

Attachment 5:

Additional backup material

- Technical Expert Panel participant list
- Referent Sample overview
- Representative examples of published peer-reviewed journal articles using data from other iterations of the NS-CSHCN (listed below); these analyses will be repeated with data from the 2008 – 2009 NS-CSHCN to establish trend data.

Bonnie Strickland, Merle McPherson, Gloria Weissman, Peter van Dyck, Zhihuan J. Huang, and Paul Newacheck. Access to the Medical Home: Results of the National Survey of Children With Special Health Care Needs. *Pediatrics* 2004; 113: 1485-1492

Merle McPherson, Gloria Weissman, Bonnie B. Strickland, Peter C. van Dyck, Stephen J. Blumberg, and Paul W. Newacheck. Implementing Community-Based Systems of Services for Children and Youths With Special Health Care Needs: How Well Are We Doing? *Pediatrics* 2004; 113: 1538-1544.

- Tailored refusal conversion letter to eligible households
- Thank you letter

SLAITS National Survey of Children with Special Health Care Needs Technical Expert Panel Participants

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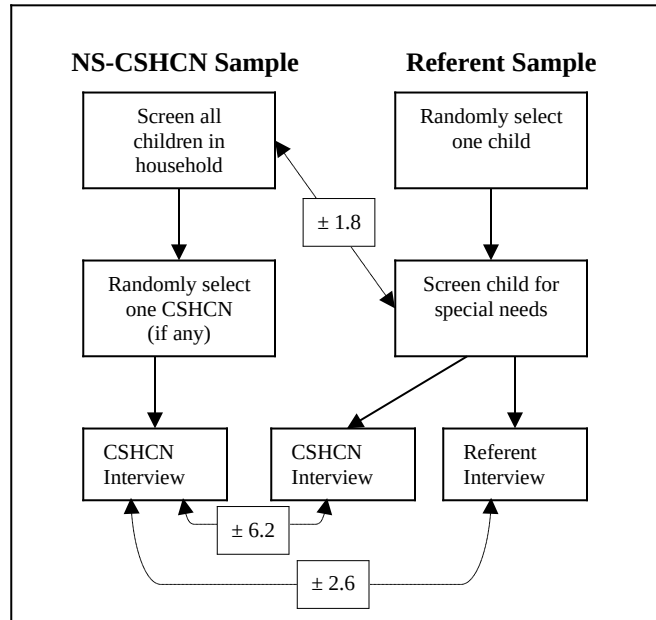
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Referent Sample

Overview

- A less-than one-minute screener will be administered in identified households to determine whether there are children under age 18 in the household.
- One child will be randomly selected from each identified household with children. No effort will be made to select the child on the basis of health characteristics.
- This child will be the target for the CSHCN Screener and subsequent interview. The interview will consist of all sections of the interview for CSHCN, with the exception of Section __.
- The referent sample will consist of different households than the NS-CSHCN sample. No household would be eligible for both a CSHCN interview and a referent sample interview.
- A national sample size of 6,000 interviews will be completed. From a national sample of 6,000 children, we would expect approximately 780 – 1,080 completed interviews for CSHCN and 4,920 – 5,220 completed interviews for children without special needs.
- From a sample this size, we would be able to detect (with 80% power and 95% significance):

- A minimum difference of 2.6 percentage points in the prevalence of any key characteristic between CSHCN and children without special needs
- A minimum difference of 1.8 percentage points in the prevalence of CSHCN by screening method (i.e., all children in household vs. one child)
- A minimum difference of 6.2 percentage points in the prevalence of any key characteristic between CSHCN from the main sample and CSHCN from the referent sample



Benefits

- Children without special needs can be compared with CSHCN.
- The referent sample provides the opportunity to examine differences in prevalence estimates and potential biases when all children in the household are screened (as done in the NS-CSHCN) and when only one child in the household is screened (as proposed for the referent sample).

Risks

- A referent sample including CSHCN may yield different prevalence and impact estimates for CSHCN, raising questions about which estimates are more accurate.
- The referent sample may include children who report elevated service use needs (or other impacts) but who do not screen in on the CSHCN Screener. This may raise questions about the efficacy of the screener.

Incentives: tailored refusal conversion letter sent to eligible households

DEPARTMENT OF HEALTH & HUMAN SERVICES

**Public Health
Service
Centers for Disease
Control and
Prevention**

**National Center for
Health
Statistics
3311 Toledo Road
Hyattsville,
Maryland**

Dear Parent or Guardian,

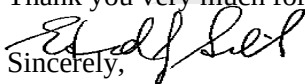
The CDC needs your help!

Recently, your family was asked to participate in the National Survey of Children with Special Health Care Needs, but we have not been able to complete the interview yet. We hope you will reconsider our request. Information about your child and other children will help the Centers for Disease Control and Prevention develop programs to promote the health of children in your state and throughout the United States.

We hope you will share this important information with us by telephone when an interviewer calls to ask you to participate in the study. If you would like to participate right away, please call the toll-free telephone number 1-866-XXX-XXXX.

Your household is very important to the study because it has been scientifically selected and cannot be replaced. All information collected for this study is confidential and protected by federal law. The back of this letter provides answers to some questions you might have and ways to get additional information about the survey.

Thank you very much for your help with this important research.

Sincerely,


Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

P.S. In appreciation for your time and effort, we have enclosed \$5. We will send an additional \$10 in cash once you complete the interview.

BACK PAGE INCENTIVE LETTER

Why is this study being conducted?

The Centers for Disease Control and Prevention is committed to improving the health and well-being of all children, especially children with special health care needs. State and federal health authorities are depending on the results of this study to help them understand how best to meet the needs of children with special health care needs.

How will this information be used?

Maternal and Child Health Agencies in your state will use this information to improve programs and services for children with special health care needs and their families. The federal government will also use this information to learn about the types of support services that states need for children's health and well-being. You may visit <http://www.cdc.gov/nchs/slaits.htm> to find general information about the study. To find results from the last time the survey was done, please visit <http://www.cdc.gov/nchs/about/major/slaits/nscshcn.htm>.

How do I know that my information will remain private?

As required by law, we will take all possible steps to protect your privacy. The collection of information in this survey is authorized by Section 306 of the Public Health Service Act. The Public Health Service Act is Volume 42 of the US Code, Section 242k. The confidentiality of your responses is assured by Section 308(d) of this Act.

Information that you provide is used for statistical research only. The results of this research are published only in the form of summary statistics. Your name and your child's name are never associated with any published information.

Participation in the study is voluntary. You may choose not to answer any question that you do not wish to answer or to end your participation at any time.

How can I find out more about this survey?

If you have any questions about this research study, please call 1-800-XXX-XXXX. If your questions are about your rights as a participant in this research study, you may also call the office of the Research Ethics Review Board at the National Center for

Health Statistics, toll free, at 1-800-223-8118. Please leave a brief message with your name and phone number. Say that you are calling about Protocol # 200X-XX. Your call will be returned as soon as possible.

Thank you letter

DEPARTMENT OF HEALTH & HUMAN SERVICES
Health Service

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**Centers for Disease
Control and
Prevention**

**National Center for
Health Statistics
3311 Toledo Road
Hyattsville,
Maryland 20782**

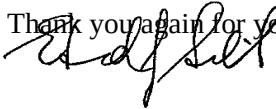
Dear Parent or Guardian,

Thank you for taking part in the National Survey of Children with Special Health Care Needs. The information that you gave about your child will help the Centers for Disease Control and Prevention develop programs to promote the health of children in your state and throughout the United States.

In appreciation for your time and effort spent answering our questions, we have enclosed \$10.

If you would like more information about this survey, you can visit the study's web site at <http://www.cdc.gov/nchs/about/major/slaits/nscshcn.htm>, or call the toll-free telephone number for the study at 1-866-XXX-XXXX.

Thank you again for your help with this important research.



Sincerely,

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

