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The role of migration and choice of denominator on the prevalence of cerebral palsy

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Abstract

AIM—Differential migration and choice of denominator have been hypothesized to contribute to differences between period prevalence and birth prevalence of cerebral palsy (CP). The purpose of this study was to evaluate the effects of migration and choice of denominator on the prevalence of CP.

METHOD—Data from the Metropolitan Atlanta Developmental Disabilities Surveillance Program and census and birth certificate files were used to calculate various CP prevalence estimates for 2000.

RESULTS—The overall CP period prevalence was 3.2 (95% confidence interval [CI] 2.7–3.8) per 1000 8-year-olds and was similar for those born in Atlanta who resided there at age 8 years (3.3; 95% CI 2.7–4.1) and those born outside Atlanta who moved into Atlanta by age 8 years (3.0; 95% CI 2.3–3.9). CP prevalence in these two migration strata was similar by sex and race/ethnicity. CP birth prevalence of 8-year-olds in Atlanta in 2000 was 2.0 (95% CI 1.6–2.5) per 1000 live births in 1992.

INTERPRETATION—The authors found no evidence to support the hypothesis that differential in-migration explained higher period than birth prevalence of CP in Atlanta. Comparability of CP prevalence across geographic areas will be enhanced if future studies report both period and birth prevalence.

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DISCLAIMER

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.

Data on the prevalence of cerebral palsy (CP) are used to plan for the service and resource needs of individuals with CP and may identify opportunities to prevent or reduce the severity of CP. CP prevalence is estimated by population-based registries and surveillance systems in many countries, but methods for calculating prevalence vary, making comparisons difficult.[1] Although CP is often not diagnosed until after the age of 2 years,[2,3] a common method of estimating CP prevalence is to use birth cohort denominators and compute prevalence as the number of children with CP per 1000 live births. We refer to estimates based on this method as *birth prevalence*. Population-based registries in Europe, Australia, and the United States have used this method and consistently find CP prevalence to be approximately 2 per 1000 live births.[4–6] For these registries and surveillance programs, CP case status is not confirmed until age 4, 5, or 8 years.[4–10] As a result, the birth prevalence numerator and denominator are enumerated at different times, often several years apart. If children who migrated from their birthplace or died before case confirmation are excluded from the birth prevalence numerator, but not the denominator, birth prevalence will be underestimated.

Studies in other parts of the world, including the United States, frequently report prevalence per 1000 children residing in a given geographic area during a given period, regardless of birthplace. These estimates, referred to as *period prevalence*, use census data for the denominator and yield generally higher prevalence estimates.[7–13] For example, the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), a population-based, multiple-source, active surveillance system in the United States, has consistently reported CP period prevalence estimates of approximately 3 to 4 per 1000 8-year-olds. This is nearly 50% higher than most birth prevalence estimates, including birth prevalence estimates reported by the same system.[6–10] By using children compared with live births as the denominator, the period prevalence numerator and denominator are ascertained at the same point in time and are, therefore, subject to the same survival and migration effects. Many factors, in addition to denominator choice, may contribute to variations in CP prevalence across monitoring programs, including methodological differences in case ascertainment as well as varied levels of perinatal risk. However, it has been suggested that the higher period prevalence estimates in Atlanta may be partially or wholly attributable to selective in-migration of families of children with CP, perhaps for services, and the choice of children compared with live births as the denominator.[14,15]

The purpose of this paper is twofold: (1) to assess whether CP prevalence was higher among 8-year-olds who migrated into Atlanta compared with children who were born in Atlanta and still resided there at age 8 years; and (2) to evaluate the choice of denominator on CP prevalence in Atlanta.

METHOD

For this analysis, CP period prevalence is the number of 8-year-olds with CP among all 8-year-olds living in Atlanta, Georgia, during 2000. CP period prevalence has two components: (1) non-migrant period prevalence, the number of children with CP among children who have resided in Atlanta since birth (1992); and (2) in-migrant period prevalence, the number of children with CP among children who migrated into Atlanta after

birth (1992). CP birth prevalence is the number of 8-year-olds with CP among 1992 live births or live births who survived to 1 year of age. The components of birth prevalence are: (1) non-migrant birth prevalence, the number of children with CP among children born in Atlanta in 1992 who still lived there in 2000; (2) out-migrant birth prevalence, the number of children with CP among children who moved out of Atlanta after birth (1992); and (3) the number of children with CP among children who died between birth or 1 year of age and 2000.

Numerator data

Data for the number of 8-year-olds with CP living in Atlanta in 2000 were obtained from MADDSP. In 2000, MADDSP monitored CP in five counties (Clayton, Cobb, DeKalb, Fulton, Gwinnett) in metropolitan Atlanta. For surveillance purposes, CP is defined as a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising at any time during brain development.[16] The case definition by Mutch et al[16] was modified to include children with a brain-damaging event after 28 days of life (postneonatal CP).[7–10] A CP case was defined as a child born in 1992 who resided in Atlanta during 2000 and who had a documented diagnosis of CP or physical findings consistent with CP in an evaluation by a qualified professional at or after age 2 years. Children aged 8 years in 2000 suspected of having CP were identified by screening and abstracting evaluations at multiple educational and health sources. Data were abstracted into one composite record per child and reviewed by trained clinicians using a specified protocol to determine whether the identified children met the CP surveillance case definition. Case ascertainment, clinician review, and quality assurance details have been reported elsewhere.[7–10] Children with CP were linked to birth and death vital statistics records to identify maternal county of residence at the time of the child's birth and to exclude those children with CP who died before the surveillance year.

Period prevalence numerator—Data on birthplace were used to stratify 8-year-olds with CP living in Atlanta in 2000 by migration status. The numerator for period prevalence (n=135) comprised both non-migrant (n=82) and in-migrant (n=53) children with CP, including those with postneonatally acquired CP (n=12: five non-migrants, seven in-migrants).

Birth prevalence numerator—The numerator for birth prevalence included non-migrant children with congenital CP (n=77). Non-migrant children with postneonatally acquired CP (n=5) were excluded. Data on cases of CP among children who died or migrated out of Atlanta between 1992 and 2000 were not available.

Denominator data

Period prevalence denominator—Data on the number of 8-year-olds living in Atlanta in 2000 were obtained from the US Census Public Use Microdata Set (PUMS).[17] PUMS data were obtained from a 5% sample of census respondents and included several questions not included in the overall census. Respondents were asked whether they were born in Georgia and if they had lived at the same address on 1 April 1995, 5 years prior to the census date of 1 April 2000. Therefore, although decennial, intercensal, and postcensal

estimates are typically used for the MADDSP prevalence estimates,[7–10,18] the additional PUMS information allowed us to stratify 8-year-olds living in Atlanta in 2000 (*n*=42 579) into non-migrants and in-migrants in order to correspond as closely as possible to the stratification of the numerator data. Non-migrants were defined as 8-year-olds born in Georgia who resided in Atlanta in 2000 and on 1 April 1995 (*n*=24 974). The number of in-migrant children (*n*=17 615) was obtained by subtracting the number of non-migrant children from the total number of 8-year-olds living in Atlanta in 2000. The PUMS data include state of birth, but not birthplace, at the county level, and the residency questions covered only 5 years prior to the census. Thus, the non-migrant denominator is an overestimate since it includes children born in Georgia outside Atlanta who moved to Atlanta before 1 April 1995 and the in-migrant denominator is an underestimate since it excludes children born in Georgia outside of Atlanta who migrated into Atlanta before 1 April 1995.

Birth prevalence denominator—Data on all 1992 Atlanta live births (*n*=38 195) were available from the Georgia Bureau of Vital Statistics. From linkage of the live birth and infant death files, we obtained the count of 1992 Atlanta live births surviving to 1 year of age (*n*=37 852).

Sociodemographic and clinical characteristics of children with CP

We stratified period prevalence estimates by sex and race/ ethnicity. We also compared selected characteristics of non-migrant and in-migrant children with CP, including sex, race/ ethnicity, census area median household income, CP subtype, and co-occurring developmental disabilities (intellectual disability, autism spectrum disorder, hearing loss, vision impairment), and a documented diagnosis of CP. The results for racial/ethnic groups other than White non-Hispanic and Black non-Hispanic were not presented because of small numbers. Children with CP were linked to block group data from the 2000 United States decennial census to obtain information on median household income, a proxy for socio-economic status. The 95% confidence intervals (CIs) were calculated using the Poisson approximation to the binomial distribution. Differences in proportions were calculated using χ^2 tests with a binomial distribution and *p*-value set at <0.05.

MADDSP functions as a public health authority under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule and met applicable Institutional Review Board and privacy/confidentiality requirements.

RESULTS

For MADDSP (2000), the overall period prevalence of CP was 3.2 (95% CI 2.7–3.8) per 1000 8-year-olds (Fig. 1), calculated as a weighted average of non-migrant and in-migrant period prevalence. The non-migrant CP period prevalence of 3.3 (95% CI 2.7–4.1) per 1000 was not statistically different from the in-migrant CP period prevalence of 3.0 (95% CI 2.3–3.9) per 1000.

Among children with CP, male-to-female prevalence ratios (PRs) were similar among non-migrant (PR 1.6; 95% CI 1.0–2.5) and in-migrant children (PR 1.3; 95% CI 0.7–2.2).

Prevalence ratios of Black non-Hispanic to White non-Hispanic children were also similar among non-migrants (PR 1.5; 95% CI 1.0–2.4) and in-migrants (PR 1.1; 95% CI 0.6–2.0; Table I). Non-migrant and in-migrant children with CP had similar distributions of low, middle, and high socio-economic status. Just over 80% of non-migrant children had spastic CP, compared with 70% of in-migrant children (p=0.34). Approximately 60% of non-migrant and in-migrant children had at least one co-occurring developmental disability. Nearly all had a documented CP diagnosis, regardless of migration status (98–99%).

We calculated birth prevalence using non-migrant children with congenital CP (n=77) and 1992 live births (n=38 195). This yielded a prevalence of 2.0 (95% CI 1.6–2.5) per 1000 live births, which was unchanged when 1-year survivors were used in the denominator. This estimate of CP birth prevalence does not include CP cases among out-migrant children or childhood deaths owing to lack of available data. Therefore, in an attempt to approximate the portion of the 1992 birth cohort that remained in Atlanta, we restricted the numerator to non-migrant children with congenital CP (n=77) and the denominator to non-migrant 8-year-olds (n=24 962). This resulted in a prevalence estimate of 3.1 (95% CI 2.5–3.9), which was substantially higher than the prevalence obtained using live births in the denominator.

DISCUSSION

It has been hypothesized that differential migration patterns can cause period prevalence to be higher than birth prevalence in communities where availability of high-quality education and clinical resources for children with developmental disabilities influences a family's decision to move into a specific geographic area after birth.[14,15] We found no evidence that CP prevalence differed for children who moved into Atlanta compared with those who were born in and remained in Atlanta. In addition, in-migrant children with CP were similar to non-migrant children with CP by demographic variables, CP subtype, and presence of a co-occurring developmental disability. These results are not consistent with the hypothesis that the higher CP prevalence reported by MADDSP results only from selective in-migration of children with CP seeking services. It is possible that families migrating out of Atlanta are less likely than those remaining in Atlanta to have a child with CP, leaving a population that is relatively enriched for CP. The difference between birth prevalence and period prevalence was at least partially explained by the underestimation of birth prevalence as calculated using only non-migrant cases among all 1992 live births.

The use of a live birth denominator is predicated on the etiology of and risk factors for CP occurring from the pre-natal period through the first few years of life.[14] Although this risk period is reasonable, given the likely prenatal or perinatal origin of most CP cases, case confirmation for CP registries and surveillance programs occurs later in childhood; more specifically at age 8 years for the MAD-DSP and age 4 or 5 years for surveillance programs in Europe and Australia.[5–10] Case confirmation after age 4 years may avoid inclusion of children whose earlier motor findings or impairment(s) owing to progressive disorders do not subsequently meet CP criteria.[2,3] The extended interval between the period of risk and the time of CP confirmation gives ample time for children with CP to migrate out of the original birth cohort. Therefore, accurate calculation of birth prevalence requires the ability to identify all children with CP who died or migrated out of the birth cohort's geographical

area prior to case confir-mation age. Underestimation will occur if these children are not counted and a fixed live birth or 1-year-survivor denominator is used.

We tried to better estimate birth prevalence by restricting the denominator to non-migrant children, the portion of the 1992 birth cohort that remained in Atlanta, to correspond with the non-migrant cases in the numerator. The resulting estimate of 3.1 per 1000 was substantially higher than the estimate using all live births. This would be a valid estimate of birth prevalence if CP prevalence among out-migrant children was similar to CP prevalence among non-migrant children. However, CP prevalence among non-migrant children could be higher than prevalence among out-migrant children if families of children with CP are more likely to remain in Atlanta than families of children without CP.

We conducted a sensitivity analysis (Appendix) to examine how low out-migrant CP prevalence would need to be to result in a birth prevalence of approximately 2 per 1000. We estimated a denominator of out-migrants (*n*=13 231) from this birth cohort by subtracting non-migrant children estimated by the PUMS (*n*=24 964) from the 1992 live births (*n*=38 195), and set different values for CP prevalence among out-migrants, ranging from 0.5 to 4.5 per 1000. The contribution of deaths was assumed to be negligible. Birth prevalence approached 2 per 1000 only when the CP prevalence among out-migrants was assumed to be extremely low – 0.5 cases per 1000 – with CP non-migrant prevalence of approximately 3 cases per 1000. The possibility of an inflated CP period prevalence due to families of children with CP being both more likely to stay and more likely to move into Atlanta suggests the need for research related to the impact of CP on families in the United States such as parents foregoing opportunities for advancement because of healthcare considerations.

Metropolitan Atlanta Developmental Disabilities Surveillance Program cerebral palsy period prevalence estimates are comparable with other United States estimates, ranging from 3.0 to 4.0 per 1000 children (Table II).[8–12] The most recent CP prevalence estimate from the National Health Interview Survey, a nationally representative sample of children from 3 years through to 17 years of age, was 3.9 per 1000 children.[12] This survey, based on parental report, was a random sample of the United States non-institutionalized population and, therefore, unlikely to have been subject to the differential migration suggested to occur in Atlanta. Although parents of young children with an early suspicion of CP may have responded positively despite lack of confirmation of a CP diagnosis, we do not believe that this possible over-reporting would account for an overall increase of approximately 1 per 1000.

Another example of consistent period prevalence estimates is from the Autism and Developmental Disabilities Monitoring (ADDM) Network, which monitors CP prevalence in the United States using MADDSP methods. Period prevalence estimates from this network range from 2.7 to 3.3 per 1000 8-year-olds.[8–10] Not all ADDM sites were solely in urban areas, so differential in-migration or residential stability owing to the presence of high-quality developmental disability services was less likely to have been a factor for period prevalence. Even when the proportion of in-migrant CP cases was low, such as approximately 20% in Alabama, prevalence based on live births was substantially lower

than prevalence based on census data (Table II). This suggests that the inability to include the number of out-migrant CP cases or those that died contributed to artificially low birth prevalence estimates. Because the birth prevalence denominator reflects the entire underlying birth cohort while the numerator is restricted to non-migrant children only, birth prevalence data should be used cautiously to identify birth characteristics associated with CP. This issue of unknown out-migration is also applicable to registries outside the United States. The extent to which it contributes to the generally lower birth prevalence estimates, ranging from 1.5 to 2.6 per 1000 live births, compared with those in the United States is worthy of further exploration (Table II).

A limitation of our analysis is that the closest we could approximate the non-migrant period prevalence denominator was by subsetting 8-year-olds residing in Atlanta in 2000 to include those born in Georgia and living in Atlanta for the previous 5 years. We were not able to exclude, from the non-migrant denominator, children who were born elsewhere in the state of Georgia, outside of Atlanta, but who moved into Atlanta by age 3 years. Ideally, these children should have been reclassified and added to the 17 615 in-migrant children. Correcting for this misclassification would have resulted in a lower in-migrant CP prevalence. A lower in-migrant prevalence provides further support that the higher overall CP period prevalence is not entirely driven by higher prevalence CP among in-migrants than non-migrants. Our PUMS data may not be representative of the residency of all 8-year-olds in Atlanta in 1995; however, since the PUMS samples were selected at random, we assumed no systematic bias in migration information.

We found that in-migrant CP period prevalence did not differ from non-migrant CP period prevalence; however, they both may be higher than birth prevalence if children with CP are more likely to move into or stay in Atlanta after birth for financial reasons or because of concerns about access to services. Prevalence among live births was underestimated because of the inability to ascertain CP among children who died or moved out of Atlanta. Our sensitivity analyses indicated that out-migrant CP prevalence would have to be as low as 0.5 per 1000 to result in an overall period prevalence approximating the observed birth prevalence. It is likely that the actual birth prevalence of CP in Atlanta is closer to 3 per 1000, higher than birth prevalence from non-United States surveillance systems. To provide comparability among CP prevalence estimates in different geographical areas, we encourage other monitoring programs to consider calculating both period and birth prevalence. If period prevalence in the United States is found to be higher than period prevalence in other developed countries, then further examination of migration and survival patterns as well as differences in the distribution of risk factors across various populations could help to explain global differences in CP prevalence.

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ABBREVIATIONS

MADDSP	Metropolitan Atlanta Developmental Disabilities Surveillance Program
PUMS	Public Use Microdata Set

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What this paper adds

- Period prevalence of CP was similar among in-migrants and non-migrants; both significantly higher than birth prevalence.
- Consideration of migration and survival patterns is necessary to compare birth and period CP prevalence.
- Use of different denominators complicates comparison of CP prevalence estimates.
- Reporting both birth and period prevalence would enhance our understanding of CP prevalence worldwide.

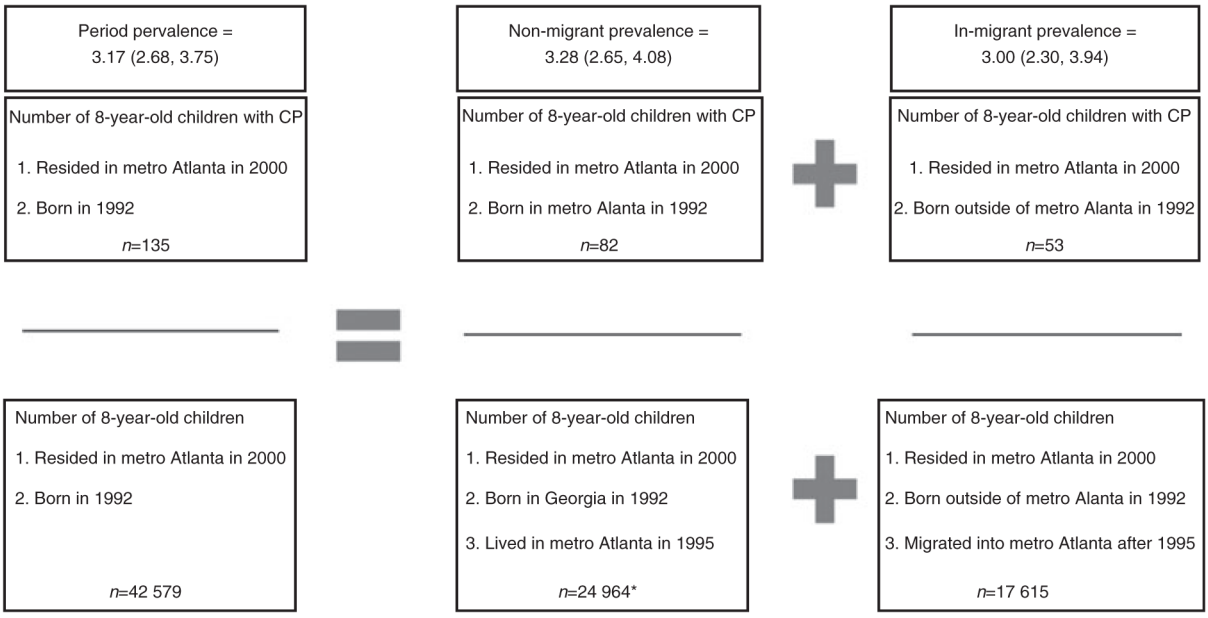

Figure 1.

Role of migration on cerebral palsy (CP) period prevalence using data from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) and US Census Public Use Microdata Sample (PUMS), 2000. *Includes children born in Georgia in 1992 but outside of metropolitan (metro) Atlanta who moved into metro Atlanta by age 3 years. We were unable to classify these children into the in-migrant denominator.

Table I

Characteristics of cerebral palsy (CP) prevalence by residence at time of birth, Metropolitan Atlanta Developmental Disabilities Surveillance Program, 2000

	Overall[a]	Non-migrants			In-migrants		
	Prevalence per 1000 (95% CI)	8y-olds in Atlanta with CP (*n*=82) (%)	8y-olds in Atlanta (*n*=24 964) (%)	Prevalence per 1000 (95% CI)	8y-olds in Atlanta with CP (*n*=53) (%)	8y-olds in Atlanta (*n*=17 615) (%)	Prevalence per 1000 (95% CI)
Male	3.61 (2.89–4.50)	50 (61.0)	12 298 (49.3)	4.07 (3.08–5.36)	29 (54.7)	8 604 (48.8)	3.37 (2.34, 4.85)
Female	2.58 (2.00–3.36)	32 (39.0)	12 666 (50.7)	2.50 (1.79–3.57)	24 (45.3)	9 011 (51.2)	2.66 (1.79, 3.97)
White NH	2.73 (2.08–3.57)	29 (35.4)	11 326 (45.4)	2.56 (1.77–3.68)	24 (45.3)	8 118 (46.1)	2.96 (1.98, 4.41)
Black NH	3.65 (2.87–4.61)	48 (58.5)	12 427 (49.8)	3.86 (2.91–5.13)	22 (41.5)	6 757 (38.4)	3.26 (2.14, 4.94)

[a] Children with postneonatally acquired CP are included. CI, confidence interval; NH, non-Hispanic.

Table II

Population-based estimates of cerebral palsy (CP) period and birth prevalence

Location	Birth years	*N* of children with CP resident in area at time of case confirmation	*N* (%) of children with CP born to residents in the area	Choice of denominator	Prevalence per 1000[a] (95% CI)
United States					
Autism and Developmental Disabilities Cerebral Palsy Monitoring Network[7,8,10][b]					
Alabama:	1998–2000	235	190 (80.9)	8y-olds	3.3 (2.9–3.8)
32 counties in north and central Alabama				Live births	2.6 (2.2–3.0)
Georgia:	1992–2000	804	476 (59.2)	8y-olds	3.5 (3.3–3.8)
Five counties in metropolitan Atlanta				Live births	2.2 (2.0–2.4)
Missouri:	1998–2000	148	115 (77.7)	8y-olds	2.9 (2.4–3.3)
Five counties in metropolitan St Louis				Live births	2.2 (1.8–2.6)
Wisconsin:	1998–2000	186	137 (73.7)	8y-olds	2.7 (2.3–3.1)
10 counties in southeastern Wisconsin				Live births	2.0 (1.7–2.4)
National Health Interview Survey, National Center on Health Statistics[11,12][b]					
US random sample	1980–2005	324	–	3–17y-olds	3.9
US random sample	1980–2002	305	–	3–17y-olds	4.0
International					
Surveillance of Cerebral Palsy in Europe[4][e]					
Isere County, France[c]	1980–1989	261	196 (75.1)	Live births	1.8 (1.6–2.0)
Haute Garonne, France	1976–1985	253	159 (62.8)	Live births	1.7 (1.4–2.0)
Scotland, UK	1984–1990	781	731 (93.6)	Live births	1.6 (1.5–1.7)
Cork and Kerry, Eire	1976–1990	232	232 (100.0)	Live births	1.5 (1.3–1.8)
Northern Ireland, UK	1981–1990	645	616 (95.5)	Live births	2.3 (2.1–2.5)
Gotheburg region, Sweden	1976–1990	649	624 (96.1)	Live births	2.1 (1.9–2.3)
Northern England, UK	1976–1990	261	272 (100.0)[d]	Live births	2.1 (1.8–2.4)
Oxford region, UK	1984–1990	611	550 (90.0)	Live births	2.3 (2.1–2.5)
Mersey region, UK	1976–1989	881	919 (100.0)[d]	Live births	2.2 (2.1–2.4)
East Denmark	1976–1990	892	1010 (96.7)[d]	Live births	2.6 (2.5–2.8)
Viterbo province, Italy	1977–1990	65	61 (93.8)	Live births	2.2 (1.6–2.9)

Location	Birth years	*N* of children with CP resident in area at time of case confirmation	*N* (%) of children with CP born to residents in the area	Choice of denominator	Prevalence per 1000[a] (95% CI)
Australian Cerebral Palsy Register[5b]					
South Australia	1993–2003	–	380	Live births	1.9 (1.7–2.1)
Victoria	1993–2003	–	1 253	Live births	1.8 (1.7–1.9)
Western Australia	1993–2003	–	758	Live births	2.7 (2.5–2.9)

[a] Prevalence estimates reflect 1980 to 1990 birth cohorts only and children with CP whose mothers were resident in area at time of delivery.

[b] Includes children whose CP was attributable to a postneonatal etiology.

[c] Due to considerable out-migration, current resident case children were used for prevalence for Isere County.

[d] Children resident in the area at the time of registration might have been fewer than the number of those children born in area if children moved out of area before case confirmation.

[e] Of 13 centers, eight were able to identify children with postneonatal etiology. This 7.8% were excluded from these estimates. CI, confidence interval.

APPENDIX

EFFECT OF OUT-MIGRATION ON BIRTH PREVALENCE OF CEREBRAL PALSY (CP)

Out-migrant numerator	Out-migrant denominator[a]	Out-migrant CP prevalence	Non-migrant numerator	Non-migrant denominator	Non-migrant CP prevalence	Total prevalence numerator	Total live birth prevalence denominator	Total prevalence per 1000 live births[b]
7	13 231	0.5	77	24 964	3.1	84	38 195	2.2
13	13 231	1.0	77	24 964	3.1	90	38 195	2.4
20	13 231	1.5	77	24 964	3.1	97	38 195	2.5
26	13 231	2.0	77	24 964	3.1	103	38 195	2.7
33	13 231	2.5	77	24 964	3.1	110	38 195	2.9
40	13 231	3.0	77	24 964	3.1	117	38 195	3.1
46	13 231	3.5	77	24 964	3.1	123	38 195	3.2
53	13 231	4.0	77	24 964	3.1	130	38 195	3.4
60	13 231	4.5	77	24 964	3.1	137	38 195	3.6

[a] Derived from subtracting the number of non-migrants from the US Census Public Use Microdata Sample (n=24 964) from the number of live births from the birth certificate data (n=38 195).

[b] Prevalence of childhood deaths not included as assumed to be negligible.