

Survey Methods

The National Survey of Children with Special Health Care Needs (NS-CSHCN) was fielded using the State and Local Area Integrated Telephone Survey (SLAITS) mechanism. SLAITS is conducted by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC). It uses the same large-scale random-digit-dial sampling frame as the CDC's National Immunization Survey.⁸

Over 4 million telephone numbers were randomly generated for inclusion in the NS-CSHCN. After eliminating numbers that were determined to be non-residential, nonworking, or assigned to cell phones, the remaining numbers were called to identify households with children under 18 years of age. When households with children were identified, all children in the household were screened for special health care needs.

In households where two or more children were identified as having special needs, one child was randomly sampled to be the subject of the detailed interview.

The goal was to complete approximately 750 interviews regarding a sampled child with special health care needs in each of the 50 States and the District of Columbia. The number of households screened in each State in order to identify these 750 CSHCN varied depending on the prevalence of CSHCN in each State.

Estimates for Louisiana are based on interviews conducted in 2006 only; interviews conducted before the August and September 2005 hurricanes are not included.

Questionnaire

CSHCN were identified using the CSHCN Screener, which consists of five questions concerning common health care consequences experienced by CSHCN. The questionnaire for sampled CSHCN included sections regarding health and functional status, access to care, care coordination, satisfaction with care, health insurance coverage, adequacy of health care coverage, impact of the child's special needs on the family, and demographic information about the child, respondent, and household.

The questionnaire was translated into Spanish, Mandarin, Cantonese, Vietnamese, and Korean. Overall, 944 special-needs interviews were conducted in Spanish and 21 were conducted in the four Asian languages.

The respondent was the parent or guardian in the household who was most knowledgeable about the health and health care of the children under 18 years of age. For 78 percent of the children, the respondent was the mother. Respondents for the remaining children were fathers (16 percent) or other relatives or guardians (6 percent).

Data Collection

Data collection began on April 5, 2005 and ended on February 5, 2007, with interviews conducted from telephone centers in Chicago, Illinois; Downers Grove, Illinois; and Las Vegas, Nevada. A computer-assisted telephone interviewing system was used to collect the data. From 192,083 households with children, 364,481 children were screened for special health care needs and 40,465 interviews were completed regarding CSHCN. The special-needs interview completion rate, which is the proportion of interviews completed after a child with special needs was selected in the household, was 96.2 percent. The national weighted response rate, which includes the cooperation rate as well as the resolution rate (the proportion of telephone numbers identified as residential or nonresidential) and the screening completion rates (the proportion of households successfully screened for children and for CSHCN), was 56.1 percent. Overall response rates ranged from 49.3 percent in New Jersey to 68.3 percent in North Dakota.

Data Analysis

For producing the population-based estimates in this report, the data records for each screening interview and for each special needs interview were assigned a sampling weight. These weights are based on the probability

of selection of each household telephone number within each State, with adjustments that compensate for households that have multiple telephone numbers, for households without telephones, and for nonresponse.

With data from the U.S. Census Bureau, the weights were also adjusted by age, sex, race, ethnicity, income, highest level of education among adults in the household, and household size to provide a dataset that was more representative of each State's population of children less than 18 years of age. Analyses were conducted using statistical software that accounts for the weights and the complex survey design. Responses of "don't know" and "refuse to answer" were counted as missing data.

Accuracy of the Results

The data from the NS-CSHCN are subject to the usual variability associated with sample surveys. Small differences between survey estimates may be due to random survey error and not to true differences among children or across States.

The precision of the survey estimates is based on the sample size and the measure of interest. Estimates at the national level will be more precise than estimates at the State level. Estimates of the prevalence of special health care needs among all children will be more precise than estimates of the health and health care of CSHCN. The margin of error for the national prevalence estimate is 0.2 percentage points. For national estimates of the health and health care for all CSHCN, the maximum margin of error is 1.3 percentage points. For State prevalence estimates, the maximum margin of error is 1.3 percentage points. For the State indicators, the maximum margin of error is 7.4 percentage points, though most of the State indicators have a margin of error less than 4 percentage points.

Availability of the Data

Except for data suppressed to protect the confidentiality of the survey subjects, all data collected in the NS-CSHCN are available to the public on the NCHS and HRSA's Maternal and Child Health Bureau Web sites.

For children in racial groups that do not represent at least 5 percent of the population in a State, the child's race was coded as "other."

In other cases, information on the child's race is included in the data set but not reported in this chartbook. Because the number of interviewed children in a racial group was small, the relative standard error of the estimate was greater than 30 percent. Estimates with relative standard errors greater than 30 percent are not considered reliable or precise. Data documentation and additional details on the methodology are also available online.

Endnotes

- McPherson M, Arango P, Fox H, Lauer C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137-140, 1998.
- Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: Development and evaluation of a short screening instrument. *Ambulatory Pediatrics*, 2002 Jan-Feb; 2(1):38-48.
- Chen E, Martin AD, Matthews KA. Understanding health disparities: The role of race and socioeconomic status in children's health. *American Journal of Public Health*, 96:702-708, 2006.
- Mendoza FS, Fuentes-Afflick E. Latino children's health and the family-community health promotion model. *Western Journal of Medicine*, 170:85-92, 1999.
- Newacheck P, Halfon N. Prevalence and impact of disabling childhood chronic conditions. *American Journal of Public Health*. 88(4):610-617, 1998.
- Benson V, Marano MA. Current estimates from the National Health Interview Survey. National Center for Health Statistics. *Vital and Health Statistics*, 10(199), 1998.
- American Academy of Pediatrics Committee on Children with Disabilities. Care coordination: Integrating health and related systems of care for children with special health care needs. *Pediatrics* 1999;104(4): 978-981.
- Zell ER, Ezzati-Rice TM, Battaglia MP, Wright RA. National immunization survey: The methodology of a vaccination surveillance system. *Public Health Reports* 115:65-77, 2000.