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Prevalence and Co-occurring Developmental, Neurological, and Mental Health Conditions of Cerebral Palsy Among Children in the United States: 2016–2021

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Abstract

Introduction: Monitoring cerebral palsy (CP) prevalence and co-occurring conditions is crucial for planning lifelong support, but recent national estimates are somewhat limited.

Methods: We analyzed data on U.S. children aged 2–17 years from the 2016–2021 National Survey of Children's Health, conducted annually using a cross-sectional design, to calculate nationally representative prevalence estimates of ever-diagnosed CP, overall and by selected demographic and perinatal characteristics. Three-year estimates were compared to evaluate changes over time. Co-occurring conditions were assessed among children aged 3–17 years with a current CP diagnosis. We estimated prevalence ratios (PR) to quantify differences between groups.

Results: The overall prevalence of CP was 3.1 per 1,000 children, with a higher prevalence among boys (3.6/1,000) than girls (2.5/1,000) and children born with low and very low birthweight (46.6 and 7.1/1,000, respectively) and premature (12.7/1,000); differences by race/ethnicity did not reach statistical significance (non-Hispanic [NH] White: 2.9, NH Black: 4.2, and NH other: 4.5/1,000. There were no clear changes in CP prevalence over time, but caregiver-rated severe CP increased from 16.8% (2016–2018) to 30.3% (2019–2021). Most children with CP had at least one co-occurring condition, about four times more prevalent than in children without CP, with the largest differences for intellectual disability (PR = 43) and epilepsy or seizure disorder (PR = 69).

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Consent to Participate Not applicable.

Consent for Publication Not applicable.

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Discussion: There is a significantly higher prevalence of co-occurring developmental, neurological, and mental health conditions among children with CP compared to those without, highlighting the diverse services and resources that may be needed to optimally support this population as they transition into adulthood.

Keywords

Cerebral palsy; Prevalence; Co-occurring conditions; Children; National survey of children's health

Introduction

Cerebral palsy (CP) is a disorder of movement and posture that leads to activity limitations and is caused by abnormal development or damage to the developing brain during gestation, infancy, or early childhood (Rosenbaum et al., 2006; Morgan et al., 2018). Some children initially thought in early life to have CP may later lose the diagnosis (Nelson & Ellenberg, 1982; Chen et al., 2020). Understanding CP prevalence and its co-occurring conditions is crucial, as children with CP often have significant health and service needs (Cogswell et al., 2022). Previous data indicate that the prevalence of CP in children in the United States has been stable in the past decades, with the most recent estimate, from the 2016–2018 National Survey of Children's Health (NSCH), reporting a CP prevalence of 2.9 per 1,000 children, which align with findings from other survey and surveillance data (Casseus & Cheng, Zablotsky et al., 2019; 2021; Maenner et al., 2016; Arneson et al., 2009; Kirby et al., 2011; Christensen et al., 2014). U.S. estimates are generally higher than those in Europe and do not show the downward temporal trend seen in many countries (McIntyre et al., 2022).

Previous studies have estimated the prevalence of co-occurring conditions associated with CP, such as epilepsy, intellectual disability (ID), autism spectrum disorder (ASD), and attention deficit/hyperactivity disorder (ADHD), often focusing on individual conditions or a limited set of conditions across different populations (Boulet et al., 2009; Christensen et al., 2014; National Guideline Alliance (UK), (2017); Casseus & Cheng, 2021; Chen et al., 2024). More recent estimates of CP prevalence and a broader assessment of co-occurring conditions in U.S. children are important for evaluating the public health implications of CP and guiding the development of services to support affected children.

We sought to provide updated estimates of CP prevalence among children in the United States using data from the 2016–2021 NSCH, overall and by selected demographic and perinatal characteristics. Additionally, we analyzed prevalence patterns and severity over time and examined the prevalence of co-occurring developmental, neurological, and mental health conditions among children with CP.

Methods

Data Source and Measures

This analysis used data collected from the 2016–2021 National Survey of Children's Health (NSCH). The NSCH was designed to generate nationally- and state-representative estimates of key health or health- related indicators for noninstitutionalized children aged 0 through

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17 years in the United States. Detailed information about the survey design and methods can be found elsewhere (Ghandour et al., 2018; United States Census Bureau, 2018, 2018, 2019, 2020, 2023, 2023). Briefly, one child per household was randomly selected to be the subject of a detailed age-specific survey. A parent or guardian (referred to hereinafter as parent) who was knowledgeable about the child's health and healthcare needs answered the survey questions using self-administered web or paper-based questionnaires.

The parent was asked whether a doctor or other healthcare provider had ever told them that their child has any of the following conditions: CP, epilepsy or seizure disorder, anxiety problems, depression, autism or autism spectrum disorder (ASD) including diagnoses of Asperger's disorder or pervasive developmental disorder, and attention deficit disorder or attention-deficit/hyperactivity disorder (ADHD). Additionally, the parent was queried on whether a doctor, other healthcare provider, or educator had ever told them that the child has any of the following conditions: behavioral or conduct problems, developmental delay, intellectual disability, speech or other language disorder, and learning disability. If the parent responded "yes" to any of the items, a follow-up question was asked regarding whether this child currently has the condition. Parents also were asked whether the child has serious difficulty walking or climbing stairs (applicable to 6–17 years old only), difficulty dressing or bathing (applicable to 6–17 years old only), deafness or problems with hearing, and blindness or problems with seeing even when wearing glasses. A child was considered to have a condition or difficulty if there was an affirmative response to the above-mentioned questions. The parents of children with a current CP diagnosis were asked to rate the severity of CP as mild, moderate, or severe. Survey questions regarding these conditions were asked consistently over the study years (2016–2021), and minor wording or format changes can be found in the NSCH full length survey instruments available at: https://www.childhealthdata.org/learn-about-the-nsch/survey-instruments. Our preliminary analysis revealed that over 10% of children ever diagnosed with CP did not currently have this diagnosis, and current CP status was not asked in the 2022–2023 NSCH. Since characteristics of those with a past diagnosis may differ from those currently diagnosed, data from 2022 to 2023 are not included in this report.

Selected demographic and perinatal characteristics considered included the child's sex, race/ethnicity (non-Hispanic [NH] White, NH Black, NH other, Hispanic), age group, highest caregiver education, birthweight, and gestational age.

Data Analysis

Children aged 2–17 years (n = 208,027) were identified in the 2016–2021 NSCH combined data. A total of 824 (< 0.5%) children were excluded because of missing information on the child's ever-diagnosed CP status, resulting in a total of 207,203 children for the primary analysis.

First, we estimated the prevalence of ever being diagnosed with CP (referred to hereinafter as CP prevalence) and stratified by demographic and perinatal characteristics and calculated the prevalence ratios (PR) and 95% confidence intervals (CIs) to compare CP prevalence estimates between demographic and perinatal subgroups.

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Second, to assess changes over time and enhance analytic sample sizes, three-year CP prevalence estimates overall and by selected demographic characteristics were calculated and compared for 2016–2018 and 2019–2021.

Next, we calculated percentages of children with a current diagnosis of CP among children who ever had CP and estimated percentages of children who had serious difficulty walking or climbing stairs (6–17 years old only), difficulty dressing or bathing (6–17 years old only), as well as parent-rated severity of CP among children with a current diagnosis of CP during 2016–2021 and also compared these estimates between 2016–2018 and 2019–2021. Chi-square tests were used to examine differences in these percentages between the two study periods.

Lastly, we calculated percentages and 95% CIs of children with current CP or without current CP (never diagnosed with CP and ever diagnosed but not currently diagnosed with CP) who had other parent-reported developmental, neurological, and mental health conditions including developmental delay, learning disability, speech/language disorder, intellectual disability, behavioral or conduct problems, ADHD, ASD, epilepsy or seizure disorder, blindness or problems with seeing, deafness or problems with hearing, anxiety problems, and depression, throughout the period of 2016–2021.PR and 95% CIs were calculated to compare prevalence estimates of these conditions between children with and without current CP. This analysis focused on children aged 3–17 years, as many of these conditions are unlikely diagnosed among younger children.

Sampling design variables and weights were incorporated in all analyses to allow for generating estimates that were nationally representative of U.S. children living in noninstitutional settings using SAS callable SUDAAN version 11.0.0 (RTI International, Cary, NC).

Results

During 2016–2021, the overall prevalence of ever having a CP diagnosis was 3.1 per 1000 children aged 2–17 years old in the United States (95% CI: 2.7, 3.5) (Table 1). CP was more prevalent among boys (3.6 per 1000 [95% CI: 3.0, 4.4]) than among girls (2.5 [2.0, 3.0]). The prevalence of CP was slightly higher among children aged 10–13 years old (3.7 [2.9, 4.6]) compared to those aged 2–9 years (2.6 [2.1, 3.3]), but did not differ by household educational attainment. The prevalence of CP appeared slightly elevated among children who were NH Black and NH other race/ethnicity, compared to NH White, but differences did not reach statistical significance. The prevalence estimate was significantly higher in children born with very low birth weight (46.6 per 1000, [95%CI: 34.3, 62.9]), low birth weight (7.1 [5.3, 9.5]), or prematurely (12.7[10.2, 15.7]) compared to those with normal birthweight (1.9 [1.6, 2.3]) or term birth (1.8 [1.5, 2.2]).

Figure 1 shows the CP prevalence overall and by selected demographic characteristics for 2016–2018 and 2019–2021 (See Table S1 estimates). No clear changes were observed in the overall prevalence or across any subgroups between the two time periods.

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During 2016–2021, 88.2% (95%CI: 82.8%, 92.0%) of children aged 2–17 years old who had ever received a diagnosis of CP were reported to currently have CP. Among children aged 6–17 years old with current CP, 56.8% (95%CI: 48.4%, 64.7%) had difficulty walking or climbing stairs and 63.7% (55.3%, 71.4%) had difficulty dressing or bathing, and no changes were seen over time. Among children aged 2–17 years with current CP in 2016–2021, 40.3% were reported as mild CP (95%CI: 33.7%, 47.2%), 36.5% as moderate (29.7%, 43.8%), and 23.3% as severe (18.0%, 29.5%). The percentage of reported severe CP significantly increased from 16.8% (95%CI: 11.7%, 23.6%) in 2016–2018 to 30.3% (95% CI: 21.7%, 40.6%) in 2019–2021 ($p = 0.037$) (Table 2).

During 2016–2021, children aged 3–17 years old with a current CP diagnosis had a significantly higher prevalence of one or more developmental, neurological, or mental health conditions, as compared to those without CP: 91.2% (95%CI: 87.3%, 94.0%) versus 23.7%(23.3%, 24.1%) for any condition; 84.9% (77.8%, 90.0%) versus 17.7% (17.3%, 18.1%) for another developmental disability; 50.3% (42.9%, 57.7%) versus 3.5% (3.3%, 3.8%) for a neurological condition; and 27.4% (21.0%, 34.9%) versus 8.9% (8.6%, 9.1%) for a mental health condition (Table 3). The most prevalent condition was developmental delay: 78.1% (71.1%, 83.8%), followed by learning disability: 62.4% (54.6%, 69.6%) and speech/language disorder: 57.9% (50.2%, 65.2%). The largest differences in prevalence between children with and without a current CP diagnosis were observed for epilepsy or seizure disorder (PR: 69.3, 95% CI: 55.1–87.2) and intellectual disability (PR: 42.8, 95% CI: 35.0–52.3).

Discussion

We observed a similar CP prevalence estimate for U.S. children during 2016–2021, 3.1 per 1,000 children aged 2–17 years, as has been seen in earlier years in the same survey, as well as from NHIS, and other survey and surveillance sources (Cogswell et al., 2022; Casseus & Cheng, 2021; Zablotsky et al., 2019; Maenner et al., 2016; Arneson et al., 2009; Kirby et al., 2011; Christensen et al., 2014). Consistent with previous data, we observed a higher prevalence of CP among boys and strong associations with lower birthweight and prematurity.

No clear changes were observed in the overall prevalence of CP in 2016–2018 (3.3 per 1,000 children), and 2019–2021 (2.8 per 1,000 children). These results are congruent with the consistent frequency of low birth weight and preterm birth, both strong risk factors for CP (Korzeniewski et al., 2018), observed in the US during this period (Osterman et al., 2023; Khan et al., 2023).

There were no significant changes in the percentages of children with current CP experiencing difficulty walking or climbing stairs, or with difficulty dressing or bathing between 2016 and 2018 and 2019–2021. This suggests that the severity of motor impairment related to these activities remained consistent over the two time periods. However, the percentage of parent-reported cases of severe current CP significantly increased from 16.8% in 2016–2018 to 30.3% in 2019–2021. Research has shown that caregivers encountered multiple challenges in adjusting their lifestyles to meet the needs of children with CP

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(Dlamini et al., 2023). This reported increase in severity may suggest increased mental health concerns and challenges in accessing medical care for children with CP during the COVID-19 pandemic (Lai et al., 2023), potentially exacerbating some symptoms of children with CP and influencing parents' overall perception of their child's condition. Further monitoring parent-reported cases of severe CP could identify whether estimates return to pre-pandemic levels or continue to rise and help understand factors contributing to the changes.

This study also provides nationally representative prevalence estimates of selected co-occurring developmental, neurological, and mental health conditions among U.S. children aged 3–17 years with a current CP diagnosis. Our findings indicate approximately nine out of ten children with CP have at least one of these selected co-occurring conditions, which is almost 4 times more prevalent than in children without CP. More than half of children with CP have developmental delay (78%), learning disability (62%), and speech/language disorder (58%), which are 9 to 15 times higher than the prevalence observed for children without CP. Relative to children without CP, the largest relative differences in prevalence were observed for intellectual disability and epilepsy or seizure disorder (43 and 69 times more prevalent in children with CP relative to children without CP, respectively). These prevalence estimates for each individual co-occurring developmental or neurological condition were in the range of or aligned with previous estimates (Boulet et al., 2009; Christensen et al., 2014; National Guideline Alliance (UK), (2017); Casseus & Cheng, 2021; Chen et al., 2024). We also observed that approximately one out of four children with CP experienced anxiety or depression, a prevalence closely aligned with the pooled prevalence of mental health symptoms (28%) using the Child Behavior Checklist reported in a meta-analysis of studies among children and adolescents with CP (Downs et al., 2018).

Moreover, mental health conditions in children with CP, especially when they also have complex co-occurring developmental and neurological conditions, may not be as readily recognized or addressed as other well-established conditions. An analysis of 2016–2020 NSCH data revealed that 75.5% of children aged 6–17 years with CP had a mental health disorder including anxiety, depression, behavioral disorders, and ADHD. Notably, only 21.5% of children with CP received mental health care (Cribb et al., 2023). The high prevalence of these co-occurring conditions in children with CP indicates that in addition to mobility assistance, many other services may be needed to optimally support children with CP. According to an analysis of 2014–2018 NHIS data, 72% of children with CP required medical services from specialists—significantly higher than children with ADHD (26%), ASD (35%), or no developmental disabilities (12%) (Cogswell et al., 2022).

This analysis is subject to limitations. The data are based on parent report and the presence of CP and co-occurring conditions was not verified in medical records, which subjects the data to recall bias. In addition, children with the condition(s) but without a diagnosis would not be captured in these data. Even after combining six or three years of data, the effective sample size was small for some subgroups, leading to less stable or unreliable estimates.

Data describing the prevalence of CP, including co-occurring conditions and groups most likely to be impacted, can be used to identify and plan for services to support people

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with CP and their families. This analysis provides more recent, nationally representative prevalence estimates of CP among children in the United States and estimates of co-occurring developmental, neurological, and mental health conditions among those affected by CP. Although the prevalence of CP and the severity of physical difficulties have remained constant in the United States in recent years, the high prevalence of co-occurring conditions among this population highlights the need for the multiple types of healthcare services and supports. These insights inform efforts to provide comprehensive and optimal care for children with CP and their families. Further monitoring of parent-reported cases of severe CP could aid in understanding whether estimates return to pre-pandemic levels or continue to rise, and factors associated with the changes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data Availability

Data are publicly available on the U.S. Census Bureau website.

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Significance

What is already known on this subject?

Although previous studies indicate that cerebral palsy (CP) prevalence has remained stable over past decades and is linked to various conditions, recent national data on CP prevalence and co-occurring conditions are limited. Monitoring this information and enhancing our understanding of its impact is essential for planning lifelong support and services.

What this study adds?

This study reveals that 91% of children with CP experience co-occurring developmental, neurological, or mental health conditions, while CP prevalence remains stable among U.S. children. Our findings highlight the need for various services and supports for this population into adulthood.

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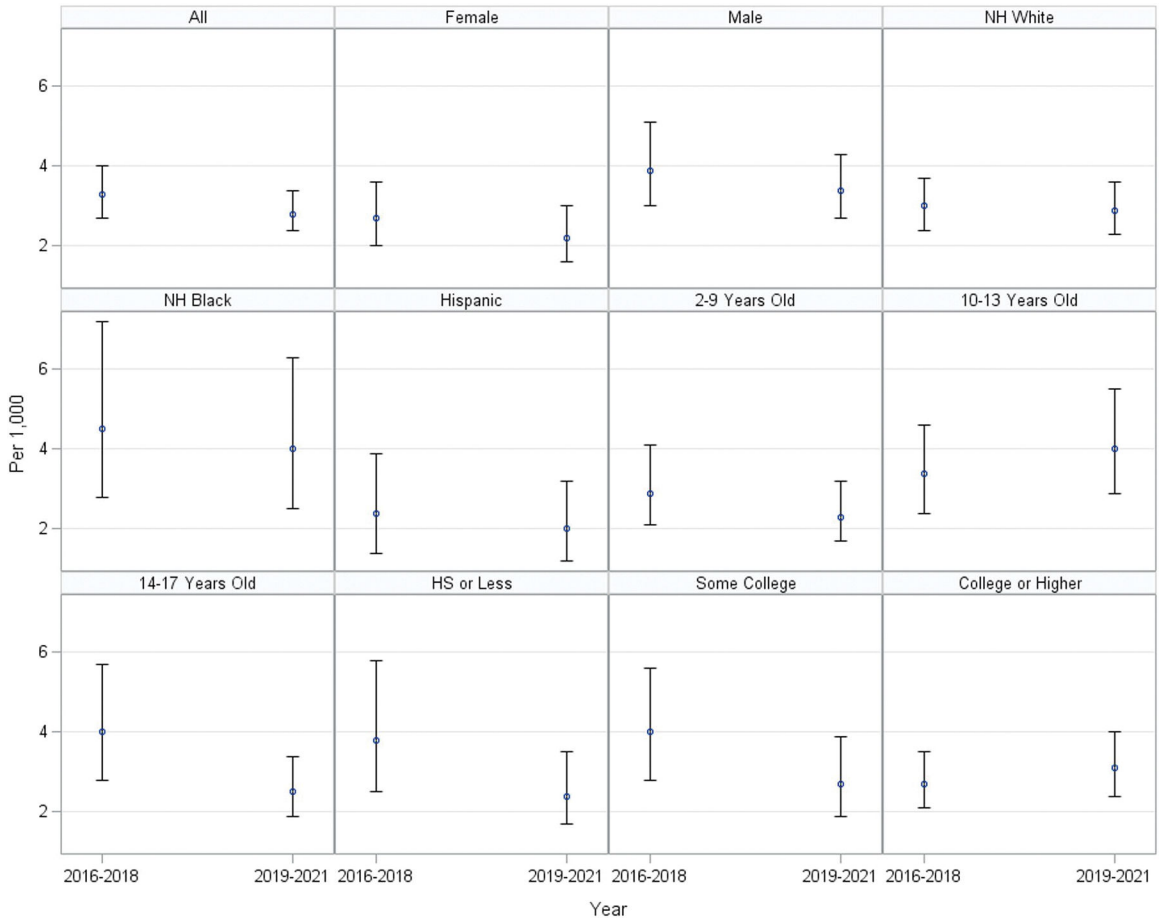


Fig. 1.

Weighted Prevalence Estimates of Ever-diagnosed Cerebral Palsy and 95% Confidence Intervals for Children Aged 2–17 Years and by Selected Demographic Characteristics, National Survey of Children Health, 2016–2018, and 2019–2021. *NH* non-Hispanic, *HS* high school. Education levels show the highest adult education in the family. The subgroup of NH other is excluded from this figure due to potentially unreliable estimates based on a relative standard error > = 30%

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Table 1

Prevalence of Ever-diagnosed cerebral palsy in children aged 2 to 17 years, by selected demographic and perinatal characteristics, National survey of children health, 2016–2021

Characteristic	Unweighted cases	Weighted prevalence per 1000 (95%CI)	Weighted prevalence ratio (95%CI)
Total (*n*=207,203)	699	3.1 (2.7, 3.5)	NA
Sex			
Female	307	2.5 (2.0, 3.0)	Ref
Male	392	3.6 (3.0, 4.4)	**1.48 (1.13, 1.94)**
Race/ethnicity			
NH White	453	2.9 (2.5, 3.4)	Ref
NH Black	72	4.2 (3.0, 5.9)	1.44 (1.00, 2.08)
NH other	90	4.5 (2.8, 7.1)	1.52 (0.93, 2.47)
Hispanic	84	2.2 (1.5, 3.1)	0.73 (0.50, 1.08)
Child age (year)			
2–9	284	2.6 (2.1, 3.3)	Ref
10–13	188	3.7 (2.9, 4.6)	**1.40 (1.02, 1.93)**
14–17	227	3.3 (2.6, 4.2)	1.24 (0.89, 1.72)
Highest adult education in family[†]			
HS or less	135	3.1 (2.3, 4.2)	Ref
Some college	176	3.4 (2.6, 4.3)	1.08 (0.73, 1.59)
College or higher	384	2.9 (2.4, 3.5)	0.94 (0.66, 1.32)
Birthweightf			
Very low birth weight (< 1,500 g)	155	46.6 (34.3, 62.9)	**24.66 (17.37, 35.01)**
Low birth weight (1500 g-2,499 g)	122	7.1 (5.3, 9.5)	**3.76 (2.68, 5.28)**
Not low birth weight (>=2,500 g)	380	1.9 (1.6, 2.3)	Ref
Premature (born > 3 weeks before the due date)[†]			
Yes	300	12.7 (10.2, 15.7)	**6.92 (5.24, 9.14)**
No	383	1.8 (1.5, 2.2)	Ref

CI confidence interval, *NH* non-Hispanic, *HS* high school, *n* unweighted sum

[†]Children with missing responses for demographic and perinatal variables were excluded from the corresponding analysis: highest adult education in family: 0.6%, birthweight: 5.8%, and premature: 1.6%; Confidence intervals of weighted prevalence ratios in bold indicate that the interval does not include 1.

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Table 2

Physical difficulties and parent-rated cerebral palsy severity among children with current cerebral palsy, National survey of children health, 2016–2021

	2016–2021		2016–2018		2019–2021		
	Unweighted cases	**Weighted prevalence (95%CI)**	**Unweighted cases**	**Weighted prevalence (95%CI)**	**Unweighted cases**	**Weighted prevalence (95%CI)**	***p*-value†**
Difficulty walking or climbing stairs (6–17 years old)	257	56.8 (48.4, 64.7)	128	54.9(42.5, 66.7)	129	59.0 (48.6, 68.7)	0.612
Difficulty dressing or bathing (6–17 years old)	284	63.7 (55.3,71.4)	147	63.2(50.2, 74.5)	137	64.4 (54.3, 73.4)	0.878
Caregiver rated severity (2–17 years old)	265	40.3 (33.7, 47.2)	125	43.4(33.9, 53.5)	140	36.8 (28.4, 46.2)	Reference
Mild	203	36.5 (29.7, 43.8)	103	39.8(30.1, 50.2)	100	32.8(24.1,43.0)	0.935
Moderate Severe	140	23.3 (18.0, 29.5)	66	16.8(11.7, 23.6)	74	30.3 (21.7, 40.6)	0.037

A total of 491 children with a current diagnosis of CP were identified among 155,178 children aged 6–17 years. A total of 616 children with a current diagnosis of CP were identified among 208,027 children aged 2–17 years; A small percentage of missing data on physical difficulties or parents rated severity, ranging from 2.0–3.9% was excluded from the corresponding analysis in the table; CI: confidence interval

†Derived from design adjusted chi-square tests for changes in the prevalence between 2016–2018 and 2019–2021

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Table 3

Developmental, neurological, and mental health conditions among children aged 3 to 17 years with and without current cerebral palsy, National survey of children health, 2016–2021

	Children with a current CP diagnosis, *n* = 592		Children without a current CP diagnosis, *n* = 192,671		
Current conditions	**Unweighted cases**	**Weighted prevalence (95% CI)**	**Unweighted cases**	**Weighted prevalence (95% CI)**	**Weighted prevalence ratio (95% CI)**
Any conditions[¶]	511	91.2 (87.3, 94.0)	48,203	23.7 (23.3, 24.1)	3.85 (3.70, 4.01)
Any other developmental conditions[†]	492	84.9 (77.8, 90.0)	35,668	17.7 (17.3, 18.1)	4.79 (4.45, 5.16)
Developmental delay	447	78.1 (71.1, 83.8)	10,132	5.1 (4.9, 5.3)	15.24 (13.90, 16.70)
Learning disability	354	62.4 (54.6, 69.6)	13,688	6.9 (6.6, 7.1)	9.08 (8.01, 10.30)
Speech/language disorder	343	57.9 (50.2, 65.2)	10,147	5.5 (5.3, 5.8)	10.45 (9.11, 11.99)
Intellectual disability	226	43.0 (35.8, 50.5)	1,925	1.0 (0.9, 1.1)	42.78 (34.97, 52.34)
Behavioral or conduct problems	140	23.4 (17.9, 29.9)	14,399	7.0 (6.8, 7.3)	3.33 (2.57, 4.31)
Attention deficit hyperactivity disorder	101	16.4 (12.0, 21.9)	19,496	8.9 (8.6, 9.2)	1.84 (1.36, 2.50)
Autism spectrum disorder	75	12.2 (8.3, 17.5)	5,715	2.8 (2.6, 3.0)	4.33 (2.96, 6.34)
Any neurological conditions[‡]	295	50.3 (42.9, 57.7)	5,741	3.5 (3.3, 3.8)	14.25 (12.13, 16.74)
Epilepsy or seizure disorder	210	36.7 (29.7, 44.3)	1,078	0.5 (0.5, 0.6)	69.30 (55.05, 87.24)
Blindness or problems with seeing, even when wearing glasses	166	26.8 (21.1, 33.4)	2,679	1.9 (1.7, 2.0)	14.36 (11.22, 18.39)
Deafness or problems with hearing	58	11.7 (7.6, 17.8)	2,372	1.4 (1.2, 1.5)	8.69 (5.58, 13.54)
Any mental health conditions[§]	154	27.4 (21.0, 34.9)	21,745	8.9 (8.6, 9.1)	3.09 (2.40, 3.99)
Anxiety problems	149	25.9 (19.6, 33.3)	20,017	8.0 (7.8, 8.3)	3.22 (2.47, 4.21)
Depression	47	# 9.8 (5.3, 17.4)	8,757	3.6 (3.4, 3.7)	[#]2.75 (1.51, 5.02)

Among 194,051 children aged 3–17 years, 193,263 had data on current CP diagnosis; Children without a current CP diagnosis include children ever diagnosed with CP who reported not having a current CP diagnosis

A small percentage of missing data, ranging from 0.2–3.4% was excluded from the corresponding analysis for any conditions listed in the table

n: unweighted sum. CI: confidence interval

[†]One or more of the 7 developmental conditions, regardless of the number of conditions reported

[‡]One or more of the 3 neurological conditions, regardless of the number of conditions reported

[§]One or two mental health conditions, regardless of the number of conditions reported

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¶One or more of the 12 conditions listed in the table, regardless of the number of conditions reported

#Potentially unreliable estimate based on a relative standard error > = 30% and < 50% or comparison based on a group with a potentially unreliable estimate