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# Prevalence of Cerebral Palsy in 8-Year-Old Children in Three Areas of the United States in 2002: A Multisite Collaboration

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## What's Known on This Subject

Cerebral palsy (CP) is the most common cause of motor disability of childhood. The prevalence of CP has been reported to range from 1.5 to 3.0 cases per 1000 live births or 1000 children. There have been few recent studies of the prevalence of CP in the United States.

## What This Study Adds

This report of CP prevalence from a multisite collaboration in 2002 contributes new knowledge to the epidemiology of CP in the United States.

## ABSTRACT

**OBJECTIVE.** The goal was to estimate the prevalence of cerebral palsy and cerebral palsy subtypes among children in 3 areas of the United States by using a population-based surveillance system.

**METHODS.** Using methods developed by the Centers for Disease Control and Prevention Metropolitan Atlanta Developmental Disabilities Surveillance Program, investigators from the Autism and Developmental Disabilities Monitoring Network conducted surveillance of cerebral palsy among 8-year-old children living in northern Alabama, metropolitan Atlanta, and southeastern Wisconsin in 2002 ( $N = 114\ 897$ ). Cross-sectional data were collected through retrospective record review from multiple sources. Cases were linked to birth certificate and census files to obtain additional information. Period prevalence estimates were calculated per 1000 children 8 years of age.

**RESULTS.** The average prevalence of cerebral palsy across the 3 sites was 3.6 cases per 1000, with notably similar site-specific prevalence estimates (3.3 cases per 1000 in Wisconsin, 3.7 cases per 1000 in Alabama, and 3.8 cases per 1000 in Georgia). At all sites, prevalence was higher in boys than girls (overall boy/girl ratio: 1.4:1). Also, at all sites, the prevalence of cerebral palsy was highest in black non-Hispanic children and lowest in Hispanic children. At all sites, the prevalence among children living in low- and middle-income neighborhoods was higher than that among children living in high-income neighborhoods. Spastic cerebral palsy was the most common subtype (77% of all cases), with bilateral spastic cerebral palsy dominating the spastic group (70%).

**CONCLUSION.** These findings contribute new knowledge to the epidemiology of cerebral palsy in the United States. The similarities in prevalence rates and patterns of cerebral palsy reported for 8-year-old children at 3 geographically distinct sites provide evidence of the reliability of the surveillance methods used by the Autism and Developmental Disabilities Monitoring Network.

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### Key Words

prevalence, cerebral palsy, developmental disabilities, population-based surveillance

### Abbreviations

ADDM—Autism and Developmental Disabilities Monitoring  
CP—cerebral palsy  
SES—socioeconomic status  
CI—confidence interval

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CEREBRAL PALSY (CP) is the most common cause of motor disability in childhood. Most previous population-based studies reported the prevalence of CP to range from 1.5 to 3.0 cases per 1000 live births or 1000 children.<sup>1-3</sup> The estimated lifetime cost of CP in the United States is nearly \$1 million per person (2003 dollars).<sup>4</sup> Although recent improvements in rehabilitation and surgical care can improve functional outcomes and quality of life for individuals with CP, researchers have made relatively little progress in understanding the causes of CP and in developing strategies for primary prevention. In addition, 2 of the leading risk factors for CP, namely, preterm birth and multiple births, have increased in frequency in recent decades in the United States and other developed countries. There is some evidence of an association between improved rates of survival of infants born prematurely and/or at very low birth weight and increasing prevalence of CP,<sup>5-7</sup> but this finding has not been consistent<sup>8-10</sup> and recent data from Europe indicated a decline between the birth years 1980 and 1996 in the prevalence of CP among survivors of preterm birth.<sup>11</sup>

Monitoring of the prevalence of CP and determination of whether changes in risk factors (such as birth weight distribution and number of multiple births) affect the prevalence of CP over time require ongoing, systematic, population-based surveillance. Population-based monitoring of CP prevalence also helps determine service needs for affected children and their families. Descriptions of the frequency of CP subtypes in the population may also yield clues regarding etiology, and studies of functioning can help clinicians and other service providers develop more coordinated, more holistic care.

The Autism and Developmental Disabilities Monitoring (ADDM) Network was funded by the Centers for Disease Control and Prevention in 2000 to develop methods for public health monitoring of the prevalence of developmental disabilities in the United States. Important features of the ADDM Network include its retrospective record review and cross-sectional, multisite, surveillance system, which relies on multiple sources of information on individual children in a defined geographic area who have been identified administratively for service provision.<sup>12</sup> This first report from the ADDM Network provides population-based

estimates of CP prevalence among 8-year-old children in 3 US populations and examines variations in the prevalence of CP according to broad demographic characteristics and CP subtypes.

## METHODS

### Surveillance Sites and Population Characteristics

Three sites monitored the occurrence of CP among a total of 114 897 children, 8 years of age, living in surveillance areas in northern Alabama, metropolitan Atlanta, Georgia and southeastern Wisconsin in 2002 (Table 1). The race/ethnicity distributions varied among sites, with the proportion of white non-Hispanic children ranging from 40.7% (Georgia) to 69.2% (Alabama) and that of black non-Hispanic children ranging from 18.7% (Wisconsin) to 44.8% (Georgia) (Table 1). The gender distributions were similar across sites, with approximately an equal proportion of boys and girls. The sites were chosen through a competitive process on the basis of their ability to conduct developmental disability surveillance, but they were not selected to reflect a nationally representative sample. Each site met applicable local institutional review board and/or other privacy and confidentiality requirements.

### Surveillance Methods and Case Determination

#### Basis for Surveillance Methods

The methods used by the ADDM Network were based on the Centers for Disease Control and Prevention Metropolitan Atlanta Developmental Disabilities Surveillance Program, an active, population-based, multiple-source surveillance program that monitors the occurrence of developmental disabilities among 8-year-old children in metropolitan Atlanta.<sup>12-15</sup> The ADDM Network implemented the basic Metropolitan Atlanta Developmental Disabilities Surveillance Program methods, using common data abstraction, case definition, clinician review, and quality assurance procedures.

#### Definition of CP

CP is an umbrella term covering a group of nonprogressive but often changing motor impairment syndromes secondary to lesions or anomalies of the brain, arising at

TABLE 1 Population Characteristics of 8-Year-Old Children According to Site in Surveillance Year 2002

Site	Institution	Surveillance Area	8-y-Old Children in Study Area, n (%)					
			Total	White Non-Hispanic	Black Non-Hispanic	Hispanic	American Indian/Alaska Native Non-Hispanic	Asian/Pacific Islander Non-Hispanic
Alabama	University of Alabama at Birmingham	32 counties	35 472	24 552 (69.2)	9442 (26.6)	1046 (2.9)	178 (0.5)	254 (0.7)
Georgia	Centers for Disease Control and Prevention	5 counties, metropolitan Atlanta	44 299	18 038 (40.7)	19 824 (44.8)	4342 (9.8)	94 (0.2)	2001 (4.5)
Wisconsin	University of Wisconsin-Madison	10 counties, including cities of Madison and Milwaukee	35 126	23 893 (68.0)	6564 (18.7)	3419 (9.7)	193 (0.5)	1057 (3.0)
All sites			114 897	66 483 (57.9)	35 830 (31.2)	8807 (7.7)	465 (0.4)	3312 (2.9)

Data were obtained from the National Center on Health Statistics bridged-race postcensal population estimates for 2002.<sup>19</sup>

any time during brain development.<sup>16</sup> For surveillance purposes, we modified the definition used by Mutch et al<sup>16</sup> to include children with postnatally acquired CP.

#### *Case Definition*

For the 2002 surveillance year, a CP case was defined as a child born in 1994 whose parent(s) or legal guardian(s) resided in the surveillance area during 2002 and who had a documented diagnosis of CP and/or physical findings consistent with CP in an evaluation by a qualified professional. A qualified professional was defined as a physician, physical therapist, occupational therapist, nurse practitioner, or physician's assistant. Case determination was completed through record review in 2 phases, case ascertainment followed by clinician review. Linkages to vital records death files were completed at each site, to exclude children who died before the surveillance year.

#### *Case Ascertainment*

All sites used multiple nonschool sources to identify cases, including state health facilities, hospitals, clinics, diagnostic centers, and other clinical providers for children with developmental disabilities. At these sources, case finding lists were generated by using International Classification of Diseases, Ninth Revision, Clinical Modification diagnostic codes for CP and medical conditions associated with CP.<sup>17</sup> Georgia was also able to identify children through the special education programs serving the public school districts in the surveillance area. The source files were screened for evaluations containing a confirmed or suspected CP diagnosis or descriptions of physical findings consistent with CP. Demographic data, verbatim descriptions of relevant physical findings, and diagnostic summaries were abstracted for each child identified as a possible CP case. Georgia also abstracted special education service data and psychometric test results from education records. Information from multiple sources was abstracted into one composite summary record for each potential case. CP cases were linked to birth certificate and census files to provide additional demographic information. The proportion of children whose records were abstracted for CP that were determined to be cases ranged from 44% in Alabama and Wisconsin to 53% in Georgia, for an average of 47% across all 3 sites.

#### *Clinician Review*

All abstracted evaluations from the case ascertainment phase were reviewed by a CP clinician reviewer, to determine final case status. Clinician reviewers were clinicians with an advanced degree, direct clinical experience, and specialized training and/or certification in the assessment and/or diagnosis of children with CP. Clinician reviewers at the 3 sites included a developmental pediatrician, 2 senior occupational therapists, and 2 senior physical therapists.

In the absence of excludable conditions such as progressive disorders and neuromuscular diseases, children were classified as confirmed CP cases on the basis of diagnostic information and/or physical finding descrip-

tions consistent with CP at  $\geq 2$  years of age found in source records. CP subtype was determined on the basis of the classification system for spastic, dyskinetic, and ataxic CP developed by the Surveillance of Cerebral Palsy in Europe Collaborative Group.<sup>2</sup> Cases that met the surveillance case definition but whose subtype could not be assigned readily to one of the Surveillance of Cerebral Palsy in Europe categories above were classified as follows: cases with  $>1$  but no predominant subtype were classified as spastic-dyskinetic, spastic-ataxic, or dyskinetic-ataxic; those with a previous diagnosis of hypotonic CP or CP not otherwise specified plus generalized hypotonia were classified as hypotonic CP; and those with a documented diagnosis of CP but insufficient information for assignment of a subtype were classified as CP not otherwise specified.

For each confirmed case, the reviewer documented a summary impression of CP subtype and information about the first and the most-recent qualifying evaluations (evaluation date, examiner's specialty, examiner's diagnosis, and reviewer's impression of CP subtype). A qualifying evaluation was defined as an evaluation by a qualified professional that contained a CP diagnosis and/or physical findings consistent with CP.

Before independent record review, initial inter-rater reliability was established among the reviewers to standards of 90% agreement regarding case status. Ongoing reliability was evaluated with a blinded, randomly selected, 10% sample of abstracted records scored independently by 2 reviewers. Average agreement on final case status was 91% ( $\kappa = 0.81$ ). No clinical examinations of children were performed by project personnel.

#### **Statistical Analyses**

Period prevalence estimates were calculated by using, as the denominator, the number of 8-year-old children residing in each surveillance area, according to the National Center for Health Statistics vintage 2004 bridged-race postcensal population estimates from July 1, 2002.<sup>18</sup> Poisson approximation to the binomial distribution was used to calculate 95% confidence intervals (CIs) for prevalence.<sup>19</sup> Prevalence results are reported per 1000 children. Site-specific and average period prevalence estimates were calculated. Average period prevalence estimates represent the sum of cases divided by the sum of the study area populations of 8-year-old children across the 3 sites.

Race/ethnicity-specific rates used the categories white non-Hispanic, black non-Hispanic, Hispanic, American Indian/Alaska Native non-Hispanic, and Asian/Pacific Islander non-Hispanic. The race and ethnicity of each child were determined from information contained in the source records or, if information was missing, from the child's birth certificate. Median household income within a given census block group was used as a proxy indicator of socioeconomic status (SES). A  $P$  value of  $<.05$  was used for all tests of statistical significance.

An important aspect of a records-based surveillance system is the ability to locate the evaluation records that contain the necessary information to confirm case status. Sensitivity analyses were conducted by each site to evalu-

**TABLE 2 Socioeconomic and Demographic Characteristics of CP Prevalence Estimates According to Site in Surveillance Year 2002**

	Alabama	Georgia	Wisconsin	All Sites
Total CP cases, <i>n</i>	131	168	117	416
Total 8-y-old children in study area, <i>n</i> <sup>a</sup>	35 472	44 299	35 126	114 897
Total prevalence, (95% CI), cases per 1000 <sup>b</sup>	3.7 (3.1–4.4)	3.8 (3.3–4.4)	3.3 (2.8–4.0)	3.6 (3.3–4.0)
Gender-specific prevalence, (95% CI), cases per 1000				
Boys	4.6 (3.7–5.6)	4.0 (3.3–5.0)	4.1 (3.2–5.1)	4.2 (3.7–4.8)
Girls	2.8 (2.1–3.7)	3.6 (2.8–4.4)	2.6 (1.9–3.5)	3.0 (2.6–3.5)
Boy/girl ratio	1.6:1	1.1:1	1.6:1	1.4:1
Race-specific prevalence, (95% CI), cases per 1000				
White non-Hispanic	3.7 (3.0–4.6)	3.4 (2.6–4.4)	2.9 (2.3–3.7)	3.3 (2.9–3.8)
Black non-Hispanic	3.8 (2.8–5.3)	4.2 (3.4–5.3)	4.7 (3.3–6.7)	4.2 (3.6–4.9)
Hispanic	2.9 (0.9–8.9)	2.1 (1.1–4.0)	2.6 (1.4–5.1)	2.4 (1.6–3.7)
American Indian/Alaska Native non-Hispanic	– <sup>c</sup>	–	–	–
Asian/Pacific-Islander non-Hispanic	–	3.5 (1.7–7.3)	2.8 (0.9–8.8)	3.0 (1.6–5.6)
Median household income prevalence, cases per 1000 <sup>c</sup>				
Low plus middle	4.3 (3.5–5.2)	4.1 (3.5–4.9)	3.9 (3.2–4.7)	4.1 (3.7–4.6)
High	2.2 (1.5–3.2)	3.2 (2.4–4.3)	1.8 (1.2–2.7)	2.4 (2.0–3.0)
Low plus middle/high ratio	2.0:1	1.3:1	2.2:1	1.7:1

Prevalence values are presented as cases per 1000 children 8 years of age.

<sup>a</sup> Denominator data were obtained from the National Center on Health Statistics bridged-race postcensal population estimates for 2002.<sup>19</sup>

<sup>b</sup> All children were included in the total regardless of race/ethnicity, as well as children for whom race/ethnicity was unknown. Because of the lack of an appropriate denominator, multiracial or other race/ethnicity categories are not presented.

<sup>c</sup> No CP cases were identified in this racial/ethnic population.

<sup>d</sup> Median household income categories were based on the median household income block-group tertile distribution in each study area, as follows: Alabama: low: \$0 to \$30 000; middle: \$30 001 to \$40 000; high: more than \$40 000; Georgia: low: \$0 to \$44 000; middle: \$42 001 to \$68 000; high: more than \$68 000; Wisconsin: low: \$0 to \$40 000; middle: \$40 001 to \$56 000; high: more than \$56 000.

ate the impact on prevalence of source files that could not be located for review by project staff members. These analyses demonstrated that the impact of missing records was minimal, ranging from 0.6% in Wisconsin to 4.6% in Alabama and 5.9% in Georgia. To minimize potential underascertainment and overascertainment, quality control procedures were used at multiple stages in the record review, abstraction, and clinician review processes.<sup>20</sup>

## RESULTS

### Prevalence Estimates and Socioeconomic and Demographic Characteristics

The prevalence of CP in 8-year-old children in 2002 at the 3 surveillance sites was strikingly similar, ranging from 3.3 cases per 1000 (Wisconsin) to 3.8 cases per 1000 (Georgia) (Table 2). The average prevalence was 3.6 cases per 1000 (95% CI: 3.3–4.0 cases per 1000). The boy/girl ratio exceeded unity at all 3 sites, although somewhat less so in Georgia (ratio: 1.1:1) than at the other 2 sites (ratio: 1.6:1). The prevalence estimates were elevated among black non-Hispanic children at all 3 sites. The racial/ethnic disparity was most apparent in Wisconsin, where the prevalence of CP was significantly greater among black non-Hispanic children (4.7 cases per 1000; 95% CI: 3.3–6.7 cases per 1000), compared with white non-Hispanic children (2.9 cases per 1000; 95% CI: 2.3–3.7 cases per 1000;  $P < .03$ ). Overall, with the data from all 3 sites, the prevalence of CP was 4.2 cases per 1000 (95% CI: 3.6–4.9 cases per 1000) among black non-Hispanic children, compared with 3.3 cases per 1000 (95% CI: 2.9–3.8 cases per 1000) among white non-Hispanic children ( $P < .03$ ). In contrast, the prevalence among Hispanic children at all 3 sites was lower

than that for the other racial/ethnic subgroups, with an average prevalence of 2.4 cases per 1000 (95% CI: 1.6–3.7 cases per 1000).

The prevalence of CP was higher among children whose families lived in low- and middle-SES communities (range: 3.9–4.3 cases per 1000) than among those whose families lived in high-income communities (range: 1.8–3.2 cases per 1000). Overall, the prevalence of CP was 70% higher in low- and middle-income communities than in high-income communities (Table 2).

### Type of CP

At each of the 3 sites, >80% of the confirmed cases had information available on CP subtype (Table 3). Spastic CP was the most common subtype, ranging from 71% of CP cases in Georgia to 82% in Alabama, with prevalence estimates ranging from 2.6 to 3.0 cases per 1000 across the 3 sites. More specifically, bilateral spastic CP was more common than unilateral spastic CP, with prevalence estimates of 1.8 to 2.1 cases per 1000 for bilateral spastic CP (66%–73% of spastic CP cases), compared with 0.7 to 0.9 cases per 1000 for unilateral spastic CP (26%–34% of spastic CP cases) (Table 3).

### Previous Diagnosis of CP

Children were identified as having a previous diagnosis of CP if they had a documented diagnosis of CP by a qualified professional or an International Classification of Diseases, Ninth Revision, Clinical Modification diagnostic code for CP noted in their records  $\leq$  8 years of age. The proportion of cases with a previous diagnosis ranged from 92% in Wisconsin to 96% in Georgia.



**TABLE 3** Prevalence of CP Subtypes According to Site in Surveillance Year 2002

	Alabama		Georgia		Wisconsin		Average	
	n (%)	Prevalence, (95% CI)	n (%)	Prevalence, (95% CI)	n (%)	Prevalence, (95% CI)	n (%)	Prevalence, (95% CI)
Total	131	3.7 (3.1–4.4)	168	3.8 (3.3–4.4)	117	3.3 (2.8–4.0)	416	3.6 (3.3–4.0)
Spastic <sup>a</sup>	108 (82.4)	3.0 (2.5–3.7)	120 (71.4)	2.7 (2.3–3.2)	92 (78.6)	2.6 (2.1–3.2)	320 (76.9)	2.8 (2.5–3.1)
Unilateral <sup>b</sup>	32 (29.6)	0.9 (0.6–1.3)	40 (33.9)	0.9 (0.7–1.2)	24 (26.4)	0.7 (0.5–1.0)	96 (30.0)	0.8 (0.7–1.0)
Bilateral <sup>c</sup>	76 (70.3)	2.1 (1.7–2.7)	78 (66.2)	1.8 (1.4–2.2)	67 (72.8)	1.9 (1.5–2.4)	221 (69.1)	1.9 (1.7–2.2)
Dyskinetic	3 (2.3)	0.1 (0.03–0.3)	5 (3.0)	0.1 (0.05–0.3)	3 (2.6)	0.1 (0.03–0.3)	11 (2.6)	0.1 (0.05–0.2)
Ataxic	3 (2.3)	0.1 (0.03–0.3)	4 (2.4)	0.09 (0.03–0.2)	3 (2.6)	0.1 (0.03–0.3)	10 (2.4)	0.09 (0.05–0.2)
Hypotonic	3 (2.3)	0.1 (0.03–0.3)	6 (3.6)	0.1 (0.1–0.3)	2 (1.7)	0.1 (0.01–0.2)	11 (2.6)	0.1 (0.05–0.2)
Other <sup>d</sup>	14 (10.7)	0.4 (0.2–0.7)	33 (19.6)	0.7 (0.5–1.1)	17 (14.5)	0.5 (0.3–0.8)	64 (15.4)	0.6 (0.4–0.7)
Spastic hemiplegia	31 (23.7)	0.9 (0.6–1.2)	39 (23.2)	0.9 (0.6–1.2)	24 (20.5)	0.7 (0.5–1.0)	94 (22.6)	0.8 (0.7–1.0)
Spastic diplegia	39 (29.8)	1.1 (0.8–1.5)	26 (15.5)	0.6 (0.4–0.9)	28 (23.9)	0.8 (0.6–1.2)	93 (22.4)	0.8 (0.7–1.0)
Spastic quadriplegia	30 (22.9)	0.9 (0.6–1.2)	44 (26.2)	1.0 (0.7–1.3)	30 (25.6)	0.9 (0.6–1.2)	104 (25.0)	0.9 (0.8–1.1)
Spastic triplegia	1 (0.8)	0.03 (0.004–0.2)	3 (1.8)	0.07 (0.02–0.2)	1 (0.9)	0.03 (0.004–0.2)	5 (1.2)	0.04 (0.02–1.1)
Spastic monoplegia	1 (0.8)	0.03 (0.004–0.2)	1 (0.6)	0.02 (0.003–0.2)	0 (0)		2 (0.5)	0.02 (0.004–0.07)
Spastic-ataxic	1 (0.8)	0.03 (0.004–0.2)	0 (0)		1 (0.9)	0.03 (0.004–0.2)	2 (0.5)	0.02 (0.004–0.07)
Spastic-dyskinetic	6 (4.6)	0.2 (0.1–0.4)	4 (2.4)	0.09 (0.03–0.2)	3 (2.6)	0.1 (0.03–0.3)	13 (3.1)	0.1 (0.06–0.2)
Spastic NOS	6 (4.6)	0.2 (0.1–0.4)	7 (4.2)	0.2 (0.1–0.3)	9 (7.7)	0.3 (0.2–0.5)	22 (5.3)	0.2 (0.1–0.3)
Dyskinetic	3 (2.3)	0.1 (0.03–0.3)	5 (3.0)	0.1 (0.05–0.3)	3 (2.6)	0.1 (0.03–0.3)	11 (2.6)	0.1 (0.05–0.2)
Ataxic	3 (2.3)	0.1 (0.03–0.3)	4 (2.4)	0.09 (0.03–0.2)	3 (2.6)	0.1 (0.03–0.3)	10 (2.4)	0.09 (0.05–0.2)
Dyskinetic-ataxic	0 (0)		0 (0)		1 (0.9)	0.03 (0.004–0.2)	1 (0.2)	0.009 (0.001–0.06)
Hypotonic	3 (2.3)	0.1 (0.03–0.3)	6 (3.6)	0.1 (0.1–0.3)	2 (1.7)	0.1 (0.01–0.2)	11 (2.6)	0.1 (0.05–0.2)
CP not otherwise specified	7 (5.3)	0.2 (0.1–0.4)	29 (17.3)	0.7 (0.5–0.9)	12 (10.3)	0.3 (0.2–0.6)	48 (11.5)	0.4 (0.3–0.6)

Prevalence values are presented as cases per 1000 children 8 years of age.

<sup>a</sup> Includes spastic not otherwise specified (*n* = 2 in Georgia and *n* = 1 in Wisconsin).

<sup>b</sup> Includes spastic monoplegia and spastic hemiplegia.

<sup>c</sup> Includes spastic diplegia, spastic quadriplegia, and spastic triplegia. For 19 cases, CP subtype could not be further specified (*n* = 6 Alabama, *n* = 5 Georgia, *n* = 8 Wisconsin)

<sup>d</sup> Includes spastic-ataxic, spastic-dyskinetic, dyskinetic-ataxic, and CP not otherwise specified.

## DISCUSSION

We provide the first report of the prevalence and descriptive characteristics of CP from a multisite, population-based, collaborative, developmental disabilities network across the United States. Using common methods in 3 diverse US populations, the ADDM Network found remarkable similarity across sites in the overall prevalence of CP among 8-year-old children, as well as in the prevalence of broad CP subtypes and patterns of CP prevalence according to demographic categories. We found that the prevalence of CP in 8-year-old children in 2002 at the 3 ADDM CP surveillance sites was higher than that reported in several other developed countries. International population-based studies have reported the prevalence of CP at 0.7 to 5.8 cases per 1000 live births or children in the population, with most estimates at 1.5 to 3.0 cases per 1000.<sup>1,21</sup> A few reports of higher rates include population-based studies from Denmark<sup>6</sup> and Slovenia<sup>22</sup> and a national survey from the United States.<sup>23</sup> In addition, a recent study from Turkey reported an overall prevalence of 4.4 cases per 1000 children 2 to 16 years of age.<sup>24</sup> Data from metropolitan Atlanta indicated that the prevalence of CP in 8-year-old children in 2000 was 3.1 cases per 1000, higher than the typically reported prevalence estimates.<sup>3</sup>

Several factors may account for our higher prevalence of CP. All 3 study sites included  $\geq 1$  regional medical center providing advanced diagnostic and medical care services for children with developmental disabilities. The availability of such medical services may enhance the capability of a surveillance system to identify children

with CP. It is also possible that families of children with CP migrate to communities with more advanced medical services for children with developmental disabilities, potentially leading to higher prevalence estimates of CP in those areas. We were able to investigate this at 1 site, and we found that children with CP were no more likely than children in the general population to have been born out of state. In addition, similar to our study, other studies of CP prevalence were conducted in communities with comprehensive clinical services.

In addition to variations in availability and quality of services, CP prevalence studies used a number of different methods, with differences that affect both the numerator and denominator for prevalence calculations. Paneth et al<sup>1</sup> indicated that the calculation of period prevalence by using children in the population as the denominator can lead to higher prevalence rates, compared with the use of live births or neonatal survivors. As many investigators have noted, changes in medical care and other factors that are related to survival rates, especially different birth weight survival rates, can affect the prevalence of CP.<sup>5,6,12,25–31</sup> With respect to the numerator for prevalence, differences in the age of ascertainment yield different prevalence estimates.<sup>32–34</sup> Although initially some studies in Europe reported CP prevalence rates for children as young as 3 years of age, the Surveillance of Cerebral Palsy in Europe network of 14 centers decided, after harmonization of the data, to include cases of CP involving children who were  $\geq 5$  years of age.<sup>2</sup> We feel that determining the prevalence at 8

years of age yields more complete ascertainment than does determining the prevalence at younger ages. An analysis of data from metropolitan Atlanta found that the prevalence of CP, as well as most other developmental disabilities, peaked at 8 years of age. Therefore, using age 8 is likely to yield a prevalence estimate closer to the "true" prevalence, particularly as it relates to the service burden within a community. Another possible reason for our higher prevalence is the use of multiple sources of information, which is likely to yield more-complete ascertainment than is use of a single source.

Studies have differed in the inclusion or exclusion of children with postnatally acquired CP. Among the studies that included them, the proportions of children with postnatal causes varied.<sup>2,32</sup> For the 2002 surveillance year, the ADDM CP sites did not systematically collect etiologic information for CP cases. However, we have modified our surveillance system to be able to collect this information in future study years and to evaluate the impact of including postnatal cases on our prevalence estimates.

Although a total population screen, followed by clinical examinations to confirm the diagnoses, may be ideal and may yield an estimate that is closer to the "true" prevalence, this approach is usually not feasible on a population basis. We feel that our methods of screening and abstracting records for 8-year-old children from multiple sources, followed by expert clinical review of the abstracted data, are probably more thorough than those of some previous studies.

The higher prevalence of CP in boys is consistent with findings of other studies.<sup>32,33</sup> We speculate that boys who survive the neonatal period may be more medically involved and therefore at higher risk for CP. In addition, X-linked conditions such as X-linked hydrocephalus and X-linked microcephaly are associated with CP.

One important distinction between our results and those of many other studies is the ability to examine the prevalence according to race/ethnicity, because of the diverse demographic characteristics of the 3 surveillance areas. We found a significant difference in prevalence between black non-Hispanic and white non-Hispanic children overall and in Wisconsin ( $P < .03$ ) and between black non-Hispanic and Hispanic children overall ( $P < .01$ ). The increased prevalence in black non-Hispanic children was noted among 10-year-old children in metropolitan Atlanta in 1985 to 1987<sup>33</sup> and among 3- to 10-year-old children in metropolitan Atlanta in 1991.<sup>35</sup> In addition, we found significant differences between black non-Hispanic and Hispanic children in Georgia, whereas the prevalence in Hispanic children was lower than that in the other 2 racial/ethnic groups at all 3 sites. This lower prevalence in Hispanic children might reflect cultural and language issues that limit access to health care and social services. Other issues that might affect racial/ethnic differences in prevalence include different migration patterns and potential differences in genetic predisposition. Knowledge concerning developmental disabilities in Hispanic children in the United States is limited and warrants further investigation.

Across all sites, children born to families of lower and

middle SES had a higher prevalence of CP than did children born to families of higher SES (4.1 and 2.4 cases per 1000, respectively). A recent article by Sundrum et al<sup>36</sup> also found an inverse association between the risk of CP and SES in children monitored from 1982 to 1997 in the United Kingdom. Additional research is needed to determine the extent to which the observed race-specific differences in prevalence are accounted for by variations in income, as well as the role of perinatal risk factors in the observed variations in prevalence.

By examining CP subtypes, we can gain information that may improve our understanding of possible causes, because certain types of CP may be associated with recognized risk factors. For example, spastic diplegia is reported to occur more often in children with low birth weight.<sup>34</sup> Therefore, examination of changes in the prevalence of subtypes or in the distribution of subtypes may yield clues to contextual factors that may affect the risk of CP. Similar to previous prevalence reports,<sup>3,9,25,37-39</sup> most children identified with CP as part of the ADDM Network had spastic CP (77%), with bilateral spastic CP being more common than unilateral spastic CP. The proportions of children with ataxic CP (2.4%), dyskinetic CP (2.6%), and hypotonic CP (2.6%) were low but consistent across sites. Other reports of the proportions of dyskinetic and ataxic CP ranged from 1% to 7% of all cases.<sup>24,27,38,39</sup>

Differences in the prevalence of subtypes may result from definitional issues or ascertainment methods. For example, cases of purely hypotonic CP often are not reported. Across the sites using the ADDM Network surveillance protocol, reviewers consistently classified a small proportion of children as having hypotonic CP. We included hypotonic CP as a subtype because it was included in some CP prevalence studies.<sup>28</sup> For each of the ADDM Network sites, we found, on the basis of record review, that a small number of clinicians use the term "hypotonic CP" to refer to children with CP and predominant low muscle tone. If hypotonic CP cases had been excluded, the site-specific and overall average prevalence estimates would not have changed substantially (Alabama: 3.6 cases per 1000; 95% CI: 3.0-4.3 cases per 1000; Georgia: 3.7 cases per 1000; 95% CI: 3.1-4.3 cases per 1000; Wisconsin: 3.3 cases per 1000; 95% CI: 2.7-3.9 cases per 1000; average of all sites: 3.5 cases per 1000; 95% CI: 3.2-3.9 cases per 1000). Further classification of the spastic subtype according to limb involvement (ie, hemiplegia, quadriplegia, diplegia, triplegia, or monoplegia) raised issues of reliability, because findings across the 3 sites were not entirely consistent. We attribute some of the discrepancy to the availability of information in the records permitting consistent identification of specific limb involvement or variations in reviewers' interpretations of the classifications. However, other CP investigators also found that the distinction between spastic diplegia and spastic quadriplegia is particularly difficult.<sup>2,40</sup> Greater confidence was expressed by the ADDM Network reviewers and more consistent estimates were found when cases of spastic CP were classified as either unilateral or bilateral, as proposed by the Collaboration for Surveillance of CP in

Europe,<sup>2</sup> than when the limb involvement method was used.

The proportion of children with CP with no diagnosis of CP in their records before identification by the ADDM Network at 8 years of age ranged from 4% to 8% across the 3 study sites. This finding may reflect a reluctance of clinicians to use the term CP for cases with postnatal etiology, differences between a surveillance case definition and a clinical one, or failure to identify children with CP and to refer them for services.

The consistency of findings at these 3 sites supports the expansion of the ADDM Network to include projects across different states. Detailed protocols for record abstraction and clinician review permitted the 3 projects to collaborate, to achieve reliability goals, and to produce remarkably similar estimates of the prevalence of CP. However, the use of existing data for surveillance purposes has limitations, including finding records with limited information for determination of CP case status and subtype. Most clinicians provide specific diagnoses and/or rich descriptions of a child's condition, but some unintentionally omit details important for surveillance purposes. Using the ADDM Network methods, we could not confirm ambiguous findings through clinical assessment. When there was inadequate information to determine a case, reviewers erred on the side of underascertainment, which suggests that prevalence estimates might actually be higher than reported. Record review also assumes access to health care and educational systems and identification within these systems. The lower rates of CP in the Hispanic population might be attributable to lack of access to care. Although the ADDM Network approach works well for populations with access to care, it may underestimate prevalence in underserved populations.

Another limitation for the 2 sites without access to education records (Alabama and Wisconsin) was the inability to collect systematically information about special education services and comorbid disabilities, such as cognitive impairment, hearing loss, and vision impairment, because such data are found routinely only in school records. However, access to education records did not affect appreciably the prevalence of CP. The site with access to both school and nonschool sources (Georgia) identified only 4% of CP cases solely from educational sources. It is possible that, in settings with less access to tertiary health care services for children with developmental disabilities, larger proportions of children with CP would be identified only through educational records.

This report of the prevalence and population characteristics of children with CP at 3 diverse sites makes an important step forward in expanding our understanding of CP in the United States. Future analyses will examine the characteristics of children with CP and comorbid disabilities monitored at individual sites within the network. Clinician review in future surveillance years will incorporate evaluation of gross motor functioning by using the Gross Motor Function Classification System.<sup>41</sup> We need additional research using consistent, population-based methods over time and in more communities to provide a more comprehensive picture of CP among children in the United States.

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## Prevalence of Cerebral Palsy in 8-Year-Old Children in Three Areas of the United States in 2002: A Multisite Collaboration

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