



## Brief communication

## 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.

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## 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 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.

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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

**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

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

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