Frequently Asked Questions
2009-2010 National Survey of CSHCN

The questions and answers below summarize key information about the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). A detailed report on the design and operation of the survey is forthcoming and will be released online as soon as possible.

General information about the background and purpose of the survey, the approach to data collection, and the data editing procedures has been published online (**http://www.cdc.gov/nchs/slaits/cshcn.htm**) for the 2001 and 2005-2006 NS-CSHCN. However, the design and administration of the 2009-2010 NS-CSHCN were enhanced and differ somewhat from those used previously in 2001 and 2005-2006. This document highlights many of those changes. Please read this document carefully and completely before analyzing the 2009-2010 data.

BACKGROUND

Who sponsored the 2009-2010 NS-CSHCN?

- Primary funder: United States Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB)
- Additional funding for specific questions was provided by:
    - DHHS, Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities (NCBDDD)
    - Lucile Packard Foundation for Children's Health (LPFCH)

Who conducted the 2009-2010 NS-CSHCN?

- CDC's National Center for Health Statistics (NCHS), State and Local Area Integrated Telephone Survey (SLAITS) program

SAMPLE DESIGN

What was the 2009-2010 sample design?

- Cross-sectional telephone survey of US households with at least one resident child aged 0 to 17 years at the time of the interview
- Complex survey design, with stratification by state and sample type (landline or cell-phone) and with clustering of children within households
- List-assisted random-digit-dial (RDD) sample of landline telephone numbers, supplemented with an independent RDD sample of cell-phone numbers
- The NS-CSHCN used the same sampling frame as the CDC's National Immunization Survey (NIS) and immediately followed the NIS interview in selected households, using its sample for efficiency and economy.

How was eligibility determined?

- Each telephone number was called and screened for residential status and the presence of children aged 0 to 17 years at the time of the call.
- In addition, for the cell-phone sample, various telephone status questions were asked. Households contacted by cell phone were considered eligible only if they did not have a landline telephone or the respondents said they were unlikely to be reached through the landline if they had one.
- All children living in eligible households were screened for special health care needs. If no children with special health care needs (CSHCN) were identified, the call was terminated after a few demographic questions which were needed to create sampling weights.

How many children were selected as the target of the interview per household?

- One child with special health care needs was randomly selected to be the subject of the detailed interview if more than one child with special health care needs lived in the household.
- In households with one child with special health care needs, that child was selected to be the subject of the detailed interview.

What screener was used to identify children with special health care needs?

- The CSHCN Screener (Bethell et al., 2002). This tool, which was also used in 2001 and 2005-2006, includes five stem questions on general health needs. Followup questions determine whether a reported need is the result of a chronic health condition. Those with affirmative responses to at least one stem question and the followup questions are considered CSHCN.
- The CSHCN Screener is designed to reflect MCHB's consequences-based definition of CSHCN (McPherson et al., 1998): *Children with special health care needs are those who have... 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.*
- Several questions (CSHCN1_C, CSHCN2_C, CSHCN3_C, and CSHCN4_C) related to special health care needs were included with the CSHCN Screener in 2009-2010. These questions are not used to identify CSHCN.

QUESTIONNAIRE

The questionnaire is at: **http://www.cdc.gov/nchs/data/slaits/NS_CSHCN_Questionnaire_09_10.pdf**.

What were the major additions to the content of the survey since 2005-2006?

- "Has a doctor or other health care provider ever told you that child had the condition?" was added for all 20 conditions.
- Brain injury was added to the condition list.
- Severity of ADD/ADHD, depression, anxiety problems, behavior or conduct problems, autism, developmental delay, intellectual disability, epilepsy, and brain injury
- Reasons for difficulties or delays obtaining community-based services and frustration obtaining needed services
- Parental involvement in shared decision making
- Number of preventive doctor visits and the number of preventive dental visits
- Child's age when first receiving special education services
- Receipt of early intervention services before age 3, for CSHCN 3-17 years
- Complementary and alternative health care use
- Receipt of developmental screening, for CSHCN aged 1-5 years
- Reduced job opportunities due to the child's health
- Medication type and treatment for CSHCN with Attention Deficit Disorder or Attention-Deficit/Hyperactivity Disorder, added at the request of NCBDDD
- Hospital admissions, immigrant status, internet access, and use of the internet for care coordination, for CSHCN in California, added at the request of LPFCH
- Additions to the Demographic s section include a family roster of all relationships to the child with special health care needs, highest education of mother and father and guardian, marital status of the selected child's parents, and a question asking if the respondent owns or rents the home.

What were the major deletions to the content of the survey since 2005-2006?

- Difficulty seeing or hearing without assistive devices
- Delayed or foregone health care
- Need and unmet need for medical supplies
- Need and unmet need for interpreters, except for CSHCN in California
- Ease of service use
- Satisfaction with community-based services
- Need for additional income to cover the child's medical expenses

DATA COLLECTION

When were the data collected?

- July 7, 2009 through March 2, 2011

Who was the respondent?

- A parent or guardian with knowledge of the health and health care of the children in the household. For the completed CSHCN interviews, 75% of the respondents were mothers (biological, step, foster, or adoptive), 17% were fathers (biological, step, foster, or adoptive), 6% were grandparents, and 2% were other relatives or guardians.

What was the average interview length?

- The mean interview length for special-needs cases from the landline sample was 33 minutes, 16 seconds, and the median time was 31 minutes, 46 seconds.
- The mean interview length for special-needs cases from the cell-phone sample was 36 minutes, 38 seconds, and the median time was 34 minutes, 58 seconds.
- The NS-CSHCN interview followed the NIS interview in selected households. The length of the NS-CSHCN interview was shorter for these households because some demographic and household questions were administered as part of the NIS and not repeated during the NS-CSHCN. The times above are for households that were not eligible for the NIS.

How many interviews were completed?

- A total of 372,698 children were screened for special health care needs in the 50 states and DC. The number of children screened in each state ranged from 5,911 (KY) to 10,290 (CA).
- Screened children lived in 196,159 households. The number of households screened in each state ranged from 3,166 (OK) to 5,502 (CA).
- Detailed interviews were completed for 40,242 CSHCN. The number of CSHCN with detailed interviews ranged from 751 (DC) to 878 (TX). The target number of completed interviews (750) was achieved in every state and DC.
- Of the total number of detailed interviews, 2,991 were completed with the cell-phone sample. The number of detailed interviews completed with cell-phone sample in each state ranged from 25 (DC) to 157 (TX). The target number of completed interviews with cell-phone sample (45) was not achieved in 8 states and DC, in part because respondents with cell-phone numbers from these areas reported living in other states.
- In addition to the totals presented above, 5,611 children from 3,150 households were screened for special health care needs in the U.S. Virgin Islands (USVI). Detailed interviews were completed for 344 CSHCN in USVI. Data from USVI have not been included in the recently released data files and will not be considered further in this document.

What was the overall response rate?

- The response rate is the number of completed interviews as a proportion of the number of eligible units in the sample. Due to nonresponse prior to completion of the screeners, the eligibility status is not observed for all sample units, and the number of eligible units in the sample must be estimated. For surveys with multiple screening stages, such as the NS-CSHCN, response rates can vary widely as a result of the assumptions used to estimate the number of eligible units among units with unknown eligibility. Response rates using different assumptions will be published in the forthcoming report on the design and operation of the survey.
- In 2001 and 2005-2006, the response rate calculation used for the NS-CSHCN divided the units with undetermined eligibility into three groups corresponding to non-respondents to different stages of eligibility determination (household resolution, age and telephone status eligibility, and special-needs eligibility). The proportion of eligible units among units of unknown eligibility was assumed to vary for each group and to equal the proportion of eligible units among units whose eligibility status was successfully determined at that stage.

- Using this approach, the weighted national response rate for special-needs interviews in 2009-2010 was 43.7% for the landline sample, 15.2% for the cell-phone sample, and 25.5% for the combined sample. State-level rates for the combined sample varied from 21.7% (NV) to 36.0% (VT).
- The NS-CSHCN interview completion rate, defined as the proportion of households known to include CSHCN that completed all sections up to and including Section 7 of the NS-CSHCN interview, was 83.6% for the landline sample, 76.6% for the cell-phone sample, and 80.8% for the combined sample. State-level rates for the combined sample varied from 73.9% (HI) to 86.2% (VT).

Do the differences in the response rates between the landline and cell-phone samples reflect large differences in the potential for nonresponse bias?

- No. Response rates are highly sensitive to the assumed rate of eligibility among the units for which the eligibility status has not been observed. They are also sensitive to definitions used to determine which cases are eligible or ineligible. The assumed rates of eligibility and the definitions to determine eligibility differed for the landline and cell-phone samples.
- Realization rates do not suffer from these limitations. The realization rate (Skalland, 2011) is defined as the ratio of the unadjusted survey estimate of the size of the target population to the true size of that population, as obtained from an external source.
- Children in cell-phone-only households were realized through the cell phone sample at nearly the same rate as children in landline households were realized through the landline sample (28.8% and 29.0%, respectively).

Were incentives to participate used?

- To improve the likelihood that eligible households would participate in the survey, a detailed incentive plan was implemented. Cases eligible for an incentive were known age-eligible households that had not completed the CSHCN Screener and/or interview. The value of the incentive and the timing of the incentive offer were varied as part of an experiment on the use of incentives. The maximum total value offered to any household was $15.
- Of all age-eligible households, 37% became eligible for an incentive. A total of 50,312 households that completed the CSHCN Screener received an incentive, and 10,545 households that completed the detailed interview received an incentive.

What languages in addition to English were used to conduct the interviews?

- The NS-CSHCN questionnaire was professionally translated into Spanish, Mandarin, Cantonese, Vietnamese, and Korean. During data collection, 1,048 detailed interviews were completed by a Spanish-language interviewer and 25 detailed interviews were completed by an Asian-language interviewer.

DATA FILES

How many interviews were included on the final data files?

- Three data files were released:

  - The CSHCN Interview File includes data for 40,242 CSHCN (one record for each child with special health care needs randomly selected as the interview target).
  - The Household File includes data for 196,159 households (one record for every household, regardless of whether or not the household included a child with special health care needs).
  - The Screener File includes data for 371,617 children (one record for every age-eligible child).

- The Screener File has fewer records than the number of children screened, because data for 1,081 children were suppressed to protect the confidentiality of households with large numbers of children. Sampling weights were adjusted to ensure that estimates based on the screener file were unchanged.

Are the three data files linkable?

- Yes, the three data files are linkable. Every screened child's household has a corresponding record in the Household File, regardless of whether a detailed interview was completed. Each interviewed child's household has a corresponding record in the Household File, and each child with a detailed interview has a corresponding record in the Screener File.
- At the household level, the files can be linked using IDNUMR, a unique household identification number. All files contain the IDNUMR variable. At the child level, these files can be linked using IDNUMXR, a unique child identification number. The Screener File and the CSHCN Interview File contain the IDNUMXR variable.
- Analysts interested in merging all three files are encouraged to first merge the Household File and the Screener File using IDNUMR and then merge the resulting file with the CSHCN Interview File using IDNUMXR.

Where can I find more information about variables suppressed to protect confidentiality and about derived variables?

- Please refer to the *Design and Operation of the National Survey of Children with Special Health Care Needs, 2005-2006*, available at: **http://www.cdc.gov/nchs/data/series/sr_01/sr01_045.pdf**
- To protect the confidentiality of individual respondents and children, responses for the race variable were collapsed to three categories: white only, African American or black only, and other race. The "other race" category includes children with multiple race and children for whom only one of the other three categories (Asian, American Indian or Alaska Native, and Native Hawaiian or Other Pacific Islander) was reported. This approach is different from the approach used in 2001 and 2005-2006.

SAMPLING WEIGHTS

How were the data weighted?

- Three sets of weights were produced: a household weight, a child screener weight, and a child interview weight. The weighting scheme began with a base sampling weight, which was the inverse of probability of the selection of the phone number. Adjustments to the base sampling weight included the following steps and calculations, and unless otherwise noted, were applied to the landline and cell-phone samples independently prior to their being combined.

    o Adjustment for non-resolution of released telephone numbers
    o Adjustment for incomplete cell-phone-only/mainly screener (cell sample only)
    o Adjustment for incomplete age-eligibility screener
    o Adjustment for incomplete special needs screener
    o Adjustment for multiple cell phone lines (cell sample only)
    o Adjustment so that the samples from all quarters jointly represent the corresponding full population
    o Adjustment of household weights for noncoverage of children in phoneless households
    o Adjustment of household weights for overlap of the landline and cell-phone samples
    o Attenuation of cell-phone sample household weights to minimize variance while controlling for bias
    o Raking adjustment of combined household weights
    o Raking adjustment of combined child screener weights
    o Adjustment for subsampling of CSHCN
    o Adjustment for nonresponse to the CSHCN interview
    o Adjustment of CSHCN interview weights for overlap of the landline and cell-phone samples
    o Attenuation of cell-phone sample CSHCN interview weights to minimize variance while controlling for bias
    o Raking adjustment of combined CSHCN interview weights

What was the source of independent population control totals for raking?

- 2009 American Community Survey

What are the final sampling weight variables?

- WEIGHT_I (The interview weight should be used when the unit of analysis is the child with special health care needs and the data analyzed include variables that are on the CSHCN Interview File.)
- WEIGHT_S (The screener weight should be used only when the unit of analysis is the child, and the data analyzed come solely from the Screener File and the Household File.)
- WEIGHT_H (The household weight should be used only when the unit of analysis is the household.)

ESTIMATION AND HYPOTHESIS TESTING

Who does this sample represent?

- When survey weights are used, the resulting estimates are representative of all non-institutionalized CSHCN aged 0 to 17 years in the US and in each state.
- These weighted estimates do not generalize to the population of parents, mothers, or pediatric health care providers.

Are special programs needed to analyze these data?

- Yes. For proper variance estimation, your program must be able to incorporate the complex sample design structure. Examples include SUDAAN, Stata, SPSS Complex Samples module, WesVar, the SAS SURVEY procedures, and the base program R with the separate SURVEY package.

How does the cell phone sample practically impact my data analyses?

- The specification of the complex sample design in programs capable of handling sample survey data has been slightly revised. The SAMPLE variable, which reflects the telephone sample type (landline or cell-phone), must be included when specifying the sample design. Additional programming statements (e.g., PSULEV in SUDAAN) may also be necessary.
- It is not possible to create accurate estimates for the landline and cell-phone populations separately, and the data files cannot be used to compare children from cell-phone-only households to children from landline households. This is because households in the cell-phone sample include households that have landlines but report that they are unlikely to be reached on them. In addition, the weights for the cell-phone sample were attenuated to minimize variance. Proxy cases from the landline sample were assigned a portion of the household weight associated with the cell-phone population. Therefore, limiting the analysis to either the landline or cell-phone sample cases only will misrepresent the populations and give erroneous weighted estimates.

What variables should be used to estimate variance?

- Stratum identifiers: STATE (state of residence) and SAMPLE (telephone sample type)
- Primary sampling unit (PSU) variable: IDNUMR (household identifier)
- Some analysts may be using statistical programs that only permit the specification of a single stratum variable. These users should define a new variable with 102 levels by crossing SAMPLE (2 levels) with STATE (51 levels). This new variable can then be used as the stratum variable. For example, Stata users can specify only one variable in the strata() option of svyset. This new variable (named here as STRATACROSS) can be created using the following statement:

    EGEN STRATACROSS = GROUP (STATE SAMPLE)

- SUDAAN users can identify both STATE and SAMPLE in the NEST statement. However, SUDAAN users should note that the first variable listed after the word NEST is assumed to be the stratum variable, and the second variable listed is assumed to be the PSU.   To properly identify the PSU variable, the PSULEV option must be invoked in the NEST statement as shown here:

    NEST STATE SAMPLE IDNUMR / PSULEV = 3;

Can the data be subsetted before analysis?

- The procedure of keeping only select records and list-wise deleting other records is called subsetting the data. Most software packages that analyze complex survey data will incorrectly compute standard errors for subsetted data, because subsetting the data can delete important design information needed for variance estimation. Analysts should not subset the data, with one exception: Subsetting the survey data to a particular state does not compromise the design structure. Analysts interested in examining specific population subgroups (such as children living in poverty) must use the appropriate options in their software package (e.g., SUBPOPN in SUDAAN).

WORKING WITH MISSING DATA

How are missing data identified on the data files?

- The SAS data files for the National Survey of CSHCN include special missing value codes for analysts who may wish to differentiate between different types of missing values.

  - (.B) Breakoff after screener—Variable is missing because the case broke off after completing the CSHCN Screener. If the CSHCN Screener was completed for the household and a child with special health care needs was selected for the interview, but a detailed interview was not completed, the record will be missing some demographic data that are gathered only at the end of the interview.
  - (.L) Legitimate skip—Variable is missing due to valid questionnaire paths based on a previous answer to a root question.
  - (.M) Missing in error—May indicate that the variable is missing due to interviewer or system errors. In addition, all missing values for derived variables (i.e., variables whose response was not directly provided by the respondent) receive a ".M" code regardless of the reason for the missing data.
  - (.P) Partially completed interview—Variable is missing because the respondent ended the interview after completing Section 7 but before completing the full interview.

- Data missing because the respondent did not know the answer or refused to provide the answer have been treated differently. A numeric code was used to identify these responses. Typically, unknown answers are coded as "6," "96," or "996." Refused responses are coded as "7," "97," or "997." However, the codes may be different for specific variables; therefore, analysts are encouraged to consult the data documentation and frequency lists to identify the correct codes for each variable. Failure to do so may result in inappropriate calculations, especially for variables measured using ordinal, interval, or ratio scales.

Will missing data for demographic variables be imputed?

- Nonresponse rates for questions on race, ethnicity, parental education, primary household language, household income, total number of adults in the household, and receipt of cash assistance from a welfare program were higher in 2009-2010 than in 2001 or 2005-2006.
- A nonresponse analysis shows that missingness for household income is related to several variables, including items pertaining to health and demographics. Thus, the respondents cannot be treated as a random subset of the original sample. It follows that the most common method for handling missing data in software packages, "complete-case analysis" (also known as "listwise deletion"), will generally be biased because this method deletes cases that are missing any of the variables involved in the analysis. Imputation is a more appropriate approach to handling nonresponse. An additional SAS data file that includes multiply-imputed household income data (relative to the federal poverty level) is forthcoming.
- Nonresponse analyses show that missingness for the other demographic variables is related to whether the child has special health care needs. Imputed data for these demographic variables are also forthcoming. Analysts should not estimate CSHCN prevalence for these subgroups until the imputed data are available.

GUIDELINES FOR DATA USE

The Confidential Information Protection and Statistical Efficiency Act (Section 512b) and the Public Health Service Act (Section 308d) provide that these data collected by NCHS may be used only for the purpose of health statistical reporting and analysis. Any effort to determine the identity of any reported case is prohibited by these laws. NCHS takes extraordinary measures to assure that the identity of survey subjects cannot be disclosed. All direct identifiers, as well as any characteristics that might lead to identification, have been omitted from the data set. Any intentional identification or disclosure of a person or establishment violates the assurances of confidentiality given to the providers of the information. Therefore, users must:

- Use the data in this data set for statistical reporting and analysis only;
- Make no use of the identity of any person discovered, inadvertently or otherwise, and advise the Director, NCHS, of any such discovery (301-458-4500);
- Not link this data set with individually identifiable data from any other NCHS or non-NCHS data sets.

Use of the data set signifies users' agreement to comply with the above-stated statutory-based requirements.

FURTHER INFORMATION

Whom do I contact if I have questions about the 2009-2010 NS-CSHCN after I read this document?

- We recognize that this summary may not provide all of the information that analysts need regarding the design and operation of the survey. If you have further questions, please send an email to **slaits@cdc.gov**.

What is the suggested citation for this document?

- Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey. 2009-2010 National Survey of Children with Special Health Care Needs Frequently Asked Questions. December 2011. Available from URL: **http://www.cdc.gov/nchs/slaits/cshcn.htm**

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