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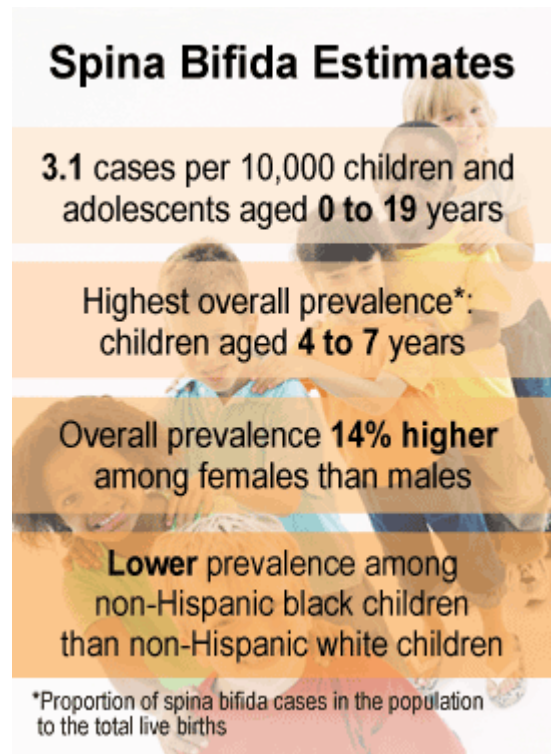
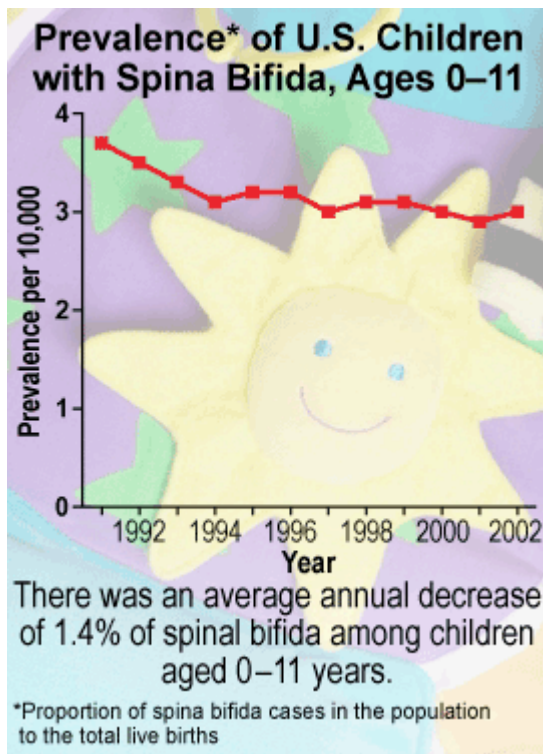
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# US Children and Adolescents with Spina Bifida

Estimates can help communities address long-term care needs of individuals with spina bifida.



The birth prevalence of spina bifida (SB) in the United States has declined in recent years. Birth prevalence is the proportion of disease cases at birth in the population to the total live births. This decline is likely due to the introduction of prenatal diagnoses and increased folic acid intake due to mandatory fortification in the US.<sup>1-5</sup>

Advances in medical treatment and technology have led to improved survival among children with spina bifida.<sup>6,7</sup> However, there has been a growing concern about whether the currently available health services for age-appropriate care will be sufficient for a potentially increasing demand for these services as a result of an expanding cohort of children with SB surviving into adolescence and adulthood.<sup>5</sup>

A newly released retrospective study was conducted using population-based birth defects surveillance data from 10 US regions. Birth defects surveillance data were obtained from Arkansas, Georgia (5 central counties of metropolitan Atlanta), California (11 counties), Colorado, Iowa, New York (New York City excluded), North Carolina, Oklahoma, Texas, and Utah.

Researchers estimated the number of children aged 0–19 years living with SB in 2002 in 10 US regions by age group, race/ethnicity, and sex. The prevalence of SB among children and adolescents in 2002 was 3.1 per 10,000, which represents approximately 24,860 children and adolescents. The SB prevalence was highest among children 4–7 years of age, lower among non-Hispanic blacks than non-Hispanic whites, and higher among females than males.

Among children and adolescents aged 0–19 years in 2002, researchers found a lower prevalence of SB among NH blacks than among NH whites, which was consistent with a previous local study.<sup>8</sup> Possible reasons for this

disparity include lower birth prevalence of SB<sup>3,4,9</sup> and lower survival probability among NH blacks than among NH whites.<sup>6,7</sup> Despite higher birth prevalence of spina bifida among the Hispanic population,<sup>3, 9–13</sup> the age- and sex-adjusted prevalence of SB among Hispanics 0–19 years was not different from the SB prevalence in the same age group among NH whites. Among children and adolescents 0–19 years, researchers found a 14% higher prevalence of SB among females than among males, and this was a consistent trend in all racial/ethnic groups (data not shown).<sup>14–17</sup> This finding differs from earlier reports that suggested no difference in SB prevalence by sex among children.<sup>8</sup>

Researchers also examined a long-term trend in prevalence of SB among children aged 0–11 years during 1991–2002. The pooled prevalence of SB among children 0–11 years consistently declined, roughly 1.4% each year, during 1991–2002 in 10 US regions.

This study, despite its limitations, provides the first estimates of SB prevalence among children and adolescents in 10 US regions, along with an extrapolated estimate of the number of children aged 0–19 living with SB in the United States. These estimates could be useful in determining the need for local and regional resources to address the long-term care needs of individuals born with SB.

## Data Source

Shin M, Besser LM, Siffel C, Kucik JE, Shaw GM, Lu C, Correa A, and the Congenital Anomaly Multistate Prevalence and Survival Collaborative. [Prevalence of Spina Bifida Among Children and Adolescents in 10 Regions in the United States](#). *Pediatrics*. 2010; 126(2):274-79.

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