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Design and Operation of the National Survey of Children with Special Health Care Needs, 2001

Program and Collection Procedures

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES Centers for Disease Control and Prevention National Center for Health Statistics

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Abstract

Objectives

This report presents the development, plan, and operation of the National Survey of Children with Special Health Care Needs (CSHCN), a module of the State and Local Area Integrated Telephone Survey. conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention. This survey was designed to produce national and State-specific prevalence estimates of CSHCN, describe the types of services that they need and use, and assess aspects of the system of care for CSHCN. This study included two additional modules to provide health care coverage estimates for all children and to collect data on the reasons that low-income uninsured children lack health care coverage. Primary funding for this survey was provided by the Maternal and Child Health Bureau, Health Resources and Services Administration.

Methods

A random-digit-dial sample of households with children under 18 years of age was selected from each of the 50 States and the District of Columbia. Depending on the health care needs of the children in each household, a detailed interview was conducted for one randomly selected child with special needs and a brief health insurance interview was conducted for one randomly selected child without special needs. The respondent was the parent or guardian who knew the most about the child's health and health care.

Results

A total of 196,888 household screening interviews were completed from October 2000 to April 2002. This resulted in 38,866 completed specialneeds interviews and 176,296 completed health insurance interviews for children without special needs. The weighted overall response rate for special-needs interviews was 61.0%.

Keywords: disabled children • chronic disease • child health services • pediatrics • health surveys • needs assessment

Design and Operation of the National Survey of Children with Special Health Care Needs, 2001

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Introduction

hrough a block grant system to create Federal-State partnerships, government Title V funds are available to help States develop and provide coordinated systems of care for children with special health care needs. Although most States provide some form of special needs care using these funds, formal evaluation of the special needs programs has proved challenging for two reasons: 1) no single method of identifying these children or operational definition of special health care needs has been accepted; and 2) States vary considerably in the levels and types of services provided. Yet, State-level data regarding the need for, use of, and barriers to care are necessary for accurate program evaluation. The National Survey of Children with Special Health Care Needs (CSHCN), detailed in this report, was designed to produce prevalence estimates of CSHCN using a standard battery of screening question, to describe the types of services that these children need and use, and to assess possible areas of improvement in the system of care for CSHCN (1). For the first time, this information is available at the State level and was collected in a manner that allows comparison across States and nationally.

State and Local Area Integrated Telephone Survey Program

The National Survey of CSHCN was conducted as a module of the State and Local Area Integrated Telephone Survey (SLAITS). The SLAITS program, sponsored by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS), is a broad-based, ongoing surveillance system available at the State and local levels for tracking and monitoring the health and well-being of children and adults. SLAITS uses the same sampling frame as the National Immunization Survey (NIS), which is conducted jointly by NCHS and the CDC's National Immunization Program (2). The NIS is a large-scale randomdigit-dial (RDD) telephone survey that screens for the presence of young children in sampled households and collects vaccination history information for eligible children. The size of the NIS sample provides an economical opportunity to survey other populations in addition to the rare population that eventually screens into the NIS itself. Through the NIS sampling frame, SLAITS modules enjoy cost savings by avoiding some of the expense of frame development, sample selection, and screening.

History of SLAITS Program

SLAITS began in 1997 with a pilot test in two States, Iowa and Washington, of a series of questions on health, including issues of access to care, health status, and insurance. In 1998, a SLAITS module concerning child well-being and welfare issues was implemented using three samples: a general RDD sample of children in Texas, known Medicaid program participants in Texas, and known Medicaid or MinnesotaCare participants in Minnesota. In 2000, SLAITS fielded the National Survey of Early Childhood Health, which collected data regarding parents' perceptions of their young children's pediatric care and examined relationships between the promotion of health in the pediatric office and promotion of health in the home (3).

The National Survey of CSHCN, the fourth study in the SLAITS series, was designed to collect data on CSHCN, children's health insurance coverage, and uninsured children from low-income households. It is the first SLAITS study to take advantage of the full NIS sampling frame to produce State-level estimates.

Background

he National Survey of CSHCN was funded by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration. MCHB, established in 1935 as part of Title V of the Social Security Act, is responsible for protecting the health of mothers and children through the development of programs and systems of care for those populations.

The 1989 Omnibus Budget Reconciliation Act enhanced the Maternal and Child Services Programs' mission with specific provisions for CSHCN, including improved access to care to be monitored by State agencies (4). Today, Title V is administered by MCHB using block grants to create Federal/State partnerships to provide family-centered, community-based, coordinated systems of care for CSHCN. A minimum of 30% of block grant funds must be used to support programs for CSHCN, and specific steps must be taken to improve service delivery for these children and their families. States have considerable flexibility in determining the services to provide and the manner in which they are provided.

To guide the development of appropriate services for children with special needs, MCHB established a work group whose mission was to create a broad and inclusive definition of what constitutes special health care needs. After considering condition-list and functional status-based approaches, the work group decided to adopt a definition based on increased service needs and to include at-risk children to facilitate program planning (5,6). The resulting definition is:

> Children with special health care needs are those 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 (6).

Using this definition and the 1994 National Health Interview Survey on Disability, researchers established an initial special health care needs prevalence rate among children of 15-20 % (7). The at-risk population was not included in this estimate as there is no accepted approach to identifying these children. In fact, there is no one accepted method of identifying CSHCN. To augment ongoing research on this subject, the pretest phase of the National Survey of CSHCN used two different batteries of questions to screen households to identify CSHCN (8,9). A description of the pretest findings appears in the "Screening for Special Health Care Needs" section.

Serving CSHCN requires a broad-ranging system of health and related types of care. These services may include specialty physician care, therapeutic services, family support services and care coordination, durable equipment and assistive devices, a variety of education-related services, and transportation services (5). Although States vary greatly in the manner used to provide these services, virtually all provide them to some extent. Accurate assessment of use and barriers to needed care are critical to program planning and evaluation because specific criteria must be met for States to receive block grant monies. "Improved needs assessments will require . . . statewide data collection systems Most state special-needs programs will require access to expertise not generally available among current staff if the demand for improved data collection is to be met." (4).

National Survey of Children with Special Health Care Needs

The National Survey of CSHCN, which collects the required data at the State level in a manner that allows comparison across States and nationally, was a major step toward providing the information necessary to accurately assess State activities and program needs. This survey was designed to achieve 750 completed special needs interviews in each of the 50 States and Washington, DC. The major research questions that the National Survey of CSHCN was designed to address were:

- What is the prevalence of special health care needs among children under 18 years of age in each State?
- Are their special health care needs and the concerns of their families being addressed?
- What is the quality of primary, specialty, and ancillary care that children receive?
- Are CSHCN receiving comprehensive care in a medical home?
- What factors are associated with the receipt of better quality, more comprehensive care?
- Do families of CSHCN have adequate insurance to pay for the services that CSHCN need?
- What is the impact of the child's health condition on the family?
- From whom are CSHCN receiving needed care coordination services?

Two additional study modules, described below, examined the following research questions:

- How does health insurance coverage for CSHCN compare with coverage for all children?
- Why do uninsured children from low-income households lack coverage, and are their families aware of Medicaid and the State Children's Health Insurance Program (SCHIP)?

Health Insurance Control Sample

The initial design of the National Survey of CSHCN called for collection of health insurance coverage data for sampled CSHCN only. Given the estimated CSHCN prevalence rate of 15-20%, many households with children would need to be screened to identify households with CSHCN. To produce estimates on health care coverage for all children and to facilitate comparison of health care coverage for children with and without special needs, the MCHB and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services (DHHS) funded the addition of a health insurance control sample of children without special needs, taking advantage of the considerable number of screened households with children. In households with one or more children who did not screen positive for a special health care need, one such child was randomly selected for the health insurance control sample interview. This interview included insurance coverage questions identical to those administered in the special needs interview.

Low-Income Uninsured Supplement

With the addition of the health insurance control sample, the National Survey of CSHCN was expected to gather an unprecedented amount of children's health insurance coverage data. Taking advantage of the opportunity provided by this study, ASPE funded a module to gather data

for uninsured children from low-income households on their parents' knowledge and use of SCHIP and Medicaid programs. The goal for this module was to estimate the prevalence of uninsured, low-income children who may qualify for Medicaid or SCHIP, but are not enrolled in the program, and to determine the reasons why these children are not enrolled. Regardless of special-needs status, all sampled children who were uninsured and who resided in a household with an annual income below 200% of the DHHS Federal Poverty Guidelines received the Low-Income Uninsured Supplement. Eligible children without special needs were also asked a subset of health care access and barrier questions from the special-needs interview.

The data collected with this supplement supported the Department's evaluation of the SCHIP program, as mandated by Congress in the Balanced Budget Refinement Act of 1999. Congress stipulated that the Department's evaluation include the collection of information about why many children eligible for SCHIP are not enrolled. Funds for this supplement came, in part, from the Congressional allocation for this evaluation.

Missouri Supplemental Sample

As noted earlier and described in detail later, the National Survey of CSHCN was designed to achieve 750 completed special-needs interviews in each of the 50 States and Washington, DC. Each State also had the option of requesting and funding additional special-needs interviews to produce more precise estimates within their State. The Bureau of Special Health Care Needs in the Missouri Department of Health and Senior Services was the only State agency that exercised this option. To accommodate Missouri's request for an additional 750 special-needs interviews (for a total of 1,500), a separate supplemental sample was created. This sample was fielded independently of the NIS, but otherwise was fielded using the same methods and questionnaire as another National Survey of CSHCN sample. The purpose of the Missouri supplemental sample was to provide data on the prevalence, health care needs, and impact of special health care needs in the State. Therefore, health insurance control sample interviews and Low-Income Uninsured Supplement interviews were not administered to households in this sample. Households with children in this sample completed only the National Survey of CSHCN special-needs screening and special-needs interview, as applicable.

Sample Design

ike all SLAITS modules, the National Survey of CSHCN took ▲ advantage of the large number of screening calls required for the NIS. To accomplish the goal of 750 completed special-needs interviews in each State, telephone numbers were initially selected from the telephone numbers randomly generated for the NIS screening effort. Therefore, the procedures for drawing the NIS sample were the first steps in the procedures for drawing the National Survey of CSHCN sample. However, because of the scope of the National Survey of CSHCN, an additional sample was necessary to augment the NIS sample in certain States.

The next two sections describe the basic NIS sample design and serve as a nontechnical description of the National Survey of CSHCN sample design and allocation procedures. Appendix I of this report includes a more technical description of the National Survey of CSHCN sample design and weighting procedures. For more detail on the NIS sample design, readers are encouraged to obtain chapter 3 of the 1999 National Immunization Survey Sample Design Report (10), which is available from NCHS. Further information regarding the NIS itself can be found in National Immunization Survey: The Methodology of a Vaccination Surveillance System (2000) (11).

The National Immunization Survey Sampling Plan

The NIS was established to monitor vaccination levels of very young children within geographic areas called Immunization Action Plan (IAP) areas. These 78 nonoverlapping IAP areas encompass the entire United States, and each IAP area is within the borders of a single State. Every 3 months (or calendar quarter), the NIS selects a random sample of telephone numbers in all 78 IAP areas. The NIS screens almost 1 million households per year to identify those containing at least one child ages 19 to 35 months. These children are the primary targets of immunization programs. Because only 5% of households in the United States contain children in this age range, a large number of households are screened to identify households with eligible children. SLAITS modules use this NIS screening sample.

In the United States, telephone numbers consist of an area code (3 digits), a prefix or exchange (3 digits), and a suffix (4 digits). A random sample of telephone numbers can be chosen by randomly selecting an area code and prefix combination currently in use and appending a randomly chosen four-digit number between 0000 and 9999. This RDD sample would be a simple random sample of telephone numbers from the frame of all possible telephone numbers.

For the NIS, telephone numbers are selected for screening through list-assisted RDD methods. Before the selection of the sample of telephone numbers, banks of 100 consecutive numbers in the same area code and prefix combination that contain zero directory-listed telephone numbers-that is, banks of 100 numbers that have a low probability of containing working residential numbers-are deleted from the sampling frame. For this step, the NIS uses the GENESYS Sampling System (a proprietary product of Marketing Systems Group), which in turn uses a file of directory-listed residential numbers from Donnelley Marketing Information Services (DMIS). A simple random sample of 10-digit

telephone numbers is then drawn from the retained banks of 100 numbers. Known business and nonworking telephone numbers are removed from this sample prior to dialing.

Each remaining telephone number is then called by an interviewer, and if it belongs to a household, the person answering the telephone is asked if there are any children 19-35 months of age living or staying in the household. If NIS age-eligible children are in the household, a household respondent is interviewed about each age-eligible child's immunization history and the demographic characteristics of the household. The NIS interviewer also asks for permission to contact the immunization providers of the children to obtain vaccination information from the child's medical record.

National Survey of CSHCN Sampling Plan

The goal of the National Survey of CSHCN sample design procedures was to generate samples representative of the State populations of children both with and without special health care needs. An additional goal of the National Survey of CSHCN was to obtain State-specific sample sizes that 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%.)

To achieve these goals, State samples were designed to obtain 750 completed interviews with CSHCN. A target number of health insurance control sample interviews was not set. Rather, in each household with children that was screened to complete the 750 required special-needs interviews in each State, a health insurance control sample interview was initiated if at least one child without special needs was identified. Thus the total number of health insurance control sample interviews was a function of the number of households with children screened.

The number of CSHCN to be selected in each IAP area was determined by allocating the total of 750

children in the State to each IAP area within the State in proportion to the total projected number of households with CSHCN in the IAP area. (The projected number of households with CSHCN in each IAP area was adjusted as needed based on the initial data collected from the survey.) Given this allocation, the number of households that needed to be screened in each IAP area was calculated using the expected proportion of households with children under 18 years of age in the IAP area. Then, the number of telephone numbers that needed to be called was computed using the expected working residential number rate. The number of telephone numbers drawn was increased to compensate for the fact that not all respondents would agree to participate and, therefore, there would be some degree of nonresponse.

In 14 States (Hawaii, Idaho, Iowa, Mississippi, Missouri, Nebraska, Nevada, New Mexico, Oklahoma, Oregon, South Dakota, Utah, Virginia, and Wyoming), there was insufficient NIS sample available to obtain the desired number of completed interviews for the National Survey of CSHCN. Therefore, additional telephone numbers were drawn using the GENESYS Sampling System in the same manner described in the section above. Table A shows by State the proportion of the National Survey of CSHCN sample that was augmented for each State. That is, for each State in table A, the proportion listed is the proportion of telephone numbers that were called specifically for the National Survey of CSHCN.

Because of the repeated quarterly selection of NIS sample in each IAP area, some telephone numbers were selected more than once over the course of the 6-quarter National Survey of CSHCN data collection period. Such numbers were not contacted a second time for the study. Instead, these cases were automatically finalized. Response rates reflect the final disposition of a telephone line from its original sampling.

With the exception of the augmentation sample, each selected telephone number was called and screened for residential status and for the presence of NIS age-eligible

Table A. Augmentation sample by State

State	Percent of State sample called only for National Survey of CSHCN ¹
Hawaii	25.8
Idaho	20.3
lowa	2.4
Mississippi	13.0
Missouri ²	45.4
Nebraska	9.7
Nevada	17.4
New Mexico	2.5
Oklahoma	8.7
Oregon	2.6
South Dakota	14.6
Utah	29.0
Virginia	17.1
Wyoming	5.5

¹CSHCN is children with special health care needs. ²The proportion in Missouri is larger than the proportion in other states because of the Missouri Supplemental Sample described earlier in this report.

children. NIS interviews were conducted if NIS age-eligible children lived in the household. If NIS age-eligible children did not live in the household, interviewers asked if there were any children under age 18 living in the household. Then, regardless of whether an NIS interview was conducted, if children were in the household, a series of questions were asked about their health care needs to determine special health care needs status. If any children in the household were identified as having special health care needs, one was randomly selected (i.e., sampled) for a detailed interview. Similarly, if there were children without special needs, one was randomly selected for a health insurance control sample interview. Therefore, eligible households with children could have either one or two children selected for an interview, depending on the care needs of the children in the household.

Screening for Special Health Care Needs

ne of the main goals of the National Survey of CSHCN was to provide State-level estimates of the prevalence of CSHCN. As mentioned in the introduction, there is no single accepted method of identifying CSHCN. Therefore, careful consideration of the screening methodology for the study was necessary.

Comparing Screening Instruments (Pretest I)

To assist in the decision of which screening instrument to use, an initial pretest was designed to test two different screening instruments developed to identify special health care needs in children. The first instrumentthe CSHCN Screener-was developed as part of the Foundation for Accountability's (FACCT) Child and Adolescent Health Measurement Initiative. The CSHCN Screener includes five stem questions on general health care needs that could be the consequence of chronic health conditions (e.g., need for special therapies or need for prescription medication). If a child currently experiences one of these consequences, followup questions determine whether this health care need is the result of a medical, behavioral, or other health condition, and whether the condition has lasted or is expected to last for 12 months or longer. Those with affirmative answers to the stem and both followup questions are considered to have a special health care need (9).

The second instrument was the **Ouestionnaire for Identifying Children** with Chronic Conditions-Revised Version (QuICCC-R), which was developed by Ruth Stein and her colleagues at the Albert Einstein College of Medicine, Yeshiva University (8). Like the CSHCN Screener, this instrument also assesses whether a child experiences certain consequences that suggest a special health care need. Rather than five general stem questions, however, the QuICCC-R asks about 16 stem questions designed to capture more specific experiences (e.g., special diets, hospitalizations, or special arrangements in school). The series of followup questions for most experiences are similar to those for the CSHCN Screener.

Pretest I Methods

Data collection for this pretest took place between March 3 and May 30, 2000. At this time, the SLAITS National Survey of Early Childhood Health was also in the field. Based on the sample requirements necessary for that study, eight States were identified as having sufficient remaining NIS samples for the pretest: Alabama, Iowa, Montana, Nevada, New Jersey, Pennsylvania, Tennessee, and West Virginia. Thus, the pretest sample was not expected to mirror the nationally representative sample used for the main study.

Both screeners were administered in every household with children. To avoid bias related to screener order, the order of screener administration was alternated. In 50.2% of the cases, the CSHCN Screener was administered first, whereas the remaining 49.8% of the cases received the QuICCC-R first. To facilitate the assessment of the screening instruments, in cases where a child screened positive for special health care needs on either screener, an open-ended question asked the respondent to name the type of medical, behavioral, or other health condition that the child had.

In households with at least one child who was identified through the use of either screener as having a special health care need, one such child was sampled and the special-needs interview was administered. In addition, a subsample of children without special health care needs was administered the health insurance control sample interview. A total of 1.284 households with children were screened, resulting in the completion of 2,420 child-level screening interviews, 445 special-needs interviews, and 606 health insurance control sample interviews. Interviews were conducted only in English. Low-Income Uninsured Supplement interviews were not conducted during this pretest.

Pretest I Results

A detailed description of the pretest results has been published in *Ambulatory Pediatrics* (9,12). In summary, the order of administration of the two special-needs screening instruments did not have an effect on the proportion of children identified as having a special health care need by either set of questions.

More children were identified as having special health care needs with the QuICCC-R (23.6%) than with the CSHCN Screener (16.0%). Still, the agreement between the two screening instruments was very high, with 90% of the children classified similarly by both screeners. In 10% of the cases (n = 237), a child with special health care needs was identified by only one of the two screeners. The vast majority (89%) of these discrepant cases were identified as having special needs by just the QuICCC-R. Twenty-seven children (11%) were identified by the CSHCN Screener only. This result was not surprising given that the OuICCC-R includes several more items than the CSHCN Screener, offering more opportunities for a child to qualify as having a special health care need.

When parents were asked the open-ended question about the child's condition, children identified as having special health care needs by the QuICCC-R only were less likely to have a named chronic condition, compared to children who screened positively on both screeners. The children identified by the QuICCC-R only were also less likely to have a condition that parents reported as severe and were less likely to use health care services (12). Another consideration in the selection of the screener was the length of time necessary to administer each. Longer screeners would cost more to administer. The mean household administration time for the CSHCN Screener was 2 minutes 6 seconds, compared with 3 minutes 55 seconds for the QuICCC-R. Given that agreement between the screeners was very high, the CSHCN Screener appeared to be a cost-effective screening tool.

Based on these results, a decision was made by the principal funding agency to adopt the CSHCN Screener for the National Survey of CSHCN. The CSHCN Screener questions, as presented in the National Survey of CSHCN, are listed in table B. Some readers may note that the order of the first two questions is different from the question order published in the research literature on the CSHCN Screener (9). The results of the second pretest in appendix VII includes an explanation about why the order was changed for the National Survey of CSHCN.

Questionnaire

he framework for the National Survey of CSHCN was initially discussed in August 1999. A panel consisting of State and Federal Title V Program directors, representatives from Family Voices and the Association for Maternal and Child Health Programs, health services researchers, and survey design experts identified 10 content domains of greatest epidemiological and policy importance (health and functional status, health insurance coverage, adequacy of health insurance coverage, public program participation, access to health care, health care utilization, care coordination, satisfaction with services, impact on the family, and demographics). A subset of this panel then assembled questions to capture these domains and recommended the screeners to be tested (see table C for a list of panel members).

Where possible, questions and batteries from existing surveys were used for the National Survey of CSHCN to permit comparisons with these surveys and to reduce the need for extensive pretesting. The questions were drawn from the National Health Interview Survey (conducted by NCHS), the Consumer Assessment of Health Plans Survey (sponsored by the Agency for Healthcare Research and Quality), the Promoting Healthy Development Survey and the Living with Illness Survey (developed by FACCT), the Questionnaire for Identifying Children with Chronic Conditions (13), Your

Table B. CSHCN Screener questions used in the National Survey of Children with Special Health Care Needs

Introductory statements

The following questions are about any kind of health problems, concerns, or conditions that may affect your child's behavior, learning, growth, or physical development. Some of these health problems may affect your child's abilities and activities at school or at play. Some of these problems affect the kind or amount of services your child may need or use.

Ste	m question	Followup questions
1.	Does your child need	or use more medical care, mental health or educational services than is usual for most children of the same age? (IF YES) Is your child's need for medical care, mental health, or educational services because of any medical, behavioral, or other health condition?
		(IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
2.	Does your child curren	ntly need or use medicine prescribed by a doctor, other than vitamins? (IF YES) Is your child's need for prescription medicine because of any medical, behavioral, or other health condition?
		(IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
3.	Is your child limited or	prevented in any way in his or her ability to do the things most children of the same age can do? (IF YES) Is your child's limitation in abilities because of any medical, behavioral, or other health condition?
		(IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
4.	Does your child need	or get special therapy, such as physical, occupational, or speech therapy? (IF YES) Is your child's need for special therapy because of any medical, behavioral, or other health condition?
5.	Does your child have	(IF YES) Is this a condition that has lasted or is expected to last 12 months or longer? any kind of emotional, developmental, or behavioral problem for which he or she needs treatment or counseling?
		(IF YES) Has your child's emotional, developmental, or behavioral problem lasted or is it expected to last 12 months or longer?

NOTE: For households with more than one child, the phrase "does your child" was replaced with "do any of your children." Affirmative answers were followed by a question asking for the names or ages of the children with that particular health care consequence. The followup questions were then asked separately for each named child.

Table C. Panel members (August 1999)

Name	Affiliation (in 1999)
Christina Bethell, Ph.D.	Foundation for Accountability
Stephen Blumberg, Ph.D	National Center for Health Statistics, CDC ¹
Treeby Brown, M.A.	Association of Maternal and Child Health Programs
Gil Buchanan, M.D.	Arkansas Department of Health
Marcie Cynamon, M.A.	National Center for Health Statistics, CDC ¹
Trena Ezzati-Rice, M.S.	National Center for Health Statistics, CDC ¹
Cathy Hess, M.S.W.	Association of Maternal and Child Health Programs
Deborah Klein Walker, Ed.D	Massachusetts Department of Health
Cassie Lauver, A.C.S.W.	Kansas Department of Health and the Environment
Jeffrey Lobas, M.D., M.P.A	Iowa Child Health Specialty Clinics
Jennifer Madans, Ph.D.	National Center for Health Statistics, CDC ¹
Stephanie McDaniel	Association of Maternal and Child Health Programs
Peggy McManus, M.H.S	MCH Policy Research Center
Merle McPherson, M.D	Maternal and Child Health Bureau, HRSA ²
Kerry Nesseler, R.N., M.S.	Maternal and Child Health Bureau, HRSA ²
Paul Newacheck, Dr.P.H.	
(chairperson)	University of California at San Francisco
Ruth Stein, M.D.	Yeshiva University
Bonnie Strickland, Ph.D.	Maternal and Child Health Bureau, HRSA ²
Peter van Dyck, M.D., M.P.H.	Maternal and Child Health Bureau, HRSA ²
Gloria Weissman, Ph.D.	Maternal and Child Health Bureau, HRSA ²
Nora Wells, M.Ed.	Family Voices / Federation for Children with Special Needs

¹CDC is Centers for Disease Control and Prevention. ²HRSA is Health Resources and Services Administration.

²HRSA is Health Resources and Services Administration.

Voice Counts (a survey developed by Family Voices and Brandeis University), and prior SLAITS modules.

Content

The National Survey of CSHCN questionnaire was designed to immediately follow a completed NIS interview in households with an NIS-eligible child or the NIS screener in households without an NIS-eligible child. The questionnaire was divided into 12 sections, summarized below.

1.) *Age-Eligibility Screening*—This section consists of the introduction to the interview and the question to determine if any children under 18 years of age live in the household.

2.) Special Health Care Needs Screening—In this section, all children under 18 years old in the household were rostered, with sex, date of birth, race, and ethnicity gathered for each child. For sampled children, additional items included the relationship of the respondent to the sampled child(ren) and the educational level of the respondent or, in cases where the respondent was not the mother of the sampled child(ren), the educational level of the mother and whether the mother resided in the household. The CSHCN Screener was also administered in this section. **3.)** *Health and Functional Status*—This section includes questions regarding the sampled child's physical, mental, behavioral, learning, and developmental conditions and the impact of these conditions on the child's life.

4.) Access to Care, Utilization, and Unmet Needs—The questions in this section address the availability of medical services for the sampled children and their families and the degree to which they used them. More specifically, respondents were asked about the types of medical services the child required in the last year, whether they had experienced any problems accessing medical care for the sampled child, whether they had delayed medical treatment for the child, and if so, the reasons for the delay.

5.) Care Coordination—In this section, the respondents were asked whether a professional (e.g., a case manager) helped coordinate care for the sampled child. If professional assistance was received, additional questions assessed the quality of this assistance.

6.) Satisfaction With Care—This section asked respondents about the medical care provided to the sampled child and the communication between the child's doctor and the child's parents or guardians.

7.) *Health Insurance*—The goal of this section was to establish whether sampled children had comprehensive health insurance coverage. Comprehensive coverage was defined as insurance that pays for both doctor visits and hospital stays. The section included questions asking whether a sampled child was covered by any of a series of common types of medical insurance. Respondents with insured children were asked about any interruptions in the insurance coverage that might have occurred in the past. For uninsured children, information was collected on how long it had been since they last had medical coverage.

8.) Adequacy of Health Care Coverage—Respondents with insured children were asked about adequacy of health coverage. They were asked to rate the cost and benefits of, and their satisfaction with, the insurance plans in which the children were enrolled.

9.) *Impact on the Family*—This section included questions regarding the impact that a child's special health care needs have on the child's family. It assessed financial and time burdens and the ways in which the families were coping with them.

11.) Income and Other Demographics—In this section, respondents were asked about their income, government program participation, number of telephone lines in their household, interruptions in their telephone service during the past year, and their ZIP codes. The annual household income was mapped to DHHS Federal Poverty Guidelines. This made it possible to categorize the household's income relative to the poverty level.

12.) Medicaid and SCHIP Knowledge and Experience—The questions in this section, part of the Low-Income Uninsured Supplement, assessed the respondent's level of knowledge about Medicaid and SCHIP programs in their State. The respondents were also asked how easy or difficult they believed it was to enroll in these programs and whether they had ever attempted to enroll the sampled child. Those who had not enrolled were asked their reasons for not doing so. 13.) Utilization and Barriers to Care Questions for Low-Income/ Uninsured Children Without Special Health Care Needs—In this section, part of the Low-Income Uninsured Supplement, respondents with children who had no special health care needs were asked questions regarding the health problems of these children, medical services that they used, and the impact on the families of any health problems these children might have.

All households with children received the questions in sections 1 and 2, above. The special-needs interview consisted of sections 3–9 and 11. The health insurance control sample interview consisted only of sections 7 and 11. The Low-Income Uninsured Supplement interview consisted of sections 12 and 13. The questionnaire did not include "Section 10," which was a label reserved for use but not needed.

A copy of the questionnaire appears in appendix II. Appendix III provides a listing of changes made in the questionnaire over the course of the study. Appendix IV contains the DHHS Federal Poverty Guidelines tables used to determine household poverty status during interview administration and a description of the process for assigning poverty status to households.

Computer-Assisted Telephone Interviewing

The National Survey of CSHCN was conducted using a computerassisted telephone interview (CATI) system. The CATI data collection method employs computer software that presents the questionnaire on computer screens to each interviewer. The computer program guides the interviewer through the questionnaire, automatically routing the interviewer to appropriate questions based on answers to previous questions. Interviewers enter survey responses directly into the computer, and the CATI program determines if the selected response is within an allowable range, checks it for consistency against other data collected during the interview, and saves the responses into a survey data file.

On-line help facilities are available to aid interviewers in administering the CATI questionnaire. This data collection technology reduces the time required for transferring, processing, and releasing data, and it ensures the accurate flow of the questionnaire.

The National Survey of CSHCN questionnaire was programmed as a module of the NIS, integrating the two surveys into a single interview. The instrument made full use of the CATI system's ability to check whether a response was within a legitimate range, to follow skip patterns, to fill State-specific information in questions as applicable (for example, names of State Medicaid and SCHIP programs), and to employ pick lists for response categories. Certain household and demographic questions were identical in the NIS and National Survey of CSHCN portions of the interview. If a respondent answered these questions during NIS administration, the system was programmed so that the questions were not repeated in the National Survey of CSHCN. Instead, the answers to these questions in the NIS were copied to the data file for the National Survey of CSHCN, as appropriate.

National Survey of CSHCN Stand-Alone Questionnaire

As noted earlier, the amount of sample required to reach the target number of completed special-needs interviews for the National Survey of CSHCN exceeded the NIS sample available in some IAP areas. For these IAP areas, an additional National Survey of CSHCN-only sample was created. Respondents in this augmentation sample did not receive any questions from the NIS screener or interview. Rather, the CATI system was programmed to begin with the National Survey of CSHCN.

Pretests of the CATI Instrument

Once initial programming was completed, the instrument underwent rigorous testing to ensure correct functioning of the CATI system, and two pretests were conducted. The first pretest (discussed previously) was designed primarily to test two different screening instruments developed to identify special health care needs in children. The second pretest (discussed in appendix VII) was designed primarily to investigate the impact of different advance mailings and introductory scripts on NIS and National Survey of CSHCN response rates. In addition to their primary purposes, these pretests also suggested improvements that could be made to the CATI programming and to the questionnaire. The findings were incorporated into the final CATI instrument.

Interviewer Training

bt Associates Incorporated and their subcontractors conducted all interviews for the National Survey of CSHCN. The initial data collection staff for the National Survey of CSHCN was recruited during October and November 2000. To offset interviewer attrition, interviewer recruitment and training continued throughout the duration of the study. Interviewer training was conducted by staff from Abt Associates in their telephone centers in Chicago, Illinois; Las Vegas, Nevada; and Amherst, Massachusetts. The use of several telephone centers made it possible to maintain the level of interviewer coverage needed to call such a large sample in multiple time zones. (Interviews were conducted from 9 a.m. to 9 p.m. in each of the six time zones covered by the 50 States.) The numbers of interviewers who completed training each month in each location are included in table D.

Training sessions for the pretests and the main survey began with an introduction to the study and its sponsors, the reasons for conducting the study, and other background information. This background included discussion on how the National Survey of CSHCN was conducted in conjunction with the NIS, the age-eligibility ranges for the two studies, the length of time required to conduct Table D. Number of interviewers trained by month and telephone center location

Month	Chicago	Las Vegas	Amherst	Total
All months	680	332	172	1,184
October 2000	145	102	0	247
November 2000	43	29	26	98
December 2000	10	0	0	10
January 2001	55	16	0	71
February 2001	83	34	12	129
March 2001	34	29	11	74
April 2001	31	0	30	61
May 2001	32	20	19	71
June 2001	53	28	19	100
July 2001	49	11	24	84
August 2001	14	16	0	30
September 2001	26	21	0	47
October 2001	45	11	0	56
November 2001	34	10	11	55
December 2001	26	5	20	51

both surveys, and the procedures to be followed for gaining cooperation for each study. The main interviewer goals (e.g., number of completed interviews and expected time frame for data collection) were also discussed.

Mock interviews were conducted to acquaint interviewers with the questionnaire and to provide them with the project knowledge and refusal aversion skills necessary to conduct an interview. Two types of mock interviews were performed: trainer-led interviews in which the trainer carried out the role of the respondent and the interviewers conducted the interview using the CATI system, and dual mock interviews in which one trainee performed the role of the interviewer while the other acted as the respondent. Trainer-led mock interviews included discussions of the goals of each questionnaire section and of specific questions. Extra attention was given to specific questions in the screener and to specific sections on child health status, specialty care, care coordination, and health care coverage.

A final mock interview and written evaluation were administered at the end of the training session. The mock interview was standardized, thus allowing interviewers to be evaluated against the same standard on their ability to navigate through CATI, gain cooperation, and answer frequently asked questions from respondents. The written evaluation was administered to reinforce what was learned during the training sessions. Each trainer was provided with a written evaluation answer guide to rate the proficiency level of the interviewer. Interviewers had to successfully complete both evaluations to collect data for the National Survey of CSHCN.

Data Collection

elephone interviewing for the main study began on October 17, 2000, and was completed on April 30, 2002. Data collection included a total of 196,888 screening interviews with households having children, 38,866 special-needs interviews, 176,296 health insurance control sample interviews, and 9.935 Low-Income Uninsured Supplement interviews. As noted earlier, each child eligible for the Low-Income Uninsured Supplement interview also was the subject of a completed special-needs interview or health insurance control sample interview. Thus, the total number of completed child-level interviews was 215,162 (that is, the sum of 38,866 and 176,296). These children were randomly selected from the 373,055 completed child-level screener interviews (see figure 1). Table E details the total number of interviews completed by type and State.

Not all States have 750 completed special-needs interviews because of the nature of the sample. In each State, to reach the target of 750 interviews, the number of telephone lines dialed was based on estimates of the proportion that would reach age-eligible households, the

proportion of these households that would have a child with special health care needs, and the proportion of these households that would be willing to complete an interview. Some States narrowly failed to meet the data collection target, and other States exceeded the target. Adding or dropping telephone lines at the end of the data collection period (to more closely reach the target) was not recommended because biased estimates may result if some lines are called less frequently or over shorter periods of time than others. An average of seven calls were made to each telephone number to complete an interview; the median was three.

Advance Letter

Advance letters have been shown to decrease nonresponse by increasing study legitimacy (14). An advance letter (shown in appendix V) was mailed to presumed households when a mailing address could be identified for sampled telephone numbers-40.0% of the telephone numbers randomly generated and 62.3% of the telephone numbers dialed by the interviewers. Recipients were asked to participate in a voluntary study on the immunization of their children and the types of health and related services that their children need and use. The letter advised recipients that their telephone numbers had been chosen randomly, and indicated that they might be called in the next few weeks. A toll-free telephone number was provided for those who wished to participate immediately or to learn more about the study.

As described earlier, for IAP areas requiring a sample beyond that available through the NIS, an additional sample was created. Households in the augmentation sample with an identified mailing address were mailed an advance letter different from that used for NIS sample households. This advance letter asked respondents to participate in a study regarding the types of health and related services that their children need and use. No mention was made of the NIS nor of immunizations.

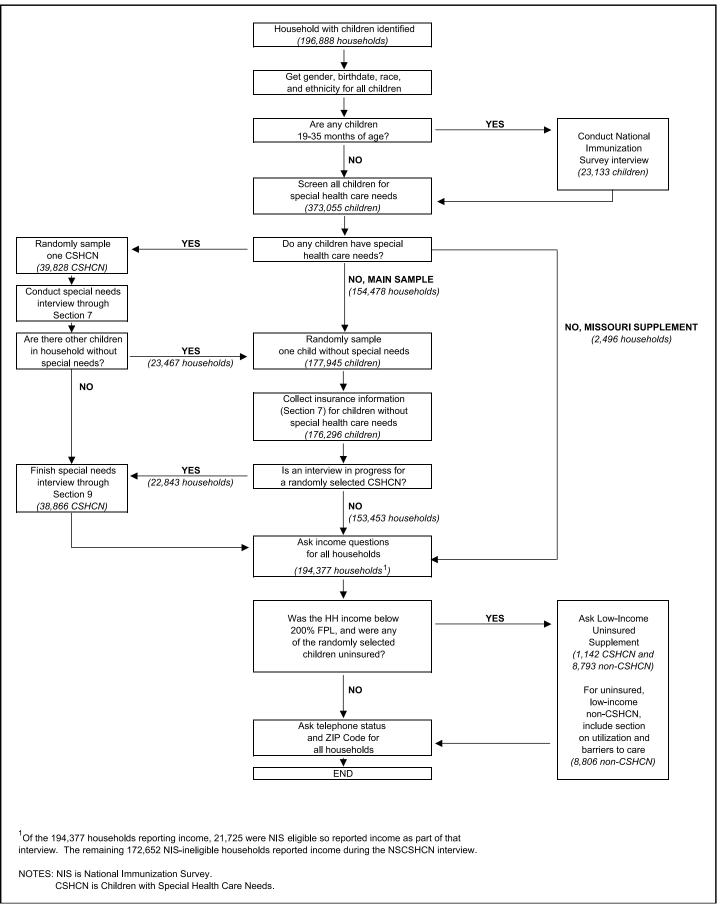


Table E. Number of completed interviews by State and type of interview

	Numl	ber of completed intervi	Number of CSHCN ¹ screening interviews completed		
State	Special-needs interviews	Health insurance control sample interviews	Low-Income Uninsured Supplement Interviews	Households with children	Children under 18 years of age
All States	38,866	176,296	9,935	196,888	373,055
Alabama	749	3,493	213	3,843	6,904
Alaska	746	4,034	208	4,333	8,567
Arizona	751	3,948	419	4,276	8,558
Arkansas	749	3,297	280	3,655	6,622
California	759	4,661	408	4,967	9,688
Colorado	744	3,818	306	4,129	7,893
Connecticut	742	3,148	60	3,469	6,426
Delaware	742	2,977	112	3,339	6,185
District of Columbia	748	3,641	181	4,048	7,422
Florida	748	3,744	352	4,135	7,422
	748	3,690	215	4,077	7,490
Hawaii	747	4,633	112	4,976	9,397
Idaho	745	3,774	307	4,049	8,387
Illinois	745	3,710	199	4,027	7,774
Indiana	747	3,221	113	3,553	6,760
lowa	751	3,640	131	3,948	7,798
Kansas	748	3,036	169	3,400	6,555
Kentucky	745	3,015	164	3,412	6,054
Louisiana	749	2,847	273	3,235	5,966
Maine	742	2,808	139	3,124	5,650
Maryland	750	2,968	83	3,345	6,184
Massachusetts	744	3,084	53	3,434	6,430
	748	3,154	107	3,485	6,657
Michigan	749				,
Minnesota		3,331	115	3,612	6,967
	743	3,639	238	4,005	7,390
Missouri ²	1,493	3,142	97	6,742	12,834
Montana	742	3,676	355	4,006	7,670
Nebraska	747	3,461	120	3,777	7,458
Nevada	747	4,243	425	4,553	8,932
New Hampshire	750	2,976	113	3,320	6,151
New Jersey	744	3,766	205	4,107	7,537
New Mexico	751	3,836	298	4,170	8,124
New York	748	3,953	149	4,308	8,044
North Carolina	739	3,239	201	3,624	6,448
North Dakota	746	3,640	182	3,949	7,550
Ohio	766	3,239	108	3,597	6,855
Oklahoma	745	3,219	289	3,589	6,720
	745	3,316	203	3,650	6,920
			137		
Pennsylvania	748	3,525		3,874	7,334
Rhode Island	750	3,058	70	3,378	6,146
South Carolina	745	3,291	150	3,647	6,668
South Dakota	741	3,847	179	4,120	8,223
Tennessee	747	3,199	102	3,567	6,354
Texas	751	3,722	541	4,088	7,854
Utah	742	3,635	253	3,896	8,892
Vermont	748	2,989	49	3,312	6,076
Virginia	747	2,903	111	3,288	5,843
Washington	756	3,185	91	3,517	6,660
West Virginia	748	3,061	187	3,441	6,040
Wisconsin	750	3,333	81	3,642	6,959
	749	3,531	259	3,850	7,456

¹CSHCN is children with special health care needs.

²Some Missouri numbers are larger than those seen in other States because of the Missouri Supplemental Sample described earlier in this report.

Toll-Free Telephone Number

A toll-free telephone number was provided in the advance letter and in

answering machine messages. Potential respondents could use this number to alert the interviewers that there were no children in the study's age range living or staying in their household, to ask questions about the study, or to complete an interview. During the data collection, 22,957 calls were received on this line, 65.2% of which were from households calling to indicate that they did not have a child eligible for the study. A total of 4,815 respondents who called the toll-free telephone number had age-eligible children and completed an interview.

Informed Consent

Consent for study participation was obtained from National Survey of CSHCN respondents as soon as it was determined that their household contained an age-eligible child. Respondents were informed about the voluntary nature of the survey, the authorizing legislation, and confidentiality of data collected. In addition, the informed-consent script provided information about the content of the survey and the expected duration. The informed-consent process also ensured that the person most knowledgeable about the children's health had received the consent information and agreed to participate. The Institutional Review Boards at NCHS and Abt Associates Incorporated approved these procedures.

Assurance of Confidentiality

Participation in surveys conducted by NCHS is voluntary, and information collected on individuals is confidential. For the National Survey of CSHCN, assurance of confidentiality was provided to potential respondents as part of the informed consent procedures. In the CATI system, interviewers acknowledged that they read the following script to potential respondents:

> Your answers will be kept strictly private, in accordance with the Public Health Service Act. I can provide you with the legal description if you like. It guarantees that any answers that identify you or your family will not be shared with anyone other than the agency doing this survey.

If a respondent requested the legal description, the interviewer read the following:

The Public Health Service Act is Volume 42 of the US Code, Section 242K. The collection of information in this survey is authorized by Section 306 of this Act. The confidentiality of your responses is assured by Section 308d of this Act.

Section 308d of the Public Health Service Act states that:

No information, if an establishment or person supplying the information or described in it is identifiable, obtained in the course of activities undertaken or supported under section...306,...may be used for any purpose other than the purpose for which it was supplied unless such establishment or person has consented (as determined under regulations of the Secretary) to its use for such other purpose and in the case of information obtained in the course of health statistical or epidemiological activities under section...306, such information may not be published or released in other form if the particular establishment or person supplying the information or described in it is identifiable unless such establishment or person has consented (as determined under regulations of the Secretary) to its publication or release in other form.

Strict procedures are used to prevent disclosure of confidential data in survey operations and data dissemination.

Selection of Sampled Children

All children under 18 years of age living or staying in selected households were screened with the CSHCN Screener for the presence of special health care needs. In households where a single child screened positive for a special health care need, that child was, by default, the child selected for the detailed special-needs interview. If more than one child in the household screened positive, one such child was randomly selected for the detailed interview.

Children with a negative screen for special health care needs were eligible for the health insurance control sample interview. In households where a single child screened negative for a special health care need, that child was, by default, the child selected for the health insurance control sample interview. If more than one child in the household screened negative, one such child was randomly selected for the insurance interview.

If a household had children with and without special needs, both interviews were administered in that household. Thus, in households with children under 18 years, there were three possible sampling outcomes:

- One child selected for the special health care needs interview and no child selected for the health insurance control sample interview.
- One child selected for the health insurance control sample interview and no child selected for the special health care needs interview.
- One child selected for the special health care needs interview and one child selected for the health insurance control sample interview.

At most, two children were selected (i.e., sampled) for an interview in any given household.

Sampled children of either type who were uninsured and who resided in a household with an annual income below 200% of the DHHS Federal Poverty Guidelines received the Low-Income Uninsured Supplement interview. Households where respondents refused or were unable to provide income information were considered to be below 200% of the poverty level and therefore qualified for the Low-Income Uninsured Supplement if the selected child was also uninsured.

Selection of Respondent

The respondent for the National Survey of CSHCN was the parent or guardian in the household who was most knowledgeable about the children's health and health care. In the majority of households, the respondent was the child's mother or father (or female or male guardian). Table F provides further information regarding the relationship of respondents to the sampled children.

In most households with multiple children, a single adult was the parent or guardian most knowledgeable about the health and health care of all children in

Table F. Number and percent of respondents by relationship to sampled child

Relationship of respondent to sampled child	Number	Percent
Total	215,162	100.0
Mother or female guardian	169,854	78.9
Father or male guardian	36,891	17.2
Grandparent	5,087	2.4
Other relative/friend	3,205	1.5
Unknown	61	< 0.05
Don't know/refused	64	< 0.05

the household. In some households, however, there was a different knowledgeable adult for each child. In such households, the objective was to complete the initial screening interview with the person who could provide the most information about all the children in the household, even though that person may not have been the person most knowledgeable about each child.

However, once the initial screening was completed and if a child with special health care needs was in the household, the parent or guardian who was most knowledgeable about the health of that child was the designated respondent for the remainder of the questionnaire. Thus, if the screener respondent did not know as much about the child sampled for the special-needs interview as another adult in the household did, the interview was conducted with the more knowledgeable respondent.

A parent, guardian, or other adult older than 17 years of age was not identified in 198 households. No interviews were conducted in these households, even if an emancipated minor living there was also the parent of a younger child.

Interviews in Spanish

The National Survey of CSHCN was designed to produce estimates of the number of CSHCN and the impact of those needs. Because excluding the age-eligible households with children where an interview could not be conducted in English would have resulted in a biased sample, it was important to develop methods to include these households. Interviews in Spanish were conducted in the telephone centers, and data collection in 10 additional languages was completed by field staff. This section details the procedures for Spanish interviewing. The next section details the procedures for other languages.

The Spanish-language version of the National Survey of CSHCN questionnaire was produced by translating the completed English questionnaire into Spanish and then translating it back into English. The two components of this process were completed by independent contractors. At the conclusion of translation. discrepancies were resolved in consultation with the contractors, and the resulting translation was incorporated into the CATI instrument. A final review was then conducted by a team of experienced Spanish-language telephone interviewers and supervisors, who evaluated the translation for accuracy and cultural appropriateness. Issues raised during this final review were resolved in consultation with the original translators, and the CATI instrument was finalized.

For data collection and sample management purposes, a calling queue was used for households thought by interviewers to be Spanish-speaking. A CATI flag indicated such households. An appointment was set for National Survey of CSHCN cases with the Spanish-language flag, and they were delivered, via the CATI system, to bilingual interviewers who were trained to conduct interviews in both Spanish and English. A total of 9,604 households with children in the Spanish-language queue were screened, resulting in the completion of 807 Spanish-language special-needs interviews, 9,266 health insurance control sample interviews, and 2,700 Low-Income Uninsured Supplement interviews. These cases

account for 4.9% of all screened households, 2.1% of all special-needs interviews, 5.3% of all health insurance control sample interviews, and 27.2% of all Low-Income Uninsured Supplement interviews.

Interviews in Languages Other Than English or Spanish

To determine which languages other than English or Spanish were most likely to be encountered during survey administration, data from the NIS were used to estimate the expected number of households with children, by language. These data revealed that 90% of such households spoke 1 of the following 10 languages: Korean, Vietnamese, Mandarin, Japanese, Russian, Cantonese, Polish, French, Tagalog (the language of the Philippines), and Italian.

An independent contractor, Asian Translations, translated the National Survey of CSHCN questionnaire into each of the 10 identified languages. Translated questionnaires were individually reviewed by a second professional translation company (Pacolet International) and by Abt Associates staff fluent in the respective language. Each questionnaire was then thoroughly reviewed by the field interviewers to ensure the cultural appropriateness of the questionnaire's text. Any discrepancies between the original translations and the reviewers' comments were resolved in consultation with Asian Translations.

To identify which cases were eligible for interviewing in the 10 languages, English-speaking telephone interviewers first identified cases in which respondents spoke neither English nor Spanish. These cases were then forwarded to specialized interviewers within the telephone center who conducted a preliminary screening for NIS-eligible children with the assistance of an AT&T Language Line interpreter. If this screening identified a child between the ages of 19 and 35 months, an NIS interview was administered using the interpreter. If no children between 19 and 35 months of age were

identified, the interviewer immediately screened for the presence of other children under the age of 18 in the household. Once this age screening (and the NIS interview, if applicable) was completed, the interview terminated. For households with children under the age of 18 identified during this process, interviewers were asked to indicate the language spoken by the respondent. If the language indicated was one of the 10 selected for National Survey of CSHCN interviewing, the case was removed from the CATI system for delivery to trained field interviewers. Field staff then contacted these cases to complete special-needs screening and all applicable interviews, via a hard-copy instrument.

Queue building for the National Survey of CSHCN began on October 17, 2000. To ensure a sufficient workload for other-language interviewers, cases were allowed to accrue for several months prior to interviewer recruitment and training. The first cases were released to bilingual field interviewers on March 8, 2001.

Of the 1,383 households with children identified and called by other-language interviewers, 1,304 (94.3%) were screened for the presence of special health care needs. Of those screened households, 1,281 (98.2%) completed a detailed special-needs interview or health insurance control sample interview, as applicable. A total of 1,263 health insurance control sample interviews, 48 special-needs interviews, and 117 Low-Income Uninsured Supplement interviews were completed. These other-language cases account for 0.7% of all screened households, 0.1% of all special-needs interviews, 0.7% of all health insurance control sample interviews, and 1.2% of all Low-Income Uninsured Supplement interviews. A summary of interviews completed, by language, appears in table G.

Interview Length

The length of the full household interview varied considerably by the special-needs status of the children in the household, the number of children sampled, and the insurance and poverty

Table G. Number and type of interviews completed, by language

Language	Special needs interview	Health insurance control sample interview	Low-Income Uninsured Supplement interview	Number of screened households
Total	38,866	176,296	9,935	196,888
English	38,011	165,767	7,118	185,973
Spanish	807	9,266	2,700	9,604
Vietnamese	3	249	6	254
Cantonese	4	178	13	181
Mandarin	1	175	17	182
Korean	1	163	32	165
Russian	23	127	14	141
Tagalog	6	135	11	136
French	1	105	18	110
Japanese	4	78	2	81
Polish	5	49	4	50
Italian	0	4	0	4

status of the sampled children. Mean and median interview lengths were therefore calculated by household and interview type. These times also varied by NIS eligibility because some demographic and household questions necessary for both the NIS and the National Survey of CSHCN were already administered as part of the NIS interview. These questions were not repeated during the National Survey of CSHCN interview.

The mean and median interview lengths by household type and by NIS eligibility are presented in table H. The mean and median interview lengths by type of interview, by NIS eligibility, and by section are presented in table J. Interview times shown for NIS-eligible households exclude administration time for the NIS interview itself.

Interview Breakoffs

In households where an interview was begun but not completed, specially trained interviewers attempted to convert the incomplete interview into a completed interview. By the end of the data collection period, 11,026 interviews were completed with households that had originally refused to participate (5.7% of completed interviews). However, conversion was not successful with 58,588 identified households with children (2.2% of the total sample). The majority of these households (56,190) broke off the interview before completing the special-needs screening and before eligibility could be determined. Of these 56,190 households, 3,203 broke off during administration of the NIS interview, which preceded the National Survey of CSHCN interview.

Table H. Average length of National Survey of Children with Special Health Care Needs interview in minutes and seconds, by household type and National Immunization Survey eligibility

	NIS-eligible		NIS-ii	eligible	
Type of household	Mean	Median	Mean	Median	
Households in which only a child with special needs was sampled	18:54	16:02	23:26	20:34	
Households in which only a child without special needs was sampled Households in which both a child with	6:21	4:10	8:55	7:13	
and a child without special needs were sampled	22:37	18:50	25:42	22:34	

NOTES: NIS is National Immunization Survey. NIS eligibility refers to household eligibility. NIS-eligible households include at least one child between 19 and 35 months of age. The NIS-eligible child in the household may or may not have been the child sampled for the National Survey of Children with Special Health Care Needs interview.

Table J. Average length of National Survey of Children with Special Health Care Needs interview in minutes and seconds, by interview type, by section, and by National Immunization Survey eligibility

	NIS-	eligible	NIS-ineligible	
Type and section of interview	Mean	Median	Mean	Median
Special-needs interview				
Overall Length	18:59	17:31	23:36	22:13
Section 1: Age-Eligibility Screening.	1:06	0:45	2:05	1:25
Section 2: Special Health Care Needs Screening	2:34	1:46	3:28	3:03
Section 3: Health and Functional Status.	1:34	1:24	1:55	1:44
Section 4: Access to Care - Utilization and Unmet Need	4:21	4:01	4:58	4:26
Section 5: Care Coordination	0:45	0:33	0:47	0:35
Section 6: Satisfaction with Care	1:59	1:52	2:07	1:56
Section 7: Health Insurance	1:29	1:14	1:29	1:19
Section 8: Adequacy of Health Care Coverage	1:41	1:31	1:47	1:38
Section 9: Impact on the Family.	2:17	2:09	2:21	2:10
Section 11: Income and other Demographics	1:30	0:58	2:43	2:24
Health insurance control sample interview				
Overall Length	6:39	4:57	8:48	7:56
Section 1: Age-Eligibility Screening.	1:19	0:46	2:03	1:23
Section 2: Special Health Care Needs Screening	2:17	1:24	2:46	2:25
Section 7: Health Insurance	1:22	1:13	1:25	1:16
Section 11: Income and other Demographics	1:25	0:54	2:29	2:14
Low-income uninsured supplement				
Overall Length	7:00	6:31	7:23	6:59
Section 12: Medicaid and SCHIP ¹ Knowledge/Experience	3:03	2:53	3:01	2:49
Section 13: Utilization and Barriers to Care Questions	3:58	3:37	4:21	4:05

¹SCHIP is State Children's Health Insurance Program.

NOTES: NIS is National Immunization Survey. NIS eligibility refers to household eligibility. NIS-eligible households include at least one child between 19 and 35 months of age. The NIS-eligible child in the household may or may not have been the child sampled for the National Survey of CSHCN interview.

For the remaining 52,987 households that progressed past the NIS screener or interview but ended the interview before special-needs screening was completed, the most common point for ending the interview was at the initial introduction to the National Survey of CSHCN interview. This introductory script included an overview of topics that would be covered during the interview and details regarding informed consent, and it was read in both NIS-eligible and NIS-ineligible households. NIS-eligible households were somewhat more likely to end the interview at this point (49.2% of breakoffs in NIS-eligible households, compared with 45.2% of breakoffs in NIS-ineligible households). NIS-eligible households had already spent time completing the NIS interview, and these respondents may have been reacting to the stated estimate of the length of the National Survey of CSHCN included in this introduction. Because these households had young children, these incomplete interviews may also have

been related to the demands of taking care of such children. Another common point for ending the interview prior to screener completion was at the question that asked for the dates of birth for all of the children in the household. NIS-eligible households were also more likely than NIS-ineligible households to end the interview at this point (35.5% of breakoffs in NIS-eligible households, compared with 15.6% of breakoffs in NIS-ineligible households). A third common location for ending the interview prior to special-needs screener completion was the item that asked for the parent or guardian in the household who was most knowledgeable regarding the health of the children. NIS-ineligible households were more likely to break off at this point (32.7% of breakoffs in NIS-ineligible households, compared with only 6.5% of breakoffs in NIS-eligible households). This is likely because the preferred National Survey of CSHCN respondent and the NIS respondent were typically the same person, meaning that the correct

respondent was already engaged with the interviewer.

Among cases that prematurely ended the interview after special-needs screening was completed and a child was sampled (n = 2,398, 0.1% of the total sample), there was little commonality in the location where the interview was terminated.

Cases Pending at Close of Data Collection

Most of the cases pending at the end of the data collection period were those in which the telephone number had not yet been resolved as residential or nonresidential (75.9% of the pending cases and 12.6% of the initial sample). A smaller number of cases had been resolved as households without respondent eligibility being determined, and an even smaller number of households with an eligible respondent did not complete the interview (3.8% and 0.1% of the initial sample, respectively).

Response Rates

Response rates provide one measure of the potential for nonresponse bias-that is, the possibility that the sample interviewed differs from the actual population in some meaningful way. Three separate weighted response rates were calculated for the National Survey of CSHCN to reflect the potential for nonresponse bias in (a) the sample of children screened for special needs. (b) the sample of CSHCN for whom the special-needs interview was completed, and (c) the sample of children for whom health insurance data were collected. These response rates, based on the Council of American Survey Research Organizations (CASRO) guidelines, were calculated in accordance with the American Association for Public Opinion Research's Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for RDD Telephone Surveys and In-Person Household Surveys (15) and using the assumptions for Response Rate #3 detailed by Ezzati-Rice et al. (16).

Response rates for telephone surveys are typically lower than response rates for household in-person surveys because some telephone numbers ring with no indication of whether the number belongs to a household or to a business. The national resolution rate, which measures the proportion of sampled telephone numbers that could be identified as residential or nonresidential, was 86.5% for the National Survey of CSHCN. When called, the majority of the 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 that provided no indication whether the caller reached a residence or a business. This resolution rate is one component of the three overall response rates.

Special-Needs Screener Response Rate

Screening for the National Survey of CSHCN took place in two stages—initial age-eligibility screening in all households, followed by special-needs screening in households with at least one child less than 18 years of age. The national household completion rate for the initial age-eligibility screener was 94.9%, with 76.2% of age-eligible households completing the special-needs screener.

When possible, all children in each age-eligible household with children were screened for special needs. A child-level special-needs screener completion rate can be calculated that measures the proportion of children screened from all households identified with age-eligible children. The total number of children in NIS-ineligible households was established at the time of initial age screening. However, in NIS-eligible households, the total number of children less than 18 years of age in such households was not determined until later, within the NIS interview itself. In 79 NIS-eligible households, the NIS interview was not completed to this point so the NIS question regarding number of children in the household was not asked. These households were known to be age-eligible, but the number of children in each household was not known. Therefore, to calculate the child-level special-needs screener completion rate, the total number of children under 18 vears of age (for these 79 households) was imputed as the average number of children in NIS-eligible households that did complete the NIS question regarding number of children.

The child-level special-needs screener completion rate was 77.2%. The weighted CASRO special-needs screener response rate was then calculated as the product of the household-level resolution rate (86.5%), the household-level age-screener completion rate (94.9%), and the child-level special-needs screener completion rate (77.2%). This national response rate was 63.4%. Weighted State special-needs screener response rates ranged from 55.0% in New Jersey to 74.2% in South Dakota. (See table K.)

Special-Needs Interview Response Rate

The special-needs interview response rate looks at the potential for nonresponse bias among estimates derived from the special-needs interview. It is necessarily lower than the special-needs screener response rate because additional bias is possible if special-needs interviews were not completed in all screened households with CSHCN. The child-level special-needs interview completion rate, which measures the proportion of interviews completed among screened, eligible, and sampled children, was 97.6%.

The weighted CASRO special-needs interview response rate was calculated as the product of the household-level resolution rate (86.5%), the householdlevel age-screener completion rate (94.9%), a household-level special-needs screener completion rate, and the child-level special-needs interview completion rate (97.6%). Because the unit of analysis for the detailed special-needs interview was the sampled special-needs child, the calculation of this response rate uses a household-level rather than a child-level special-needs screener completion rate. This completion rate, which measures the proportion of age-eligible households in which special-needs screening was completed, was 76.2% (as indicated earlier). Thus, the national special-needs interview response rate was 61.0%. Weighted State special-needs interview response rates ranged from 53.3% in New Jersey to 72.0% in Montana.

Health Insurance Interview Response Rate

With the inclusion of the health insurance control sample for children with special health care needs, health

Table K. Weighted response rates, nationally and by State

		Househ complet	old-level ion rates	Child	level completio	on rates	Overall CASRO ¹ response rates		
State	Household- level resolution rates	Age screener	Special- needs screener	Special- needs screener	Special- needs interview	Health insurance interview ²	Special- needs screener ³	Special- needs interview ⁴	Health insurance interview ⁵
National	86.5	94.9	76.2	77.2	97.6	98.8	63.4	61.0	61.8
Alabama	87.9	95.4	76.6	77.6	98.3	98.8	65.0	63.2	63.5
Alaska	88.9	95.3	82.8	82.7	98.2	99.3	70.1	68.9	69.7
Arizona	86.8	95.2	76.5	77.5	97.0	98.6	64.0	61.3	62.3
Arkansas	90.8	96.5	78.8	80.1	97.5	98.8	70.1	67.3	68.2
California	85.3	94.1	74.6	75.4	97.9	99.2	60.5	58.6	59.4
Colorado	86.4	95.7	79.0	80.0	97.5	99.1	66.1	63.6	64.7
Connecticut	84.6	94.5	76.1	77.3	97.4	98.7	61.8	59.2	60.0
Delaware	82.2	94.6	75.9	77.2	96.1	98.3	60.0	56.7	58.0
District of Columbia	82.8	95.0	76.8	77.8	96.3	98.3	61.2	58.2	59.4
Florida	84.6	94.5	74.2	75.2	97.3	98.4	60.1	57.8	58.4
Georgia	87.4	95.1	76.0	77.3	96.3	98.5	64.3	60.8	62.2
Hawaii	90.3	92.2	72.6	73.0	97.8	99.0	60.8	59.1	59.8
Idaho	90.1	96.2	82.6	83.4	98.4	99.0	72.3	70.5	70.9
Illinois	86.5	95.0	75.5	76.7	97.4	98.6	63.1	60.5	61.2
Indiana	88.2	95.3	74.9	76.1	97. 4 97.7	98.8	64.0	61.6	62.3
lowa	90.9	95.9	79.2	80.8	97.4	98.7	70.4	67.2	68.1
Kansas	89.0	95.9 96.0	79.2	79.6	97.4 97.3	98.7	68.0	65.6	66.5
Kentucky	89.7	90.0 95.9	75.1	75.6	97.9 97.9	99.0	65.0	63.2	63.9
Louisiana	89.4	93.9 94.4	73.7	75.0	97.9 97.0	99.0 98.1	62.5	60.3	61.1
Maine	89.2	96.5	80.3	81.1	98.3	99.2	69.8	67.9	68.5
Maryland	84.0	94.2	76.2	77.3	97.3	98.3	61.2	58.7	59.3
Massachusetts	83.7	95.1	76.0	77.2	97.9	98.8	61.4	59.2	59.7
Michigan	86.6	95.1	76.8	77.3	97.8	98.8	63.7	61.9	62.5
Minnesota	90.1	95.6	79.1	79.9	99.1	99.4	68.8	67.5	67.7
Mississippi	88.7	94.9	75.7	76.9	95.9	98.2	64.7	61.1	62.6
	88.3	94.0	76.9	77.7	97.3	98.6	64.5	62.1	62.9
Montana	91.2	97.1	82.2	82.6	98.9	99.3	73.1	72.0	72.2
Nebraska	91.5	96.0	80.1	81.4	97.5	99.0	71.5	68.6	69.6
Nevada	84.0	94.4	76.3	77.6	97.9	99.0	61.5	59.2	59.8
New Hampshire	85.7	95.6	78.1	79.1	98.0	99.0	64.8	62.7	63.3
New Jersey	78.9	93.5	74.1	74.6	97.6	98.9	55.0	53.3	54.0
New Mexico	89.8	95.4	79.8	81.1	97.2	98.8	69.4	66.4	67.5
New York	83.9	94.4	73.9	74.5	97.0	98.5	59.0	56.8	57.6
North Carolina	87.5	95.7	76.8	77.8	98.0	98.7	65.2	63.1	63.5
North Dakota	91.4	96.7	81.8	83.2	98.3	99.1	73.5	71.1	71.7
Ohio	89.2	95.5	76.5	77.1	98.0	98.9	65.7	63.9	64.4
Oklahoma	88.9	95.2	76.9	78.0	97.6	98.6	66.0	63.5	64.1
Oregon	89.3	96.0	79.8	80.4	98.0	99.0	68.9	67.0	67.7
Pennsylvania	84.8	95.9	76.0	77.5	96.8	98.4	63.0	59.8	60.8
Rhode Island	86.5	95.3	77.2	77.6	97.9	98.9	63.9	62.3	62.9
South Carolina	87.9	95.3	75.9	77.3	97.8	98.9	64.8	62.2	63.0
South Dakota	92.6	96.9	81.4	82.7	97.6	98.9	74.2	71.3	72.3
Tennessee	87.4	95.1	75.0	76.2	97.9	98.9	63.4	61.1	61.7
Texas	87.3	94.1	75.5	76.8	97.4	98.5	63.1	60.4	61.0
Utah	89.0	95.4	79.8	81.3	97.1	98.7	69.0	65.8	66.9
Vermont	90.2	96.5	82.0	83.0	98.2	99.1	72.3	70.1	70.7
Virginia	85.6	94.7	77.4	78.6	97.3	98.7	63.7	61.1	62.0
Washington	88.1	95.0	79.1	79.9	98.4	99.2	66.9	65.1	65.7
West Virginia	88.3	96.2	77.7	79.1	97.8	98.9	67.2	64.5	65.3
Wisconsin	88.0	96.4	79.2	80.2	98.6	99.3	68.0	66.3	66.7
Wyoming	91.1	96.6	82.5	83.5	97.7	99.1	73.5	70.9	72.0

¹CASRO is Council of American Survey Research Organizations.

²Depending on a child's special-needs status, the health insurance questions were asked as part of either the special-needs interview or the health insurance control sample interview. The health insurance interview completion rate is calculated for all sampled children, regardless of special-needs status.

³ Special-needs screener response rate is the product of the household-level resolution rate, the household-level age-screener completion rate, and the child-level special-needs screener completion rate.

⁴Special-needs interview response rate is the product of the household-level resolution rate, the household-level age-screener completion rate, the household-level special-needs screener completion rate, and the child-level special-needs interview completion rate.

⁵Health insurance interview response rate is the product of the household-level resolution rate, the household-level age-screener completion rate, the household-level special-needs screener completion rate, and the child-level health insurance interview completion rate.

insurance data were collected for children regardless of their special-needs status. The health insurance interview response rate provides one measure of the potential for nonresponse bias among estimates derived from these data. The weighted CASRO health insurance interview response rate was calculated as the product of the household-level resolution rate (86.5%), the household-level age-screener completion rate (94.9%), the householdlevel special-needs screener completion rate (76.2%), and a child-level health insurance interview completion rate. This latter completion rate, which measures the proportion of eligible sampled children (regardless of special-needs status) for whom health insurance data were collected, was 98.8%. Thus, the national health insurance interview response rate was 61.8%. Weighted State health insurance interview response rates ranged from 54.0% in New Jersey to 72.3% in Montana.

The final disposition of the sampled telephone numbers is summarized in table L. More detailed information regarding final sample disposition and national unweighted household response rate calculations appears in appendix VI.

Efforts to Maximize Response Rates

As detailed earlier, a number of approaches were used to maximize response rates for the National Survey of CSHCN. To summarize, these approaches included:

- Careful attention to the introductory questionnaire script to ensure that it engaged the interest of potential respondents and provided clear information regarding the study sponsor,
- An advance mailing to households having directory-listed telephone numbers to establish the legitimacy of the study and increase rapport prior to the first contact,
- Thorough pretesting of the survey instrument to ensure that it was clear to respondents and not unduly burdensome,
- A toll-free telephone number to allow respondents to contact Abt staff, encouraging potential respondents to obtain information about the study, immediately establish study eligibility, and voice any concerns,
- A Spanish-language version of the survey instrument to reduce nonresponse bias among Spanishspeaking households,

 Table L. Final disposition of the National Survey of Children with Special Health Care

 Needs sample

Final disposition	Number of selected telephone lines	Percent of total telephone lines selected
Total	2,620,484	100.0
Not resolved as residential/nonresidential	329,205	12.6
Dut of scope (i.e., business, nonworking, fax/modem)	1,371,845	52.4
Known household, age eligibility not determined	43,972	1.7
ge-screened household, no child in age range.	621,122	23.7
nown age-eligible household, special needs eligibility not determined	57,453	2.2
pecial needs eligibility determined, no child ampled ¹	2,496	0.1
creened eligible household, interview not completed	2,070	0.1
creened eligible household, partially	328	<0.05
Completed interview	191,993	7.3

¹In the Missouri Supplemental Sample, children were not sampled for the health insurance control sample interview.

- Implementation of an other-language interviewing component in which the questionnaire was translated into 10 languages other than English and Spanish and administered by specially trained interviewers fluent in these languages,
- A sample management plan that ensured that the correct number of cases were in the field at any given time and provided daily review of appointment and refusal case status to ensure timely recontact,
- An interviewer training program in refusal aversion to reduce the number of unresolved cases and refusals from eligible respondents, and
- Refusal conversion attempts by specially trained interviewers who prepared case-specific strategies for each conversion call based on call history.

The first two strategies received special attention during a second pretest of the survey. This pretest was designed to investigate a full range of advance mailing and introductory script alternatives in an effort to increase NIS and National Survey of CSHCN response rates. Details regarding the second pretest appear in appendix VII.

Quality Control

o ensure high quality data, program staff continually monitored the interviewers, the sample selection procedures, the consistency of the data, and the estimation procedures.

Quality Control of Interviewing

Telephone Center supervisors were available to interviewing staff at all times to resolve any questions or concerns about a case. Supervisors regularly observed the data collection process to informally monitor interviewers. In addition, supervisory staff used remote telephone and computer-monitoring technology to evaluate whether the interviewers performed according to project specifications. This formal monitoring was conducted to see that introductory materials were properly read, that item wording and sequence of the questionnaire were followed correctly, that respondent questions were answered properly, and that any vague responses were properly probed. Computer monitoring also allowed supervisors to ascertain whether answers were entered accurately into the CATI system.

Supervisory staff monitored 5% of all calls made for the National Survey of CSHCN. Selection of interviewers for monitoring was automated using an algorithm that ensured that newly trained interviewers were monitored more often than experienced interviewers. Experienced interviewers were prioritized for monitoring based upon the length of time since their last monitoring scores. Each interviewer was typically monitored at least once a week; however, some interviewers were monitored more often.

Sample Monitoring and Quality Control

The prepared sample of telephone numbers was checked to ensure that it met the sample design specifications. The sample was monitored on a daily basis to ensure that the pace of data collection was consistent across the data collection period and to prevent the unnecessary release of excess cases to the telephone centers. Daily analyses of the dynamics in the sample were produced to assist in timely sample management decision-making.

Data Quality Control

The CATI system was programmed to help ensure complete and accurate data collection, using automated data checking techniques such as responsevalue range checks and consistency edits during the interview process. These features enabled interviewers to obtain needed clarifications while still on the telephone with the respondent. Throughout data collection, interview data were reviewed for consistency between fields, appropriate responsevalue ranges, skip logic patterns, and missing information.

Procedures for Developing Sampling Weights

his section provides a nontechnical overview of the weighting procedures for the National Survey of CSHCN. A more detailed and technical description is in appendix I.

Household Screener Weight

A household weight was generated for analysis of households that completed a screener interview. For example, analysis of the proportion of households with CSHCN would use the household screener weight. This weight is composed of a base sampling weight, an adjustment for multiple telephone lines, and adjustments for householdlevel nonresponse. The final, adjusted weight is poststratified so that the sum of the household weights for each State matches the number of households with children as projected from the 2000 census.

Base Sampling Weight

The goal of the National Survey of CSHCN was to complete at least 750 interviews for CSHCN in each State over 18 months. First, the total number of telephone lines required to obtain this number of completed interviews was estimated. Then, enough NIS sample to obtain the requisite number of completed cases for the National Survey of CSHCN for each quarter was selected. Some IAP-area samples contained too few telephone numbers to obtain the desired number of completed cases. In these areas, additional telephone numbers (i.e., augmentation sample) were randomly selected to reach the National Survey of CSHCN targets.

The telephone lines selected for screening for the National Survey of CSHCN represent a random sample of all possible telephone lines in each geographic area. The probability that any given telephone line will be selected from the population of all possible telephone lines can be calculated:

If there were 1,000 total telephone lines in a given area and 100 of those lines were selected for the study, the probability that any single telephone line would be selected is 100/1000, or 0.10.

Each telephone line selected for the National Survey of CSHCN represents some larger number of telephone lines in the geographic area. This number can be calculated as the inverse of the probability of selection for any single telephone line:

> If the probability of selection for any single telephone line was 0.10, then each telephone line selected represents 1/.10, or 10, telephone lines in the geographic area.

This number—the inverse of the probability of selection for any single telephone line—is the base sampling weight and was attached to each completed household interview in that geographic area. The base sampling weights vary by geographic area, but were the same for every completed interview within that geographic area. Because the population of telephone numbers did not change much by quarter, the base sampling weight was calculated for the overall survey and not separately for each quarter.

Adjustment for Households With Multiple Telephone Lines

If a household has multiple voice-use telephone lines, this household has a greater chance of being included in the survey than does a household with only a single voice-use telephone line.

Because the National Survey of CSHCN is a survey of households and of children in those households, each household in a given State should have an equal probability of being in the sample. To adjust for the increased probability of households with multiple telephone lines being included in the sample, the base sampling weight is divided by the number of voice-use telephone lines in the household:

If a household had two voice-use telephone lines, this household could be included in the sample two times. If it was included twice, the household would represent 10 (base sampling weight) x 2 (number of $telephone \ lines) = 20 \ households.$ To adjust the weight so that the multiple-line household in the sample represents the same number of households in the geographic area as does a single-line household in the sample, the base sampling weight (10) is divided by the number of telephone lines (2). With an adjusted weight of 5, this household (had it been selected twice) would still represent only 10 households.

First Form of Nonresponse: Unknown Household Status

When the selected telephone lines are called, three results are possible:

- It is determined that the telephone line belongs to a household.
- It is determined that the telephone line is not a working residential number, but is a business number or a nonworking number.
- The status is undetermined because the telephone rings without an answer, the person answering the telephone hangs up immediately, or the telephone-answering device does not indicate whether the telephone line belongs to a household.

This third category includes some household telephone lines, but the exact number of household telephone lines in this category is unknown. Still, the completed household interviews must represent the households in this "unknown" category. When the number of households in the unknown category is large, the weight for each completed household interview must be increased substantially. When the number of households in the unknown category is small, the weight for each completed household interview must be increased only slightly. This proportional adjustment is the first unit nonresponse adjustment.

The size of the adjustment is based on the size of the "unknown" category

after all telephone numbers have been called several times and is based on previous research in which telephone company business offices reported on the number of households among the "unknown" numbers. This adjustment varies based on geographic area, telephone area code, and whether the telephone line was directory-listed. When many telephone numbers in a geographic area and area code go unanswered and most of these numbers are highly likely to be households, the weights for completed interviews in that geographic area and area code are increased greatly. When few telephone numbers in a geographic area and area code go unanswered or few of these numbers are likely to be households, the weights for completed interviews in that geographic area and area code are increased only slightly.

In other words, based on the frequency of the nonresponse in a given area, compensation is made for this nonresponse by proportionately increasing the weights for those interviews that could be completed in that area. The completed interviews, therefore, represent the households in the "unknown" category.

Second Form of Nonresponse: Unknown Household Eligibility

When a household has been identified, three results are possible:

- It is determined that the household includes an age-eligible child and is, therefore, eligible for further screening.
- It is determined that the household does not include a child and is, therefore, not eligible.
- The screening interview is not completed, and the eligibility of the household is unknown.

This third category includes some age-eligible households. However, the exact number of age-eligible households in this category is unknown. Still, the completed household interviews must represent the age-eligible households in this "unknown" category. When the number of age-eligible households in the unknown category is large, the weight for each completed household interview must be increased a great deal. When the number of age-eligible households in the unknown category is small, the weight for each completed household interview must be increased only slightly. This proportional adjustment is the second unit nonresponse adjustment.

The size of the adjustment is based on the size of the first two categories. That is, the proportion of age-eligible households in the unknown category is assumed to be the same as the proportion of age-eligible households among all households where the screening interview for the presence of children was completed. This adjustment varies based on geographic area. When the age-eligibility for many households in a geographic area is unknown, and a high proportion of the completed eligibility interviews in that area revealed age-eligible children, the weights for completed interviews in that geographic area and sample are increased greatly. When the ageeligibility for only a few households in a geographic area and sample is unknown or few of the completed eligibility interviews in that area revealed age-eligible children, the weights for completed interviews in that geographic area and sample are increased only slightly.

In other words, based on the frequency of nonresponse to the age-eligible screening interview in a given area and in a given sample, compensation is made for this nonresponse by proportionately increasing the weights for those interviews that could be completed in that area. The completed interviews, therefore, represent the age-eligible households in the "unknown" category.

Third Form of Nonresponse: Eligible Households Who Do Not Complete the Screener

When an age-eligible household has been identified, two results are possible:

- The CSHCN Screener is completed.
- The CSHCN Screener is not completed.

The completed household screeners must represent the households in this "incomplete" category. When the number of incomplete screeners is large, the weight for each completed household screener must be increased substantially. When the number of incomplete screeners is small, the weight for each completed household screener must be increased only slightly. This proportional adjustment is the third unit nonresponse adjustment.

The size of the adjustment is based on the size of the two categories and is calculated simply as the ratio of the total number of age-eligible households to the number of completed screener interviews. This adjustment varies based on geographic area.

In other words, based on the frequency of nonresponse among age-eligible households in a given area and in a given sample, this nonresponse is compensated by proportionately increasing the weights for those screeners that could be completed in that area. The completed screeners, therefore, represent the age-eligible households with incomplete screeners.

Poststratification of Household Weight

Despite the weighting efforts and the nonresponse adjustments, the estimated number of households with children is unlikely to perfectly match the population sampled. Any discrepancies are likely to be due to random sampling error and nonrandom response biases. Increased nonresponse based on household size or income is an example of this nonrandom bias. The previous nonresponse adjustments used completed screener interviews to adjust for incomplete screeners and, therefore, assume that households with completed screeners are similar to households with incomplete screeners. Poststratification adjusts the weights to match population control totals for key demographic information obtained from an independent source.

For the National Survey of CSHCN, the independent source was the 2000 census count of households with children. July 2001 is the midpoint of the data collection period for the National Survey of CSHCN data file. The projection of census data to that date was accomplished by computing the quarterly exponential growth from the 1990 census to the 2000 census and applying that growth rate to the next 5 quarters.

Although State-by-State counts of households with children were available from the census, more detailed data were not available at the time that the weighting was planned. To identify demographic subgroups, the Current Population Survey (CPS) was used instead. Proportions were determined using an average of the 1999 CPS March Supplement, the 2000 CPS March Supplement, and the 2001 CPS March Supplement; this averaging was intended to produce more stable estimates for the control totals.

By combining the census population counts with the CPS proportional estimates, the National Survey of CSHCN household State-level weights were adjusted so that the sum of the weights equals the 2000 census population counts projected to July 2001 for the following groups:

- Number of households with one, two, and three or more children
- Number of households with children in each of three nonoverlapping race/ethnicity categories
- Number of households with children in each State and the District of Columbia
- Number of households with children that have a household income in each of five nonoverlapping categories
- Number of households with children that have nonresident mothers, and number of households with children that have resident mothers in each of four nonoverlapping educational attainment categories

The poststratification adjustment also adjusts for the potential bias that may exist because the National Survey of CSHCN, as a telephone survey, could not select households without a telephone at the time of the survey. To make this adjustment, the poststratification control totals from the CPS were split: one control total for telephone households with children and one control total for those without telephones or with an interruption in telephone service for at least 1 week

during the past 12 months. The proportion allocated to each group was based on the average from 1999, 2000, and 2001 CPS data for households with children without telephones and the National Survey of CSHCN data for households with interrupted telephone service. Households with interrupted telephone service were included in the weighting process because there is evidence that households with telephones at the time of the survey, but with interruptions in telephone service during the year, are more similar to households with no telephone service at the time of the survey than households with uninterrupted telephone service during the year (17–19). Therefore, nonresponse by households without a telephone can be somewhat compensated for by proportionately increasing the weights for those interviews that could be completed in households with interrupted service. In this way, completed interviews in households with interrupted service represent the incomplete interviews in households without telephone service at the time of the interview.

Truncation of Large Household Weights

Extremely large weights were truncated to prevent a small number of cases with large weights from having undue influence on the estimates. The technical appendix describes how the weights were truncated.

Child Screener Weight

A child screener weight was generated to analyze information available from the screener interview. For example, the proportion of children with a special health care need would be weighted using the child screener weight. Demographic information and information regarding special health care needs status is collected for each resident child. The weight for screened children begins with the final household weight, but is adjusted so that the final child screener weight sums to the number of children in the nation, as estimated from the 2000 census and the Current Population Survey. This

poststratification process is described below.

Poststratification of Child Screener Weight

Despite the weighting efforts and the nonresponse adjustments, the estimated number of children is unlikely to match the population sampled. Any discrepancies are likely to be due to random sampling error and nonrandom response biases. These biases include increased nonresponse based on age, sex, or race of the child. Poststratification adjusts the weights to match population control totals for key demographic variables obtained from an independent source.

For the child screener weight, the independent source was the 2000 census count of children, stratified by sex, age, and race/ethnicity. The CPS March Supplement data (averaged across 1999, 2000, and 2001) were used to produce proportions for the other demographic items of interest. The child screener State-level weights were adjusted so that the sum of the weights equals the 2000 census population counts projected to July 2001 for the following groups:

- Number of male and female children in three age categories
- Number of children in each of five nonoverlapping race/ethnicity categories
- Number of children residing in each State and the District of Columbia
- Number of children in households with one, two, and three or more children
- Number of children in households that have a household income in each of five nonoverlapping categories
- Number of children who have nonresident mothers, and number of children who have resident mothers in each of four nonoverlapping educational attainment categories

The poststratification control totals were split into children in households that have telephones and children in households with an interruption in telephone service for at least 1 week during the past 12 months. The proportion allocated to each group was based on the 1999 and 2000 CPS data for children in households without telephones and the National Survey of CSHCN data for children in households with interrupted telephone service.

Truncation of Large Screener Weights

Extremely large weights were truncated to prevent a small number of cases with large weights from having undue influence on the estimates. The technical appendix describes how the weights were truncated.

Child Interview Weight

A child interview weight was generated for analysis of information available from the interview. For example, the proportion of children with health insurance or the proportion of CSHCN with barriers to needed care would be weighted using the child interview weight. This weight also begins with the poststratified, adjusted household weight. This weight is adjusted for interview nonresponse and for the number of children in the household. The adjusted weight is poststratified so that the final child interview weight sums to the number of children in the nation, as estimated from the 2000 census and the Current Population Survey.

Fourth Form of Nonresponse: Sampled Children for Whom an Interview Is Not Completed

When a child has been sampled, two results are possible:

- An interview is completed.
- An interview is not completed.

The completed child interviews must represent the children who were sampled, but did not complete the interview. When the number of incomplete interviews is large, the weight for each completed child interview must be increased substantially. When the number of incomplete interviews is small, the weight for each completed child interview must be increased only slightly. This proportional adjustment is the fourth unit nonresponse adjustment.

The size of the adjustment is based on the size of the two categories and is calculated simply as the ratio of the total number of sampled children to the number of completed interviews. This adjustment varies based on geographic area. In other words, based on the frequency of nonresponse among sampled children in a given area and in a given sample, compensation is made for this nonresponse by proportionately increasing the weights for those interviews that could be completed in that area. The completed interviews, therefore, represent the sampled children with incomplete interviews.

The logic of this adjustment is the same regardless of whether the child was sampled for a special-needs interview or a health insurance control sample interview. However, the adjustment was calculated separately depending on whether the weight was attached to a completed special-needs interview or a completed health insurance control sample interview. The completed special-needs interviews, therefore, represent the sampled CSHCN with incomplete interviews, and the completed health insurance control sample interviews represent the sampled children without special needs with incomplete interviews.

Adjustment for Multiple-Child Households

One child with special health care needs was randomly selected from among all children with special needs in the household, and one child without special needs was randomly selected from among all children without special needs in the household. In households with multiple eligible children, the randomly selected child represents all of the nonselected children in the household. Therefore, the sampling weight for this completed interview must be increased to reflect the fact that this completed interview represents multiple children in that household.

This adjustment multiplies the adjusted child weight (the household weight adjusted for nonresponse in the interview) by the number of eligible children in the household. For

Poststratification of Child Interview Weight

The poststratification of the child interview weight is similar to that of the child screener weight because the population of inference is the same—all children in the United States. The child interview weight is further poststratified so that the proportion of CSHCN in the weighted interview file matches the proportion observed in the weighted child screener file. This final dimension is determined by using the final, poststratified child screener weight to estimate the national proportion of CSHCN.

Truncation of Large Interview Weights

Extremely large weights were truncated to prevent a small number of cases with large weights from having undue influence on the estimates. The technical appendix describes how the weights were truncated.

Quality Control

Staff compared the formulas for the weights and adjustments developed by the sampling statistician with the actual weights and adjustments constructed by the statistical programmer. The variables delivered by the data collection staff to the statistical programmer were used in independent calculations of the weights to check the programmer's implementation of the statistician's weighting specifications.

In addition to this independent check, univariate statistics were produced and reviewed for the adjustments and weights. Reviewers used general knowledge about the size of the population and expectations for IAP-area behavior. For example, interview cooperation rates are typically lower in certain IAP areas (e.g., urban centers) than others (e.g., States in the South and Midwest). This tendency was borne out in the National Survey of CSHCN. In addition, the sums of the various weights were compared to ensure that the differences were in the expected direction (e.g., the sum of the child weights is larger than the sum of the household weights).

Data Files

F our separate but linkable SAS (v8) data files were created that were based on the completed interviews. The files reflect all data collected during the survey field period with the exception of variables or records suppressed to protect the confidentiality of the respondents.

Screener File-This file contains one record for each child under 18 years of age residing in a household where the CSHCN Screener was completed. An age-eligible household is defined as one with at least one child who is under 18 years of age. The screener was determined to be complete if question FACCT5 A ("Has the child's emotional, developmental, or behavioral problem lasted or is it expected to last 12 months or longer?") had a nonmissing value for that child. Incomplete screening interviews are not included in this file. This file (n =372,174) includes the answers to the CSHCN Screener as well as the child's age, sex, race, ethnicity, and State of residence. Except for the household identification number, the variables in this file are limited to those assessed at the child level. This file can be used to produce estimates of the proportion of children who have special health care needs and for most demographic characteristics of those children.

Household File—This file contains one record for each age-eligible household screened, regardless of whether a detailed special-needs interview or a brief health insurance control sample interview was completed. This file (n = 196,888) includes all information about the household, including State of residence, household size, total number of CSHCN living in the household, household income (reported relative to the Federal poverty level), and whether the household resides in a metropolitan statistical area. All variables in this file are at the household level. This file can be used to produce estimates of the proportion of households that contain at least one CSHCN and for characteristics of those households.

CSHCN Interview File—This file contains one record for each CSHCN who was randomly sampled to be the subject of the detailed special-needs interview and for whom an interview was completed. It should be noted that not all CSHCN selected for an interview at the screener level went on to complete an interview. This file (n =38,866) includes all information from the detailed interview, including the relationship of the respondent to the sampled child, health and functional status, access to care, experience with care, adequacy of care, health insurance, and the impact of the special health care need on the family. This file can be used to produce a wide range of estimates of the health of CSHCN.

Insurance Analysis File—This file contains one record for each child who was randomly sampled to be the subject of the detailed special-needs interview or the brief health insurance control sample interview and for whom such an interview was completed. Not all children selected for an interview at the screener level completed an interview. This file (n = 215, 162) includes a series of health care coverage summary variables for each child. In addition, for eligible children, this file contains all information from the Low-Income Uninsured Supplement. It includes the brief set of health status and health care utilization variables that were included in this supplement. (For CSHCN, the health care coverage, health status, and health care utilization variables on this file duplicate the information contained in the CSHCN Interview File.) The file can be used to produce estimates of the proportion of children who have various types of health care coverage, to produce a wide range of estimates of the health of low-income uninsured children, and to produce estimates of

their parents' knowledge and experiences with Medicaid and SCHIP.

All four data sets 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 interviewed CSHCN has a corresponding record in the Screener File and the Insurance Analysis 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, CSHCN Interview, and Insurance Analysis Files contain the IDNUMXR variable.

Editing

Concurrent with the development of the CATI questionnaire, a detailed plan for checking and editing the data in the CATI instrument was developed. The intention was to design into the CATI software consistency checks across data elements, valid range codes, and a method to identify incorrect codes entered by interviewers. To the extent that the CATI software could be developed to perform these tasks, the efficiency of postsurvey data cleaning and processing was increased.

The CATI system was designed to perform edits as an interviewer enters data into the computer system. These edits dealt with errors that could be reconciled while the respondent was on the telephone and focused, in particular, on items critical to the conduct of the study. The CATI edit specifications were designed to correct respondent errors during the interview (for example, a respondent saying two children lived in the household, but providing only one birth date) and to identify and correct data-entry error by interviewers (for example, a child is reported to have seen a doctor four times in the past year, but the interviewer attempts to enter 44 times). To the extent possible without making the CATI system overly

complicated, out-of-range and inconsistent responses resulted in a warning screen for the interviewer, who was trained to correct errors as they occurred. These messages were designed primarily to prevent data entry errors and respondent errors and not to challenge respondents who gave logically inconsistent responses.

The two main types of CATI edits were range checks and consistency checks. A range violation would result in visual notification to the CATI interviewer (a pop-up box). In most cases, the interviewer would have to enter a valid response to continue the interview. However, some extreme responses would produce a warning, and the interviewer would be instructed to verify the answer provided by the respondent. If the respondent confirmed the unusually small or unusually large value, the interviewer was allowed to continue. A consistency violation would also result in a pop-up box indicating that an inconsistency between two responses had been detected. The interviewer would then have the opportunity to change one or both of the values entered. In some cases, the interviewer had the option to proceed if the respondent confirmed the inconsistent values. There are trade-offs between incorporating every possible type of error check into a CATI system and overall performance of the CATI system and the use of development resources. To reconcile this trade-off, post-CATI edits were developed to resolve problems that did not require access to the respondent. Any problems that could not be resolved without further access to the respondent were left inconsistent.

After the preprogrammed edits were run, the first step in the data cleaning process was verification of the valid number of cases in the data file. After verifying the number of cases, initial data frequencies were produced and reviewed. Each variable's range of permissible values was examined for any additional invalid values or unusual distributions. When invalid values occurred, they were blanked out. Nested variables (i.e., variables that are only asked when based on a response to a previous question) were linked to their root variables, and questionnaire paths were traced. If blank values already existed for a variable, they were checked to see whether they were allowable (e.g., due to legitimate skip patterns in the questionnaire) or missing in error. Records that were missing responses for unknown reasons were left missing.

Missing Data

The CATI system is designed to minimize missing data. However, some data are missing. Most analysts ignore records with missing data regardless of the reasons for the missing data. However, SAS provides a mechanism for analysts who may wish to differentiate between different types of missing values. The following key provides a description of the various codes that were used to represent missing data in each of the Screener, Household, CSHCN Interview, and Insurance Analysis Files.

(.N) Not in universe (sample logic)—Respondents skipped entire section of questions based on eligibility criteria (e.g., special health care needs, demographic characteristics).

(.L) Legitimate skip (question logic)—Respondents skipped one or more questions within a section because of an answer selected for a root question.

(.P) Partially completed case— Question not answered because the respondent ended the interview prior to completing this question. A partial complete indicates the interview was completed at least through the end of Section 7. These cases are included in the CSHCN Interview and Insurance Analysis Files, even though data are missing for questions that were asked late in the interview.

(.M) Missing in error—A response should have been captured for this question, but was not. Data may be missing in error if records were not properly transferred or stored after a case was finished, the rules for returning to a previous question were not properly followed by an interviewer, or the recorded answer was determined to be invalid. (.A) Added question—This question was added after the start of data collection and the respondent was interviewed, but before the question was added to the interview. Questions added after the start of data collection include items regarding mother's education, mother's residence, transitional health care and vocational needs for CSHCN reaching adulthood, reasons for not enrolling the sampled child in Medicaid or SCHIP programs, and a followup question concerning whether reported insurance was provided through an employer.

(.B) Break off after a screener was completed—If a screener was completed for the household, but a detailed special-needs interview or a health insurance control sample interview was not completed, the record will be missing some household demographic data that are gathered only at the end of the interview. This value is used only in the Household File to indicate why no data exist for such cases.

(.X) No recoded response—These cases did not have a recoded verbatim response for this variable. (For a further explanation, see "Coding of Verbatim Answers" below.)

Because SAS treats all of the above codes similarly in statistical analyses (i.e., as missing data), analysts using SAS who are not interested in the reasons for the missing data may continue to analyze data as usual.

It is important to note that derived variables (i.e., variables whose response was not directly provided by the respondent) do not include the detailed coding of missing data. All missing values for derived variables received a ".M," regardless of the reason for the missing data. Similarly, ".M" was used when derived variables were suppressed to protect the confidentiality of the survey participants.

Data missing because the respondent did not know the answer or refused to provide the answer have been treated differently. Rather than assigning a missing value to these records, 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.

Imputation of Household Income for Uninsured Children

The Low-Income Uninsured Supplement was asked in all households below 200% of DHHS Federal Poverty Guidelines where the sampled child was uninsured. If a respondent refused to provide income or gave a "don't know" response to the income questions, the CATI system assumed that the respondent's household was below 200% of the Federal poverty level and administered this Supplement if the sampled child was uninsured. Some households with higher incomes will be included in this group. Some analysts interested in uninsured children from only low-income households may wish to exclude households with missing income data before analyzing the Low-Income Uninsured Supplement. Other analysts interested in uninsured children from only low-income households may wish to impute an income value to these cases.

Analysts who desire an imputed income variable for uninsured children with missing income data may use "POV200_I," which is an indicator that the child's household is predicted to be below 200% of the Federal poverty level. This prediction is based on a logistic regression model built using survey data from uninsured children with reported income data. Details about the calculation and fit of the model are available from NCHS.

When necessary for the calculation of sampling weights, other missing values were imputed. Because the imputed values were developed for weighting purposes rather than analytic purposes, these imputed data have not been included on the data files.

Coding of Verbatim Answers into Question Responses

Beginning in January 2001, 33 open-ended verbatim text boxes were added to the survey to capture more specific information when "other" responses were selected as an answer to a stem question. These text boxes allowed interviewers to record an exact response from the respondent, rather than simply selecting an "other" response with no additional information.

At the end of the data collection period, an attempt was made to recode the verbatim responses captured into an existing response category in the stem question. A number of new response categories and variables were added to the interview data file to reflect common responses that were not part of the original set of response categories. For reference, these added response categories and variables have been included in the final CATI specifications (appendix II) after the "other" category in lists of response options; these categories were not available to interviewers during questionnaire administration. When recoding was not necessary for a particular record or when the new variable was not relevant to the verbatim response given, ".X" was assigned as the missing value.

Edits to Protect Confidentiality

NCHS takes extraordinary measures to ensure that the identity of survey subjects cannot be disclosed. The risk of inadvertent disclosure of confidential information about individual respondents is higher with a publicly released data set having detailed geography variables, a detailed and extensive set of survey observations, and a sizeable proportion of the total population of interest. Coarsening a data set by suppressing survey variables, collapsing multiple variables into one, collapsing response categories for other variables, and/or introducing noise in the data are common techniques to reduce the risk of inadvertent disclosure.

In these data files, household income has been suppressed, but a measure of income relative to the Federal poverty level has been included. Hispanic origin (yes/no) has been reported separately from race, but specific Hispanic origin (e.g., Mexican) has been suppressed. The specific language of the interview has been suppressed, but an indicator has been included to identify interviews that were not conducted entirely in English. The relationship of the respondent to the child has been suppressed when the respondent was not the parent of the child.

Geography

Geographic information that would identify the specific IAP area in States with multiple IAP areas has been suppressed. However, State identifiers are included in all files. In addition, an indicator identifying whether the household resides inside or outside of a metropolitan statistical area (MSA) has been included for some States. This indicator was suppressed whenever the population for either the MSA areas or the non-MSA areas was less than 500,000 persons. This resulted in the suppression of the MSA identifier in 16 States. The MSA identifier was suppressed in Connecticut, Delaware, Hawaii, Massachusetts, Maryland, New Hampshire, Nevada, and Rhode Island because the non-MSA population was too small. The MSA identifier was suppressed in Idaho, Maine, and Montana because the MSA population was too small. The MSA identifier was suppressed in Alaska, North Dakota, South Dakota, Vermont, and Wyoming because both the non-MSA population and the MSA population were too small.

Race

Respondents were permitted to identify all possible categories that described the child's race. Nationally, responses for the race variable have been collapsed to four categories: white only, African-American or black only, other race, and multiple race. The "other race" category includes 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. Children for whom more than one race was identified (e.g., Asian and Native Hawaiian) were included in the "multiple race" category. The "other race" category also includes children for whom a single verbatim response was provided that could not reliably be coded to a particular race. Examples of these responses are Central American, Brazilian, and Puerto Rican. The coding of verbatim responses to race categories was based on census guidelines.

In several States, however, minority group populations are sufficiently large that the release of additional race categories was possible. To identify these States, data from the decennial 2000 census were examined to identify minority groups that comprise at least 5% of the total population of children in the State. Based on this criterion, the data files identify American Indian or Alaska Native children in Alaska, Arizona, Montana, New Mexico, North Dakota, Oklahoma, and South Dakota. Asian children's race is reported for children in California, New Jersey, New York, and Washington. The data files identify both Asian children and Native Hawaiian and Pacific Islander children in Hawaii.

Number of Children in Household

The CSHCN Screener data and demographic information were collected for every child in every household with children. However, the information on the total number of children in each household significantly increases the risk of inadvertent disclosure of confidential information in households with large numbers of children. Therefore, the number of children reported to be living in a household was top-coded to suppress the identity of large households, with the specific top code determined by State. To determine the top-code for a particular State, weighted data from the decennial 1990 census were used to estimate the proportion of households with children in each State that include six or more children. If at least 1/2 of 1% of

the population of households with children included six or more children, then a top-code of six children was used for that State. Otherwise, a top-code of five children was used. (In all States, at least $\frac{1}{2}$ of 1% of the population of households with children included five or more children.) This resulted in 21 States with a top-code of five children. To complete the masking of households with a large number of children, records in the Screener File were suppressed at random from these large households to achieve the five- or six-child State-dependent threshold in each of these large households. Only children who were not the subject of a detailed special-needs interview or a health insurance control sample interview were eligible for suppression.

From the 373,055 records in the original Screener File, 881 records (0.2%) were suppressed. Sampling weights for the remaining records in the Screener File were adjusted to ensure that estimates for the prevalence of CSHCN in each State and for the prevalence of CSHCN from large households in each State were unchanged. Weights for the suppressed records in each State were summed based on the child's special-needs classification (i.e., with or without special needs) and then redistributed by special-needs status to the screening records that remained for the households with large numbers of children in that State. That is, weights for suppressed CSHCN from large households were reallocated to remaining CSHCN from large households, and weights for suppressed non-CSHCN from large households were reallocated to remaining non-CSHCN from large households. This reallocation of weights was accomplished by using a ratio adjustment for the weights of the remaining records, with the exception that weights for children who were the subjects of a detailed special-needs interview or a health insurance control sample interview were left unchanged.

Age

In these data files, both the child's date of birth and the date of the interview have been suppressed, but the

child's age (in years) at the time of the interview has been reported. A risk of inadvertent disclosure exists in households with multiple children of the same age (e.g., triplets, quadruplets) and in households with multiple sets of children of the same age (e.g., two sets of twins). Randomly adding a year of age to or subtracting a year of age from randomly selected children in selected households masked these records. Of the 196,888 households screened, the ages of children in 131 households were adjusted.

Other

Several other frequency variables have been top-coded to suppress outliers at the high end of the distribution of responses. Due to their unusual characteristics, records including these outliers might have been more readily identifiable.

- For the number of doctor visits for any reason in the past year for CSHCN (C6Q01R), 21 visits or more is the maximum reported and responses between 11 visits and 20 visits have been collapsed into two categories (11–15 and 16–20).
- For the number of doctor visits for any reason in the past year for non-CSHCN who were eligible for the Low-Income Uninsured Supplement, 11 visits or more is the maximum reported.
- For the number of days missed from school due to illness or injury (C3Q14R), 11 days or more is the maximum reported.
- For the hours per week that health care at home for the child was provided (C9Q03R), 21 hours or more is the maximum reported, and responses between 11 hours and 20 hours have been collapsed into a single category.
- For the hours per week arranging or coordinating care for the child (C9Q04R), 21 hours or more is the maximum reported, and responses between 11 hours and 20 hours have been collapsed into a single category.
- For the total number of adults living in the households (TOTADULT),

four adults or more is the maximum reported.

For the education level of the child's mother
 (MOTHER_EDUCR), bachelor's degree or more advanced study is the maximum reported, and other responses have been collapsed into four additional categories (no more than eighth grade education; some high school completed, but no high school diploma or GED; high school graduate or GED completed; and associate's degree or some college completed).

Analysts interested in working with data that were suppressed to protect confidentiality may access unmodified data files through the NCHS Research Data Center (RDC). This facility, designed for the researcher outside of NCHS, is located in Hyattsville, Maryland. Data files housed in the RDC may also be accessed remotely via e-mail. For more information about how to apply for access, analysts may visit their Web site at http://www.cdc.gov/ nchs/r&d/rdc.htm.

Derived Variables on Screener File

AGE—The child's age in years was derived from the reported month, day, and year of each child's birth in question C2Q01. In cases where a valid value for the year of birth was not provided, the respondent was asked for the child's age in months (C2Q02) and/or years (C2Q02A). To calculate the age for each child, the date of birth was compared to the date that the child was first identified as eligible (which may have been prior to the date that the actual interview was completed). Valid values for age are 0 through 17, where "0" means younger than 1 year. For some cases, a valid age in years could not be calculated; the respondent did not know or refused to specify the child's date of birth or age. These cases are coded as missing (.M).

HISPANIC—This indicator of whether the sampled child is of Hispanic or Latino origin was derived using data collected in variables C1001_01 through C1001_10 and CW10Q01A. Respondents who did not identify a Hispanic ethnicity during administration of C1001_01 through C1001_10, but did provide an answer indicating Hispanic ethnicity as part of a verbatim response to the race question, were coded with a value of "1" for the variable HISPANIC.

INTERVIEW—This is an indicator that either a detailed special-needs interview or a health insurance control sample interview was completed for the screened child.

NEEDTYPE—The special-needs status of each child was derived from responses to the CSHCN Screener (FACCT1, FACCT1_A, FACCT1_B, FACCT2, FACCT2_A, FACCT2_B, FACCT3, FACCT3_A, FACCT3_B, FACCT4, FACCT4_A, FACCT4_B, FACCT5, and FACCT5_A).

RACER, RACENAAN, RACEASIA, and RACE_HI—These race classification variables were derived by using data collected in variables C1002_01 through C1001_08 and CQ10Q02A. Based on guidelines from the Office of Management and Budget, data from CW10Q03 have been suppressed.

SEX—This indicator was created from C2Q03.

Derived Variables on Household File

HHSTATUS—This variable indicates whether a detailed interview was completed for any children living in the household.

MSASTATR—This indicator, identifying whether the household resides inside or outside a metropolitan statistical area (MSA), was suppressed to protect confidentiality in 16 States.

NM_NSPR—This variable represents the total number of children in the household without a special health care need. As noted previously, some screener records have been suppressed to protect the confidentiality of large households. This variable is based on the screener records that remain, and therefore may be inaccurate for large households.

NM_NSPFR—This variable represents the total number of female

children in the household without a special health care need. As noted for NM_NSPR, this variable also may be inaccurate for large households.

NM_NSPMR—This variable represents the total number of male children in the household without a special health care need. As noted for NM_NSPR, this variable also may be inaccurate for large households.

NM_SPR—This variable represents the total number of children in the household with a special health care need. As noted for NM_NSPR, this variable also may be inaccurate for large households.

NM_SPFR—This variable represents the total number of female children in the household with a special health care need. As noted for NM_NSPR, this variable also may be inaccurate for large households.

NM_SPMR—This variable represents the total number of male children in the household with a special health care need. As noted for NM_NSPR, this variable also may be inaccurate for large households.

OTH_LANG—This flag can be used as a proxy indicator that the interview was administered in a language other than English. For sample management purposes, a calling queue was used for households identified as requiring an interviewer capable of conducting a non-English screener/ interview. OTH_LANG indicates such households. If the screener or interview was conducted in English on subsequent calls, this flag was not reset. However, past research demonstrated that the flag reliably indicated the language of interview administration in over 97% of cases.

POVLEVEL—This indicator was created using total household members (C11Q01_A) and the household income value. If data for either of these two components were missing, refused, or had a "don't know" response, this measure was assigned a missing value code. The household income value was the actual dollar amount reported by respondents who reported an exact household income (C11Q01). However, when respondents did not supply a specific dollar amount for household income, it was necessary to go through a series (i.e., cascade) of questions asking respondents whether the household income was below, exactly at, or above threshold amounts (W9Q02 through W9Q12A). If respondents did not complete the income cascade, either because they refused or did not know the answer to one of the cascade questions, this measure was assigned a missing value code. Once an income-tohousehold-size measure was computed, it was compared with DHHS Federal Poverty Guidelines. More detail about the development of this poverty indicator is available in appendix IV.

TOTADULT—The total number of adults in the household was derived by subtracting the total number of children in the household from the total number of persons in the household (C11001 A). During data collection, the CATI system did not reconcile the total number of persons reported as living in the household with the total number of children reported in that household. Therefore, the number of children screened in a single household could be greater than the total number of persons reported as living in the household. When this occurred, the total number of adults was assigned a missing value code (.M).

TOTKIDSR—This variable represents the total number of children aged 0 to 17 years in the household. As noted for NM_NSPR, this variable also may be inaccurate for large households.

TOTKIDFR—This variable represents the total number of female children aged 0 to 17 years in the household. As noted for NM_NSPR, this variable also may be inaccurate for large households.

TOTKIDMR—This variable represents the total number of male children aged 0 to 17 years in the household. As noted for NM_NSPR, this variable also may be inaccurate for large households.

Derived Variables on CSHCN Interview File

C6Q01R—The number of visits to a doctor or other health care provider was derived from C6Q01.

HPCARE1F and HPCARE2F— These flags indicate whether the interviewer accessed a question-specific, online job aid with supplemental information regarding professional care coordination.

Derived Variables on CSHCN Interview and Insurance Analysis Files

The child's type of health insurance coverage could be reported several ways within the health insurance section of the questionnaire. Therefore, categorical indicators have been derived to simplify analyses of type of coverage. Because lack of health care coverage could be reported several ways, categorical indicators have also been derived to simplify analyses of uninsurance at the time of the survey, uninsurance during the year prior to the survey, and the length of the uninsurance spell (for currently uninsured children).

CHIPNAME—This flag indicates whether an SCHIP program name could be provided to respondents for the State in which the sampled child resides. An SCHIP program name could not be provided if the State does not offer SCHIP insurance or if the State's SCHIP program shares the same name as the Medicaid program. CHIPNAME also indicates if the name of the State's Medicaid expansion program was provided instead of the SCHIP program name.

MEDICAID—Medicaid coverage was reported either directly (C7Q01 or C7Q10_01) or by State Medicaid program name (C7Q08 or C7Q10C). In eight States, Medicaid coverage may also have been reported at C7Q02. For more details, see the description of the SCHIP variable.

MILITARY—Some type of military coverage was reported either directly (C7Q04 or C7Q10_06), by military program name (C7Q08 or C7Q10C) or by naming a program that is supplemental to TRICARE or CHAMPUS (C7Q08 or C7Q10C).

NATIVINS—Comprehensive services from a facility supported by the Indian Health Service or a Native American Corporation were reported either directly (C7Q10_07) or by program name (C7Q08 or C7Q10C).

OTHERINS—Comprehensive insurance coverage other than Medicaid, SCHIP, Title V, private, or military coverage was reported. This category includes Medicare (C7Q10 02 or C7Q10_05). The category also includes cases where a respondent reported (in C7008 or C7010C) an apparently valid plan name (e.g., Aetna, Blue Cross Blue Shield) or a valid plan type (e.g., HMO, IPA), but where this insurance could be obtained by either private or public means. To be included in this category, the reported insurance was required to cover both doctor visits and hospital stays (C7Q08A or C7Q10B).

OTHPUB—The coverage reported (in C7Q08 or C7Q10C) could not be classified reliably as Medicaid or SCHIP, but it was clear from the response that it was publicly obtained.

PRIVATE—Comprehensive private coverage was reported either directly (C7Q03 or C7Q10_08) or by naming a program or program type (e.g., PPOs) that can only be privately obtained (C7Q08 or C7Q10C). This category also includes insurance provided by an employer or union as indicated by the verbatim response to C7Q08 (e.g., "Teamster's insurance") or by C7Q08B. To be included in this category, the reported insurance was required to cover both doctor visits and hospital stays (C7Q03A or C7Q08A or C7Q10A or C7Q10B).

SCHIP—SCHIP coverage was reported either directly (C7O02 or C7Q10_04) or by State SCHIP program name (C7Q08 or C7Q10C). In eight States, C7Q02 asked about the State's Medicaid expansion program. These States are Alaska, Arkansas, District of Columbia, Idaho, Louisiana, Nebraska, New Mexico, and Wisconsin (see CHIPNAME). In these States, affirmative responses to this variable include insurance obtained through the Medicaid expansion program. If States did not offer SCHIP insurance or if the State's SCHIP program shares the same name as the Medicaid program, the SCHIP indicator was set to a missing value.

SINGLINS—The insurance reported, either directly (C7Q10_09) or

indirectly (C7Q08 or C7Q10C), could be classified as covering only a single type or single place of service. Examples of insurance covering single types of service include dental, vision, and accident coverage. An example of insurance that covers a single place of service is foreign government insurance (e.g., the Mexican Social Security System). This category also includes special discount programs offered by some service providers (e.g., Healthy Options Card) and special funding sources (or "pools" of money) that permit certain providers to recoup some of their medical costs (e.g., Amish Aid Society, Colorado Indigent Care Program).

TITLEV—Title V coverage was reported either directly (C7Q06 or C7Q10_03) or by Title V program name (C7Q08 or C7Q10C).

UNKINS—The respondent reported coverage in C7Q08 or C7Q10C that could not clearly be classified as comprehensive. Examples include school, family, and supplemental coverage. This category also includes cases where the respondent reported an unknown acronym (e.g., PPL, PTO).

UNINS—This variable indicates that the child was uninsured at the time of the survey. A positive value for this variable indicates that the respondent did not report any insurance coverage; reported coverage, but indicated that it was not comprehensive; or reported only native insurance or single type/place insurance.

UNINS_YR—This variable indicates that the child was uninsured at the time of the survey or at some time during the 12 months prior to the survey.

MS_UNINS—This variable, which indicates the number of months without coverage during the 12 months prior to the survey, was derived from C7Q11, C7Q12, C7Q13, and C7Q14. This variable was not ascertained if the respondent reported an insurance type that was not considered comprehensive insurance (e.g., by reporting Indian Health Service coverage at C7Q10_07, a single service plan at C7Q10_09, noncomprehensive private insurance at C7Q10A, or a plan type at C7Q08 or C7Q10C that could not be classified as comprehensive). If a child was less than 12 months of age and was uninsured for his/her entire lifetime, MS_UNINS was set to 12 months.

YS_UNINS—This variable, which indicated the number of years since an uninsured child was last insured, was derived from C7Q13. This variable was not ascertained if MS_UNINS was not ascertained, and this variable is missing for children who are currently insured and for children who have been uninsured for less than 12 months. There is one exception. If a child was less than 12 months of age and was uninsured for his/her entire lifetime, YS_UNINS was set to "never insured."

MOTHER_EDUCR—The highest level of education attained by the mother of the sampled child was derived from C2Q04, CW10Q04, and CW10Q04A.

RELATION—Information collected in question C2Q04 regarding the relationship of the respondent to the sampled child has been collapsed into three categories.

Dummy Variables

When respondents were permitted to provide multiple answers for the same question, a variable was created for each possible answer. The values for these new dummy variables are "yes, this answer was given," and "no, this answer was not given." When respondents could not or did not provide an answer to the question, a value of "don't know" or "refused" is reported for each of the dummy variables.

- C4Q5_1B is represented by C4Q5_1B1 to C4Q5_1B16.
- C4Q5_2B is represented by C4Q5_2B1 to C4Q5_2B16.
- C4Q5_3B is represented by C4Q5_3B1 to C4Q5_3B16.
- C4Q5_4B is represented by C4Q5_4B1 to C4Q5_4B16.
- C4Q5_5B is represented by C4Q5_5B1 to C4Q5_5B16.
- $C4Q5_{6B}$ is represented by $C4Q5_{6B1}$ to $C4Q5_{6B16}$.
- C4Q5_7B is represented by C4Q5_7B1R to C4Q5_7B6R and C4Q5_7B7 to C4Q5_7B16.
- C4Q6_1B is represented by C4Q6_1B1 to C4Q6_1B16.
- C4Q6_2B is represented by

C4Q6_2B1 to C4Q6_2B16.

- C4Q6_3B is represented by C4Q6_3B1 to C4Q6_3B16.
- C7Q15 is represented by C7Q15R01 to C7Q15R10.
- C12Q1A is represented by C12Q1A01 to C12Q1A25.
- C12Q6B is represented by C12Q6B01 to C12Q6B12.
- C13Q61B is represented by C13Q61B1R to C13Q61B1R6R.
- C13Q62B is represented by C13Q62B1R to C13Q62B1R6R.
- C13Q63B is represented by C13Q63B1R to C13Q63B1R.
- C13Q64B is represented by C13Q64B1R to C13Q64B1R6R.
- C13Q65B1R to C13Q65B12R.
- C13Q66B is represented by C13Q66B1R to C13Q66B16R.
- C13Q67B is represented by C13Q67B1R to C13Q67B1R6R.

Additional Data Notes

If a respondent refused to provide income or gave a "don't know" response to the income questions, the CATI system assumed that the respondent's household was below 200% of poverty and should ask the question about cash assistance (C11Q11) for these households. A programming error in the system resulted in missing data on this question for 183 cases with missing income.

The question about the mother's residence (C2Q04_A) was not added to the CATI instrument until late in 2000. For interviews completed before the question was added, this variable was coded to indicate that the mother lived with the child if the respondent was identified as the sampled child's mother. Otherwise, the special code for added questions (.A) was used to define cases where data are missing because the interview was completed before the question was added.

Several questions in the specialneeds interview were applicable only for children of certain ages. The CATI system was programmed to ask only the age-appropriate questions. However, for unknown reasons, a small number of children received questions that were not appropriate for their ages. Adjustments during data cleaning corrected for these errors:

- C3Q12R was created from C3Q12;
- C3Q13R from C3Q13;
- C4Q05_07R from C4Q05_07;
- C4Q5_7AR from C4Q5_7A;
- C4Q5_7B1R from C4Q5_7B1;
- C4Q5_7B2R from C4Q5_7B2;
- C4Q5_7B3R from C4Q5_7B3;
- C4Q5_7B4R from C4Q5_7B4;
- C4Q5_7B5R from C4Q5_7B5;
- C4Q5_7B6R from C4Q5_7B6;
- C4Q05_11R from C4Q05_11;
- C4Q5_11AR from C4Q5_11A;
- C4Q05_12R from C4Q05_12;
- C4Q05_12AR from C4Q05_12A;
- C6Q0AR from C6Q0A;
- C6Q0A_AR from C6Q0A_A;
- C6Q0A_BR from C6Q0A_B; and
- C6Q0BR from C6Q0B.

In addition, a programming error resulted in the omission of the question on early intervention services (C3Q12) for CSHCN who were 2 years of age (24–35 months) at the time of the interview.

Estimation and Hypothesis Testing

he National Survey of CSHCN data were obtained through a complex sample design involving clustering of children within households and stratification of households within States. To produce estimates that are representative of children nationally and within each State, sampling weights must be used. These sampling weights were developed to account for complex sample design and to include adjustments for multiple-telephone households, unit nonresponse, and noncoverage of nontelephone households. The sampling weight also included adjustments to known population control estimates.

As described earlier, three sampling weights have been developed for the National Survey of CSHCN. These weights should be used for both national and State-level analyses.

Household weight (WEIGHT_H)— This weight is on the Household File and is used for producing estimates that are representative of households with children nationally and within each State. A household weight has been associated with every age-eligible household screened. This weight should be used only when the unit of analysis is the household.

Screener weight (WEIGHT_S)— This weight is on the Screener File and is used for producing estimates that are representative of children nationally and within each State. A screener weight has been associated with every child screened, regardless of whether a detailed special-needs interview or a brief health insurance control sample interview has been completed. This 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.

Screener weight (WEIGHT S)— This weight is on the CSHCN Interview File and the Insurance Analysis File. When used with the CSHCN Interview File, this weight produces estimates that are representative of CSHCN nationally and within each State. When used with the Insurance Analysis File, this weight produces estimates that are representative of children nationally and within each State. An interview weight has been associated with every child interviewed. This weight should be used only when the unit of analysis is the child and the data analyzed include variables that are on the CSHCN Interview File or the Insurance Analysis File.

Variables Used for Variance Estimation

Because of the complex design of the National Survey of CSHCN, the household records and the child-level screener and interview records have unequal weights. Therefore, statistical software programs that assume simple random sampling will most often compute standard errors that are too low. Tests of statistical hypotheses may then suggest statistically significant differences or associations that are misleading. However, computer programs are available that provide the capability of variance estimation for complex sample designs (e.g., SUDAAN, Stata, WesVar). To provide the user with the capability of estimating the complex sample variances for the National Survey of CSHCN data, stratum identifiers and primary sampling unit (PSU) codes have been provided on the data files. These variables and the sample weights are necessary to calculate variances.

It should be noted that the stratum identifiers reported on the data set are not identical to the strata used for drawing the sample. In States with multiple Immunization Action Plan (IAP) areas, independent samples were selected from each IAP area in proportion to the total number of households with children in each IAP area. Therefore, these IAP areas should be considered strata for variance estimation. However, disclosure of the specific IAP area for each child (even if the code were scrambled) could increase the risk of disclosure of a respondent's identity. For example, the IAP area with the lowest frequency of responses in New Jersey would be readily identifiable as Newark. In the absence of IAP-specific identifiers, data users should use the State identifier (STATE) as the stratum identifier. By using the State identifier rather than the suppressed IAP identifier, the standard errors for national and State estimates with key variables are affected only slightly and not in a consistent direction. The PSU for the National Survey of CSHCN is the household and is represented on the data sets by the unique household identifier, IDNUMR.

The overall number of persons in this survey is sufficient for most statistical inference purposes. However, analyses of some rare responses and analyses of subclasses can lead to estimators that are unreliable. Small sample sizes used in the variance calculations may also produce unstable estimates of the variances. Consequently, these analyses require that the user pay particular attention to the coefficient of variation for the estimates of means, proportions, and totals.

Variance Estimation Using SUDAAN

Standard errors for the National Survey of CSHCN can be obtained using the Taylor-series-approximation method that is available in software such as SUDAAN, SAS, and Stata. As noted previously, the State should be identified as the stratum variable and the household should be identified as the primary sampling unit.

The simplifying assumption that PSUs have been sampled with replacement allows most complex survey sample design computer programs to calculate Taylor-series standard errors in a straightforward way. This method requires no recoding of design variables, but is statistically less efficient (and therefore more conservative) than some other methods because the PSU unit is treated as being sampled with replacement within the stratum unit. For SUDAAN, the data file needs to be sorted by stratum (STATE) and PSU (IDNUMR) prior to invoking SUDAAN. The following SUDAAN design statements are used for analyses at the household level:

PROC . . . DESIGN = WR; NEST STATE IDNUMR; WEIGHT WEIGHT_H;

For analyses of the Screener File data at the child level, replace "WEIGHT_H" with "WEIGHT_S." For analyses of the CSHCN Interview File or Insurance Analysis File data, replace "WEIGHT_H" with "WEIGHT I."

It should be noted that other variance estimation procedures are also applicable to the National Survey of CSHCN. Specifically, the jackknife method with replicate weights and the bootstrap resampling method with replicate weights can also be used (via software such as WesVar) to obtain standard errors that fully reflect the impact of the weighting adjustments on standard errors.

Variance Estimation for Subsets of Data

Most analyses of the National Survey of CSHCN data will focus on specific population subgroups, such as CSHCN in only one State or CSHCN living in poverty. Some analysts will, therefore, be tempted to delete all records outside of the domain of interest to work with smaller data files and to run computer jobs more quickly. This procedure of keeping only select records and list-wise deleting other records is called subsetting the data. Subsetted data that are appropriately weighted can be used to generate correct point estimates (e.g., estimates of population subgroup frequencies or means), but most software packages that analyze complex survey data will incorrectly compute standard errors for subsetted data. When complex survey data are subsetted, the sample design structure is often compromised because the complete design information is not available. Subsetting the data can delete important design information needed for variance estimation (e.g., deleting all records for certain subgroups may result in entire PSUs being removed from the design structure).

The National Survey of Children with Special Health Care Needs was designed to provide independent data sets for each of the 50 States and the District of Columbia. Subsetting the survey data to a particular State does not compromise the design structure of the survey. That is, standard errors calculated in SUDAAN for a particular State will not be affected if the data set has been subsetted to that particular State.

However, subsetting to specific population subgroups (within or across States) can result in incorrect standard errors. For example, subsetting the data to those CSHCN who live in poverty within a specific State will result in incorrectly calculated standard errors. Typically, the standard errors for subsetted data will be inflated, resulting in a higher probability of type-II error (i.e., failing to detect significant differences that do, in fact, exist). SUDAAN has a SUBPOPN option that allows for targeting of specific subpopulations for analysis while retaining the full unsubsetted data set that includes the full sample design information. Analysts interested in specific population subgroups are

encouraged to use SUBPOPN rather than subsetting the data sets.

Weighted Frequencies, Prevalence Estimates, and Standard Errors

Weighted frequencies of the number of households having a child with special health care needs and the number of CSHCN by State appear in appendix IX. Prevalence estimates and standard errors are also provided. Analysts may wish to replicate this table to determine if they are using the weights correctly.

Guidelines for Data Use

which is the goal of mutual benefit, NCHS requests that recipients of data files cooperate in certain actions related to their use.

Any published material derived from the data should acknowledge NCHS as the original source. The suggested citation, "Data Source: Centers for Disease Control and Prevention. National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001," should appear at the bottom of all tables. It should also include a disclaimer that credits any analyses, interpretations, or conclusions reached to the author (recipient of the file) and not to NCHS, which is responsible only for the initial data. Consumers who wish to publish a technical description of the data should make a reasonable effort to ensure that the description is not inconsistent with that published by NCHS.

The Public Health Service Act (Section 308d) provides that data collected by NCHS may be used only for health statistical reporting and analysis. Any effort to determine the identity of any reported case is prohibited by this law. 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, are 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.
- 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.

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Appendix I

Sampling and Sampling Weights Technical Summary

Sample Design

The basic design objective of the National Survey of CSHCN was to select a sample of 750 children with special health care needs under 18 years of age in each State and the District of Columbia. This sample was selected over a period of 18 months by first identifying households with children under the age of 18 and then screening within these households for the presence of CSHCN. In all households where CSHCN were present, one such child was selected. In all households where children without special health care needs were present, one such child was also selected. Therefore, the number of children without special health care needs that was selected in a State depended upon the number of households with children that needed to be screened to reach a sample of 750 CSHCN. In households in which both types of children were present, two children (one of each type) were selected. If the sampled children, with or without special health care needs, were uninsured and the household income was below 200% of poverty as determined by the DHHS Federal Poverty Guidelines, the sampled children were also eligible to receive the Low-Income Uninsured Supplement.

Drawing NIS Sample

The sample of households selected for screening for the National Survey of CSHCN was a subsample of the households screened for the National Immunization Survey (NIS), a continuous list-assisted random-digit-dial (RDD) survey administered in each of 50 State and 28 metropolitan Immunization Action Plan (IAP) areas. Therefore, the sampling design for the selection of households in the National Survey of CSHCN was essentially the same as the design for the selection of households in the NIS. A brief description of the procedure for the selection of households in the NIS is given below. For more detail on the NIS sample design, readers are encouraged to obtain chapter 3 of the *1999 National Immunization Survey Sample Design Report*, which is available from NCHS. Further information regarding the NIS itself can be found in Zell et al.'s *National Immunization Survey: The Methodology of a Vaccination Surveillance System* (2000) (11).

Associating Telephone Numbers with IAP Areas

To draw a sample of telephone numbers in an IAP area, one must compile a list of all telephone numbers that belong to that area. For some IAP areas, this step is straightforward. For example, when the IAP area is a State with a single area code, the list would consist of all telephone numbers within the central-office codes that are in service in that area code. (Combined, an area code and a central-office code form a "prefix area." For example, when a telephone number is 617-555-1234, 617-555 is the prefix area corresponding to the 555 central office in the 617 area code.)

For other IAP areas, this step encounters a number of complications. When the IAP area is a city, county, or combination of counties, some prefix areas may cover part of the IAP area and part of an adjacent IAP area. In such situations, the NIS applies a plurality rule: If at least 50% of the directory-listed households in a prefix area fall inside an IAP area, the prefix area is assigned to that IAP area.

Drawing Initial NIS Sample

The sample frame for an IAP area consists of banks of 100 consecutive telephone numbers within the prefix areas assigned to the IAP area. For example, the numbers from 617-555-7100 to 617-555-7199 constitute a working bank in the 617-555 prefix area. Banks that contain zero directory-listed residential telephone numbers are excluded from the frame because they have very little chance of containing working residential numbers. For this preliminary step, the GENESYS Sampling System (a proprietary product of Marketing Systems Group) uses a file of directory-listed residential numbers from Donnelley Marketing Information Services (DMIS). The result is a file that lists the remaining banks (the "1+ working banks"). From the 1+ working banks, a random sample of complete 10-digit telephone numbers is drawn for each quarter in such a way that each number has a known and equal probability of being selected. Within each IAP area, the sample is then segmented into replicates, or representative subsamples, with each replicate containing sample telephone numbers from each of the 78 IAP areas. Segmenting the sample into replicates allows the release of telephone numbers over time in a controlled manner.

Updating NIS Sampling Frame

The set of telephone banks with at least one directory-listed residential telephone number changes over time. As a result, the sampling frame of 1+ working banks also needs to be updated. The recent phenomenon of frequent area-code splits has produced additional changes to the sampling frame. The GENESYS database reflects those changes in a quarterly update. Marketing Systems Group (MSG) has developed a separate sampling frame for each IAP area. Quarterly, the database is examined to determine whether currently included banks should be assigned to different IAP areas and to assign newly included banks to IAP areas. The rules for assignment are the same as in the initial definitions of the IAP areas. When all modifications have been made to the GENESYS database, a number of checks ensure that all changes have been applied correctly and that the new database produces samples that are consistent with those produced prior to the changes. These checks compare the number of active banks and RDD-selectable lines in each IAP area before and after the update. At the same time, the actual exchanges assigned to each IAP area before and after the update are compared. Small changes are expected—new banks are put into service as new numbers are assigned. If a major discrepancy occurs in any of these checks, MSG is notified of the

difference and asked to provide documentation of the reasons for the change.

Forming NIS Sample Replicates

The total size of the initial sample for an IAP area is calculated according to the formula:

Total Sample Size = (1.5)T/(AC), where:

- T is the quarterly target number of completed interviews for the IAP area (this target number of completes ranges from 101 to 129);
- A is the proportion of telephone numbers that remain after identifiable business and nonworking numbers have been removed (as discussed below); and
- C is the proportion of telephone numbers sent to the interviewers in the telephone center that result in a completed interview.

In the formula, A and C are specific to the IAP area. They are adjusted each quarter, taking into account the results from previous quarters. The target, T, may also reflect the results in the previous quarters; for example, if the three previous quarters have not produced their target total of completes, T is raised accordingly. The factor 1.5 allows for variation in actual performance among IAP areas and among quarters.

The total sample selected is then randomly divided into 26 replicates; the first 24 are equal in size, and the last 2 are one-half that size. This procedure permits smoother release of the sample (at the rate of one or two replicates per week) for each IAP area separately, as needed. Toward the end of the quarter, the half-size replicates allow tighter control over the total amount of sample released. The aim is to produce an even distribution of work in the telephone center over the course of a quarter and to give all cases an equal probability of being completed.

Removing Business and Nonworking Numbers

In a traditional RDD survey, all sampled telephone numbers are given to interviewers for dialing. Because over one-half of all selected telephone numbers are businesses or are unassigned, a large part of the interviewers' efforts may be to identify and remove these numbers from the active sample. MSG has produced companion products to their GENESYS Sampling System that can quickly and accurately reduce the size of this task.

First, the selected sample is matched against a GENESYS data file that contains telephone numbers that are directory listed in a business (yellow pages) and not in a residential (white pages) section. Any business numbers so identified are removed from the sample.

Second, numbers listed in residential white pages are identified and temporarily set aside.

Third, a hardware system, GENESYS-ID Plus, screens the remaining sample to remove a portion of the nonworking numbers. (The GENESYS-ID Plus system was used for Pretest II and the main survey. GENESYS-ID, the precursor to GENESYS-ID Plus, was used for Pretest I.) Using personal computers with special hardware and software, this system (the "autodialer") automatically dials the telephone numbers to detect nonworking numbers. This is indicated by the familiar tri-tone signal for out-of-service numbers, by an extended period of silence, or by continuous noise on the line. If the telephone number being dialed starts to ring, GENESYS-ID Plus hangs up immediately. (Fewer than 6% of the numbers dialed actually ring at the receiving end.) To further reduce the chance of annoyance if a residential number rings, the residential pages directory-listed numbers identified in step two are not dialed, and the **GENESYS-ID** Plus equipment is operated only during daytime hours on weekdays.

Finally, the residential white pages directory-listed numbers are combined with those that were not removed by the autodialers to produce the sample for the telephone centers. Together these steps cull out approximately 35% of the sampled lines in the NIS sample.

Obtaining Addresses for Advance Letters

To obtain addresses that correspond to telephone numbers in the sample, the

numbers for each replicate are sent to a company that provides this matching service. This computerized name-andaddress-locating service uses a database of over 160 million residential and business telephone numbers, including unpublished telephone numbers. In some instances, by customer preference, a listing may not contain a street address. The resulting file contains both numbers with and without listing matches. Matched listings contain a business or residential identifier.

"Do Not Call" Requests

The NIS maintains a file containing telephone numbers of people who have requested that they not be called. Each quarter's sample is compared with this file, and numbers in the "Do Not Call" list are not included in the quarterly sample of numbers loaded into the CATI system.

Duplicate Telephone Numbers

Because of the repeated quarterly selection of the sample in each IAP area, it is possible that some telephone numbers will be selected for the NIS more than once. To avoid respondent problems created by recontacts for the same survey, a further step of processing unduplicates the sample numbers selected for the NIS. Each complete replicate sample file is compared with all sample files released during the previous quarters. Detailed records are kept of all area code splits to ensure accurate unduplication.

Similarly, because of the repeated quarterly selection of the NIS sample in each IAP area, some telephone numbers were selected more than once over the course of the National Survey of CSHCN data collection period. Such numbers were not contacted a second time for the National Survey of CSHCN. Instead, these cases were automatically finalized. Response rates reflect the final disposition of a telephone line from its original sampling.

National Survey of CSHCN Sample Design and Allocation

The number of CSHCN required to be selected in each IAP area was determined by allocating the total of 750 children in the State to each IAP area within the State in proportion to the total number of households with CSHCN in the IAP area. Based on this allocation, the number of households that needed to be screened in each IAP area was calculated using the expected proportion of households with children in the eligible age range and having special health care needs in the IAP area. Original State-level estimates of the proportion of households with age-eligible children were obtained from the Current Population Survey (CPS) and applied to all IAP areas within a State. These initial estimates were replaced with actual IAP area-specific age-eligibility rates experienced in early National Survey of CSHCN replicates. These rates were continually updated throughout the data collection period. The original estimate of the proportion of households with CSHCN was based on the 1994 National Health Interview Survey-Disability Supplement-and was applied to all IAP areas. As with the age-eligibility estimates, this initial estimate was replaced with actual IAP area-specific special-needs eligibility rates experienced in early National Survey of CSHCN replicates. These rates were also updated throughout the data collection period.

The number of telephone numbers that needed to be called was then computed, using the expected working residential telephone number rate. The number of telephone numbers drawn was increased to compensate for a degree of nonresponse, given the assumption that not all respondents would agree to participate.

A random subsample of the required number of telephone numbers for the National Survey of CSHCN in each IAP area was selected from the NIS sample. These numbers were called in an attempt to identify households and to establish study eligibility in those households. Any household with at least one child under 18 years of age was considered eligible. One child with special health care needs and/or one child without special health care needs were then selected at random from each household that had such children. As indicated earlier, if a household contained both children with special health care needs and children without special health care needs, then one child was selected at random from each group. That is, in some households, two children were sampled. The selection of the sample was spread over six quarters of NIS data collection. The split of the total sample across quarters varied across IAP areas.

Sampling Weights

To produce population-based estimates, each respondent household and child for whom complete data were available was assigned a sampling weight. These sampling weights compensate for varying probabilities of selection of households and children because of stratification by IAP area and clustering of children within households. Also, the weights are needed to account for nonresponding households and for noncoverage of households without telephones (i.e., only households with telephones were included in the sampling frame).

The sampling weight combines (a) the IAP area base weight, which reflects the probability of selecting the household telephone number, (b) an adjustment for households with multiple telephone numbers, and (c) adjustments for unit nonresponse at various phases of identification and data collection. The method of determining the overall weight for each respondent household and child in the survey is described below.

Three weights were determined. The first weight is the household weight, which is used for the estimation of population values relating to household characteristics and the analysis of household variables. The second weight is the child screener weight, which is attached to all of the children in a selected household. The third weight is the child interview weight, which is attached to selected children in each household for whom complete data are available.

Household Weight

Base Sampling Weight

As mentioned, a sample of telephone numbers was selected in each IAP area, spread over six quarters of NIS data collection. In the NIS, an independent sample of telephone numbers is selected each quarter. A telephone number could have been selected for the National Survey of CSHCN in any of the 6 quarters of the data collection period. Once a telephone number was selected, it was not selected again for data collection in subsequent quarters. To compute the base sampling weight, the overall probability of selection considering the probabilities of selection in the different quarters was determined.

Let the number of quarters over which the total sample is selected be q(i.e., 6, because the sample was selected over 6 quarters). Let p denote the overall probability of selection of the telephone number of the household.

Therefore,
$$p = \sum_{i=1}^{\gamma} p_i$$
 where p_i is the

probability of selecting the telephone number in the *i*th quarter. Thus

$$p_{i} = \prod_{j=1}^{i} (1 - p_{j-1}) \frac{n_{i}}{N_{i}}$$

Taking $p_0 = 0$, results in $p_1 = n_1 / N_1$ for the first quarter,

$$p_2 = (1 - p_1) \frac{n_2}{N_2}$$

for the second quarter,

$$p_3 = (1 - p_1) (1 - p_2) \frac{n_3}{N_3}$$

for the third quarter, and so forth for each of the remaining quarters.

The base sampling weight for a household in a particular IAP area is given by w = 1 / p. Generally, this weight is the same for all households within an IAP area.

Because the selection of telephone numbers uses simple random sampling,

the probability of selection in each IAP area in each quarter is simply the number of telephone numbers selected divided by the total number of telephone numbers available for selection.

Households with Multiple Telephone Lines

The base sampling weight of eligible households that have multiple voice-use telephone lines was adjusted to compensate for the higher probability of selection of these households. The adjustment divides the base sampling weight by the number of telephone lines in that household. Let t_k denote the number of telephone lines in the kth household in an IAP area. The adjusted base sampling weight for that household is given by $w_k = w / t_k$. If the household had only one telephone line, then the adjusted weight is the same as the base sampling weight.

Unit Nonresponse Adjustment 1 (Residential Status Unknown)

When a selected telephone number is called, three results are possible: (a) the number called is a household, (b) the number called is not a working residential number (it could be a business number or nonworking number), or (c) there is nonresponse to the screening attempt, and, therefore, the status of the telephone number is unknown. In the National Survey of CSHCN, several call attempts were made before a number was assigned as unknown status. The method of adjusting the base sampling weight to account for possible residential numbers in the third category is the same as the method used in the National Immunization Survey. This method is described in detail in the 1994 National Immunization Survey Methodology Report (10). In the NIS, information external to the survey is used to reallocate these unknown numbers to either residential or nonresidential numbers.

When *n* telephone numbers are called in an IAP area, let the number of telephone numbers in each of the three categories mentioned above be n_1 , n_2 , and n_3 , respectively. The first nonresponse adjustment factor is $A_1 = n_1 + \hat{n}_{31} / n_1$ where \hat{n}_{31} is the

estimated number of households among n_3 , the "status unknown" category. The procedure for estimating the number of households in the unknown category is based on a study conducted in 1994 in which telephone company business offices were asked to report on the status of a sample of category 3 telephone numbers (20). The results of the study showed that the proportion of residential numbers varies according to the region, whether the telephone number was directory listed, and the type of noncontact (e.g., ring-no-answer versus answering machine). Therefore, the nonresponse adjustment factor within each IAP area was calculated for a set of numbers defined by region, disposition code, and whether the number was directory listed. To keep the notation simple, the adjustment factor is denoted by A_1 , although it could be different for different households within each IAP area. The nonresponseadjusted base sampling weight after nonresponse adjustment 1 for the kth household in an IAP area is given by $A_1 w_k$. The adjusted weight is for all known households.

Unit Nonresponse Adjustment 2 (Households of Unknown Age Eligibility)

A second form of nonresponse may occur because a household does not complete the screener questions relating to the age-eligibility of the household for the survey. Therefore, for these telephone numbers identified as belonging to a household, there is no determination of eligibility. A description of the adjustment for this form of nonresponse follows.

Let the number of households screened to be eligible out of the n_1 households contacted be q_1 . Let the number of households screened to be ineligible be q_2 . Let q_3 denote the number of households that are nonrespondents to the eligibility question. The result is $n_1 = q_1 + q_2 + q_3$. The nonresponse adjustment to the sampling weight to account for not being able to determine the eligibility of q_3 households is given by

$$A_{2} = \frac{\sum_{k=1}^{n_{1}} A_{1}w_{k}}{\sum_{k=1}^{q_{1}+q_{2}} A_{1}w_{k}}$$

The nonresponse-adjusted base sampling weight after nonresponse adjustment 2 is given by $A_2A_1w_k$. The adjusted weight is determined for all eligible households.

Unit Nonresponse Adjustment 3 (Nonresponse by Age-Eligible Households)

An age-eligible household was considered a nonrespondent if data regarding the special needs status of children in the household were not obtained. The weights of other responding households were increased to account for this nonresponse. These adjustments were made within an IAP area.

Let the number of households in which a screener was not completed be q_{r1} out of the total of q_1 households. The nonresponse adjustment factor is

$$A_{3} = \frac{\sum_{k=1}^{q_{1}} A_{1}A_{2}w_{k}}{\sum_{k=1}^{q_{r1}} A_{1}A_{2}w_{k}}$$

The final nonresponse-adjusted base sampling weight is the product of the adjustments and weights described thus far. The adjusted weight is $w_{ak} = A_1 A_2 A_3 w_k$. This adjusted household weight is determined for all eligible households in which a screening interview was completed.

Poststratification Weight Adjustment Including Adjustment for Noncoverage of Nontelephone Households

Poststratification separates the actual sample into cells, or strata, defined by characteristics related to response propensities and to characteristics of interest in the survey. Then the weighted distribution of completed interviews over the cells is brought into agreement with a corresponding set of population totals by adjusting the weight using a ratio estimator. This weighting adjustment is intended to compensate for noncoverage and for differential unit nonresponse. Poststratification adjustment of the weights may also reduce the variance of the estimates if there is homogeneity within poststrata with respect to the characteristics of interest.

The poststratification variables used for dividing the National Survey of CSHCN sample into poststratification cells for adjustment of the household weights were the following:

- 1. Number of children under 18 years of age;
- 2. Race and ethnicity of the children;
- 3. Mother's education;
- 4. Income; and
- 5. Telephone service status.

The number of children under the age of 18 was chosen as a poststratification variable because it was conjectured that the number of children within a household might have an impact on response propensities. For example, parents with more children may have less time available for the survey. In addition, parents with more children may have fewer resources available to care for each child, and parents with fewer resources may be less likely to provide preventive health care for their children (21, 22).

Race and ethnicity were included in the poststratification adjustment because it is well documented that Hispanic children, non-Hispanic black children, and other minority children suffer greater health disparities and face more barriers to health care than white children (23, 24). Research also suggests that response propensity may differ for certain race and ethnic groups (25, 26).

Mother's education was included in the poststratification adjustment because RDD studies tend to disproportionately represent higher-educated groups (27). Based on unweighted proportions, the National Survey of CSHCN suffered similarly. Because it was suspected that mother's education may also be related to child health, a decision was made to poststratify on this dimension.

Income was chosen as a poststratification variable because it is

related to health care outcomes and to health insurance coverage rates. Also, research indicates that survey response is related to household income; low-income groups are often underrepresented in telephone surveys because of difficulties contacting low-income households by telephone (28).

Finally, because RDD studies are unable to capture households that lack telephone service at the time of interview, poststratification included an indicator of any interruption in telephone service. Prior research indicates that adjusting the weights of households that report an interruption in telephone service within the past year can reduce the bias associated with this type of noncoverage (17–19).

The sample of interviewed households was divided into cells representing more detailed categories of each variable listed above. Poststratification adjustments were not done in each cell formed by the cross-classification of the different categories of the stratification variables because control totals for each cell were not available. Only the marginal population control totals were determined. Therefore, for adjusting the weights, raking (29) was used. Raking is a poststratification method that can be used when only marginal control totals are known.

Missing values for variables required for poststratification of households in the sample were imputed either by Weighted Sequential Hotdeck or through the use of models. Details regarding the imputation appear in table I.

The number of households in each State in 2001 was estimated by taking 2000 decennial census totals and projecting these totals to July 2001 using data from the 1990 and 2000 census. The distribution of households by the number of children under 18 years was obtained by averaging the estimates from the 1999, 2000, and 2001 CPS. This distribution was then applied to the previously established control total for each State, providing the control totals for each householdsize category. Similarly the distributions of households by race/ethnicity, income, and mother's education were determined in the same manner from the CPS and then applied to the total number of households.

Establishing control totals required to adjust the weights for noncoverage of nontelephone households was done as follows. First, the CPS estimate of the percent of nontelephone households in the State was obtained. This proportion was applied to the known number of households to establish the number of households with and without telephones in the State. Using National Survey of CSHCN data, the weighted percent of telephone households with a service interruption within the past year was determined. This percent was then applied to the known number of telephone households (from the CPS) to give the number of households in the State with an interruption in service. The number of telephone households without interruptions in telephone service formed one control total. The number of households without telephones plus the number of telephone households with interruptions in service formed the other control total. The weights of interviewed households in the sample without interruptions in service were raked so that the sum of the weights equaled the known number of telephone households without interruptions in telephone service. Similarly, the weights of telephone households with interruptions in telephone service were raked in the sample so that the sum of the weights agreed with the sum of the number of nontelephone households and the number of telephone households with interruptions in telephone service. As indicated earlier, these weight adjustments were done through raking so that the aggregated weights agreed with the totals in other margins.

The poststratified weight is the final household weight used for the estimation and analysis of householdlevel variables. This weight for the *k*th household in an IAP area will be denoted by w_{fk} where *f* represents the final weight. Final household weights appear in the National Survey of CSHCN Household Data File, denoted by WEIGHT_H. Household weighting detail by State appears in table II.

Table I. Variables with imputed values

Variable	Number of missing values	Imputation method
 Age	278	Weighted sequential hotdeck
Gender	630	Weighted sequential hotdeck
Race	3,059	Stage 1: Majority rule within household
		Stage 2: Weighted sequential hotdeck
Hispanic origin	1,624	Stage 1: Majority rule within household
		Stage 2: Weighted sequential hotdeck
Number of telephone lines	2,613	Unweighted sequential hotdeck
Interrupted telephone service	3,241	Majority rule within dataset
Mother's residency	6,941	Stage 1: Data copied from other sampled child within household, if applicable
		Stage 2: Weighted sequential hotdeck
Mother's education	7,894	Stage 1: Data copied from other sampled child within household, if applicable
		Stage 2: Weighted squential hotdeck
Household income	23,323	Combination of weighted sequential hotdeck and regression modeling

NOTE: Number missing for age, gender, race, and Hispanic origin are from a total of 373,055 screened children. Number missing for number of telephone lines, interrupted telephone service, and household income are from a total of 196,888 screened households. Number missing for mother's residency is from a total of 215,163 interviewed children. Number missing for mother's education is from a total of 205,388 interviewed children with a resident mother or where residency was also missing.

Child Screener Weight

To determine the child screener weight, the final household weight w_{fk} was initially used. This weight was attached to all of the children in a selected household, including children with special health care needs.

The next step was to adjust these weights so that the sum of the weights over all children screened agreed with known marginal control totals for the following variables, which were drawn from the 2000 census or the CPS as described previously:

- 1. Number of children under 18 years of age in the household (census)
- 2. Sex of the child (census)
- 3. Age of the child (census)
- 4. Race and ethnicity of the child (census)
- 5. Mother's education (CPS)
- 6. Household income (CPS)
- 7. Telephone service status (CPS)

The poststratification weight adjustment was again done through raking, using the control totals. The final raked child screener weight is denoted by w_{fkj} . This is the weight for the *j*th child in the *k*th household. This weight is used for producing child-level estimates using data collected at the time of screening for special health care needs. For example, this weight is used to estimate the number of children in the population with special health care needs and without special health care needs based on the screener sample. Final child-level screener weights appear in the National Survey of CSHCN Screener Data File, denoted by WEIGHT_S. Child screener weighting detail by State appears in table III.

Child Interview Weight

Let the number of children with special health care needs in the *k*th household in an IAP area be N_{ks} and the number of children in the same household without special health care needs be N_{ks} . The total number of children in the household is $N_k = N_{ks} + N_{ks}$. Not all households contain both types of children.

One child of each type was selected from every household with such children. That is, in households in which only CSHCN were present, one child with special health care needs was selected at random. This was also the case for households having only children without special health care needs. In households where both types of children were present, two children (one from each group) were selected. The sampling weight for a selected child with special health care needs is $w_k^{cs} = w_{fk} N_{ks}$. That is, the final household weight is multiplied by the number of CSHCN in a household. Similarly, the weight for a selected child without special health care needs is given by $w_k^{c\bar{s}} = w_{fk} N_{k\bar{s}}$.

Child-Level Interview Nonresponse Adjustment

Data were not obtained for all children selected for interview. Therefore, the weights were adjusted using those children for whom data were available to account for those children for whom no data were collected. The nonresponse adjustment factor A_4 within an IAP area was computed as follows.

Let the number of households containing children with special health care needs out of the q_{r1} responding households be q_{r1l} and the number of households without special health care needs children be q_{r1o} . Note that $q_{r1l} + q_{r1o} \neq q_{r1}$ because households may contain both types of children.

Let the number of households in which special-needs interviews are completed among the q_{r1l} households be q_{r1l}^* . Similarly, let the number of households in which interviews are completed regarding children without special needs be q_{r1o}^* . The nonresponse adjustment factor for the interview nonresponse by children with special health care needs is given by

$$A_{4}^{s} = \frac{\sum_{k=1}^{q_{rls}} w_{fk} N_{ks}}{\sum_{k=1}^{q_{rls}^{*}} w_{fk} N_{ks}}$$

The numerator gives the estimated number of CSHCN based on all the

Table II: Summary statistics for household weights by State

Location	Unweighted sample size	Minimum weight	Maximum weight	Mean weight	Median weight	Sum of weights
	3,843	21.6	826.6	164.8	135.9	633,213
Alaska	4,333	2.3	98.6	22.2	18.1	96,217
Arizona	4,276	18.9	825.7	164.2	142.2	701,975
Arkansas	3,655	16.2	514.9	102.9	93.4	376,217
California	4,967	89.1	4,820.1	938.3	738.6	4,660,434
Colorado	4,129	16.0	730.7	146.0	126.2	603,026
Connecticut	3,469	16.5	581.6	131.6	110.8	456,615
Delaware	3,339	3.0	165.6	32.4	29.2	108,020
District of Columbia	4,048	1.0	78.4	15.0	12.3	60,663
Florida	4,135	37.1	2,602.3	494.7	403.6	2,045,750
Georgia	4,077	34.5	1,495.5	295.9	245.5	1,206,444
Hawaii	4,976	5.5	156.4	31.0	26.8	154,205
Idaho	4,049	5.4	235.7	46.3	40.4	187,365
Illinois	4,027	36.1	2,361.5	417.8	304.9	1,682,545
Indiana.	3,553	27.4	1,185.7	237.1	222.6	842,287
lowa	3,948	22.0	427.9	97.3	85.1	384,017
Kansas	3,400	15.0	533.1	109.5	100.2	372,336
Kentucky	3,412	18.0	837.7	166.3	143.8	567,503
	3,235	26.5	1,008.1	201.5	170.5	651,767
Maine	3,124	10.1	163.8	53.6	48.8	167,298
Maryland	3,345	21.2	928.6	224.5	215.9	750,796
-	3,434	27.2	1,241.5	237.1	179.2	814,354
Massachusetts		60.4	,		321.5	
Michigan.	3,485	29.4	1,782.6 933.9	389.0 184.7	147.6	1,355,716
Minnesota	3,612		532.2			666,965
	4,005	13.2		104.6	85.8	418,898
Missouri	6,742	15.2	572.0	114.3	102.6	770,476
Montana	4,006	5.5	122.0	30.1	27.3	120,533
Nebraska	3,777	5.5	305.6	61.4	55.6	231,785
Nevada	4,553	8.7	313.7	62.1	54.7	282,519
New Hampshire	3,320	7.1	201.8	51.3	40.7	170,265
New Jersey	4,107	5.3	1,404.0	277.9	238.5	1,141,447
New Mexico	4,170	6.3	324.3	63.9	52.6	266,530
New York	4,308	67.3	2,905.5	578.7	489.5	2,493,133
North Carolina	3,624	62.4	1,618.0	311.8	267.6	1,129,975
North Dakota	3,949	3.3	106.0	21.1	19.8	83,501
Ohio	3,597	78.4	1,713.1	428.0	368.6	1,539,501
Oklahoma	3,589	18.8	677.3	134.6	115.9	483,195
Oregon	3,650	16.3	639.9	124.6	106.4	454,812
Pennsylvania	3,874	64.9	2,026.8	404.2	373.0	1,566,042
Rhode Island	3,378	3.5	202.4	40.2	31.5	135,701
South Carolina	3,647	12.5	779.4	155.8	136.3	568,071
South Dakota	4,120	4.4	123.5	24.7	21.8	101,624
Tennessee	3,567	26.3	1,145.5	223.9	191.4	798,614
Texas	4,088	65.1	3,816.3	759.2	636.3	3,103,493
Utah	3,896	12.4	295.8	84.9	79.1	330,626
Vermont	3,312	3.8	124.1	24.5	24.2	81,294
Virginia	3,288	47.0	1,516.5	299.5	265.8	984,725
Washington	3,517	21.0	1,166.3	232.5	209.5	817,765
West Virginia	3,441	6.1	355.6	67.3	53.7	231,687
Wisconsin	3,642	43.8	931.4	195.7	173.3	712,688
	3,850	3.0	73.6	17.6	17.8	67,694

responding screener households. The denominator gives the estimated number of CSHCN based on the households in which an interview was completed. Similarly, the adjustment factor for adjusting the weights of children without special health care needs is

$$A_{4}^{\vec{s}} = \frac{\sum_{k=1}^{q_{fln}} w_{fk} N_{k\bar{s}}}{\sum_{k=1}^{q_{fln}} w_{fk} N_{k\bar{s}}}$$

The nonresponse adjusted sampling weights for responding children are $w_{ak}^{cs} = A_4^{s} w_k^{cs}$ and $w_{ak}^{c\bar{s}} = A_4^{\bar{s}} w_k^{c\bar{s}}$.

Poststratification Weight Adjustment for Child Interview Weights

The two weights given above, one for children with special health care needs and the other for children without special health care needs, were adjusted through raking so that the sum of the weights over all children agreed with all control totals used for child screener weights and with the estimated number

Table III. Summary statistics for child-level screener weights by State

Location	Unweighted sample size	Minimum weight	Maximum weight	Mean weight	Median weight	Sum of weights
	6,904	22.4	817.3	163.3	139.3	1,127,669
Alaska	8,548	2.0	110.9	22.5	19.3	192,035
Arizona	8,542	14.8	947.0	166.1	139.8	1,418,531
Arkansas	6,616	14.9	517.7	103.5	93.0	684,979
California	9,662	73.5	4,992.6	973.8	774.8	9,409,329
Colorado	7,864	14.2	661.8	143.7	124.2	1,130,228
Connecticut	6,411	18.3	450.0	132.7	113.4	850,434
Delaware	6,181	3.3	160.2	32.1	28.8	198,202
District of Columbia	7,400	1.1	76.9	15.4	12.1	113,592
Florida	7,572	37.0	2,490.7	494.0	398.0	3,740,251
Georgia	7,479	36.6	1,497.3	297.1	253.9	2,221,968
Hawaii	9,382	3.0	168.8	31.6	21.5	296,433
Idaho	8,366	4.1	225.8	44.9	39.5	375,814
Illinois	7,761	33.6	2,614.3	421.8	321.0	3,273,265
Indiana	6,744	22.8	1,178.4	234.7	221.2	1,583,139
lowa	7,766	20.2	470.4	94.2	84.3	731,619
Kansas	6,517	19.1	420.4	110.0	102.9	717,189
Kentucky	6,032	20.6	962.3	165.0	145.5	995,298
	5,964	30.0	939.4	203.4	175.1	1,213,280
Maine	5,646	9.4	163.6	52.9	48.3	298,779
Maryland	6,161	20.9	1,165.0	223.6	199.8	1,377,380
Massachusetts	6,411	25.4	1,255.7	235.9	170.3	1,512,618
Michigan.	6,637	57.5	1,958.1	392.0	330.3	2,601,971
Minnesota	6,946	24.3	933.8	186.8	150.2	1,297,776
Mississippi	7,374	10.9	532.2	105.1	83.8	774,961
			559.9			
Missouri	2,824	13.1		112.0	98.4	1,436,144
Montana	7,652	5.0	112.5	30.0	26.7	229,440
Nebraska	7,420	6.4	277.6	60.7	52.3	450,307
Nevada	8,911	6.9	306.6	61.2	51.1	545,758
New Hampshire	6,127	5.9	255.4	51.0	41.3	312,538
New Jersey	7,506	5.6	1,407.1	282.5	237.5	2,120,366
New Mexico	8,110	3.9	416.3	63.4	47.0	514,548
New York	8,030	77.7	2,931.9	587.2	501.9	4,715,393
North Carolina	6,432	51.2	1,592.8	312.1	261.7	2,007,262
North Dakota	7,527	3.4	106.8	21.1	20.5	158,451
Ohio	6,844	66.6	2,039.3	422.4	367.3	2,890,941
Oklahoma	6,684	17.0	728.6	134.0	110.9	895,334
Oregon	6,905	18.7	598.0	124.4	105.1	859,043
Pennsylvania	7,322	66.2	1,993.1	399.1	361.5	2,921,955
Rhode Island	6,134	5.9	172.0	40.7	35.1	249,864
South Carolina	6,662	7.4	766.3	152.6	129.5	1,016,521
South Dakota	8,213	3.8	124.7	24.5	20.9	200,821
Tennessee	6,338	26.5	1,119.1	223.6	195.3	1,417,039
Texas	7,848	60.5	3,854.2	765.9	642.4	6,010,424
Utah	8,850	12.1	222.7	82.2	77.6	727,596
Vermont	6,064	3.4	123.9	24.4	22.9	147,660
Virginia	5,826	41.7	1,443.5	302.6	266.0	1,763,111
Washington	6,629	21.0	1,124.0	232.7	207.3	1,542,437
West Virginia	6,034	5.9	338.0	65.6	52.2	395,774
Wisconsin	6,948	41.9	870.3	197.7	176.9	1,373,917
Wyoming	7,448	2.8	61.9	17.1	17.9	127,241

of children with and without special health care needs obtained using the final child screener weight.

The final raked weights are denoted by w_{fkj}^{cs} and $w_{fkj}^{c\bar{s}}$. These weights are used for the analysis of child-level variables and appear in the CSHCN Interview Data File and the Insurance Analysis Data File, denoted by WEIGHT_I. Because these two files are child-level data files, this single variable contains the final child-level weight for both children with and without special needs. Child interview weighting detail for CSHCN by State appears in table IV. Weighting detail for children without special health care needs appears in table V.

Trimming Weights

In sample surveys, very large or extreme sampling weights are often truncated or "trimmed" as large variation in weights can result in large sampling variances of the survey estimates. This is especially true if the sampling weights are not correlated with the values or characteristics of interest. In such cases, the few observations having very large weights may unduly contribute to the overall estimate. Sometimes, large variation in weights is a result of the design in which the probabilities of selection of sampling units are positively correlated with

Table IV: Summary statistics for child-level interview weights for children with special health care needs, by State

Location	Unweighted sample size	Minimum weight	Maximum weight	Mean weight	Median weight	Sum of weights
Alabama	749	23.1	1,385.8	203.8	156.6	152,648
Alaska	746	2.5	198.4	27.6	22.1	20,556
Arizona	751	16.7	1,855.2	204.3	147.7	153,410
Arkansas	749	21.6	891.0	129.6	101.8	97,077
California	759	89.9	10,195.2	1277.8	973.0	969,867
Colorado	744	18.0	1299.4	174.5	139.4	129,818
Connecticut	742	24.6	997.7	159.7	121.3	118,517
elaware	742	6.4	292.1	41.0	34.6	30,409
District of Columbia	748	2.4	153.6	20.9	14.3	15,625
lorida	750	72.2	4,532.4	650.8	450.0	488,090
Georgia	748	42.0	2,861.2	377.1	294.4	282,103
lawaii	747	3.2	307.3	43.5	32.1	32,495
Jaho	745	5.8	435.7	58.2	44.8	43,358
linois	745	62.8	4,288.5	509.3	340.8	379,436
ndiana	743	32.9	2,138.0	301.2	244.6	224,996
DWA	751	23.5	673.3	120.3	94.8	90,334
(ansas	748	26.7	960.8	141.3	115.3	105,694
	740	28.2	1,392.5	209.7	167.5	156,211
-	749	27.9	1,840.0	257.9	199.3	193,150
ouisiana	749 742	10.0	349.5	62.3	51.1	,
	742	24.3		278.8	228.2	46,243
			1,899.1			209,097
lassachusetts	744	46.1	2,243.1	298.2	206.7	221,840
lichigan	748	71.4	3,226.7	482.4	341.7	360,837
	749	26.5	1,651.5	214.9	150.5	160,946
lississippi	743	11.1	990.2	133.9	90.9	99,518
1issouri	1,493	8.9	1,612.0	144.6	107.2	215,818
1ontana	742	5.7	229.8	36.4	27.9	26,981
lebraska	747	11.5	562.9	76.9	58.3	57,450
levada	747	7.2	584.9	78.5	59.6	58,639
lew Hampshire	750	8.0	448.9	62.7	48.1	47,059
lew Jersey	744	14.2	2,424.2	358.6	257.5	266,804
lew Mexico	751	7.4	677.8	76.5	51.8	57,421
lew York	748	114.1	5,332.6	746.2	593.5	558,173
Iorth Carolina	739	49.7	2,719.7	379.9	283.1	280,771
lorth Dakota	746	5.3	182.1	26.3	21.8	19,651
Dhio	766	100.3	3,702.0	526.0	398.9	402,881
)klahoma	745	19.8	1,213.0	174.3	120.0	129,858
Dregon	745	23.2	1,156.4	152.2	115.3	113,418
Pennsylvania	748	84.8	3,513.2	507.1	404.5	379,291
Rhode Island	750	7.0	240.8	47.0	37.7	35,265
outh Carolina	745	16.2	1,113.2	180.3	142.1	134,358
outh Dakota	741	5.8	223.3	30.6	24.8	22,669
ennessee	747	37.6	1,822.5	265.9	210.1	198,647
exas	751	154.5	7,071.1	962.1	706.5	722,558
ltah	742	19.9	622.5	107.6	83.2	79,832
′ermont	748	3.2	214.7	30.6	25.4	22,886
′irginia	747	54.3	1,798.5	361.9	288.6	270,347
Vashington	756	40.2	1,627.4	278.8	227.4	210,739
Vest Virginia	748	8.4	585.7	88.5	58.4	66,201
Visconsin	750	41.0	1,522.4	245.9	188.8	184,422
Vyoming	749	2.8	140.2	21.3	18.9	15,940

values of observations on those units. Large weights can also be a result of sample selection procedures and adjustments for unit nonresponse.

It should be noted that a trimming procedure, while reducing the variance of the estimates, may result in increased bias in the estimates. The objective of trimming is to reduce the variance so that the reduction more than compensates for the increase in bias. Therefore, trimming is usually minimized as much as possible.

No strict rules or procedures for defining extreme weights or for trimming such weights exist, and various methods of weight trimming are practiced. In the case of some surveys that employ weighting, the size of the nonresponse and other adjustments to the base sampling weights are restricted to avoid large final weights altogether. Other surveys examine the distribution of the final weights to identify extreme weights and to propose trimming rules. This method is more common because it is easier to identify extreme weights by looking at the entire distribution of the weights.

For the National Survey of CSHCN, the method of examining the distribution of the final weights to identify extreme weights before trimming was used. Restricting the size of the nonresponse adjustments was not attempted because the unit nonresponse adjustments,

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Table V. Summary statistics for child-level interview weights for children without special health care needs, by State
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Location	Unweighted sample size	Minimum weight	Maximum weight	Mean weight	Median weight	Sum of weights
Alabama	3,493	26.0	1,447.9	279.1	220.3	975,021
Alaska	4,034	3.4	215.0	42.5	33.6	171,479
Arizona	3,948	19.3	2,312.8	320.4	229.1	1,265,121
Arkansas	3,297	14.1	910.3	178.3	133.7	587,902
California	4,661	66.4	10,452.0	1810.7	1308.5	8,439,462
Colorado	3,818	15.4	1,321.3	262.0	207.8	1,000,410
Connecticut	3,148	20.4	1,109.6	232.5	202.4	731,917
Delaware	2,977	2.9	292.6	56.4	41.8	167,793
District of Columbia	3,641	0.9	159.5	26.9	17.7	97,967
Florida	3,744	51.1	4,754.6	868.6	660.0	3,252,161
Georgia	3,690	36.4	2,986.1	525.7	368.0	1,939,865
Hawaii	4,633	2.9	347.9	57.0	36.7	263,938
Idaho	3,774	6.6	453.0	88.1	70.1	332,456
Illinois	3,710	30.8	4,853.9	780.0	551.2	2,893,829
Indiana	3,221	20.6	2,134.0	421.7	325.4	1,358,143
lowa	3,640	23.3	880.9	176.2	150.9	641,285
Kansas	3,036	18.5	957.1	201.4	167.1	611,495
Kentucky	3,015	27.5	1,488.0	278.3	221.4	839,087
Louisiana	2,847	25.5	1,951.9	358.3	275.5	1,020,130
Maine	2,808	14.0	421.9	89.9	75.1	252,536
Maryland	2,968	20.0	2,063.0	393.6	307.5	1,168,283
Massachusetts	3,084	25.5	2,345.4	418.5	307.0	1,290,778
Michigan.	3,154	51.2	3,709.6	710.6	535.0	2,241,134
Minnesota	3,331	25.1	1,733.4	341.3	256.3	1,136,830
	3,639	9.0	1,069.5	185.6	135.0	675,443
Mississippi		23.9			309.9	1,220,326
Missouri	3,142		1,660.1	388.4		, ,
	3,676	6.1	284.6	55.1	45.5	202,459
Nebraska	3,461	8.8	566.6	113.5	92.9	392,857
	4,243	8.9	605.1	114.8	90.2	487,119
New Hampshire	2,976	8.5	456.8	89.2	69.8	265,479
	3,766	5.6	2,703.3	492.2	394.6	1,853,562
	3,836	3.5	857.0	119.2	81.7	457,127
	3,953	78.1	5,331.2	1051.7	831.1	4,157,220
North Carolina	3,239	55.0	2,785.2	533.0	416.2	1,726,491
North Dakota	3,640	3.4	213.1	38.1	30.2	138,800
Ohio	3,239	85.3	3,906.8	768.2	604.6	2,488,060
Oklahoma	3,219	15.9	1,302.2	237.8	181.7	765,476
Oregon	3,316	24.0	1,176.8	224.9	187.0	745,625
Pennsylvania	3,525	63.1	3,534.7	721.3	583.0	2,542,664
Rhode Island	3,058	5.8	350.0	70.2	53.7	214,599
South Carolina	3,291	6.4	1,367.5	268.1	208.7	882,163
South Dakota	3,847	4.1	233.2	46.3	37.4	178,152
Tennessee	3,199	38.3	1,911.1	380.9	315.8	1,218,392
Texas	3,722	57.8	7,652.9	1420.7	1123.1	5,287,866
Utah	3,635	17.4	842.8	178.2	145.8	647,764
Vermont	2,989	3.9	233.8	41.7	31.7	124,774
Virginia	2,903	52.5	2,589.5	514.2	420.1	1,492,764
Washington	3,185	21.3	2,084.8	418.1	359.5	1,331,698
West Virginia	3,061	8.3	604.2	107.7	83.1	329,573
Wisconsin	3,333	45.6	1,735.4	356.9	301.0	1,189,495
Wyoming	3,531	2.8	158.3	31.5	24.4	111,301

generally, were not large. Alternatively, rather than restricting the size of the adjustments, the weights could have been trimmed after each adjustment. To do so, rules for determining outlier weights would have had to be specified at each stage. As mentioned earlier, identification of outlier weights in the distribution of final weights is easier than attempting to identify such outliers at each weighting stage, particularly since some large national weights in the National Survey of CSHCN result from the State-level design of the sample.

A decision was made to define a weight as extreme if it exceeded 5 times the mean weight. (The standard deviation of weights was not used to guide trimming because it is affected by extreme weights.) Using the final, poststratified child screener weight as an example, a formal description of the trimming process applied follows. This process occurred for each of the poststratified weights produced (i.e., household, child screener, interview).

Let w_{jkj} denote the final poststratified sampling weight for the *j*th child in the sample. Let the number of respondent children in the sample with a final sampling weight be *n*. Compute the mean of these weights. Let w_m be the mean of these weights. Any weight exceeding the value $5w_m$ is truncated and the weight set equal to $5w_m$. Typically, once trimming has been done, the weights of those observations with untrimmed weights are increased such that the sum of the new weights equals the sum of the weights before trimming. Assume that we have trimmed k weights. The sum of the original

weights is $\sum_{i=1}^{n} w_{fkj}$. The sum of the new weights is $\sum_{i=1}^{n-k} w_{fkj} + k (5w_m)$.

The two sums should be equal. Therefore, the untrimmed weights are adjusted by a factor that is equal to

$$\frac{\sum_{i=1}^{n} w_{fkj} - k(5w_m)}{\sum_{i=1}^{n-k} w_{fkj}}$$

This adjustment is done as a part of raking the weights so that the sum of the weights agrees with various control totals in the other margins.

National Estimates

The State sampling weights are used to obtain estimates for each State. To obtain national estimates of totals, State estimates should be aggregated. For computing national estimates of ratios (e.g., the proportion of children with special health care needs among all children nationally), the ratio is produced by aggregating the State estimates and dividing this number by the total number of children in the United States, again by aggregating the State totals.

Standard Errors of Estimates

Because of the complex design of the National Survey of CSHCN, the household records, child-level screener records, and interview records have unequal weights. Therefore, statistical software programs that assume simple random sampling will most often compute standard errors that are too small. Tests of statistical hypotheses may then reveal statistically significant differences or associations that are misleading. However, computer programs are available that provide the capability of variance estimation for complex sample designs (e.g., SUDAAN, Stata, WesVar). To provide the user with the capability of estimating the complex sample variances for the National Survey of CSHCN data, stratum identifiers and primary sampling unit (PSU) codes have been provided on the data files. These variables and the sample weights are necessary for the calculation of variances.

It should be noted that the stratum identifiers reported on the data set are not identical to the strata used for drawing the sample. In States with multiple IAP areas, independent samples were selected from each IAP area in proportion to the total number of households with children in each IAP area. Therefore, these IAP areas should be considered strata for variance estimation. However, disclosure of the specific IAP area for each child (even if the code were scrambled) could increase the risk of disclosure of a respondent's identity. For example, the IAP area with the lowest frequency of responses in New Jersey would be readily identifiable as Newark. In the absence of IAP-specific identifiers, data users should use the State identifier (STATE) as the stratum identifier. By using the State identifier rather than the suppressed IAP identifier, the standard errors for national and State estimates with key variables are affected only slightly and not in a consistent direction. The PSU for the National Survey of CSHCN is the household and is represented on the data sets by the unique household identifier, IDNUMR.

The overall number of persons in this survey is sufficient for most statistical inference purposes. However, analyses of some rare responses and analyses of subclasses can lead to estimators that are unreliable. Small sample sizes used in the variance calculations may also produce unstable estimates of the variances. Consequently, these analyses require that the user pay particular attention to the coefficient of variation for the estimates of means, proportions, and totals.

Standard errors for the National Survey of CSHCN can be obtained using the Taylor-series-approximation method, which is available in software such as SUDAAN, SAS, and Stata. As noted previously, the State should be identified as the stratum variable and the household should be identified as the primary sampling unit.

The simplifying assumption that PSUs have been sampled with replacement allows most complex survey sample design computer programs to calculate Taylor-series standard errors in a straightforward way. This method requires no recoding of design variables, but is statistically less efficient (and therefore more conservative) than some other methods because the PSU unit is treated as being sampled with replacement within the stratum unit. For SUDAAN, the data file needs to be sorted by stratum (STATE) and PSU (IDNUMR) prior to invoking SUDAAN. The following SUDAAN design statements are used for analyses at the household level:

PROC . . . DESIGN = WR; NEST STATE IDNUMR; WEIGHT WEIGHT_H;

For analyses of the Screener File data at the child level, replace "WEIGHT_H" with "WEIGHT_S." For analyses of the CSHCN Interview File or Insurance Analysis File data, replace "WEIGHT_H" with "WEIGHT_I."

The instructions given above for variance estimation assume that the weights are fixed. That is, in repeated samples of households and children, the weights attached to each child in an IAP area are assumed to be constant. But the final weights are obtained after various adjustments to the base sampling weight. These adjustments depend on the sample selected. Therefore, the variance estimates do not reflect the sampling variability of the weights. Thus, to a certain extent, there is underestimation of variance. In addition, there is a slight overestimation of variance due to the assumption of with-replacement sampling of households when actually households were selected without replacement. The extent of underestimation depends on the variability in weights in repeated samples. The underestimation may not be severe because the sample sizes are large. Also, the weights have been raked to multiple control totals.

It should be noted that other variance estimation procedures are also applicable to the National Survey of CSHCN. Specifically, the jackknife method with replicate weights and the bootstrap resampling method with replicate weights can also be used (via software such as WesVar) to obtain standard errors that fully reflect the impact of the weighting adjustments on standard errors. For the NIS, jackknife variance estimates of vaccination coverage rates were computed, but were found to be very similar to the estimates obtained using Taylor series approximation.

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Appendix

Computer-Assisted Telephone Interview Specifications

SLAITS NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

COMPLETE INTERVIEW SECTIONS 1-13

Public reporting burden of this collection of information is estimated to average 15 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a respondent is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road, MS D-24, Atlanta, GA 30333, ATTN: PRA (0920-0406). Do not return the completed form to this address.

Confidential Information

Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence by Abt Associates and CDC, will be used only for purposes stated in this study, and will not be disclosed or released to anyone other than authorized staff of CDC without the consent of the individual or establishment in accordance with Section 308(d) of the Public Health Service Act (42 U.S.C. 242).

OMB Control Number: 0920-0406 Expiration Date: May 7, 2002

1	NIS-ELIGIBLE CASE	
	Hello, my name is {INTERVIEWER NAME}. I am calling on l Control and Prevention. We're conducting a nationwide immuni children under 4 years of age are receiving all of the recommen- diseases. Your telephone number has been selected at random to questions I have will take only a few minutes.	zation study to find out how many ded vaccinations for childhood
2 (SI)	Am I speaking to someone who lives in this household who is or	ver 17 years of age?
	(1) YES, I AM THAT PERSON	.[skip to #3]
	(2) THIS IS ABUSINESS	.We are interviewing only in private residences. Thank you.
	(3) NEW PERSON COMES TO PHONE	.[RE-READ INTRO]
	(4) DOES NOT LIVE IN HOUSEHOLD	May I speak with someone who lives in this household? [1F "NO" SET CALLBACK].
	(5) NO PERSON AT HOME OVER 17	May I speak with someone who lives in this household who is over seventeen years old? [IF "NO" SET CALLBACK].
	F R SAYS 'GROUP QUARTERS': BARRACKS, DORMITORI SHOULD BE CODED AS "DOES NOT LIVE IN HOUSEHOLI	
3 (ISC.200) 4 (ISC.205)	We need to talk with the parent or guardian who lives in this hou most about the health and health care of the child or children und	

{OTHER NAME}

[SKIP TO #6]

[SKIP TO #5]

Section 1. NS-CSHCN ELIGIBILITY/SCREENING

2

3 (15

(1) Myself

5 (ISC.240) Because the rest of the survey asks about the health and health care of the child or children under 18, may I speak with {PERSON'S NAME} now? (1) Yes, that's me. (SAME RESPONDENT) ISKIP TO #61 (1) Yes (NEW PERSON COMES TO THE PHONE). [SKIP BACK TO #1] (2) No......When would be a good time for me to call back and talk with {R.P. name]? (S3_LTR) A letter describing this study may have been sent to your home recently. Do you remember seeing 6 the letter? (1) Yes (2) No HELP BOX: EVEN IF RESPONDENT DID NOT RECEIVE A LETTER, WE ARE REQUIRED TO REPEAT THIS INFORMATION BEFORE BEGINNING THE INTERVIEW.

NS-CSHCN INTRO

7

Before we continue, I'd like you to know that your participation in this research is voluntary. You can skip any questions you don't want to answer, or end the interview without penalty. Your answers will be kept strictly private, in accordance with the Public Health Service Act. I can provide you with the specific legal citation if you like. It guarantees that any answers that identify you or your family will not be shared with anyone other than the agency doing this survey. Depending on the health characteristics of your children, these questions take between 5 and 25 minutes, but for most families, it's around 10 minutes. In order to evaluate my performance, my supervisor may record and listen as I ask the questions. 'I'd like to continue now unless you have any questions.

(1) CONTINUE WITH INTERVIEW

- (2) HUNG UP DURING INTRODUCTION DURING 1ST/2ND SENTENCE
- (3) HUNG UP DURING INTRODUCTION DURING 3RD/4TH SENTENCE
- (4) HUNG UP DURING INTRODUCTION DURING $5^{\text{TH}}/6^{\text{TH}}$ SENTENCE
- (5) HUNG UP DURING INTRODUCTION DURING $7^{\text{TH}}/8^{\text{TH}}$ SENTENCE

<u>HELP BOX</u>: The Public Health Service Act is Volume 42 of the US Code, Section 242k. The collection of information in this survey is authorized by Section 306 of this Act. The confidentiality of your responses is assured by Section 308d of this Act. 8 S_UNDR18 How many p

How many people less than 18 years old live in this household?

ANSWER IS:	
"1" OR GREATER	(skip to #10)
"0", "DON'T KNOW", OR "REFUSED"	(skip to: #9

9 (NOCHILD)

10

These are all the questions I have. I'd like to thank you on behalf of the Centers for Disease Control and Prevention for the time and effort you have spent answering these questions. [TERMINATE]

(IF #8 = NUMBER OF NIS-ELIGIBLE CHILDREN, CONFIRM AGE/NAME INFORMATION AND SKIP TO #17)

You hav	e previously	y given the r ase tell me t	name(s) and	birth date(s) of [REAI) NAMES I		e age of 18?	(H)→
	Child1	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7	Child 8	Child 9
Date of Birth	11	11	11	11	11	11	11	11	1 1
	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97	DK (96) REF (97)				
What is the age of [CHILD 1, CHILD 2] child in years?									
[REPEAT FOR EACH CHILD]	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)
	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)
So that I will know how to refer to the year old during the									
interview, what is his or her first name or initials?	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)

[RECORD ON HELPSHEET, THEN SKIP TO AGE CONF]

HELP BOX:

"DON'T KNOW" or "REFUSED"

 INTERVIEWER CAN PROCEED USING NAME, AGE, OR BIRTHDATE TO REFER TO THE CHILD. IF ALL ARE REFUSED, TERMINATE INTERVIEW.

(S3_LTR) A letter describing this study may have been sent to your home recently. Do you remember seeing

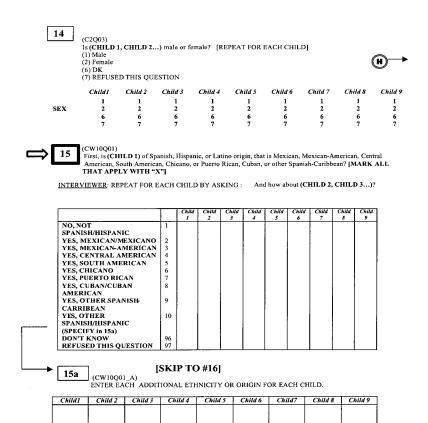
NIS INELIGIBLE CASE

(1) Yes Hello, my name is {INTERVIEWER NAME}. I am calling on behalf of the Centers for Disease (2) No 1 Control and Prevention. We're conducting a nationwide immunization study to find out how many children under 4 years of age are receiving all of the recommended vaccinations for childhood HELP BOX: EVEN IF RESPONDENT DID NOT RECEIVE A LETTER, WE ARE REQUIRED TO diseases. Your telephone number has been selected at random to be included in the study. The REPEAT THIS INFORMATION BEFORE BEGINNING THE INTERVIEW. questions I have will take only a few minutes. Am I speaking to someone who lives in this household who is over 17 years of age? 2 (SI) 7 **NS-CSHCN INTRO** Before we continue, I'd like you to know that your participation in this research is voluntary. You can private residences. Thank you. skip any questions you don't want to answer, or end the interview without penalty. Your answers will (3) NEW PERSON COMES TO PHONE...... [RE-READ INTRO] be kept strictly private, in accordance with the Public Health Service Act. I can provide you with the specific legal citation if you like. It guarantees that any answers that identify you or your family will not be shared with anyone other than the agency doing this survey. Depending on the health live in this household? [IF "NO" characteristics of your children, these questions take between 5 and 25 minutes, but for most families, SET CALLBACKI. it's around 10 minutes. In order to evaluate my performance, my supervisor may record and listen as I ask the questions. I'd like to continue now unless you have any questions. (5) NO PERSON AT HOME OVER 17......May I speak with someone who (1) CONTINUE WITH INTERVIEW lives in this household who is (2) HUNG UP DURING INTRODUCTION - DURING 1ST/2ND SENTENCE (3) HUNG UP DURING INTRODUCTION – DURING $3^{RD}/4^{TH}$ SENTENCE over seventeen years old? [IF "NO" SET CALLBACK]. (4) HUNG UP DURING INTRODUCTION – DURING $5^{TH}/6^{TH}$ SENTENCE (5) HUNG UP DURING INTRODUCTION - DURING 7TH/8TH SENTENCE HELP BOX: IF R SAYS 'GROUP QUARTERS': BARRACKS, DORMITORIES, HOSPITALS, SCHOOLS ETC., CASE SHOULD BE CODED AS "DOES NOT LIVE IN HOUSEHOLD". HELP BOX: The Public Health Service Act is Volume 42 of the US Code, Section 242k. The collection of information in this survey is authorized by Section 306 of this Act. The confidentiality of your responses is assured by Section 308d of this Act. 3 (ISC,200) We need to talk with the parent or guardian who lives in this household who knows the most about the health and health care of the child or children under 18. Who would that be? S UNDR18 8 How many people less than 18 years old live in this household? (ISC.205) 4 [SKIP TO #6] (1) Myself **ISKIP TO #51** _{OTHER NAME} ANSWER IS: **ISKIP TO #10** "1" OR GREATER 5 (ISC.240) **[SKIP TO: #9**] "0", "DON'T KNOW", OR "REFUSED" Because the rest of the survey asks about the health and health care of the child or children under 18, may I speak with {PERSON'S NAME} now? (NOCHILD) 9 (1) Yes, that's me. (SAME RESPONDENT) ISKIP TO #61These are all the questions I have. I'd like to thank you on behalf of the Centers for Disease (2) Yes (NEW PERSON COMES TO THE PHONE). [SKIP BACK TO #1] Control and Prevention for the time and effort you have spent answering these questions. [TERMINATE] (3) No......When would be a good time for me to call back and talk with {R.P. name]?

6

the letter?

	g with your your housel		l, what is th	e month, da	y and year o	of birth of ea	ch of the ch	iildren 🕞)►	M1 (MULTIAGE) Since you have more than one child who isycars old I need a way to refer to each of them during the interview. Could you please tell me their first name or initials?
	Child1	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7	Child 8	Child 9	1 - YES [RECORD IN BOX "A" OF HELP SHEET & SKIP TO #14]
Date of Birth	/ /	/ /	11	11	11	11	1 1	11	11	6 - DON'T KNOW 7 - REFUSED
	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) REF (97	DK (96) REF (97)					
What is the age of [CHILD 1,										M2 (REFNAME1)
CHILD 2] child in years?									<u>-</u>	I would like to assure you that ALL information will be kept in strict confidence and will be summarized for research purposes only. Since you have two or more children of the same age, we must have some
	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	YEARS MONTH (CIRCLE)	For rescaled puppess with: Since you have two or more chiraction in same age, we make mare some way to tell them apart. This is important so that we can understand things like whether children with certain characteristics use medical services more or less than other children. You could give me a first name, nickname or their initials.
	DK (96) REE (97)	DK (96) REF (97)	DK (96) REF (97)	DK (96) RFF (97)	DK (96) REF (97)	(1) RESPONDENT WILL GIVE NAMES				
*****ASK NEXT (UESTION	ONLY IF I		ENT REQU		T YOU REF	ER TO CH	ILD BY NA	ME***	[SKIP BACK TO $\#12a$. Record names there and on helpsheet (H1) then skip to $\#17$ if nis-eligible, or $\#14$ if non-nis-eligible].
 know how to refer to the year old during the interview, what is 						. <u> </u>				(2) REFUSAL SKIP TO M3
his or her first name or initials? [ALL SKIP TO #			1151111					• • • • • • •		M3 (REFNAME2) These are all the questions I have. I would like to thank you on behalf of the Centers for Disease Control and Prevention for the time and effort you have spent answering these questions. [TERMINATE]
 INTERV 	r "REFUS N "96" FO IEWER CA	ED" R "DON'T	KNOW" AI DE WITH II	ND "97" FC NTERVIEW)R REFUSE / USING N	ED. AME OR A	GE,			AGE-CONF So, you have a (fill with year in age for all children 2 years old or older, or month in age for all children under 2 years old including age for any NIS-eligible children, i.e., 12 month old, 10 year old, 15 year old). Is that correct? (1) YES (2) NO (RETURN TO #10 FOR CORRECTION)



			T	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7	Child 8	Child 9
WHITE BLACK/A Americ			1 2			2						-
	AN INDIAN		3									
ASIAN			5									
	HAWAIIAN ISLANDER		6								i i	
	SPECIFY IN		8									
DON'T KI REFUSEI	NOW D THIS QUE	STION	96 97									
				[S]	KIP 1	'O #1	ôb]					•
16a	ENTEI	R EACH /	ADDI	TONAL	RACE.							
Child1	Child 2	Child 3		Child 4	Chi	ld 5	Child	6 C	hild7	Chil	d 8]	Child 9
					T							
				<u>,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,</u>	+							<u></u>

Now, I'm going to read a list of categories. Please choose one or more of the following categories to describe (CHILD 1)'s race. Is (CHILD 1) White, Black or African American, American Indian, Alaska

16b

16

(CW10Q02)

 \Rightarrow

 $\frac{|\text{NTERVJEWER}}{|\text{NTERVJEWER}} \text{ was more than one racial category selected for any single child in $$\#16/$#16a? Yes (skip to 16c) $$ no (skip to $$17)$ No (skip to $$17)$$

ANY OF THE GROUPS. MULTIPLE RACES MAY BE SELECTED.



Which do you feel best describes (MULTI-RACE CHILD 1, CHILD 2 ...,) 's race?

HELP BOX: NOTE THAT THIS QUESTION REQUIRES THE RESPONDENT TO SELECT A SINGLE ANSWER. IF THE RESPONDENT CONTINUES TO STATE MULTIPLE RACES, PROBE BY STATING THAT YOU UNDERSTAND, AND REREAD THE QUESTION. IF THE RESPONDENT STILL CONTINUES TO OFFER MULTIPLE RESPONSES, MARK "REFUSED SPECIFIC QUESTION" BELOW.

		Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7	Child 8	Child 9
WHITE	1									
BLACK/AFRICAN	2									
AMERICAN										
AMERICAN INDIAN	3									
ALASKA NATIVE	4									
ASIAN	5				1					
NATIVE HAWAIIAN	6									
PACIFIC ISLANDER	7									
OTHER	8									
DON'T KNOW	96									
REFUSED THIS QUESTION	97									

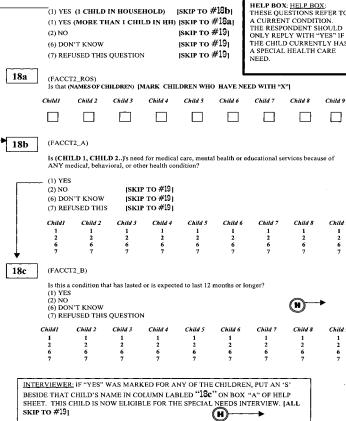
[SKIP TO #17]

SPECIAL HEALTH CARE NEEDS SCREENING

17 (SC1_INTRO)

The next questions are about any kind of health problems, concerns, or conditions that may affect your (child/children)'s behavior, learning, growth, or physical development. Some of these health problems may affect your (child/children)'s abilities and activities at school or at play. Some of these problems affect the kind or amount of services your (child/children) may need or use.

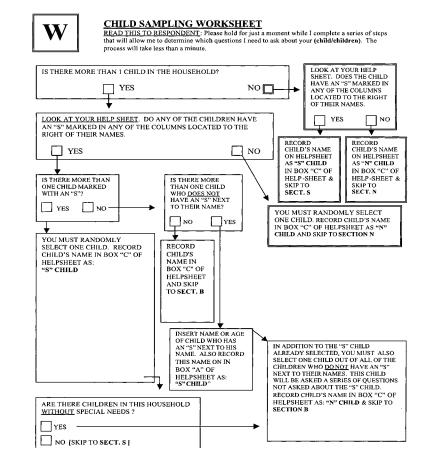
	2) our child/Do : nal services tl					care, mental	health, or		19				r children)	currently ne	ed or use <u>m</u>	edicine press	ribed by a d	octor,
(1) YE (2) NC (6) DC (7) RE	(1) YES (1 CHILD IN HOUSEHOLD) [SKIP TO #18b] (1) YES (MORE THAN 1 CHILD IN HH) [SKIP TO #18a] (2) NO [SKIP TO #19] (6) DON'T KNOW [SKIP TO #19] (7) REFUSED THIS QUESTION [SKIP TO #19] (FACCT2_ROS) Is that (NAMES OF CHILDREN)					THESE QU A CURREN THE RESP ONLY REP THE CHILI	X: <u>HELP BC</u> ESTIONS R T CONDIT ONDENT S PLY WITH ⁴ D CURREN L HEALTH (EFER TO ION. HOULD 'YES" IF TLY HAS		(1) YES (1) YES (2) NO (6) DON	(1 CHILD	IN HH) IAN 1 CHI	LD IN HH)	SKIP TO SKIP	#19a] #20] #20] #20]	HELP BOX: drugs such a medication a THESE QUE TO CURRE THE RESPO ONLY REPI THE CHILD HAS A SPE CARE NEEI	s headache re not incluc STIONS RI NT CONDIT NDENT SH Y WITH " CURRENT CIAL HEAL	ied. EFER TONS. IOULD YES" IF LY
		HILDREN) [MARK CHI	LDREN WH	D HAVE NE	ED WITH "?	("]		19a	(FACCI					L			
Child]	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7	Child 8	Child 9						LDREN WHO				
										Child1	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7	Child 8	Child 9
ANY 1 _ (1) YE (2) NC	IILD 1, CHII medical, beha	vioral, or oti [SKI	ner health co P TO #19]		d health or e	ducational se	ervices beca	use of	► <u>19</u> b				ed for prescr	iption medic	ine because	of ANY me	dical, behav	oral, or
(7) RE	ON'T KNOW	s įski	р то #19] р то #19]							(2) NO (6) DK (7) REF		рто #20) рто #20 рто #20	i					
<i>Child1</i> 1 2 6 7	Child 2 1 2 6 7	Child 3 1 2 6 7	Child 4 1 2 6 7	Child 5 1 2 6 7	Child 6 1 2 6 7	<i>Child 7</i> 1 2 6 7	Child 8 1 2 6 7	Child 9 1 2 6 7		<i>Child1</i> 1 2 6 7	Child 2 1 2 6 7	Child 3 1 2 6 7	Child 4 1 2 6 7	Child 5 1 2 6 7	Child 6 1 2 6 7	Child 7 1 2 6 7	Child 8 1 2 6 7	Child 9 1 2 6 7
(FACC									19c	(FACCI	1 B)							
(1) YE (2) NC (6) DC				ted to last 12	months or le	onger?	(H)	•	190	Is this a (1) YES (2) NO (6) DON	condition the		·	ed to last 12	months or l	onger?	H _	→
Child I	Child 2 1	Child 3 1	Child 4 1	Child 5 1	Child 6 1	Child 7	Child 8 1	Child 9 1		()	USED THIS	-						
2 6 7	2 6 7	1 2 6 7	1 2 6 7	2 6 7	2 6 7	2 6 7	2 6 7	1 2 6 7		<i>Child1</i> 1 2 6 7	Child 2 1 2 6 7	Child 3 1 2 6 7	Child 4 1 2 6 7	Child 5 1 2 6 7	Child 6 1 2 6 7	Child 7 1 2 6 7	Child 8 1 2 6 7	Child 9 1 2 6 7
DE THAT	<u>R:</u> IF "YES" I CHILD'S N CHILD IS N]	AME IN CO	DLUMN LA	bled " 18c	" ON BOX	"A" OF HE	LP		INTERVIEWE THAT CHILD CHILD IS NOV	S NAME IN	COLUMN	LABLED "	19 с " он в	OX "A" OF	HELP SHE	ET. THIS	Е	



18

20	(FACCT3) (Is your child/Are any of your children) <u>limited or prevented</u> in any way in (his or her/their) ability to do the things most children of the same age can do?	21	(FACCT4) (Does your child occupational, or s) need or get	special ther	<u>apy</u> , such as	physical,	
	(1) YES (1 CHILD IN HH) [SKIP TO #20b] HELP BOX: Limited or prevented: Things the child can't do as much or can't do at all that do as much or can't do at all that do as much or can't do at all that most children the same age can do. (2) NO [SKIP TO #21] most children the same age can do. (6) DON'T KNOW [SKIP TO #21] THE RESPONDENT SHOULD (7) REFUSED THIS QUESTION [SKIP TO #21] CURRENTLY HAS A SPECIAL HEALTH CARE NEED.		 (1) YES (1 CHII (1) YES (MORE (2) NO (6) DON'T KNO (7) REFUSED TI 	THAN 1 CI	HILD IN HH ISKIP ISKIP	то #22] то #22]	#21aj	HELP BOX THESE QUI A CURREN THE RESPO ONLY REPI THE CHILD A SPECIAL NEED.	ESTIONS RI T CONDITI ONDENT SH LY WITH " O CURRENT	EFER TO ON. HOULD YES" IF "LY HAS
20a	(FACCT3_ROS) Is that (NAMES OF CHILDREN) [MARK CHILDREN WHO HAVE NEED WITH "X"]	21a	(FACCT4_ROS) Is that (NAMES O		MARK CH	ILDREN WE	IO HAVE N	EED WITH "	x"]	
	Child1 Child 2 Child 3 Child 4 Child 5 Child 6 Child 7 Child 8 Child 9		Childl Child	2 Child.	3 Child 4	Child 5	Child 6	Child 7	Child 8	Child 9
▶ 20b	(FACCT3_A)	→ 21b	(FACCT4_A)							
	Is (CHILD 1, CHILD 2)'s limitation in abilities because of ANY medical, behavioral, or other health condition?		Is (CHILD 1, CI health condition?		eed for specia	al therapy be	cause of AN	Y medical, b	chavioral, o	other
	(1) YES (2) NO [SKIP TO #21] (6) DK [SKIP TO #21] (7) REFUSED [SKIP TO #21]			SKIP TO #2 SKIP TO #2 SKIP TO #2	221					
↓ 20c	Child 2 Child 3 Child 4 Child 5 Child 6 Child 7 Child 8 Child 9 1 1 1 1 1 1 1 1 2 2 2 2 2 2 2 2 2 6 6 6 6 6 6 6 6 7 <td< td=""><td>Ļ</td><td>Child1 Child 1 1 2 2 6 6</td><td>1 2 6</td><td>1 2 6</td><td>1 2 6</td><td>Child 6 1 2 6</td><td>Child 7 1 2 6</td><td>Child 8 1 2 6</td><td>Child 9 1 2 6</td></td<>	Ļ	Child1 Child 1 1 2 2 6 6	1 2 6	1 2 6	1 2 6	Child 6 1 2 6	Child 7 1 2 6	Child 8 1 2 6	Child 9 1 2 6
	(FACCT3_B)	21c	7 7 (FACCT4_B)	7	7	7	7	7	7	7
	Is this a condition that has lasted or is expected to last 12 months or longer? (1) YES		Is this a condition (1) YES	n that has last	ed or is expe	cted to last 12	2 months or	longer?	_	
	(2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION		(1) TES (2) NO (6) DON'T KNO (7) REFUSED TI		ON				H	>
	Child 1 Child 2 Child 3 Child 5 Child 6 Child 7 Child 8 Child 9	c	Child1 Child 2	Child 3	Child 4	Child 5	Child 6	Child 7	Child 8	Child 9
	$\begin{array}{cccccccccccccccccccccccccccccccccccc$		1 1 2 2	1 2	1 2	1	1 2	1	1 2	1 2
	, , , , , , , , , , , , , , , , , , ,		6 6 7 7	6 7	7	6 7	6 7	6 7	7	7
THAT CHIL	VER: IF "YES" WAS MARKED FOR ANY OF THE CHILDREN, PUT AN 'S' BESIDE D'S NAME IN COLUMN LABLED "20C" ON BOX "A" OF HELP SHEET. THIS OW ELIGIBLE FOR THE SPECIAL NEEDS INTERVIEW. [ALL SKIP TO #21]	THAT CHILD'S	L IF "YES" WAS M NAME IN COLUN ELIGIBLE FOR T	IN LABLED	" 21с " он	BOX "A" O	F HELP SH	EET. THIS	DE	

22 _{(FA}	behavior (1) YES (1) YES (2) NO (6) DON	al problem f	or which (ho IN BH) IAN ICHII	./she/they)	have any kin need(s) <u>treatr</u> [SKIP TO 7 [SKIP TO ⁷ [SKIP TO ¹ [SKIP TO ¹ [SKIP TO ¹	<u>nent or coun</u> #22b] #22a] WI WI		nental, or	
developm problems THESE Q	ental or beha such as stunt UESTIONS	vioral proble ed growth. I REFER TO	em. Emotion Behavioral p A CURREN	al problems roblems suc T CONDIT	or guidance s such as depr h as aggressi ION. THE F CIAL HEAL	ession or scl ve behavior RESPONDE	sizophrenia. or Attention NT SHOULI	Developmer Deficit Disc	ntal rder.
22a	(FACCT Is that ()		HLDREN) IM	IARK CHII	DREN WHO	HAVE NET	D WITH "X	"]	
	Child1	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7	Child 8	Child 9
22b					velopmental	or behaviora	l problem la	sted or is it	
	(1) YES (2) NO (6) DK (7) REF		°TO "w"] °TO "w"] °TO "w"]				Œ)	→
	Child1 1 2 6 7	Child 2 1 2 6 7	Child 3 1 2 6 7	Child 4 1 2 6 7	Child 5 1 2 6 7	Child 6 1 2 6 7	Child 7 1 2 6 7	Child 8 1 2 6 7	Child 9 1 2 6 7
INTERVIEWER: THAT CHILD'S N CHILD IS NOW 1	NAME IN C	OLUMN LA	bled "22	b " on bo	X "A" OF H	ELP SHEET	. THIS	M	►



N

Next I have some more general questions.

N25 (C2Q04_A)

What is your relationship to ("N" CHILD)?

(01) MOTHER (STEP, FOSTER, ADOPTIVE) OR FEMALE GUARDIAN
(02) FATHER (STEP, FOSTER, ADOPTIVE) OR MALE GUARDIAN
(03) SISTER OR BROTHER (STEP/FOSTER/HALF/ADOPTIVE)
(04) IN-LAW OF ANY TYPE
(05) AUNT/UNCLE
(06) GRANDPARENT
(07) OTHER FAMILY MEMBER
(08) FRIEND
(96) DON'T KNOW
(97) REFUSED THIS QUESTION

N26 (CW10Q04)

What is the highest grade or level of school that you have completed?

(01) 8TH GRADE OR LESS
(02) SOME HIGH SCHOOL, BUT DID NOT GRADUATE
(03) HIGH SCHOOL GRADUATE OR GED
(04) SOME POST HIGH SCHOOL, BUT NOT A BACHELOR'S DEGREE (B.A.)
(05) COLLEGE GRADUATE - BACHELOR'S DEGREE OR B.A.
(06) SOME GRADUATE OR PROFESSIONAL SCHOOL (WITH AND WITHOUT A DEGREE.
(96) DON'T KNOW
(97) REFUSED THIS QUESTION N27

(CW10Q04_A)

[INTERVIEWER: IF RESPONDENT IS MOTHER, SKIP TO [SECTION 7A, #80] What is the highest grade or level of school that ("N" CHILD)'s mother has completed?

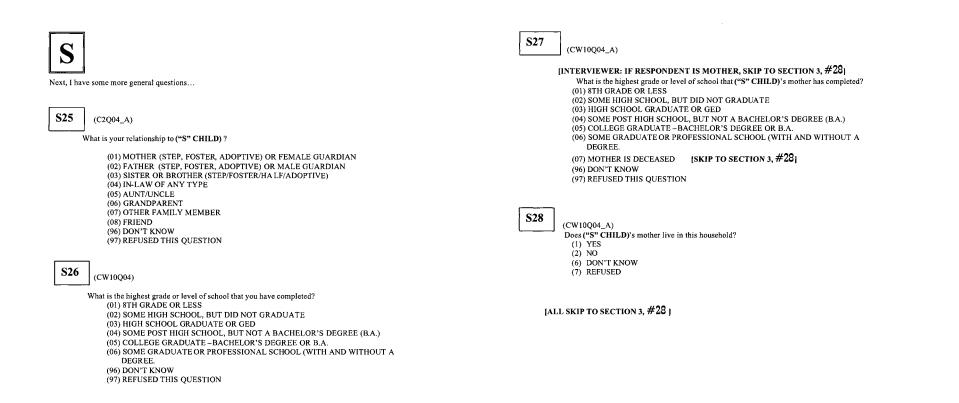
(01) 8TH GRADE OR LESS
(02) SOME HIGH SCHOOL, BUT DID NOT GRADUATE
(03) HIGH SCHOOL GRADUATE OR GED
(04) SOME POST HIGH SCHOOL, BUT NOT A BACHELOR'S DEGREE (B.A.)
(05) COLLEGE GRADUATE OR PROFESSIONAL SCHOOL (WITH AND WITHOUT A DEGREE.
(07) MOTHER IS DECEASED ISKIP TO SECTION 7A, #80]
(96) DON'T KNOW
(97) REFUSED THIS QUESTION

N28 (CW10004 A)

Does ("N" CHILD)'s mother live in this household?

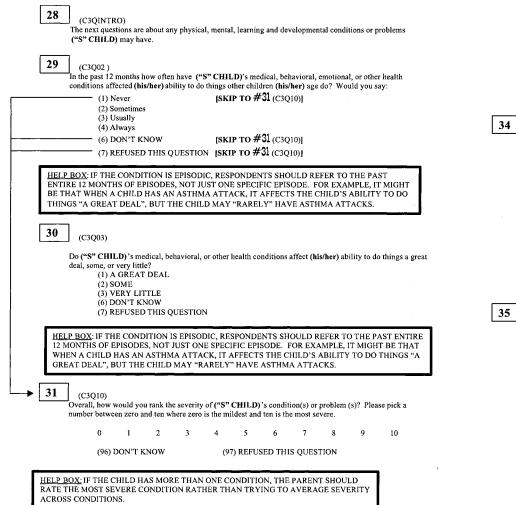
(1) YES
 (2) NO
 (6) DON'T KNOW
 (7) REFUSED

[ALL SKIP TO SECTION 7A, #80]



	B28
	(CW10Q04_A)
	[INTERVIEWER: IF RESPONDENT IS MOTHER, SKIP TO #B30]
Next I have some more general questions.	What is the highest grade or level of school that ("S" CHILD)'s mother has completed? (01) 8TH GRADE OR LESS (02) SOME HIGH SCHOOL, BUT DID NOT GRADUATE
B25 (C2Q04_1)	 (03) HIGH SCHOOL GRADUATE OR GED (04) SOME POST HIGH SCHOOL, BUT NOT A BACHELOR'S DEGREE (B.A.) (05) COLLEGE GRADUATE -BACHELOR'S DEGREE OR B.A. (04) COLLEGE GRADUATE CONSERVICIAL SCHOOL (WITH AND WITHOUT A
What is your relationship to ("S" CHILD.) ?	(06) SOME GRADUATE OR PROFESSIONAL SCHOOL (WITH AND WITHOUT A DEGREE.
 (01) MOTHER (STEP, FOSTER, ADOPTIVE) OR FEMALE GUARDIAN (02) FATHER (STEP, FOSTER, ADOPTIVE) OR MALE GUARDIAN (03) SISTER OR BROTHER (STEP/FOSTER/HALF/ADOPTIVE) (04) IN-LAW OF ANY TYPE (05) AUNT/UNCLE (06) GRANDPARENT (07) OTHER FAMILY MEMBER (08) FRIEND 	(07) MOTHER IS DECEASED [SKIP TO # B30] (96) DON'T KNOW (97) REFUSED THIS QUESTION B29 (CW10Q04_A) Does ("S" CHILD)'s mother live in this household? (1) YES
(96) DON'T KNOW	(1) YES (2) NO
(97) REFUSED THIS QUESTION	(6) DON'T KNOW
	(7) REFUSED
B26 (C2Q04_2)	B30 (CW10Q04_A)
What is your relationship to ("N" CHILD) ? (01) MOTHER (STEP, FOSTER, ADOPTIVE) OR FEMALE GUARDIAN (02) FATHER (STEP, FOSTER, ADOPTIVE) OR MALE GUARDIAN (03) SISTER OR BROTHER (STEP/FOSTER/HALF/ADOPTIVE) (04) IN-LAW OF ANY TYPE (05) AUNTUNCLE (06) GRANDPARENT (07) OTHER FAMILY MEMBER (08) FRIEND (96) DON'T KNOW (97) REFUSED THIS QUESTION B27	 [CW1004_A] [INTERVIEWER: IF RESPONDENT IS MOTHER, SKIP TO SECTION 3, #28] What is the highest grade or level of school that ("N" CHILD)'s mother has completed? (01) STH GRADE OR LESS (02) SOME HIGH SCHOOL, BUT DID NOT GRADUATE (03) HIGH SCHOOL GRADUATE OR GED (04) SOME POST HIGH SCHOOL, BUT NOT A BACHELOR'S DEGREE (B.A.) (05) COLLEGE GRADUATE - BACHELOR'S DEGREE OR B.A. (06) SOME GRADUATE OR PROFESSIONAL SCHOOL (WITH AND WITHOUT A DEGREE. (07) MOTHER IS DECEASED [SKIP TO SECTION 3, #28] (96) DON'T KNOW (97) REFUSED THIS QUESTION
(CW10Q04)	
 What is the highest grade of school that you have completed? (01) 8TH GRADE OR LESS (02) SOME HIGH SCHOOL, BUT DID NOT GRADUATE (03) HIGH SCHOOL GRADUATE OR GED (04) SOME POST HIGH SCHOOL, BUT NOT A BACHELOR'S DEGREE (B.A.) (05) COLLEGE GRADUATE -BACHELOR'S DEGREE OR B.A. (06) SOME GRADUATE OR PROFESSIONAL SCHOOL (WITH AND WITHOUT A DEGREE. (96) DON'T KNOW 	B31 (CW10Q04_A) Does ("N" CHILD)'s mother live in this household? (1) YES (2) NO (6) DON'T KNOW (7) REFUSED
(97) REFUSED THIS QUESTION	[ALL SKIP TO SECTION 3, #28]

Section 3. HEALTH AND FUNCTIONAL STATUS



32 (C3Q11)

Which of the following statements best describes ("S" CHILD)'s health care needs? ("S" CHILD)'s health care needs change all the time, ("S" CHILD)'s health care needs change only once in a while, or ("S" CHILD)'s health care needs are usually stable?

(1) CHILD'S HEALTH CARE NEEDS CHANGE ALL THE TIME
(2) CHILD'S HEALTH CARE NEEDS CHANGE ONLY ONCE IN A WHILE
(3) CHILD'S HEALTH CARE NEEDS ARE USUALLY STABLE
(4) NONE OF THE ABOVE
(6) DON'T KNOW
(7) REFUSED THIS QUESTION

(C3012)

[IF CHILD IS 2 OR OLDER, SKIP TO #35 (C3Q13)]

Does ("S" CHILD) receive services from a program called Early Intervention Services? Children receiving these services often have an Individualized Family Service Plan.

(1) YES	[SKIP TO #37 (C4Q01)]
(2) NO	[SKIP TO #37 (C4Q01)]
(6) DON'T KNOW	[SKIP TO #37 (C4Q01)]
(7) REFUSED THIS QUESTION	[SKIP TO #37 (C4Q01)]

<u>HELP BOX</u>: Early Intervention Services are defined as: family training, counseling, and home visits; health services; medicine; nursing; nutrition; occupational therapy; physical therapy; psychological services; service coordination services; social work services; special instruction; speech-language therapy; transportation, communication or mobility devices; and vision and hearing services.

5 (C3Q13)

Does ("S" CHILD) receive services from a program called Special Educational Services? Children receiving these services often have an Individualized Education Plan.

YES
 NO
 DON'T KNOW
 REFUSED THIS QUESTION

HELP BOX: Special education is any kind of special school, classes or tutoring.

(C3Q14)	Section 4. ACCESS TO CARE: UTILIZA' NEEDS	FION AND UNMET
[IF AGE IS 0-4 YEARS, SKIP TO # 37 C4Q0A] During the past 12 months, that is since (I YEAR AGO TODAY), about how many days did ("S" CHILD) miss school because of illness or injury? [NOTE: A SCHOOL YEAR IS 240 DAYS] [ENTER ALL THREE DIGITS]	37 (C4Q0A) Is there a place that ("S" CHILD) USUALLY goes to when (he/sl (his/her) health?	
(000) NONE (994) DID NOT GO TO SCHOOL (995) HOME SCHOOLED (996) DON'T KNOW (997) REFUSED THIS QUESTION	(1) YES [SKIP TO #3 (2) THERE IS NO PLACE [SKIP TO #4 (3) THERE IS MORE THAN ONE PLACE [SKIP TO #3 (6) DON'T KNOW [SKIP TO #4 (7) REFUSED THIS QUESTION [SKIP TO #4	11 C4Q02] 19] 11 C4Q02]
(all skip to #37)	38 (C4Q0B) What kind of place is it? Is it a doctor's office, emergency room, hospital outpatient departm	uent, clinic, or some other place?
	 (01) DOCTOR'S OFFICE (02) HOSPITAL EMERGENCY ROOM (03) HOSPITAL OUTPATIENT DEPARTMENT (04) CLINIC OR HEALTH CENTER (05) SCHOOL(NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC.) (06) SOME OTHER PLACE	[skip to #40 (c4q01)] [skip to #40 (c4q01)] [record verbatim response] AND [skip to #40 (c4q01)]
	(07) DOESN'T GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED THIS QUESTION	ISKIP TO #41 (C4Q02)] ISKIP TO #41 (C4Q02)] ISKIP TO #41 (C4Q02)] ISKIP TO #41 (C4Q02)]
	 (C4Q0B) What kind of place does ("S" CHILD) go to most often? Is it a doctor's office, emergency room, hospital outpatient department (01) DOCTOR'S OFFICE (02) HOSPITAL EMERGENCY ROOM (03) HOSPITAL OUTPATIENT DEPARTMENT (04) CLINIC OR HEALTH CENTER (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, I (06) SOME OTHER PLACE (07) DOES NOT GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED THIS QUESTION 	

36

Page	
60	
Series	
<u>, -</u>	
No.	
4 1	

needs routine preventive care, such as a phy (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION HELP BOX: Clinical preventive care includes c discussions about how to keep your child health 41 (C4Q02) What kind of place does ("S" CHILD) US a physical examination or well child check. (01) DOES NOT GET REVENTIVE C (02) DOCTOR'S OFFICE (03) HOSPITAL EMERGENCY ROOM (04) HOSPITAL OUTPATIENT DEPAR (05) SCHOOL (NURES'S OFFICE, AT (06) SCHOOL (NURES'S OFFICE, AT (07) SOME OTHER PLACE (08) DOES NOT GOT O ONE PLACE M (05) DON'T KNOW (96) DON'T KNOW (97) REFUSED 42 (C4Q02A) A personal doctor or nurse is the health prethat you think of as ("S" CHILD)'s person (1) YES (2) NO (6) DON'T KNOW	[SKIP TO #42 C4Q02A] [SKIP TO #41 C4Q02] [SKIP TO #42 C4Q02A] [SKIP TO #42 C4Q02A] [SKIP TO #42 C4Q02A] heck-ups, immunizations, health screening tests, and y. UALLY go to when (he/she) needs routine preventive care, such as up? ARE ANYWHERE CTMENT HLETIC TRAINER'S OFFICE, ETC) [RECORD VERBATIM RESP ONSE] MOST OFTEN	43 44 45 45b	 (01) GÉNERAL DOCTOR (SUCH A FAMILY MEDICINE, INTERN, (02) PEDIATRICIAN (03) OTHER SPECIALIST (SUCH A GYNECOLOGISTS). (04) NURSE PRACTITIONER (05) PHYSICIAN'S ASSISTANT (06) OTHER	AS SURGEONS, HEART DOCTORS, OBSTE [RECORD V ed health care. By health care I mean medical services, physical, occupational, or speech the inths, have you delayed or gone without health [SKIP TO #46INT C4Q05] [SKIP TO #46INT C4Q05] I SKIP TO #46INT C4Q05] or do not get needed health care. Did you dela lth care provider's office on the telephone? for ("S" CHILD) because) You couldn't get ar	TRICIANS OR VERBATIM RESPONSE] care as well as other kinds rapies, and special care for ("S" CHILD)?
			(6) DON T KNOW (7) REFUSED THIS QUESTION	I	

41 ↳

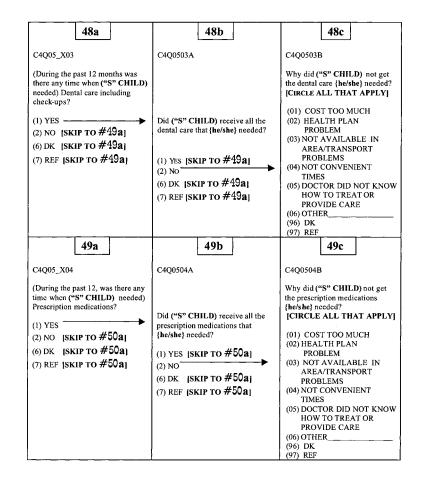
►**H** 42

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45c
         (C4004 C)
                                                                                                                                   45h
                                                                                                                                            (C4Q04_H)
      (Did you delay or not get health care for ("S" CHILD) because) The clinic or doctor's office was not open
                                                                                                                                          (Did you delay or not get health care for ("S" CHILD) because) The type of health care was not covered by
       when you could get there?
                                                                                                                                          your health plan?
               (1) YES
                                                                                                                                                  (1) YES
               (2) NO
                                                                                                                                                  (2) NO
               (6) DON'T KNOW
                                                                                                                                                  (6) DON'T KNOW
              (7) REFUSED THIS QUESTION
                                                                                                                                                  (7) REFUSED THIS QUESTION
45d
         (C4Q04_D)
                                                                                                                                   45i
      (Did you delay or not get health care for ("S" CHILD) because) Transportation was a problem?
                                                                                                                                            (C4004 I)
              (1) YES
                                                                                                                                          (Did you delay or not get health care for ("S" CHILD) because) You could not get approval from your health
               (2) NO
                                                                                                                                          plan or doctor?
              (6) DON'T KNOW
                                                                                                                                                 (1) YES
              (7) REFUSED THIS QUESTION
                                                                                                                                                  (2) NO
                                                                                                                                                  (6) DON'T KNOW
                                                                                                                                                  (7) REFUSED THIS QUESTION
45e
         (C4O04 E)
                                                                                                                                   45j
      (Did you delay or not get health care for ("S" CHILD) because) You didn't have enough money to pay the
                                                                                                                                             (C4Q04_J)
      health care provider?
                                                                                                                                         (Did you delay or not get health care for ("S" CHILD) because) Once you get there, ("S" CHILD) has to wait
              (1) YES
                                                                                                                                          too long to see the health care provider?
              (2) NO
                                                                                                                                                  (1) YES
              (6) DON'T KNOW
                                                                                                                                                  (2) NO
              (7) REFUSED THIS QUESTION
                                                                                                                                                 (6) DON'T KNOW
                                                                                                                                                 (7) REFUSED THIS QUESTION
45f
                                                                                                                                   45k
         (C4Q04_F)
                                                                                                                                             (C4Q04_K)
       (Did you delay or not get health care for ("S" CHILD) because) The type of care ("S" CHILD) needed was
                                                                                                                                         (Did you delay or not get health care for ("S" CHILD) because) You have language, communication, or
       not available in your area?
                                                                                                                                         cultural problems with the health care provider?
              (1) YES
                                                                                                                                                 (1) YES
              (2) NO
                                                                                                                                                 (2) NO
              (6) DON'T KNOW
                                                                                                                                                 (6) DON'T KNOW
              (7) REFUSED THIS QUESTION
                                                                                                                                                 (7) REFUSED THIS OUESTION
45g
         (C4Q04_G)
       (Did you delay or not get health care for ("S" CHILD) because) The health care provider did not have the
                                                                                                                                   451
                                                                                                                                            (C4Q04_L)
       skills ("S" CHILD) needed?
                                                                                                                                          (Did you delay or not get health care for ("S" CHILD) because) Going to appointments conflicts with
              (1) YES
                                                                                                                                          other responsibilities at home or at work?
              (2) NO
                                                                                                                                                  (1) YES
              (6) DON'T KNOW
                                                                                                                                                  (2) NO
              (7) REFUSED THIS QUESTION
                                                                                                                                                 (6) DON'T KNOW
                                                                                                                                                 (7) REFUSED THIS QUESTION
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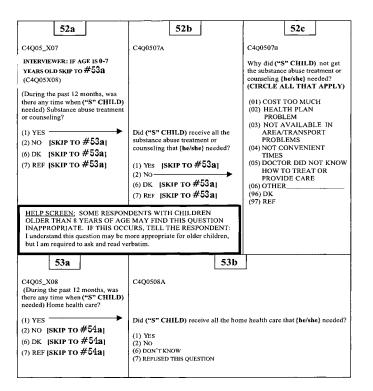
46INT

During the past 12 months, was there any time when (S CHILD) needed any of the following services:

46a	46b			46c	
C4Q05_X01 During the past 12 months was	C4Q0501A		C4Q0501B Why did ("	S" CHILD) not get
 but ing the past prime when ("S" CHILD) needed routine preventive care, such as a physical examination or well child check-up? (1) YES (2) NO [SKIP TO #47a] (6) DK [SKIP TO #47a] (7) REF [SKIP TO #47a] 	Did ("S" CHILD) rec routine preventive care needed? (1) YES [SKIP TO (2) NO (6) DK [SKIP TO (7) REF [SKIP TO	# 47a1 # 47a1 # 47a1	the routine {he/she} ne [CIRCLE (01) COST (02) HEA PROI (03) NOT ARE. PROI (04) NOT TIME (05) DOC KNO	preventive reded? ALL THA TOO MUC LTH PLAN BLEM AVAILAB AVAILAB AVAILAB AVAILAB S TOR DID N W HOW T ROVIDE C ER	care AT APPLY] CH VORT ENT NOT O TREAT
47a	47b	J		47c]
C4Q05_X02 (During the past 12 months, was there any time when ("S" CHILD) needed) Care from a specialty doctor? (1) YES (2) NO [SKIP TO #48a] (6) DK [SKIP TO #48a] (7) REF [SKIP TO #48a]	C4Q0502A Did ("S" CHILD) rec care from a specialty of {he/she} needed? (1) YES [SKIP TO #	octor that	(02) HEAI PROE (03) NOT A AREA PROB (04) NOT (om a special ceded? ALL THA TOO MU(LTH PLAN BLEM AVAILABI A/TRANSP(SLEMS CONVENIJ	Ity doctor T APPLY] CH LE IN ORT
HELP BOX: Specialty doctors focus These include cardiologists, ear, no For example pulmonologists work v	(6) DK [SKIP TO # (7) REF [SKIP TO # on one part of your child se and throat doctors, su	48aj 's health. rgeons, etc.	HOW PROV	-	3



50a	50b	50c
C4Q05_X05	C4Q0505A	C4Q0505B
(During the past 12 months was there any time when ("S" CHILD) needed) Physical, occupational or speech therapy? (1) YES (2) NO [SKIP TO #51a] (6) DK [SKIP TO #51a] (7) REF [SKIP TO #51a]	Did (*S " CHILD) receive all the physical, occupational or speech therapy that {he/she} needed? (1) YES [SKIP TO #51a] (2) NO (6) DK [SKIP TO #51a] (7) REF [SKIP TO #51a]	Why did (*S [°] CHILD) not get the physical, occupational or speech thorapy that {he/she} needed? (CIRCLE ALL THAT APPLY) (01) COST TOO MUCH (02) HEALTH PLAN PROBLEM (03) NOT AVAILABLE IN AREA/TRANSPORT PROBLEMS (04) NOT CONVENIENT TIMES (05) DOCTOR DID NOT KNOW HOW TO TREAT OR PROVIDE CARE (06) OTHER (96) DK (97) REF
51a	51b	51c
C4Q05_X06	C4Q0506A	С4Q0506В
(During the past 12 months, was there any time when ("S" CHILD) needed) Mental health care or counseling?		Why did ("S" CHILD) not get the mental health care or counseling {he/she} needed?
(1) YES (2) NO [SKIP TO #52a] (6) DK [SKIP TO #52a] (7) REF [SKIP TO #52a]	Did ("S" CHILD) receive all the mental health care or counseling that {he/she} needed? (1) YES [SKIP TO #52a] (2) NO (6) DK [SKIP TO #52a] (7) REF [SKIP TO #52a]	(CIRCLE ALL THAT APPLY) (01) COST TOO MUCH (02) HEALTH PLAN PROBLEM (03) NOT AVAILABLE IN AREA/TRANSPORT PROBLEMS (04) NOT CONVENIENT TIMES (05) DOCTOR DID NOT KNOW HOW TO TREAT OR PROVIDE CARE (06) OTHER (96) DK (97) REF



54a	54b
C4Q05_X09	C4Q0509A
(During the past 12 months was there any time when ("S" CHILD) needed) Eyeglasses or vision care?	
(1) YES (2) NO [SKIP TO #55a]	Did ("S" CHILD) receive all the eyeglasses or vision care that {he/she} needed?
(6) DK [SKIP TO #55a] (7) REF [SKIP TO #55a]	(1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION
55a	55b
C4Q05_X10	C4Q0510A
(During the past 12 months, was there any time when ("S" CHILD) needed) Hearing aids or hearing care?	
(1) YES (2) NO [SKIP TO #56a]	Did ("S" CHILD) receive all the hearing aids or hearing care that {he/she} needed?
(6) DK [SKIP TO #56a] (7) REF [SKIP TO #56a]	(1)YES (2) No (6) DON'T KNOW (7) REFUSED THIS QUESTION

56a	56b
C4Q05_X11	C4Q0511
INTERVIEWER: IF AGE IS 4-2, SKIP TO #58a. (During the past 12 months, was there any time when (*3° CHLD) needed) Mobility aids or devices, such as canes, crutches, wheelchairs, or scooters? (1) YES (2) NO [SKIP TO #57a] (6) DK [SKIP TO #57a] (7) REF [SKIP TO #57a]	Did ("S" CHILD) receive all the mobility aids or devices that {he/she} needed? (1) YES (2) NO (6) DON'T KNOW (7) REFUSED

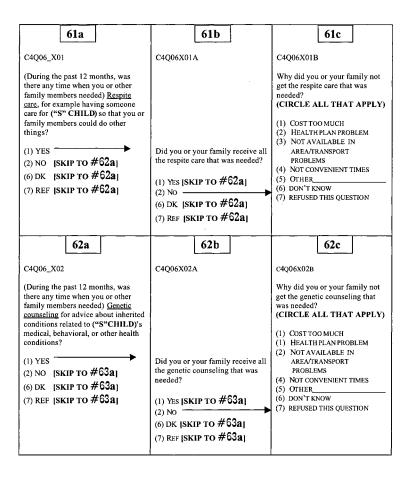
57a	57b
C4Q05_X12 (During the past 12 months, was there any time when ("S" CHILD) needed) Communication aids or devices, such as communication boards?	C4Q0512A
(1) YES (2) NO [SKIP TO #58a] (6) DK [SKIP TO #58a] (7) REF [SKIP TO #58a]	Did ("S" CHILD) receive all the communication aids or devices that {he/she} needed? (1) YES (2) No (6) DON'T KNOW (7) REFUSED THIS QUESTION

58a	58b
C4Q05_X13	C4Q0513A
(During the past 12 months, was there any time when ("S" CHILD) needed) Medical supplies? (1) YES (2) NO [SKIP TO #59a] (6) DK [SKIP TO #59a] (7) REF [SKIP TO #59a]	Did ("S" CHILD) receive all the medical supplies that {he/she} needed? (1)YES (2) No (6) DON'T KNOW (7) REFUSED THIS QUESTION
<u>HELP BOX</u> : Some examples of medical supplies include medicine, bandages and sponges. These are items that are disposable.	
59a	C4Q051 59b
C4Q05_X14	
(During the past 12 months, was there any time when ("S" CHILD) needed) Other medical equipment? (1) YES (2) NO [SKIP TO #60INT] (6) DK [SKIP TO #60INT] (7) REF [SKIP TO #60INT]	Did ("S" CHILD) receive all the medical equipment that {he/she} needed? (1)YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION
<u>HELP BOX</u> : Some examples of medical equipment include hardware such as a wheelchair, hospital bed, oxygen tank and a pressure machine. These are items that are not disposable.	

60INT

During the past 12 months, was there any time when you or other family members needed any of the following services because of (S CHU D)'s health:

because of (S CHILD)'s health:		
60 C4Q06_X0A (During the past 12 months, was there any time when you or other family members needed) Professional care coordination among different health care providers and services that the child uses? (1) YES (2) NO [SKIP TO #Gla] (6) DK [SKIP TO #Gla] (7) REF [SKIP TO #Gla]	60b C4Q06X0AA Did you or your family receive all the professional care coordination that was needed? (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION	
child gets all the services that are nee for you. This person may have differ	o assists in coordinating care is a pers- cded and makes sure that these scrvice: ent titles, such as case manager or a cr THIS HELP BOX TO RESPONDENT	es fit together in a way that works are coordinator."



63a	63b	63c
C4Q06_X03	C4Q06X03A	C4Q06X03B
(During the past 12 months, was there any time when you or other family members needed) <u>Mental</u> <u>health care or counseling</u> related to ("S" CHILD)'s medical, behavioral, or other health conditions?		Why did you or your family not get the mental health care or counseling that was needed (CIRCLE ALL THAT APPLY)
(1) YES (2) NO [SKIP TO #64] (6) DK [SKIP TO #64] (7) REF [SKIP TO #64]	Did you or your family receive all the mental health care or counseling that was needed? (1) YES [SKIP TO #64] (2) NO (6) DK [SKIP TO #64] (7) REF [SKIP TO #64]	(1) COST TOO MUCH (2) FEALTH FLAN FROBLEM (3) NOT AVAILABLE IN AREA/TRANSPORT FROBLEMS (4) NOT CONVENIENT TIMES (5) OTHER (6) DON'T KNOW (8) REFUSED THIS QUESTION

64

64a

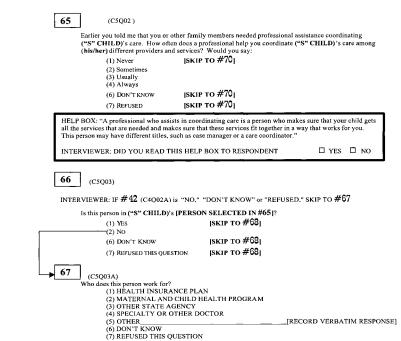
(C4Q07) In the past 12 months, how much of a problem, if any, was it to get a referral to a specialist that your child needed to see? Was it a big problem, a small problem, or not a problem? (1) A BIG PROBLEM

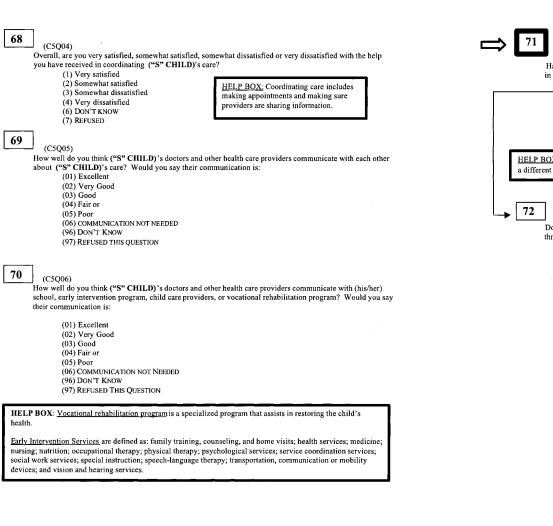
- (2) A SMALL PROBLEM
- (2) A SMALL FROBLEM (3) NOT A FROBLEM (4) CHILD DID NOT NEED TOSEE A SPECIALIST IN THE PAST 12 MONTHS (5) DON'T NEED REFERRALS (6) DON'T KNOW
- (7) REFUSED THIS QUESTION

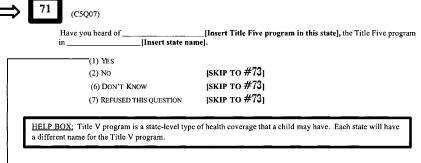
<u>HELP BOX</u>: Specially doctors focus on one part of your child's health. These include cardiologists, ear, nose and throat doctors, surgeons, etc. Example: pulmonologists work with breathing problems like asthma.

INTERVIEWER: IF ANSWER TO #60 (C4Q06_X0A) IS: "NO", "DON'T KNOW", OR "Refused", SKIP TO #70 (C5Q06), OTHERWISE SKIP TO #65.

Section 5. CARE COORDINATION







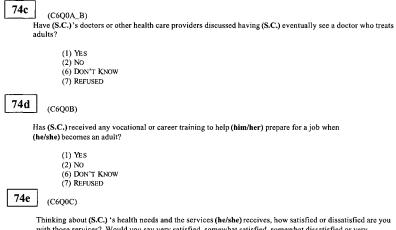
(C5Q08)

Does ("S" CHILD) get any health care services, care coordination, medications, equipment, or supplies through the Title V program?

(1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION

Section 6. SATISFACTION WITH CARE

73		ER THAN 12 MONTHS Since (his/her) birth, how many alth care provider? Do not count visits while staying	(1) YES (2) NO
i i	NUMBER OF VISITS		(6) DON'
	(000) NO VISITS IN PAST 12 MONTH	s iskip to #751	(7) REFUS
	(996) DON'T KNOW		
	(997) REFUSED THIS QUESTION	(skip to #75)	74d (C6Q0B)
74	(C6Q01_A)		II. (6.0)
	I have [ANSWER FROM #73] visits. Is that cor	rect?	Has (S.C.) receive
	(1) YES [SKIP TO #75]		(he/she) becomes a
	(2) NO [SKIP BACK TO #73]		(1) YES (2) NO
INT	ERVIEWER: IF YOU CONFIRMED "0" VISITS,	skip to #79a (C7Q03)	(6) DON'1
74	_		(7) REFUS
74:	(C6Q0A)		74e (C600C)
	(IF S.C. IS 12 YEARS OLD OR YOUNGER, S		74e (C6Q0C)
	Have (S.C.)'s doctors or other health care provide needs might change when (he/she) becomes an ad	rs talked with you or (S.C.) about how (his/her) health care lult?	Thinking about (S with those service
	(1) YES		dissatisfied?
	(2) NO [SKIP TO ##74d]		
	(6) DON'T KNOW [SKIP TO ##74d]		(1) Very s
	(7) REFUSED ISKIP TO ##74d		(2) Some
			(3) Some
74			(4) Very (
74	b (C6Q0A_A)		(6) DON'1
	Has a plan for addressing these changing needs be providers?	en developed with (S.C)'s doctor or other health care	(7) Refus
	(1) YES		74f (C600D)
	(1) TES (2) NO		/4I (C6Q0D)
	(6) DON'T KNOW		This bir - should
	(7) REFUSED		Thinking about 1



(S.C.) 's health needs and the services (he/she) receives, how satisfied or dissatisfied are you ces? Would you say very satisfied, somewhat satisfied, somewhat dissatisfied or very

satisfied what satisfied ewhat dissatisfied dissatisfied T KNOW ISED

Thinking about the services (S.C.) needs, are those services organized in a way that makes them easy to use? Would you say this is true never, sometimes, usually or always?

- (1) Never (2) Sometimes (2) Sometimes(3) Usually(4) Always(6) DON'T KNOW
- (7) REFUSED

```
79
          (C6Q06)
      In the past 12 months, how often did ("S" CHILD)'s doctors or other health care providers help you feel like a
      partner in (his/her) care? Would you say:
               (1) Never
               (2) Sometimes
               (3) Usually
               (4) Always
               (6) DON'T KNOW
(7) REFUSED THIS QUESTION
 79a
 INTERVIEWER: LOOK ON BOTTOM OF HELP SHEET. IS THERE AN "S" CHILD ONLY OR IS THERE BOTH AN 
"S" CHILD AND AN "N" CHILD?
   "S" CHILD ONLY [CONTINUE 7A]
                                                          S" AND "N" CHILD [SKIP TO SECTION 7B]
```

(1) Never (2) Sometimes (3) Usually (4) Always

- (6) DON'T KNOW
- (7) REFUSED THIS QUESTION
- 77

76

75

(C6Q02)

(C6Q03)

(1) Never

(3) Usually

(4) Always

(2) Sometimes

(6) DON'T KNOW (7) REFUSED THIS QUESTION

say:

(C6Q04) When ("S" CHILD) is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs? Would you say: (1) Never (2) Usually (3) Sometimes (4) Always (6) DON'T KNOW

In the past 12 months/[WHEN S.C. IS YOUNGER THAN 12 MONTHS] Since (his/her) birth, how often

did ("S" CHILD)'s doctors and other health care providers spend enough time with (him/her)? Would you

In the past 12 months/[WHEN S.C. IS YOUNGER THAN 12 MONTHS] Since (his/her) birth, how often did ("S" CHILD)'s doctors or other health care providers listen carefully to you? Would you say:

(7) REFUSED THIS QUESTION

78

(C6Q05)

Information about a child's health or health care can include things such as the causes of any health problems, how to care for the child now, and what changes to expect in the future. In the past 12 months, how often did you get the specific information you needed from ("S" CHILD)'s doctors and other health care providers? Would you say:

(1) Never (2) Usually (3) Sometimes (4) Always

(6) DON'T KNOW (7) REFUSED THIS QUESTION

Section 7A. HEALTH INSURANCE (Households with One Sampled Child)

80 (C7Q03) Now I have a few questions about health insurance and health care coverage for (CHILD). At this time, is (CHILD) covered by health insurance that is provided through an employer or union or obtained directly from an insurance company? [IF ONLY PLAN NAME OFFERED, PROBE: Is this insurance provided through an employer or union or obtained directly from an insurance company? DO NOT INCLUDE DENTAL, VISION, SCHOOL, OR

ACCIDENT INSURANCE.] (1) Yes [SKIP TO #81 (C7Q03A)] (1) Yes [SKIP TO #81 (C7Q03A)]

(2) NO	[SKIP TO #82 (C7Q01)]
(6) DON'T KNOW	ISKIP TO #82 (C7Q01)]
(7) REFUSED THIS QUESTION	[SKIP TO #82 (C7Q01)]

HELP BOX: THESE TYPES OF HEALTH INSURANCE MAY REFER TO ANY TYPE OF HEALTH INSURANCE, INCLUDING HEALTH MAINTENANCE ORGANIZATIONS (HMO'S) OTHER THAN PUBLIC PROGRAMS. THESE PLANS MAY BE PROVIDED IN PART OR FULLY BY A PERSON'S EMPLOYER OR UNION, OR PURCHASED DIRECTLY BY THE INDIVIDUAL. IF RESPONDENT ASKS WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU UNDERSTAND THEIR CONCERN, BUT THESE QUESTIONS WERE WRITTEN TO INCLUDE ANY ADDITONAL HEALTH COVERAGE RESPONDENTS MIGHT HAVE.

IF NECESSARY, TO HELP RESPONDENT DETERMINE WHAT KIND OF INSURANCE THEY HAVE, PROBE: Did you get that insurance through an employer? Does it help pay for both doctor visits and hospital stays?

81 (C7003A)

Does this health insurance help pay for both doctor visits and hospital stays?

(1) YES (2) NO (6) DON'T KNOW

(6) DON'T KNOW(7) REFUSED THIS QUESTION

82

(H)

(1) YES (2) NO

(6) DON'T KNOW

(7) REFUSED THIS QUESTION

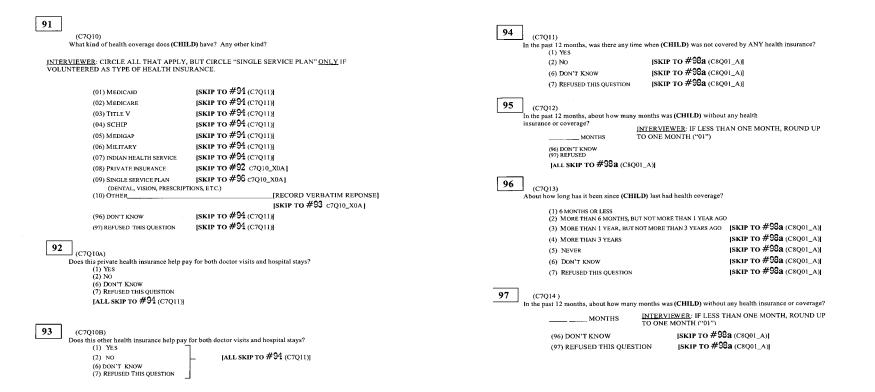
HELP BOX: MEDICAID IS A FEDERALSTATE MEDICAL ASSISTANCE PROGRAM. IT SERVES LOW-INCOME PEOPLE OF EVERY AGE. MEDICAL BILLS ARE PAID FROM FEDERAL, STATE AND LOCAL TAX FUNDS. PATIENTS USUALLY PAY NO PART OF COSTS FOR COVERED MEDICAL EXPENSES. IT IS RUN BY STATE AND LOCAL GOVERNMENTS WITHIN FEDERAL GUIDELINES. IF RESPONDENT ASKS WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU UNDERSTAND THEIR CONCERN, BUT THESE QUESTIONS WERE WRITTEN TO INCLUDE ANY ADDITONAL HEALTH COVERAGE RESPONDENTS MIGHT HAVE. THE TWO MOST IMPORTANT THINGS TO HELP THE RESPONDENT O DETERMINE WHAT TYPE OF INSURANCE THEY HAVE ARE WHERE IT COMES FROM AND WHAT IT COVERS. IF NECESSARY, TO HELP RESPONDENT DETERMINE WHAT KIND OF INSURANCE THEY HAVE, PROBE: DId you get that insurance through an employer? Does it help ap for both doctry wisis and hospital stays?

At this time, is (CHILD) covered by the State Children's Health Insurance Program or S-CHIP? In this state, the program is sometimes called 2 IINSERT S-CHIP NAME (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION HELP BOX: THE STATE CHILDREN'S HEALTH INSURANCE PROGRAM (SCHIP), CREATED UNDER TITLE XXI OF THE SOCIAL SECURITY ACT, EXPANDS HEALTH COVERAGE TO UNINSURED CHILDREN WHOSE FAMILIES EARN TOO MUCH FOR MEDICAID BUT TOO LITTLE TO AFFORD PRIVATE COVERAGE, IF RESPONDENT ASKS WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU UNDERSTAND THEIR CONCERN, BUT THESE QUESTIONS WERE WRITTEN TO INCLUDE ANY ADDITONAL HEALTH COVERAGE RESPONDENTS MIGHT HAVE THE TWO MOST IMPORTANT THINGS TO HELP THE RESPONDENT TO DETERMINE WHAT TYPE OF INSURANCE THEY HAVE ARE WHERE IT COMES FROM AND WHAT IT COVERS. IF NECESSARY, TO HELP RESPONDENT DETERMINE WHAT KIND OF INSURANCE THEY HAVE, PROBE: Did you get that insurance through an employer? Does it help pay for both doctor visits and hospital stays? (\mathbf{H}) (C7Q04) At this time, is (CHILD) covered by military health care, TRICARE, CHAMPUS, or CHAMP-VA? 84 (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION HELP BOX: "TRICARE" IS A MANAGED HEALTH CARE PROGRAM FOR ACTIVE DUTY AND RETIRED MEMBERS OF THE UNIFORMED SERVICES, THEIR FAMILIES, AND SURVIVORS, "CHAMPUS" IS A PROGRAM OF MEDICAL CARE FOR DEPENDENTS OF ACTIVE OR RETIRED MILITARY PERSONNEL "CHAMP-VA" IS MEDICAL INSURANCE FOR DEPENDENTS OR SURVIVORS OF DISABLED VETERANS. IF RESPONDENT ASKS WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU UNDERSTAND THEIR CONCERN, BUT THESE QUESTIONS WERE WRITTEN TO INCLUDE ANY ADDITONAL HEALTH COVERAGE RESPONDENTS MIGHT HAVE. THE TWO MOST IMPORTANT THINGS TO HELP THE RESPONDENT TO DETERMINE WHAT TYPE

(C7002)

OF INSURANCE THEY HAVE ARE WHERE IT COMES FROM AND WHAT IT COVERS. IF NECESSARY, TO HELP RESPONDENT DETERMINE WHAT KIND OF INSURANCE THEY HAVE, PROBE: Did you get that insurance through an employer? Does it help pay for both doctor visits and hospital stays?

(C7Q06) At this time, is (CHILD) enrolled in a Title Five program? In(STATE), the program is sometimes called(STATE TITLE V NAME). (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION	88a Is this health insurance provided through an employer? (1) YE s (2) NO (6) DON'T KNOW (7) REFUSED
HELP BOX: TITLE FIVE IS A STATE LEVEL TYPE OF HEALTH COVERAGE THAT A CHILD MAY HAVE. EACH STATE WILL HAVE A DIFFERENT NAME FOR THE TITLE FIVE PROGRAM. IF RESPONDENT ASKS WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU UNDERSTAND THEIR CONCERN, BUT THESE QUESTIONS WERE WRITTEN TO INCLUDE ANY ADDITONAL HEALTH COVERAGE RESPONDENTS MIGHT HAVE. THE TWO MOST IMPORTANT THINGS TO HELP THE RESPONDENT TO DETERMINE WHAT TYPE OF INSURANCE THEY HAVE ARE WHERE IT COMES FROM AND WHAT IT COVERS. IF NECESSARY, TO HELP RESPONDENT DETERMINE WHAT KIND OF INSURANCE THEY HAVE, PROBE: Did you get that insurance through an employer? Does it help pay for both doctor visits and hospital stays? 86 (C7Q07) At this time, is (CHILD) covered by any other kind of health insurance or health care plan that pays for services obtained from hospitals, doctors, and other health professionals? (DO NOT INCLUDE DENTSLY, VISION, SCHOOL, OR ACCIDENT INSURANCE]	89 INTERVIEWER: INSERT ANSWERS FROM HELP SHEET AND FOLLOW DIRECTIONS BELOW #81 #82 #83 #84 #85 #88
(1) YES (2) NO [SKIP TO #89] (6) DON'T KNOW [SKIP TO #89] (7) REFUSED THIS QUESTION [SKIP TO #89]	if box contains any "yes" answer, skip to $#94$ (C7Q11). otherwise, continue to $#90$.
87 (C7Q08) What kind of health plan is it? [IF ONLY INITIALS OR PARTIAL PLAN NAME OFFERED, PROBE FOR FULL NAME]. DO NOT INCLUDE DENTAL, VISION, SCHOOL, OR ACCIDENT INSURANCE. IF ONE OF THESE PLANS OFFERED ONLY, BACK UP TO PREVIOUS QUESTION AND CHANGE ANSWER TO 'NO'] RECORD VERBATIM RESPONSE	90 (C7Q09) It appears that (SELECTED CHILD) does not have any health insurance coverage to pay for services from both hospitals and doctors and other health professionals. Is that correct? (1) YE's [SKIP TO #96] (C7Q13)] (2) NO [SKIP TO #91] (6) DON'T KNOW [SKIP TO #982 (C9Q01)] (7) REFUSED THIS QUESTION
Does this health insurance help pay for both doctor visits and hospital stays? (1) YES (2) NO [SKIP TO #89] (6) DON'T KNOW [SKIP TO #89] (7) REFUSED THIS QUESTION [SKIP TO #89]	



Section 7B. HEALTH INSURANCE

98 (C7015) (HOUSEHOLDS WITH TWO SAMPLED CHILDREN) During the months when (CHILD) DID have health coverage, what kind of health coverage did (CHILD) H 80 have? [PROBE: Any other kind?] (C7O03) Now I have a few questions about health insurance and health care coverage for ("S" CHILD). At this time, (01) MEDICAID is ("S" CHILD) covered by health insurance that is provided through an employer or union or obtained (02) MEDICARE directly from an insurance company? (03) TITLE V [IF ONLY PLAN NAME OFFERED, PROBE: Is this insurance provided through an employer or union or (04) SCHIP obtained directly from an insurance company? DO NOT INCLUDE DENTAL, VISION, SCHOOL, OR ACCIDENT INSURANCE.] (05) MEDIGAP (06) MILITARY (07) INDIAN HEALTH SERVICE (1) YES [SKIP TO #81 (C7Q03A)] (08) PRIVATE INSURANCE (09) SINGLE SERVICE PLAN (DENTAL, VISION, PRESCRIPTIONS, ETC.) [SKIP TO #82 (C7Q01)] (2) NO [RECORD VERBATIM RESPONSE (10) OTHER [SKIP TO #82 (C7Q01)] (6) DON'T KNOW (96) DON'T KNOW [SKIP TO #82 (C7Q01)] (97) REFUSED (7) REFUSED THIS QUESTION HELP BOX; THESE TYPES OF HEALTH INSURANCE MAY REFER TO ANY TYPE OF HEALTH 98a (NO DATA) INSURANCE, INCLUDING HEALTH MAINTENANCE ORGANIZATIONS (HMO'S) OTHER THAN PUBLIC PROGRAMS. THESE PLANS MAY BE PROVIDED IN PART OR FULLY BY A PERSON'S INTERVIEWER: INSERT ANSWERS FROM ITEMS INDICATED EMPLOYER OR UNION, OR PURCHASED DIRECTLY BY THE INDIVIDUAL. IF RESPONDENT ASKS WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU UNDERSTAND THEIR CONCERN, BUT THESE QUESTIONS WERE WRITTEN TO INCLUDE ANY ADDITONAL #91 HEALTH COVERAGE RESPONDENTS MIGHT HAVE. IF NECESSARY, TO HELP RESPONDENT Response #81 DETERMINE WHAT KIND OF INSURANCE THEY HAVE, PROBE: Did you get that insurance through an Response 2 #92 #82 employer? Does it help pay for both doctor visits and hospital stays? Response 3 #83 #93 Response 4 #84 Response 5 (H) 81 #85 (C7Q03A) Response 6 #85 Does this health insurance help pay for both doctor visits and hospital stays? Response 7 (1) YES (2) NO (6) DON'T KNOW IF ANY BOX CONTAINS ANY "YES" ANSWER (1), CIRCLE "INSURED" UNDER THIS CHILD'S (7) REFUSED THIS QUESTION NAME IN BOX C OF HELPSHEET AND CONTINUE TO #98b OTHERWISE CIRCLE "UNINSURED," AND CONTINUE TO #98b 82 (C7Q01) At this time, is ("S" CHILD) covered by Medicaid, a health insurance program for persons with certain income levels and persons with disabilities? [INSERT IF APPLICABLE: In this state, the program is]. [STATE MEDICAID NAME] sometimes called 98b (NO DATA) (1) YES INTERVIEWER: IS THIS IS AN "S" CHILD? (2) NO (6) DON'T KNOW NO [SKIP TO SECTION 11] (7) REFUSED THIS QUESTION YES HELP BOX: MEDICAID IS A FEDERAL-STATE MEDICAL ASSISTANCE PROGRAM. IT SERVES LOW-INCOME PEOPLE OF EVERY AGE. MEDICAL BILLS ARE PAID FROM FEDERAL, STATE AND LOCAL TAX FUNDS. PATIENTS USUALLY PAY NO PART OF COSTS FOR COVERED MEDICAL EXPENSES. IT IS RUN BY STATE AND LOCAL GOVERNMENTS WITHIN FEDERAL GUIDELINES. IF RESPONDENT ASKS IF YOU CIRCLED "UNINSURED" FOR THIS CHILD, SKIP TO WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU UNDERSTAND THEIR **SECTION 9, OTHERWISE SKIP TO SECTION 8** CONCERN, BUT THESE QUESTIONS WERE WRITTEN TO INCLUDE ANY ADDITONAL HEALTH COVERAGE RESPONDENTS MIGHT HAVE. THE TWO MOST IMPORTANT THINGS TO HELP THE RESPONDENT TO DETERMINE WHAT TYPE OF INSURANCE THEY HAVE ARE WHERE IT COMES FROM AND WHAT IT COVERS. IF NECESSARY, TO HELP RESPONDENT DETERMINE WHAT KIND OF INSURANCE THEY HAVE, PROBE: Did you get that insurance through an employer? Does it help pay for both doctor visits and hospital stays?



(C7Q02) At this time, is (***S" CHILD**) covered by the State Children's Health Insurance Program or S-CHIP? In this state, the program is sometimes called [INSERT S-CHIP NAME].

(1)	YES
(2)	NO
(6)	DON'T KNOW
(7)	REFUSED THIS QUESTION

HELP BOX: THE STATE CHILDREN'S HEALTH INSURANCE PROGRAM (SCHIP), CREATED UNDER TITLE XXI OF THE SOCIAL SECURITY ACT, EXPANDS HEALTH COVERAGE TO UNINSURED CHILDREN WHOSE FAMILLES EARN TOO MUCH FOR MEDICAID BUT TOO LITTLE TO AFFORD PRIVATE COVERAGE. IF RESPONDENT ASKS WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU UNDERSTAND THEIR CONCERN, BUT THESE QUESTIONS WERE WRITTEN TO INCLUDE ANY ADDITONAL HEALTH COVERAGE RESPONDENTS MIGHT HAVE. THE TWO MOST IMPORTANT THINGS TO HELP THE RESPONDENT TO DETERMINE WHAT TYPE OF INSURANCE THEY HAVE ARE WHERE IT COMES FROM AND WHAT IT COVERS. IF NECESSARY, TO HELP RESPONDENT DETERMINE WHAT KIND OF INSURANCE THEY HAVE, PROBE: Did you get that insurance through an employer? Does it help pay for both doctor visits and hospital stays?

(H) 84

(C7Q04) At this time, is ("S" CHILD) covered by military health care, TRICARE, CHAMPUS, or CHAMP-VA?

- (1) YES
- (2) NO (6) DON'T KNOW

(7) REFUSED THIS QUESTION

HELP BOX:

"TRICARE" IS A MANAGED HEALTH CARE PROGRAM FOR ACTIVE DUTY AND RETIRED MEMBERS OF THE UNIFORMED SERVICES, THEIR FAMILIES, AND SURVIVORS.

"CHAMPUS" IS A PROGRAM OF MEDICAL CARE FOR DEPENDENTS OF ACTIVE OR RETIRED MILITARY PERSONNEL.

"CHAMP-VA" IS MEDICAL INSURANCE FOR DEPENDENTS OR SURVIVORS OF DISABLED VETERANS.

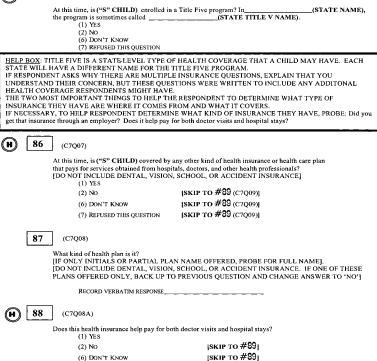
IF RESPONDENT ASKS WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU UNDERSTAND THEIR CONCERN, BUT THESE QUESTIONS WERE WRITTEN TO INCLUDE ANY ADDITONAL HEALTH COVERAGE RESPONDENTS MIGHT HAVE.

THE TWO MOST IMPORTANT THINGS TO HELP THE RESPONDENT TO DETERMINE WHAT TYPE OF

INSURANCE THEY HAVE ARE WHERE IT COMES FROM AND WHAT IT COVERS. IF NECESSARY, TO HELP RESPONDENT DETERMINE WHAT KIND OF INSURANCE THEY HAVE, PROBE:

Did you get that insurance through an employer? Does it help pay for both doctor visits and hospital stays?





(7) REFUSED THIS QUESTION

[SKIP TO #89]

Is this health insurance provided through an employer?

(1) YES (2) NO (6) DON'T KNOW (7) REFUSED

89

INTERVIEWER: INSERT ANSWERS FROM HELP SHEET AND FOLLOW DIRECTIONS BELOW

#81	
#82	
#83	
#84	
#85	
#88	

IF BOX CONTAINS ANY "YES" ANSWER (1), SKIP TO #94 (C7Q11). Otherwise, continue to #90.



(C7Q09) It appears that ("\$" CHILD) does not have any health insurance coverage to pay for services from both hospitals and doctors and other health professionals. Is that correct? (SUP T d # S6 (C7013))

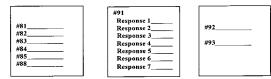
(1) YES	[SKIP TO #90 (C7Q13)]
(2) NO	[SKIP TO #91 (C7Q10)]
(6) DON'T KNOW	(skip to #98a)
(7) REFUSED THIS QUESTION	įskip to #98aj
(7) REFUSED THIS QUESTION	[SKIP TO # 96a]

	age does ("S" CHILD) have? Any other kind? Y, BUT CIRCLE "SINGLE SERVICE PLAN" <u>ONLY</u> IF
VOLUNTEERED AS TYPE OF HEALTH INS	SURANCE.
(01) MEDICAID	[SKIP TO #94 (C7Q11)]
(02) MEDICARE	[SKIP TO #94 (C7Q11)]
(03) TITLE V	[SKIP TO #94 (C7Q11)]
(04) SCHIP	[SKIP TO #94 (C7Q11)]
(05) MEDIGAP	[SKIP TO #94 (C7Q11)]
(06) MILITARY	[SKIP TO #94 (C7Q11)]
(07) INDIAN HEALTH SERVICE	[SKIP TO #94 (C7Q11)]
(08) PRIVATE INSURANCE	[SKIP TO #92 C7Q10_X0A]
(09) SINGLE SERVICE PLAN	[SKIP TO #96 C7Q10_X0A]
(DENTAL, VISION, PRESCRII (10) OTHER	PTIONS, ETC.) [RECORD VERBATIM RESPONSE
	[SKIP TO #93 C7010, X0A]
(96) DON'T KNOW	[SKIP TO #94 (C7Q11)]
(97) REFUSED THIS QUEST ION	ISKIP TO #94 (C7011)
	pay for both doctor visits and hospital stays?
Does this private health insurance help (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION	pay for both doctor visits and hospital stays?
Does this private health insurance help (1) YEs (2) NO (6) DON'T KNOW	pay for both doctor visits and hospital stays?
Does this private health insurance help (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION [SKIP TO #94 (C7Q11)] (C7Q10B)	pay for both doctor visits and hospital stays? ay for both doctor visits and hospital stays?
Does this private health insurance help (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION [SKIP TO #94 (C7Q11)] (C7Q10B) Does this other health insurance help pr (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION 94 (C7Q11)	ay for both doctor visits and hospital stays?
Does this private health insurance help (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION [SKIP TO #94 (C7Q11)] (C7Q10B) Does this other health insurance help pa (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION 94 (C7Q11) In the past 12 months, was there any tim	ay for both doctor visits and hospital stays? [ALL SKIP TO #94 (C7Q11)]
Does this private health insurance help (1) YES (2) NO (3) DON'T KNOW (7) REFUSED THIS QUESTION [SKIP TO #94 (C7Q11)] (C7Q10B) Does this other health insurance help po (1) YES (6) DON'T KNOW (7) REFUSED THIS QUESTION 94 (C7Q11) In the past 12 months, was there any tim (1) YES	ay for both doctor visits and hospital stays?

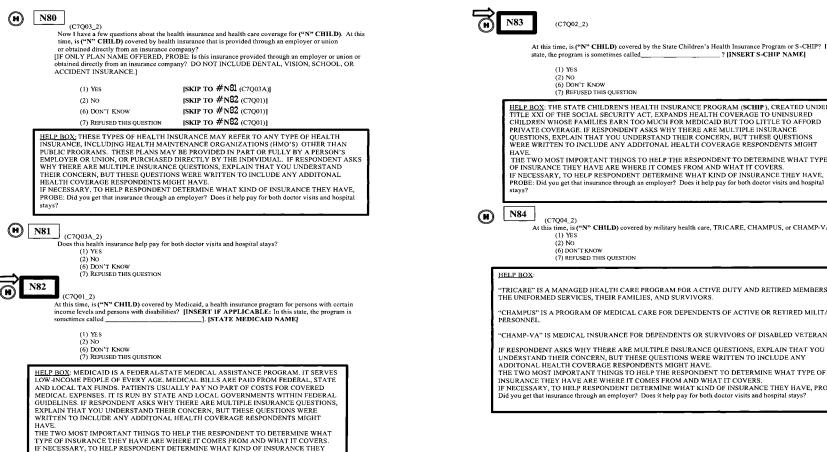
95	CC7Q12) In the past 12 months, about how many months was ("S" CHILD) wit any health insurance or coverage? <u>INTERVIEWER</u> : IF LESS THA TO ONE MONTHS (%) REFUSED (%) REFUSED (ALL SKIP TO #98a)	
	[ALL SKIP TO # 50a]	
96	(C7Q13) About how long has it been since ("S" CHILD) last had health covera	gc?
	(1) 6 MONTHS OR LESS	
	(2) MORE THAN 6 MONTHS, BUT NOT MORE THAN 1 YEAR AGO (3) MORE THAN 1 YEAR, BUT NOT MORE THAN 3 YEARS AGO	iskip to #98a1
	(4) MORE THAN 3 YEARS	[SKIP TO #98a]
	(4) MORE HIAN 3 YEARS (5) NEVER	[SKIP TO #98a]
		ISKIP TO #98a1
	(6) DON'T KNOW(7) REFUSED THIS QUESTION	[SKIP TO #98a]
97	TO ONE MONTHS TO ONE MONTH ("01")	hout any health insurance or coverage? AN ONE MONTH, ROUND UP
	(96) DON'T KNOW [SKIP TO #98a]	
	(97) REFUSED THIS QUESTION [SKIP TO #98a]	
98	(C7Q15) During the months when ("S" CHILD) DID have health coverage, wh ("S" CHILD) have? [PROBE: Any other kind?] (01) MEDICAID	at kind of health coverage did
	(0) MEDICARE (02) MEDICARE (03) TITLE V (04) SCHIP (05) MEDICAP (06) MILITARY	
	(07) INDIAN HEALTH SERVICE (08) PRIVATE INSURANCE	
	(05) FRIVATE INSUGANCE (09) SINGLE SERVICE PLAN (DENTAL, VISION, PRESCRIPTIONS, (10) OTHER (96) DON'T KNOW (07) REFUSED	ETC.) [RECORD VERBATIM RESPONSE]



INTERVIEWER: INSERT ANSWERS FROM ITEMS INDICATED



IF ANY BOX CONTAINS ANY "YES" ANSWER (1), CIRCLE "INSURED" UNDER THIS CHILD'S NAME IN BOX C OF HELPSHEET AND CONTINUE TO #N80. OTHERWISE CIRCLE "UNINSURED," AND CONTINUE TO #N80.



N83

HAVE.

stays?

N84

(C7Q02_2)

(1) YES

(2) NO (6) DON'T KNOW

(C7Q04_2)

(1) YES

(2) NO (6) DON'T KNOW

state, the program is sometimes called

(7) REFUSED THIS QUESTION

(7) REFUSED THIS QUESTION

At this time, is ("N" CHILD) covered by the State Children's Health Insurance Program or S-CHIP? In this

HELP BOX: THE STATE CHILDREN'S HEALTH INSURANCE PROGRAM (SCHIP), CREATED UNDER TITLE XXI OF THE SOCIAL SECURITY ACT. EXPANDS HEALTH COVERAGE TO UNINSURED

CHILDREN WHOSE FAMILIES EARN TOO MUCH FOR MEDICAID BUT TOO LITTLE TO AFFORD

WERE WRITTEN TO INCLUDE ANY ADDITONAL HEALTH COVERAGE RESPONDENTS MIGHT

THE TWO MOST IMPORTANT THINGS TO HELP THE RESPONDENT TO DETERMINE WHAT TYPE

IF NECESSARY, TO HELP RESPONDENT DETERMINE WHAT KIND OF INSURANCE THEY HAVE,

PROBE: Did you get that insurance through an employer? Does it help pay for both doctor visits and hospital

"TRICARE" IS A MANAGED HEALTH CARE PROGRAM FOR A CTIVE DUTY AND RETIRED MEMBERS OF

"CHAMPUS" IS A PROGRAM OF MEDICAL CARE FOR DEPENDENTS OF ACTIVE OR RETIRED MILITARY

"CHAMP-VA" IS MEDICAL INSURANCE FOR DEPENDENTS OR SURVIVORS OF DISABLED VETERANS.

IF NECESSARY, TO HELP RESPONDENT DETERMINE WHAT KIND OF INSURANCE THEY HAVE, PROBE

IF RESPONDENT ASKS WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU

INSURANCE THEY HAVE ARE WHERE IT COMES FROM AND WHAT IT COVERS.

At this time, is ("N" CHILD) covered by military health care, TRICARE, CHAMPUS, or CHAMP-VA?

PRIVATE COVERAGE. IF RESPONDENT ASKS WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU UNDERSTAND THEIR CONCERN, BUT THESE QUESTIONS

OF INSURANCE THEY HAVE ARE WHERE IT COMES FROM AND WHAT IT COVERS.

? [INSERT S-CHIP NAME]

HAVE, PROBE: Did you get that insurance through an employer? Does it help pay for both doctor visits and hospital stays?

(C7Q06_2) At this time, is ("N" CHILD) enrolled in a Title Five program? In	N88 (C7Q08A_2) Does this health insurance help pay for both doctor visits and hospital stays?
(STATE NAME), the program is sometimes called, [STATE TITLE V NAME] (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION	(1) YES [SKIP TO #N89] (2) No [SKIP TO #N89] (6) DON'T KNOW [SKIP TO #N89] (7) REFUSED THUS QUESTION [SKIP TO #N89]
HELP BOX: TITLE FIVE IS A STATE LEVEL TYPE OF HEALTH COVERAGE THAT A CHILD MAY HAVE. EACH STATE WILL HAVE A DIFFERENT NAME FOR THE TITLE FIVE PROGRAM. IF RESPONDENT ASKS WHY THERE ARE MULTIPLE INSURANCE QUESTIONS, EXPLAIN THAT YOU UNDERSTAND THEIR CONCERN, BUT THESE QUESTIONS WERE WRITTEN TO INCLUDE ANY ADDITONAL HEALTH COVERAGE RESPONDENTS MIGHT HAVE. THE TWO MOST IMPORTANT THINGS TO HELP THE RESPONDENT TO DETERMINE WHAT TYPE OF INSURANCE THEY HAVE ARE WHERE IT COMES FROM AND WHAT IT COVERS. IF NECESSARY, TO HELP RESPONDENT DETERMINE WHAT TIND OF INSURANCE THEY HAVE, PROBE: Did you get that insurance through an employer? Does it help pay for both doctor visits and hospital stays?	N88a Is this health insurance provided through an employer? (1) YES (2) NO (6) DON'T KNOW (7) REFUSED
N86 (C7Q07_2) At this time, is ("N" CHILD) covered by any other kind of health insurance or health care plan that pays for services obtained from hospitals, doctors, and other health professionals? [DO NOT INCLUDE DENTAL, VISION, SCHOOL, OR ACCIDENT INSURANCE] (1) YES (2) NO [SKIP TO # N 89] (6) DO NT KNOW [SKIP TO # N 89] (6) DO NT KNOW [SKIP TO # N 89] (7) REFUSED THIS QUESTION [SKIP TO # N 89] (7) REFUSED THIS QUESTION [SKIP TO # N 89] (7) R87 (C7Q08_2)	N89 (INSURANCE WORKSHEET) INTERVIEWER: INSERT ANSWERS FROM HELP SHEET AND FOLLOW DIRECTIONS BELOW #N81
What kind of health plan is it? [IF ONLY INITIALS OR PARTIAL PLAN NAME OFFERED, PROBE FOR FULL NAME]. [DO NOT INCLUDE DENTAL, VISION, SCHOOL, OR ACCIDENT INSURANCE. IF ONE OF THESE PLANS OFFERED ONLY, BACK UP TO PREVIOUS QUESTION AND CHANGE ANSWER TO 'NO'] RECORD VERBATIM RESPONSE	if box contains any "yes" answer (1), skip to #N94 (c7q11). otherwise, continue to #N90 .

(H) N90

(C7Q09) It appears that ("N" CHILD) does not have any health insurance coverage to pay for services from both hospitals and doctors and other health professionals. Is that correct?

this and doctors and other neurin professionals. Is that correctly	
(1) YES	[SKIP TO #N96 (C7Q13)]
(2) NO	[SKIP TO #N91 (C7Q10_2)]
(6) Don't Know	iskip to #991
(7) REFUSED THIS QUESTION	įskip to #99j

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N94 (C7Q11_2) In the past 12 months, was there any time when ("N" CHILD) was not covered by ANY health insurance? At this time, what kind of health coverage does ("N" CHILD) have? Any other kind? (1) YES INTERVIEWER: CIRCLE ALL THAT APPLY, BUT CIRCLE "SINGLE SERVICE PLAN" ONLY IF VOLUNTEERED AS TYPE OF HEALTH INSURANCE. **ISKIP TO #99**] (2) NO [SKIP TO #99] (6) DON'T KNOW [SKIP TO #99] (7) REFUSED THIS QUESTION **ISKIP TO #N94** (C7Q11)] **ISKIP TO #N94** (C7Q11) ISKIP TO #N94 (C7011)] N95 (C7Q12_2) In the past 12 months {or his/her birth}, about how many months was ("N" CHILD) without any health insurance or coverage? ISKIP TO #N94 (C7011) [SKIP TO #N94 (C7Q11)] INTERVIEWER: IF LESS THAN ONE MONTH, ROUND UP TO ONE MONTH ("01") [SKIP TO #N94 (C7Q11)] (96) DON'T KNOW (97) REFUSED [SKIP TO #N94 (C7Q11)] [SKIP TO #N92 C7Q10_X0A] [SKIP TO #99] [SKIP TO #N96 C7Q10_X0A] [RECORD VERBATIM RESPONSE] N96 (C7Q13_2) [SKIP TO #N93 C7Q10_X0A] About how long has it been since ("N" CHILD) last had health coverage? [SKIP TO #N94 (C7Q11)] (1) 6 MONTHS OR LESS ISKIP TO #N94 (C7011)] (2) MORE THAN 6 MONTHS, BUT NOT MORE THAN 1 YEAR AGO (3) More than 1 year, but not more than 3 years ago [SKIP to #99 (C8Q01_A)] ISKIP TO #99 (C8001 A) (4) MORE THAN 3 YEARS Does this private health insurance help pay for both doctor visits and hospital stays? [SKIP TO #99 (C8Q01_A)] (5) NEVER [SKIP TO #99 (C8Q01_A)] (6) DON'T KNOW ISKIP TO #99 (C8001 A) (7) REFUSED THIS QUESTION

N93_ (C7Q10B_2)

N91

(C7Q10_2)

(01) MEDICAID

(02) MEDICARE

(03) TITLE V

(04) SCHIP

(05) MEDIGAP

(06) MILITARY

(10) OTHER

N92 (C7Q10A_2)

(96) DON'T KNOW

(07) INDIAN HEALTH SERVICE

(08) PRIVATE INSURANCE

(09) SINGLE SERVICE PLAN

(97) REFUSED THIS QUESTION

(1) YES
 (2) NO
 (6) DON'T KNOW
 (7) REFUSED THIS QUESTION

[SKIP TO #N94 (C7Q11)]

(DENTAL, VISION, PRESCRIPTIONS, ETC.)

Does this other health insurance help pay for both doctor visits and hospital stays?

(1) YES (2) NO

(6) DON'T KNOW(7) REFUSED

[ALLSKIP TO #N94 (C7Q11)]

N97 (C7Q14_2)

In the past 12 months {or since his/her birth}, about how many months was ("N" CHILD) without any health insurance or coverage? INTERVIEWER: IF LESS THAN ONE MONTH, ROUND UP TO ONE MONTH ("01")

MONTHS

(96) DON'T KNOW [SKIP TO #99] (97) REFUSED THIS QUESTION [SKIP TO #99]

N98 (C7Q15_2)

(0	1) MEDICAID	
(O	2) MEDICARE	
ò	3) TITLE V	
(C	4) SCHIP	
- io	5) MEDIGAP	
(0	6) MILITARY	
(0	7) INDIAN HEALTH SERVICE	
(0	8) PRIVATE INSURANCE	
(C	9) SINGLE SERVICE PLAN (DENTAL, VISION,	PRESCRIPTIONS, ETC.)
- à	0) OTHER	[RECORD VERBATIM RESP ONSE]
Ġ	6) DON'T KNOW	
Ò	7) REFUSED	

99

INTERVIEWER: INSERT ANSWERS FROM ITEMS INDICATED

(NO DATA)

#N81 #N82 #N83 #N84 #N85 #N88	#N91 Response 1 Response 2 Response 4 Response 5 Response 6 Response 7	#N92 #N93
--	--	--------------

IF ANY BOX CONTAINS ANY "YES" ANSWER (1), CIRCLE "INSURED" UNDER "N" CHILD'S NAME IN BOX C OF HELPSHEET. OTHERWISE CIRCLE "UNINSURED.

INTERVIEWER: LOOK AT HELPSHEET. IF "UNINSURED" IS CIRCLED FOR "S" CHILD, SKIP TO SECTION 9. OTHERWISE SKIP TO SECTION 8.

Section 8. ADEQUACY OF HEALTH CARE COVERAGE

100	(C8Q01_A) The next questions are about ("S" CHILD)'s health insurance or health care plans. Does ("S" CHILD)'s health insurance offer benefits or cover services that meet (his/her) needs? Would you say: (1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED THIS QUESTION
101	(C8Q01_B) Are the costs not covered by (*S'' CHILD)'s health insurance reasonable? Would you say: (1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED THIS QUESTION
102	(C8Q01_C) Does ("S" CHILD)'s health insurance allow (him/her) to see the health care providers (he/she) needs? Would you say: (1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED THIS QUESTION
103	(C8Q02) In the past 12 months, have you called or written to any of ("S" CHILD)'s health care plans with a complaint or problem? (1) YES

- (1) YES (2) NO
- (2) NO (6) DON'T KNOW
- (7) REFUSED THIS QUESTION

Section 9. IMPACT ON THE FAMILY 104 (C8Q03) We want to know your rating of all your experience with ("S" CHILD)'s current health care plan(s). Use 108 any number from zero to ten where zero is the worst health plan possible and 10 is the best health care plan (C9Q01) possible. How would you rate ("S" CHILD)'s health care plan(s) now? The next question is about the amount of money paid during the past 12 months for ("S" CHILD)'s medical or another source. But do include out-of pocket payments for all types of health-related needs such as medications, special foods, adaptive clothing, durable equipment, home modifications and any kind of (96) DON'T KNOW therapy. During the past 12 months, would you say that the family paid more than \$500, \$250-\$500, (97) REFUSED THIS QUESTION less than \$250, or nothing for ("S" CHILD)'s medical care? -(1) MORE THAN \$500 105 (C8Q04) [SKIP TO #110 (C9Q02)] (2) \$250-\$500 If you had the chance, would you switch to a different health care plan for ("S" CHILD)? Would you say: [SKIP TO #110 (C9Q02)] (3) LESS THAN \$250 (1) Definitely yes (2) Probably yes [SKIP TO #110 (C9Q02)] (4) NOTHING, \$0 (3) Probably not or [SKIP TO #110 (C9Q02)] (6) DON'T KNOW (4) Definitely not (6) DON'T KNOW [SKIP TO #110 (C9Q02)] (7) REFUSED THIS QUESTION (7) REFUSED THIS QUESTION 109 106 (C9Q01_A) (C8Q05) During the past 12 months, would you say that the family paid \$500-\$1000, \$1000-\$5000, or Do you have enough information about how ("S" CHILD)'s health plan(s) works? more than \$5000 for ("S" CHILD)'s medical care? (1) YES (2) No (1) MORE THAN \$5000 (6) DON'T KNOW (2) \$1001-\$5000 (7) REFUSED THIS QUESTION (3) \$501-\$1000 (6) DON'T KNOW (7) REFUSED THIS QUESTION 107 (C8Q06) Do you believe ("S" CHILD)'s health plan(s) is good for children with special health care needs? (1) YES 110 C9Q02 (9.2) (2) NO Many families provide health care at home such as changing bandages, care of feeding or breathing (6) DON'T KNOW equipment, giving medication and therapies, and providing transportation to appointments. Do you or (7) REFUSED THIS QUESTION other family members provide health care at home for ("S" CHILD)? (1) YES ISKIP TO #113 (C9004)] (2) NO **ISKIP TO #113** (C9004)1 (6) DON'T KNOW

(7) REFUSED THIS QUESTION [SKIP TO #113 (C9Q04)]

care. Please do not include health insurance premiums or costs that were or will be reimbursed by insurance

111

(C9Q03) How many hours per week do you or other family members spend providing this kind of care?

HOURS PER WEEK

(000) LESS THAN ONE HOUR (168) AROUND THE CLOCK (996) DON'T KNOW (997) REFUSED THIS QUESTION

112

I have (ANSWER FROM #111) hours. Is that correct?

(1) YES

(C9Q03_A)

(2) NO [SKIP BACK TO #111]

113

(C9Q04)

How many hours per week do you or other family members spend arranging or coordinating ("S" CHILD)'s care? By this I mean making appointments, making sure that care providers are exchanging information, and following up on ("S" CHILD)'s care needs.

HOURS PER WEEK

(000) LESS THAN ONE HOUR (996) DON'T KNOW (997) REFUSED THIS QUESTION

114 (C9Q04_A)

> I have (ANSWER FROM #113) hours. Is that correct? (1) YES (2) NO [SKIP BACK to #113]

115

(C9Q05) Has ("S" CHILD)'s health conditions caused financial problems for your family? (1) YES (2) NO

(6) DON'T KNOW

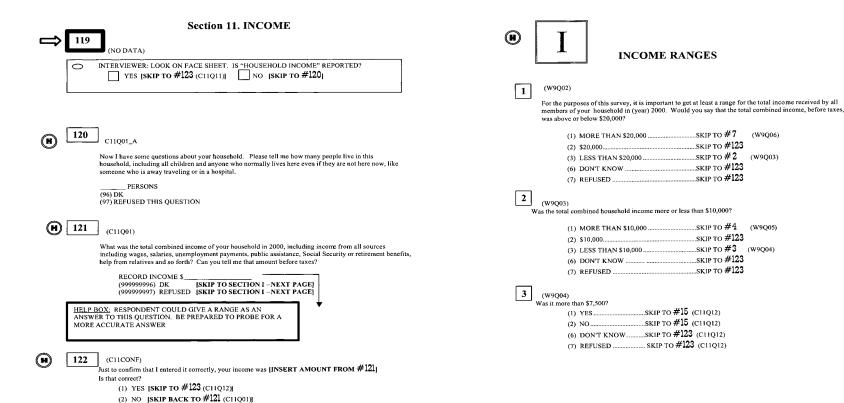
(7) REFUSED THIS QUESTION

116 (C9Q06) Have you or other family members cut down on the hours you work to care for ("S" CHILD)? (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION 117 (C9Q07) Have you needed additional income to cover ("S" CHILD)'s medical expenses? (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION 118

(C9Q10)

Have you or other family members stopped working because of ("S" CHILD)'s health conditions? (1) YES (2) NO (6) DON'T KNOW

(7) REFUSED THIS QUESTION



4 (W9Q05) Was it more than \$15,000?

	YES				
(2)	NO	SKIP	то	#6	(W9Q05B)
	DON'T KNOW				
(7)	REFUSED	SKIP	то	#123	(C11Q12)

5

(W9Q05A) Was it more than \$17,500?

	SKIP TO #15 (C11Q12)
(2) NO	SKIP TO #15 (C11Q12)
(6) DON'T KNOW	SKIP TO #123 (C11Q12)
(7) REFUSED	SKIP TO #123 (C11Q12)

6

(W9Q05B) Was it more than \$12,500

	SKIP TO #15 (C11Q12)
(2) NO	SKIP TO #15 (C11Q12)
	SKIP TO #123 (C11Q11)
(7) REFUSED	SKIP TO #123 (C11Q11)

7 (W9q06)

- (11)400)	
Was the total combined household income more or less than \$40,000?	
(1) MORE THAN \$40,000	SKIP TO #8 (W9Q06A)
(2) \$40,000	skip to #123
(3) LESS THAN \$40,000	SKIP TO #11 (W9Q07)
(6) DONT KNOW	skip to #123
(7) REFUSED	skip to #123

8 (W9Q06A) Was the total co

the total combined household income more or less than \$60,000?	
(1) MORE THAN \$60,000	SKIP TO #14 (W9Q08)
(2) \$60,000	skip to #123
(3) LESS THAN \$60,000	SKIP TO #9 (W9Q06B)
(6) DONT KNOW	skip to #123
(7) REFUSED	skip to #123

9

(W9Q06B) Was the total combined household income more or less than \$50,000?

(1) MORE THAN \$50,000 SKIP T	o #15
(2) \$50,000 SKIP Te	o #123
(3) LESS THAN \$50,000 SKIP T	o #10 (W9Q06C)
(6) DONT KNOW SKIP T	o #123
(7) REFUSED SKIP T	o #123

10 (W9Q06C)

Was the total combined household income more or less than \$45,000?

(1) MORE THAN \$45,000	skip to #15
(2) \$45,000	skip to #123
(3) LESS THAN \$45,000	skip to #15
(6) DONT KNOW	skip to #123
(7) REFUSED	skip to #123

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state

11 (W9007)

Was the total combined household income more or less than \$30,000?

(1) MORE THAN \$30,000	skip to #12 w9ç
(2) \$30,000	skip to #123
(3) LESS THAN \$30,000	skip to #13 (w
(6) DONT KNOW	skip to #123
(7) REFUSED	skip to #123

12

(W9007A)

(W9Q07B)

(W9Q08)

Was the total combined household income more or less than \$35,000?

(1) MORE THAN \$35,000	skip to #15
(2) \$35, 000	skip to #123
(3) LESS THAN \$35,000	skip to #15
(6) DONT KNOW	skip to #123
(7) REFUSED	skip to #123

13

Was the total combined household income more or less than \$25,000?

(1)	MORE THAN \$25,000	skip to #15
(2)	\$25,000	sкip to #123
(3)	LESS THAN \$25,000	sкip to #15
(6)	DONT KNOW	skip to #123
(7)	REFUSED	skip to #123

14

Was the total combined household income more or less than \$75,000?

(1) MORE THAN \$75,000	skip to #15
(2) \$75,000	skip to #123
(3) LESS THAN \$75,000	skip to #15
(6) DONT KNOW	skip to #123
(7) REFUSED	skip to #123

15 W9Q12 (CHECK_I12) BASED ON THE RANGE ALREADY IDENTIFIED, THIS NEXT QUESTION WILL BE FILLED WITH A DOLLAR AMOUNT THAT FALLS WITHIN THE RANGE AND IS EQUIVALENT TO 50%, 100%, 133%, 150%, 185%, 200%, 300%, OR 400% OF THE FEDERAL POVERTY LEVEL BASED ON THE NUMBER OF FAMILY MEMBERS. IF THE RANGE IDENTIFIED IS NARROW ENOUGH THAT NONE OF THESE POVERTY LEVEL CUTOFFS FALL WITHIN THE RANGE. THEN SKIP TO #123. FOR A FEW RANGES, TWO ADDITIONAL QUESTIONS WILL BE NEEDED. Would you say this income was above or below [\$REF] ? MORE THAN [\$REF] [WHEN INDICATED, ASK #16] 16 W9Q12a. Would you say this income was above or below [SREF] ? MORE THAN [\$REF]1 [GO TO #123] 123 (C11Q12) Does (CHILD) receive SSI, that is Supplemental Security Income? (1) YES [SKIP to #125 C11011] (2) NO ISKIP to #125 C110111 (6) DON'T KNOW [SKIP to #125 C11Q11] (7) REFUSED THIS QUESTION 124 (C11Q13) Is this for a disability (he/she) has? (1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION (C11011)

(ASK ONLY IN HOUSEHOLDS WITH INCOME BELOW 200% POVERTY)

cash assistance from a state or county welfare program, such as _____

At any time during the past 12 months, even for one month, did anyone in this household receive any

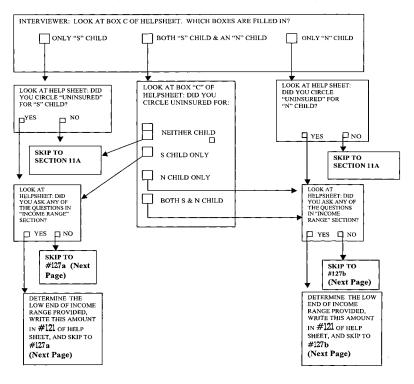
125

TANF namej?

(1) YES (6) DON'T KNOW (2) NO (7) REFUSED



Please hold for just a moment while I determine which questions to ask for the final part of this interview.



Û	Û
127a (NO DATA)	127b (NO DATA)
FOLLOW THE GRID AND DIRECTIONS BELOW TO DETERMINE WHICH QUESTIONS TO ASK NEXT.	FOLLOW THE GRID AND DIRECTIONS BELOW TO DETERMINE WHICH QUESTIONS TO ASK NEXT.
(1) LOOK AT HELPSHEET #120 TO DETERMINE THE NUMBER OF PEOPLE LIVING IN HOUSEHOLD.	(1) LOOK AT HELPSHEET #120 TO DETERMINE THE NUMBER OF PEOPLE LIVING IN HOUSEHOLD.
(2) FIND THAT NUMBER ON THE GRID BELOW.	(2) FIND THAT NUMBER ON THE GRID BELOW.
(3) FOLLOW THAT NUMBER	(3) FOLLOW THAT NUMBER
TO: Lower 48 Alaska Hawaii	TO: O Lower 48 O Alaska O Hawaii
(4) WRITE THE NUMBER HERE:	(4) WRITE THE NUMBER HERE:
(5) IF THE NUMBER LISTED IN GRID GREATER THAN ANSWER #121 ON HELPSHEET, SKIP TO SECTION 12, IF NOT SKIP TO SECTION 11A (C11Q14).	(5) IF THE NUMBER LISTED IN GRID GREATER THAN ANSWER #121 ON HELPSHEET, SKIP TO SECTION 13, IF NOT SKIP TO SECTION 11A (C11Q14).

2000 Poverty Levels ¹				
# of People	200% of Poverty Level	200% of Poverty Level	200% of Poverty Level	
Living in the Household	LOWER 48 STATES (& Washington D.C.)	ALASKA	HAWAU	
2	22,500	28,120	25,860	
3	28,300	35,380	32,540	
4	34,100	42,640	39,220	
5	39,900	49,900	45,900	
6	45,700	57,160	52,580	
7	51,500	64,420	59,260	
8	57,300	71,680	65,940	
9	63,100	78,940	73,200	
10	68,900	86,200	79,880	
11	74700	93,460	86,560	
12	80500	100,720	93,240	
13	86300	107,980	99,920	
14	92100	115,240	106,600	
15	97900	122,500	113,280	
16	103700	129,760	119,960	
17	109500	137,020	126,640	
18	115300	144,280	133,320	

2001 Poverty Levels					
# of People Living in the Household	200% of Poverty Level LOWER 48 STATES (& Washington D.C.)	200% of Poverty Level ALASKA	200% of Poverty Level HAWAII		
2	23,220	29,020	26,720		
3	29,260	36,580	33,660		
4	35,300	44,140	40,600		
5	41,340	51,700	47,540		
6	47,380	59,260	54,480		
7	53,420	66,820	61,420		
8	59,460	74,380	68,360		
9	65,500	81,940	75,300		
10	71,540	89,500	82,240		
11	77,580	97,060	89,180		
12	83,620	104,620	96,120		
13	89,660	112,180	103,060		
14	95,700	119,740	110,000		
15	101,740	127,300	116,940		
16	107,780	134,860	123,880		
17	113,820	142,420	130,820		
18	119,860	149,980	137,760		

¹ Poverty levels based on 2000 guidelines were used with 1999 income for interviews conducted from October 17, 2000 through December 31, 2000, and with 2000 income for interviews conducted from January 1, 2001 through February 26, 2001. Poverty levels based on 2001 guidelines and 2000 income were implemented on February 27, 2001.

Section 13. UTILIZATION AND BARRIERS TO CARE QUESTIONS FOR LOW-INCOME/UNINSURED CHILDREN WITHOUT SPECIAL HEALTH CARE NEEDS

128 (C13Q1)

Now I have some other questions about ("N" CHILD).

INTERVIEWER: IF CHILD IS 0-4 YEARS OLD, SKIP TO #129 (C13Q2)

During the past 12 months, that is since (1 YEAR AGO TODAY), about how many days did ("N" CHILD) miss school because of illness or injury?

(1) NONE (2) DID NOT GO TO SCHOOL (3) HOME SCHOOLED (96) DON'T KNOW (97) REFUSED

129

(C13Q2) Is there a place that ("N" CHILD) "usually" goes to if (he/she) is sick or you need advice about (his/her) health?

(1) YES	јзкір то #130а (С13Q3)]
(2) THERE IS NO PLACE	[SKIP TO #131a (C13Q4)]
(3) THERE IS MORE THAN ONE PLACE	јѕкір то #130b (с13Q3) ј
(6) DON'T KNOW	[SKIP TO #131a (C13Q4)]
(7) REFUSED THIS QUESTION	[SKIP TO #131a (C13Q4)]

130a (C13Q3)

What kind of place is it? Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?

(01) DOCTOR'S OFFICE (OR HMO)	[SKIP TO #131 (C13Q4)]
(02) HOSPITAL EMERGENCY ROOM	[SKIP TO #131 (C13Q4)]
(03) HOSPITAL OUTPATIENT DEPARTMENT	ISKIP TO #131 (C13Q4) J
(04) CLINIC OR HEALTH CENTER	[SKIP TO #131 (C13Q4)]
(05) SCHOOL (NURSE'S OFFICE,	[SKIP TO #131 (C13Q4)]
ATHLETIC TRAINER'S OFFICE, ETC)	
(06) SOME OTHER PLACE	[RECORD VERBATIM RESPONSE]
	[SKIP TO #131 (C13Q4a)]
(07) DOES NOT GO TO ONE PLACE MOST OFTEN	[SKIP TO #131a (C13Q4a)]
(96) DON'T KNOW	[SKIP TO #131a (C13Q4a)]
(97) Refused this question	[SKIP TO #131a (C13Q4a)]

130b

What kind of place does ("N" CHILD) go to most often? Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?

(01) DOCTOR'S OFFICE (OR HMO)	[SKIP TO #131 (C13Q4)]
(02) HOSPITAL EMERGENCY ROOM	[SKIP TO #131 (C13Q4)]
(03) HOSPITAL OUTPATIENT DEPARTMENT	[SKIP TO #131 (C13Q4)]
(04) CLINIC OR HEALTH CENTER	[SKIP TO #131 (C13Q4)]
(05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC)	[SKIP TO #131 (C13Q4)]
	-
(06) SOME OTHER PLACE	[RECORD VERBATIM RESPONSE]
 (06) SOME OTHER PLACE	[RECORD VERBATIM RESPONSE] [SKIP TO #131 (C13Q4a)] [SKIP TO #131a (C13Q4a)] [SKIP TO #131a (C13Q4a)] [SKIP TO #131a (C13Q4a)]

131 (C13Q4)

Is that [PLACE SELECTED IN #130a/130b] the same place ("N" CHILD) usually goes when (he/she) needs routine preventive care, such as a physical examination or checkup?

(she) needs routine preventive care, su	ch as a physical examination or checkup?
(1) YES	[SKIP TO #131b (C13Q4B)]
(2) NO	
(6) DON'T KNOW	[SKIP TO #131b (C14Q4B)]
(7) REFUSED THIS QUESTION	[SKIP TO #131b (C14Q4B)]

131a

- (C13Q4A) What kind of place does ("N" CHILD) USUALLY go to when (he/she) needs routine preventive
- care, such as a physical examination or check-up?
 - (1) DOES NOT GET PREVENTIVE CARE ANYWHERE (2) DOCTOR'S OFFICE

 - (3) HOSPITAL EMERGENCY ROOM (4) HOSPITAL OUTPATIENT DEPARTMENT
 - (5) CLINIC OR HEALTH CENTER
 - (6) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC.)
 - (7) SOME OTHER PLACE_ [RECORD VERB. RESPONSE]
 - (8) DOES NOT GO TO ONE PLACE MOST OFTEN
 - (96) DON'T KNOW
 - (97) REFUSED THIS QUESTION

131b

(C13Q4B)

A personal doctor or nurse is the health provider who knows ("N" CHILD) best. Do you have one person that you think of as ("N" CHILD)'s personal doctor or nurse?

(1) YES	[SKIP TO #131c (C13Q4)]
(2) NO	[SKIP TO #132 (C13Q5)]
(6) DON'T KNOW	[SKIP TO #132 (C13Q5)]
(7) REFUSED THIS QUESTION	[SKIP TO #132 (C13Q5)]

131c (C13Q4C)

(96) DON'T KNOW (97) REFUSED

Is this person a general doctor, pediatrician, specialist, nurse practitioner, or physician's assistant?

(01) GENERAL DOCTOR (SUCH AS A DOCTOR IN GENERAL PRACTICE, FAMILY MEDICINE, INTERNAL MEDICINE) (02) PEDIATRICIAN (03) OTHER SPECIALIST (SUCH AS OB-GYN, SURGEONS, HEART DOCTORS, PSYCHIATRISTS, ALLERGY DOCTORS, SKIN DOCTORS, OBSTETRICIANS, OR GYNECOLOGISTS) (04) NURSE PRACTITIÓNER (05) PHYSICIAN'S ASSISTANT (06) OTHER_ [RECORD VERB. RESPONSE] 132 (C13Q5)

People often delay or do not get needed health care. By health care I mean medical care as well as other kinds of care like dental care, mental health services, physical, occupational or speech therapies, and special education services. In the past 12 months, have you delayed or gone without health care for ("N" CHILD)?

(1) YES (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION

HELP SCREEN: A parent that attempts to treat a child by themselves but then takes the child to a doctor should not be considered a delay in health care. FOR EXAMPLE A CHILD WITH A COUGH OR SORE THROAT WHO IS GIVEN COUGH SYRUP AT HOME, BUT THE COUGH SYRUP DOES NOT HELP OR WORK.



During the past 12 months, was there any time when (N CHILD) needed any of the following services:

133a	133b	133c
(C13Q06_01)	(C13Q601A)	
During the past 12 months was there any time when ("N" CHILD) needed routine preventive care, such as a physical examination or well child check- up? (1) YES (2) NO (SKIP TO #134a) (6) DK (SKIP TO #134a) (7) REF (SKIP TO #134a)	Did ("N" CHILD) receive all the routine preventive care that (he/she) needed? (1)YES (SKIP TO #134a) (2) No (6) DK (SKIP TO #134a) (7) REF (SKIP TO #134a)	Why did (*N' CHILD) not receive all the routine preventive care (he/she) needed? (CIRCLE ALL THAT APPLY) (1) COST TOO MUCH (2) HEALTH PLAN PROBLEM (3) NOT AVAILABLE IN AREA/TRANSPORT PROBLEMS (4) NOT CONVENIENT TIMES (5) DOCTOR DID NOT KNOW HOW TO TREAT OR PROVIDE CARE (6) OTHER (96) DON'T KNOW (97) REFUSED THIS QUESTION
134a	134b	134c
(C13Q6_02)	(C13Q6_02A)	(C13Q6_02A)
(During the past 12 months, was there any time when ("N" CHILD) needed) Care from a specialty doctor?		Why did ("N" CHILD) not get the care from a specialty doctor that {he/she} needed? (CIRCLE ALL THAT APPLY)
(1) YES (2) NO (SKIP TO #135a) (6) DK (SKIP TO #135a) (7) REF (SKIP TO #135a)	Did (*N" CHILD) receive all the care from a specialty doctor that {he/she} needed? (1)YES (SKIP TO #135a) (2) NO (6) DK (SKIP TO #135a) (7) REF (SKIP TO #135a)	 COST TOO MUCH HEALTH PLAN PROBLEM NOT AVAILABLE IN AREA/TRANSPORT PROBLEMS OT CONVENIENT TIMES DOCTOR DID NOT KNOW HOW TO TREAT OR PROVIDE CARE OTHER OTHER (6) OTHER (96) DON'T KNOW (97) REFUSED THIS QUESTION
HELP SCREEN: SPECIALTY DOCTO CHILD'S HEALTH. THESE INCLUDE O THROAT DOCTORS, SURGEONS, ETC. WITH BREATHING PROBLEMS LIKE AN	CARDIOLOGISTS, EAR, NOSE AND EXAMPLE: PULMOLOGISTS WORK	

135a]		135b			135c	
(C13Q6_03)		(C13Q6_0	3A)				
(During the past 12 n there any time when needed) Dental care i check-ups? (1) YES (2) NO (SKIP TO (6) NO (SKIP TO (7) REF (SKIP TO	("N"CHILD) ncluding #135.1a) #135.1a)			(C13Q6_03A) Why did ("N" CHILD) not get the dental care that {he/she} needed? (CIRCLE ALL THAT APPLY) (1) COST TOO MUCH (2) HEALTH PLAN PROBLEM (3) NOT AVAILABLE IN AREA/TRANSPORT PROBLEMS (4) NOT CONVENIENT TIMES (5) DOCTOR DID NOT KNOW HOW TO TREAT OR PROVIDE CARE (6) OTHER (96) DON'T KNOW (97) REFUSED THIS QUESTION		(she) (APPLY) BLEM N PROBLEMS TIMES NOW HOW VIDE CARE	
135.1a]		135.1b			135.1c	
 (C13Q6_04) (During the past 12 m there any time when (*N" CHILD) neede Prescription medicati (1) YES (2) NO (SKIP TO # (6) DK (SKIP TO # (7) REF (SKIP TO # 	1) ons? +136a) +136a)	prescriptio needed? (1)YES (SF (2) NO (6) DK (SF	4A) CHILD) recc n medicatior (IP TO #1 KIP TO #1	ns {he/she} 36a) 36a)	the prescri {he/she} n (CIRCLE (1) COST (2) HEAL (3) NOT A AREA (4) NOT C (5) DOCTO TO TR (6) OTHEI (96) DON"	"N" CHILD ption medica eeded? ALL THAT TOO MUCH TH PLAN PRO WAILABLE II TRANSPORT I ON VENIENT 1 DR DID NOT K EAT OR PROV R	APPLY) BLEM N PROBLEMS NIMES NOW HOW VIDE CARE

136a	136b	136c
(C13Q6_05) (During the past 12 months was there any time when ("N" CHILD) needed) Physical, occupational or speech therapy? (1) YES (2) NO (SKIP TO #137a) (6) DK (SKIP TO #137a) (7) REF (SKIP TO #137a)	(C13Q6_05A) Did ("N" CHILD) receive al physical, occupational, or spu- therapy that {he/she} needed (1)YES (SKIP TO #137a) (2) NO	eech (1) COST TOO MUCH ? (2) HEALTH PLAN PROBLEM (3) NOT AVAILABLE IN
137a	(6) DK (SKIP TO #137a) (7) REF (SKIP TO #137a) 137b	
(C13Q06_06) (During the past 12 months, was there any time when ("N" CHILD)needed) Mental health care or counseling? (1) YES (2) NO (SKIP TO #138a) (6) DK (SKIP TO #138a) (7) REF (SKIP TO #138a)	(C13Q06_06A) Did ("N" CHILD)receive all mental health care or counsel that {he/she} needed? (1) YES (SKIP TO #138a) (2) NO (6) DK (SKIP TO #138a) (7) REF (SKIP TO #138a)	ing (1) COST TOO MUCH (2) HEALTH PLAN PROBLEM (3) NOT AVAILABLE IN AREA/TRANSPORT PROBLEMS (4) NOT CONVENIENT TIMES (5) DOCTOR DID NOT KNOW HOW TO TREAT OR PROVIDE CARE

	-	
138a	138b	138c
(C13Q06_07) INTERVIEWER: IF AGE IS 0-7 YEARS OLD SKIP TO#139a (During the past 12 months, was there any time when ("N" CHILD) needed) Substance abuse treatment or counseling? (1) YES (2) NO (SKIP TO #139a) (6) DK (SKIP TO #139a) (7) REF (SKIP TO #139a) (7) REF (SKIP TO #139a) (7) REF (SKIP TO #139a) (7) REF (SKIP TO #139a) HELP SCREEN: SOME RESPONI OLDER THAN & YEARS OF AGE QUESTION INAPPROPRIATE. II THE RESPONDENT: I understand appropriate for older children but I i verbatim.	MAY FIND THIS THIS OCCURS, TELL this question may be more	Why did ("N" CHILD) not get the substance abuse treatment or counseling (he/she) needed? (CHECK ALL THAT APPLY) (1) COST TOO MUCH (2) HEALTH PLAN PROBLEM (3) NOT AVAILABLE IN AREA/TRANSFORT PROBLEMS (4) NOT CONVENIENT TIMES (5) DOCTOR DID NOT KNOW HOW TO TREAT OR PROVIDE CARE (6) OTHER (96) DON'T KNOW (97) REFUSED THIS QUESTION
139a	139b	
(C13Q06_09) (During the past 12 months, was there any time when ("N" CHILD) needed) Eyeglasses or vision care? (1) YES (2) NO (SKIP TO #140a) (6) DK (SKIP TO #140a) (7) REF (SKIP TO #140a)	(C13Q06_09A) Did (*N" CHILD) receive all the cycglasses or vision care that (he/she} needed? (1) YES (2) No (6) DK (7) REF	

140a	140b		
(C13Q06_10)	(C13Q06_10A)		
(During the past 12 months, was there any time when ("N" CHILD) needed) Hearing aids or hearing care?			
(1) YES (2) NO (SKIP TO #141) (6) DK (SKIP TO #141) (7) REF (SKIP TO #141)	Did ("N" CHILD) receive all the hearing aids or hearing care that {he/she} needed? (1) YES (2) NO (6) DK (7) REF		

141 (C13Q7)

In the past 12 months, how many times did ("N" CHILD) visit a doctor or other health care provider? <u>DO NOT</u> count visits while staying overnight in a hospital.

142 (C13Q7A)

1 have [INSERT ANSWER FROM #141] visits. Is that correct? (1) YES (2) NO [SKIP BACK TO #141] 143

(C13Q8) The next question is about the amount of money paid during the past 12 months for ("N" CHILD)'s medical care. Please do not include health insurance premiums or cost that were or will be reimbursed by insurance or another source. But do include out-of pocket payments for all types of health-related needs such as medications, special foods, adaptive clothing, durable equipment, home modification, and any kind of therapy. During the past 12 months, would you say that the family paid more than \$500, \$250-\$500, less than \$250, or nothing for ("N" CHILD)'s medical care?

More than \$500	
(2) \$250-\$500	[SKIP TO #145a (C13Q10)]
(3) Less than \$250	[SKIP TO #145a (C13Q10)]
(4) Nothing, \$0	[SKIP TO #145a (C13Q10)]
(6) DON'T KNOW	[SKIP TO #145a (C13Q10)]
(7) REFUSED THIS QUESTION	[SKIP TO #145a (C13Q10)]

<u>HELP BOX</u>: RESPONDENT MAY GIVE A RANGE AS AN ANSWER TO THIS QUESTION. BE PREPARED TO PROBE FOR A MORE ACCURATE ANSWER.

144 (C13Q9)

During the past 12 months would you say that the family paid \$500-\$1000, \$1000-\$5000, or more than \$5000 for ("N" CHILD)'s medical care?

- (1) More than \$5000
- (2) \$1001-\$5000(3) \$501-\$1000
- (6) DON'T KNOW
- (7) REFUSED THIS QUESTION



(C13Q10)

Has ("N" CHILD)'s health care caused financial problems for your family? (1) YES (2) NO (6) DON'T KNOW

(7) REFUSED THIS QUESTION

INTERVIEWER: IS THERE AN "S" CHILD IN THIS HOUSEHOLD?

○ YES [SKIP TO #145c] ○ NO [SKIP TO SECTION 12 (NEXT PAGE)]

145c

LOOK AT BOX "C" OF HELPSHEET: IS THE "S" CHILD INSURED?

 \bigcirc yes [skip to sect. 12 (next section) & ask questions for $\underline{``N"}$ [CHILD]

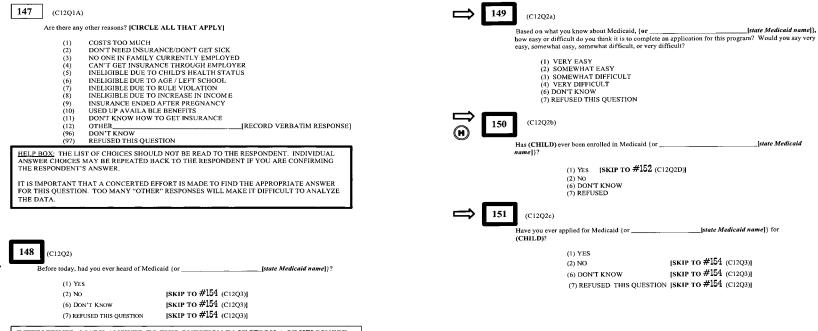
ONO [SKIP TO SECTION 12A]

Section 12. MEDICAID AND SCHIP KNOWLEDGE AND EXPERIENCE (Households with One Sampled Child)

	-				
146	(C12Q1)				
	Earlier, you t	old me that {CH	[LD] does not have health in:	surance. What is the n	nain reason
	{CHILD} do	es not have healt	h insurance now?		
		STS TOO MUC			
	(02) DC	'N'T NEED INSU	JRANCE/DON'T GET SICK		
	(03) NC	ONE IN FAMI	LY CURRENTLY EMPLOY	ED	
	(04) CA	N'T GET INSU	ANCE THROUGH EMPLO	OYER	
	(05) INI	ELIGIBLE DUE	TO CHILD'S HEALTH STA	TUS	
	(06) INI	ELIGIBLE DUE	TO AGE / LEFT SCHOOL		
	(07) INI	ELIGIBLE DUE	TO RULE VIOLATION		
	(08) INI	ELIGIBLE DUE	TO INCREASE IN INCOM	E	·
	(09) INS	SURANCE END	ED AFTER PREGNANCY		
	(10) US	ED UP AVAILA	BLE BENEFITS		
	(11) DO	N'T KNOW HO	W TO GET INSURANCE		
	(12) OT	HER		[RECORD VE	RBATIM RESPONSE]
	(96) DO	N'T KNOW	ISKIP TO #148 (C12Q2)	1	5
	(97) RI	EFUSED	ISKIP TO #148 (C12Q2)	1	

HELP BOX: THE LIST OF CHOICES SHOULD NOT BE READ TO THE RESPONDENT. INDIVIDUAL ANSWER CHOICES MAY BE REPEATED BACK TO THE RESPONDENT IF YOU ARE CONFIRMING THE RESPONDENT'S ANSWER.

IT IS IMPORTANT THAT A CONCERTED EFFORT IS MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY "OTHER" RESPONSES WILL MAKE IT DIFFICULT TO ANALYZE THE DATA.



INTERVIEWER: MARK ANSWER TO THIS QUESTION IN SECTION A OF HELPSHEET. IF ANSWER TO THIS QUESTION WAS "YES," CIRCLE "HEARD OF MEDICAID" FOR THIS CHILD IN SECTION C OF HELPSHEET. IF ANSWER WAS "NO," "DON'T KNOW" OR "REFUSED," CIRCLE "HAVE NOT HEARD OF MEDICAID" FOR THIS CHILD IN SECTION C OF HELPSHEET.

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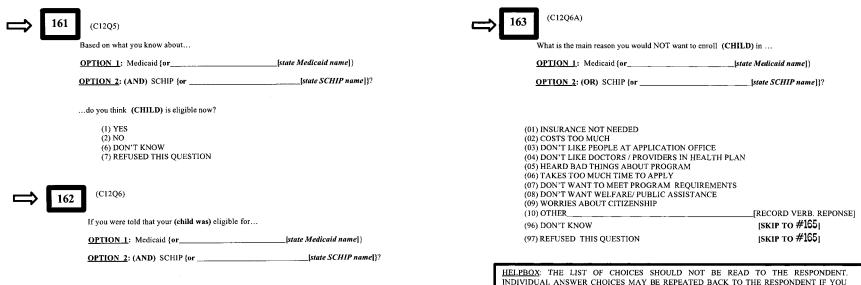
(C12Q2d)	(C12Q3a)
When was the last time that you applied for Medicaid {or[state Medicaid name]} for (CHILD)?	International Based on what you know about[state SCHIP name], how easy or difficult do you think it is to complete an application for this program? Would you say very easy, somewhat afficult, or very difficult?
[ENTER NUMBER] 153 (C12Q2d1) [MARK PERIOD]	 (1) VERY EASY (2) SOMEWHAT EASY (3) SOMEWHAT DIFFICULT (4) VERY DIFFICULT (6) DON'T KNOW (7) REFUSED THIS QUESTION
DAYS YEAR(S) WEEK(S) DON'T KNOW	
MONTH(S) REFUSED	Has (CHLD) ever been enrolled in
INTERVIEWER: FOR EACH STATE, THE SCHIP PLAN CAN BE EITHER A MEDICAID EXPANSION PLAN OR A STANDALONE PLAN. THIS HOUSEHOLD LIVES IN A STATE WHERE: STATE WHERE: STATE. [SKIP TO #159c] State is s-chip and medicaid have same name or no schip in state. [skip to #159c] State is s-chip in this state	(1) YES [SKIP TO #159a] (2) NO (6) DON'T KNOW (7) REFUSED (C12Q3e) Have you ever applied for
155 (C12Q3)	(7) REFUSED [SKIP TO #159c]
Before today, had you ever heard of	

SECTION C OF HELPSHEET.

159a (C12Q3d) When was the last time that you applied for[state SCHIP name] for (CHILD) ?	(C12Q4)
[ENTER NUMBER]	IF "HEARD OF MEDICAID" IS CIRCLED READ "OPTION 1" FOR REST OF SECTION. IF "HEARD OF SCHIP" IS CIRCLED READ "OPTION 2" FOR REST OF SECTION. IF RESPONDENT HAS HEARD OF BOTH, READ BOTH OPTIONS.
MARK PERIOD DAYS YEAR(S) WEEK(S) DON'T KNOW MONTH(S) REFUSED	Where did you first hear about OPTION 1: Medicaid {or[state Medicaid name]} OPTION 2: (AND) SCHIP {or[state SCHIP name]}?
159c (NO DATA) INTERVIEWER: LOOK AT HELPSHEET. DID RESPONDENT ANSWER #148 "YES"? YES [SKIP TO #160] NO SKIP TO #159d NO 159d INTERVIEWER: LOOK AT HELPSHEET. DID RESPONDENT ANSWER #155 "YES"? YES [SKIP TO #160] NO SKIP TO SECTION 11A	(01) RADIO, TV (02) NEWSPAPER, MAGAZINE (03) FLYER, POSTER (04) OUTREACH WORKER (05) WELFARE OFICE/CASE WORKER (06) WIC (07) HEALTH CARE PROVIDER/CLINIC/HOSPITAL (08) CHILD'S SCHOOL (09) FRIEND OR FAMILY MEMBER (10) OTHER[RECORD VERBATIM RESPONSE] (96) DON'T KNOW (97) REFUSED THIS QUESTION
	 HELP BOX: IF RESPONDENT HAS HEARD OF PROGRAM FROM MORE THAN ONE SOURCE, PROBE FOR WHERE THEY FIRST HEARD ABOUT IT. IF THEY CANNOT CHOOSE ONE SOURCE, CODE "DON'T KNOW".

THE LIST OF CHOICES SHOULD NOT BE READ TO THE RESPONDENT. INDIVIDUAL ANSWER CHOICES MAY BE REPEATED BACK TO THE RESPONDENT IF YOU ARE CONFIRMING THE RESPONDENT'S ANSWER. IT IS IMPORTANT THAT A CONCERTED EFFORT IS MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY "OTHER" RESPONSES WILL MAKE IT DIFFICULT TO ANALYZE THE DATA.

.



... would you want to enroll (him/her)?

(1) YES	įskip to #165 ₁
(2) NO (6) DON' T KNOW	(skip to #165)
(7) REFUSED THIS QUESTION	[skip to #165]

HELPBOX: THE LIST OF CHOICES SHOULD NOT BE READ TO THE RESPONDENT. INDIVIDUAL ANSWER CHOICES MAY BE REPEATED BACK TO THE RESPONDENT IF YOU ARE CONFIRMING THE RESPONDENT'S ANSWER. IT IS MPORTANT THAT A CONCERTED EFFORT IS MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY "OTHER" RESPONSES WILL MAKE IT DIFFICULT TO ANALYZE THE DATA.

164 (C12Q6B)	16	(NO DATA)		
Any	other reasons? [CIRCLE ALL THAT APPLY]		INTERVIEWER: WA	AS THE ANSWER TO <u>EIT</u>	<u>her</u> #150 <u>or</u> #157 "yes"?
	(01) INSURANCE NOT NEEDED (02) COSTS TOO MUCH		YES [SK	LIP TO SECTION 11A]	NO [CONTINUE]
INDIVIDUAL ARE CONFIL EFFORT IS I	(03) DON'T LIKE PEOPLE AT APPLICATION OFFICE (04) DON'T LIKE PEOPLE AT APPLICATION OFFICE (05) HEARD BAD THINGS ABOUT PROGRAM (06) TAKES TOO MUCH TIME TO APPLY (07) DON'T WANT TO MEET PROGRAM APPLICATION REQUIREMENTS (08) DON'T ACCEPT WELFARE/ DON'T WANT TO BE IN PUBLIC PROGRAM (09) WORRIES ABOUT CITIZENSHIP (10) OTHER REASONS (96) DON'T KNOW (97) REFUSED THIS QUESTION THE LIST OF CHOICES SHOULD NOT BE READ TO THE RESPONDENT. L ANSWER CHOICES SHOULD NOT BE READ TO THE RESPONDENT. L ANSWER CHOICES MAY BE REPEATED BACK TO THE RESPONDENT IF YOU RMING THE RESPONDENT'S ANSWER. IT IS IMPORTANT THAT A CONCERTED MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY ESPONSES WILL MAKE IT DIFFICULT TO ANALYZE THE DATA.		<u>OPTION 2</u> : (AND) S but not made it throug (1) YES (2) NO (6) DON'T KN	d {or	o SECTION 11Aj o SECTION 11A
			In which program did	you attempt to enroll (CHIL)))?
164a	(C12Q6C)		(OPTION 1)	(1) Medicaid {or	
104a	[IF #161 NE '1' THEN SKIP #165, ELSE ASK.] What is the main reason (S.C.) is not enrolled in Medicaid {or {state Medicaid name}} or [state S- CHIP name]?		(OPTION 2) (OPTION 1 & 2)	 (2)	state Medica
	·			(6) DON'T KNOW	
 (01) INSURANCE NOT NEEDED (02) COSTS TOO MUCH (03) DON'T LIKE PEOPLE AT APPLICATION OFFICE (04) DON'T LIKE DOCTORS / PROVIDERS IN HEALTH PLAN (05) HEARD BAD THINGS ABOUT PROGRAM (06) TAKES TOO MUCH TIME TO APPLY (07) DON'T WANT TO MEET PROGRAM APPLICATION REQUIREMENTS (08) DON'T ACCEPT WELFARE/ DON'T WANT TO BE IN PUBLIC PROGRAM (09) WORRIES ABOUT CITIZENSHIP (11) APPLICATION IS PENDING (10) OTHER[FILL VERBATIM RESPONSE] (96) DON'T KNOW (97) REFUSED 	 (02) COSTS TOO MUCH (03) DON'T LIKE PEOPLE AT APPLICATION OFFICE (04) DON'T LIKE DOCTORS / PROVIDERS IN HEALTH PLAN (05) HEARD BAD THINGS ABOUT PROGRAM (06) TAKES TOO MUCH TIME TO APPLY (07) DON'T WANT TO MEET PROGRAM APPLICATION REQUIREMENTS (08) DON'T ACCEPT WELFAREL DON'T WANT TO BE IN PUBLIC PROGRAM (09) WORRIES ABOUT CITIZENSHIP 			(7) REFUSED THIS QUI	STION

IT IS IMPORTANT THAT A CONCERTED EFFORT IS MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY "OTHER" RESPONSES WILL MAKE IT DIFFICULT TO ANALYZE THE DATA.

Section 12A. MEDICAID AND SCHIP KNOWLEDGE AND (C12Q7B) **EXPERIENCE** (Households with Two Sampled Children) Why did you not finish the process to apply for [this program/these programs]? 146 (C12Q1_1) Earlier, you told me that {"S" CHILD} does not have health insurance. What is the main reason (01) TOO CONFUSING OR COMPLICATED {"S" CHILD} does not have health insurance now? (02) TOO TIME CONSUMING; FORMS TOO LONG (03) LANGUAGE/COMPREHENSION/LITERACY PROBLEMS (1) COSTS TOO MUCH (04) COULDN'T GET TO APPLICATION OFFICE WHEN OPEN (2) DON'T NEED INSURANCE/DON'T GET SICK (05) TRANSPORTATION PROBLEMS GETTING TO OFFICE (3) NO ONE IN FAMILY CURRENTLY EMPLOYED (4) CAN'T GET INSURANCE THROUGH EMPLOYER (06) COULDN'T GET THROUGH ON TELEPHONE (07) DIDN'T HAVE ALL THE PAPERS NEEDED TO ENROLL (5) INELIGIBLE DUE TO CHILD'S HEALTH STATUS (6) INELIGIBLE DUE TO AGE / LEFT SCHOOL (08) PEOPLE AT APPLICATION OFFICE NOT HELPFUL (7) INELIGIBLE DUE TO RULE VIOLATION (09) TOLD CHILD INELIGIBLE B/C INCOME TOO HIGH (8) INELIGIBLE DUE TO INCREASE IN INCOME (10) QUESTIONS TOO PERSONAL (9) INSURANCE ENDED AFTER PREGNANCY (11) DON'T LIKE DOCS/PROVIDERS IN PLAN (10) USED UP AVAILABLE BENEFITS (12) GOT INSURANCE SOME OTHER WAY (11) DON'T KNOW HOW TO GET INSURANCE [RECORD VERBATIM RESPONSE] (13) OTHER (12) OTHER_ [RECORD VERBATIM RESPONSE] (96) DON'T KNOW (96) DON'T KNOW įskip to#148j (97) REFUSED THIS OUESTION ISKIP TO#1481 (97) REFUSED THIS QUESTION HELP BOX: THE LIST OF CHOICES SHOULD NOT BE READ TO THE RESPONDENT. INDIVIDUAL **ISKIP TO SECTION 11A** ANSWER CHOICES MAY BE REPEATED BACK TO THE RESPONDENT IF YOU ARE CONFIRMING THE RESPONDENT'S ANSWER. IT IS IMPORTANT THAT A CONCERTED EFFORT IS MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY "OTHER" RESPONSES WILL MAKE IT DIFFICULT TO ANALYZE

THE DATA.

168

147 (C12Q1A1)

Are there any other reasons? [CIRCLE ALL THAT APPLY]

- COSTS TOO MUCH (1)
- DON'T NEED INSURANCE/DON'T GET SICK (2)
- NO ONE IN FAMILY CURRENTLY EMPLOYED (3)
- (4) CAN'T GET INSURANCE THROUGH EMPLOYER
- (5) INELIGIBLE DUE TO CHILD'S HEA LTH STATUS
- INELIGIBLE DUE TO AGE / LEFT SCHOOL (6)
- (7)INELIGIBLE DUE TO RULE VIOLATION
- INELIGIBLE DUE TO INCREASE IN INCOME (8)
- (9) INSURANCE ENDED AFTER PREGNANCY
- USED UP AVAILA BLE BENEFITS (10)
- DON'T KNOW HOW TO GET INSURANCE (11)
- (12) OTHER
- DON'T KNOW (96)
- REFUSED THIS QUESTION (97)

HELP BOX: THE LIST OF CHOICES SHOULD NOT BE READ TO THE RESPONDENT. INDIVIDUAL ANSWER CHOICES MAY BE REPEATED BACK TO THE RESPONDENT IF YOU ARE CONFIRMING THE RESPONDENT'S ANSWER.

[RECORD VERBATIM RESPONSE]

IT IS IMPORTANT THAT A CONCERTED EFFORT IS MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY "OTHER" RESPONSES WILL MAKE IT DIFFICULT TO ANALYZE THE DATA.

148

(C12Q1_2) Earlier, you told me that {"N" CHILD} does not have health insurance. What is the main reason {"N" CHILD} does not have health insurance now?

(01) COSTS TOO MUCH (02) DON'T NEED INSURANCE/DON'T GET SICK (03) NO ONE IN FAMILY CURRENTLY EMPLOYED (04) CAN'T GET INSURANCE THROUGH EMPLOYER (05) INELIGIBLE DUE TO CHILD'S HEALTH STATUS (06) INELIGIBLE DUE TO A GE / LEFT SCHOOL (07) INELIGIBLE DUE TO RULE VIOLATION (08) INELIGIBLE DUE TO INCREASE IN INCOME (09) INSURANCE ENDED AFTER PREGNANCY (10) USED UP AVAILABLE BENEFITS (11) DON'T KNOW HOW TO GET INSURANCE (12) OTHER [RECORDVERBATIM RESPONSE] [SKIP TO #150] (96) DON'T KNOW

(97) REFUSED THIS QUESTION [SKIP TO #150]

HELP BOX: THE LIST OF CHOICES SHOULD NOT BE READ TO THE RESPONDENT. INDIVIDUAL ANSWER CHOICES MAY BE REPEATED BACK TO THE RESPONDENT IF YOU ARE CONFIRMING THE RESPONDENT'S ANSWER.

IT IS IMPORTANT THAT A CONCERTED EFFORT IS MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY "OTHER" RESPONSES WILL MAKE IT DIFFICULT TO ANALYZE THE DATA.

149 (C12Q1A2)

Are there any other reasons? [CIRCLE ALL THAT APPLY]

```
(01) COSTS TOO MUCH
(02) DON'T NEED INSURANCE/DON'T GET SICK
(03) NO ONE IN FAMILY CURRENTLY EMPLOYED
(04) CAN'T GET INSURANCE THROUGH EMPLOYER
(05) INELIGIBLE DUE TO CHILD'S HEALTH STATUS
(06) INELIGIBLE DUE TO A GE / LEFT SCHOOL
(07) INELIGIBLE DUE TO RULE VIOLATION
(08) INELIGIBLE DUE TO INCREASE IN INCOME
(09) INSURANCE ENDED AFTER PREGNANCY
(10) USED UP AVAILABLE BENEFITS
(11) DON'T KNOW HOW TO GET INSURANCE
                                                     [RECORDVERBATIM RESPONSE]
(12) OTHER
(96) DON'T KNOW
(97) REFUSED THIS QUESTION
```

HELP BOX: THE LIST OF CHOICES SHOULD NOT BE READ TO THE RESPONDENT. INDIVIDUAL ANSWER CHOICES MAY BE REPEATED BACK TO THE RESPONDENT IF YOU ARE CONFIRMING THE RESPONDENT'S ANSWER

IT IS IMPORTANT THAT A CONCERTED EFFORT IS MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY "OTHER" RESPONSES WILL MAKE IT DIFFICULT TO ANALYZE THE DATA.



(1) YES

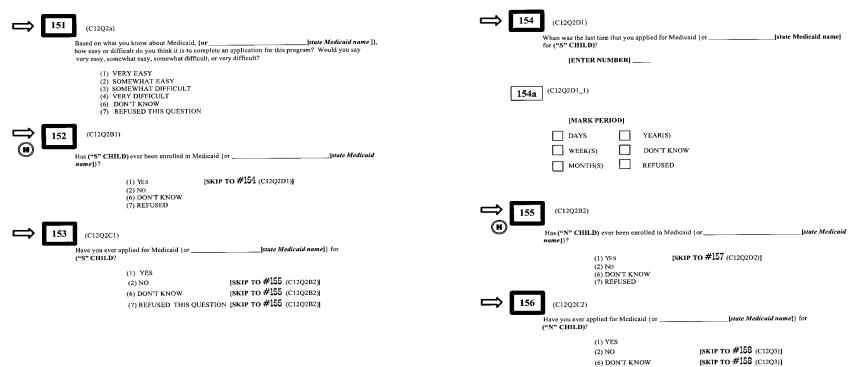
(2) NO

(6) DON'T KNOW

Before today, had you ever heard of Medicaid {or _____ (SKIP TO #158 (C12O3) [SKIP TO #158 (C12Q3)] [SKIP TO #158 (C12Q3)] (7) REFUSED THIS QUESTION

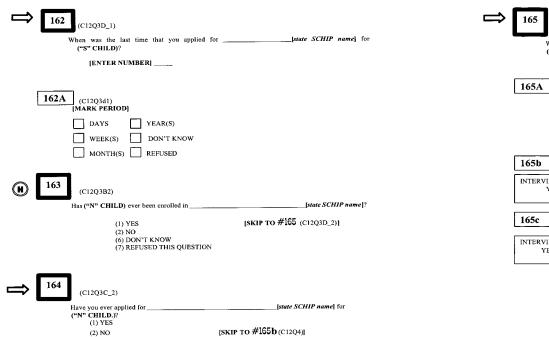
[state Medicaid name]}?

INTERVIEWER: MARK ANSWER TO THIS QUESTION IN SECTION A OF HELPSHEET. IF ANSWER TO THIS QUESTION WAS "YES," CIRCLE " HEARD OF MEDICAID" FOR BOTH CHILDREN IN SECTION C OF HELPSHEET. IF ANSWER WAS "NO," "DON'T KNOW" OR "REFUSED," CIRCLE "HAVE NOT HEARD OF MEDICAID" FOR BOTH CHILDREN IN SECTION C OF HELPSHEET.



(7) REFUSED THIS QUESTION [SKIP TO #158 (C12Q3)]

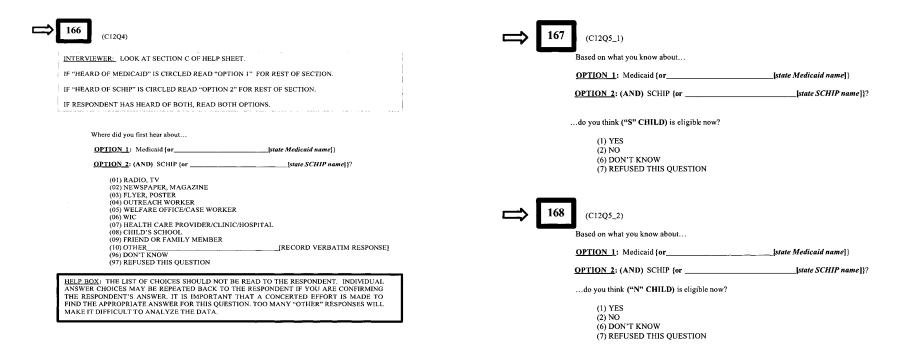
(C12Q2D2) When was the last time that you applied for Medicaid {or[state Medicaid name]} for ("N" CHILD)? [ENTER NUMBER]	(C12Q3A) Based on what you know about[state SCHIP name], how easy or difficult do you think it is to complete an application for this program? Would you say very easy, somewhat easy, somewhat difficult, or very difficult? (1) Very easy (2) Somewhat casy
157A (C12Q2d1) [MARK PERIOD] DAYS YEAR(S) WEEK(S) DON'T KNOW MONTH(S) REFUSED	(2) Somewhat difficult (3) Very difficult (4) Very difficult (6) DON'T KNOW (7) REFUSED THIS QUESTION (C12Q3B1) Has ("S" CHILD) ever been enrolled instate SCHIP name!?
158 INTERVIEWER: FOR EACH STATE, THE SCHIP PLAN CAN BE EITHER A MEDICAID EXPANSION PLAN OR A STANDALONE PLAN. THIS HOUSEHOLD LIVES IN A STATE WHERE: S-CHIP AND MEDICAID HAVE SAME NAME OR NO SCHIP IN STATE. (SKIP TO #165b) S-CHIP AND MEDICAID DO NOT HAVE THE SAME NAME OR THERE IS S-CHIP IN THIS STATE	(1) YES [SKIP TO #162 (C4Q3D_1)] (2) NO (6) DON'T KNOW (7) REFUSED THIS QUESTION (C12Q3C_1) Have you ever applied for[state SCHIP name] for (%5° CHILD.)?
(C12Q3) Before today, had you ever heard of[state SCHIP name]? (1) YES (2) NO[SKIP TO #165b] (6) DON'T KNOW[SKIP TO #165b] (7) REFUSED THIS QUESTION[SKIP TO #165b] INTERVIEWER: MARK ANSWER TO THIS QUESTION IN SECTION A OF HELPSHEET. ALSO IF THE ANSWER TO THIS QUESTION WAS "YES," CIRCLE " HEARD OF S-CHIP" FOR BOTH CHILDREN IN SECTION C OF HELPSHEET. IF ANSWER WAS "NO," "DON'T KNOW" OR "REFUSED," CIRCLE "HAVE NOT HEARD OF S-CHIP" FOR BOTH CHILDREN IN SECTION C OF HELPSHEET.	(1) YES (2) NO [SKIP TO #163] (6) DON'T KNOW [SKIP TO #163] (7) REFUSED THIS QUESTION [SKIP TO #163]



[SKIP TO #165b (C12Q4)] (6) DON'T KNOW **[SKIP TO #165b** (C12Q4)] (7) REFUSED THIS QUESTION

(C12Q3D_2) [STATE SCHIP NAME] for When was the last time that you applied for _____ ("N"CHILD)? [ENTER NUMBER] 165A (C12Q3D1_2) MARK PERIOD DAYS YEAR(S) WEEK(S) DON'T KNOW MONTH(S) REFUSED (NO DATA) INTERVIEWER: LOOK AT HELPSHEET. DID RESPONDENT ANSWER #152 "YES"? YES [SKIP TO #166] NO [SKIP TO #165c]

INTERVIEWER: LOOK AT HELPSHEET, DID RESPONDENT ANSWER #158a "YES"? NO [SKIP TO SECTION 11A] YES [SKIP TO #166]





(C12Q6)

If you were told that ("S" CHILD) OR ("N" CHILD) were eligible for ...

OPTION 1: Medicaid {or______[state Medicaid name]}

OPTION 2: (AND) SCHIP {or ______ [state SCHIP name]}?

...would you want to enroll (him/her/them)?

(1) YES	(skip to #172)
(2) NO	[SKIP TO #170 (C12Q6A)]
(6) DON' T KNOW	[SKIP TO #172 (C12Q7_1)]
(7) REFUSED THIS QUESTION	[SKIP TO #172(C12Q7_1)]

HELP BOX: A RESPONDENT MAY ANSWER THIS QUESTION WITH "I'M NOT SURE", OR "MAYBE". IF THIS OCCURS, CODE ANSWER AS "DON'T KNOW".



What is the main reason you would NOT want to enroll ("S" CHILD) OR ("N" CHILD) in ... OPTION 1: Medicaid {or______[state Medicaid name]} OPTION 2: (OR) SCHIP {or _____ [state SCHIP name]}? (01) INSURANCE NOT NEEDED (02) COSTS TOO MUCH (03) DON'T LIKE PEOPLE AT APPLICATION OFFICE (04) DON'T LIKE DOCTORS / PROVIDERS IN HEALTH PLAN (05) HEARD BAD THINGS ABOUT PROGRAM (06) TAKES TOO MUCH TIME TO APPLY (07) DON'T WANT TO MEET PROGRAM REQUIREMENTS (08) DON'T WANT WELFARE/ PUBLIC ASSISTANCE (09) WORRIES ABOUT CITIZENSHIP [RECORD VERBATIM RESPONSE] (10) OTHER___ (96) DON'T KNOW [SKIP TO #172 (C12Q7_1)] **ISKIP TO #172** (C12Q7_1)] (97) REFUSED THIS QUESTION

HELPBOX: THE LIST OF CHOICES SHOULD NOT BE READ TO THE RESPONDENT. INDIVIDUAL ANSWER CHOICES MAY BE REPEATED BACK TO THE RESPONDENT IF YOU ARE CONFIRMING THE RESPONDENT'S ANSWER. IT IS MPORTANT THAT A CONCERTED EFFORT IS MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY "OTHER" RESPONSES WILL MAKE IT DIFFICULT TO ANALYZE THE DATA.

171 (C12Q6B)	172 (NO DATA)
Any other reasons? [CIRCLE ALL THAT APPLY]	interviewer: was the answer to #152 <u>or</u> #160 "yes"?
(01) INSURANCE NOT NEEDED (02) COSTS TOO MUCH (03) DON'T LIKE PEOPLE AT APPLICATION OFFICE	YES [SKIP TO #175] NO [CONTINUE]
(04) DON'T LIKE DOCTORS / PROVIDERS IN HEALTH PLAN (05) HEARD BAD THINGS ABOUT PROGRAM (06) TAKES TOO MUCH TIME TO APPLY (07) DON'T WANT TO MEET PROGRAM APPLICATION REQUIREMENTS (08) DON'T ACCEPT WELFARE/ DON'T WANT TO BE IN PUBLIC PROGRAM	C12Q7_1) Have you ever tried to enroll ("S" CHILD) in
(09) WORRIES ABOUT CITIZENSHIP	OPTION 1: Medicaid {or[state Medicaid name]}
(10) OTHER[RECORD VERBATIM RESPONSE] (11) NO OTHER REASONS	<u>OPTION 2</u> ; (OR) SCHIP {or[state SCHIP name}}?
(96) DON'T KNOW (97) REFUSED THIS QUESTION	but not made it through the whole process?
HELP BOX: THE LIST OF CHOICES SHOULD NOT BE READ TO THE RESPONDENT. INDIVIDUAL ANSWER CHOICES MAY BE REPEATED BACK TO THE RESPONDENT IF YOU ARE CONFIRMING THE RESPONDENT'S ANSWER. IT IS IMPORTANT THAT A CONCERTED EFFORT IS MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY "OTHER" RESPONSES WILL MAKE IT DIFFICULT TO ANALYZE THE DATA.	(1) YES (2) NO ISKIP TO #175] (6) DON'T KNOW [SKIP TO #175] (7) REFUSED THIS QUESTION [SKIP TO #175] (C12Q7A_1) In which program did you attempt to enroll ("S" CHILD.)?
	(OPTION 1) (1) Medicaid {or
171a (C12Q6C) (IF #167 NE '1' THEN SKIP TO #172, ELSE ASK.)	
What is the main reason (S.C.) (or S.C.) (is/are) not enrolled in Medicaid {or [state Medicaid name]} or [state SCHIP name]?	(OPTION 2) (2)[State SCHIP name] (OPTION 1 & 2) (3) Both Medicaid (or[state Medicaid name] and[state SCHIP name]
(01) INSURANCE NOT NEEDED (02) COSTS TOO MUCH (03) DON'T LIKE PEOPLE AT APPLICATION OFFICE (04) DON'T LIKE DOCTORS / PROVIDERS IN HEALTH PLAN (05) HEARD BAD THINGS ABOUT PROGRAM (06) TAKES TOO MUCH TIME TO APPLY (07) DON'T WANT TO MEET PROGRAM APPLICATION REQUIREMENTS (08) DON'T ACCEPT WELFARE/ DON'T WANT TO BE IN PUBLIC PROGRAM (09) WORRIES ABOUT CITIZENSHIP (11) APPLICATION IS PENDING (10) OTHER[FILL VERBATIM RESPONSE] (96) DON'T KNOW (97) REFUSED HELP BOX: THE LIST OF CHOICES SHOULD NOT BE READ TO THE RESPONDENT.	(6) DON'T KNOW (7) REFUSED THIS QUESTION

INDIVIDUAL ANSWER CHOICES SHOULD NOT BE REPATED BACK TO THE RESPONDENT IF YOU ARE CONFIRMING THE RESPONDENT'S ANSWER.

IT IS IMPORTANT THAT A CONCERTED EFFORT IS MADE TO FIND THE APPROPRIATE ANSWER FOR THIS QUESTION. TOO MANY "OTHER" RESPONSES WILL MAKE IT DIFFICULT TO ANALYZE THE DATA.

174b (C12Q7B_1)	(C12Q7A_2)
Why did you not finish the process to apply for [this program/these programs]?	In which program did you attempt to enroll ("N" CHILD)?
 TOO CONFUSING OR COMPLICATED TOO TIME CONSUMING; FORMS TOO LONG LANGUAGE/COMPREHENSION/LITERACY PROBLEMS LANGUAGE/COMPREHENSION/LITERACY PROBLEMS COULDN'T GET TO APPLICATION OFFICE WHEN OPEN TRANSPORTATION PROBLEMS GETTING TO OFFICE 	(OPTION 1) (1) Medicaid {or[state Medicaid name]}
(6) COULDN'T GET THROUGH ON TELEPHONE(7) DIDN'T HAVE ALL THE PAPERS NEEDED TO ENROLL	(OPTION 2) (2)[State SCHIP name]
(8) PEOPLE AT APPLICATION OFFICE NOT HELPFUL (9) TOLD CHILD INELIGIBLE B/C INCOME TOO HIGH (10) QUESTIONS TOO PERSONAL (11) DON'T LIKE DOCS/PROVIDERS IN PLAN	(OPTION 1 & 2) (3) Both Medicaid {orstate Medicaid name] andstate SCHIP name]
(12) GOT INSURANCE SOME OTHER WAY (13) OTHER	(6) DON'T KNOW
(97) REFUSED THIS QUESTION	(7) REFUSED THIS QUESTION
INTERVIEWER: WAS THE ANSWER TO #155 <u>or</u> #163 "YES"?	(C12Q7B_2) Why did you not finish the process to apply for [this program/these programs]?
YES [SKIP TO SECTION 11A] NO [CONTINUE] OPTION (C1207_2) Have you ever tried to enroll ("N" CHILD) in OPTION 1: Medicaid {or [state Medicaid name]} OPTION 2: (OR) SCHIP (or [state SCHIP name])? but not made it through the whole process? (1) YES (2) NO [SKIP TO #179 (C11014)]	 (1) TOO CONFUSING OR COMPLICATED (2) TOO TIME CONSUMING; FORMS TOO LONG (3) LANGUAGE/COMPREHENSION/LITERACY PROBLEMS (4) COULDN'T GET TO APPLICATION OFFICE WHEN OPEN (5) TRANSPORTATION PROBLEMS GETTING TO OFFICE (6) COULDN'T GET THROUGH ON TELEPHONE (7) DIDN'T HAVE ALL THE PAPERS NEEDED TO ENROLL (8) PEOPLE AT APPLICATION OFFICE NOT HELPFUL (9) TOLD CHILD INELIGIBLE B/C INCOME TOO HIGH (10) QUESTIONS TOO PERSONAL (11) DON'T LIKE DOCS/PROVIDERS IN PLAN (12) GOT INSURANCE SOME OTHER WAY (13) OTHER[RECORDVERBATIM RESPONSE] (96) DON'T KNOW
(2) NO $[SKIP TO #179 (C11014)]$ (6) DON'T KNOW $[SKIP TO #179 (C11014)]$	(97) REFUSED THIS QUESTION
(6) DON T KNOW [SKIP TO $\#$ 179 (C11Q14)] (7) REFUSED THIS QUESTION [SKIP TO $\#$ 179 (C11Q14)]	

SECTION 11A. TELEPHONE LINE AND HOUSEHOLD 182 INFORMATION (C11Q17) Do you have a third home phone number in addition to the two you have already told me about? (1) YES **[SKIP TO #185** (C11Q20)] 179 (2) NO [SKIP TO #185 (C11Q20)] (6) DON'T KNOW INTERVIEWER: LOOK ON FACESHEET. WHAT IS WRITTEN AFTER "TELEPHONE LINE/HH INFORMATION? VES [SKIP TO #188] NO [SKIP TO #179a] [SKIP TO #185 (C11Q20)] (7) REFUSED THIS QUESTION 183 (C11Q18) 179a (C11Q14) The next questions are about the telephone numbers in your household. Do you have any other home phone numbers in addition to {AREA CODE AND TELEPHONE NUMBER CALLED}? Is this third number for home use only, for business use only, or for both home and business use? (1) Home only **ISKIP TO #185** (C11020) (1) YES (2) Business only (SKIP TO #185 (C11Q20)) (2) NO (3) Both home and business ISKIP TO #185 (C11020) (6) DON'T KNOW [SKIP TO #185 (C11Q20)] (6) DON'T KNOW ISKIP TO #185 (C11020) (7) REFUSED THIS QUESTION (7) REFUSED THIS QUESTION [SKIP TO #185 (C11Q20)] 180 C11Q15 (FAM.110) 184 Is this second number for home use only, for business use only, or for both home and business use? (C11Q19) Is this third number used only for computer or fax communications? (1) Home only (1) YES [SKIP TO #182 (C11Q17)] (2) Business only (3) Both home and business (2) NO **[SKIP TO #185** (C11Q17)] (6) DON'T KNOW (6) DON'T KNOW (7) REFUSED [SKIP TO #185 (C11Q17)] (7) REFUSED THIS QUESTION 185 (C11020) During the past 12 months, has your household been without telephone service for 1 week or more? 181 (1) YES (C11Q16) Is this second number used only for computer or fax communications? [SKIP TO #187 (C11Q22)] (2) NO (1) YES [SKIP TO #187 (C11Q22)] (2) NO (6) DON'T KNOW (6) DON'T KNOW (7) REFUSED THIS QUESTION (SKIP TO #187 (C11022)) (7) REFUSED

186a (C11Q21_A)

For how long was your household without telephone service in the last 12 months?

ENTER NUMBER

186b (C11Q21)	
DAYS	YEAR(S)
WEEK(S)	DON'T KNOW
MONTH(S)	REFUSED THIS QUESTION

187 (C11Q22)

Please tell me your zip code.

(99996) DON'T KNOW (99997) REFUSED THIS QUESTION

188

(CWEND)

Those are all the questions I have. I'd like to thank you on behalf of the Centers for Disease Control and Prevention for the time and effort you've spent answering these questions. If you have any questions about this survey, you may call my supervisor toll-free at 1-800-290-1296. If you have questions about your rights as a survey participant, you may call the chairman of the Institutional Review Board at 1-800-223-8118. Thank you again.

[TERMINATE]

Appendix III

Summary of CATI Instrument Changes

1. On October 23, 2000, the phrase "At this time" was added at the beginning of insurance questions C7Q01, C7Q02, C7Q03, C7Q04, C7Q06, and C7Q07. For example, the wording of question C7Q06 changed from "Is (S.C.) enrolled in a Title 5 program?" to "At this time, is (S.C.) enrolled in a Title 5 program?"

2. On October 26, 2000, the order of the first four questions in Section 7 was changed so that the items regarding private insurance would be first in the series. In addition, the introduction used with the first item was revised, and the word "private" was removed from questions C7Q03 and C7Q03A. The first four questions in the original insurance section were:

C7Q01 (7.1)—The next questions are about all types of health insurance and health care coverage (S.C.) may have. Is (S.C.) covered by Medicaid, a health insurance program for persons with certain income levels and persons with disabilities? [FILL IF APPLICABLE: In this State, the program is sometimes called [STATE PROGRAM].

C7Q02 (7.2)—*Is* (*S.C.*) *covered by*[*S*-*CHIP name*]?

C7Q03 (7.3)—Is (S.C.) covered by private health insurance, that is health insurance obtained through employment or unions or purchased directly?

C7Q03a—Does this private health insurance help pay for both doctor visits and hospital stays?

3. On December 19, 2000, two questions were added in households where the respondent was not the mother of the sampled child. The first asked the education of the sampled child's mother (CQ10Q04A), and the second inquired whether she lived in the household (C2Q04_A). 4. On January 5, 2001, a new question—C7Q08B—was added to Section 7.

5. On February 2, 2001, open-ended text boxes were added to some existing questions to record verbatim answers from respondents whose answer did not clearly fit into the response categories provided. Text boxes were added to the following questions:

- C4Q0B
- C4Q02
- C4Q02B
- C4Q0501B
- C4Q0502B
- C4Q0503B
- C4Q0504B
- C4Q0505B
 C4Q0506B
- C4Q0506BC4Q0507B
- C4Q0507B
 C4Q0601B
- C4Q0601B
 C4Q0602B
- C4Q0603B
- C4Q00031
 C5Q03A
- C7Q10
- C7Q15
- C12Q1
- C1201A
- C12Q4
- C12Q6A
- C12Q6B
- C12Q7B
- C13Q3
- C13O4A
- C13Q4C
- C13Q61B
- C13Q62B
- C13Q63B
- C13Q64B
- C13Q65B
- C13Q66B
- C13Q67B

6. During the data collection and cleaning for the National Survey of Children with Special Health Care Needs, it became clear that children who were eligible for the National Immunization Survey (NIS), but who had not done the NIS interview, were being identified during the National Survey of CSHCN interview. On February 2, 2001, the CATI system was revised to return the interviewer to the NIS interview if one or more NIS-eligible children were identified during National Survey of CSHCN rostering. 7. On July 5, 2001, six new questions were added to Section 6:

- C6Q0A
- C6Q0A_A
- C6Q0A_B
- C6Q0B
- C6Q0C
- C6Q0D

8. On October 15, 2001, two questions were added to Section 12 on October 15, 2001:

- C12Q6C
- C12Q6C0E

Appendix IV

Procedures for Assigning Household Poverty Status

The Department of Health and Human Services (DHHS) publishes Federal Poverty Guidelines for the determination of household poverty status. These guidelines are produced annually and developed separately for the 48 contiguous States (plus the District of Columbia), Alaska, and Hawaii. The National Survey of CSHCN used DHHS guidelines to assign household poverty status. Year 2000 guidelines were used with 1999 income for interviews conducted from October 17, 2000, through December 31, 2000, and with 2000 income for interviews conducted from January 1, 2001, through February 26, 2001 (tables VI-VIII). Year 2001 guidelines were implemented on February 27, 2001, and used for the remainder of the data collection period (tables IX-XI). The tables were used to group households into the following poverty status categories:

- Category AA— Below 50% of Poverty
- Category A— Above 50% of Poverty but Below 100% of Poverty

- Category B— Above 100% of Poverty but Below 133% of Poverty
- Category C— Above 133% of Poverty but Below 150% of Poverty
- Category D— Above 150% of Poverty but Below 185% of Poverty
- Category E— Above 185% of Poverty but Below 200% of Poverty
- Category F— Above 200% of Poverty but Below 300% of Poverty
- Category G— Above 300% of Poverty but Below 400% of Poverty
- Category H— Above 400% of Poverty

Two variables were used to determine a National Survey of CSHCN household's poverty status: the number of people residing in a household and the household's income during the prior year. It was possible for income data to be gathered using one of three different methods during National Survey of CSHCN administration-a respondent could provide an exact income, provide an income range based on a closedended series of questions, or provide an income range using a set of cascade questions revised to allow exact determination of household poverty status in cases where that would not otherwise be possible. A brief description of each of these methods of gathering income data, and the household poverty status assignment process used for each appears below.

Respondent Reported Exact Income—When a respondent reported an exact income, poverty status was assigned by simply comparing the number of household members and the exact income reported with the appropriate guidelines table.

Respondent Reported Income Range Based on a Closed-Ended Series of Questions—When respondents did not supply a specific dollar amount for household income, it was necessary to go through a series of questions asking respondents whether the household income was below, exactly at, or above threshold amounts. A matrix was then created to categorize responses to these income cascade questions. Each cell in the matrix was assigned to one of the following income categories:

- Less than \$7,500
- \$7,500 to \$9,999
- \$10,000 to \$12,499
- \$12,500 to \$14,999
- \$15,000 to \$17,499
- \$17,500 to \$19,999
- \$20,000 to \$24,999
- \$25,000 to \$29,999
- \$30,000 to \$34,999
- \$35,000 to \$39,999
- \$40,000 to \$44,999
- \$45,000 to \$49,999
- \$50,000 to \$59,999
 \$60,000 to \$74,999
- \$60,000 to \$74,999
- \$75,000 or higher

Table VI. Year 2000 guidelines for poverty ranges based on total family members for families in the 48 contiguous States and the District of Columbia

- Family size	Percent of Federal poverty level									
	50	100	133	150	185	200	300	400		
2	\$ 5,625	\$11,250	\$14,963	\$16,875	\$ 20,813	\$ 22,500	\$ 33,750	\$ 45,000		
3	\$ 7,075	\$14,150	\$18,820	\$21,225	\$ 26,178	\$ 28,300	\$ 42,450	\$ 56,600		
4	\$ 8,525	\$17,050	\$22,677	\$25,575	\$ 31,543	\$ 34,100	\$ 51,150	\$ 68,200		
5	\$ 9,975	\$19,950	\$26,534	\$29,925	\$ 36,908	\$ 39,900	\$ 59,850	\$ 79,800		
6	\$11,425	\$22,850	\$30,391	\$34,275	\$ 42,273	\$ 45,700	\$ 68,500	\$ 91,400		
7	\$12,875	\$25,750	\$34,248	\$38,625	\$ 47,638	\$ 51,500	\$ 77,250	\$103,000		
8	\$14,325	\$28,650	\$38,105	\$42,975	\$ 53,003	\$ 57,300	\$ 85,950	\$114,600		
9	\$15,775	\$31,550	\$41,962	\$47,325	\$ 58,368	\$ 63,100	\$ 94,650	\$126,200		
10	\$17,225	\$34,450	\$45,819	\$51,675	\$ 63,733	\$ 68,900	\$103,350	\$137,800		
11	\$18,675	\$37,350	\$49,676	\$56,025	\$ 69,098	\$ 74,700	\$112,050	\$149,400		
12	\$20,125	\$40,250	\$53,533	\$60,375	\$ 74,463	\$ 80,500	\$120,750	\$161,000		
13	\$21,575	\$43,150	\$57,390	\$64,725	\$ 79,828	\$ 86,300	\$129,450	\$172,600		
14	\$23,025	\$46,050	\$61,247	\$69,075	\$ 85,193	\$ 92,100	\$138,150	\$184,200		
15	\$24,475	\$48,950	\$65,104	\$73,425	\$ 90,558	\$ 97,900	\$146,850	\$195,800		
16	\$25,925	\$51,850	\$68,961	\$77,775	\$ 95,923	\$103,700	\$155,550	\$207,400		
17	\$27,375	\$54,750	\$72,818	\$82,125	\$101,288	\$109,500	\$164,250	\$219,000		
18	\$28,825	\$57,650	\$76,675	\$86,475	\$106,653	\$115,300	\$172,950	\$230,600		

Table VII. Year 2000 guidelines for poverty ranges based on total family members for families in Alaska

Family size	Percent of Federal poverty level									
	50	100	133	150	185	200	300	400		
2	\$ 7,030	\$14,060	\$18,700	\$ 21,090	\$ 26,011	\$ 28,120	\$ 42,180	\$ 56,240		
3	\$ 8,845	\$17,690	\$23,528	\$ 26,535	\$ 32,727	\$ 35,380	\$ 53,070	\$ 70,760		
4	\$10,660	\$21,320	\$28,356	\$ 31,980	\$ 39,442	\$ 42,640	\$ 63,960	\$ 85,280		
5	\$12,475	\$24,950	\$33,184	\$ 37,425	\$ 46,158	\$ 49,900	\$ 74,850	\$ 99,800		
6	\$14,290	\$28,580	\$38,011	\$ 42,870	\$ 52,873	\$ 57,160	\$ 85,740	\$114,320		
7	\$16,105	\$32,210	\$42,839	\$ 48,315	\$ 59,589	\$ 64,420	\$ 96,630	\$128,840		
8	\$17,920	\$35,840	\$47,667	\$ 53,760	\$ 66,304	\$ 71,680	\$107,520	\$143,360		
9	\$19,735	\$39,470	\$52,495	\$ 59,205	\$ 73,020	\$ 78,940	\$118,410	\$157,880		
10	\$21,550	\$43,100	\$57,323	\$ 64,650	\$ 79,735	\$ 86,200	\$129,300	\$172,400		
11	\$23,365	\$46,730	\$62,151	\$ 70,095	\$ 86,451	\$ 93,460	\$140,190	\$186,920		
12	\$25,180	\$50,360	\$66,979	\$ 75,540	\$ 93,166	\$100,720	\$151,080	\$201,440		
13	\$26,995	\$53,990	\$71,807	\$ 80,985	\$ 99,882	\$107,980	\$161,970	\$215,960		
14	\$28,810	\$57,620	\$76,635	\$ 86,430	\$106,597	\$115,240	\$172,860	\$230,480		
15	\$30,625	\$61,250	\$81,463	\$ 91,875	\$113,313	\$122,500	\$183,750	\$245,000		
16	\$32,440	\$64,880	\$86,290	\$ 97,320	\$120,028	\$129,760	\$194,640	\$259,520		
17	\$34,255	\$68,510	\$91,118	\$102,765	\$126,744	\$137,020	\$205,530	\$274,040		
18	\$36,070	\$72,140	\$95,946	\$108,210	\$133,459	\$144,280	\$216,420	\$288,560		

Table VIII. Year 2000 guidelines for poverty ranges based on total family members for families in Hawaii

Family size	Percent of Federal poverty level									
	50	100	133	150	185	200	300	400		
2	\$ 6,465	\$12,930	\$17,197	\$19,395	\$ 23,921	\$ 25,860	\$ 38,790	\$ 51,720		
3	\$ 8,135	\$16,270	\$21,639	\$24,405	\$ 30,100	\$ 32,540	\$ 48,810	\$ 65,080		
4	\$ 9,805	\$19,610	\$26,081	\$29,415	\$ 36,279	\$ 39,220	\$ 58,830	\$ 78,440		
5	\$11,475	\$22,950	\$30,524	\$34,425	\$ 42,458	\$ 45,900	\$ 68,850	\$ 91,800		
6	\$13,145	\$26,290	\$34,966	\$39,435	\$ 48,637	\$ 52,580	\$ 78,870	\$105,160		
7	\$14,815	\$29,630	\$39,408	\$44,445	\$ 54,816	\$ 59,260	\$ 88,890	\$118,520		
8	\$16,485	\$32,970	\$43,850	\$49,455	\$ 60,995	\$ 65,940	\$ 98,910	\$131,880		
9	\$18,300	\$36,600	\$48,678	\$54,900	\$ 67,710	\$ 73,200	\$109,800	\$146,400		
10	\$19,970	\$39,940	\$53,120	\$59,910	\$ 73,889	\$ 79,880	\$119,820	\$159,760		
11	\$21,640	\$43,280	\$57,562	\$64,920	\$ 80,068	\$ 86,560	\$129,840	\$173,120		
12	\$23,310	\$46,620	\$62,005	\$69,930	\$ 86,247	\$ 93,240	\$139,860	\$186,480		
13	\$24,980	\$49,960	\$66,447	\$74,940	\$ 92,426	\$ 99,920	\$149,880	\$199,840		
14	\$26,650	\$53,300	\$70,889	\$79,950	\$ 98,605	\$106,600	\$159,900	\$213,200		
15	\$28,320	\$56,640	\$75,331	\$84,960	\$104,784	\$113,280	\$169,920	\$226,560		
16	\$29,990	\$59,980	\$79,773	\$89,970	\$110,963	\$119,960	\$179,940	\$239,920		
17	\$31,660	\$63,320	\$84,216	\$94,980	\$117,142	\$126,640	\$189,960	\$253,280		
18	\$33,330	\$66,660	\$88,658	\$99,990	\$123,321	\$133,320	\$199,980	\$266,640		

Respondents who went through the cascade of income questions were assigned a household income value that was the midpoint of their new income category as determined by their location in the matrix. Respondents with an income range of \$75,000 or higher were assigned an income value of \$100,000, based on the median income reported for such households during the National Survey of CSHCN administration. Household poverty status was then assigned by comparing the number of household members and the assigned income amount with the appropriate guidelines table.

When respondents did not complete the income cascade, either because they refused or did not know the answer to one of the cascade questions, household poverty status could not be assigned. (It is worth noting, however, that households with unknown poverty status still qualified for the Low-Income Uninsured Supplement if the selected child was uninsured.)

Respondent Reported Income Range Based on Revised Series of Cascade Questions—In some cases, the income categories described above encompassed one or more income breaks for determining household poverty status. In such cases, additional income cascade questions beyond the standard set were asked to permit definitively assigning poverty status. Respondents were assigned a household income value that was the midpoint of their new income category as determined by the additional income cascade question(s). For example, the income break indicating that a two-person household in the contiguous 48 States was below 50% of poverty (using the 2001 guidelines) was \$5,805. This income break is encompassed in the income category of "<\$7,500." Therefore, an additional cascade question asked whether the

Table IX. Year 2001 guidelines for poverty ranges based on total family members for families in the 48 contiguous States and the District of
Columbia

– Family size	Percent of Federal poverty level									
	50	100	133	150	185	200	300	400		
2	\$ 5,805	\$11,610	\$15,441	\$17,415	\$ 21,479	\$ 23,220	\$ 34,830	\$ 46,440		
3	\$ 7,315	\$14,630	\$19,458	\$21,945	\$ 27,066	\$ 29,260	\$ 43,890	\$ 58,520		
4	\$ 8,825	\$17,650	\$23,475	\$26,475	\$ 32,653	\$ 35,300	\$ 52,950	\$ 70,600		
5	\$10,335	\$20,670	\$27,491	\$31,005	\$ 38,240	\$ 41,340	\$ 62,010	\$ 82,680		
8	\$11,845	\$23,690	\$31,508	\$35,535	\$ 43,827	\$ 47,380	\$ 71,070	\$ 94,760		
,	\$13,355	\$26,710	\$35,524	\$40,065	\$ 49,414	\$ 53,420	\$ 80,130	\$106,840		
3	\$14,865	\$29,730	\$39,541	\$44,595	\$ 55,001	\$ 59,460	\$ 89,190	\$118,920		
)	\$16,375	\$32,750	\$43,558	\$49,125	\$ 60,588	\$ 65,500	\$ 98,250	\$131,000		
0	\$17,885	\$35,770	\$47,574	\$53,655	\$ 66,175	\$ 71,540	\$107,310	\$143,080		
1	\$19,395	\$38,790	\$51,591	\$58,185	\$ 71,762	\$ 77,580	\$116,370	\$155,160		
2	\$20,905	\$41,810	\$55,607	\$62,715	\$ 77,349	\$ 83,620	\$125,430	\$167,240		
3	\$22,415	\$44,830	\$59,624	\$67,245	\$ 82,936	\$ 89,660	\$134,490	\$179,320		
4	\$23,925	\$47,850	\$63,641	\$71,775	\$ 88,523	\$ 95,700	\$143,550	\$191,400		
5	\$25,435	\$50,870	\$67,657	\$76,305	\$ 94,110	\$101,740	\$152,610	\$203,480		
6	\$26,945	\$53,890	\$71,674	\$80,835	\$ 99,697	\$107,780	\$161,670	\$215,560		
7	\$28,455	\$56,910	\$75,690	\$85,365	\$105,284	\$113,820	\$170,730	\$227,640		
8	\$29,965	\$59,930	\$79,707	\$89,895	\$110,871	\$119,860	\$179,790	\$239,720		

Table X. Year 2001 guidelines for poverty ranges based on t	total family members for families in Alaska
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Family size	Percent of Federal poverty level									
	50	100	133	150	185	200	300	400		
2	\$ 7,255	\$14,510	\$19,298	\$ 21,765	\$ 26,844	\$ 29,020	\$ 43,530	\$ 58,040		
3	\$ 9,145	\$18,290	\$24,326	\$ 27,435	\$ 33,837	\$ 36,580	\$ 54,870	\$ 73,160		
4	\$11,035	\$22,070	\$29,353	\$ 33,105	\$ 40,830	\$ 44,140	\$ 66,210	\$ 88,280		
5	\$12,925	\$25,850	\$34,381	\$ 38,775	\$ 47,823	\$ 51,700	\$ 77,550	\$103,400		
6	\$14,815	\$29,630	\$39,408	\$ 44,445	\$ 54,816	\$ 59,260	\$ 88,890	\$118,520		
7	\$16,705	\$33,410	\$44,435	\$ 50,115	\$ 61,809	\$ 66,820	\$100,230	\$133,640		
8	\$18,595	\$37,190	\$49,463	\$ 55,785	\$ 68,802	\$ 74,380	\$111,570	\$148,760		
9	\$20,485	\$40,970	\$54,490	\$ 61,455	\$ 75,795	\$ 81,940	\$122,910	\$163,880		
10	\$22,375	\$44,750	\$59,518	\$ 67,125	\$ 82,788	\$ 89,500	\$134,250	\$179,000		
11	\$24,265	\$48,530	\$64,545	\$ 72,795	\$ 89,781	\$ 97,060	\$145,590	\$194,120		
12	\$26,155	\$52,310	\$69,572	\$ 78,465	\$ 96,774	\$104,620	\$156,930	\$209,240		
13	\$28,045	\$56,090	\$74,600	\$ 84,135	\$103,767	\$112,180	\$168,270	\$224,360		
14	\$29,935	\$59,870	\$79,627	\$ 89,805	\$110,760	\$119,740	\$179,610	\$239,480		
15	\$31,825	\$63,650	\$84,655	\$ 95,475	\$117,753	\$127,300	\$190,950	\$254,600		
16	\$33,715	\$67,430	\$89,682	\$101,145	\$124,746	\$134,860	\$202,290	\$269,720		
17	\$35,605	\$71,210	\$94,709	\$106,815	\$131,739	\$142,420	\$213,630	\$284,840		
18	\$37,495	\$74,990	\$99,737	\$112,485	\$138,732	\$149,980	\$224,970	\$299,960		

household income was above, at, or below \$5,800 (based on rounding rules described in the notes to tables XII– XVII). If the household reported an income below \$5,800, their assigned income value would be \$2,900, the midpoint of their income range based on answers to all of the cascade questions.

Once the household income value was determined, household poverty status was assigned by comparing the number of household members and the assigned income amount with the appropriate guidelines table. Using DHHS guidelines, tables were developed to provide reference values for the additional income cascade questions. Due to a programming error, reference values using 1999 guidelines were inadvertently used with 1999 income from October 17, 2000, through December 31, 2000, and with 2000 income from January 1, 2001, through February 26, 2001. (Tables XII–XIV present the reference values based on 1999 guidelines that were incorrectly used prior to February 26, 2001.) Poverty levels reported in the data file have been corrected to reflect the correct 2000 guidelines for interviews conducted during these periods (see tables VI–VIII). However, the exact poverty level could not be determined for 164 households because the 1999-guideline-based reference values do not perfectly map onto the 2000-guideline-based values.

Corrected reference values using 2001 guidelines with 2000 income were implemented on February 27, 2001 (tables XV–XVII).

Table XI. Year 2001 guidelines for poverty ranges based on total family members for families in Hawaii

		Percent of Federal poverty level											
Family size	50	100	133	150	185	200	300	400					
2	\$ 6,680	\$13,360	\$17,769	\$ 20,040	\$ 24,716	\$ 26,720	\$ 40,080	\$ 53,440					
3	\$ 8,415	\$16,830	\$22,384	\$ 25,245	\$ 31,136	\$ 33,660	\$ 50,490	\$ 67,320					
4	\$10,150	\$20,300	\$26,999	\$ 30,450	\$ 37,555	\$ 40,600	\$ 60,900	\$ 81,200					
5	\$11,885	\$23,770	\$31,614	\$ 35,655	\$ 43,975	\$ 47,540	\$ 71,310	\$ 95,080					
6	\$13,620	\$27,240	\$36,229	\$ 40,860	\$ 50,394	\$ 54,480	\$ 81,720	\$108,960					
7	\$15,355	\$30,710	\$40,844	\$ 46,065	\$ 56,814	\$ 61,420	\$ 92,130	\$122,840					
8	\$17,090	\$34,180	\$45,459	\$ 51,270	\$ 63,233	\$ 68,360	\$102,540	\$136,720					
9	\$18,825	\$37,650	\$50,075	\$ 56,475	\$ 69,653	\$ 75,300	\$112,950	\$150,600					
10	\$20,560	\$41,120	\$54,690	\$ 61,680	\$ 76,072	\$ 82,240	\$123,360	\$164,480					
11	\$22,295	\$44,590	\$59,305	\$ 66,885	\$ 82,492	\$ 89,180	\$133,770	\$178,360					
12	\$24,030	\$48,060	\$63,920	\$ 72,090	\$ 88,911	\$ 96,120	\$144,180	\$192,240					
13	\$25,765	\$51,530	\$68,535	\$ 77.295	\$ 95.331	\$103.060	\$154,590	\$206,120					
14	\$27,500	\$55,000	\$73,150	\$ 82,500	\$101,750	\$110,000	\$165,000	\$220,000					
15	\$29,235	\$58,470	\$77,765	\$ 87,705	\$108,170	\$116,940	\$175,410	\$233,880					
16	\$30,970	\$61,940	\$82,380	\$ 92,910	\$114,589	\$123,880	\$185,820	\$247,760					
17	\$32,705	\$65,410	\$86,995	\$ 98,115	\$121,009	\$130,820	\$196,230	\$261,640					
18	\$34,440	\$68,880	\$91,610	\$103,320	\$127,428	\$137,760	\$206,640	\$275,520					

							Reported ra	inge of house	ehold income						
Family size	Less than \$7,500	\$7,500– \$9,999	\$10,000– \$12,499	\$12,500– \$14,999	\$15,000– \$17,499	\$17,500– \$19,999	\$20,000– \$24,999	\$25,000– \$29,999	\$30,000– \$34,999	\$35,000– \$39,999	\$40,000– \$44,999	\$45,000– \$49,999	\$50,000– \$59,999	\$60,000– \$74,999	\$75,000 and over
2	5,500	А	11,100	В	16,600	D	22,100	F	33,200	G	G	Н	Н	Н	н
3	6,900	А	А	13,900	В	18,500	D	27,800	F	F	41,700	G	55,500	Н	Н
4	AA	8,400	А	А	16,700	В	22,200	D	30,900/ 33,400	F 36,100/	F	F	G	66,800	Н
5	AA	AA	А	А	А	19,500	В	26,000	D	39,000	F	F	58,600	G	80,000
6	AA	AA	11,200	A	А	А	22,300	В	33,500	D	41,300	F	F	67,000	90,000
7	AA	AA	AA	А	A	A	А	В	33,500	37,700	D	46,500	F	F	100,000
8	AA	AA	AA	14,000	А	А	А	28,000	В	37,200	42,000	D	51,800/ 56,000	F	85,000/ 110,000
9	AA	AA	AA	AA	AA	А	А	А	В	В	41,000	46,200	57,000	61,600	90,000/ 125,000
10	AA	AA	AA	AA	16,800	А	А	А	33,600	В	В	С	D	62,200/ 67,200	100,000/ 135,000
11	AA	AA	AA	AA	AA	18,200	А	А	А	36,400	В	48,500	54,700	67,400/ 72,900	110,000/ 145,000
12	AA	AA	AA	AA	AA	AA	А	А	А	А	В	В	52,200/ 59,000	72,600	80,000/ 120,000
13	AA	AA	AA	AA	AA	AA	21,000	А	А	А	42,100	В	56,000	63,200	85,000/ 125,000
14	AA	AA	AA	AA	AA	AA	22,500	А	А	А	А	В	В	67,400	90,000/ 135,000
15	AA	AA	AA	AA	AA	AA	23,900	А	А	А	А	47,700	В	63,400/ 71,600	95,000/ 145,000
16	AA	AA	AA	AA	AA	AA	AA	AA	А	А	А	А	В	67,200	100,000/ 150,000
17	AA	AA	AA	AA	AA	AA	AA	26,700	А	А	А	А	53,400	71,000	105,000/ 160,000 110,000/
18	AA	AA	AA	AA	AA	AA	AA	28,100	А	А	А	А	56,200	В	170,000

Table XII. Year 1999 reference value table for additional income cascade questions for families in the 48 contiguous States and the District of Columbia

NOTE: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was uses than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000. Were income was entirely within one poverty range for each letter shown is listed in the first bulleted section under "Procedures for Assigning Household Poverty Status"

		Reported range of household income													
Family size	Less than \$7,500	\$7,500– \$9,999	\$10,000– \$12,499	\$12,500– \$14,999	\$15,000– \$17,499	\$17,500– \$19,999	\$20,000– \$24,999	\$25,000– \$29,999	\$30,000– \$34,999	\$35,000– \$39,999	\$40,000– \$44,999	\$45,000– \$49,999	\$50,000– \$59,999	\$60,000– \$74,999	\$75,000 and over
2	6,900	А	А	13,800	В	18,400	С	27,700	F	F	41,500	G	55,400	н	Н
3	AA	8,700	А	A	В	В	23,100	26,000	32,200	F	F	F	52,100	69,600	Н
4	AA	AA	A	A	А	A	20,900	27,800	31,400	38,700	41,800	F	F	62,700	80,000
5	AA	AA	А	A	A	A	В	В	32,500	36,600	D	48,800	F	73,200	100,000
6	AA	AA	AA	14,000	А	А	А	27,900	В	37,100	41,900	D	51,700/ 55,800	F	85,000/ 110,000 95,000/
7	AA	AA	AA	AA	15,700	А	А	А	31,400	В	41,800	47,100	58,200	62,800 64.800/	125,000/ 105.000/
8	AA	AA	AA	А	А	А	А	В	В	В	В	46,500	52,400 51,200/	70,000	140,000 75,000/
9	AA	AA	AA	AA	AA	19,200	А	А	А	38,500	В	В	57,700	71,200	115,000/ 85,000/
10	AA	AA	AA	AA	AA	AA	21,000	А	А	А	42,000	В	55,900	63,000	125,000/ 90,000/
11	AA	AA	AA	AA	AA	AA	22,800	А	А	А	В	В	В	68,300 73,600/	135,000/ 100,000/
12	AA	AA	AA	AA	AA	AA	А	А	А	А	А	49,000	В	65,200	145,000
13	AA	AA	AA	AA	AA	AA	AA	26,300	А	А	А	А	52,600	69,900	105,000/ 160,000 110,000/
14	AA	AA	AA	AA	AA	AA	AA	28,000	А	А	А	А	56,100	В	170,000
15	AA	AA	AA	AA	AA	AA	AA	А	А	А	А	В	В	В	120,000/ 180,000
16	AA	AA	AA	AA	AA	AA	AA	AA	31,600	А	А	А	В	63,100	125,000/ 190,000
17	AA	AA	AA	AA	AA	AA	AA	AA	33,300	А	А	А	А	66,600	135,000/ 200,000 140,000/
18	AA	AA	AA	AA	AA	AA	AA	AA	А	А	А	А	А	70,200	210,000

NOTE: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was over \$75,000. When income was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions

							Reported ra	inge of house	ehold income						
Family size	Less than \$7,500	\$7,500– \$9,999	\$10,000– \$12,499	\$12,500– \$14,999	\$15,000– \$17,499	\$17,500– \$19,999	\$20,000– \$24,999	\$25,000– \$29,999	\$30,000– \$34,999	\$35,000– \$39,999	\$40,000– \$44,999	\$45,000– \$49,999	\$50,000– \$59,999	\$60,000– \$74,999	\$75,000 and over
2	6,400	А	А	А	16,900	19,100	23,500 21,200/	E	F	38,200	G	Н	50,900	Н	Н
3	AA	8,000	А	А	16,000	В	24,000	D	31,900	F	F	47,900	G	63,900	Н
4	AA	AA	А	А	A	19,200	В	28,800	С	38,400	F	F	57,600	G	75,000
5	AA	AA	11,200	А	А	A	22,500	С	33,700	D	41,500	E	F	67,400	90,000
6	AA	AA	AA	AA	А	А	A	В	С	38,500	D	47,500	51,400 53,500/	F	75,000/ 105,000 85,000/
7	AA	AA	AA	14,500	А	А	А	28,900	В	38,500	43,400	D	57,900	F	115,000
8	AA	AA	AA	А	16,100	А	А	В	32,200	В	42,800	48,300	D	64,300	95,000/ 130,000
9	AA	AA	AA	AA	AA	AA	А	А	A	А	В	47,100	53,100	65,500/ 70,800	105,000/ 140,000
10	AA	AA	AA	AA	AA	19,300	А	А	А	38,700	В	В	51,400/ 58,000	71,500	75,000/ 115,000
11	AA	AA	AA	AA	AA	AA	20,900	А	А	А	41,900	В	55,700	62,800	85,000/ 125,000/ 90,000/
12	AA	AA	AA	AA	AA	AA	22,600	А	А	А	А	А	В	67,700 64,300/	135,000/ 95,000/
13	AA	AA	AA	AA	AA	AA	AA	AA	А	А	А	48,400	В	72,600	145,000/ 105,000/
14	AA	AA	AA	AA	AA	AA	AA	AA	А	А	А	В	51,600	68,600	155,000/ 100,000/
15	AA	AA	AA	AA	AA	AA	AA	27,400	А	А	А	В	54,900	73,000	165,000/ 115,000/
16	AA	AA	AA	AA	AA	AA	AA	29,000	А	А	А	А	58,100	В	175,000/ 125,000/
17	AA	AA	AA	AA	AA	AA	AA	AA	А	А	А	А	А	61,300	125,000/ 185,000 130,000/
18	AA	AA	AA	AA	AA	AA	AA	AA	32,300	А	А	А	А	64,600	195,000/

NOTE: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was over \$75,000. When income was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000 to me either endpoint of the reported range of household income. Letters rather than values signify that the reported range of household Pov

		Reported range of household income													
Family size	Less than \$7,500	\$7,500– \$9,999	\$10,000- \$12,499	\$12,500– \$14,999	\$15,000– \$17,499	\$17,500– \$19,999	\$20,000– \$24,999	\$25,000– \$29,999	\$30,000– \$34,999	\$35,000– \$39,999	\$40,000– \$44,999	\$45,000– \$49,999	\$50,000– \$59,999	\$60,000- \$74,999	\$75,000 and over
							21,500/								
2	5,800	A	11,600	В	С	D	23,200	F	F	G	G	46,400	Н	Н	Н
3	AA	A	A	A	В	В	21,900	27,100	F	F	43,900	G	58,500	Н	Н
4	AA	8,800	A	A	A	В	23,500	26,500	32,700	F	F	F	53,000	70,600	Н
5	AA	AA	А	А	A	A	В	27,500	31,000	38,200	41,300	F	F	62,000	85,000
6	AA	AA	11,800	А	A	A	23,700	В	31,500	D	43,800	47,400	F	71,100	95,000
7	AA	AA	AA	13,400	А	А	А	26,700	В	С	D	D	53,400	F	80,000/ 105,000
8	AA	AA	AA	AA	А	А	А	А	В	В	С	D	55,000	F	90,000/ 120,000 100,000/
9	AA	AA	AA	AA	16,400	А	Α	А	32,800	В	43,600	С	D	65,500	130,000
10	AA	AA	AA	AA	AA	А	А	А	А	В	В	47,600	53,700 51,600/	66,200/ 71,500	105,000/ 145,000 80,000/
11	AA	AA	AA	AA	AA	19,400	А	А	А	38,800	В	В	58,200	71,800	115,000
12	AA	AA	AA	AA	AA	AA	А	А	А	А	41,800	В	55,600	62,700	85,000/ 125,000
13	AA	AA	AA	AA	AA	AA	22,400	А	А	А	А	В	В	67,200 63,600/	90,000/ 135,000 95,000/
14	AA	AA	AA	AA	AA	AA	23,900	А	А	А	А	47,900	В	71,800	145,000
15	AA	AA	AA	AA	AA	AA	AA	А	А	А	А	А	В	67,700	100,000/ 155,000
16	AA	AA	AA	AA	AA	AA	AA	26,900	А	А	А	А	53,900	71,700	110,000/ 160,000
17	AA	AA	AA	AA	AA	AA	AA	28,500	А	А	А	А	56,900	В	115,000/ 170,000 120,000/
18	AA	AA	AA	AA	AA	AA	AA	AA	А	А	А	А	А	В	180,000

Table XV. Year 2001 reference value table for additional income cascade questions for families in the 48 contiguous States and the District of Columbia

NOTE: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was uses than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000. Were income was entirely within one poverty range. The poverty range for each letter shown is listed in the first bulleted section under "Procedures for Assigning Househ

		Reported range of household income													
Family size	Less than \$7,500	\$7,500– \$9,999	\$10,000– \$12,499	\$12,500– \$14,999	\$15,000– \$17,499	\$17,500– \$19,999	\$20,000– \$24,999	\$25,000– \$29,999	\$30,000– \$34,999	\$35,000– \$39,999	\$40,000– \$44,999	\$45,000– \$49,999	\$50,000– \$59,999	\$60,000– \$74,999	\$75,000 and over
								26,800/							
2	AA	A	A	A	В	19,300	21,800	29,000	F	F	43,500	G	58,000	Н	Н
3	AA	9,100	A	A	A	18,300	В	27,400	33,800	36,600	F	F	54,900	73,200	Н
4	AA	AA	11,000	A	A	A	22,100	В	33,100	D	E	F	F	66,200	90,000
5	AA	AA	AA	А	А	А	А	В	В	38,800	D	47,800	51,700	F	80,000/ 105,000
6	AA	AA	AA	AA	А	А	А	А	В	В	С	D	54,800	F	90,000/ 120,000
0	700		703	700	~	A	~	~	D	D	0	D	54,000	61,800/	100,000/
7	AA	AA	AA	AA	16,700	А	А	А	33,400	В	В	С	С	66,800	135,000
					,				,					,	110,000/
8	AA	AA	AA	AA	AA	18,600	А	А	А	37,200	В	В	55,800	68,800	150,000
															80,000/
9	AA	AA	AA	AA	AA	AA	A	A	A	A	41,000	В	54,500	61,500	125,000
							~~						_		90,000/
10	AA	AA	AA	AA	AA	AA	22,400	A	A	A	A	В	В	67,100	135,000
11	AA	AA	AA	AA	AA	AA	AA	А	А	А	А	48,500	В	64,500/ 72,800	95,000/ 145,000
11	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	40,500	Б	72,800	145,000/
12	AA	AA	AA	AA	AA	AA	AA	26,200	А	А	А	А	52,300	69,600	155,000/
	,		701	701	,	,	,	20,200					02,000	00,000	110,000/
13	AA	AA	AA	AA	AA	AA	AA	28,000	А	А	А	А	56,100	В	170,000
															120,000/
14	AA	AA	AA	AA	AA	AA	AA	AA	A	А	A	A	Α	В	180,000
															130,000/
15	AA	AA	AA	AA	AA	AA	AA	AA	31,800	A	A	A	A	63,700	190,000
10				AA					00 700	٨	^	А	•	67 400	135,000/
16	AA	AA	AA	AA	AA	AA	AA	AA	33,700	A	A	A	A	67,400	200,000 140,000/
17	AA	AA	AA	AA	AA	AA	AA	AA	AA	А	А	А	А	71,200	215,000/
	,	, , , ,	701	, , , ,	701	,	,	, , , ,	, , , ,				~	,,,200	150,000/
18	AA	AA	AA	AA	AA	AA	AA	AA	AA	37,500	А	А	А	А	225,000

NOTE: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was over \$75,000. When income was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions

							Reported ra	ange of house	hold income						
Family size	Less than \$7,500	\$7,500– \$9,999	\$10,000– \$12,499	\$12,500– \$14,999	\$15,000– \$17,499	\$17,500– \$19,999	\$20,000– \$24,999	\$25,000– \$29,999	\$30,000– \$34,999	\$35,000– \$39,999	\$40,000– \$44,999	\$45,000– \$49,999	\$50,000– \$59,999	\$60,000– \$74,999	\$75,000 and over
2	6,700	А	А	13,400	В	С	D	26,700	F	F	G	G	53,400	Н	Н
3	AA	8,400	А	А	16,800	В	22,400	D	31,100/ 33,700	F	F	F	G	67,300	н
4	AA	AA	А	А	Â	А	В	27,000	Ď	37,600	F	F	F	G	80,000
5	AA	AA	11,900	А	А	А	23,800	В	31,600	D	44,000	47,500	F	71,300	95,000
6	AA	AA	AA	13,600	А	А	А	27,200	В	36,200	D	D	54,500	F	80,000/ 110,000 90,000/
7	AA	AA	AA	AA	А	А	А	А	В	В	С	46,100	56,800	61,400	125,000
8	AA	AA	AA	AA	AA	А	А	А	А	В	В	С	51,300	63,200/ 68,400	105,000/ 135,000
9	AA	AA	AA	AA	AA	18,800	А	А	А	37,700	В	В	56,500	69,700	115,000/ 150,000
10	AA	AA	AA	AA	AA	AA	А	А	А	А	41,100	В	54,700	61,700	80,000/ 125,000
11	AA	AA	AA	AA	AA	AA	22,300	А	А	А	А	В	В	66,900	90,000/ 135,000
12	AA	AA	AA	AA	AA	AA	24,000	А	А	А	А	48,100	В	63,900/ 72,100	95,000/ 145,000 105,000/
13	AA	AA	AA	AA	AA	AA	AA	А	А	А	А	А	51,500	68,500	155,000/ 155,000/ 110,000/
14	AA	AA	AA	AA	AA	AA	AA	27,500	А	А	А	А	55,000	73,200	165,000/ 115,000/
15	AA	AA	AA	AA	AA	AA	AA	AA	А	А	А	А	58,500	В	175,000/ 125,000/
16	AA	AA	AA	AA	AA	AA	AA	AA	31,000	А	А	А	А	61,900	125,000/ 185,000 130,000/
17	AA	AA	AA	AA	AA	AA	AA	AA	32,700	А	А	А	А	65,400	130,000/ 200,000 140,000/
18	AA	AA	AA	AA	AA	AA	AA	AA	AA	А	А	А	А	68,900	205,000

NOTE: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was over \$75,000. When income was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$900 from either endpoint of the reported range of household income was entirely within one poverty range. The poverty range for each letter shown is listed in the first bulleted sesction under "Procedures for Assigning Household Poverty Status" of appendix IV.

Appendix V

Advance Letters

Letter Used in 2000 with NIS Sample



Centers for Disease Control and Prevention

National Center for Health Statistics 6525 Belcrest Road Hyattsville, Maryland 20782-2003

FROM THE DIRECTOR NATIONAL CENTER FOR HEALTH STATISTICS

Within the next few weeks, your household will be called to take part in an important national study being conducted by the <u>U.S. Department of Health and Human Services</u>. This study provides important information for measuring the progress of vaccination for young children for the country.

Childhood immunization rates are at an all-time high of 78%, but many children have not received all of their immunizations. The Department of Health and Human Services is committed to improving immunization services and reducing the costs of vaccines. Local, state, and federal health authorities depend on the results of this study to measure the progress of immunization for the country.

Your participation is likely to require only one or two minutes of your time. You may call our tollfree telephone number (1-800-290-1296) to participate immediately or visit the study's web site at <u>http://www.cdc.gov/nis</u> to learn more about the study. If you have a child between 1 and 3 years of age, please take a moment to locate the child's immunization records. They will help you during the interview.

We are relying on your help to make this study a success. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate. The information we are gathering will help shape health care policy in the years ahead.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. When the interviewer calls, you will be asked a few questions to determine whether or not your household is eligible for participation in this study. If your household is selected, the interview should take only about fifteen minutes to complete.

This study is authorized by the Public Health Service Act [Secs. 306 & 2102 (a)(7)], and by law, information you provide during the interview will be kept strictly confidential. The information reported in this survey will be summarized for research purposes only.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D. Director

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¹ If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-290-1296 be called.

Letter Used in 2001 with NIS Sample



Centers for Disease Control and Prevention

National Center for Health Statistics 6525 Belcrest Road Hyattsville, Maryland 20782-2003

FROM THE DIRECTOR NATIONAL CENTER FOR HEALTH STATISTICS

Within the next few weeks, your household will be called to take part in an important national study being conducted by the **U.S. Department of Health and Human Services**. This study provides important information for measuring the progress of vaccination for young children for the country.

Childhood immunization rates are at an all-time high of 78%, but many children have not received all of their immunizations. The Department of Health and Human Services is committed to improving immunization services and reducing the costs of vaccines. Local, state, and federal health authorities depend on the results of this study to measure the progress of immunization for the country.

The results of this study also help local, state, and federal health authorities understand how to improve health care services for all children. Therefore, some households may be asked questions about the types of health and related services their children need or use.

You may call the study's toll-free telephone number (1-800-290-1296) to participate immediately or to obtain more information about the study's background and content. You may also visit the study's web site at <u>http://www.cdc.gov/nis</u> for more information. If you have a child between 18 and 35 months of age, please take a moment to locate the child's immunization records. They will help you during the interview.

We are relying on your help to make this study a success. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate. The information we are gathering will help shape health care policy in the years ahead.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. When the interviewer calls, you will be asked a few questions to determine whether or not your household is eligible for participation in this study.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

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

If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-290-1296 be called.

CDC 64.124 (1/01) C1

Page 124
Series 1, No. 41

Letter Used in 2002 with NIS Sample



Centers for Disease Control and Prevention

National Center for Health Statistics 6525 Belcrest Road Hyattsville, Maryland 20782-2003

FROM THE DIRECTOR NATIONAL CENTER FOR HEALTH STATISTICS

Within the next few weeks, your household will be called to take part in an important national study being conducted by the <u>U.S. Department of Health and Human Services</u>. This study provides important information for measuring the progress of vaccination for young children for the country.

Childhood immunization rates are at an all-time high of 78%, but many children have not received all of their immunizations. The Department of Health and Human Services is committed to improving immunization services and reducing the costs of vaccines. Local, state, and federal health authorities depend on the results of this study to measure the progress of immunization for the country.

The results of this study also help local, state, and federal health authorities understand how to improve health care services for all children. Therefore, some households may be asked questions about the types of health and related services their children need or use.

You may call Jim Murphy at the study's toll-free telephone number (1-800-290-1296) to participate immediately or to obtain more information about the study's background and content. You may also visit the study's web site at <u>http://www.cdc.gov/nis</u> for more information. If you have a child between 18 and 35 months of age, please take a moment to locate the child's immunization records. They will help you during the interview.

We are relying on your help to make this study a success. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate. The information we are gathering will help shape health care policy in the years ahead. If you would like to learn more about your rights as a respondent, please contact the Chair of the Institutional Review Board at 1-800-223-8118.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. When the interviewer calls, you will be asked a few questions to determine whether or not your household is eligible for participation in this study.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Eddell

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

If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-290-1296 be called.

CDC 64.124 (1/02) C102

Letter Used in 2000–02 with Augmentation Sample



Centers for Disease Control and Prevention

National Center for Health Statistics 6525 Belcrest Road Hyattsville, Maryland 20782-2003

FROM THE DIRECTOR NATIONAL CENTER FOR HEALTH STATISTICS

Within the next few weeks, your household may be called to take part in an important national study about the health of children and teenagers. The survey is being conducted by the U.S. Department of Health and Human Services.

We are relying on your help to make this study a success. Local, state, and federal health authorities depend on the results of this study to measure the progress of health care for the country. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate. The information we are gathering will help shape health care policy in the years ahead.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. This study is authorized by the Public Health Service Act [Secs. 306 & 2102 (a)(7)], and by law, information you provide during the interview will be kept strictly confidential. The information reported in this survey will be summarized for research purposes only.

You may call our toll-free telephone number (1-800-290-1296) to participate immediately or visit the study's web site at <u>http://www.cdc.gov/nis</u> to learn more about the study. This study has been approved by the NCHS Institutional Review Board. If you have questions about your rights as a study participant, you may call Margot Palmer, Institutional Review Board chairman, toll-free at 1-800-223-8118.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D. Director

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If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-290-1296 be called.

CDC 64.124 (02/01) A1

Appendix VI

Disposition Code Frequencies and Response Rate Calculations

Table XVIII. Frequencies of disposition codes for National Survey of Children with Special Health Care Needs

Disposition code by name	Disposition category	Frequency	Percent of total
		2,620,484	100.00
No contact	UH	178,910	6.83
3+ Fax/modem prior to any contact	Z	51,388	1.96
2+ Temporarily not in service	Z	35,813	1.37
Nonworking number	Z	197,250	7.53
Number changed	Z	15,354	0.59
Answering machine - known household	UOC	2,545	0.10
Answering machine - nonresidential	Z	17,909	0.68
Answering machine - residential status unknown	UH	38,213	1.46
5		5	
Answering service - known household	Z		< 0.005
Answering service - nonresidential	Z	209	0.01
Answering service - residential status unknown	UH	154	0.01
Spanish case - residential status unknown	UH	260	0.01
Other language case - residential status unknown	UH	573	0.02
Physical/mental impairment case - residential status unknown	UH	306	0.01
Appointment at introduction - residential status unknown	UH	4,260	0.16
Callback at introduction - residential status unknown	UH	467	0.02
Broken appointment at introduction - residential status unknown	UH	4,727	0.18
Hangup during introduction	UH	20,688	0.79
Refusal at introduction	UH	80,647	3.08
Callback - known household	UOC	4,350	0.17
Appointment - known household	UOC	1,089	0.04
Broken apppointment - known household	UOC	2,131	0.08
Refusal - kown household	UOC	32,831	1.25
NIS-level callback	UOS	318	0.01
	UOS	221	
NIS-level appointment			0.01
NIS-level - broken appointment	UOS	144	0.01
NIS-level refusal	UOS	2,520	0.10
Not residential	Z	115,646	4.41
Refusal prior to NS-CSHCN item C2Q01	UOS	35,942	1.37
Callback prior to NS-CSHCN item C2Q01	UOS	4,633	0.18
Appointment prior to NS-CSHCN item C2Q01	UOS	3,411	0.13
Refusal prior to NS-CSHCN item FACCT1	UOS	7,336	0.28
Callback prior to NS-CSHCN item FACCT1	UOS	596	0.02
Appointment prior to NS-CSHCN item FACCT1	UOS	713	0.03
Refusal prior to NS-CSHCN item FACCT5	UOS	169	0.01
Callback prior to NS-CSHCN item FACCT5	UOS	106	< 0.005
Appointment prior to NS-CSHCN item FACCT5	UOS	81	<0.005
Refusal prior to NS-CSHCN item C8Q01	R	1,564	0.06
Callback prior to NS-CSHCN item C8Q01	R	262	0.01
Appointment prior to NS-CSHCN item C8Q01	R	244	0.01
Refusal - partial interview	P	259	0.01
	P		
Callback - partial interview	r	21	< 0.005
Broken appointment - partial interview	P	6	< 0.005
Appointment - partial interview	P	42	< 0.005
Other language case - known household, unknown age eligibility	UOC	1,026	0.04
Other language case - known age-eligible household	Y	1,263	0.05
Screened - emancipated minor household ¹	XC	198	0.01
Screened - no age-eligible children	XC	620,924	23.70
Screened age-eligible household in Missouri Supplemental Sample, no child sampled ²	XS	2,496	0.10
Completed household interview	I	180,967	6.91
Converted household interview	I	11,026	0.42
GENESYS-resolved numbers	Z	938,271	35.81

¹Interviews were not conducted in households in which no one over the age of 17 resided.

²Only special-needs interviews were conducted in the Missouri Supplemental Sample.

NOTES: NIS is National Immunization Survey. NSCSHCN is National Survey of Children with Special Health Care Needs.

Table XIX. Unweighted response rate calculations for National Survey of Children with Special Health Care Needs

Disposition categories and response rates	Frequency or calculated rate	Code or formula
Summary of disposition categories		
Completed interviews at the household level	191,993	I
Partial interviews at the household level	328	Р
Unknown residential status	329,205	UH
Known household, unknown age eligibility	43,972	UOC
Known age-eligible household, unknown special needs eligibility	56,190	UOS
Refusal, screened, and eligible	2,070	R
Screened for age-eligibility, no eligible child	621,122	XC
Screened for special needs, no child sampled	2,496	XS
Known age-eligible household, other language	1,263	Y
Out of scope (i.e., business, nonworking, fax/modem)	1,371,845	Z
Total	2,620,484	
Calculation of response rates		
nterview completion rate (ICR)	98.3	(I+P) / (I+P+R)
Special-needs screener completion rate (SNSCR)	77.4	(I+P+R+XS) / (I+P+R+XS+Y+UOS)
Age screener completion rate (ASCR)	95.2	(I+P+R+Y+UOS+XS+XC) / (I+P+R+Y+UOS+XS+XC+UOC)
, , ,		(I+P+R+Y+UOS+XS+XC+UOC+Z) /
Resolution rate (RR)	87.4	(I+P+R+Y+UOS+XS+XC+UOC+Z+UH)
CASRO ¹ rate	63.4	(ICR)(SNSCR)(ASCR)(RR)

¹CASRO is Council of American Survey Research Organizations.

Appendix VII

National Survey of CSHCN: Pretest II

Because the National Survey of CSHCN shared the same sampling frame with the NIS, with NIS administration occurring prior to administration of the National Survey of CSHCN, it was important that acceptable response rates for both studies be obtained. Lower than anticipated response rates, for both the NIS and the National Survey of CSHCN, were observed in the first National Survey of CSHCN pretest. The interview completion rate was 97.0%, the screener completion rate was 79.9%, and the resolution rate was 87.8%. The CASRO response rate, derived from the product of the three rates described above, was 68.0%. In comparison, the CASRO response rate for the NIS across the 11 IAP areas used in the first pretest was 73.4%. (It should be noted that in contrast to the main study, a single screener completion rate was calculated for the pretests. This screener completion rate, which combines the two stages of eligibility determination, artificially inflates the overall response rate. Because this incorrect calculation was not detected until well after the conclusion of both pretests, it has not been recalculated here.)

Therefore, a second pretest was designed to identify a method of integrating the NIS and the National Survey of CSHCN that would achieve acceptable response rates for both projects. Because the low response rates for the first pretest were primarily a result of increased breakoffs at the beginning of NIS administration, the second pretests concentrated on methods that would increase response at this early stage-that is, improvements to the advance letter and introductory script text. To investigate a full range of alternatives to increase NIS and National Survey of CSHCN response rates, four letter conditions and three introductory script conditions were tested. The individual advance letter and introductory script conditions were

joined to create seven advance letter and/or introductory script combinations, described below.

NIS Advance Letter and NIS Introduction (Control Group)—In this control condition, the advance letter already in use for the NIS was mailed to households with an identified address. The current NIS introductory script was administered.

No Advance Letter and Low-Content Introductory Script—No advance letters were mailed to households regardless of whether they had an identified address. A low-content introductory script (mentioning only that the study was about children and teenagers in the respondent's State) was administered.

No Advance Letter and High-Content Introductory Script—No advance letters were mailed to households regardless of whether they had an identified address. A highcontent introductory script (which explicitly stated that the study was about children and teenagers with special health needs and included information about the random selection of numbers for the study and its expected length in most households) was administered.

Revised NIS Advance Letter 1 and Low-Content Introductory Script—An advance letter specifically describing the content of both the NIS and the National Survey of CSHCN interviews and omitting mention of the NIS age-eligibility range was mailed to households with an identified address. A low-content introductory script (mentioning only that the study was about children and teenagers in the respondent's State) was administered.

Revised NIS Advance Letter 1 and High-Content Introductory Script—An advance letter specifically describing the content of both the NIS and the National Survey of CSHCN interviews and omitting mention of the NIS age-eligibility range was mailed to households with an identified address. A high-content introductory script (which explicitly stated that the study was about children and teenagers with special health needs and included information about the random selection of numbers for the study and its expected length in most households) was administered.

Revised NIS Advance Letter 2 and Low-Content Introductory Script—A generic advance letter, describing the content of the interview more generally, was mailed to households with an identified address. A low-content introductory script (mentioning only that the study was about children and teenagers in the respondent's State) was administered.

Revised NIS Advance Letter 2 and High-Content Introductory Script—A generic advance letter, describing the content of the interview more generally, was mailed to households with an identified address. A high-content introductory script (which explicitly stated that the study was about children and teenagers with special health needs and included information about the random selection of numbers for the study and its expected length in most households) was administered.

The advance letters used in Pretest II appear in appendix VIII. The introductory texts used were as follows:

NIS Introductory Script—"Hello, my name is {name of interviewer}. I'm calling on behalf of the Centers for Disease Control and Prevention. We're conducting a nationwide immunization study to find out how many children under 4 years of age are receiving all of the recommended vaccinations for childhood diseases. Your telephone number has been selected at random to be included in the study. The questions I have will take only a few minutes."

Low-Content Introductory Script—"Hi, my name is {name of interviewer}. I am calling on behalf of the Centers for Disease Control and Prevention and the National Center for Health Statistics. We are doing a survey about the health of children and teenagers in {name of State}."

High-Content Introductory Script—"Hi, my name is {name of interviewer}. I am calling on behalf of the Centers for Disease Control and Prevention and the National Center for Health Statistics. We are doing a nationwide study about the special health needs of children and teenagers. Your number has been selected at random to be included in the study. For most people, the questions I have will take only a few minutes."

Pretest II Sample Design and Selection

The Pretest II sample consisted of four national replicates created for NIS administration, drawn in the manner described in appendix I of this report. One replicate was used for the control group. The other three replicates were used for the experimental conditions. Each of the three experimental replicates was first assigned to an advance letter condition. Then, each of these replicates was split into two half-replicates, with one half-replicate assigned to the low-content introduction group and the other half-replicate assigned to the high-content introduction group. The result was six independent samples with the control group sample comprising a seventh.

The Pretest II sample was designed so that response rates for the four individual letter conditions and three individual introductory script conditions could be examined. However, it should be noted that each is confounded with its partnered letters or scripts. With a minimum sample of 20,000 lines and a one-sided test at a 5% level of significance, it was anticipated that the following differences would be detectable with 80% power:

- A decrease of 0.46 percentage points in the NIS age-eligibility rate assuming a current eligibility rate of 3.8%. The age-eligibility rate is defined as the percent of households that contain a child who is age eligible for the study (i.e., a child between 19 and 35 months of age).
- A decrease of 1.2 percentage points in the NIS CASRO response rate assuming a current rate of 70%.

As mentioned earlier, the low response rates observed in Pretest I were primarily a result of increased breakoffs at the beginning of NIS administration. Therefore, the second pretest concentrated on methods that would increase response at this early stage. Thus, the experiment was designed to examine differences in NIS response rates rather than National Survey of CSHCN response rates. An increase in response at the NIS level would also benefit the National Survey of CSHCN because households were being successfully identified and initially screened.

It is important to note that because national replicates created for the NIS were used for Pretest II, the sample did not perfectly mirror the expected sample for the main National Survey of CSHCN. The NIS sample focuses equally on each of the 78 IAP areas (50 States and 28 metropolitan areas), and the National Survey of CSHCN was designed to provide representative State-level estimates. Therefore, using national replicates created for the NIS meant that the pretest used more urban sample than would be used for the main study.

In a cost-saving effort, 75% of the pretest sample was flagged for an abbreviated special-needs interview that included only the early questionnaire sections. In addition, children without special needs were not sampled for health insurance control sample interviews, and Low-Income Uninsured Supplement interviews were not administered in this portion of the sample. This plan allowed for the full sample to be used in evaluating advance letters and introductory scripts, and provided a formal "dress rehearsal" of the full special-needs interview, the health insurance control sample interview, and the Low-Income Uninsured Supplement in 25% of the sample. In this 25% of the sample, children without special needs were subsampled from every other household with such children.

Pretest II Training

For the second pretest of the National Survey of CSHCN, the data collection staff were identified during August 2000. A total of 219 interviewers in the Abt Associates' Chicago and Las Vegas telephone centers were identified based on their NIS experience, interviewing skills, supervisor evaluations, and production rates on the NIS. Training was conducted in both Chicago and Las Vegas to ensure full coverage of interviewing hours (9 a.m.–9 p.m. in each time zone).

Each interviewer administered only one variant of the introduction. During training, particular attention was paid to ensuring that the interviewers delivered the different introductions in the same way to minimize any effect due to the confounding of interviewer and introduction. The specific purposes of the second pretest were communicated to interviewers.

Pretest II Data Collection

For the experimental groups where an advance letter was used, an address was matched to 45.9% of the sampled telephone numbers. It is important to note that because all households could not be matched with an address, there were households in each of the experimental conditions (as well as 100% of the no-letter experimental condition) that were not mailed an advance letter.

Data collection began on August 9, 2000, and ended on November 13, 2000. A total of 10,116 households with children were screened, resulting in 2,265 special-needs interviews (1,682 abbreviated interviews and 583 full-length interviews), and 1,988 health insurance control sample interviews. A total of 124 Low-Income Uninsured Supplement interviews were also completed.

A Spanish-language version of the CATI questionnaire was incorporated into Pretest II. From 819 known eligible households where Spanish was the primary language, 705 completed the special-needs screening. From these 705 households, 186 households had children sampled for an interview, and 176 completed the interview for their sampled children. A total of 78 interviews regarding a child with special health care needs and 97 health insurance control sample interviews were completed (4.1% of total interviews conducted). Twenty-eight Low-Income Uninsured Supplement interviews were completed in these households.

Pretest II Overall Response Rates

In addition to response rates by experimental condition, overall response rates for the total combined Pretest II sample were calculated. The interview completion rate, a measure of completed interviews among eligible respondents, was 97.4%. The screener completion rate, which measures the number of known households identified as having an eligible respondent, was 85.1%. The resolution rate, indicating the proportion of telephone numbers that could be identified as residential or nonresidential, was 87.4%. The CASRO response rate, derived from the product of the three rates described above, was 72.5%. (As before, it should be noted that, in contrast to the main study, a single screener completion rate was calculated for this pretest. This screener completion rate, which combines the two stages of eligibility determination, artificially inflates the overall response rate. Because the results of this pretest were evaluated and decisions were made using this earlier calculation, it has not been recalculated here.)

Pretest II Results

Details regarding NIS and National Survey of CSHCN response rates by the condition observed in the second pretest are provided in table XX. Rates are provided for each of the seven advance letter-introductory script combinations, followed by rates for each experimental letter and introductory script group individually.

Tests of statistical significance were performed comparing individual letter and introductory script groups. When comparing the NIS introduction with the alternative introductions, all differences in the key indicators between the control and experimental groups were significant. When comparing the NIS advance letter with the no-letter condition, all differences in the key indicators between the two groups were significant except for the NIS age-eligibility rate. When comparing the NIS advance letter with the revised advance letter conditions, all differences in the key indicators between the control and the experimental groups were significant except for the NIS age-eligibility rate and the resolution rate.

Based on the significant differences in key indicators between the control group and each of the experimental groups, it was concluded that the NIS advance letter and introduction were the most beneficial for both National Survey of CSHCN and NIS response rates, and this combination was selected for National Survey of CSHCN use.

Additional Testing (CSHCN Screener Question Order)

Although the purpose of the second pretest was to investigate alternatives to increase NIS and National Survey of CSHCN response rates, an additional test was incorporated to address a concern raised during analysis of Pretest I data. During Pretest I, the order of administration for the CSHCN Screener and QuICCC-R was alternated. The first question of both screening instruments asked whether the sampled child used prescription medication. Regardless of screener order, several respondents reported during the first screener that their children did not use prescription medication and then contradicted themselves during the second screener, reporting that the children did use prescription medication. Because administration of the screeners was preceded with a somewhat lengthy introduction (see table B), it was hypothesized that it may have been cognitively difficult for respondents to move directly from the introduction to the first screening question, thus resulting in the apparent underreporting of prescription medication use during administration of the initial screening instrument.

To determine whether prescription medication reporting differed based on the location of the question relative to the introduction (i.e., just after the screener introduction vs. later in the screener), the order of the first and second questions on the CSHCN Screener (selected for use based on Pretest I results) were alternated during Pretest II. One of these questions assessed prescription drug use and the other assessed the child's need for or use of more medical services than most children of the same age.

Pretest results suggested that the location of the prescription medication item did not have a significant effect on the overall proportion of children identified as using prescription medications or as having a special health care need. However, when respondents were asked about prescription drug use immediately following the screener introduction, the proportion of children identified with special health care needs varied significantly across the advance letter/introductory script treatment conditions that were part of the pretest. The lowest rate occurred in the group who received the current NIS advance letter and introductory script, which were ultimately chosen for use in the main study.

When the item regarding use of medical services was asked first, no significant difference was found in the proportion of CSHCN identified across the letter/introduction treatment groups. In addition, administering the item regarding use of medical services immediately following the screener introduction resulted in a significant increase in the proportion of CSHCN with "above average need/use of services" and who "need/use specialized therapies." Based on these results, a decision was made to administer the item regarding use of medical services first, followed by the prescription medication item, during the main study.

Table XX. Response rates and eligibility rates for the National Immunization Survey and the National Survey of Children with Special Health Care Needs, by experimental condition (Pretest II)

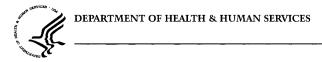
		NIS response rates					onal Survey of CSH response rates	Eligibility rates		
Experimental condition	Sample size	Interview completion rate	Screener completion rate	Resolution rate	CASRO response rate	Interview completion rate	Screener completion rate	CASRO response rate	Percent of households that include NIS-eligible children	Percent of households with children that include CSHCN
	Number					Percent				
- Control group										
NIS letter and introduction	22,537	90.0	95.8	81.7	70.5	98.7	91.1	73.5	3.7	21.5
No letter and low-content introductory										
script	10,928	82.0	88.7	80.4	58.5	96.8	82.0	63.8	3.7	24.7
No letter and high-content	10,000	89.9	01.4	78.8	647	98.2	84.9	65.7	4.0	23.4
introductory script	10,929	89.9	91.4	/0.0	64.7	98.2	84.9	05.7	4.0	23.4
introductory script	11,119	87.4	89.5	81.8	64.0	98.6	83.9	67.7	3.1	23.7
Revised NIS letter 1 and high-content	,			• • • •						
introductory script	11,118	88.8	92.5	80.2	65.9	98.3	86.9	68.5	4.0	22.7
Revised NIS letter 2 and low-content										
introductory script	11,002	93.5	89.6	81.5	68.3	99.0	83.8	67.6	3.3	23.6
Revised NIS letter 2 and high-content	11.000	00.0	00.0	70.0	07.0	00.0	00.0	007	0.0	00.0
	11,002	90.8	92.6	79.9 79.6	67.2	96.8 97.5	86.3	66.7	3.6 3.8	22.6 24.0
No letter	21,857 22,237	86.1 88.2	90.0 91.0	79.6 81.0	61.6 65.0	97.5 98.4	83.5 85.5	64.8 68.1	3.8 3.5	24.0 23.2
Revised NIS letter 2	22,237	88.2 92.1	91.0 91.1	80.8	67.7	98.4 97.9	85.2	67.4	3.5	23.2
Low-content introductory script	22,004 33,049	92.1 87.4	89.3	80.8	63.4	97.9 98.1	83.4	66.5	3.5 3.4	23.1
High-content introductory script	33,049	89.8	92.1	79.6	65.9	97.8	86.2	67.1	3.4	24.0

NOTES: NIS is National Immunization Survey. CSHCN is children with special health care needs. CASRO is Council of American Survey Research Organizations.

Appendix VIII

Pretest II Advance Letters

NIS Advance Letter



Centers for Disease Control and Prevention

National Center for Health Statistics 6525 Belcrest Road Hyattsville, Maryland 20782-2003

FROM THE DIRECTOR NATIONAL CENTER FOR HEALTH STATISTICS

Within the next few weeks, your household will be called to take part in an important national study being conducted by the **U.S. Department of Health and Human Services**. This study provides important information for measuring the progress of vaccination for young children for the country.

Childhood immunization rates are at an all-time high of 78%, but many children have not received all of their immunizations. The Department of Health and Human Services is committed to improving immunization services and reducing the costs of vaccines. Local, state, and federal health authorities depend on the results of this study to measure the progress of immunization for the country.

Your participation is likely to require only one or two minutes of your time. You may call our tollfree telephone number (1-800-290-1296) to participate immediately or visit the study's web site at <u>http://www.cdc.gov/nis</u> to learn more about the study. If you have a child between 1 and 3 years of age, please take a moment to locate the child's immunization records. They will help you during the interview.

We are relying on your help to make this study a success. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate. The information we are gathering will help shape health care policy in the years ahead.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. When the interviewer calls, you will be asked a few questions to determine whether or not your household is eligible for participation in this study. If your household is selected, the interview should take only about fifteen minutes to complete.

This study is authorized by the Public Health Service Act [Secs. 306 & 2102 (a)(7)], and by law, information you provide during the interview will be kept strictly confidential. The information reported in this survey will be summarized for research purposes only.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D Director

If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-290-1296 be called.

CDC 64.124 (7/00)

Revised NIS Advance Letter 1



DEPARTMENT OF HEALTH & HUMAN SERVICES

Centers for Disease Control and Prevention

National Center for Health Statistics 6525 Belcrest Road Hyattsville, Maryland 20782-2003

FROM THE DIRECTOR NATIONAL CENTER FOR HEALTH STATISTICS

As part of an important study conducted by the U.S. Public Health Service, parents nationwide are being interviewed over the telephone about the health of their children. The interview includes questions about vaccinations, types of medical care received, prescription medicines, allergies, and health insurance. The information you provide will help shape health care policy in the years ahead.

Within the next few weeks, your household may be called to take part in this study. Your telephone number was selected at random using scientific methods and your address was obtained through commercial listings.

We are relying on your help to make this study a success. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate.

This survey is authorized by the Public Health Service Act. All of your answers will be kept confidential. The answers from all survey participants will be combined into summary reports and used only for statistical research. No identifying information will be reported. Participation is voluntary and will in no way affect any benefits you may receive now or in the future. You may end the interview at any time.

If you have any questions about the study, please call our toll-free number, 1-800-290-1296, or visit the study's web site at http://www.cdc.gov/nis to learn more about the study. This study has been approved by the National Center for Health Statistics Institutional Review Board. If you have questions about your rights as a study participant, you may call the Institutional Review Board chairman, toll-free at 1-800-223-8118.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D. Director

If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-290-1296 be called.

CDC 64.124 (7/00)

Revised NIS Advance Letter 2



DEPARTMENT OF HEALTH & HUMAN SERVICES

Centers for Disease Control and Prevention

National Center for Health Statistics 6525 Belcrest Road Hyattsville, Maryland 20782-2003

FROM THE DIRECTOR NATIONAL CENTER FOR HEALTH STATISTICS

Within the next few weeks, your household will be called to take part in an important study being conducted by the **U.S. Public Health Service**. Parents nationwide are being interviewed over the telephone about the health of their children. The interview includes questions about vaccinations, medical services, childcare, and health insurance.

The information collected by this survey will be used by government agencies, universities, private health planners, and researchers to study the health care needs of America's children. By participating in this important survey, you will help provide better information for health policy and decisions.

You may call our toll-free number (1-800-290-1296) to participate immediately or visit the study's web site at <u>http://www.cdc.gov/nis</u> to learn more about the study. If you have a child between 1 and 3 years of age, you may be asked about your child's immunizations. Please take a moment to locate your child's immunization records. They will help during the interview.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. When the interviewer calls, you will be asked a few questions to determine whether or not your household will be selected for participation in the study.

This study is authorized by the Public Health Service Act [Secs. 306 &2102 (a)(7)], and by law, information you provide during the interview will be kept strictly confidential. The information reported in this survey will be summarized for research purposes only so that you and your family cannot be identified. Participation is voluntary and will in no way affect any benefits you may receive now or in the future. You may end the interview at any time.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D. Director

¹ If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-290-1296 be called.

CDC 64.124 (7/00)

Appendix IX

Key Prevalence Estimates and Weighted Frequencies

Table XXI. Unweighted and weighted estimates of the frequency and prevalence of households with children with special health care needs

Location	Total unweighted number of households	Total weighted estimate of number of households	Unweighted number of households with CSHCN	Weighted estimate of number of households with CSHCN	Standard error of weighted estimate of number of households with CSHCN	Percent of households with children that include CSHCN	Standard error of percent of households with children that include CSHCN
 Total	196,888	38,632,318	39,865	7,737,063.1	59,687.891	20.03	0.149
Alabama	3,843	633,213	764	128,337.3	5,069.513	20.27	0.768
Alaska	4,333	96,217	761	16,751.4	622.724	17.41	0.636
Arizona	4,276	701,975	774	125,157.8	4,908.192	17.83	0.680
Arkansas	3,655	376,217	768	81,244.5	3,026.590	21.60	0.775
California	4,967	4,660,434	778	792,768.0	31,662.705	17.01	0.652
Colorado	4,129	603,026	763	115,438.8	4,442.038	19.14	0.710
Connecticut	3,469	456,615	762	100,692.1	3,702.321	22.05	0.786
Delaware	3,339	108,020	772	24,824.4	937.250	22.98	0.835
District of Columbia	4,048	60,663	777	12,477.5	508.067	20.57	0.791
Florida	4,135	2,045,750	773	403,851.0	16,897.956	19.74	0.779
Georgia	4,077	1,206,444	777	227,733.4	9,168.072	18.88	0.733
Hawaii	4,976	154,205	765	25,337.8	1,007.679	16.43	0.628
Idaho	4,049	187,365	757	34,794.2	1,364.509	18.57	0.707
	4,027	1,682,545	765	323,241.3	14,140.032	19.21	0.796
Indiana.	3,553	842,287	767	183,853.4	6,939.229	21.83	0.793
lowa	3,948	384,017	771	75,285.4	2,803.239	19.61	0.707
Kansas	3,400	372,336	770	86,413.8	3,127.604	23.21	0.809
Kentucky	3,412	567,503	762	127,359.5	4,759.948	22.44	0.810
	3,235	651,767	774	151,432.1	6,040.353	23.23	0.885
Maine	3,124	167,298	755	39,332.7	1,379.329	23.51	0.811
Maryland	3,345	750,796	733	172,913.1	6,337.893	23.03	0.822
Massachusetts	3,434	814,354	761	181,367.4	7,278.166	22.27	0.850
Michigan.	3,485	1,355,716	766	300,070.8	10,987.023	22.13	0.788
Minnesota	3,405	666,965	756	136,773.6	5,385.552	20.51	0.779
Mississippi	4,005	418,898	730	84,031.6	3,494.544	20.06	0.789
Missouri	6,742	770,476	1536	173,565.0	4,598.965	22.53	0.577
Montana	4,006	120,533	751	23,294.1	4,598.905	19.33	0.697
Nebraska	4,008 3,777	231,785	768	47,604.4	1,803.301	20.54	0.750
Nevada	4,553	282,519	765	50,167.5	1,938.562	17.76	0.661
New Hampshire	3,320	170,265	765	39,793.9	1,461.461	23.37	0.827
New Jersey	4,107	1,141,447	765	223,438.9	8,857.077	19.58	0.743
	4,170	266,530	773	50,240.2	2,092.909	18.85	0.750
New York	4,308	2,493,133	773	461,956.6	17,549.155	18.53	0.681
North Carolina	3,624	1,129,975	755	236,690.6	9,270.912	20.95	0.787
North Dakota	3,949	83,501	760	16,448.0	631.391	19.70	0.727
Ohio	3,597	1,539,501	782	338,552.0	12,078.291	21.99	0.763
Oklahoma	3,589	483,195	764	106,403.0	4,323.200	22.02	0.843
Oregon	3,650	454,812	760	96,601.2	3,766.244	21.24	0.794
Pennsylvania	3,874	1,566,042	774	300,554.9	11,169.996	19.19	0.699
Rhode Island	3,378	135,701	766	31,015.1	1,191.592	22.86	0.843
South Carolina	3,647	568,071	765	119,099.3	4,566.062	20.97	0.775
South Dakota	4,120	101,624	759	18,481.0	704.974	18.19	0.678
Tennessee	3,567	798,614	763	167,459.1	6,398.086	20.97	0.779
Texas	4,088	3,103,493	773	582,194.2	22,006.251	18.76	0.693
Utah	3,896	330,626	765	65,862.8	2,390.641	19.92	0.706
Vermont	3,312	81,294	763	19,393.4	727.002	23.86	0.853
Virginia	3,288	984,725	768	224,330.4	8,308.792	22.78	0.820
Washington	3,517	817,765	768	177,378.3	6,491.898	21.69	0.776
West Virginia	3,441	231,687	765	53,706.0	2,188.947	23.18	0.890
Wisconsin	3,642	712,688	763	147,562.9	5,449.864	20.71	0.745
Wyoming	3,850	67,694	768	13,787.4	514.526	20.37	0.736

NOTE: CSHCN is children with special health care needs.

Table XXII. Unweighted and weighted estimates of the frequency and prevalence of children with special health care needs

Location	Total unweighted number of children	Total weighted estimate of number of children	Unweighted number of CSHCN	Weighted estimate of number of CSHCN	Standard error of weighted estimate of number of CSHCN	Percent of children who have special health care needs	Standard error of percent of children who have special health care needs
 Total	372,174	73,166,625	48,690	9,360,355.9	83,169.267	12.79	0.108
Alabama	6,904	1,127,669	924	152,648.1	6,537.369	13.54	0.542
Alaska	8,548	192,035	937	20,556.4	851.483	10.71	0.430
Arizona	8,542	1,418,531	962	153,410.3	7,039.059	10.82	0.481
Arkansas	6,616	684,979	927	97,077.2	4,111.419	14.17	0.564
California	9,662	9,409,329	966	969,867.5	47,555.525	10.31	0.479
Colorado	7,864	1,130,228	923	129,817.8	5,452.531	11.49	0.458
	6,411	850,434	914	118,517.2	4,620.513	13.94	0.525
Delaware	6,181	198,202	953	30,409.4	1,291.651	15.34	0.614
District of Columbia	7,400	113,592	968	15,625.2	806.572	13.76	0.657
Florida	7,400	3,740,251	935	488,090.2	22,254.741	13.05	0.657
Georgia	7,479	2,221,968	933	282,103.1	12,595.436	12.70	0.545
Hawaii	9,382	2,221,908	943	32,495.1	1,543.562	10.96	0.539
Idaho	8,366	375,814	939	43,357.7	1,917.276	11.54	0.480
			939 921			11.54	0.484
	7,761	3,273,265 1,583,139		379,436.4	17,298.450 9,727.121		
	6,744	, ,	933	224,995.7	,	14.21	0.575
lowa	7,766	731,619	943	90,334.0	3,573.603	12.35	0.470
Kansas	6,517	717,189	957	105,694.0	4,298.685	14.74	0.573
Kentucky	6,032	995,298	934	156,210.9	6,237.064	15.70	0.605
	5,964	1,213,280	948	193,150.3	8,387.507	15.92	0.653
Maine	5,646	298,779	911	46,242.7	1,758.372	15.48	0.565
Maryland	6,161	1,377,380	950	209,097.4	8,617.701	15.18	0.601
Massachusetts	6,411	1,512,618	924	221,840.3	10,251.915	14.67	0.643
Michigan	6,637	2,601,971	951	360,836.6	15,282.428	13.87	0.565
Minnesota	6,946	1,297,776	899	160,946.3	7,051.913	12.40	0.521
Mississippi	7,374	774,961	945	99,517.9	4,650.262	12.84	0.564
Missouri	12,824	1,436,144	1,927	215,817.6	6,437.388	15.03	0.422
Montana	7,652	229,440	897	26,980.9	1,111.378	11.76	0.469
Nebraska	7,420	450,307	945	57,450.4	2,421.299	12.76	0.512
Nevada	8,911	545,758	910	58,638.8	2,558.446	10.74	0.445
New Hampshire	6,127	312,538	923	47,058.7	1,995.021	15.06	0.600
New Jersey	7,506	2,120,366	948	266,803.8	11,929.674	12.58	0.534
New Mexico	8,110	514,548	927	57,420.6	2,553.109	11.16	0.479
New York	8,030	4,715,393	944	558,173.3	24,028.101	11.84	0.482
North Carolina	6,432	2,007,262	884	280,770.6	11,758.102	13.99	0.548
North Dakota	7,527	158,451	912	19,651.2	815.113	12.40	0.485
Ohio	6,844	2,890,941	959	402,881.2	16,206.778	13.94	0.538
Oklahoma	6,684	895,334	949	129,857.7	5,898.818	14.50	0.614
Oregon	6,905	859,043	912	113,418.1	4,768.648	13.20	0.534
Pennsylvania	7,322	2,921,955	970	379,291.1	15,825.409	12.98	0.517
Rhode Island	6,134	249,864	930	35,265.4	1,397.543	14.11	0.539
South Carolina	6,662	1,016,521	932	134,358.1	5,516.712	13.22	0.526
South Dakota.	8,213	200,821	928	22,668.7	950.646	11.29	0.453
	6,338	1,417,039	899	198,647.3	8,185.739	14.02	0.553
Texas	7,848	6,010,424	950	722,557.6	30,852.510	12.02	0.333
Utah	8,850	727,596	979	79,832.3	3,229.320	10.97	0.493
Vermont	6,064	147,660	979	22,885.8	972.468	15.50	0.427
	5,826	1,763,111	923 921	22,885.8 270,346.8	10,903.805	15.33	0.619
Virginia				210,346.8			
	6,629	1,542,437	917	,	8,264.031	13.66	0.525
West Virginia	6,034	395,774	924	66,201.0	3,157.156	16.73	0.722
Wisconsin	6,948	1,373,917	955	184,422.3	7,394.004	13.42	0.507
Wyoming	7,448	127,241	950	15,939.5	640.274	12.53	0.484

NOTE: CSHCN is children with special health care needs.

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