# OMB CHANGE REQUEST PACKAGE (83-C)

## Information Collection Request classification ii (revision)

State and Local Area Integrated Telephone Survey
**OMB # 0920-0406**

Three-year generic clearance granted April 9, 2008
Expires April 30, 2011

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Revised March 11, 2009

# Section A: Justification

## 1. Circumstances making the collection of information necessary

**Background**

This submission to the Office of Management and Budget (OMB) by the State and Local Area Integrated Telephone Survey program (SLAITS, OMB control number 0920-0406) requests approval to implement the main 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). The dress rehearsal, conducted in January 2009, was approved under the terms of our generic three-year clearance issued in April 2008. We are prepared to begin data collection for the main survey (scheduled to occur over seven calendar quarters) starting in early April 2009, pending OMB approval. Based on dress rehearsal findings, revisions have been made to the 2009-2010 instrument and procedures which are described in this package. Due to the number of question-level changes, the post-dress rehearsal instrument revisions and findings are listed in Attachment 5 to ease review.

To quickly summarize, the dress rehearsal was conducted from January 29 to February 1, 2009. Interviewers contacted 546 households with children, identified 168 households with CSHCN, and completed interviews with approximately 130 of these households. Approximately 50 interviews (in whole or in part) were directly monitored by SLAITS staff members. An interviewer debriefing followed the dress rehearsal. Monitoring confirmed that the procedures were well thought out and successful, as no problems were noted. Many questions performed quite well in the instrument, and we did not have to delete or revise entire sections. Minor issues with programming, grammar, punctuation, spelling, points of emphasis, or help screen text were found but have already been resolved. Overall, we were very pleased with the results, and we are moving forward to implement the main module.

The purpose of the survey is to provide estimates of the prevalence and characteristics of children with special health care needs (CSHCN); and to describe their health and functional status and types of services they need and use at various geographic levels. The 2009-2010 survey will be able to produce representative estimates at various geographical levels: for the nation as a whole, each of the 50 states and the District of Columbia (DC), and for two United States (US) territories (Guam [pending funding] and the US Virgin Islands [USVI]). Guam and the USVI have been identified to have weak to non-existant maternal and child health data sources, so these data will help immensely. The CSHCN targeted as the subject of this interview are 0 to 17 years of age, non-institutionalized, and live in households with a landline telephone. Absolutely no children will be interviewed during the course of data collection; the respondent will be the parent or guardian who knows about the health and health care of the sampled CSHCN.

This is the third survey iteration which is conducted by the SLAITS mechanism. Like its predecessors in 2001 and 2005-2006, it is funded by the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). For reasons of economy and to reduce overall burden on the public, this SLAITS module will use the sampling frame of the Centers for Disease Control and Prevention's (CDC) National

Immunization Survey (NIS), which is exempt from OMB Paperwork Reduction Act (PRA) review under legislative authority[1].

The NS-CSHCN screens households for children with special health care needs status after the NIS interview is completed. The data collection contractor has integrated the NS-CSHCN and NIS instruments such that the NS-CSHCN interview will launch upon completion of the NIS interview or after determining the household is NIS ineligible. If one or more CSHCN is/are identified, the respondent will segue to the full NS-CSHCN detailed interview. In households with more than one CSHCN, one will be randomly selected for the detailed survey.

The content of this NS-CSHCN (Attachment 2) again focuses on the health and functional status of CSHCN; their access to health care, use of health care services, and unmet needs; care coordination; receipt of family-centered care and shared decision-making; their transition to health care providers who only treat adults; developmental screening (for CSHCN between 1 and 3 years of age only); health insurance; adequacy of health care coverage; impact on the family; family composition; and demographic and socioeconomic characteristics of the household. Interviews for the 2009-2010 survey will be conducted in English, Spanish, and four Asian languages including Cantonese, Mandarin, Vietnamese, and Korean using translated questionnaires.

Two new features include conducting the survey in the USVI and Guam, and collecting or confirming contact information from a subsample of up to 6,000 households for a possible followback survey. State and DC target sample sizes are set at 750 completed detailed CSHCN interviews; Guam and USVI are set to 625.

This survey will provide analysts, researchers, and public health officials timely, high quality, and comparable data to assess the impact and unmet needs of CSHCN to plan and evaluate programs, and develop policy related to Title V of the Social Security Act. Under Title V, the Federal MCHB provides block grants to states to improve the health of children and their families. By law, 30% of the Federal block grant funding must be spent on CSHCN. This survey meets the need of States for uniform data to report progress toward achieving performance goals for key health indicators and 2020 programmatic objectives. The NS-CSHCN has proven to be of immense value not only to its federal sponsor, but also to state-level Maternal and Child Health (MCH) programs.

Law and regulation that authorizes this data collection:

NCHS is authorized to collect data under Section 306 of the Public Health Service Act (42 USC 242k). Text from this section of the code was submitted in the three-year generic clearance package and is not included in this request.

## Privacy Impact Assessment

(i) Overview of the data collection system:

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[1] Specifically, the National Childhood Vaccination Injury Act of 1986 (PL 99-660), Title III, Part A, Section 311, #7 established data collection systems to monitor immunization and Part B, Section 321 waives the PRA for all activities under the Act.

The respondent will be an adult parent or guardian who lives in the household and is knowledgeable about the health and health care of the sampled CSHCN. Data will be collected with Random-Digit-Dial (RDD) telephone methodology, by trained interviewers using a state-of-the-art Computer Assisted Telephone Interviewing (CATI) program in centralized telephone centers located in two large American cities. Both telephone center sites will use identical data collection and training methods. The automatic dialer is based in one site and issues calls to the next available interviewer regardless of location, which is invisible to respondents. Caller ID usually registers the contractor's name unless local companies truncate or change the display, an operation they control.

The contractor will conduct all sample management and data collection, and will maintain NS-CSHCN data and sampled case information until the project ends in September 2011. Confidential data will be maintained by NCHS on a server equipped with firewalls and access limited to two people. Through its website, NCHS will release one or more public use files (PUF) that do not contain identifiable information. Following review by an internal nondisclosure committee, the public use files are available for use indefinitely at no charge.

(ii) Items of information to be collected: A minimal amount of information in identifiable form (IFF) is collected by the data collection contractor. This process was generically described in the earlier package. To reiterate, this is not a new procedure.

Information in Identifiable Form

The NS-CSHCN will provide numerous national, state, and territory-level estimates on child and family-level characteristics, in addition to information on health care use and provider visits. Although the majority of the data collected are not considered personally identifiable, some fit the definition of IFF. A list of all IFF data items is highlighted below, and all were approved in past packages by OMB to be collected. The only data that will be released to the public or become part of the public use files below is age in months or years for the sampled child, which may be perturbed if necessary to maintain confidentiality. None of the other IFF data will be released to the public or become part of public-use files.

The IIF are collected by the contractor, and once separated from interview data, the file is transmitted to the CDC using a secure data network. These data are not accessible to anyone other than the NCHS Project Director and the project's computer scientist.

IFF categories:

- telephone number
- mailing address obtained through a telephone and address matching procedure (or directly from some respondents).
- first name or initials of the sampled child
- date of birth for children in the household (for NIS-eligible households only)
- age in months or years for children in the household (for NIS-ineligible households only)

Why the information is being collected, (ii) the intended use of the information: The IFF listed above are collected for several reasons.

- Telephone numbers are linked to addresses whenever possible so that an introductory letter (Attachment 3) can be sent to the households prior to being called for an interview. The phone number and address are on a Record of Calls file which is separate from the interview file, and is never released to the public. Also, the monetary remuneration is sent via first class mail. The address information is either confirmed from the earlier matching activity or obtained from households if the only known information is the telephone number.
- The child's name or initials are collected to identify the person to whom the questions refer. To reduce the respondent's cognitive burden and make questionnaire administration less awkward (e.g., by not having to repeatedly ask about the "X-year old child", the child's name or initials may be substituted in the computerized interviewing system.
- The date of birth and child's age variables are collected to determine household eligibility, and eligibility for certain age-specific questions (such as questions about adolescents, which are not relevant for infants). The date of birth is not released on the public use file. Again, the child's age may be perturbed if necessary.

No breaches of confidentiality have occurred in the history of SLAITS. Interviewers are constantly monitored and cannot bring any personal items into the interview area. This is done to ensure that information is not removed from the call center. Identifying information is kept separate from interview data and transmitted separately. Re-contact information for a possible longitudinal component will be stripped from the other data and kept on a secure server at NCHS with access limited to authorized persons only. The NIS calls over four million telephone lines across the country so it is very difficult to piece together information to identify individuals. All contractor and NCHS project staff follow strict procedures to collect, monitor, and analyze these data.

(iii) Identification of website(s) and website content directed at children under 13 years of age: SLAITS hosts a website located at www.cdc.gov/nchs/slaits.htm. Absolutely no information or website subpages are directed at children under the age of thirteen years.

## 2. Purpose and use of information collection

NS-CSHCN results have been thoroughly utilized at the state level, and by health-related non-profit advocacy groups and health researchers. Federal agencies and many state Maternal and Child Health agencies in particular have used NS-CSHCN data extensively, and will continue to do so when the 2009 – 2010 data are released. These data are of great practical utility to the federal and state governments.

Specifically, these data will be used to measure progress toward achieving six core outcomes identified and monitored by MCHB, which track implementation of community-based systems of services for CSHCN and serve as performance measures for state Title V programs and block grant applications. We anticipate these data will be also included in the Congressionally-mandated National Healthcare Quality and Disparities Reports, published by the Agency for Healthcare Research and Quality (AHRQ), as data were included in these reports from the 2001 and 2005-2006 survey iterations.

Without these 2009 – 2010 NS-CSHCN data, maternal and child health programs at the state and national levels funded by the multibillion-dollar Title V program (administered by MCHB) would not be able to evaluate their performance or assess unmet needs for CSHCN in a consistent manner. The rationale for the need to continue to collect NS-CSHCN data in 2009 and 2010 is clear: it will provide key, up-to-date, uniform, comparable, and comprehensive data, which can be analyzed at various geographic levels, and that are not available in toto from any other source. Only the NS-CSHCN contains enough state and territory-level sample to generate representative estimates for many indicators. No other data source offers this capacity.

## 3. Use of improved information technology and burden reduction

This information was previously described in detail in the three year generic clearance package, and the proposed survey will use identical procedures. In summary, sampled landline telephone numbers are dialed using auto-dialing equipment. A Computer Assisted Telephone Interview (CATI) system will be used to reduce the respondent's burden. It will keep track of the call outcomes and date, time of day, and length of each call, in addition to detailed notes maintained by the interviewers. It also ensures that skip patterns are followed properly. Teletype machine (TTY) administration is available to interview deaf respondents.

## 4. Efforts to identify duplication and use of similar information

We used a variety of methods to determine the existence of duplicate data collections, such as literature and data base searches, attending national and state meetings, and consulting with Federal agencies. This is also the only population-based survey within the Federal government designed specifically to produce state, national, and selected territory-level data for CSHCN with the MCHB CSHCN definition.[2] Although other Federal and non-Federal surveys such as the Medical Expenditures Panel Survey (MEPS, OMB# 0935-0118) may collect data with the same screener battery (the CSHCN Screener[3]) to identify CSHCN, they do not focus entirely on the special health care needs of the child, and do not collect extensive data on topics specific to CSHCN and the MCHB core outcomes.

## 5. Impact on small businesses or other small entities

No small businesses will be involved in this data collection. This is a household population-based survey.

## 6. Consequences of collecting the information less frequently

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[2] McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of Children with Special Health Care Needs. *Pediatrics.* 1998;102:137-139.

[3] Bethell CD, Read D, Stein RE, et al. Identifying children with special health care needs: development and evaluation of a short screening tool. *Ambul Pediatr*. 2002;2:38-48.

Data for this module are collected periodically, at an interval appropriate to monitor improvements in health, programs, and access to medical care (approximately every four years depending on MCHB funding). Except for a relatively small subsample of approximately 6,000 households, respondents are asked to participate only once. These households will be asked for contact information for an intended follow up survey.

There are no legal obstacles to reduce the burden.

## 7. Special circumstances related to the guidelines of 5 CFR 1320.5

This request fully complies with the regulation 5 CFR 1320.5.

## 8. Comments in response to the Federal Register notice and efforts to consult outside the agency

A. Federal Register Notice:
Per the terms of our most recent clearance, SLAITS is not required to publish a separate Federal Register (FR) notice for the proposed NS-CSHCN because this topic was specifically listed in the three-year generic clearance FR notice.

B. Consultation with persons outside the agency:
Senior managers from MCHB guide the format and content decisions in collaboration with NCHS and contractor staff. Subject-matter experts in child health, CSHCN and Title V, survey methodologists, federal and state program directors, and individuals representing federal partner agencies were convened as a 2009-2010 NS-CSHCN Technical Expert Panel (TEP) on April 10, 2008. The TEP offered expert guidance on availability of similar data, reporting format and data elements, methodology, instrument construction, clarity and completeness of content, and analysis plans. Questionnaire modifications reflect the informed decisions of this group in consultation with a much wider audience. A subset of technical experts can be consulted regarding methodological, programming, sampling, weighting, or post-stratification issues when necessary.

On June 20, 2008 SLAITS and MCHB staff convened a separate 2009-2010 NS-CSHCN Working Group (WG) meeting of survey methodology experts to focus on response rates and representative samples. The charge to the WG was to provide authoritative input and sound recommendations to improve data quality and population coverage; reverse or stem the decline in the survey response rate; offer a prioritized list of suggestions to evaluate effectiveness; develop realistic options to implement within budget constraints; and help develop a long-term research plan.

Additionally, in 2008 the National Center for Health Statistics Board of Scientific Counselors Review Committee released a final evaluation of the overall SLAITS program, not just the NS-CSHCN module, which emphasized the program’s efficiency, effectiveness, value, flexibility, and uniqueness.

We plan to update the Department of Health and Human Services (DHHS) Data Council periodically on our activities. Selected experts who have been consulted extensively and are knowledgeable about the NS-CSHCN and SLAITS mechanism are listed below and in Attachment 6.

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Other public contacts & opportunities for public comment:
SLAITS staff members often receive formal and informal input at conferences and through email about the utility of various items and subjects in previous NS-CSHCN iterations.

The SLAITS informational website (www.cdc.gov/nchs/slaits.htm) offers module-specific subpages, which are available at all times as an option for data users and interested parties to elect to be kept up to date on NS-CSHCN activities and product releases. Survey participants are also provided multiple ways to contact NCHS about the NS-CSHCN. Calls about the survey routinely come into the NCHS Research Ethics Review Board, CDC-Info, and the Project Director; letters and e-mail are sent to NCHS project staff. The SLAITS website provides convenient ways for respondents and data users to get in touch with SLAITS staff.

Senior managers at MCHB have systematically requested input from their user communities such as state health departments, state-level CSHCN and Title V program directors, and similar entities. Suggestions are given careful consideration during the planning process to ensure the maximum utility of the data.

## 9. Explanation of Any Payment or Gift to Respondents

Like all telephone surveys, there has been a consistent need to improve the interview completion and screener completion rates for SLAITS modules. Our experience has repeatedly demonstrated that of all survey modifications, incentive use has the most dramatic effect on improving response rates. NCHS wishes to continue its use of monetary incentives in the NS-CSHCN to combat unit non-response. Monetary incentives were used in the 2005-2006 NS-CSHCN, but this experiment did not include a control group. A control group is included in the proposed 2009-2010 protocol. Overall, the 2005-2006 NS-CSHCN incentive effort resulted in an additional 3,151 completed interviews, which improved the overall unweighted response rate by 3.6 percentage points.[4]

Although all interviewers are trained in refusal aversion, the contractor trains especially adept interviewers to be refusal converters in its CATI center. The refusal converters not only have a prior track record for success in gaining cooperation by recognizing explicit and implicit respondent concerns, but also receive additional training regarding ways to handle situations in a non-coercive manner. These refusal converters call households that refused participation during the initial contact to address respondents' concerns. At any time during the call process, if a "hard" or definitive hostile refusal is given, the case is immediately finalized. SLAITS cases that refuse participation twice with a "soft" refusal (including their NIS call history) are automatically deactivated and receive a "cooling off" period of at least 10 days prior to any subsequent calls. These cases have never said "no I will not participate" but instead typically indicate they don't have time, or it is not a good time and to call back. These "soft refusal" cases are given an opportunity for a final refusal, regardless of the refusal characteristics. Upon this refusal, the case is finalized.

Since gaining cooperation has become even more difficult over time, we have demonstrated a need to offer incentives. As with several previously approved SLAITS modules, we wish to continue our experimentation with monetary incentives. Building on our prior experimentation, with the start of interviewing in calendar Quarter 2 (Q2) 2009, an incentive experiment is proposed to examine which of four incentive methodologies best balances response rates, cost-efficiency, and the best overall survey quality.

The incentive protocols for four groups are triggered by the number of respondent refusals. Note that the counts of refusals are added across both the NIS and NS-CSHCN. As a case moves from the NIS to the NS-CSHCN, it carries with it the number of refusals (if any), that it had in the NIS. The full NS-CSHCN Q2 sample will be divided into four groups of equal size, each of which will be assigned an incentive group. A decision regarding which approach to adopt in subsequent quarters will be made based on the performance of each incentive group in Q2.

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[4] Blumberg SJ, Welch EM, Chowdhury SR, Upchurch HL, Parker EK, Skalland BJ. Design and operation of the National Survey of Children with Special Health Care Needs, 2005-2006. National Center for Health Statistics. Vital Health Stat 1(45). 2008.

Group 0: This is a control (no incentive) group. Any known age-eligible household that refuses twice in the NIS and NS-CSHCN combined will be mailed a conversion letter conveying the importance of their participation in the NS-CSHCN (Attachment 3). These households will then be contacted again after a delay of approximately two weeks. If the respondent refuses again, the case will finalize and will not receive any additional calls or letters. Those cases for which there is no address information will receive no further contact after the second refusal.

Group 1: Any known age-eligible household that refuses twice in the NIS and NS-CSHCN combined will be mailed a letter with $5 enclosed and promising $10 more for further participation (Attachment 3). Those cases for which there is no address information will be offered $15 verbally upon re-contact for further participation. These households will be re-contacted after approximately a two week delay. If the respondent refuses again, the case will finalize and will not receive any additional calls or letters.

Group 2: Any known age-eligible household that refuses once within the NIS or NS-CSHCN will be offered $10 upon re-contact, once they are within the SLAITS module, for further participation. Households that refuse for a second time will be mailed a letter with $5 enclosed and promising $10 more for further participation (Attachment 3). Those cases for which there is no address information will be offered $15 verbally upon re-contact for further participation. These households will be re-contacted after approximately a two week delay. If the respondent refuses again, the case will finalize and will not receive any additional calls or letters.

Group 3: As soon as a household is determined to be age-eligible and within the SLAITS module, they will be offered $5 (during that same phone call) for participation in the NS-CSHCN. Households that refuse twice in the NIS and NS-CSHCN combined will be mailed a conversion letter conveying the importance of their participation in the NS-CSHCN and reminding them of the $5 incentive offer (Attachment 3). These households will then be contacted again after a delay of approximately two weeks. If the respondent refuses again, the case will finalize and will not receive any additional calls or letters. Those cases for which there is no address information will receive no further contact after the second refusal.

This remuneration protocol has been approved by the Institutional Review Board (IRB) of the contractor, and the NCHS Research Ethics Review Board (ERB).

A separate memo will be sent that will describe the final agreed-upon experimental groups and protocol.

## 10. Assurance of confidentiality provided to respondents

Privacy Impact Assessment Information:

A. It has been determined that the Privacy Act does apply. The applicable System of Records Notice (SORN) number is 09-20-0164, "Health and Demographics Surveys Conducted in Probability Samples of the United States Population."

## B. Information security, Assurance of Confidentiality:

Confidentiality will be provided to respondents under an Assurance of Confidentiality, per Section 308(d) of the Public Health Service Act (42 USC 242m) as follows:

> "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 304, 306, or 307 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 304 or 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."

In addition, legislation covering confidentiality is provided according to section 513 of the Confidential Information Protection and Statistical Efficiency Act (PL 107-347) which states:

> "Whoever, being an officer, employee, or agent of an agency acquiring information for exclusively statistical purposes, having taken and subscribed the oath of office, or having sworn to observe the limitations imposed by section 512, comes into possession of such information by reason of his or her being an officer, employee, or agent and, knowing that the disclosure of the specific information is prohibited under the provisions of this title, willfully discloses the information in any manner to a person or agency not entitled to receive it, shall be guilty of a class E felony and imprisoned for not more than 5 years, or fined not more than $250,000, or both."

Interviewers, supervisors, and staff receive thorough training on legal and ethical obligations. All employees and contract staff sign an Affidavit of Nondisclosure as a condition of employment. Standards for Federal government surveys highlight the importance of the interviewers' responsibilities under the Privacy Act of 1974 (5 U.S.C. 552a), the Privacy Act Regulations (34 CFR Part 5b), Section 308(d) of the Public Health Service Act (42 U.S.C. 242m), the Confidential Information Protection and Statistical Efficiency Act (CIPSEA, Section 513 of PL 107-347), HIPAA (for the NIS), and other regulations.

In addition to the statutes cited, SLAITS, contractor, and subcontractor staff routinely employ measures to safeguard privacy and confidentiality. These include:

- when confidential materials are moved between locations, records are maintained to insure that there is no loss in transit,
- hard copies of confidential information are stored in secure areas when not in use,

- access to the data processing and storage areas is controlled, with only authorized personnel allowed in the computer rooms and computer tape libraries,
- individual data banks and files are protected by passwords and other techniques, which prohibit access by non-approved project staff,
- building security forces are on duty 24 hours, seven days per week at all sites,
- public use data releases are reviewed and approved by the NCHS Disclosure Review Board (DRB), and
- potential respondents are invited to view our SLAITS website (www.cdc.gov/nchs/slaits.htm) to explore the legitimacy of the survey in the advance letter.

Prior to data collection, all respondents are assured of the confidentiality of their responses and the voluntary nature of the survey in the NIS advance letter (Attachment 3) and upon initial telephone contact with the household respondent. The following statement will be provided to respondents:

> “Before we continue, I’d like you to know that taking part in this research is voluntary. You may choose not to answer any questions you don’t wish to answer, or end the interview at any time. We are required by Federal laws to develop and follow strict procedures to protect your information and use your answers only for statistical research. I can describe these laws if you wish. In order to review my work, my supervisor may record and listen as I ask the questions. I’d like to continue now unless you have any questions”.

After this statement is read, the interview will begin. If the respondent asks for the legal citation, the following statement will be recited:

> “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, and the Confidential Information Protection and Statistical Efficiency Act. Would you like me to read the Confidential Information Protection provisions to you?”

If the respondent says ‘yes’, the following statement will be read:

> “The information you provide will be used for statistical purposes only. In accordance with the Confidential Information Protection provisions of Title V, Subtitle A, Public Law 107-347 and other applicable Federal laws, your responses will be kept confidential and will not be disclosed in identifiable form to anyone other than employees or agents. By law, every employee of the National Center for Health Statistics, the National Center for Immunization and Respiratory Disease, and its agent, the National Opinion Research Center who works on this survey has taken an oath and is subject to a jail term of up to 5 years, a fine of up to $250,000, or both, if he or she willingly discloses ANY identifiable information about you or your household members.”

All NCHS collaborators, contractors, and subcontractors will be required to sign confidentiality statements as required prior to using any data, and thus become 'designated agents' of NCHS. The NCHS Confidentiality Officer reviews NS-CSHCN materials submitted for institutional review and for release in file format.

Finally, the following statement appears on a PDF copy of instruments posted on the SLAITS website and in the CATI program for reference.

**NOTICE:** Public reporting burden of this collection of information is estimated to average 25 minutes per response, including the time for reviewing instructions, searching existing data resources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person 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-E11, Atlanta, GA 30333; ATTN: PRA (0920-0406).

**Assurance of Confidentiality:** All information which would permit identification of an individual, a practice, or an establishment will be held confidential, and will be used only by NCHS staff, contractors, and agents only when required and with necessary controls, and will not be disclosed or released to other persons without the consent of the individual or establishment in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m) and the Confidential Information Protection and Statistical Efficiency Act (PL-107-347).

IRB approval:

This module has been reviewed and approved by the NCHS Research ERB and the contractor's IRB. The NCHS ERB approval announcement is Attachment 4.

## 11. Justification for sensitive questions

No sensitive questions are included in the NS-CSHCN instrument.

## 12. Estimates of annualized burden hours and costs

A. Respondent Burden

Based on prior survey work, NCHS requests 13,407 burden hours annually for main implementation of the NS-CSHCN. The calculation of average respondent burden is based on previous NS-CSHCN modules and dress rehearsal time estimates. Just under 122,000 households will be screened (n = 121,972) for an average of 3 minutes each, or 6,099 burden hours. Once one or more resident CSHCN is identified, adult respondents in almost 20,000 households (n=19,750) will complete the detailed CSHCN interview for an average of 22 minutes, or 7,308 burden hours. On average, the NS-CSHCN takes approximately 25 minutes to administer.

The main survey involves a short screener as many people in the population must be contacted to identify the subgroup we wish to survey.

NS-CSHCN

Table 1 indicates the annualized total burden hour estimate for this module estimated for a three minute screening procedure and a 22 minute interview, for a total of 25 minutes for households that contain at least one child identified as a CSHCN. The interview will be much shorter for households that do not contain children and those with children but with no CSHCN. These estimates are based on sample size projections and experience from previous NS-CSHCN modules.

Table 1. Annualized burden hours.

| **Type of respondent** | **Form** | **Number of respondents** | **Number of responses per respondent** | **Average Burden per Response (in hours)** | **Response burden** |
|---|---|---|---|---|---|
| Resident adult parent or guardian who knows about the CSHCN's health & health care | Main survey implementation-household screener | 121,972 | 1 | 3/60 | 6,099 |
| Resident adult parent or guardian who knows about the CSHCN's health & health care | Main survey implementation-household survey | 19,750 | 1 | 22/60 | 7,308 |
| | | | | **TOTAL** | 13,407 |

B. Annualized Cost to Respondents

The latest publicly available data (May 2007) are from the Occupational Employment Statistics Survey (OES), a mail survey that measures occupational employment for wage and salary workers in non-farm establishments in the US. The OES collects data from over 1.2 million business establishments through six semiannual panels over a three year period. It is sponsored by the Department of Labor, Bureau of Labor Statistics, and uses the OMB-required occupational classification system (the Standard Occupational System (SOC)).

The mean hourly wage rate in May 2007 was $19.56/hour across all occupations. At an average wage rate of $19.56/hour and an average burden of 6.6 minutes for 121,972 respondents (including those who screen out of the survey), the average cost per respondent listed in Table 2 is $2.15, for a total average estimated cost of $262,240 per year. This estimated cost does not represent an out-of-pocket expense, but represents a monetary value attributed to the time spent to screen for and/or complete the interview. Since the NS-CSCHN is a population-based survey, it is not possible to break out the respondent cost by major occupational groups (such as management; legal; or computer or mathematical occupations, et cetera).

Table 2. Costs to respondents.

| Number of | Frequency of | Average estimated | Total average estimated |
|---|---|---|---|

| respondents | response | cost per respondent | cost per year |
|---|---|---|---|
| 121,972 | 1 | $2.15 | $262,240 |

## 13. Estimates of other total annual cost burden to respondents or recordkeepers

No capital or maintenance costs are involved.

## 14. Annualized cost to the Federal government

An estimate of the average annual cost to the government for a SLAITS module depends on the size of the survey (for example, the desired number of completed interviews), the length and complexity of the interview, characteristics of the target population, and prevalence of the key health characteristic of interest. Costs for SLAITS modules are paid through either a contractual or Interagency Agreement (IAA) mechanism.

We estimate the typical annual cost of a CSHCN survey for parents or guardians of youth ages 0 to 17 years of age that can produce state and national estimates at approximately $6 million, as summarized below.

| | |
|---|---|
| Survey support from NCHS staff | less than $1 million dollars annually |
| Additional CDC-related costs | less than $500,000 per year |
| Data collection | ~ $3 million per year |
| Other costs | ~$1.5 million |

The Interagency Agreement (IAA) with MCHB includes all costs for contractor and Federal staff salaries; survey planning, design, and development; training; field pretesting; coding; data collection, weighting and preliminary estimation; printing of survey materials; file release, possible incentives used to address non-response; and staff observation (travel and per diem).

## 15. Explanation for program changes or adjustments

No change.

## 16. Plans for tabulation and publication and project time schedule

Analyses of 2009-2010 NS-CSHCN data will be performed at the person, household, and family levels, beginning with initial baseline descriptive analyses. Baseline measures will be compared among states and the nation, and to previous survey results. We will perform trend analyses based on previously published work from the 2001 and 2005-2006 surveys. We anticipate the 2009-2010 data will be released approximately 6 to 9 months following the end of data collection.

**Proposed timeline:**

| | |
|---|---|
| Pretest findings delivered to NCHS | early February 2009 |
| Production ready questionnaire sent to contractor | late February 2009 |
| Revisions to programming, testing, training materials, production-level recruitment & training | February – March 2009 |
| Quarter 2 full interview production training | late March 2009 |
| Quarter 2 full interview production start | early April 2009, pending OMB approval |
| Data collection ends | December 2010 |
| Public Use File released | August 2011 |

## 17. Reason(s) display of OMB expiration date is inappropriate

N/A. Not requesting exemption.

## 18. Exceptions of certification for Paperwork Reduction Act submissions

There are no exceptions to the certification.

# Section B.

# Collection of Information Employing Statistical Methods

## 1. Respondent Universe and Sampling Methods

The target population for the State and Local Area Integrated Telephone Survey (SLAITS) 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) is children with special health care needs (CSHCN) 0 to 17 years of age. The universe from which the sample is drawn is all households with landline telephones. The respondents for all questions will be the resident parent or guardian over the age of 18 years who knows about the health and health care of the CSHCN. Absolutely no children under age 18 years will be interviewed. All resident children will be screened for special health care needs status. In households with one or more special needs children, one CSHCN will be randomly sampled for a detailed interview.

SLAITS uses the National Immunization Survey (NIS) sampling frame, the size of which provides an economical opportunity to survey other populations in addition to the rare population that eventually screens into the NIS itself. For the 2009 – 2010 NS-CSHCN, the NIS sampling frame will be used to identify and complete 750 detailed interviews in households that contain a CSHCN in each of the 50 states, the District of Columbia (DC), and 625 each in Guam and the United States Virgin Islands (USVI).

For more information on the NIS or NIS sampling methods, please refer to the website of the NIS sponsor, CDC's National Center for Immunization and Respiratory Diseases (NCIRD) www.cdc.gov/vaccines, or NCIRD's webpage entitled 'Statistics and Surveillance: Immunization Coverage in the US' at http://www.cdc.gov/vaccines/stats-surv/imz-coverage.htm#nis.

**Sample design.** The sample of households selected for the NS-CSHCN will be a subsample of households with landline telephones. There may be a need to develop a small independent sample of telephone numbers for SLAITS called "augmentation sample" to meet target sample sizes, which is developed in the same fashion as the regular sample (described in the prior packages). The only difference is that this sample is not screened for the NIS prior to administration of the relevant SLAITS module. This SLAITS-only sample would not receive the NIS advance letter, NIS screener, or NIS interview, but may receive an advance letter (Attachment 3).

We expect the design effects for this survey will be comparable to those of previous SLAITS studies.

**Oversampling subpopulations.** There will be no oversampling to identify adequate numbers of households with a particular characteristic.

**Estimation procedures**. All data will be weighted to national and state control total estimates to produce population-based estimates of totals, means and proportions. A sampling weight will be calculated for each CSHCN. At this time, we anticipate the 2009-2010 survey weighting strategy will mirror the 2005-2006 weighting procedure.

Three weights will be produced: a household screener weight, a child-level screener weight, and a child-level interview weight. Numerous non-response adjustments will be applied to the base sampling weight to reflect the probability of selection of the household's landline telephone number. These adjustments account for households that have multiple landline telephone numbers; unknown household status; unknown household eligibility; non-telephone households; and eligible households who do not complete the CSHCN Screener.

The child-level interview weight will be adjusted to account for households that contain multiple CSHCN, and for sampled CSHCN who do not complete a detailed interview. Final post-stratification calculations will be made at the person-level through marginal adjustments to compensate for any imbalance in the age, sex, and race/ethnicity groupings in the sample. State-level population estimates by age, sex, and race/ethnicity published by the U.S. Bureau of the Census will be used as population control totals for this adjustment. Data from CDC's National Health Interview Survey (NHIS, OMB number 0920-0214) will also be used to assess whether additional adjustments are necessary for the characteristics of households without fixed telephone lines (i.e., cellular phone only households, or cellular phone mostly households). The standard error for key estimates will be calculated using a Taylor linearization approach with SUDAAN software to accommodate the complex sample design and calculate accurate standard errors.

Additional technical details concerning sample design and survey execution can be found in the design and operation reports for past NS-CSHCN iterations. Documentation for the 2001 and 2005-2006 NS-CSHCN modules is available at www.cdc.gov/nchs/slaits.htm under the module-specific webpage, and the webpage entitled "Publications and selected presentations using SLAITS data" under "Design and Operations Reports".

**Degree of Accuracy.** For each module, the primary analytic variable determines the sample size. To determine the sample size necessary for reasonable levels of precision, the baseline prevalence of a key statistic is estimated.

**NS-CSHCN sample:**
Assuming the estimate is for a 50% statistic for the NS-CSHCN, the sample percentages for a state will have a margin of error of plus or minus 3.58 percentage points based on a sample size of 750. For a 50% statistic, the national NS-CSHCN estimates will have a margin of error of plus or minus 0.5 percentage points at the 95% confidence interval based on a sample size of 39,500. The power to detect differences in a given child characteristic between subgroups or states depends on the size of the samples being compared.

## 2. Procedures for the collection of information

In consultation with NCHS, the data collection contractor draws the sample, designs and conducts interviewer and supervisor trainings, plans the interview operations, and implements and monitors the survey interview procedures. The contractor also develops the data files, draft documentation, and preliminary and final sampling weights.

SLAITS staff members provide specifications for sample design, specific questionnaire content, detailed interview instructions, and procedures to measure quality control; monitor interviews through direct observation; and maintain continuous communication with the data collection contractor.

The SLAITS 2009-2010 NS-CSHCN questionnaire will immediately follow administration of the NIS interview or screener in eligible households, as the two surveys will be seamlessly integrated in the Computer Assisted Telephone Interviewing (CATI) data collection program. The NS-CSHCN age and screener questions are listed in Attachment 1, and the detailed CSHCN interview questions are listed in Attachment 2. Certain household and demographic questions are identical in the NIS and NS-CSHCN, and the CATI system is programmed so these questions are not repeated in both surveys to reduce respondent burden. The respondent will be the parent or guardian who lives in the household and is knowledgeable about the health and health care of the sampled CSHCN. The questionnaire sections cover health and functional status of CSHCN; their access to health care, use of health care services, and unmet needs; care coordination; receipt of family-centered care and shared decision-making; their transition to health care providers who only treat adults; developmental screening (for CSHCN between 1 and 3 years of age only); health insurance; adequacy of health care coverage; impact on the family; family composition; and demographic and socioeconomic characteristics of the household.

**Data collection, entry, and file preparation.**
The dress rehearsal was conducted in January 2009 to test the survey instrument programming and overall survey procedures. We are prepared to start collecting data for the main survey in early April 2009 (pending OMB approval), and continue through December 2010. The NIS advance letter will be sent to sample households for which the randomly-generated telephone numbers can be matched to valid addresses.

After data collection, editing and weighting are completed, the 2009-2010 NS-CSHCN release will include a series of linked household-level, child screening-level, and child interview-level data files with all information necessary for analysis. The data files will contain appropriate demographic information on the focal child, respondent, and household, as well as substantive health and health-related data. Final sampling weights will be assigned to each child-level and household-level observation to permit users to generate national and state estimates. The methodology will be described thoroughly in a survey design and operations report that accompanies the release of the data files.

## 3. Methods to maximize response rates and deal with nonresponse

Response rates provide one measure of the potential for nonresponse bias but are not the sole indicator of survey and data quality. Although telephone survey response rates have declined, the telephone as a mode of data collection is still one of the most useful and economical means to obtain population-based data. Successful conduct of a SLAITS module depends on a combination of techniques to maximize response rates and understand the impact of nonresponse on data quality. Standard proven survey procedures have been refined through deliberate testing and experience over time. Among those techniques routinely implemented in SLAITS modules are the:

- use of a carefully constructed advance letter for those households where a name and address are available (approximately 58% of the sample[5]),
- effective interviewer recruitment and training,
- thorough review of confidentiality, privacy, and security requirements,
- maintenance of a toll-free number and website to facilitate participation,
- flexible interview schedules to maximize convenience to the respondent,
- carefully scripted answering machine and voice mail messages,
- high-quality instrument translation for other language interviews,
- judicious use of incentives,
- quality control and interviewer monitoring, and
- refusal aversion/conversion training with experienced interviewers.

Answering machine messages are left on every third call where no contact with the household is made so long as no more than one message is left in any given week. An exception to this rule is made if the respondent missed a scheduled appointment. In cases of missed appointments an answering machine message is always left to let the respondent know an attempt was made to keep the appointment, regardless of the frequency of previous answering machine messages.

Even these measures do not assure high response rates. For each SLAITS module, analysis is conducted to evaluate the extent to which nonsampling error impacts data quality. Comparison to other surveys and related data, expected demographic characteristics, interview breakoffs, and other qualitative and quantitative measures will be constantly reviewed and assessed. Should changes to the survey design be warranted due to low response rates, OMB and ERB will be consulted.

A thorough non-response bias analysis was recently completed to examine the impact on data quality for the 2005-2006 NS-CSHCN[6], and a similar analysis is projected to accompany the release of the 2009-2010 data file. For the 2005-2006 survey, nonresponse occurred at each of four survey stages: (1) for some telephone numbers, it was never determined whether the number belonged to a household (i.e., unresolved telephone numbers); (2) some households that were identified did not complete the age-eligibility screener; (3) some households that screened as age-eligible did not complete the special-needs screener; and (4) some households that were identified as containing at least one CSHCN did not complete the detailed interview. Generally, nonresponse bias can be thought of as the degree to which nonrespondents differ from respondents in key survey variables. This quantity is generally unknown, and nonresponse analyses attempt to measure this difference using one or more approaches: response rate comparison across subgroups, use of rich sampling frame data or supplemental matched data, comparison to similar estimates from other sources, and studying

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[55] Blumberg et al, 2008.

[6] NORC. Nonresponse bias analysis, draft #2, 2005-2006 National Survey of Children with Special Health Care Needs. Chicago, IL: National Opinion Research Center (NORC) at the University of Chicago. Unpublished. March 7, 2008.

variations within the existing survey. Each approach was used to explore five key national survey estimates. A similar strategy will be used to examine the 2009-2010 data.

Overall response rates will be calculated with the Council of American Survey Research Organizations (CASRO) formulae in accordance with the American Association for Public Opinion Research's *Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys*[7], specifically response rate #4. Two weighted overall response rates were calculated for the 2005-2006 NS-CSHCN: (1) the special-needs screener response rate, which reflects the potential for bias in the main sample of children screened for special health care needs, and (2) the special-needs interview response rate, which reflects the potential for bias in the sample of CSHCN for whom the special-needs interview was completed. Among families with CSHCN, we obtained a 96.2% special-needs interview completion rate[8]. However, it is highly unlikely that an 80% CASRO rate will be achieved due to the downward trend in survey response rates regardless of mode. Efforts to counterbalance the trend through incentives and other techniques are successful to a point.

**Other Languages**. The NS-CSHCN questionnaire will be translated into Spanish and four Asian languages including Cantonese, Mandarin, Vietnamese, and Korean.

While the Spanish questionnaire will be administered via the computer aided telephone interviewing (CATI) system, given the expected low incidence of the other languages, a different procedure will be used to screen and interview these households. The NIS uses specially trained interviewers to determine the necessary language with assistance from a firm called Language Line Services, for over 170 languages. If the household is determined to include children but no one speaks English, Spanish, or one of the four Asian languages, the case will be finalized. If Spanish or one of the four Asian languages is spoken in a household that contains children, age and special-needs screening will occur. Eligible cases will then be assigned to the appropriate language queue to be called later by a specially trained NORC interviewer who speaks that language.

## 4. Tests of procedures or methods to be undertaken

The January 2009 dress rehearsal verified CATI programming and survey procedures; a summary of results are included in Attachment 5.

As with several previously approved SLAITS modules, we wish to continue our experimentation with monetary incentives. Building on our prior experimentation, with the start of interviewing in calendar Quarter 2 (Q2) 2009 (pending OMB approval), an incentive experiment is proposed to examine which of four incentive methodologies best balances response rates, cost-efficiency, and the best overall survey quality.

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[7] The American Association for Public Opinion Research. 2006. *Standard Definitions:Final Dispositions of Case Codes and Outcome Rates for Surveys. 4th edition*. Lenexa, Kansas: AAPOR.

[8] Blumberg SJ, et al (2008). Page 17.

The incentive protocols for four groups are triggered by the number of respondent refusals. Note that the counts of refusals are added across both the NIS and NS-CSHCN. As a case moves from the NIS to the NS-CSHCN, it carries with it the number of refusals (if any), that it had in the NIS. The full NS-CSHCN Q2 sample will be divided into four groups of equal size, each of which will be assigned an incentive group. A decision regarding which approach to adopt in subsequent quarters will be made based on the performance of each incentive group.

## 5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

The following person was consulted on the statistical aspects of the design and data collection for SLAITS:

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The following person is responsible for the collection and analysis of SLAITS data:

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Additional experts and consultants knowledgeable about the SLAITS mechanism and/or specific modules are listed in Attachment 6.

## List of attachments to this Supporting Statement (Parts A & B)

1. Screener: 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) instrument
2. Survey: 2009-2010 NS-CSHCN instrument
3. Letters (NIS, augmentation, refusal conversion, thank you)
4. Text of approval notice issued by the National Center for Health Statistics (NCHS) Research Ethics Review Board (ERB) for full implementation of the 2009-2010 NS-CSHCN
5. Dress rehearsal results
6. Roster of expert staff and consultants involved in SLAITS mechanism or module-level planning