



Published in final edited form as:

Pediatrics. 2019 October ; 144(4): . doi:10.1542/peds.2019-0811.

Prevalence and Trends of Developmental Disabilities among Children in the US: 2009-2017

Benjamin Zablotsky, PhD^a, Lindsey I. Black, MPH^a, Matthew J. Maenner, PhD^b, Laura A. Schieve, PhD^b, Melissa L. Danielson, MSPH^b, Rebecca H. Bitsko, PhD^b, Stephen J. Blumberg, PhD^a, Michael D. Kogan, PhD^c, Coleen A. Boyle, PhD^b

^aCenters for Disease Control and Prevention, National Center for Health Statistics, Hyattsville, Maryland ^bCenters for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Atlanta, Georgia ^cHealth Resources and Services Administration, Maternal and Child Health Bureau, Rockville, Maryland

Abstract

Objective—To study the national prevalence of ten developmental disabilities in US children aged 3–17 years and explore changes over time by associated demographic and socioeconomic characteristics using the 2009–2017 National Health Interview Survey (NHIS).

Methods—Data come from the NHIS, a nationally-representative survey of the civilian noninstitutionalized population. Parents reported physician or other health care professional diagnoses of attention-deficit/hyperactivity disorder (ADHD); autism spectrum disorder (ASD); blindness; cerebral palsy; moderate to profound hearing loss; learning disability (LD); intellectual disability (ID); seizures; stuttering or stammering; and other developmental delays. Weighted percentages for each of the selected developmental disabilities and any developmental disability were calculated between 2009–2017 and stratified by selected demographic/socioeconomic characteristics.

Results—From 2009–2011 to 2015–2017, there were overall significant increases in the prevalence of any developmental disability (16.2% to 17.8%, $p < .001$), ADHD (8.5% to 9.5%, $p < .01$), ASD (1.1% to 2.5%, $p < .001$), and ID (0.9% to 1.2%, $p < .05$), but a significant decrease for any other developmental delay (4.7% to 4.1%, $p < .05$). The prevalence of any developmental disability increased among boys, children ages 12–17, non-Hispanic white and Hispanic children,

Address correspondence to: Benjamin Zablotsky, National Center for Health Statistics, 3311 Toledo Road, Hyattsville, MD, 20782, bzablotsky@cdc.gov, 301-458-4621.

Contributors' Statement Page

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

Conflicts of interest: None to disclose.

Financial disclosure: The authors have indicated that they have no financial relationships relative to this article to disclose.

Disclaimer: The views expressed in this article are those of the authors and do not necessarily reflect the official policies of the U.S. Department of Health and Human Services, the Health Resources and Services Administration, or the Centers for Disease Control and Prevention, nor does mention of the department or agency names imply endorsement by the U.S. government.

children with private insurance only, and children with birthweights $\geq 2,500$ grams. An increase in prevalence of any developmental disability was also seen for children living in urban areas and with less educated mothers.

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

Table of Contents Summary

From the 2009–2017 NHIS, there was a 9.5% increase in the prevalence of developmental disabilities among children aged 3–17.

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 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 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 ten developmental disabilities. However, few papers have been published detailing the prevalence for the full set of conditions, instead focusing on one or a small group of these conditions.^{5–10} The most recent NHIS-based estimate on all ten conditions covered 1997–2008,¹¹ examining changes in prevalence over the time period. The prevalence was found to be 13.9% among children ages 3–17 for 1997–2008.

This paper updates this estimate of developmental disabilities, using data from the 2009–2017 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 2009–2017 NHIS, conducted by the National Center for Health Statistics (NCHS). NHIS is a nationally representative survey of the civilian noninstitutionalized population.^a 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 2009–2017, the family completion rate ranged from 65.7%–81.6%; among households with children, the completion rate for the child questionnaire ranged from 89.8%–92.3%, yielding an overall response rate of 60.6–74.6%.^b

Children aged 3–17 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 Box 1. Parents were asked whether or not their child had ten 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 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 intellectual disability throughout, regardless of year.

Selected demographic and socioeconomic characteristics included age, sex, urbanicity of residence (dichotomized as urban/rural^c), race and ethnicity, current 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 birthweight (defined as less than 2,500 grams).

Weighted percentages of children who had each of the selected developmental disabilities and any developmental disability were calculated for the overall time period 2009–2017 and stratified by the selected demographic and socioeconomic characteristics. Differences

^aFor more information about the NHIS please visit https://www.cdc.gov/nchs/nhis/about_nhis.htm

^bFor 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

^cUrban was defined as areas consisting of urbanized areas of 50,000 or more people and urban clusters of 2,500–49,999 persons; rural was defined as all other areas not included within the urban definition; see <https://www.census.gov/geo/reference/urban-rural.html>

between percentages of developmental disabilities by selected demographic and socioeconomic characteristics were first evaluated using chi-squares at the $p < 0.05$ level. Significant differences within groups were then evaluated using pairwise comparisons. Three-year pooled estimates of each of the selected developmental disabilities and any developmental disability were calculated for 2009–2011, 2012–2014 and 2015–2017 overall and by selected demographic and socioeconomic characteristics. Linear and quadratic trends over time were tested 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 using SUDAAN version 11.0. Joinpoint was used to test for inflection points in the prevalence of any developmental disability over the time period 1997–2017, which includes estimates published previously on the same composite indicator of any developmental disability.¹¹

Results

Prevalence

During 2009–2017, the overall prevalence of any developmental disability among children aged 3–17 years in the United States was 16.93%, ranging from 0.16% for blindness to 9.04% for ADHD (Table 1a, Table 1b, Table 1c).

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/stammering or any other developmental delay, and less likely to be diagnosed with seizures than children 3–5 years. Boys were more likely than girls to be diagnosed with any developmental disability, specifically with ADHD, ASD, CP, LD, ID, stuttering/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 or stuttering/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 DD when compared to 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 to 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 to uninsured children, but were less likely to be diagnosed with LD. Children with low birthweight (less than 2,500 grams) were more likely to be diagnosed with any and each of the specific developmental disabilities when compared to children of normal birthweight.

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

Children in families living at less than 200% of the FPL were more likely to have been diagnosed with each developmental disability, except ASD. Children with a rural residence compared to 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% to 17.76%; an increase of 9.5%), comparing the years 2009–2011 to 2015–2017. During this time period, significant increases were also observed for ADHD (8.47% to 9.54%; an increase of 12.6%), ASD (1.12% to 2.49%; an increase of 122.3%), and ID (0.93% to 1.17%; an increase of 25.8%), but a significant decrease was seen for the category of “other developmental delay” (4.65% to 4.06%; a decrease of 12.7%) (See Table 2).

Figure 1 shows prevalence trends of any developmental disability for an expanded time period. From 1997–2017, the prevalence of any developmental disability significantly increased (38.3%) from 12.84% to 17.76%. While the trend appeared more pronounced from 1997–2008 than 2009–2017, there were no inflection points detected between 1997–2017, indicating that the rates of increase between 1997–2008 and 2009–2017 were not significantly different.

Demographic and Socioeconomic Characteristics

Between 2009–2017, 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 normal birthweights. 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 groups, and children living in urban areas (See Table 3). The observed prevalence increases were of similar magnitude for children with low birthweights, children living with mothers who have less than a high school education, and children living in rural areas were not statistically significant, perhaps due to smaller sample sizes for these subgroups.

Discussion

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

Attention-Deficit/Hyperactivity Disorder

The increase in prevalence of diagnosed ADHD among US children and adolescents since the late 1990s has been well-documented,^{12–14} though 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 that measure symptoms and impairment against DSM diagnostic criteria.¹⁷ The American Academy of Pediatrics (AAP) 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 pharmacological and non-pharmacological treatments that have been and continue to be developed to address ADHD symptoms and associated negative functioning.¹⁹

Autism Spectrum Disorder

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 healthcare provider and school practices for ASD screening, diagnosis, and classification continue 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 18–24 months and ongoing monitoring of a child’s development as recommended by the AAP 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 documented that much of the observed prevalence increase reported in each successive survey were 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 approximately 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 DSM-5 criteria.²⁹

Intellectual Disability

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 1997–2008¹¹ when the survey asked about “mental retardation”, but was 72% higher in 2011–2013 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 (e.g. 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 datasets.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 birthweight was lower than 2,500 grams, non-Hispanic white children, children with public insurance, children with mothers with less than a college education, and children living in a household below 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. Previous research has 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 and colleagues,¹¹ suggest 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 2009–2011 to 2015–2017.

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 utilization, and family sociodemographic characteristics of children with developmental disabilities. Estimates produced from the NHIS can be interpreted as nationally representative when weights and the complex survey design variables are implemented in an analysis, providing powerful evidence of the proportion and

number of non-institutionalized children affected by developmental disabilities in 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 due to smaller sample sizes (e.g. rural residents). Second, the reliance on parent report could result in misreporting of child's diagnoses as 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 National Survey of Children's Health (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 [available as an online supplement], 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 CDC'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 2009–2017, resulting in a growing population of children (approximately 1 out of every 6) with one 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 interventions⁴⁴ which have been shown to improve long-term outcomes for those diagnosed with a developmental disability.⁴⁵

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Funding source: No external funding for this manuscript

Abbreviations

ASD	Autism spectrum disorder
ADHD	Attention-deficit/hyperactivity disorder
DD	Developmental disability
ID	Intellectual disability
LD	Learning disability
NHIS	National Health Interview Survey
NSCH	National Survey of Children's Health

References

1. Boulet SL, Boyle CA, Schieve LA. Health care use and health and functional impact of developmental disabilities among US children, 1997–2005. *Arch Pediatr Adolesc Med*. 2009;163(1):19–26. [PubMed: 19124699]
2. Baio J, Wiggins L, Christensen DL, Maenner MJ, Daniels J, Warren Z et al. Prevalence of autism spectrum disorder among children aged 8 years – autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR Surveill Summ*. 2018;67(6):1–23.
3. Magaña S, Parish SL, Rose RA, Timberlake M, Swaine JG. Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellect Dev Disabil* 2012;50(4):287–299. [PubMed: 22861130]
4. Robinson LR, Holbrook JR, Bitsko RH, Hartwig SA, Kaminski JW, Ghandour R et al. Differences in health care, family, and community factors associated with mental, behavioral, and developmental disorders among children aged 2–8 years in rural and urban areas—United States, 2011–2012. *MMWR Surveill Summ* 2017;66(8):1–11.
5. Pastor PN, Reuben CA, Duran CR, Hawkins LD. Association between diagnosed ADHD and selected characteristics among children aged 4–17 years: United States, 2011–2013. *NCHS Data Brief* 2015;201:1–7.
6. Zablotsky B, Black LI, Blumberg SJ. Estimated prevalence of children with diagnosed developmental disabilities in the United States, 2014–2016. *NCHS Data Brief* 2017;291:1–8.
7. McGuire DO, Tian LH, Yeargin-Allsopp M, Dowling NF, Christensen DL. Prevalence of cerebral palsy, intellectual disability, hearing loss, and blindness, National Health Interview Survey, 2009–2016. *Disabil Health J*. 2019; doi: 10.1016/j.dhjo.2019.01.005
8. Winter S, Autry A, Boyle C, Yeargin-Allsopp M. Trends in the prevalence of cerebral palsy in a population-based study. *Pediatrics*. 2002;110(6):1220–1225. [PubMed: 12456922]
9. Houtrow AJ, Larson K, Olson LM, Newacheck PW, Halfon N. Changing trends of childhood disability, 2001–2011. *Pediatrics*. 2014;134(3):530–538. [PubMed: 25136051]
10. Maenner MJ, Blumberg SJ, Kogan MD, Christensen D, Yeargin-Allsopp M, Schieve LA. Prevalence of cerebral palsy and intellectual disability among children identified in two US National Surveys, 2011–2013. *Annals of Epidemiology*. 2016;26(3):222–226. [PubMed: 26851824]
11. Boyle CA, Boulet S, Schieve LA, Cohen RA, Blumberg SJ, Yeargin-Allsopp M et al. Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*. 2010;127(6):1034–1042.
12. Akinbami LJ, Liu X, Pastor PN, Reuben CA. Attention deficit hyperactivity disorder among children aged 5–17 years in the United States, 1998–2009. *NCHS Data Brief*. 2011;70:1–8.
13. Nyarko KA, Grosse SD, Danielson ML, Holbrook JR, Visser SN, Shapira S. Treated prevalence of attention-deficit/hyperactivity disorder increased from 2009 to 2015 among school-aged children

- and adolescents in the United States. *J Child Adolesc Psychopharmacol*. 2017;27(8):731–734. [PubMed: 28328236]
14. Visser SN, Danielson ML, Bitsko RH, Holbrook JR, Kogan MD, Ghandour R et al. Trends in the parent-report of health care provider-diagnosed and medicated attention deficit/hyperactivity disorder: United States, 2003–2011. *J Am Acad Child Adolesc Psychiatry*. 2014;53(1):34–46. [PubMed: 24342384]
 15. Polanczyk GV, Willcutt EG, Salum GA, Kieling C, Rohde LA. ADHD prevalence estimates across three decades: An updated systematic review and meta-regression analysis. *Int J Epidemiol*. 2014;43(2):434–442. [PubMed: 24464188]
 16. Rydell M, Lundström S, Gillberg C, Lichtenstein P, Larsson H. Has the attention deficit hyperactivity disorder phenotype become more common in children between 2004 and 2014? Trends over 10 years from a Swedish general population sample. *J Child Psychol Psychiatry*. 2018;59(8):863–871. [PubMed: 29484650]
 17. Walkup JT, Stossel L, Rendleman R. Beyond rising rates: Personalized medicine and public health approaches to the diagnosis and treatment of attention-deficit/hyperactivity disorder. *J Am Acad Child Adolesc Psychiatry*. 2014;53(1):14–46. [PubMed: 24342381]
 18. American Academy of Pediatrics. ADHD: Clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *Pediatrics*. 2011;128(5):1007–1022. [PubMed: 22003063]
 19. Caye A, Swanson JM, Coghil D, Rohde LA. Treatment strategies for ADHD: An evidence-based guide to select optimal treatment. *Mol Psychiatry*. 2019;24(3):390–408. [PubMed: 29955166]
 20. Elsabbagh M, Divan G, Koh YJ, Kim YS, Kauchali S, Marcín C et al. Global prevalence of autism and other pervasive developmental disorders. *Autism Res*. 2012;5(3):160–179. [PubMed: 22495912]
 21. Matson JL, Kozlowski AM. The increasing prevalence of autism spectrum disorders. *Research in Autism Spectrum Disorders*. 2011;5(1):418–425.
 22. Worley JA, Matson JL, Sipes M, Kozlowski AM. Prevalence of autism spectrum disorders in toddlers receiving early intervention services. *Research in Autism Spectrum Disorders*. 2011;5(2):920–925.
 23. Johnson CP, Myers SM. Identification and evaluation of children with autism spectrum disorders. *Pediatrics*. 2007;120(5):1183–1215. [PubMed: 17967920]
 24. Hansen SN, Schendel DE, & Parner ET (2015). Explaining the increase in the prevalence of autism spectrum disorders: the proportion attributable to changes in reporting practices. *JAMA pediatrics*, 169(1), 56–62. [PubMed: 25365033]
 25. Blumberg SJ, Bramlett MD, Kogan MD, Schieve LA, Jones JR, Lu MC. Changes in prevalence of parent-reported autism spectrum disorder in school-aged US children: 2007 to 2011–2012. *National Center for Health Statistics Reports*. 2013;65:1–11.
 26. Schieve LA, Rice C, Yeargin-Allsopp M, Boyle CA, Kogan MD, Drews C et al. Parent-reported prevalence of autism spectrum disorders in US-born children: an assessment of changes within birth cohorts from the 2003 to the 2007 National Survey of Children’s Health. *Matern Child Health J*. 2012;16(1):151–157.
 27. Centers for Disease Control and Prevention. Parental report of diagnosed autism in children, aged 4–17 years, United States, 2003–2004. *MMWR Morb Mortal Wkly Rep*. 2006;55(17):481–486. [PubMed: 16675944]
 28. Zablotsky B, Black LI, Maenner MJ, Schieve LA, Blumberg SJ. Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey. *National Center for Health Statistics Reports*. 2015;87:1–20.
 29. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Arlington, VA: American Psychiatric Publication; 2013.
 30. Stavrakantonaki M, Johnson TP. Effects of Rosa’s law on intellectual disability reporting. *Public Opinion Quarterly*. 2018;82(3):593–604.
 31. Shattuck PT. The contribution of diagnostic substitution to the growing administrative prevalence of autism in US special education. *Pediatrics*. 2006;117(4):1028–1037. [PubMed: 16585296]

32. Durkin MS, Maenner MJ, Benedict RE, Van Naarden Braun K, Christensen D, Kirby RS et al. The role of socio-economic status and perinatal factors in racial disparities in the risk of cerebral palsy. *Dev Med Child Neurol*. 2015;57(9):835–843. [PubMed: 25808915]
33. Danielson ML, Bitsko RH, Ghandour RM, Holbrook JR, Kogan MD, Blumberg SJ. Prevalence of parent-reported ADHD diagnosis and associated treatment among U.S. children and adolescents, 2016. *J Clin Child Adolesc Psychol*. 2018;47(2):199–212. [PubMed: 29363986]
34. Schieve LA, Tian LH, Rankin K, Kogan MD, Yeargin-Allsopp M, Visser S et al. Population impact of preterm birth and low birth weight on developmental disabilities in US children. *Ann Epidemiol*. 2016;26(4):267–274. [PubMed: 27085382]
35. Anderson NJ, Neuwirth SJ, Lenardson JD, Hartley D. Patterns of care for rural and urban children with mental health problems. <https://www.ruralhealthresearch.org/publications/883> 2013 Accessed 12 October 2018.
36. Smalley KB, Yancey CT, Warren JC, Naufel K, Ryan R, Pugh JL. Rural mental health and psychological treatment: a review for practitioners. *J Clin Psychol*. 2010;66:479–489. [PubMed: 20222125]
37. US Department of Health and Human Services. Health Resources and Services Administration. Designated health professional shortage areas (HPSA) statistics.
38. Institute of Medicine. Quality through collaboration: the future of rural health. Washington, DC: National Academies Press; 2005 <https://www.nap.edu/read/111140/chapter/1>
39. Kogan M, Vladutiu C, Schieve L, Ghandour R, Blumberg S, Zablotsky B et al. The prevalence of parent-reported autism spectrum disorder among US children. *Pediatrics*. 2018;142(6):1–11.
40. 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 Morb Mortal Wkly Rep*. 2012;61(3):1–19.
41. Christensen DL, Bilder DA, Zahorodny W, Pettygrove S, Durkin MS, Fitzgerald RT et al. Prevalence and characteristics of autism spectrum disorder among 4-year-old children in the autism and developmental disabilities monitoring network. *J Dev Behav Pediatr*. 2016;37(1):1–8. [PubMed: 26651088]
42. Blumberg SJ, Zablotsky B, Avila RM, Colpe LJ, Pringle BA, Kogan MD. Diagnosis lost: Differences between children who had and who currently have an autism spectrum disorder diagnosis. *Autism*. 2016;20(7):783–795. [PubMed: 26489772]
43. Boulet SL, Schieve LA, Boyle CA. Birth weight and health and developmental outcomes in US children, 1997–2005. *Matern Child Health J*. 2011;15(7):836–844. [PubMed: 19902344]
44. Vohra R, Madhavan S, Sambamoorthi U, St Peter C Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*, 2014;18(7):815–826. [PubMed: 24353274]
45. Majnemer A Benefits of early intervention for children with developmental disabilities In *Seminars in Pediatric Neurology* (Vol. 5, No. 1, pp. 62–69). Elsevier, 1998.

What's Known on this Subject

Previous work found health disparities in diagnosed developmental disabilities by demographic and socioeconomic characteristics among US children. Changes in awareness, knowledge, healthcare services access, and improved measurement make it important to continue to monitor prevalence changes in the population.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

What this Study Adds

This study presents new nationally representative data on the prevalence of developmental disability, recent demographic trends, and estimates by urban or rural residence.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

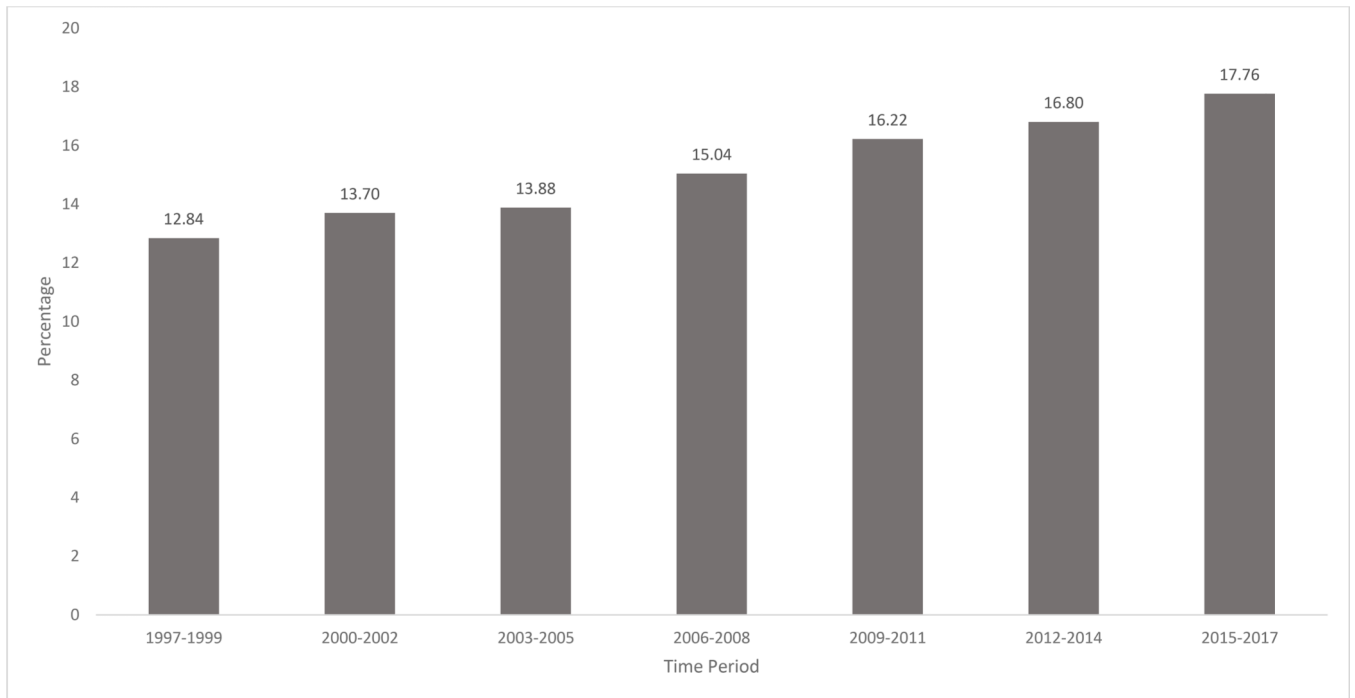


Figure 1. Prevalence of any developmental disability among children ages 3–17 years in the United States, 1997–2017

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 autism spectrum disorder became a standalone question with an expanded list of eligible conditions, including Asperger’s disorder and pervasive developmental disorder.

Prevalence of Developmental Disabilities in Children Aged 3 to 17 Years, by Selected Demographic and Socioeconomic Factors, NHIS, 2009–2017.

Table 1a.

Condition	Total (%)	Age, %			Sex, %		Race and Ethnicity, %			
		3–5	6–11	12–17	Boys	Girls	Non-Hispanic White	Non-Hispanic Black	Non-Hispanic Other	Hispanic
		Any developmental disability	10.55	17.35 ^a	19.73 ^{ab}	21.55	12.11 ^c	18.47	19.02	12.67 ^{de}
ADHD	2.13	9.26 ^a	12.30 ^{ab}	12.44	5.48 ^c	10.74	9.85 ^d	6.59 ^{de}	5.66 ^{def}	
Autism spectrum disorder	1.68	1.75	1.75	2.66	0.78 ^c	1.95	1.54 ^d	1.77	1.34 ^{df}	
Blind/unable to see at all	0.10	0.19	0.16	0.15	0.17	0.14	0.17	0.14	0.20	
Cerebral palsy	0.28	0.28	0.35	0.40	0.21 ^c	0.32	0.42	0.32	0.22	
Moderate to profound hearing loss	0.45	0.73 ^a	0.62	0.69	0.56	0.68	0.63	0.68	0.50	
Learning disability	3.30	8.02 ^a	9.71 ^{ab}	9.56	5.85 ^c	8.03	9.10 ^d	5.79 ^{de}	7.07 ^{def}	
Intellectual disability	0.63	1.03 ^a	1.41 ^{ab}	1.41	0.78 ^c	1.05	1.35	0.90	1.14	
Seizures, past 12 months	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 months	2.73	2.26 ^a	1.43 ^{ab}	2.75	1.27 ^c	1.55	3.40 ^d	1.41 ^e	2.53 ^{def}	
Other developmental delay	4.67	4.70	3.92 ^{ab}	5.49	3.22 ^c	4.90	4.44	3.81 ^d	3.39 ^{de}	

NOTES: ADHD is attention-deficit/hyperactivity disorder, HS is high school

^f Urban includes Urbanized Areas (UAs) of 50,000 or more people and Urban Clusters (UCs) of at least 2,500 and less than 50,000 people. All remaining areas are considered rural.

^a Significantly different from children ages 3–5 ($p < 0.05$).

^b Significantly different from children ages 6–11 ($p < 0.05$).

^c Significantly different from boys ($p < 0.05$).

^d Significantly different from Non-Hispanic white children ($p < 0.05$).

^e Significantly different from Non-Hispanic black children ($p < 0.05$).

^f Significantly different from Non-Hispanic other children ($p < 0.05$).

Prevalence of Developmental Disabilities in Children Aged 3 to 17 Years, by Selected Demographic and Socioeconomic Factors, NHIS, 2009–2017.

Table 1b.

Condition	Health Insurance Status, %			Birthweight, %	
	Private Only	Any Public	No Coverage	<2500 grams	2500 grams
Any developmental disability	13.75	21.82 ^g	13.37 ^h	23.96	16.06 ⁱ
ADHD	7.50	11.68 ^g	5.54 ^{gh}	10.77	8.68 ⁱ
Autism spectrum disorder	1.45	2.23 ^g	0.96 ^{gh}	2.18	1.73 ⁱ
Blind/unable to see at all	0.07	0.28 ^g	0.16	0.52	0.12 ⁱ
Cerebral palsy	0.17	0.53 ^g	0.12 ^h	1.65	0.17 ⁱ
Moderate to profound hearing loss	0.42	0.94 ^g	0.49 ^h	1.06	0.60 ⁱ
Learning disability	5.43	11.12 ^g	6.26 ^{gh}	11.58	7.27 ⁱ
Intellectual disability	0.59	1.86 ^g	0.64 ^h	2.23	0.94 ⁱ
Seizures, past 12 months	0.52	1.13 ^g	0.67 ^h	1.61	0.69 ⁱ
Stuttered or stammered, past 12 months	1.22	3.19 ^g	1.52 ^h	3.14	1.93 ⁱ
Other developmental delay	3.50	5.84 ^g	2.80 ^{gh}	9.23	3.90 ⁱ

^gSignificantly different from children with only private health insurance ($p<0.05$).^hSignificantly different from children with any public health insurance ($p<0.05$).ⁱSignificantly different from children with low birthweight ($p<0.05$).

Prevalence of Developmental Disabilities in Children Aged 3 to 17 Years, by Selected Demographic and Socioeconomic Factors, NHIS, 2009–2017.

Table 1c.

Condition	Maternal Education, %		College or Greater	Federal Poverty Level, %		Urbanicity ^l , %	
	Less than HS	HS / Some College		<200%	200%	Urban	Rural
Any developmental disability	17.30	18.09	13.87 ^{jk}	19.88	14.63 ^l	16.42	19.05 ^m
ADHD	7.59	9.97 ^j	7.30 ^k	10.31	8.05 ^l	8.51	11.23 ^m
Autism spectrum disorder	1.42	1.73	1.87	1.81	1.68	1.78	1.57
Blind/unable to see at all	0.27	0.161	0.10 ^l	0.23	0.10 ^l	0.15	0.19
Cerebral palsy	0.23	0.32	0.30	0.37	0.26 ^l	0.30	0.36
Moderate to profound hearing loss	0.83	0.65	0.48 ^j	0.87	0.44 ^l	0.58	0.84 ^m
Learning disability	9.66	8.38 ^j	5.29 ^{jk}	10.13	5.89 ^l	7.50	8.75 ^m
Intellectual disability	1.48	1.12 ^j	0.80 ^{jk}	1.48	0.81 ^l	1.06	1.28
Seizures, past 12 months	1.00	0.89	0.50 ^{jk}	1.06	0.55 ^l	0.75	0.88
Stuttered or stammered, past 12 months	3.21	2.05 ^j	1.21 ^{jk}	2.95	1.30 ^l	2.08	1.81
Other developmental delay	4.00	4.62 ^j	4.20	5.04	3.88 ^l	4.32	4.62

^jSignificantly different from children living with mothers with less than HS education ($p < 0.05$).

^kSignificantly different from children living with mothers with HS or some college education ($p < 0.05$).

^lSignificantly different from children living in families with FPL under 200% ($p < 0.05$).

^mSignificantly different from children living in an urban setting ($p < 0.05$).

Table 2. Trends in Prevalence of Specific Developmental Disabilities in Children Aged 3 to 17 Years, NHIS, 2009–2017

Condition	n (unweighted)	2009–2011 (%)	2012–2014 (%)	2015–2017 (%)	Percent Change 2009–2011 versus 2015–2017	P for linear trend
Any developmental disability	14,743	16.22	16.80	17.76	9.5	<.001
ADHD	7,918	8.47	9.10	9.54	12.6	.001
Autism spectrum disorder	1,550	1.12	1.60	2.49	122.3	<.001
Blind/unable to see at all	139	0.16	0.16	0.16	0.0	.87
Cerebral palsy	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
Learning disability	6,871	7.86	7.51	7.86	0.0	.99
Intellectual disability	1,021	0.93	1.21	1.17	25.8	.04
Seizures, past 12 months	668	0.83	0.70	0.78	-6.0	.61
Stuttered or stammered, past 12 months	1,771	2.04	1.90	2.13	4.4	.61
Other developmental delay	3,798	4.65	4.43	4.06	-12.7	.01

NOTE: ADHD is attention-deficit/hyperactivity disorder

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 autism spectrum disorder 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.

Table 3.

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 versus 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 groups, years							
3–5	3,361	10.10	10.52	11.04	9.3	.23	.94
6–11	5,236	16.48	17.85	17.71	7.5	.08	.19
12–17	6,146	19.19	18.86	21.14	10.2	<.001	.02
Sex							
Boys	9,689	20.43	21.50	22.72	11.2	<.001	.89
Girls	5,054	11.85	11.90	12.59	6.2	.17	.46
Race and ethnicity							
Non-Hispanic white	7,855	17.36	18.75	19.37	11.6	<.001	.45
Non-Hispanic black	2,387	19.38	17.34	20.32	4.9	.42	<.001
Non-Hispanic other	1,184	11.66	13.50	12.72	9.1	.39	.19
Hispanic	3,317	13.10	13.48	14.98	14.4	.02	.35
Health insurance							
Private only	6,212	12.86	13.84	14.57	13.3	<.001	.77
Any public	7,670	21.69	21.29	22.47	3.6	.30	.21
Uninsured	802	13.10	13.22	13.97	6.6	.58	.80
Birthweight							
Low (<2500 grams)	1,803	22.77	23.75	25.47	11.9	.10	.79
Normal (≥ 2500 grams)	11,623	15.17	16.05	16.97	11.9	<.001	.97
Family characteristics							
Maternal education							
Less than HS	2,047	16.55	16.58	18.95	14.5	.06	.22

	n (unweighted)	2009–2011 (%)	2012–2014 (%)	2015–2017 (%)	Percent Change 2009–2011 versus 2015–2017	P for linear trend	P for quadratic trend
HS / Some college	7,722	17.07	18.13	19.16	12.2	<.001	.97
College or greater	3,300	13.05	14.09	14.36	6.4	.06	.51
Federal poverty level							
<200%	7,379	19.30	19.45	20.85	8.0	.04	.25
200%	7,364	13.71	14.65	15.50	13.1	<.001	.92
Urbanicity ¹							
Urban	11,658	15.81	16.08	17.37	9.9	<.001	.16
Rural	3,085	17.85	19.87	19.54	9.5	.09	.19

NOTES: HS is high school.

¹Urban includes Urbanized Areas (UAs) of 50,000 or more people and Urban Clusters (UCs) of at least 2,500 and less than 50,000 people. All remaining areas are considered rural.

Box 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?” ¹ 2011–2013: “Has a doctor or health professional ever told you that [survey child] had autism/autism spectrum disorder?” ¹ 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?” ¹
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?” ²
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?”

NOTES: 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/stammering are asked of children 2–17 years of age.

¹Condition 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.

²In 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].