

Findings from the 2009-2010 National Survey of Children with Special Health Care Needs

January 19, 2012
2:30 –3:30 p.m. ET

Questions and Answers

Q: When I checked the maps today they were still identified as being from the 2005/2006 survey. When could we expect to have maps representing the new data?

A: (Christina Bethell) The State Ranking Maps will be updated with the 2009/10 NS-CSHCN data by mid-February.

Q: Some of the indicators from the 2005-06 survey are missing from the 2009-10 survey. Are there still more data that needs to be released?

A: (Michael Kogan) Some of the indicators changed, so it may appear that some of the indicator data are missing. Yes, the imputed data on poverty and some demographic variables still need to be released.

Q: How can I gain access to the NS-CHSCN data for research purposes? Is the general public allowed access to the raw data without identifying information included? How can we see the questionnaire?

A: (Christina Bethell, Stephen Blumberg) The microdata files and questionnaire are currently available to download on the NCHS website: <http://www.cdc.gov/nchs/slait/cshcn.htm>

DRC Indicator Data Sets include all records and variables from the NCHS public use data files for the surveys. Additional content includes dozens of variables corresponding to measures of children's health status, health care quality and system performance featured in the DRC online data query. Also provided are variables used for DRC subpopulation comparisons and analyses by any state, District of Columbia or HRSA region. SPSS, SAS and STATA datasets are available, and variables are formatted and clearly labeled. These datasets will be available once imputed data is finalized.

Q: Where can we obtain list of special health care needs that were included? How do you define functional difficulty or function? I am particularly interested in congenital heart disease.

A: (Christina Bethell) A list of specific conditions asked about on the 2009/10 NS-CSHCN, as well as the functional difficulties can be viewed here: <http://childhealthdata.org/docs/cshcn/2009-cshcn-conds-func-diff.pdf>

Heart disease, including congenital heart disease can be viewed.

Q: How did the eligibility sub-component of quality indicator #5 compare to the other sub-components, and what was the range across states?

A: (Christina Bethell) Nationally, 10.8% of CSHCN had difficulties or delays getting services for child because he/she was not eligible for services, ranging from 5.3-17.2% across states. This compares to other difficulties or delays getting services: service not available (11.2), waiting lists/backlogs (17.8), cost (14.9), trouble getting needed information (9.0), and other reasons (3.0). Each subcomponent can be viewed on the DRC data queries under the “Additional and Details for Core Outcomes”.

Q: Is the change in wording on Outcome 5 specific to the type of service being sought (e.g., medical, dental, etc.)?

A: (Christina Bethell) No, MCHB Core Outcome #5 does not address specific services. This outcome addresses whether CSHCN can easily access community based services. The outcome is comprised of seven non-specific questions. Parents are asked “During the past 12 months, did you have any difficulties or delays getting services for your child”: (1) due to eligibility, (2) due to availability, (3) due to problems getting appointments, (4) due to cost, (5) due to trouble getting needed information, or (6) for any other reason. In addition, parents are asked how often they were frustrated in efforts to get services for their child. Due to the wording of the questions, parents can answer the question based on all types of services sought in the past 12 months.

Although specific service needs are not addressed in Outcome #5, the 2009/10 NS-CSHCN included a list of 14 specific health care services and equipment. For each services/equipment, parents are asked whether their child needed the service and whether they received all needed services. This identified CSHCN who had unmet needs for specific types of health care services and equipment. Each of these items is currently available on the Data Resource Center.

Q: Is there a way to find data for a specific community to compare to state and national estimates? Is there any way to break down information by county?

A: (Christina Bethell, Stephen Blumberg) Currently, the public use data files for the surveys have state identifiers and a binominal variable identifying whether or not children live in a metropolitan statistical areas (MSA). This indicator is suppressed whenever the population for the MSA or non-MSA area is less than 500,000 persons. Zip codes are collected by the National Center for Health Statistics (NCHS), however, these data are not released in the public use data file due to confidentiality restrictions. It is possible to analyze these zipcode data on site at the NCHS’ Research Data Center in Hyattsville, MD. Interested researchers must first submit a proposal to the Research Data Center. Go to www.cdc.gov/rdc for more information about the Research Data Center and the proposal process.

Synthetic estimates are also a way in which you can obtain local estimates using national data. A synthetic estimate is a prevalence estimate for a local area that is calculated by using descriptive or demographic data for local areas combined with state prevalence values. It is similar in concept to an indirect adjustment. A local estimate is most likely to differ from a state estimate if the demographic distribution at the local area differs from that of the state and the prevalence of the indicator varies by the same demographic factor. For more information on synthetic estimates, view our Local Uses of National and State Data Brief at <http://childhealthdata.org/docs/nsch-docs/local-use-of-state-data-and-synthetic-estimates.pdf>

Q: Is there a mechanism for using the CSHCN questionnaire for a specific population of CSHCN not as part of the whole US sampling project? Can you generate state and national reports based on type of special needs?

A: (Christina Bethell, Stephen Blumberg) The CSHCN Screener has been validated to be used in national surveys, community level surveys and in practices to identify CSHCN. For more information on the CSHCN Screener, please see the CSHCN Screener Fast Facts: <http://childhealthdata.org/docs/cshcn/cshcn-screener-cahmi-quickguide-pdf.pdf>

To obtain a copy of the CSHCN Screener, please email cahmi@ohsu.edu .

The questionnaire for the 2009-2010 NS-CSHCN is in the public domain and may be reproduced, copied, or used by other researchers without permission. On the DRC, we do not have national or state-level reports based on type of special health care need. However, all individual data queries have the option to view data by special health care need. We will take this concept of a new profile into consideration while drafting our new profiles for the 2009/10 NS-CSHCN.

Q: Will state level analyses (that are statistically valid) be available for CYSHCN with more severe issues compared with those with less serious issue? Will states be able to request special data runs from the Data Resource Center?

A: (Christina Bethell) Indicators on the DRC website can be viewed at the state level, unless the sample size is insufficient. These state level analyses are statistically valid; however, caution should be taken when the estimate is grayed out, representing >30% RSE. Additionally, each indicator can be viewed by special health care need. Under the “Compare Subgroups” in the upper right hand corner of any Data Query page, select “Specific Types of Special Health Care Need”. This allows you to compare CSHCN based on how they met the CSHCN Screener, and consequently their severity of condition.

Q: Is any of the data from these surveys comparable to European Values Survey or those from Australia and Canada?

A: (Christina Bethell) The data from the 2009/10 NS-CSHCN was primarily collected to assess the current health and systems of care for Children with Special Health Care Needs. The European Values Survey is a series of longitudinal surveys that aim to measure the personal, community and political values of a population. Therefore, the questions do not appear to be comparable across the two surveys.

Q: What does imputed data mean?

A: (Christina Bethell, Stephen Blumberg) Imputation is a statistical technique that attempts to address missing data in sample survey datasets through simulation. Data can be missing for a number of reasons: the respondent either did not know the answer to question(s); chose to skip question(s); refused to answer question(s); or question(s) were erroneously not asked. A high level of missing data limits the ability of analysts to draw conclusions from the survey. To derive the imputed values, an imputation algorithm or model is developed to predict data for the missing variable(s) by taking the observed values into account.

Due to the high number of cases with missing values on the race/ethnicity, primary household language, education, and income variables, imputation was used to derive values for these cases. The imputation model generated these predicted values based on Census data for the child's neighborhood, other demographics provided by the respondent, and other information collected in the survey. More information on the specific imputation process used in the NS-CSHCN will be available in the Design & Operations Manual published by NCHS.

Q: Do the tables produced within the web interface use imputed figures for disaggregated groups with elevated non-response rates?

A: (Christina Bethell) The tables displayed on the DRC website are generated using the public use files provided by NCHS. At this time, imputation has not been completed for the 2009/10 NS-CSHCN; therefore, none of the data on the DRC website for the 2009/10 NS-CSHCN contains imputed data. If imputed data is used on the DRC website, a Data Alert will appear notifying you of the use of single or multiple imputation methods for the data you are viewing.

Q: I would like to hear more about specific findings with regard to children with autism from the NS-CSHCN.

A: (Christina Bethell) According to the 2009/10 NS-CSHCN, 7.9% of CSHCN currently have autism, Asperger's Disorder, pervasive developmental disorder (PDD) or other autism spectrum disorder (ASD). The autism prevalence questions are asked of CSHCN age 2-17 years only. Additionally, the 2009/10 NS-CSHCN included questions regarding the severity of autism and the age of initial diagnosis. Each of these items can be viewed on the DRC website at the national and state level, and can be stratified by subgroups at the national level.

Condition-specific reports were generated using the 2005/06 NS-CSHCN, which allowed for the comparison of multiple indicators among CSHCN with and without a specific condition. These reports will be updated using the 2009/10 NS-CSHCN data and be available at a later date.

Q: Are the updated SLAITS survey data on Health and Functional Status (Survey Section 3) available online? I'm particularly interested in the Question: Anemia or sickle cell disease (S3Q25)

A: (Christina Bethell) The 2009/10 NS-CSHCN Survey Sections data is currently in development. Expected release of all Survey Sections items is mid-February. Regarding your interest in prevalence of blood problems and prevalence of anemia, these are currently available under the MCHB Core Outcomes and Key Indicators on the DRC website. These specific items are included under "CSHCN Health and Functional Status" and "Prevalence of 20 individual current chronic health conditions among CSHCN." Question S3Q25 was asked separately regarding anemia, sickle cell, hemophilia and "something else." Due to small sample size, only prevalence of anemia is displayed. For more information on prevalence of specific blood problems, please contact the CAHMI at cahmi@ohsu.edu.

Q: When are the findings of the Survey of Pathways expected to be available and where will it be posted? Will there be state-specific information? Will it also be available for ADHD? Was OT included as one of the services in the Pathways survey?

A: (Stephen Blumberg) We anticipate that most findings from the Survey of Pathways to Diagnosis and Services will be published in peer-reviewed journal manuscripts. Public use data files from the survey are in clearance and will be published as soon as possible pending clearance. Sample sizes are too small to permit state-specific findings. The target population for the survey was school-aged children ever diagnosed with autism spectrum disorder, intellectual disability, and/or developmental delay. Some of those children also have ADHD, but children with ADHD who did not have one of the three qualifying conditions are not included in the Pathways survey. Yes, both school-based and other occupational therapy were included as services in the Pathways survey.

Q: Could you talk briefly how the child weight was developed for the cell phone sample?

A: (Stephen Blumberg) The weighting scheme began with a base sampling weight, which was the inverse of probability of the selection of the phone number. Base sampling weights for the cell-phone sample then went through a series of 16 adjustments. See <http://www.cdc.gov/nchs/data/slait/s/NSCSHCNfags2009.pdf> for a list of those adjustments. These adjustments included attenuating the weights for the cell-phone sample to minimize variance. Proxy cases from the landline sample were assigned a portion of the household weight associated with the cell-phone population.

Q: How do you come up with the sample size of 750 CSHCN per State? Does this sample size allow for estimates of disparities by subgroups based on income, ethnicity, or age?

A: (Stephen Blumberg) The target sample size of 750 completed detailed CSHCN interviews per state was selected so that state-specific sample sizes were sufficiently large to permit precise estimates of the characteristics of CSHCN in each state. Sufficient precision was defined as a maximum relative standard error of 10% for all point estimates greater than 15%. Estimates for population subgroups within each state may have greater relative standard errors. Precision depends on the relative size of the population subgroups and the magnitude of the point estimate.

Q: How is reservation data captured for CSHCN?

A: (Stephen Blumberg) Sampled telephone numbers for the NS-CSHCN are selected using random-digit dialing. Landline phone numbers located on reservations and cell-phone numbers owned by persons living on reservations have the same probability of selection as any other telephone number in the state. The questionnaire does not ask parents whether the child lives on a reservation.

Q: Do you mind explaining again what “resolution rate” means?

A: (Stephen Blumberg) The resolution rate is the proportion of sampled telephone numbers that could be identified as residential or nonresidential. When called, the majority of unresolved telephone numbers rang with no answer. Most of the other unresolved numbers either reached persons or machines who hung up before identifying themselves or reached answering machines/voice-mail services that provided no indication whether the caller reached a residence or business.

Q: Where are the results of the 2011 supplement for children ages 6-17 with ASD, intellectual impairment, and/or developmental delays as referenced by Dr. Blumberg?

A: (Stephen Blumberg) We anticipate that most results from the Survey of Pathways to Diagnosis and Services will be published in peer-reviewed journal manuscripts. Public use data files from the survey are in clearance and will be published as soon as possible pending clearance.

Q: Could you speak a little bit more on combining the questions on dental visits and well-child visits? Were the questions asked separately and then the answers combined during coding or was it just one question? Why were the questions combined?

A: (Stephen Blumberg) Questions on dental visits and well-child visits were asked separately, and the publicly available data files include responses to each of these separate questions. Researchers may create composite indicators using these questions if they wish.

Q: Was the survey solely parent response or did you also include for kids old enough to answer questions? Did you include both teens and parents perceptions about functional abilities?

A: (Stephen Blumberg) The NS-CSHCN only interviewed a parent or guardian with knowledge of the health and health care of the children in the household. Teenagers did not respond for themselves.

Q: On the removal of the interpreter question: Is it not likely that families who need interpreters could be the ones that "hung up" without even speaking? It seems hard to believe, e.g. in major cities that this would not be a significant issue.

A: (Stephen Blumberg) The removal of the interpreter question (“Do you need an interpreter help speak with his/her doctors or other health care providers?”) has no impact on the use of interpreters and translated questionnaires for the collection of the survey data. Interviews were conducted in Spanish and four Asian languages. If a respondent answered the phone in a language other than English, interviewers asked “What language do you speak?” If the respondent was unable to respond or hung-up, professional translation services were used to identify which languages were spoken by persons living in the household.

Q: Wouldn't the disparities in these core performance measures be greater if the wireless phone contacts were more successful?

A: (Stephen Blumberg) Not necessarily. As a result of survey weighting, wireless-only households are included in weighted estimates in approximately the same proportion as such households exist in the population. Higher response rates within the cell-phone sample would not change the relative weight given to such households. This weighting strategy assumes that the characteristics of wireless-only households who did respond are similar to the characteristics of wireless-only households that did not respond. If this assumption is incorrect, then nonresponse bias would result. It is unknown whether such bias, if it did exist, would increase or decrease observed disparities.

Q: Why the decline in Quality Indicators #2, #3, and #6?

A: (Bonnie Strickland) We have no way of determining the cause of the decline in these indicators. At the national level, the decline on Indicator #6 was not significantly lower, but the significant decline in medical home and insurance could have been influenced by high under- and-unemployment rates in the nation during the survey period. Other contributors may be that, with the prominent discussions leading up to and including health care reform, the public, including families of children with special health care needs, became more knowledgeable about what they should expect from the health care system.

Q: Are there specific sub-components of Quality Indicator 2 that contributed more to the decrease in % of children meeting that indicator in 2009/10 vs. 2005/6?

A: (Bonnie Strickland) There were decreases in almost all subcomponents for medical home.

Q: In terms of the decreases seen in the six CYSHCN indicators, do you think this could have anything to do with an increase in the awareness about these issues and perhaps we are now getting a more accurate measure for these indicators?

A: (Bonnie Strickland) That’s certainly a possibility although we have no way of verifying that possibility. Certainly, as concepts like medical home, health care transition, and insurance adequacy become more familiar to the public, and families become more knowledgeable about what they should expect from their child’s health care provider and the system, they are in a better position to evaluate these questions critically, and provide a more informed response.

Q: Do you know if this data has ever been utilized within the Department of Education to examine the Exceptional Student Education program?

A: (Bonnie Strickland) To our knowledge the data have not been utilized by the Department of Education. We have shared data informally on numerous occasions and venues, and there are current efforts at the national level to better align data sources across agencies.

Q: Can you identify causes for the decline of the Medical Home concept and give examples of how actively involved families working in Title V programs across the nation can better guide families of children using CYSHCN Title V programs through the MCHB?

A: (Bonnie Strickland) See above. We can't determine the cause for the decline on the Medical Home Indicator (#2). However, we do know that almost all components of medical home decline. Contributors may have included high under- and- unemployment rates in the nation during the survey period. Other contributors may be that, with the prominent discussions leading up to and including health care reform, the public, including families of children with special health care needs, became more knowledgeable about what they should expect from the health care system. Families are key resources in making sure that families know what they should expect from their health care provider. The Family to Family Health Education and Information Centers (F2Fs), funded through ACA, are an excellent example of how informed family networks can provide this information to families at the state and national level.

Q: Is there an ability to analyze and trend specific outcomes comparing CSHCN who directly access Title V program services versus CSHCN who do not access or participate in Title V programs/services?

A: (Bonnie Strickland) No. We have no way to determine which children in the survey directly access Title V program services. This item was included in the very first NS-CSHCN, but was eliminated after the first survey because very few respondents understood the question/had any knowledge of Title V/or whether they received any service from the program.

Q: Will the survey's findings be implemented to help change the laws be introduced to legislature state-wide and federally to make the changes of in laws to implement found needed changes for children with special healthcare needs? Will these changes be added to the curricular requirements for teachers or those who are becoming teachers?

A: (Bonnie Strickland) The intention and hope is that these data will be utilized.

Q: Will there be a longitudinal follow-up related to the transition to adulthood questions? e.g., Will older adolescents be surveyed again to see what their experiences with the health care system are as adults? During the actual transition to adulthood?

A: (Michael Kogan) At this time we do not anticipate having a longitudinal follow-up focused on transition issues.

Q: Does the National Survey of Children's Health contain information about CSHCH as well? If so, what are the strengths of the National Survey of Children with Special Health Care Needs as opposed to the National Survey of Children's Health?

A: (Michael Kogan) Both surveys ask the screener questions that determine whether a child was categorized as having special health care needs. In the NSCH, it is possible to compare CSHCN to children without special needs in a variety of areas. The strength of the NS-CSHCN is that you can get much more detailed information on the health care and family experiences of this population.

Q: Is the question on complementary and alternative medicine new?

A: (Michael Kogan) Yes.

Q: What questions are asked about diabetes and tobacco use or exposure?

A: (Michael Kogan) For diabetes, we ask whether the parent/guardian had ever been told by a health care provider that their child had diabetes, and if so, whether they currently have diabetes. There are no questions on tobacco use or exposure.

Q: With the increased level of detail of each of the conditions studied in the survey, was there delineation between Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder, Not Otherwise Specified in the 2009-2010 National Survey?

A: (Michael Kogan) No, we felt that would be difficult given that it's a parent-report survey.

Q: When you report the data will you use the HP2020 population template and Standard errors?

A: This is not known at this time.

About the MCHIRC

The Maternal and Child Health Information Resource Center (MCHIRC) is dedicated to the goal of helping MCH practitioners on the Federal, State, and local levels to improve their capacity to gather, analyze, and use data for planning and policymaking.

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This question and answer sheet was created by moderator Sarah Lifsey, MPP.

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