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## Prevalence of cerebral palsy and intellectual disability among children identified in two U.S. National Surveys, 2011–2013

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### Abstract

**Purpose**—Cerebral palsy (CP) and intellectual disability (ID) are developmental disabilities that result in considerable functional limitations. There are few recent and nationally representative prevalence estimates of CP and ID in the United States.

**Methods**—We used two U.S. nationally representative surveys, the 2011–2012 National Survey of Children’s Health (NSCH) and the 2011–2013 National Health Interview Survey (NHIS), to determine the prevalence of CP and ID based on parent report among children aged 2–17 years.

**Results**—CP prevalence was 2.6 (95% confidence interval [CI]: 2.1–3.2) per 1000 in the NSCH and 2.9 (95% CI: 2.3–3.7) in the NHIS. ID prevalence was 12.2 (95% CI: 10.7–13.9) and 12.1 (95% CI: 10.8–13.7) in NSCH and NHIS, respectively. For both conditions, the NSCH and NHIS prevalence estimates were similar to each other for nearly all sociodemographic subgroups examined.

**Conclusions**—Despite using different modes of data collection, the two surveys produced similar and plausible estimates of CP and ID and offer opportunities to better understand the needs and situations of children with these conditions.

### Keywords

Intellectual disability; Cerebral palsy; Developmental disabilities; Prevalence

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

## Introduction

Developmental disabilities (DDs) are a heterogeneous group of chronic conditions defined by problems in cognitive, behavioral, or physical functioning [1,2]. Cerebral palsy (CP) is the most common pervasive childhood motor disability. Intellectual disability (ID; also called intellectual developmental disorder, and formerly called mental retardation) is characterized by impaired cognitive and adaptive functioning in conceptual, practical, and social domains [3]. Children with CP and ID frequently have other co-occurring developmental and health conditions [4]. There are few recent and nationally representative prevalence estimates of CP and ID in the United States (US).

The U.S.-based Autism and Developmental Disabilities Monitoring (ADDM) Network reported CP-prevalence estimates of 3.1–3.6 per 1000 8-year-old children living in several U.S. regions in 2000–2008 [5–7]. Other high-income countries including Australia, Canada, the United Kingdom, and Norway reported lower CP prevalence (1.4–2.1 per 1000 live births) during comparable time periods [8–11]. Some have posited the higher U.S.-based point-prevalence estimates are an artifact of migration patterns whereby children with CP are more likely to reside in areas monitored by surveillance systems, but a subsequent analysis did not support this hypothesis [12,13].

There are few studies reporting ID prevalence in the United States. Data from the 2006 through 2008 National Health Interview Survey (NHIS) indicate that 6.7 per 1000 U.S. children aged 3–17 years had been diagnosed with ID (per parent/guardian report of past diagnosis of “mental retardation”) [14]. An ID surveillance system in metropolitan Atlanta reported stable prevalence from 1991–2010 (range: 10.6–14.9 per 1000 8-year-old children, average 13.0 per 1000 children) [15].

Prevalence estimates of these conditions are important for understanding disparities within important sociodemographic subgroups, identifying potential risk factors, and anticipating the service needs for affected individuals. In this study, we estimated the prevalence of CP and ID among U.S. children from two independent U.S. health surveys, NHIS and the National Survey of Children’s Health (NSCH). These surveys are complementary in that they both collect nationally representative data on children’s health conditions via parent and/or guardian report, and they included identical CP and ID questions in the most recent survey administrations. However, mode of survey of administration differed; NHIS is conducted in-person and NSCH is a random-digit-dial telephone survey. The NHIS is an in-depth survey of health conditions, limitations, health care access, and service use, whereas the NSCH covers child well-being topics including child development, activities and flourishing, family functioning, parental health and behaviors, and neighborhood characteristics.

In addition to estimating national prevalence, the recent addition of ID and CP questions to NSCH provided us with a unique opportunity to compare whether parental report of these two disabilities would yield comparable estimates across two independent population-based surveys. Between-survey comparisons have been previously performed for other childhood conditions to help assess the reliability of prevalence estimates [16]. Using recent data from

the NHIS and NSCH, we compared the overall prevalence of CP and ID and the prevalence within different demographic subgroups (age, sex, race/ethnicity, and parental education).

## Methods

We used data from the 2011–2012 NSCH and the 2011–2013 NHIS. We describe and compare the characteristics of both surveys in Table 1. Extensive technical details for the NSCH and NHIS have been previously described [17–19].

Although the content of the two surveys varies, both included very similar questions on CP and ID (and several other DDs). Parents and/or guardians were asked: “Has a doctor or other health professional ever told you that [child] had [condition]?” For ID, the questions asked about both “intellectual disability” and “mental retardation.” The exact wordings for the questions are included in Table 1.

In the NSCH, parents who responded affirmatively to the previously mentioned CP/ID stem questions were asked several follow-up questions including whether the child currently (at the time of survey) has the condition. For children with current CP, parents were asked to describe the child’s usual ability to walk using a response scheme analogous to the Gross Motor Function Classification System. For children with current ID, parents were asked to describe the condition as mild, moderate, or severe.

Our study samples included children aged 2–17 years ( $n = 85,637$  in NSCH; and  $n = 34,503$  in NHIS); children under 2 years were excluded because DDs are often not diagnosed in very young children. In addition, we excluded children with unknown or missing CP or ID status ( $<0.1\%$  in both surveys). We examined the prevalence of CP and ID by common demographic characteristics that were available in both surveys: sex, race-ethnicity, age, and parental (or guardian) educational attainment. A small proportion of NSCH observations had missing demographic information; these were excluded from the corresponding stratified analysis and summarized in Table 2.

We used the R survey package to account for the survey designs and nationally representative sampling weights in all analyses. The weighted NHIS samples could be readily combined and analyzed in R [20]. We calculated prevalence odds ratios (pOR) and 95% confidence intervals (95% CIs) to compare prevalence estimates between demographic subgroups.

## Results

### Cerebral palsy prevalence

The prevalence of CP was similar in the NSCH and NHIS samples (2.6 and 2.9 per 1000 children, respectively, Table 2). Although the prevalence estimates for specific sociodemographic subgroups were less precise, the confidence intervals for estimates from NSCH overlapped those from NHIS for 12 of the 13 subgroups we examined; the only exception being for males. The male-female ratio based on the NSCH indicated a lower CP prevalence among males (pOR = 0.6, 95% CI: 0.4–0.9), but the NHIS ratio suggested a higher male prevalence (pOR = 2.2, 95% CI: 1.4–3.6). In both samples, CP prevalence was

higher among non-Hispanic black versus non-Hispanic white children but the difference was only significant in the NSCH sample. Prevalence did not differ by child age in either survey. In both surveys, we observed an inverse (but nonsignificant) relationship between CP prevalence and family educational attainment.

### **Intellectual disability prevalence**

The prevalence of ID was also similar in the NSCH and NHIS samples (12.2 and 12.1 per 1000 children, respectively, Table 2). Prevalence estimates and patterns by sociodemographic subgroups were also similar. In both samples, ID prevalence was higher among boys than girls, ID prevalence was lower among children younger than 10 years of age (vs. older children), and children from families with more than a high school education were half as likely to have ID as children from families with less than a high school education. ID prevalence was significantly higher among non-Hispanic black than non-Hispanic white children in the NSCH sample; a similar association was observed in the NHIS sample, but it narrowly missed statistical significance.

### **Comparison of “ever diagnosed” and “currently has condition” in the NSCH sample**

Among the NSCH sample of children that had ever been diagnosed with CP, 86% reported that they currently had CP. Similarly, the ID prevalence based on current condition was 87% that of the ever diagnosed estimate (Table 3). Within specific sociodemographic subgroups the percentage of children “ever diagnosed” that “currently” had the condition ranged from 70% to 98% for CP and 77% to 93% for ID.

Fifty-five percent of children described as currently having CP could walk without assistance; 8% could walk with assistance and 37% had limited or no walking. Thirty-four percent of children described as currently having ID were rated by their parents as mild severity, 42% were rated as moderate severity, and 24% as severe. (Data not shown in tables.)

## **Discussion**

This analysis used two nationally representative U.S. surveys to provide recent prevalence estimates for CP and ID among children. Despite using different survey modalities (telephone vs. in-person), these surveys produced similar and plausible prevalence estimates for both conditions. The consistency exhibited here is in line with a previous assessment that indicated high consistency of parent-reported autism reporting between earlier cycles of the NSCH and NHIS [4].

The CP estimates (2.6 and 2.9 per 1000 children) were also similar to the most recent estimate reported by the ADDM Network for four local U.S. population-based surveillance sites (3.1 per 1000 children) [6], and the confidence intervals for both the NSCH and NHIS estimates include the ADDM estimate. In addition, the proportions of children with CP reported to walk unassisted was very similar to findings from several previous studies [20], as was the excess prevalence among black versus white children [21–23].

The ID prevalence estimates are higher than previously reported estimates from the 2006–2008 NHIS (6.7 per 1000) [14]. This apparent increase should be interpreted with caution; earlier surveys used the term “mental retardation” which carries greater stigma than “intellectual disability” and could have influenced reporting. Although there are no comparable population-based estimates on ID based on measures of cognitive deficits and adaptive functioning criteria, similar ID prevalence estimates were reported by a metropolitan Atlanta surveillance system that used existing cognitive test scores [13]. If parents are unfamiliar with ID terminology (or if professionals use other terms to describe ID), parent-reported surveys could underestimate ID prevalence. ID commonly co-occurs with many other DDs and might not always be recognized as a distinct condition. Moreover, mild ID is often detected by school psychologists who might be more concerned that children receive appropriate educational services than with specific diagnostic labels.

Although the two surveys had identical questions on whether a child ever had either condition, the NSCH included additional questions about whether the child currently had CP or ID. “Current” estimates were somewhat lower (13% lower for CP and 14% for ID). CP and ID are typically considered chronic and nonprogressive conditions, but it is possible for some children to “outgrow” their diagnosis [24]. Alternately, imperfect parental recall (either not reporting an actual diagnosis or reporting a diagnosis that was not given) could lead to biased prevalence estimates for children ever having the condition. Whether “ever” or “current” disability is the most appropriate measure may depend on the intended purpose, and both measures are used in various studies of DDs.

These surveys offer nationally representative sampling frames, timely availability of data, and include a wealth of information for each child. The surveys have limited statistical power to precisely estimate prevalence for certain subgroups. The annual sample of children in NHIS is considerably smaller than NSCH; however, multiple years of NHIS data can be combined. Both surveys rely on parental report of a child’s diagnoses, which does not allow for complete ascertainment of important clinical features. The sampling weights for both surveys are adjusted for nonresponse, but the low response rate for the NSCH could have biased some estimates, particularly within subgroups.

We were unable to identify the reason for the discrepancy in the sex-specific CP estimates between NSCH and NHIS. Previous studies tend to show excess CP prevalence among males, so the NSCH result is less consistent with other studies [6,8,23,25–27], although it has a larger sample than NHIS. It is possible that nonresponse bias played a role. In addition, the probability of observing any statistically significant “discordant” result between the two surveys is influenced by the total number of stratified analyses that we performed and the prevalence of CP; it is conceivable that this finding occurred by chance. Notwithstanding this comparison, it is encouraging how well all other subgroup estimates—and the overall prevalence—matched. Although it is important to consider the stability of the subgroup estimates in future analyses, researchers might elect to use NHIS or NSCH data based on the availability of relevant survey items (including “current” disability or other specific domains of functioning or health) and the statistical power afforded by each survey.

These national surveys provide recent and nationally representative prevalence estimates among children in the United States for two DDs associated with substantial functional limitations. The two surveys produced similar overall prevalence estimates for ID and CP, and the CP estimates were comparable to that obtained from another U.S.-based surveillance system [6]. Because both surveys produced plausible and comparable prevalence estimates in population-based sampling frames, the surveys' abundance of additional information could be used to further quantify and characterize the health, service needs, and life situations of children affected by these conditions in the United States.

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**Table 1**

## Comparison of the NSCH and the NHIS

Characteristic	2011–2012 NSCH	2011–2013 NHIS
Survey design and target population	Multistage sampling used to represent all children aged 0–17 years in all 50 U.S. states, District of Columbia	Multistage sampling to represent all dwelling units in the US that contain members of the noninstitutionalized population
Mode of contact	Random-digit-dial telephone (landline and cellular) survey; households contacted, screened for presence of children	In-person household survey; face-to-face interviews using computer-assisted personal interviewing
Inclusion of children	One child per household was randomly selected to be survey target	One child per household randomly selected as subject for child sample survey
Respondent	Parent or knowledgeable guardian	Knowledgeable parent or caregiver
Approximate number of children included	95,000	~13,000 each year; 39,000 for 2011–2013
Frequency	Was every 4 years, with a planned redesign for it to be an annual survey beginning in 2016	Annually
Operator	Sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration and was conducted by the National Center for Health Statistics	National Center for Health Statistics
Response rate	23% (38.2% in the landline sample and 15.5% in the cellular phone)	69%–75% for child-level components
Question(s) related to cerebral palsy or intellectual disability	Please tell me if a doctor or other health care provider ever told you that [child] had the condition, even if [he/she] does not have the condition now. Cerebral palsy? Intellectual disability or mental retardation? [if yes to above question]: Does [child] currently have the condition? [if yes to the “current” question for intellectual disability]: Would you rate the condition as mild, moderate, or severe? [if yes to the “current” question for cerebral palsy]: How would you describe his/her usual ability to walk? (1. Walks without a cane, crutches or walker; 2. Walks with a cane, crutches or a walker; 3. Walks independently)	Has a doctor or health professional ever told you that [child] had an intellectual disability, also known as mental retardation? Looking at this list, has a doctor or other professional ever told you that [child] had any of these conditions? Cerebral palsy



**Table 2**  
Prevalence of cerebral palsy (CP) and intellectual disability (ID) (indicated by parent report), by selected demographic characteristics

Characteristic	National Survey of Children's Health 2011–2012, aged 2–17 years				National Health Interview Survey, 2011–2013, aged 2–17 years					
	Unweighted noncases	Unweighted cases	Weighted prevalence/1000	95% CI	Weighted Prevalence odds ratio (95% CI)	Unweighted noncases	Unweighted cases	Weighted prevalence/1000	95% CI	Weighted Prevalence odds ratio (95% CI)
Cerebral palsy (parent report of past diagnosis, ever)										
Total	85,293	312	2.6	2.1–3.2	—	34,382	102	2.9	2.3–3.7	—
Sex										
Female	41,201	146	3.3	2.4–4.5	1.0 (ref)	16,695	35	1.8	1.2–2.6	1.0 (ref)
Male	43,991	165	2.0	1.5–2.6	0.6 (0.4–0.9)	17,687	67	4.0	3.0–5.4	2.2 (1.4–3.6)
Race/ethnicity										
NH white	55,092	192	2.4	1.8–3.1	1.0 (ref)	15,182	50	3.1	2.2–4.4	1.0 (ref)
NH black	8007	43	4.6	2.8–7.4	1.9 (1.1–3.4)	5263	24	4.1	2.5–6.9	1.3 (0.7–2.5)
NH other	9191	41	3.0	1.7–5.3	1.3 (0.7–2.4)	3779	3	1.1	0.3–3.9	0.4 (0.1–1.3)
Hispanic	11,107	30	1.9	1.0–3.6	0.8 (0.4–1.6)	10,158	25	2.5	1.6–3.8	0.8 (0.5–1.4)
Child age										
2–5 years old	19,897	55	2.6	1.5–4.5	1.0 (ref)	8804	16	1.9	1.1–3.3	1.0 (ref)
6–9 years old	20,298	68	2.4	1.6–3.5	0.9 (0.5–1.9)	7926	31	3.4	2.3–5.2	1.8 (0.9–3.6)
10–13 years old	21,391	97	2.7	1.9–3.7	1.0 (0.5–2.0)	8295	25	2.6	1.6–4.3	1.4 (0.67–2.8)
14–17 years old	23,707	92	2.9	1.9–4.3	1.1 (0.6–2.2)	9357	30	3.7	2.4–5.7	2.0 (1.0–3.9)
Highest adult education in family										
Less than HS	11,727	56	3.4	2.1–5.4	1.0 (ref)	3878	10	3.6	1.7–7.5	1.0 (ref)
HS or equivalent	27,854	106	3.0	2.2–4.1	0.9 (0.5–1.6)	6943	22	3.1	1.8–5.3	0.9 (0.4–2.2)
More than HS	40,851	124	2.0	1.3–2.9	0.6 (0.3–1.1)	23,507	70	2.8	2.1–3.7	0.8 (0.4–1.7)
Intellectual disability (parent report of past diagnosis, ever)										
Total	84,364	1204	12.2	10.7–13.9	—	34,071	416	12.1	10.8–13.7	—
Sex										
Female	40,877	450	9.4	7.6–11.5	1.0 (ref)	16,590	137	7.8	6.3–9.8	1.0 (ref)
Male	43,385	754	14.9	12.6–17.7	1.6 (1.2–2.1)	17,481	279	16.3	14.0–18.8	2.1 (1.6–2.7)
Race/ethnicity										

Characteristic	National Survey of Children's Health 2011–2012, aged 2–17 years					National Health Interview Survey, 2011–2013, aged 2–17 years				
	Unweighted noncases	Unweighted cases	Weighted prevalence/1000	95% CI	Weighted Prevalence odds ratio (95% CI)	Unweighted noncases	Unweighted cases	Weighted prevalence/1000	95% CI	Weighted Prevalence odds ratio (95% CI)
NH white	54,521	743	12.3	10.5–14.4	1.0 (ref)	15,040	193	12.0	10.1–14.2	1.0 (ref)
NH black	7885	157	17.1	13.0–22.5	1.4 (1.0–1.9)	5204	84	15.5	12.1–20.0	1.3 (1.0–1.8)
NH other	9091	137	11.3	8.3–15.4	0.9 (0.7–1.3)	3753	30	9.8	6.5–14.9	0.8 (0.5–1.3)
Hispanic	10,992	143	10.1	6.4–15.8	0.8 (0.5–1.3)	10,074	109	11.5	9.0–14.5	1.0 (0.7–1.3)
Child age										
2–5 years	19,784	158	5.9	4.5–7.9	1.0 (ref)	8772	48	5.7	4.1–7.8	1.0 (ref)
6–9 years	20,106	250	11.8	9.2–15.2	2.0 (1.4–2.9)	7880	79	9.2	6.9–12.4	1.6 (1.1–2.5)
10–13 years	21,103	378	15.9	12.3–20.5	2.7 (1.8–3.9)	8181	137	17.8	14.3–22.3	3.1 (2.1–4.7)
14–17 years	23,371	418	15.0	11.8–18.9	2.5 (1.8–3.6)	9238	152	15.9	13.0–19.4	2.8 (1.9–4.1)
Highest adult education in family										
Less than HS	11,553	225	17.8	12.9–24.6	1.0 (ref)	3812	76	21.3	16.1–28.3	1.0 (ref)
HS or equivalent	27,522	425	12.4	10.2–15.1	0.7 (0.5–1.0)	6872	92	13.8	10.6–18.1	0.7 (0.4–1.0)
More than HS	40,499	461	9.7	8.0–11.8	0.5 (0.4–0.8)	23,333	248	10.4	8.9–12.1	0.5 (0.4–0.7)

CI = confidence interval; HS = high school; NH = non-Hispanic.

NSCH had a small amount of missing or “refused” responses for demographic variables, these observations were excluded from the corresponding analysis: sex: 0.1%, race/ethnicity: 2.2%, age: 0%, education: 5.7%. NHIS had complete information for demographic characteristics.

\* Confidence interval excludes 1.0 (pOR = 1.4, 95% CI: 1.01–1.9).

**Table 3**

Comparison of weighted prevalence estimates per 1000 children for “ever” versus “current” status for cerebral palsy (CP) and intellectual disability (ID); 2011e2012 National Survey of Children’s Health

Characteristic	Ever CP prevalence (95% CI)	Current CP prevalence (95% CI)	Ratio of current: ever CP	Ever ID prevalence (95% CI)	Current ID prevalence (95% CI)	Ratio of current: ever ID
Total	2.6 (2.1–3.2)	2.3 (1.8–2.8)	0.86	12.2 (10.7–13.9)	10.6 (9.1–12.3)	0.87
Sex						
Female	3.3 (2.4–4.5)	2.8 (2.0–3.8)	0.84	9.4 (7.6–11.5)	7.8 (6.2–9.8)	0.83
Male	2.0 (1.5–2.6)	1.8 (1.3–2.4)	0.89	14.9 (12.6–17.7)	13.3 (11.0–16.0)	0.89
Race/ethnicity						
Non-Hispanic white	2.4 (1.8–3.1)	1.9 (1.4–2.4)	0.79	12.3 (10.5–14.4)	10.8 (9.1–12.9)	0.88
Non-Hispanic black	4.6 (2.8–7.4)	4.2 (2.5–7.0)	0.91	17.1 (13.0–22.5)	13.9 (10.2–18.9)	0.81
Non-Hispanic other	3.0 (1.7–5.3)	2.7 (1.5–5.0)	0.90	11.3 (8.3–15.4)	8.7 (6.3–12.1)	0.77
Hispanic	1.9 (1.0–3.6)	1.8 (0.9–3.6)	0.98	10.1 (6.4–15.8)	9.4 (5.8–15.1)	0.93
Child age						
2–5 years old	2.6 (1.5–4.5)	1.8 (1.0–3.3)	0.70	5.9 (4.5–7.9)	4.7 (3.4–6.5)	0.80
6–9 years old	2.4 (1.6–3.5)	2.2 (1.4–3.3)	0.91	11.8 (9.2–15.2)	10.0 (7.6–13.3)	0.85
10–13 years old	2.7 (1.9–3.7)	2.5 (1.7–3.5)	0.92	15.9 (12.3–20.5)	13.9 (10.5–18.5)	0.87
14–17 years old	2.9 (1.9–4.3)	2.5 (1.6–3.9)	0.89	15.0 (11.8–18.9)	13.5 (10.4–17.4)	0.90
Highest adult education in family						
Less than high school	3.4 (2.1–5.4)	3.2 (2.0–5.3)	0.96	17.8 (12.9–24.6)	15.3 (10.6–21.9)	0.86
High school or equivalent	3.0 (2.2–4.1)	2.7 (1.9–3.7)	0.88	12.4 (10.2–15.1)	10.8 (8.7–13.4)	0.87
More than high school	2.0 (1.3–2.9)	1.5 (1.0–2.2)	0.78	9.7 (8.0–11.8)	8.5 (6.8–10.5)	0.87

“Ever” condition includes children that were reported to have “ever been told” they have the condition.

“Current” refers to the subset of “Ever” which gave an affirmative answer to the question “Does [child’s name] currently have [condition]?”