

## Appendix

### Methodology Overview

This appendix summarizes the methods used in preparing *Report: Children with Special Health Care Needs in California*. The 2009/10 National Survey of Children with Special Health Care Needs is the primary data source for this report. This survey uses the validated *Children with Special Health Care Needs (CSHCN) Screener*. The Screener identifies children with special health care needs (CSHCN) based on the following Maternal and Child Health Bureau definition of CSHCN, with the exception that it identifies children who currently have chronic or ongoing conditions and does not specifically seek to identify those “at risk”:

*“[children] who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”<sup>1</sup>*

For more information about the CSHCN Screener, please visit the Child and Adolescent Health Measurement Initiative (CAHMI) website at <http://www.cahmi.org/pages/Sections.aspx?section=10> or review the Screener at <http://cahmi.org/ViewDocument.aspx?DocumentID=115>.

#### 2009/10 National Survey of Children with Special Health Care Needs

The National Survey of Children with Special Health Care Needs (NS-CSHCN) is sponsored and funded by the Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services, Health Resources and Service Administration, and is conducted by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention. The purpose of the 2009/10 NS-CSHCN is to assess the prevalence and the individual and health services impact of special health care needs among children under age 18 in all 50 states and the District of Columbia. The central focus of the survey is the extent to which children with special health care needs (CSHCN) have medical homes, adequate health insurance, and access to needed services. Functional difficulties, chronic medical conditions, care coordination, satisfaction with care, and adolescent transition services also are addressed in the survey questionnaire.

During the 2009/10 NS-CSHCN, 372,698 children nationwide in 196,159 households were screened, resulting in 40,242 completed interviews for CSHCN. In California, 10,282 children in 5,502 households were screened, to obtain a total of 823 in-depth CSHCN interviews.<sup>2</sup> For each CSHCN selected as a participant in the 2009/10 NS-CSHCN, an in-depth telephone interview was conducted with the parent or guardian who is most familiar with the child’s health and health care. Interviews were performed in English, Spanish, Mandarin, Cantonese, Vietnamese, or Korean.

Survey respondents were selected according to scientific random sampling methods designed to provide a sample that is representative of the entire population of non-institutionalized children with special needs from birth through age 17 within each state and the District of Columbia. As a result, the NS-CSHCN provides estimates of the number and percentage of all CSHCN in each state,

which can be compared with results for other states, regions, and the nation. The National Center for Health Statistics creates sampling weights that are included in all public release dataset files. The sampling weights account for non-response bias (e.g., no telephone, non-residential phone number) and create individual child-level weights based on race, number of children in household, and a host of other demographic information. The result is that weighted estimates represent the population of non-institutionalized CSHCN ages 0-17 in the United States and in each state. For more information, please see the 2009/10 NS-CSHCN Design and Operations Manual.<sup>2</sup>

Results for individual survey items have been analyzed and combined to create measures of the six Maternal and Child Health Bureau (MCHB) Core Outcomes that pertain to CSHCN, and 15 child health indicators. For more information on the 2009/10 NS-CSHCN, visit <http://childhealthdata.org/learn/NS-CSHCN>. For additional information about the MCHB Core Outcomes, see *Achieving & Measuring Success: A National Agenda for Children with Special Health Care Needs*.

## Variable Definitions

Throughout the report, variable definitions are provided when they can be expeditiously given. Some concepts and their measurement require more explanation, such as medical home and shared decision making. This appendix provides measurement information for the following survey components, concepts and indicators:

### Children with Special Health Care Needs (CSHCN) Screener

The CSHCN Screener is a validated screening instrument for identifying children with special health care needs using the non-categorical, non-condition specific and consequences-based definition set forth by the Federal Maternal and Child Health Bureau. The CSHCN Screener asks whether a child currently experiences any of five different health consequences found to be most predictive of the range of health needs and consequences CSHCN experience. Children experiencing a consequence are further screened for whether this is due to a medical, behavioral, or other type of health condition that has lasted or is expected to last 12 months or longer. The five CSHCN Screener criteria for identifying CSHCN are: 1) need or use of prescription medications; 2) functional limitations impacting daily activities; 3) elevated service need or use; 4) need or use of specialized therapies; and 5) emotional, developmental or behavioral issues requiring treatment or counseling. A child must have affirmative responses on all components of each screening criteria in order to meet the criteria for having a special health care need. Some children with chronic conditions are not identified by the CSHCN Screener. Likewise, some as yet undiagnosed children also are identified. This is acknowledged and expected. For more information about the CSHCN Screener, visit <http://cahmi.org/ViewDocument.aspx?DocumentID=115>.

All children who qualify on the CSHCN Screener have an ongoing health condition; this is true based on the nature of how the questions are asked. In the NS-CSHCN, a small group of conditions are asked about. This non-exhaustive list is meant to provide national and state level prevalence estimates for certain key conditions. However, it should not be interpreted as comprehensive. Many CSHCN have conditions that are not listed in the survey.

### Complexity of Health Needs

As noted, the CSHCN Screener has five criteria in which a child can qualify to be identified as having special health care needs. “Complexity of health needs” dichotomizes CSHCN into two categories: 1) children with less complex health needs, meaning their condition is *primarily* managed by prescription medication; and 2) children with more complex health needs, meaning they have multiple service needs and consequences. It would be incorrect to say that children with less complex health needs have conditions that are *only* or *exclusively* managed by prescription medications. Many of these children also have an above average number of office visits per year even if their parent/guardian does not indicate an above routine use of services on the CSHCN Screener, or these children may experience other health consequences asked about in the survey.

### Consistent and Adequate Insurance Coverage

This measure is assessed by first establishing that CSHCN have current insurance coverage. If so, respondents are then asked whether there were any gaps in coverage in the past 12 months; this determines whether coverage was consistent. CSHCN who were uninsured any time in the past 12 months automatically have inconsistent coverage. Among those with current insurance, the adequacy of that coverage is determined by asking whether the coverage usually or always: 1) allows CSHCN to see needed providers; 2) has reasonable associated costs; and 3) meets his/her health needs. Those with current insurance coverage that is not usually or always adequate are coded as having “inadequate” coverage.

### Medical Home

The American Academy of Pediatrics’ description of a “medical home” lists seven defining components: accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. Ideally, these seven components are delivered by a doctor or other health professional who knows the child well. Five of the seven components of medical home and the presence of a personal doctor or nurse are assessed by the NS-CSHCN. The overall medical home measure is a composite score derived from five different subparts based on 19 survey items. To qualify as having a medical home, a child must meet the criteria for adequate care on every needed component:

- Has personal doctor/nurse and usual source of care for sick and well care
- Receives family centered and culturally sensitive care
- Meets care coordination measure criteria (i.e. received all care coordination when needed and is satisfied with cross-provider communications)

For more information on the history, development, and scoring of the medical home measure, see the Medical Home Data Portal: <http://www.childhealthdata.org/browse/medicalhome>. A Medical Home Manual about measuring this concept can be found at the same link.

### **Family-Centered Care**

Family-centered care is a component of the medical home measure and is based on several questions in the NS-CSHCN. Questions are asked about CSHCN who have had a health care visit in the past 12 months. To meet the family-centered care criteria, respondents must answer “usually” or “always” to all of the following items:

- Child's doctors spend enough time with him/her
- Child's doctors listen carefully to his/her parent(s)
- Child's doctors are sensitive to family culture and values
- Child's doctors provide information specific to child's health
- Child's doctors help family feel like partners

### **Care Coordination**

Care coordination also is part of the medical home measure. Effective care coordination is derived from three separate components: 1) CSHCN's families receive some type of help with care coordination; 2) CSHCN's families are very satisfied with communication among the child's doctors and other health care providers if the child visited a specialist doctor, used mental health services, received OT/PT/Speech therapy, got substance abuse treatment, or used home health care services during the past year; and 3) when such interactions are needed, families are very satisfied with how the child's doctors communicate with school, day care or other programs. Care coordination questions are only asked of children who needed coordination because they engaged in two or more services during the past 12 months.

### **Shared Decision Making**

In the 2009/10 NS-CSHCN, shared decision making is measured through questions that assess the extent to which parents of CSHCN feel that health professionals engage them in decision making about their child's health care. CSHCN meet this measure when the respondent answers that in the past 12 months, the child's health care providers usually or always: 1) discuss the range of options to consider for health care or treatment; 2) encourage the family to ask questions or raise concerns; 3) make it easy for them to ask questions or raise concerns; and 4) consider and respect what health care and treatment choices the family prefers.

### **Ease of Community-Based Service Use**

Ease of access to community-based services is determined by whether families of CSHCN report difficulties or frustration accessing services needed for their child in the past 12 months.

This measure is comprised of six types of difficulty accessing care: 1) not eligible for services; 2) services not available in their area; 3) waiting lists or other problems getting appointments; 4) issues related to cost; 5) trouble getting the information they needed; and 6) any other difficulties not mentioned. In addition, the measure also includes an assessment of how often parents were frustrated in their efforts to get services. CSHCN coded as having difficulty accessing community-based services had parents who answered yes to one of the six difficulties and answered usually or always to the frustration measure.

## Transition to Adulthood

In the 2009/10 NS-CSHCN, the successful transition to adult health care was assessed for CSHCN ages 12-17. In order to meet this measure, all four of the following items must be met:

- If a discussion about transitioning to adult care was needed, it must have happened;
- If a discussion about changing health care needs as child becomes an adult was needed, it must have happened;
- If a discussion about transitioning insurance to maintain eligibility was needed, it must have happened; and
- Doctors usually or always encouraged responsibility for self-care, such as taking medication, understanding his/her diagnosis, or following medical advice.

## Analytic Methods

As noted, this report uses the 2009/10 NS-CSHCN data to look at key measures and MCHB Core Outcomes for CSHCN in California. National data also are presented when findings highlight consistencies or disparities between California's children and children in the rest of the nation. For this report, "national" data include all states and the District of Columbia *without* California calculated into the estimate. Subpopulations of interest are age groups, race/ethnicity, income level, insurance status and type, and complexity of special health care needs. Data from the 2005/06 NS-CSHCN was used for a small number of measures and outcomes that could be meaningfully tracked over time.

Population weights are calculated at the child level; therefore, estimates represent the percentage of children, rather than the percentage of parents or the percentage of families. Point values, standard errors, and 95% confidence limits were calculated for all data presented in this report.

The statistical significance of differences observed between groups was assessed in two ways:

1. To test the independence of bivariate relationships among findings, chi-square statistical analyses employing a 0.05 level of significance were used. A chi-square test demonstrates whether variation between groups could be explained by random chance. A chi-square test p-value of <0.05 indicates that there is less than a 5 percent chance that the difference observed was due to random variation. This is an accepted standard for statistical significance. In multi-group comparisons, a p-value of <0.05 means that at least one group is statistically different from the others.
2. In order to assess multivariate relationships among findings, a series of logistic regressions were conducted. Sociodemographic factors such as age, sex, race/ethnicity and language, household income, and state were included as covariates in logistic regression models.

All analyses employed datasets coded by CAHMI<sup>3</sup> and used SPSS's Complex Sample Module<sup>4</sup> with adjustment of standard errors to account for weighting, clustering, stratification, and increased variability that result from the complex sampling design of the NS-CSHCN. Detailed methods and findings from prevalence, variations, and regression analyses are available upon request. See contact information below.

## Measuring Change Across Survey Years

Due to the increasing number of cell-phone only households, a cell phone sample was added to the sampling design and administration in 2009/10. The type of telephone sampled (landline versus cell phone) was included in the weighting and adjustment process for all analyses. Completion of the survey on a cell phone does not necessarily indicate that the household does not contain a landline telephone, only that they “may not be likely to answer” a line if one does exist.

With the inclusion of a cell-phone sample in 2009/10, MCHB and NCHS were challenged to think critically about the comparability of the most recent data with those from previous years. Preliminary analyses by NCHS indicate that observed changes (or lack of changes) since 2005/06 in comparably-measured Core Outcomes and Key Indicators may be due to both real changes over time and/or the inclusion of cell-phone interviews. The primary issue is coverage bias in 2005/06 due to the inability to adjust for undercoverage of CSHCN living in cell-only households (about 8% over the course of that survey). Because significant differences exist between the cell- and landline-samples with respect to the proportion of CSHCN who met selected indicators, not being able to account for these differences in 2005/06 limits the ability to draw conclusions about changes over the latter half of the decade. This was not an issue in 2001 as most households had landlines, rather than solely using cell phones. Given these challenges, analytic processes were adjusted to address possible coverage bias when conducting trend analyses with various survey years of the NS-CSHCN. Analyses in this report comparing 2005/06 and 2009/10 were conducted in a single concatenated file, with variables for survey year and sample type (landline vs. cell phone) included in the analyses to adjust for sampling differences and changes over time.

## Prevalence Differences Across Surveys

Prevalence of CSHCN is best expressed as a range, rather than a point estimate, as different methodologies across surveys have been shown to affect the exact prevalence rate of CSHCN. In the 2007 National Survey of Children's Health (NSCH), the prevalence of CSHCN nationally was reported as 19.2%, compared to the 2005/06 NS-CSHCN rate of 15.1%. This discrepancy can be explained by the leverage-salience theory, as described in literature comparing CSHCN prevalence rates.<sup>5</sup> Due to the purpose of the NS-CSHCN to obtain information about health care needs and consequences, parents with children with more complex health care needs may be more likely to participate in the survey regarding health need and services. Therefore, the NS-CSHCN provides a lower prevalence rate overall, but the children identified generally have more complex needs than those identified in other surveys. This also is consistent with the fact that CSHCN identified in the NS-CSHCN report experiencing greater health needs and consequences, compared to CSHCN identified in the NSCH.

In addition, the sampling methodology varies between the NS-CSHCN and the NSCH. In the NSCH a household is asked how many children under age 18 live in the house. If there is more than one, only one subject is selected for the interview and the interview proceeds. In the course of the interview, the CSHCN Screener is administered and a child may participate in the survey regardless of CSHCN status. In the NS-CSHCN, if multiple children live in the household, all children are screened for a special health care need. If more than one child is determined to have a special need, then only one child is randomly chosen to be the final interview subject. Because of the screening

process, it is hypothesized that parents make comparisons between the severity of multiple children's needs when being screened in the manner of the NS-CSHCN. Due to parental comparison of children's health care needs within the household, parents may be less likely to identify a child that has elevated health care needs if another child has more severe needs in the household. This potential comparison could lead to slightly lower prevalence estimates and slightly favors those CSHCN who are more severe compared with other CSHCN. Both surveys provide solid estimates of CSHCN prevalence, but estimating prevalence of CSHCN as a range (between 15-20%, nationally, and 10-15% in California) is the most accurate representation of this population.

## Additional Information

The Data Resource Center for Child and Adolescent Health, which is part of the Child and Adolescent Health Measurement Initiative, provides access to survey results at the state, regional, and national levels, overall and by age, race, income, insurance status, and other characteristics (<http://www.childhealthdata.org>). The website also offers background information on the NS-CSHCN and the National Survey of Children's Health in easy-to-understand formats, examples of publications and presentations using data from the survey, and links to relevant materials such as the National Center for Health Statistics information, documentation of survey methods and results, and resources for families with CSHCN. For further information on any data sources, analytic methods, or regression analysis used in this report, or to request a copy of the 2009/10 NS-CSHCN dataset, please contact the Child and Adolescent Health Measurement Initiative at the e-mail or phone number provided below.

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