

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

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

**Survey of Pathways to Diagnosis and Services:
An American Recovery and Reinvestment Act (ARRA) Project**

Prepared by:

Rosa M. Avila, MSPH
CDC/NCHS
3311 Toledo Road
Hyattsville, MD 20782-2003
301-458-4621 (RMA voice)
301-458-4035 (fax)
ravila@cdc.gov

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The State and Local Area Integrated Telephone Survey (SLAITS) mechanism is conducted by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC), with contractor assistance under OMB clearance number 0920-0406 (expires 04/30/11). This request seeks approval to:

1. Conduct data collection for a new SLAITS module, entitled the Survey of Pathways to Diagnosis and Services (SPDS), and
2. Revise the questionnaire for the 2011 SLAITS National Survey of Children's Health (NSCH).

The new Pathways Survey is an American Recovery and Reinvestment Act (ARRA) project that will conduct follow-up interviews with parents of school-aged children with certain developmental conditions who were identified in the ongoing 2009-2010 National Survey of Children with Special Health Care Needs. Primary funding for the SPDS is through the American Recovery and Reinvestment Act of 2009 (ARRA) (Public Law 111-5) funds.

The revisions to the NSCH questionnaire consist primarily of adding questions for uninsured children who live in low-income families and deleting questions in other sections to make room for these new questions. These questions are being included at the request of the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE), to provide additional information on uninsured children who may be eligible for Medicaid or the Children's Health Insurance Program (CHIP).

A. Justification for the Survey of Pathways to Diagnosis and Services

1. Circumstances making the collection of information necessary

This submission to the Office of Management and Budget (OMB) by the State and Local Area Integrated Telephone Survey program (SLAITS) requests approval to conduct the Survey of Pathways to Diagnosis and Services (SPDS), including a dress rehearsal. This is a new module in the SLAITS program, which proposes to follow-up parents of children with special health care needs (CSHCN) aged 6 to 17 years who were reported to have been told by a doctor or health care provider that the child had one of three selected development-related health conditions in the 2009 – 2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). These conditions include: 1) Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder (which will be referred to as autism/ASD); 2) any developmental delay that affects the selected child's ability to learn; and 3) intellectual disability or mental retardation. For each condition ever diagnosed, the NS-CSHCN also collects responses indicating whether the child currently has the condition.

The 2009-2010 NS-CSHCN questions were also used in the 2007 National Survey of Children's Health (NSCH). The 2007 NSCH data revealed that approximately 1-in-100 children aged 3-17 years has autism/ASD.¹ That study also revealed that nearly 40% of those ever diagnosed with

¹ Kogan MD, Blumberg SJ, Schieve LA, et al. Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics*. 2009;124(5):1395-1403.

autism/ASD did not currently have the condition. Some possible explanations offered for this surprising finding were that (a) an ASD may have been initially suspected by a health care provider based on a developmental screening, but then ruled out by a complete evaluation by a specialist, (b) these children may be those with milder symptoms and/or early diagnosis of pervasive developmental delay-not otherwise specified rather than autistic/ASD disorder, or (c) some children with a developmental delay may have been initially classified as having autism/ASD to facilitate receipt of needed services. The 2007 NSCH did not provide sufficient data to fully assess these possible explanations.

To explore possible explanations of these findings, the National Institute of Mental Health (NIMH) of the National Institutes of Health (NIH) asked the National Center for Health Statistics (NCHS) to conduct a follow-up study using funds available through the American Recovery and Reinvestment Act of 2009. In an effort to explain the 2007 findings, children in the 2009-2010 NS-CSHCN who currently have autism/ASD will be compared with children who had been diagnosed with autism/ASD but do not have it currently. To determine whether any observed differences are specific to autism/ASD, similar comparisons will be made between children who have or have had developmental delay and between children who have or have had intellectual disabilities.

In addition, NIMH is funding this follow-up survey to learn more about how these three developmental conditions are diagnosed and treated. Most population-based surveys do not identify samples of sufficient size for detailed estimates about these three specific development-related disorders or about the current health care and service needs of children with these disorders. However, the 2009-2010 NS-CSHCN is expected to collect information about approximately 35,000 CSHCN nationally, and of the CSHCN aged 6-17 years, nearly 20% are expected to currently have or have had autism/ASD, intellectual disability, and/or developmental delay. In an effort to improve recontact rates, additional contact information was collected for an estimated 22,000 interviews conducted after mid March 2010. Overall, the NS-CSHCN is expected to identify about 6,000 eligible CSHCN, from which detailed SPDS interviews will be completed for approximately 4,000 children.

In short, this follow-up study will supply critical data for Federal needs assessment; allow researchers to better understand the current procedures and shortcomings in their diagnostic, treatment, and service systems of care; and bolster future research and targeted programmatic efforts for CSHCN with the three selected development-related disorders.

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

Overview of the data collection system:

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 child. Data will be collected over household landline telephones or the respondent's cellular telephone, by trained interviewers using a state-of-the-art Computer Assisted Telephone Interviewing (CATI) program in two centralized telephone centers. Both telephone center sites will use identical data collection and training methods. The automatic dialer is based in one site and issues telephone calls to the next available interviewer regardless of location, which is invisible to respondents. Telephone numbers will be dialed with either the autodialer or by hand for cellular telephone sample to comply with the Telephone Consumer Protection Act (TCPA). Once a call is placed, the recipient's Caller ID unit usually registers the contractor's name unless local companies truncate or change the display, an operation they control. During the course of this data collection, a mail sampling frame will be included as well. Each respondent will be mailed a paper questionnaire immediately following the completed interview, unless the respondent requests not to participate.

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

Information in Identifiable Form

The information in identifiable form (IIF) needed for this survey, with the exception of parental age, has been previously collected through the 2009-2010 NS-CSHCN. Previously collected information will mainly be used to re-contact and verify eligible child and respondents. Some information may be missing; therefore the same procedures described in the earlier approved NS-CSHCN package will be used to collect this information. Although the majority of data collected are not considered personally identifiable, some fit the definition of IIF and are listed below. We may explore data linkage in this survey, but this information would not be released in the PUF. The only data from the list below that will be released to the public or become part of the public use files is state and age of the eligible child and their parent(s), which may be perturbed if necessary to maintain confidentiality. None of the other IIF 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.

IIF categories:

- name or initials of the respondent
- first name or initials of the sampled child and the respondent
- another telephone number where the respondent can be reached if the sampled telephone number is not working for any reason;
- additional telephone number type (e.g., cellular, landline, or work number)

- mailing address with zip code obtained through a telephone and address matching procedure (or directly from some respondents)
- zip code collected directly from the respondent
- state name of the state the respondent lives in
- age in months or years for children in the household
- age in years for the eligible child's parent(s)

These IIF are obtained for several reasons.

- Both the telephones and addresses are used to re-contact households that are eligible for this survey. Telephone numbers are linked to addresses whenever possible so that an advance letter (Attachment 1a) 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, 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. All mailed letters can be found in Attachment 1.
- The child's first 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 first name or initials may be substituted in the computerized interviewing system.
- The respondent's first name or initials are used to identify the person who originally participated in the 2009-2010 NS-CSHCN.
- The eligible child's age is collected to identify the eligible child selected for this survey. Again, the child's age may be perturbed before releasing the PUF if necessary.
- Age of the child's parent(s) are collected by this survey for analytical purposes specific to children with developmental disabilities research.

Identification of website(s) and website content directed at children under 13 years of age: There is no web-based data collection. The advance letter used for this survey states "You can also visit the study's website for additional study information – www.cdc.gov/nchs/slaits.htm." Absolutely no content and information on these websites or subpages is directed at children under the age of thirteen years.

2. Purpose and use of information collection

NIMH and NCHS have agreed to conduct a follow-up survey which consists of two components, a telephone questionnaire and a mail-out questionnaire, with parents of school-aged CSHCN with at least one of three selected development-related disorders as identified in the 2009 – 2010 NS-CSHCN. NCHS expects to have re-contact information for six groups of children:

- 390 school-aged CSHCN who ever but not currently have an autism/ASD diagnosis (but not currently);
- 1,320 school-aged CSHCN who currently have an autism/ASD diagnosis;
- 110 school-aged CSHCN who ever but not currently have intellectual disability (but not currently) and who have never been diagnosed with autism/ASD;

- 580 school-aged CSHCN who currently have intellectual disability, but who have never been diagnosed with autism/ASD;
- 920 school-aged CSHCN who ever but not currently have developmental delay (but not currently) and who have never been diagnosed with autism/ASD or intellectual disability.
- 1,130 school-aged CSHCN who currently have a developmental delay that affects their ability to learn, but who have never been diagnosed with autism/ASD or intellectual disability;

A committee of experts has been assembled to identify key research questions and to initially craft the content of the questionnaire for the follow-up survey. NIMH, NCHS, the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA), and CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) are the federal agencies involved in the planning process.

This survey meets specific programmatic needs of NIMH, the lead federal agency for research on mental and behavioral disorders. The stated mission of NIMH is to:

Transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for prevention, recovery and cure. For the Institute to continue fulfilling this vital public health mission, it must foster innovative thinking and ensure that a full array of novel scientific perspectives are used to further discovery in the evolving science of brain, behavior, and experience. In this way, breakthroughs in science can become breakthroughs for all people with mental illnesses.

In 2008, NIMH identified a need to generate research and promote training to chart mental illness trajectories to determine when, where, and how to intervene and develop new and better interventions that incorporate the diverse needs and circumstances of people with mental illnesses.

To our knowledge, this survey will be the only nationally representative survey on school-aged children with these selected development-related mental health disorders to assess their experiences receiving diagnoses and services. As a follow-up survey linked to the NS-CSHCN, this survey will also allow exploration of many matched health, health care service use, unmet needs, and medical home variables collected in the 2009 – 2010 survey.

As noted earlier, six groups of CSHCN have been identified and will be compared: 1) children who ever but not currently have Autism/ASD, 2) children who currently have Autism/ASD, 3) children who ever but not currently have intellectual disability, 4) children who currently have an intellectual disability, 5) children who ever but not currently have any developmental delay, and 6) children who currently have developmental delay.

During the telephone interview, parents of eligible children will be asked about a variety of retrospective topics, including co-morbidities with other mental condition or disorder, history of initial concerns about the child's development to examine the emergence of symptoms; initial and current diagnosis; treatment and services used to address the problem; the CSHCN's current behavioral and functional status; and parental perspectives of their child's development-related

condition.

These parents will also receive a mailed questionnaire which will consist of two previously tested instruments: Children's Social Behavior Questionnaire (CSBQ), and the Strengths and Difficulties Questionnaire (SDQ). The CSBQ is a tool that describes the severity and pattern of social deficits and other behaviors characteristic of pervasive developmental disorders. The CSBQ provides a profile of scores on six dimensions within the autism spectrum, thus reflecting the heterogeneity of impairments that are characteristic of ASD. The SDQ is a behavioral screening questionnaire that derives generalized scores for conduct problems, hyperactivity, emotional symptoms, peer problems, and prosocial behavior. The SDQ also includes questions related to chronicity, distress, social impairment, and burden to others. The mail out questionnaire will then include items that highlight the positive skills and abilities of their child, of which some of these questions can also be found on the 2011 NSCH.

The SPDS telephone and mailed questionnaires are located in Attachment 2 & 3. Details of data collection are provided in Section B.

Privacy Impact Assessment Information

The survey 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 SPDS contains enough sample to generate representative estimates for children with select developmental conditions at the national level. No other data source offers this capacity.

Only those NCHS employees and our full research partners who must use the personal information for a specific purpose can access and use such data. Everyone else who uses SPDS data can do so only after all identifiable information is removed.

The collection of information in identifiable form requires strong measures to ensure that private information is not disclosed in a breach of confidentiality. All NCHS employees as well as all contract staff receive appropriate training and sign a "Nondisclosure Statement." Staffs of collaborating agencies are also required to sign this statement and outside agencies are required to enter into a more formal agreement with NCHS. The transmission and storage of confidential data are protected through procedures such as encryption and carefully restricted access. See A10 for more details.

3. Use of improved information technology and burden reduction

The survey will be conducted using a CATI program in centralized telephone centers, which reduces the time required to collect, transfer, process, and release data. The CATI system also tracks all landline and cellular 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. Use of the CATI system typically reduces the average duration of interviews, compared to a paper questionnaire with identical content, thus reducing the respondent's burden. To address current needs, data collection will be expanded by including a mail sampling frame.

4. Efforts to identify duplication and use of similar information

To the best of our knowledge, this is the only population-based survey of children with select developmental conditions within the Federal government, designed specifically to produce national estimates from parent interviews that address key NIMH objectives. Although other Federal and non-Federal surveys such as the Medical Expenditures Panel Survey (MEPS, OMB# 0935-0118, expires 01/31/2013) and CDC's Behavioral Risk Factor Surveillance System (BRFSS) collect limited health data on children, they do not focus exclusively on the health, well-being, diagnostic history, and service utilization experienced by children with these select developmental conditions and their families. The Autism and Developmental Disabilities Monitoring (ADDM) Network gathers data on children with Autism/ASD. Although ADDM uses administrative (medical/school) records to yield data that may be considered to be methodologically "superior" to parent-reported data collected over the telephone, our proposed survey (SPDS) will yield important data from a previously unaddressed constituency, parents of autistic/ASD children as well as including children with other selected developmental disabilities within the study sample. To the extent that there is some overlap in content of this module with other surveys, it is necessary to insure that the full range of relevant variables are included for complex analyses of data for the SPDS sample.

We used various formal and informal 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, researchers and staff at relevant private organizations, and individual researchers. The names and organizations of the most directly involved individuals who are members of the SPDS expert panel are listed in Attachment 4. Consultation included not only issues of design and content but also knowledge of existing surveys or data, and took place in face-to-face meetings, telephone conferences, and electronic mail.

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

There is no existing national US survey that is tailored specifically on the experiences and issues faced by CSHCN with these developmental conditions. This is the first implementation of the SPDS.

Respondents are asked to respond to the SPDS only once. Selected households will be asked for contact information for a possible mail questionnaire.

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. Efforts to consult outside the agency

Survey content and key research questions were developed iteratively by a committee of external experts in conjunction with selected staff members and experts from NIMH, NCHS, MCHB, and NCBDDD. This group was first assembled by NIMH in May 2010. Members are listed in Attachment 4.

Related existing instruments and research materials were gathered from various studies, and examined for topics which were covered or overlooked in these instruments. New questions were drafted to cover nascent topics and those not addressed on prior surveys. NIMH and NCHS staff reviewed draft questions, suggested new topics for inclusion and sources of questions, and provided overall supervision throughout the questionnaire and design process for both the telephone and mail out components of the survey. To the extent possible, the final versions of the SPDS instruments contain directly comparable questions that have been previously tested and used on related surveys, and questions that are specific to this survey that have been extensively reviewed by the external experts.

9. Explanation of any payment or gift to respondents

One method for reducing nonresponse is to offer respondents a monetary token of appreciation for their participation. Monetary incentives will be offered for both the telephone and mailed components of the SPDS.

Offering an incentive payment has been shown to increase participation and response rates among parents or guardians of CSHCN. During the initial quarters of data collection on the 2009 – 2010 NS-CSHCN, an extensive incentive experiment was undertaken exploring a variety of incentive approaches. The results of this experiment demonstrated that incorporating an incentive can indeed improve response rates among parents or guardians of CSHCN. The most effective approaches combined a promised incentive with a further prepaid refusal-based incentive. Based on this experience, we will offer all SPDS eligible cases an incentive of \$20 as a promised incentive for the telephone interview. For households that initially refuse participation we will offer a further \$5 to be mailed to respondents as a prepaid incentive and accompanied by a letter reiterating the purpose and importance of the SPDS. This is similar to the incentive model employed to successfully increase response rates for two previous follow-up surveys conducted by SLAITS – the National Survey of Adoptive Parents (NSAP) and the National Survey of Adoptive Parents of Children with Special Health Care Needs (NSAP-SN). These surveys, like the SPDS, involved conducting a follow-up survey with respondents after their eligibility was determined through the administration of a parent survey. The interview completion rates that were obtained for these follow-up surveys are in line with those required for the SPDS project.

An incentive will also be offered to respondents for their further participation in the mailed component that will be conducted in conjunction with the SPDS telephone survey. In order to maximize the effect of the \$20 incentive for completing the telephone survey, the mail

questionnaire will be mailed with the telephone survey token payment. A cover letter will be included, thanking the respondent for their participation thus far, mentioning the enclosed \$20 is for prior participation, reminding the respondent of his/her agreement to participate in the mail follow-up survey, and offering respondents \$10 upon the return of the mail questionnaire.

All respondents that return the mail questionnaire will receive a \$10 token payment. As the mail questionnaire is a follow-up and as respondents are receiving the Computer-assisted telephone interview (CATI) survey token payment along with the mail out questionnaire, there is no need to include additional money as a pre-paid incentive; rapport and trust has already been built. The \$10 incentive is deemed sufficient to boost response rates for the mail questionnaire within the broader context of the overall SPDS.

10. Assurance of confidentiality provided to respondents

Interviewers, supervisors, and project staff receive thorough training on legal and ethical obligations. All employees sign an Affidavit of Nondisclosure as a condition of employment. Standards for the surveys performed for the Federal government 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 and other regulations.

An assurance of confidentiality is provided to all respondents according to section 308(d) of the Public Health Service Act (42 USC 242m) which states:

"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 (1) 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,..."

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.”

Privacy Impact Assessment Information

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.”

11. Justification for sensitive questions

Questions about their children’s mental health, development, functional status, and experiences with the health care and educational systems may be considered sensitive by some parents. However, to be eligible for this follow-up survey, these parents must have already completed the NS-CSHCN, which contains questions on similar topics. Therefore, we do not expect that parents will find the SPDS questions to be any more sensitive than those that they have already completed. Of course, participation is voluntary and parents will be reminded that they can skip any questions that they do not wish to answer.

12. Estimates of annualized burden hours and costs

The table below illustrates projected burden for SPDS (Table 1). This component was not specifically listed in the current three-year clearance package, but for each year of clearance we allocate burden for a “to-be-determined” dress rehearsal and survey implementation. Therefore, this burden is accounted for in the current clearance package.

For each component of the SPDS, the telephone questionnaire is approximately 30 minutes and the mail out questionnaire is approximately 25 minutes in length. The time to administer the telephone questionnaire sections and subsections will be reviewed throughout data collection to ensure compliance with burden estimates.

During the course of data collection for the 2009 – 2010 NS-CSHCN, we expect to collect contact information from nearly 4,500 households that contain one CSHCN with at least one of the selected development-related mental health conditions. We expect to complete telephone interviews and mail questionnaires from no more than 4,000 households (including 50 households in a dress rehearsal) with school-aged CSHCN with a development-related disability.

Table 1. Annualized burden estimate, SPDS

Respondents	SPDS Component	Number of respondents	Number of responses per respondent	Avg. burden per response (in hrs)	Total burden hours
For previously identified age & condition eligible CSHCN (in English)	Telephone questionnaire	4,000	1	30 / 60	2,000
	Mail	4,000	1	25 / 60	1,667

speaking households)	questionnaire				
Total					3,667

13. Estimates of other total annual cost burden to respondents or record-keepers

No capital or maintenance costs are involved.

14. Annualized cost to the Federal government

The cost for NCHS to conduct the Pathways Survey is approximately \$1.6 million and will be completed within 12 months. The costs are supported by NIMH through an Interagency Agreement (IAA). NIMH funds from the American Recovery and Reinvestment Act are used to support contractor salaries; survey planning, design, and development; training; field dress rehearsal; coding; data collection, weighting and preliminary estimation; printing of survey materials; file release; and incentives used to address non-response. Additional non-ARRA funds from NIMH are used to support Federal staff salaries. Details are shown below:

Table 2. Annualized cost, SPDS

Funding Source	Amount
ARRA	\$1,300,000
NIMH	\$ 310,000
NCHS/Division of Health Interview Statistics	\$ 14,000
Total Projected Cost	\$1,624,000

For more information on ARRA funds used for the SPDS please contact:

Stephen Blumberg, Ph.D.
Senior Scientist
Division of Health Interview Statistics
National Center for Health Statistics
3311 Toledo Road, Room 2112
Hyattsville, MD 20782
sblumberg@cdc.gov
301-458-4107

15. Explanation for program changes or adjustments

No change.

16. Plans for tabulation and publication and project time schedule

The projected timeline is listed in Table 3. Data products for this survey may include a national chartbook with key findings and health data briefs. Findings will be disseminated through traditional research venues such as professional meetings, conferences, peer-reviewed journals, and research posters, which are accessed and attended by academic researchers, survey methodologists, policy makers, and parent or advocacy groups for CSHCN. Study findings, publications, data files, and documentation will be available at no cost on the NCHS-SLAITS websites. Published materials will be included in publicly accessible bibliographic databases such as Medline (available through the National Library of Medicine, www.nlm.nih.gov) and may be disseminated in the lay media by medical journalists. A separate detailed methodology report will be prepared by NCHS after the survey is completed.

An announcement of the data file release will be disseminated by the CDC and NIMH Offices of Public Affairs through various listservs, including the SLAITS listserv with almost 1,000 subscribers around the world.

Table 3. Completed and Projected Time Schedule of Activities for the SPDS.

Activity	Time Schedule
Expert Panel meetings, development of draft instruments and study design	May 4, 2010: Conference call May 10, 2010: In person meeting June 1, 2010: In person meeting June 17, 2010: Conference call July 30, 2010: Conference call Sept. 27, 2010: Conference call
Draw sample of respondents	Within 1-3 weeks after OMB approval
Mail advance letters to sampled respondents	1-5 weeks after OMB approval
Train interviewers	2-5 weeks after OMB approval
Start of telephone data collection dress rehearsal	3-6 weeks after OMB approval
Start of main telephone data collection	4-8 weeks after OMB approval
Start of mail data collection	6-10 weeks after OMB approval
Completion of telephone data collection	16-20 weeks after OMB approval
Completion of mail data collection	20-28 weeks after OMB approval
Begin data processing	22-30 weeks after OMB approval
Complete data processing	24-32 weeks after OMB approval
Data Analyses	26-36 weeks after OMB approval
Publications	28-38 weeks after OMB approval

B. Collection of Information Employing Statistical Methods

1. Respondent universe and sampling methods

For the SPDS, the sample frame consists of approximately 4,500 English-speaking households which were already screened as part of the 2009 – 2010 NS-CSHCN and were identified as having a resident child with special health care needs aged 6 to 17 years of age with a development-related disability specific to the SPDS. These households will be recontacted to participate in both follow-up components, until approximately 4,000 detailed telephone interviews are achieved. The respondent will be the same parent or guardian who completed the 2009 – 2010 NS-CSHCN. Absolutely no children will be interviewed or asked to fill out the mail questionnaire during the course of data collection.

2. Procedures for the Collection of Information

At the end of the NS-CSHCN interview, respondents were told that they may be contacted for future surveys. In order to locate the original respondent at a future date, the interviewer asked for additional contact information. This information (collected since March 2010) will be used to contact and interview eligible respondents for the SPDS.

Computer-assisted telephone interviews will be conducted using the procedures described in the original SLAITS information collection request. The advance letter and introductory telephone script are found in Attachments 1a & 2. All telephone interviews (Attachment 2) will be conducted from the data collection contractor's telephone centers in Chicago, Illinois and Las Vegas, Nevada. Interviews will be regularly monitored by the contractor. The study interviews will only be conducted in English. The telephone follow-up letters can be found in Attachment 1(b and c).

At the end of the telephone survey, interviewers will request permission to mail a further follow-up survey to the respondent. Each mailed packet will include the respondent's CATI token payment, customized cover letter, mail questionnaire, and business-reply envelope. The cover letter will thank the respondent for their participation thus far, mention the enclosed \$20 is for prior participation, remind the respondent of his/her agreement to participate in the follow-up, and offer \$10 upon the return of the mail out questionnaire.

The mail questionnaire (Attachment 3) will be printed with a unique barcode on each page so that it may accurately be barcode-receipted when returned by the respondent. In addition to the barcode, unique identifiers will be printed on the bottom corners of the outer envelope, cover letter, and mail questionnaire to allow a fast and effective method for ensuring all customized materials are matched to the same individual. The unique identifier and the barcode are for internal tracking purposes only and will never appear on public data sets, eliminating potential for identification on public use data.

Four weeks after the initial mailing a telephone call will be made to all non-respondents gently prompting them to return the mail questionnaire. While most mail surveys use a postcard, not a

telephone call, to prompt response, this methodology should be more effective at increasing response rates as it is more difficult (from a social perspective) to refuse to a person than to simply throw out a postcard. If the mail questionnaire has still not been returned, another mail questionnaire will be mailed to the respondent. The second mail questionnaire will include a \$5 prepaid incentive. Upon return of the mail questionnaire, a thank you letter with the promised incentive will be mailed to all respondents. The mailed cover and follow-up letters can be found in Attachment 1 (d-g).

We anticipate completing all telephone interviews and mail questionnaires by the summer of 2011. Once all necessary steps are taken to ensure that the identity of survey subjects is protected, a publicly available data file should follow shortly thereafter. To reduce the risk of inadvertent disclosure, it is likely that the data file will be coarsened by suppressing survey variables, collapsing multiple variables into one, collapsing response categories for other variables, and/or introducing noise in the data. All data files are reviewed and approved by the NCHS disclosure review board. Analysts interested in working with data that were suppressed to protect confidentiality may access unmodified data files through the NCHS Research Data Centers.

Advance Letter

The SPDS letter invites recipients to participate in a study on the mental health of children and provides survey information in a concise format. The letter also

- advises recipients that household contact information was gathered voluntarily during a previous data collection, and indicates they will be called in the next few weeks;
- provides information about the SPDS (i.e., briefly explains the purpose of the survey and the uses of the data while mentioning SLAITS), and states that “Information about your child will help the U.S. Department of Health and Human Services develop programs to promote the health of children with these conditions in your state and throughout the United States.”;
- tells potential respondents that they may refuse to participate completely or refuse individual items, that their responses will be held in strictest confidence, the survey is voluntary, and that their responses will be used for statistical purposes only;
- includes a list of ‘frequently asked questions’ or FAQs on the back of the letter, which also cites and explains the authorizing legislation; and
- invites hard-of-hearing or deaf respondents to contact the contractor with a TTY machine at a toll free number to be interviewed.

Power Calculation

One of the goals of the survey is to allow for three sets of comparisons between groups of children: (1) Children with current autism vs. children with previous (but not current) autism; (2) Children with a current intellectual disability vs. children with a previous (but not current) intellectual disability; and (3) Children with a current developmental delay vs. children with a previous (but not current) developmental delay.

Table 3 presents the expected number of children with complete interviews falling into these groups and the minimum difference in percentage points that could be detected with 80% power for a two-sided test of no difference between the groups at the $\alpha=0.05$ level, assuming a

design/weighting effect of 3.0.

Table 3: Minimum Detectable Differences

CSHCN Group	Expected Number of Children with Complete Interviews	Minimum Detectable Difference between Current/Previous (percentage points) ¹
Current Autism	1,207	14.4
Ever had Autism	371	
Current intellectual disability	839	20.2
Ever had intellectual disability	174	
Current developmental delay	2,414	8.9
Ever had developmental delay	1,067	

¹ Detectable difference with 80% power for two-sided tests of no difference at the $\alpha=0.05$ level for estimates near 0.5, assuming a design/weighting effect of 3.0.

3. Methods to maximize response rates and deal with non-response

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 telephone 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 (Attachment 1a),
- 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,
- judicious use of incentives,
- quality control and interviewer monitoring,
- refusal aversion/conversion training with experienced interviewers, and
- A carefully constructed refusal conversion letters (Attachment 1b & 1e).

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.

In order to maximize the response from the mail component, all materials in the packet – including the envelope – will be designed to be visually inviting and alluring to potential respondents. We will draw on literature regarding pictures, text, font, and the use of color from both marketing and survey research in determining the most appropriate materials design. In addition, research suggests first-class mail optimizes response rates and as a result all SPDS mail survey materials will be sent via first class mail.

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 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. 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 attempted to measure this difference using multiple 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 variations within the existing survey. Overall, we determined that the non-response bias was minimal, and do not significantly alter the results.² A similar strategy will be used to examine the potential for nonresponse bias in the 2009 – 2010 NS-CSHCN and the SPDS.

The final overall weighted response rate for the follow-up survey is dependent on the underlying response rates for the 2009 – 2010 National Survey of CSHCN. After data collection is completed, we will calculate and report this overall weighted response rate in the required methodology report. The calculation will be consistent with the Standard Definitions provided by the American Association for Public Opinion Research (AAPOR), and the methodology report will include the specific calculations and summaries of the disposition of the sample cases. We expect to achieve at least a 70% interview completion rate, calculated as the number of completed interviews divided by the number of eligible children sampled for recontact. This would be consistent with the 76.3% unweighted interview completion rate achieved by the National Survey of Adoptive Parents, which was a follow-up survey of the 2007 National Survey of Children's Health conducted by the SLAITS program.

² 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.

4. Test of procedures or methods to be undertaken

A dress rehearsal of the first 50 interviews will be conducted with the same materials, interviewers, and questionnaires. The dress rehearsal is intended to:

- test the questionnaires, procedures, software, and instrument integration;
- ensure that the questions and questionnaires flow properly (i.e., transitions are sufficient and skip patterns are working as intended);
- examine qualitative aspects of the surveys (interpretability and ease of answering questions; parent, interviewer, and supervisor's perceptions of the survey; etc.);
- examine:
 - variable distributions to uncover floor or ceiling effects;
 - response patterns (location of break-offs, don't know, refusal responses);
 - question sensitivity;
 - response variability and analytic usefulness;
 - perceived accuracy of reporting and implausible answers
 - time referent/response categories
 - validity and reliability
 - redundancy of questions
 - all verbatim responses (i.e., generate possible new response categories for the main survey); and
- assess section administration times.

The SPDS dress rehearsal will also examine the procedures used to recontact NS-CSHCN respondents using information collected in the NS-CSHCN.

If no significant problems are found, the cases from the dress rehearsal will be kept in the data set and data collection will continue. If significant problems are found, corrections will be made and data collection will pause until the problems are fixed.

5. Individuals consulted on statistical aspects of design, data collection, and analysis

Stephen Blumberg, Ph.D.
Senior Scientist
Division of Health Interview Statistics
National Center for Health Statistics
3311 Toledo Road, Room 2112
Hyattsville, MD 20782
sblumberg@cdc.gov
301-458-4107

Kennon Copeland, M.S., Ph.D.
Director of Statistics and Methodology
National Opinion Research Center
4350 East-West Highway
Bethesda, MD 20814
Copeland-kennon@norc.org
301-634-9432

Benjamin Skalland, M.S.
Survey Statistician III
National Opinion Research Center
55 East Monroe Street
Chicago, IL 60603
Skalland-benjamin@norc.org
312-759-4020

LIST OF ATTACHMENTS

- 1) SPDS Letters
 - a) Advance Letter & FAQ
 - b) Telephone Refusal Conversion Letter
 - c) Thank You Letter (telephone interview only)
 - d) Mail Cover Letter, Instructions, & FAQ
 - e) Mail Refusal Conversion Letter
 - f) Thank You Letter (post mail conversion letter)
 - g) Thank You Letter (no mail conversion letter needed)
- 2) SPDS Telephone Interview Questionnaire
- 3) SPDS Mailed Questionnaire
- 4) SPDS Expert Panel