

^c Significantly different from children with low birth weight ($P < .05$).

TABLE 4 Prevalence of Developmental Disabilities in Children Aged 3 to 17 Years by Maternal Education, Federal Poverty Level, and Urbanicity

Condition	Maternal Education, %			FPL, %		Urbanicity ^a , %	
	Less Than HS	HS or Some College	College or Greater	<200%	≥200%	Urban	Rural
Any developmental disability	17.30	18.09	13.87 ^{b,c}	19.88	14.63 ^d	16.42	19.05 ^e
ADHD	7.59	9.97 ^b	7.30 ^c	10.31	8.05 ^d	8.51	11.23 ^e
ASD	1.42	1.73	1.87	1.81	1.68	1.78	1.57
Blind or unable to see at all	0.27	0.16 ^b	0.10 ^b	0.23	0.10 ^d	0.15	0.19
CP	0.23	0.32	0.30	0.37	0.26 ^d	0.30	0.36
Moderate to profound hearing loss	0.83	0.65	0.48 ^b	0.87	0.44 ^d	0.58	0.84 ^e
LD	9.66	8.38 ^b	5.29 ^{b,c}	10.13	5.89 ^d	7.50	8.75 ^e
ID	1.48	1.12 ^b	0.80 ^{b,c}	1.48	0.81 ^d	1.06	1.28
Seizures, past 12 mo	1.00	0.89	0.50 ^{b,c}	1.06	0.55 ^d	0.75	0.88
Stuttered or stammered, past 12 mo	3.21	2.05 ^b	1.21 ^{b,c}	2.95	1.30 ^d	2.08	1.81
Other developmental delay	4.00	4.62 ^b	4.20	5.04	3.88 ^d	4.32	4.62

HS, high school.

^a Urban includes urbanized areas of 50 000 or more people and urban clusters of at least 2500 and <50 000 people. All remaining areas are considered rural.

^b Significantly different from children living with mothers with less than an HS education ($P < .05$).

^c Significantly different from children living with mothers with an HS or some college education ($P < .05$).

^d Significantly different from children living in families with FPL <200% ($P < .05$).

^e Significantly different from children living in an urban setting ($P < .05$).

compared with an urban residence were significantly more likely to be diagnosed with any developmental disability and several conditions, including ADHD, hearing loss, and LD.

Time Trends

The prevalence of any developmental disability increased significantly (16.22%–17.76%; an increase of 9.5%), comparing the years 2009 to 2011 to 2015 to 2017. During this time period, significant increases were also observed for ADHD (8.47%–9.54%; an increase of 12.6%), ASD (1.12%–2.49%; an increase of 122.3%), and ID (0.93%–1.17%; an increase of

25.8%), but a significant decrease was seen for the category of “other developmental delay” (4.65%–4.06%; a decrease of 12.7%) (Table 5).

In Figure 1, we show prevalence trends of any developmental disability for an expanded time period. From 1997 to 2017, the prevalence of any developmental disability significantly increased (38.3%) from 12.84% to 17.76%. Although the trend appeared more pronounced from 1997 to 2008 than 2009 to 2017, there were no inflection points detected between 1997 and 2017, indicating that the rates of increase between 1997 and

2008 and 2009 and 2017 were not significantly different.

Demographic and Socioeconomic Characteristics

Between 2009 and 2017, there was a significant increase seen in the prevalence of any developmental disabilities for the oldest children (ages 12–17 years), boys, non-Hispanic white and Hispanic children, children with private insurance only, and children with normal birth weight. An increase in prevalence was also observed for children living with mothers who had a high school or some college level of education, children living in families in both FPL

TABLE 5 Trends in Prevalence of Specific Developmental Disabilities in Children Aged 3 to 17 Years, NHIS, 2009 to 2017

Condition	N (Unweighted)	2009–2011, %	2012–2014, %	2015–2017, %	Percent Change 2009–2011 vs 2015–2017	P for Linear Trend
Any developmental disability	14 743	16.22	16.80	17.76	9.5	<.001
ADHD	7918	8.47	9.10	9.54	12.6	.001
ASD	1550	1.12	1.60	2.49	122.3	<.001
Blind or unable to see at all	139	0.16	0.16	0.16	0.0	.87
CP	264	0.31	0.34	0.28	−9.7	.64
Moderate to profound hearing loss	537	0.64	0.68	0.58	−9.4	.48
LD	6871	7.86	7.51	7.86	0.0	.99
ID	1021	0.93	1.21	1.17	25.8	.04
Seizures, past 12 mo	668	0.83	0.70	0.78	−6.0	.61
Stuttered or stammered, past 12 mo	1771	2.04	1.90	2.13	4.4	.61
Other developmental delay	3798	4.65	4.43	4.06	−12.7	.01

In 2011, “mental retardation” was replaced with “intellectual disability, also known as mental retardation.” In addition, the autism categorization was expanded to include “autism spectrum disorder.” In 2014, the question on ASD became a standalone question with an expanded list of eligible conditions, including Asperger’s disorder and pervasive developmental disorder. No test of quadratic trends over the 3 trend periods was significant at the $P < .05$ level for any condition.

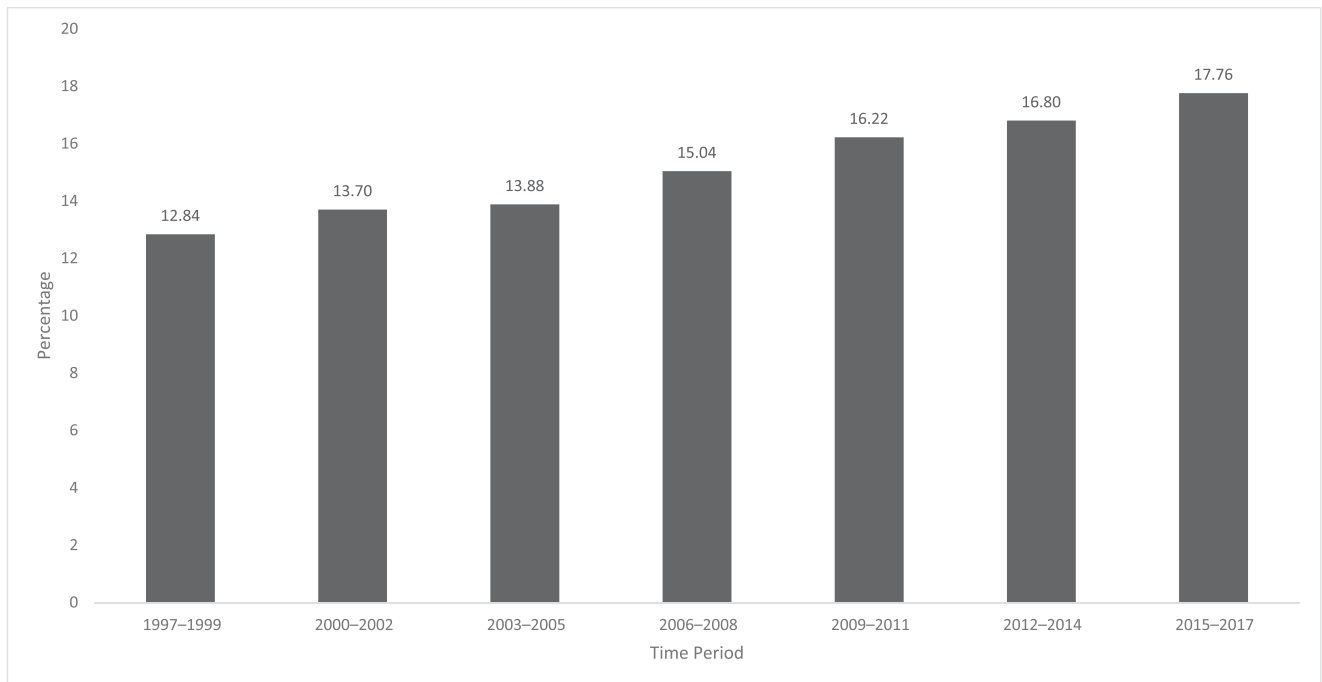


FIGURE 1

Prevalence of any developmental disability among children ages 3 to 17 years in the United States, 1997 to 2017. In 2000, the NHIS shifted from asking about only ADD to asking about ADD and ADHD. In 2008, the categorization for moderate to profound hearing loss was expanded to include “moderate trouble” hearing in addition to “a lot of trouble” hearing and deafness. In 2011, “mental retardation” was replaced with “intellectual disability, also known as mental retardation.” In addition, the autism categorization was expanded to include “autism spectrum disorder.” In 2014, the question on ASD became a standalone question with an expanded list of eligible conditions, including Asperger’s disorder and pervasive developmental disorder.

groups, and children living in urban areas (Table 6). The observed prevalence increases were of similar magnitude for children with low birth weight, children living with mothers who have less than a high school education, and children living in rural areas and were not statistically significant, perhaps because of smaller sample sizes for these subgroups.

DISCUSSION

Overall, ~1 in 6 children (~17%) between the ages of 3 to 17 in the United States were reported to have a developmental disability diagnosis between 2009 and 2017. During this time period, there was a significant increase in the overall rate of developmental disabilities, largely because of increases in the prevalence of ADHD, ASD, and ID, but with a concomitant decrease in the

prevalence of “any other developmental delay.”

ADHD

The increase in prevalence of diagnosed ADHD among US children and adolescents since the late 1990s has been well documented,¹²⁻¹⁴ although there is evidence that the prevalence of ADHD symptoms and impairment has remained steady over time.^{15,16} Taken together, this suggests that the increases in diagnosed prevalence could be driven by better identification of children who meet criteria for ADHD, as current estimates of diagnosed prevalence are in line with community-based studies in which researchers measured symptoms and impairment against *Diagnostic and Statistical Manual of Mental Disorders* diagnostic criteria.¹⁷ The American Academy of Pediatrics published updated guidelines in 2011 for the

diagnosis and treatment of ADHD, which may have influenced diagnostic practices over the study time period.¹⁸ Availability of treatment may also be related to increases in the diagnosis of ADHD, as there are many effective pharmacologic and nonpharmacologic treatments that have been and continue to be developed to address ADHD symptoms and associated negative functioning.¹⁹

ASD

The reported prevalence of ASD in the United States and other industrialized countries has shown marked increases in recent decades.^{2,20} However, understanding changes to ASD prevalence remains particularly challenging given that the diagnosis of ASD is based on a symptom profile, and health care provider and school practices for ASD screening, diagnosis, and classification continue

TABLE 6 Trends in Prevalence of Any Developmental Disability in Children Aged 3 to 17 Years by Selected Demographic and Socioeconomic Factors, NHIS, 2009–2017

	N, Unweighted	2009–2011, %	2012–2014, %	2015–2017, %	Percent Change 2009–2011 vs 2015–2017	P for Linear Trend	P for Quadratic Trend
Total	14 743	16.22	16.80	17.76	9.5	<.001	.59
Child characteristics							
Age group, y							
3–5	3361	10.10	10.52	11.04	9.3	.23	.94
6–11	5236	16.48	17.85	17.71	7.5	.08	.19
12–17	6146	19.19	18.86	21.14	10.2	<.001	.02
Sex							
Boys	9689	20.43	21.50	22.72	11.2	<.001	.89
Girls	5054	11.85	11.90	12.59	6.2	.17	.46
Race and ethnicity							
Non-Hispanic white	7855	17.36	18.75	19.37	11.6	<.001	.45
Non-Hispanic black	2387	19.38	17.34	20.32	4.9	.42	<.001
Non-Hispanic other	1184	11.66	13.50	12.72	9.1	.39	.19
Hispanic	3317	13.10	13.48	14.98	14.4	.02	.35
Health insurance							
Private only	6212	12.86	13.84	14.57	13.3	<.001	.77
Any public	7670	21.69	21.29	22.47	3.6	.30	.21
Uninsured	802	13.10	13.22	13.97	6.6	.58	.80
Birth weight							
Low (<2500 g)	1803	22.77	23.75	25.47	11.9	.10	.79
Normal (≥2500 g)	11 623	15.17	16.05	16.97	11.9	<.001	.97
Family characteristics							
Maternal education							
Less than HS	2047	16.55	16.58	18.95	14.5	.06	.22
HS or some college	7722	17.07	18.13	19.16	12.2	<.001	.97
College or greater	3300	13.05	14.09	14.36	6.4	.06	.51
FPL							
<200%	7379	19.30	19.45	20.85	8.0	.04	.25
≥200%	7364	13.71	14.65	15.50	13.1	<.001	.92
Urbanicity ^a							
Urban	11 658	15.81	16.08	17.37	9.9	<.001	.16
Rural	3085	17.85	19.87	19.54	9.5	.09	.19

HS, high school.

^a Urban includes urbanized areas of 50 000 or more people and urban clusters of at least 2500 and <50 000 people. All remaining areas are considered rural.

to evolve. Nonetheless, a sizable portion of the ASD prevalence increase is likely explained by improved identification of children with ASD related to increasing parental awareness and changing provider practices,^{21,22} including universal screening by 18 to 24 months and ongoing monitoring of a child's development as recommended by the American Academy of Pediatrics in 2007.²³

Although not directly tested in the current study, changes in diagnostic criteria and reporting practices²⁴ have been associated with increases in the number of "catch-up" diagnoses observed in older children.

In fact, results from the National Survey of Children's Health (NSCH) documented that much of the observed prevalence increase reported in each successive survey was largely explained by diagnoses in older children within given birth cohorts.^{25,26} The composition of children with ASD has also changed over the years, with the co-occurrence of ID decreasing in recent years, likely a result of broadening diagnostic criteria.^{2,27}

Finally, changes in the prevalence of ASD as measured by the NHIS may also be tied to survey measurement. An increase of ~80% was seen in the 2014 NHIS following changes to the

wording and ordering of the question capturing ASD.²⁸ Future wording changes may be required to align the ASD question with *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* criteria.²⁹

ID

In the NHIS, the increase in the prevalence of ID also appears to coincide with changes to the wording or ordering of survey questions. ID prevalence was relatively stable between 1997 and 2008¹¹ when the survey asked about "mental retardation" but was 72% higher in 2011 to 2013 when the question asked about "intellectual

disability, also known as mental retardation.”⁷ It has been hypothesized that wording changes may have decreased social desirability pressures (eg, parents may be more comfortable endorsing ID rather than mental retardation) while increasing the ability to recognize and correctly endorse the condition by including both terms.³⁰

Other Developmental Delay

“Other developmental delay” was the only condition to show a statistically significant decrease over time. It is possible that parents have become less likely to select this category because their children have increasingly been diagnosed with another specified condition on the survey. Evidence supporting this type of “diagnostic substitution” has been shown previously in special education administrative data sets.³¹

Demographic and Socioeconomic Characteristics

Patterns related to diagnosed developmental disabilities by child-level and family-level characteristics were largely similar to those found in previous studies,^{4,11,14,32–34} with a higher prevalence of any developmental disabilities and specific disorders for boys, older children, children whose birth weight was lower than 2500 g, non-Hispanic white children, children with public insurance, children with mothers with less than a college education, and children living in a household <200% of the federal poverty line.

The higher prevalence of identified disorders among children living in rural areas may be related to differences in demographic patterns and risk factors in rural areas, including greater financial difficulties and less access to amenities and treatment resources.^{4,35,36} The overall difference between urban and

rural prevalence can primarily be attributed to discrepancies seen for behavioral conditions, such as ADHD and LD. In previous research, authors have identified notable rural behavioral health barriers,^{37,38} such as lack of access to transportation and availability of specialized providers who prevent and treat symptoms of these conditions. Meanwhile, ADHD, ID, and LD were also more prevalent among older children than younger children, which may reflect that these diagnoses might not be formally recognized until a child is in school.²³

Overall, the general consistency of demographic patterns with previous studies, particularly Boyle et al,¹¹ suggests that underlying, contributing factors, such as service availability, continue to be associated with the prevalence of developmental disabilities. These same demographic subgroups that had higher prevalence of any developmental disabilities were also the groups that exhibited significant increases from 2009 to 2011 to 2015 to 2017.

Strengths and Limitations

The NHIS has several notable strengths in both its large sample size and high response rate for a national survey, allowing for analysis among subgroups of children with less common developmental disabilities. The NHIS provides timely and in-depth information on the health conditions, service use, and family sociodemographic characteristics of children with developmental disabilities. Estimates produced from the NHIS can be interpreted as nationally representative when weight and the complex survey design variables are implemented in an analysis, providing powerful evidence of the proportion and number of noninstitutionalized children affected by developmental disabilities in the United States.

Despite these strengths, some caution is warranted because of survey-related limitations. First, in some instances, statistical trend tests may have been underpowered because of smaller sample sizes (eg, rural residents). Second, the reliance on parent report could result in the misreporting of children’s diagnoses because these reports may also be subject to recall biases, particularly among parents of older children. Thirdly, there was no mechanism in place to validate parent-reported diagnoses either through clinical evaluation or educational records. However, there is notable consistency between results of the NHIS and other nationally representative surveys, including the NSCH. Recent, population-based ASD estimates have been found to be virtually identical when comparing ASD prevalence in the 2016 NSCH and the 2016 NHIS.³⁹ A broader comparison of a select set of developmental disabilities (including ASD) with comparable question wordings between multiple iterations of the NSCH and the NHIS produced comparable findings (Supplemental Table 7), suggesting further evidence of convergent validity.

Caution should typically be exercised when comparing published prevalence estimates derived from different surveillance systems and surveys with varying rigor of case ascertainment. However, it is worth noting that survey-based estimates from both the NHIS and the NSCH have fallen within the range of estimates provided by the Centers for Disease Control and Prevention’s Autism and Developmental Disabilities Monitoring Network,^{2,40,41} particularly when aligned with a comparable age group, suggesting a degree of consistency.²⁷

Finally, as parents are reporting on a lifetime diagnosis, it is likely that some children included in the current analysis no longer have a diagnosable developmental disability. It is known

that the persistence of developmental disabilities is highly variable by condition, with some children losing a diagnosis as a result of maturation or the ability to effectively manage their condition.⁴²

CONCLUSIONS

The percentage of children diagnosed with a developmental disability increased significantly between 2009 and 2017, resulting in a growing population of children

(~1 out of every 6) with 1 or more developmental disabilities. Given this growth, additional research may help to better understand the characteristics of children with developmental disabilities, the complex risk factors associated with developmental disabilities,⁴³ and the accessibility of services and interventions,⁴⁴ which have been shown to improve long-term outcomes for those diagnosed with a developmental disability.⁴⁵

ABBREVIATIONS

ADHD: attention-deficit/hyperactivity disorder
ASD: autism spectrum disorder
CP: cerebral palsy
FPL: federal poverty level
ID: intellectual disability
LD: learning disability
NHIS: National Health Interview Survey
NSCH: National Survey of Children's Health

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