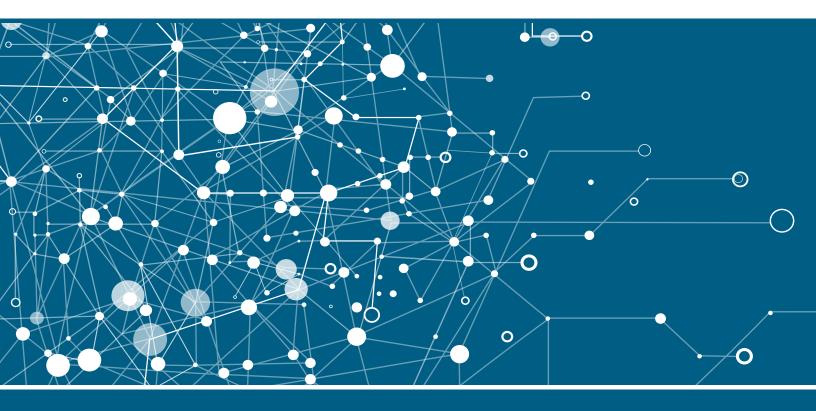
# Vital and Health Statistics

Series 1, Number 63 October 2019



Design and Operation: 2013 National Survey of Children in Nonparental Care and 2014 National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome

**Programs and Collection Procedures** 



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#### **NATIONAL CENTER FOR HEALTH STATISTICS**

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Series 1, Number 63 October 2019

# Design and Operation: 2013 National Survey of Children in Nonparental Care and 2014 National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome

Programs and Collection Procedures

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

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# Contents

scknowledgments	vi
sbstract	. 1
State and Local Area Integrated Telephone Survey (SLAITS) Program	. 2
NSCNC	.3
ample Design	. 4
Questionnaire	.6
nterviewer Training	.9
Pretesting Advance Letters Toll-free Telephone Number Selection of Respondent Informed Consent Assurance of Confidentiality Interview Length Interview Breakoffs Case Disposition at Close of Data Collection Response Rates Efforts to Maximize Response Rates Incentive Effort for NSCNC	.9 10 10 10 11 11 11 13 14
Incentive Effort for NSDATA.  Locating Respondents.  Identifying Cases Qualified for Locating.  Accurint Database Searches  Locating Protocol  Quality Control	15 16 16 16
Quality Control of Interviewing	16 17 17
Editing	17 17

# Contents—Con.

	a Files—NSCNC	
	Coding of Verbatim Answers Into Question Responses	
	Edits to Protect Confidentiality....................................	
	Dummy Variables	
	Additional Data Notes	
Dat	ra Files—NSDATA	23
	Coding of Verbatim Answers Into Question Responses	
	Edits to Protect Confidentiality	
	Derived Variables	
	ighting and Estimation Procedures	
	NSCNC Weights	
	NSDATA ADHD Weights	
	Weighting Methodology for TS Sample	
	Quality Control	
	imation and Hypothesis Testing	
	Variance Estimation Using SUDAAN or Stata	
	Variance Estimation for Data Subsets	32
Gui	delines for Data Use	33
Fur	ther Information	33
Ref	erences	33
Apı	pendix I. Technical Description for Weighting the National Survey of Children in Nonparental Care	35
Apı	pendix II. Technical Description for Weighting the National Survey of the Diagnosis and	
Tre	atment of ADHD and Tourette Syndrome	39
Apı	pendix III. NSCNC Questionnaire	13
Apı	pendix IV. NSDATA Questionnaire	27
Apı	pendix V. NSCNC Pretest	<b>‡C</b>
Apı	pendix VI. NSCNC and NSDATA Respondent Letters	16
Apı	pendix VII. Income Thresholds	51
Apı	oendix VIII. Medicaid and Children's Health Insurance Program Text Fills	53
Apı	pendix IX. NSCNC Nonresponse Bias Analysis	56
Apı	pendix X. NSDATA Nonresponse Bias Analysis	74
Te	kt Figures	
1.	Sampling framework, screening, and final disposition for NSDATA	. 5
2.	Venn diagram showing overlap of NSCNC Screener File, NLNPCG module file, and Interview File	

# Contents—Con.

ables

A.	NSCNC interviewers trained and certified, by month, 2013
В.	NSDATA interviewers trained and certified by month, 2014
C.	Final dispositions of NSCNC sample
D.	Final disposition of cases eligible for NLNPCG module
E.	Final dispositions of ADHD sample on public data file
F.	Final dispositions of TS sample on data file
G.	NSCNC component rates, by sample type
H.	NSDATA component rates, by sample type
J.	NSCNC overall response rates, by sample type
K.	NSDATA ADHD sample overall response rates, by sample type
M.	NSCNC incentive-eligible cases
N.	NSDATA incentive-eligible cases
0.	NSCNC variables requiring back-coding
P.	NSDATA ADHD module variables requiring back-coding
Q.	NSDATA TS module variables requiring back-coding
Λ	aandiy Tahlaa
Apı	pendix Tables
l.	Rules for combining valid values of P13 and P31 into new variable P36
II.	2013 federal poverty guidelines for families in the 48 contiguous states and District of Columbia
III.	2013 federal poverty guidelines for families in Alaska
IV.	2013 federal poverty guidelines for families in Hawaii
V.	2014 federal poverty guidelines for families in the 48 contiguous states and District of Columbia
VI.	2014 federal poverty guidelines for families in Alaska
VII.	2014 federal poverty guidelines for families in Hawaii
VIII.	State-specific program names for Medicaid and CHIP
IX.	Percentage of children in NSCNC, by demographic and health characteristics for respondents and nonrespondents
Χ.	Percentage of children in NSCNC, by household socioeconomic and demographic characteristics for respondents and nonrespondents
XI.	Percentage of children in NSCNC, by NSCH characteristics similar to NSCNC data elements for respondents and nonrespondents
XII.	Percentage of children in final NSCNC weighted sample and comparable population as estimated by NSCH, by demographic and health characteristics

# Contents—Con.

XIII.	Percentage of children in final NSCNC weighted sample and comparable population as estimated by NSCH, by household socioeconomic and demographic characteristics
XIV.	Percentage of children in final NSCNC weighted sample and comparable population as estimated by NSCH, by NSCH characteristics similar to NSCNC data elements
XV.	Percentage of children in NSDATA ADHD module, by demographic and health characteristics for respondents and nonrespondents
XVI.	Percentage of children in NSDATA ADHD module, by household socioeconomic and demographic characteristics for respondents and nonrespondents
XVII.	Percentage of children in NSDATA ADHD module, by NSCH characteristics similar to NSDATA ADHD data elements for respondents and nonrespondents
XVIII.	Percentage of children in final NSDATA ADHD module weighted sample and comparable population as estimated by NSCH, by demographic and health characteristics
XIX.	Percentage of children in final NSDATA ADHD module weighted sample and comparable population as estimated by NSCH, by household socioeconomic and demographic characteristics
XX.	Percentage of children in final NSDATA ADHD module weighted sample and comparable population as estimated by NSCH, by NSCH characteristics similar to NSDATA ADHD data elements

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NORC at the University of Chicago conducted all interviews for these projects. Technical assistance was contributed by Nada Ganesh, Ph.D.; Wei Zeng, M.S.; Benjamin Skalland, M.S.; Warren Jones; Jerod Dibacco; Amy Silver; and Linda Christian. Kennon Copeland, Ph.D., and Daniel Constanzo provided management support.

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Finally, thank you to the thousands of parents and other family members who were willing to share their stories. Their efforts made this project a reality.

# Design and Operation: 2013 National Survey of Children in Nonparental Care and 2014 National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome

by Benjamin Zablotsky, Ph.D., and Matthew D. Bramlett, Ph.D., National Center for Health Statistics; and Jacquelyn M. George, Josiane Bechara, M.P.P., Kathleen B. Santos, M.S., A. Elizabeth Ormson, M.S., Kim L. Williams, M.S., Alicia M. Frasier, M.P.H., and Heather M. Morrison, M.A., NORC at the University of Chicago

#### **Abstract**

#### **Objectives**

This report presents the development, plan, and operation of two follow-back surveys of the 2011–2012 National Survey of Children's Health (NSCH): the 2013 National Survey of Children in Nonparental Care (NSCNC) and the 2014 National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome (NSDATA). Both surveys were modules of the State and Local Area Integrated Telephone Survey conducted by the National Center for Health Statistics.

#### **Methods**

NSCNC and NSDATA used the 2011–2012 NSCH sample as a prescreened sample for follow-back surveying. The NSCNC sample consisted of U.S. households that had reported in NSCH that the sampled children had no biological, adoptive, or stepparents living in the household or were living with foster parents in the household. The NSDATA sample consisted of U.S. households that had reported in NSCH that the sampled child had been diagnosed with one or both of two conditions: attention-deficit/hyperactivity disorder

(ADHD) and Tourette syndrome. NSCNC was sponsored by the U.S. Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation with supplemental funding from the Annie E. Casey Foundation. NSDATA was sponsored by the National Center on Birth Defects and Developmental Disabilities.

#### **Results**

A total of 1,298 NSCNC interviews were completed from April through August 2013. The interview completion rate (i.e., cooperation rate) for eligible respondents was 74.5%. The overall response rate for NSCNC, taking into account nonresponse to NSCH, was 12%. A total of 3,018 NSDATA interviews were completed from January through June 2014. The interview completion rate for ADHD module-eligible respondents was 80.8%. Accounting for nonresponse to NSCH, the overall NSDATA response rate was 11%.

**Keywords:** child health • child health services • physical and emotional health • pediatrics

#### Introduction

This report documents the design and operation of two surveys conducted by the National Center for Health Statistics (NCHS): the 2013 National Survey of Children in Nonparental Care (NSCNC) and the 2014 National Survey of Diagnosis and Treatment of ADHD and Tourette Syndrome (NSDATA). These two surveys reinterviewed parents and caregivers of children who had been initially identified in the 2011–2012 National Survey of Children's Health (NSCH). NSCH was conducted by NCHS in 2003, 2007, and 2011–2012. NSCH is a large-scale, population-based, nationally representative survey of children living in U.S. households. Because the sample size of NSCH is large (approximately 100,000 children in each of the

three iterations), it is often useful for conducting analyses of rare subgroups, such as children in rare living conditions or children with rare health conditions.

Because both NSCNC and NSDATA were follow-back surveys to the 2011–2012 NSCH, with each using the NSCH sample as a prescreened sample to identify members of subgroups of interest for further data collection, significant overlap occurs in the methodology between the two surveys. Thus, this report documents the design and operation of both surveys. Throughout this report, sections begin by discussing aspects of survey design or operations that were common to both NSCNC and NSDATA, followed by, when needed, a subsection devoted to unique aspects of NSCNC, which is followed by a subsection devoted to unique aspects of NSDATA.

The appendices follow a similar structure, starting with a technical description for weighting of NSCNC (Appendix I) and NSDATA (Appendix II), followed by NSCNC (Appendix III) and NSDATA (Appendix IV) questionnaires. Appendix V contains information about only the NSCNC pretest, because NSDATA did not include a pretest. Appendix VI includes recruitment and thank you letters that were mailed to NSCNC and NSDATA respondents. Appendixes VII and VIII detail income thresholds and Medicaid or Children's Health Insurance Program (CHIP) state fills used for both NSCNC and NSDATA. The report concludes with the nonresponse bias analysis for NSCNC (Appendix IX) and NSDATA (Appendix X).

# State and Local Area Integrated Telephone Survey (SLAITS) Program

Both NSCNC and NSDATA, as well as NSCH, were modules of the State and Local Area Integrated Telephone Survey (SLAITS) Program. SLAITS, sponsored by NCHS, was a broadbased surveillance system available at national, state, and local levels for tracking and monitoring the health and wellbeing of children and adults. SLAITS modules such as NSCH used the same sampling frame as the Centers for Disease Control and Prevention's (CDC) National Immunization Survey (NIS) and immediately followed the NIS interview in selected households, using its sample for efficiency and economy. In the course of identifying households with age-eligible children, NIS uses a random-digit-dial (RDD) sample and computer-assisted telephone interview (CATI) technology to screen approximately 1 million households each year. The process of identifying this large number of households—most of which are ultimately age-ineligible for NIS—offered an opportunity to administer other surveys on a range of health and welfare-related topics in an operationally seamless, cost-effective, and statistically sound manner.

SLAITS modules varied in content, duration, and sample size based on the research needs of their sponsors. Sponsors worked with NCHS to establish parameters—including questionnaire design, sample size, and other survey requirements. From 2005 through 2014, NCHS contracted with NORC at the University of Chicago to administer all aspects of the survey operations, including development and testing of the CATI instrument, recruiting and training interviewers, completing the targeted number of interviews, and preparing data files and final documentation.

Following the conclusion of NSDATA, the SLAITS staff and sponsors reflected on the declining willingness of the public to participate in telephone surveys. Falling response rates on both landlines and cell phones were leading to increased costs (1). Meanwhile, the availability of high-quality address-based samples was increasing the viability and efficiency of surveys based on Internet-based Web tools and mailed paper data-collection instruments. For these reasons, the SLAITS mechanism was discontinued (2). NSCH was redesigned in 2016 by the Health Resources and Services Administration

and is now conducted as a mail and Web-based survey by the U.S. Census Bureau.

#### **History of NSCH**

In 2001, SLAITS conducted the first National Survey of Children with Special Health Care Needs (NS-CSHCN), which was designed to collect data on the special health care needs of children, children's health insurance coverage, and uninsured children from low-income households (3,4). With a target of 750 interviews per state, the 2001 NS-CSHCN was the first SLAITS study to take full advantage of the NIS sampling frame to produce state-level estimates. In 2003, SLAITS fielded the first iteration of NSCH, which examined the physical and emotional health of children aged 0-17 years (5). SLAITS facilitated the second round of NSCH in 2007 (6). The 2007 NSCH provided the prescreened sample of adopted children for the concurrent 2007 National Survey of Adoptive Parents (NSAP) (7). In 2009–2010, SLAITS fielded the third administration of NS-CSHCN, the first SLAITS survey to incorporate cell phones into its sampling frame (8).

In 2011–2012, SLAITS fielded the third administration of NSCH, a population-based RDD survey designed to collect information on a range of factors that impact the health and well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and neighborhood characteristics (9). For thencurrently uninsured children, NSCH also collected detailed information about reasons why they were uninsured, including past enrollment and application information for public health insurance programs.

The third iteration of NSCH, for the first time, collected locating information from all respondents, including address and alternate telephone numbers, for use during potential future contacts. From February 2011 through June 2012, a total of 98,019 interviews were completed with parents or guardians of children under age 18 years, roughly evenly distributed among 50 states, Washington, D.C., and the U.S. Virgin Islands. In addition to English, interviews were conducted in Cantonese, Korean, Mandarin, Spanish, and Vietnamese. Both NSCNC and NSDATA were administered as follow-back surveys to the 2011–2012 NSCH, which served as a vehicle for identifying eligible respondents.

#### **NSCNC**

Sponsored by the U.S. Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation (ASPE), with assistance from the Annie E. Casey Foundation, NSCNC is the third in a series of ASPEfunded SLAITS follow-back surveys focused on a very rare subgroup of particularly vulnerable children identified in a previous large-scale SLAITS module. ASPE had previously sponsored the 2007 NSAP (concurrent follow-back to NSCH 2007) and the 2008 National Survey of Adoptive Parents of

Children with Special Health Care Needs (follow-back to the 2005–2006 NS-CSHCN) (7,10,11).

NSCNC was administered in 2013 and was intended to reinterview households of children whose biological, adoptive, or stepparents did not live with the child during administration of the 2011–2012 NSCH, and who would still be under age 18 years at the time of the subsequent NSCNC interview.

#### **NSDATA**

Sponsored by the National Center on Birth Defects and Developmental Disabilities (NCBDDD), NSDATA was administered in 2014. NSDATA focused on children ever diagnosed with attention-deficit/hyperactivity disorder (ADHD), Tourette syndrome (TS), or both at the time of the 2011–2012 NSCH, and who were still under age 18 years at the time of NSDATA.

#### **Background**

#### **NSCNC**

Children in nonparental care do not fit neatly within any federal agency's programmatic authority. No agency is explicitly focused on them, and no program is specifically designed to benefit these children. ASPE recognized this gap in knowledge and services and developed the NSCNC research project in consultation with a variety of other interested agencies, with the aim of providing information to help a range of programs better understand the children and families they encounter, their perceived strengths and needs, and the issues they face in accessing a range of services. According to its mission statement, ASPE:

Advises the Secretary of the Department of Health and Human Services on policy development in health, disability, human services, data and science; and provides advice and analysis on economic policy. The ASPE leads special initiatives; coordinates the Department's evaluation, research, and demonstration activities; and manages cross-Department planning activities such as strategic planning, legislative planning, and review of regulations. Integral to this role, the ASPE conducts research and evaluation studies; develops policy analyses; and estimates the cost and benefits of policy alternatives under consideration by the Department or Congress (12).

ASPE funded NSCNC to learn more about nonparental families and the well-being of children in nonnparental care.

The NSCNC data set is the only nationally representative survey on children in nonparental care that measures the well-being of the children and their caregivers, and assesses their access to and utilization of various services and supports while also benefitting from the large quantity of health and well-being data that had already been collected in NSCH on these children.

Nonparental caregivers are likely to face unique hurdles in trying to secure services for the children in their care, enroll them in school, or provide health insurance coverage, but it is unknown to what extent such hurdles are surmountable because there is no prior population-based data specific to these children. Surveys that are large enough to include a reliable sample of children in nonparental care do not typically assess the problems experienced by these children or their caregivers.

The national data from NSCNC were intended for use in program evaluations, policy planning, and needs assessments, and to produce estimates that examine the child's or caregiver's health status, well-being, health care needs, and service access and utilization. NSCNC and NSCH data together provide a comprehensive picture of children in nonparental care and the families caring for them. Currently, no other federal data source can be used to provide a detailed description of this population.

#### **NSDATA**

Nationally representative population-based data are limited on the service and treatment utilization of families raising a child with ADHD or TS. Surveys that are large enough to include a reliable sample of children with ADHD do not typically examine whether treatment or access problems exist specifically for these children or their parents or guardians. There is also a scarcity of probability samples regarding TS—a gap that will also be addressed in the NSDATA study.

NSDATA was sponsored by NCBDDD, whose stated mission is:

To promote the health of babies, children, and adults and enhance the potential for full, productive living. NCBDDD works to identify the causes of birth defects and developmental disabilities, help children to develop and reach their full potential, and promote health and well-being among people of all ages with disabilities. NCBDDD was established following passage of the Children's Health Act of 2000, which required the establishment of a national center dedicated to birth defects and developmental disabilities (13).

NCBDDD funded NSDATA to provide a nationally representative population-based data set on the service and treatment utilization of families raising a child with ADHD, as well as an informational sample of children with TS. The SLAITS mechanism provided a platform to identify a cross-sectional sample of families affected by the disorders, and a means of studying the relationship between diagnostic and treatment factors and functional health status.

NSDATA is the only nationally representative survey that provides comprehensive information on the diagnostic and treatment process of ADHD among children while also benefitting from the large quantity of health and well-being

data that had already been collected in NSCH on these children.

Information collected in NSDATA is intended for use in program evaluations, policy planning, and needs assessments, and to produce estimates that examine the child's health status, well-being, and health care needs, as well as the child's and their parent's or guardian's service access and utilization. Currently, no other federal data source offers a detailed description of these populations. NSDATA 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 children diagnosed with ADHD or TS

#### **Sample Design**

The 2011–2012 NSCH was a cross-sectional telephone survey of U.S. households with at least one resident child aged 0–17 years at the time of the interview. The NSCH sample was composed of a list-assisted RDD sample of landline telephone numbers, supplemented with an independent RDD sample of cell-phone numbers. NSCH utilized a complex survey design, with stratification by state and sample type (landline or cell phone). The sampling frame for NSCH was the same sampling frame as for CDC's NIS and immediately followed the NIS interview in selected households, using the NIS sample for efficiency and economy.

Eligibility for NSCH was determined by a process in which telephone numbers were called and screened for residential status and whether the household contained children who were aged 0–17 years at the time of the call. For the cellphone sample, various telephone status questions were also asked. For the sample released in the first calendar quarter of 2011, households contacted by cell phone were considered eligible only if they did not have a landline telephone or the respondents said they were unlikely to be reached via the landline if they had one.

For the sample released in April 2011 and beyond, a "take all" approach was implemented for cell phone cases; these cases were no longer screened for cell-only/mostly status. Instead, all cell phone respondents were selected for the interview if an eligible child was in the household.

One child was randomly selected to be the subject of the detailed interview if more than one child lived in the household. In households with one child, that child was selected to be the subject of the detailed interview. Respondents were adults who lived in the household with the child and were knowledgeable about the child's health, usually a parent (most often the mother). For more information on the NSCH sample design and interview procedures, see the detailed 2011–2012 NSCH design and operation report (9).

NSCNC- and NSDATA-eligible children were identified from among cases with a completed NSCH interview. Children who were reported as not living with either a biological or adoptive parent or who were living in foster care at the time of the NSCH interview were included in the NSCNC sample. Children who were reported as ever being diagnosed with ADHD or TS at the time of the NSCH interview were included in the NSDATA sample. However, eligibility for both surveys was limited to children residing in English- or Spanishspeaking households within the 50 states and Washington, D.C., from Quarter 2, 2011, to Quarter 1, 2012. The U.S. Virgin Islands completed interviews from NSCH were deemed outof-scope; and the Quarter 1, 2011, completed interviews were excluded because the time between surveys was the longest, making recontact presumably more difficult. Finally, children who were estimated to be over age 17 years at the time of the NSCNC or NSDATA start were also removed from the pools of eligible cases. A total of 2,882 eligible children were included in the NSCNC sample, and 6,102 eligible children were included in the NSDATA sample.

#### **Conducting NSCNC**

The sampled households were called between April and July 2013 to attempt an NSCNC interview about the child. Once the NSCH respondent was reached, it was confirmed whether the child still lived with the respondent; if so, the child's age eligibility was determined. Although children estimated to be age 18 years or over at the start of data collection were excluded from the sample, other children were discovered to have reached age 18 upon screening. Only if the child was still under age 18 at the time of screening was the NSCNC interview conducted. In some cases, the NSCH respondent reported that they no longer lived with the child. For example, a child may have been able to return to his or her biological parents' household after the NSCH interview and prior to the NSCNC interview. For these special cases, a short interview was administered to those respondents, and information regarding the child's current location was collected, which trained interviewers used to attempt to locate the child. When the child was found, they attempted to conduct an interview with the child's current caregiver.

#### **Conducting NSDATA**

Households sampled for NSDATA were called between January and June 2014 to attempt a NSDATA interview about the same child that was selected for the NSCH interview. Once the NSCH respondent or the child's current guardian was reached, the child was screened for ADHD or TS by asking the respondent if he or she was ever told by a doctor or health care provider that the child had ADHD or TS. If the child was ever diagnosed with either condition, the child's age and residency eligibility was determined. As with NSCNC, only if the child was still under age 18 years and living with the respondent at the time of screening was the NSDATA

interview conducted. In some cases, the NSCH respondent reported that they no longer lived with the child. In this event, attempts to further locate the NSCH child were made.

The sample for NSDATA consisted of 6,102 children ever diagnosed in NSCH with ADHD or TS, of whom 5,940 were ever diagnosed with ADHD only, 68 were ever diagnosed with TS only, and 94 were ever diagnosed with both ADHD and TS (Figure 1). A total of 3,629 children were screened for NSDATA, and 3,471 children were considered eligible for NSDATA. Of those eligible, 3,337 children were identified as ever having had ADHD only and, therefore, were eligible for only the ADHD module; 30 children were identified as ever having had TS only and were eligible for only the TS module; and 104 children were identified as ever having had both ADHD and TS and were eligible for both modules. A total of 158 children were screened as never having either condition and were not eligible for either module. Although these children had been described as having had either or both ADHD and TS as of the NSCH interview, screening results at NSDATA reinterview were used to set eligibility for NSDATA.

Although the ADHD and TS samples consisted of prescreened cases from NSCH who had already been diagnosed with either ADHD or TS by the time of the NSCH interview,

some children with only one of the conditions (ADHD or TS) at NSCH were discovered to have been diagnosed with the other condition (TS or ADHD) at the time of NSDATA reinterview. These newly discovered ADHD (n=10) and TS (n=37) cases were included in the NSDATA ADHD and TS samples but were not included in the public data release.

In total, 2,976 ADHD module interviews (2,903 ADHD modules only and 73 combined ADHD and TS modules) and 115 TS module interviews (42 TS modules only and 73 combined ADHD and TS modules) were completed. A total of 10 ADHD module interviews came from new ADHD cases (children who had been diagnosed with TS but not with ADHD at the time of the NSCH interview but who were diagnosed with ADHD by the time of the NSDATA interview). These 10 new ADHD cases were not included in the public data release, nor are they included in the nonresponse bias analysis. They are also not included in the final sample disposition description found later in the report. A total of 37 TS module interviews came from new TS cases (children who had been diagnosed with ADHD but not TS at the time of the NSCH interview but who were diagnosed with TS by the time of the NSDATA interview). Similarly, these 37 new TS cases were not included in the weighting scheme nor the final

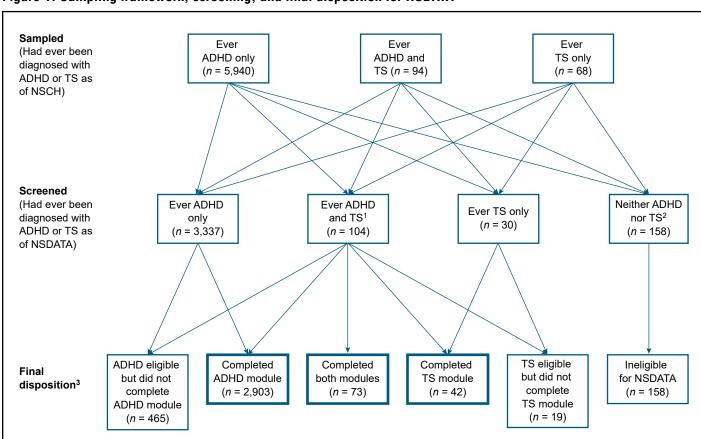


Figure 1. Sampling framework, screening, and final disposition for NSDATA

<sup>1</sup>Children with both Tourette syndrome (TS) and attention-deficit/hyperactivity disorder (ADHD) could have completed the ADHD module only, the TS module only, both modules, or neither. <sup>2</sup>National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome (NSDATA) respondents could have indicated that the child did not ever have a given condition even if the National Survey of Children's Health (NSCH) respondent said they did (NSDATA respondent did not have to be the same person as the NSCH respondent). <sup>3</sup>Based on screening, a total of 3,441 ADHD module interviews and 134 TS module interviews were possible. SOURCE: NCHS, National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, 2014.

sample disposition description found later in the report. See Figure 1 for additional details on sampling, screening, and interviewing for NSDATA.

#### Questionnaire

#### Content

The NSCNC and NSDATA questionnaires were designed as follow-back questionnaires to the 2011-2012 NSCH. NSCNC contains a separate nine-question module for NSCH respondents who reported that the sampled child no longer lives with them. This set of questions is referred to as the no longer nonparental caregiver (NLNPCG) module. Both the main NSCNC questionnaire and the NLNPCG module were telephone interviews and went through the same introduction and consent portion of the questionnaire. Respondents who lived with the sampled child qualified for the main NSCNC questionnaire, which was composed of 10 sections: 1. Household Structure; 2. Living Arrangement; 3. Parents: Characteristics and Interaction With Child; 4. Financial Support; 5. Caregiver Preparation, Long-Term Planning, and Legal Custody; 6. Caregiver and Child Interactions, Relationship, Monitoring, and Supervision; 7. Child Well-Being, Child Care, and School; 8. Caregiver Well-Being, Caregiver Physical and Mental Health, and Social Supports; 9. Services and Supports; and 10. Demographics.

NSDATA had nine sections: 1. Introduction, Screening, and Consent; 2. Diagnosis; 3. Co-occurring Disorders; 4. Treatment; 5. Symptoms and Performance/Impairment; 6. Academic and Health Discipline; 7. Family Impact of Diagnosis; 8. American Community Survey Questions; and 9. Household and Demographics.

An overview of each of these sections for each survey follows. The questionnaires are available in Appendixes III and IV.

#### **Introduction and consent**

To evaluate whether the correct respondent had been reached for the respective follow-up survey, and to determine eligibility, both questionnaires contained a brief screener section. This screener section was separated into three parts: 1) a group of questions to determine if the interviewer has reached the correct respondent to participate, and if not, locating variables in the event the person answering the call knows how to reach the intended respondent; 2) eligibility confirmation; and 3) explanation of the nature of the survey and obtaining consent.

Upon determining that the household from NSCH had been found, the interviewer asked to speak with the selected child's caregiver who had completed NSCH, or a parent or guardian who was currently living with the child and knowledgeable about the child's health. After the interviewer confirmed that they were speaking with the requested participant, or

after the person who answered the telephone self-identified as a current guardian, the interviewer asked the respondent screening questions to determine if their child was eligible. Questions included whether at the time of interview: 1) the child was under age 18, 2) the child was currently living in the household, 3) the child was not deceased, and 4) for NSDATA, the child had to have ever been diagnosed with either TS or ADHD. If all eligibility requirements were met, the interviewer proceeded with the main interview.

Once eligibility was determined, the respondent was informed of his or her rights as a survey participant. Verbal consent for study participation was then obtained and documented in the telephone instrument system. The informed consent statement informed respondents of the voluntary nature of the survey, assured them that their responses would be kept confidential, and indicated there was no penalty for not answering questions. The informed consent statement also provided information about the survey's content and expected duration. The respondent was told that he or she would receive payment (NSCNC: \$10 or NSDATA: \$20) in appreciation of his or her time. In certain refusal conversion instances, some respondents were offered payment (NSCNC: \$15 or NSDATA: \$5) to incentivize their participation. Finally, respondents were told that the interview would be recorded and monitored by a supervisor for quality purposes.

If the previous NSCH respondent was no longer living at that telephone number, and the selected child also did not live in the household, the person was asked for the NSCH respondent's name and a new telephone number. At that point, the process of re-engaging the original respondent started over from the beginning with the new telephone number.

If the sampled child no longer lived with the previous NSCH respondent, the person was told that, "We are interested in speaking with a parent or guardian of the child who is currently living with the child. Would you be able to tell us how to get in contact with this person?" If the person on the phone was unable to provide contact information for the child's new caregiver, the case was identified as requiring locating activities.

For both NSCNC and NSDATA, in accordance with U.S. Department of Health and Human Services (HHS) regulations (45 CFR 46), these procedures were reviewed and approved by the NCHS Research Ethics Review Board (ERB) and the NORC Institutional Review Board (IRB). All respondents were informed about the survey purpose, content, expected duration, confidentiality of their responses, authorizing legislation, voluntary nature of the survey, and instructions for contacting the ERB.

#### **NSCNC** questionnaire structure

• Section 0: NLNPCG—The NLNPCG module was designed for NSCH respondents who no longer lived with and cared

for the sampled child. The module was composed of nine questions that asked about the history of the child's living situation, such as where the child lived before coming to live with the former NSCH caregiver, as well as the reasons why the child's mother and father were not caring for the child at the time of the NSCH interview. This module also collected information regarding where the child was living and why the child no longer lived with the respondent.

- Section 1: Household Structure—The first section of the main NSCNC interview asked a variety of questions regarding the household structure and housing situation of the current NSCNC household. The respondent was asked their relationship to the sampled child, how many adults and children aged 17 years or under lived in the household, and whether any of the sampled child's parents now lived in the household. In this section, the respondent was also asked how long the child had been living with the current caregiver, whether such arrangement was made possible through a court or judge, and if anyone from child protective services or a foster care agency helped arrange such care.
- Section 2: Living Arrangement—Questions in this section asked the whereabouts of the sampled child prior to moving in with the respondent and while living with that respondent. This section also asked about the sampled child's siblings (if any), and how often the sampled child was in contact with their siblings.
- Section 3: Parents: Characteristics and Interaction With Child—This section asked questions about the sampled child's mother and father. The respondent was asked why the sampled child was not living with their parents (if the parents were not living in the household at the time of the NSCNC interview) and why the sampled child did not live with their parents at the time of the NSCH interview. This section also asked about the frequency of contact between the sampled child and his or her mother and father, as well as the types of roles either had in the decisions related to the sampled child's health or health care, and school or day care arrangements.
- Section 4: Financial Support—This section asked respondents about child support for the sampled child. Support payments included foster care or adoption assistance payments, Social Security survivor benefits, payments from Temporary Assistance for Needy Families or welfare, as well as child support payments from a parent. The respondent was also asked whether they received any nonmonetary support from the sampled child's parents or from friends or other relatives for taking care of the child.
- Section 5: Caregiver Preparation, Long-Term Planning, and Legal Custody—This section asked questions about how prepared the respondent had been to care for the sampled child. The respondent was also asked about any plans they may have for the future, such as acquiring a formal or legal agreement about custody or guardianship for the child. The respondent was asked how long they

- expected the child to live with them and where the child might live after living with the respondent.
- Section 6: Caregiver and Child Interactions, Relationship, and Monitoring and Supervision—During the NSCNC pretest, this section contained a series of questions that asked about the respondent's knowledge of the whereabouts of the sampled child, how the child spent their money, and how often the child was left at home without an adult or sitter. After conducting the pretest and to shorten the survey length, all questions in this section were deleted except for one that asked the respondent to describe how close their relationship was to the sampled child.
- Section 7: Child Well-Being, Child Care, and School—This
  section asked about the mental health and care of the
  sampled child. The respondent was asked whether the
  child had issues performing everyday tasks and whether
  the child had any treatment or counseling from a mental
  health professional. This section also asked the respondent
  about the kinds of difficulties they may have faced while
  enrolling the child in school, and the performance of the
  sampled child at school.
- Section 8: Caregiver Well-Being, Caregiver Physical and Mental Health, and Social Supports—This section asked the respondent questions about their physical and mental health, and about the support they may receive from their spouse or partner.
- Section 9: Services and Supports—The primary purpose of this section was to gain more information about the kind of health insurance coverage of the sampled child and the annual family income of the household. Respondents were asked whether the child was insured; what their experiences were with Medicaid; what their history and experiences were with the Children's Health Insurance Program (CHIP); if they were interested in and understood the enrollment process associated with Medicaid or CHIP; and, if parents had employer-sponsored insurance, what coverage was available to the child. This section also included questions on family income. Respondents who did not know or refused to provide exact income information were administered a brief income cascade to determine an income range. Cases that reported a household size of eight or nine and an income of \$35,000 or more were administered question S21, which filled the federal poverty threshold for the specific household size. The HHS federal poverty guideline tables, on which these fills were based, can be found in Appendix VII.
- Section 10: Demographics—This section collected demographic information about the NSCNC respondent and his or her spouse or partner (if applicable), including age, employment status, race and ethnicity, and the highest grade or year of school the respondent and spouse or partner have completed.

#### **NSDATA** questionnaire structure

- Section 1: Introduction, Screening, and Consent—The goal of this section was to evaluate whether the correct respondent had been reached, to determine eligibility, and to describe the survey and obtain consent.
- Section 2: Diagnosis—This section asked a variety of questions regarding the pathways to, timing of, and severity of the child's diagnosis. This section also asked about current diagnostic status and diagnostic context, as well as condition-related symptoms.
- Section 3: Co-occurring Disorders—The questions in this section were asked to determine whether the sampled child had ever been diagnosed with any other acute or chronic physical, mental, behavioral, learning, or developmental conditions. This section contained identical questions in both modules—cases that were eligible for both modules skipped this section in the ADHD module after having responded to those questions in the TS module
- Section 4: Treatment—This section asked whether
  the sampled children took any medications for their
  conditions and about any side effects to the medication
  that the children may have experienced. This section also
  asked about any other treatments the sampled child was
  currently receiving for difficulties with his or her emotions,
  concentration, or behavior.
- Section 5: Symptoms and Performance/Impairment— This section asked questions about the sampled child's behavior and performance in the past 6 months. Some of the topics discussed were writing, reading, and relationships with family and peers. The ADHD module included the Vanderbilt ADHD—18, an 18-item checklist of behaviors and symptoms common in children diagnosed with ADHD (14).
- Section 6: Academic and Health Discipline—This section included questions about the child's experience in school, including the type of school he or she was enrolled in (public, private, or homeschooled) and the child's school performance and behavior. This section specifically asked about grade repetition or expulsions. Cases that were eligible for both ADHD and TS modules (i.e., the child had ever been diagnosed with both ADHD and TS) skipped a number of these questions in the ADHD module after having already responded to the same questions in the TS module.
- Section 7: Family Impact of Diagnosis—This section included questions regarding the effect that the child's condition has on the child's family. It assessed financial and time burdens and the ways in which the families were coping with these burdens.
- Section 8: American Community Survey Questions—This section contained six disability questions, which were first fielded in 2008 in the American Community Survey (15). These questions asked about the child's ease or difficulty with basic functions such as speaking English,

- seeing, hearing, and making decisions. The respondent was also asked about whether the child has difficulty with daily tasks such as climbing stairs, bathing, and going on errands alone. This section contained identical questions in both modules—cases that were eligible for both modules skipped this section in the ADHD module after having responded to those questions in the TS module.
- Section 9: Household and Demographics—Questions in this section were designed to obtain information about the child's household composition. Respondents were also asked about their total family income. This section also asked respondents about whether they had insurance for the child, and to what degree insurance provided for the needs and services of the sampled child. This section contained identical questions in both modules—cases that were eligible for both modules skipped this section in the ADHD module after having responded to those questions in the TS module.

#### CATI

NSCNC and NSDATA were conducted using a CATI system. The CATI data collection method uses software that presents the questionnaire on computer screens to each interviewer. The computer program guides the interviewer through the questionnaire, automatically routing the interviewer to appropriate questions based on answers to previous questions. Interviewers enter survey responses directly into the computer, and the CATI program determines if the selected response is within an allowable range, checks it for consistency against other data collected during the interview, and saves the responses in a survey data file. On-screen help text is available to aid interviewers in administering the CATI questionnaire. This data collection technology reduces the time required for transferring, processing, and releasing data, and ensures the accurate flow of the questionnaire.

#### **Interviewer Training**

The data collection contractor NORC conducted all interviews for both NSCNC and NSDATA. Interviewer training was conducted by NORC staff at the production center located in Chicago, Illinois.

All NSCNC interviewers selected to attend the training were already-certified NORC staff, several of whom had worked on the 2011–2012 NSCH. Two types of training sessions were held: 1) telephone interview training, and 2) locator training. For NSCNC, NORC trained 40 telephone interviewers and seven locators. All staff who were trained passed all required training courses.

For NSDATA, three main trainings were conducted. The first training, conducted on January 21, 2014, consisted of six interviewers. All six interviewers selected to attend this training were existing certified staff, and several had worked on the 2011–2012 NSCH. The two subsequent trainings were

for the main launch. Two types of training sessions were held: 1) telephone interview training, and 2) locator training. For NSDATA, NORC trained 75 telephone interviewers and 15 locators. All 15 locators were trained on telephone interviewing as well. All staff who were trained passed all required training courses and certification.

#### **Training Sessions**

The interviewer training sessions began with an introduction and project overview. Interviewers were informed about the survey's purpose, sponsors, design, and goals. An overview of the screener and each section of the respective questionnaire was provided, with an emphasis on quality data collection. The relationship between NSCNC or NSDATA and NSCH was also covered. Interviewers were trained on finding the correct respondent—either the original NSCH respondent or a different caregiver living in the household with the selected child at the time of the survey contact. Interviewers for NSCNC were also trained on the NLNPCG module, with emphasis on how to determine eligibility for that module. A review of each section of the questionnaire was given, and interviewers were trained on collecting high-quality data.

Cooperation-gaining exercises were conducted throughout the training to ensure that interviewers were equipped to answer frequently asked questions (FAQs) and handle refusals. Part of the exercises included a review of the FAQs and other job aids provided for interviewers.

Training also focused on respondent confidentiality. During training, all interviewers viewed a video about NCHS confidentiality practices for federal employees and contractors and signed the NCHS Nondisclosure Affidavit. Interviewers also signed the NCHS Designated Agent Agreement, which designated them as NCHS agents able to access confidential SLAITS information.

#### **Mock Interviews**

Interviewer training utilized multiple screener mock interviews (three for NSCNC and six for NSDATA), including one full questionnaire round-robin mock interview. NSDATA training included conducting one full interview on both the ADHD and TS modules. During the mock interviews, the interviewers practiced navigating the CATI instrument and the cooperation-gaining skills they would need to succeed on the survey. Each mock interview was designed to highlight various sections of the screener and the main questionnaires, and provide different scenarios requiring alternative approaches for gaining cooperation. At the end of training, each interviewer was required to complete and pass a written certification test before being released into production. Table A summarizes the number of interviewers trained and certified for NSCNC by month, and Table B summarizes the number of interviewers trained and certified for NSDATA by month.

Table A. NSCNC interviewers trained and certified, by month, 2013

Month	Total	Total	Percent
	trained	passed	passed
March	10	10	100
May	31	31	100
Total	41	41	100

NOTE: NSCNC is National Survey of Children in Nonparental Care. SOURCE: NCHS, National Survey of Children in Nonparental Care, 2013.

Table B. NSDATA interviewers trained and certified by month, 2014

Month	Total	Total	Percent
	trained	passed	passed
January	6	6	100
February	69	69	100
Total	75	75	100

NOTE: NSDATA is National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome.

SOURCE: NCHS, National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, 2014.

#### **Locator Training**

Multiple interviewers (7 for NSCNC and 15 for NSDATA) were selected to attend an additional training focused primarily on locating eligible survey respondents. Locators were chosen based on having had prior locating experience on other projects at NORC or for prior employers. Locators were informed about locating goals and objectives, as well as how to use the locating case management system and specific free Internet search engines, and how to identify viable leads to locate the NSCH respondent. Locators learned how to transition from finding a respondent to conducting the survey in CATI. Locators also reviewed the locator scripts, job aids, and FAQs designed for contacting leads.

#### **Data Collection**

#### **Pretesting**

Before general data collection began for NSCNC, an extensive pretest of the survey was conducted. The goal of the pretesting was to allow NCHS and NORC to monitor live telephone interviews to determine what changes could be made to improve the questionnaire. As a result of the pretest, several changes were made to the questionnaire, which are outlined in Appendix V. These changes improved questionnaire flow and shortened the overall length of the interview. The net result of this pretest was a decrease in respondent burden and an improved questionnaire instrument for the telephone interviewers.

The NSCNC pretest began April 2, 2013, lasting through April 4, 2013. In total, 68 cases were screened for eligibility, and 53 cases completed the full interview. In the days following the pretest, appointments were honored, and an additional three completed interviews were accomplished before the survey was relaunched, for a total of 56 pretest completes. NSCNC interviews completed during the pretest were included as valid data in the final data file. Some questions were removed or added in response to the pretest, but these modifications did not compromise the validity of the interviews completed in the pretest. Appendix V describes the modifications in detail. Monitoring the pretest resulted in insights into ways to improve the questionnaire for interviewers and respondents while still collecting detailed and accurate data. In addition to monitoring interviews during the pretest, NORC hosted an interviewer debriefing session aimed at gathering feedback from interviewers on how the survey worked in a "live" environment. Feedback from interviewers during this debriefing session assisted NCHS in creating changes to the survey that improved clarity and efficiency for both respondents and interviewers.

The NSDATA soft launch began January 22, 2014. Because of the similarity in follow-back operations between NSCNC and NSDATA and the successful NSCNC pretest, a full pretest of NSDATA was not deemed necessary. The soft launch differs from a pretest in that if no significant problems are detected, data collection continues from the start of the soft launch until the end of data collection. By contrast, the NSCNC pretest had a planned period of cessation of data collection to allow for more extensive analysis of pretest operations and for questionnaire changes. During the 2-day NSDATA soft launch, 53 cases completed an interview—51 completed the ADHD module, and 2 completed both the TS and ADHD modules. In the days following the soft launch, appointments were honored, and an additional three completes were obtained. NSDATA interviews completed during the soft launch were included as valid data in the final data file. Some questions were removed or added in response to the soft launch, but these modifications did not compromise the validity of the interviews completed in the soft launch.

All questionnaire changes following the soft launch consisted of modifying or adding help and interviewer text, or rephrasing questions to further clarify intent to respondents. One question was split into two parts on both the ADHD and TS modules (school type: TS/ADHD\_E1 and TS/ADHD\_E2), and two questions were combined into one on the TS module (TS\_E8I and TS\_E8J). Additional answer choices were provided to ADHD\_A4\_1CA, and respondents were given the opportunity to retrieve medication bottles for questions regarding medication usage if they knew the names of only some medications their child was currently taking. Finally, in some instances, answer choices were reorganized to help interviewers with coding.

#### **Advance Letters**

When a mailing address was available, an advance letter (Appendix VI) describing the nature of the study was mailed to the household. Letters were mailed for 88.3% of eligible NSCNC sample cases and 87.7% of eligible NSDATA sample cases. The letter reminded recipients that they had completed a prior survey about children's health and that additional information about their children's health, well-being, and use of services was desired. A toll-free number was provided for those who wished to participate immediately or learn more about their rights as a respondent.

#### **Toll-free Telephone Number**

A toll-free telephone line established for the survey offered respondents the flexibility to call at their convenience if they had questions about the survey, or wanted to complete the interview or submit feedback on any aspect of the survey. Advance letters, incentive letters, answering-machine scripts, and closing scripts referenced the toll-free number, and interviewers provided that number to respondents who requested such a resource during the interview. Interviewers trained on the survey staffed the telephone line during regular dialing hours; voice mail was available during nonregular dialing hours and was reviewed daily.

#### **Selection of Respondent**

When a household was reached, interviewers asked to speak to the original NSCH respondent, or with a parent, guardian, or caregiver who was currently living with the child. Although it was preferred that the original NSCH respondent complete the survey, this was not a requirement for participation. If the selected child no longer lived with the NSCH respondent, the NSCH respondent was asked to provide contact information for the current caregiver of the selected child and to complete a short module. Attempts were then made to locate the child's current caregiver to complete the interview.

#### **Informed Consent**

After a knowledgeable respondent came to the phone, or after the person who answered the telephone identified him- or herself as a knowledgeable parent or guardian, the respondent was informed of his or her rights as a survey participant. Verbal consent for study participation was then obtained and documented in the CATI system. The consent script informed respondents of the voluntary nature of the survey, assured them that their responses would be kept confidential, and informed them that there was no penalty for not answering questions. Respondents were also told that the interview might be recorded and monitored by a supervisor for quality purposes. The incentive amount was

also provided in the informed consent statement, as well as the estimated duration of the interview.

In accordance with HHS regulations (45 CFR 46), these procedures were reviewed by the NCHS ERB and by NORC at the University of Chicago's IRB.

#### **Assurance of Confidentiality**

Participation in surveys conducted by NCHS is voluntary, and all individually identifiable information collected is confidential. For both surveys, assurance of confidentiality was provided to potential respondents as part of the informed consent procedures. In the CATI system, interviewers read the following statement 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 question you don't wish to answer, or end the interview at any time with no impact on the benefits you may receive. We are required by Federal law to develop and follow strict procedures to protect the confidentiality of your information and use your answers only for statistical research. I can describe these laws if you wish. In appreciation for your time, we will send you [NSCNC: \$10/NSDATA: \$20]. The survey will take about a half hour. In order to review my work, this call will be recorded and my supervisor may listen as I ask the questions. I'd like to continue now unless you have any questions.

If respondents requested to hear more about the federal laws, they were read the following statements:

The Public Health Service Act is Volume 42 of the U.S. Code, Section 242k. The collection of information in this survey is authorized by Section 306 of this Act. Through the National Center for Health Statistics, the confidentiality of your responses is assured by Section 308d of this Act and by the Confidential Information Protection and Statistical Efficiency Act. Would you like me to read the Confidential Information Protection provisions to you?

If respondents indicated that they would like to hear the Confidential Information Protection provisions, the interviewer read the following statement:

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 NCHS employees or agents. By law, every employee of the National Center for Health Statistics, N-O-R-C at the University of Chicago, and their agents and contractors who works on this survey has taken an oath and is subject to a jail term of up to five 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.

If respondents had any additional questions or concerns, they were directed to the project website for more information (https://www.cdc.gov/nchs/slaits.htm) and were provided a toll-free telephone number.

When NCHS (including its contractors and agents) collects personally identifiable information under a pledge of confidentiality for exclusive statistical purposes, Section 308d of the Public Health Service Act and Section 512b of the Confidential Information Protection and Statistical Efficiency Act (CIPSEA) require that confidentiality be maintained without exception. Violations of CIPSEA are a Class E felony, punishable by imprisonment for not more than 5 years, a fine not more than \$250,000, or both. NCHS, its data collection contractors, and other agents follow strict procedures to prevent disclosure of confidential data in survey operations and data dissemination.

#### Interview Length

The average NSCNC interview length was 33 minutes, 53 seconds, and the median time was 32 minutes, 23 seconds. The length of the NSDATA interview varied based on which modules were completed (i.e., ADHD, TS, or both). The average ADHD-only interview length was 37 minutes, 34 seconds, and the median time was 36 minutes, 17 seconds. The average TS-only interview length was 32 minutes, 32 seconds, and the median time was 23 minutes, 39 seconds. Interviews for which both the ADHD and TS modules were completed averaged 49 minutes, 38 seconds, with a median of 48 minutes, 31 seconds.

#### **Interview Breakoffs**

When survey interviews were terminated prior to completion, interviewers attempted to convert the case into a completed interview using refusal conversion strategies commonly used and found to be successful on previous SLAITS projects, such as offering incentives. When an interview could not be fully completed, interviews were defined as being a partial complete if the cases had at least reached the first question in Section 8, "Caregiver Well-Being, Caregiver Physical and Mental Health, and Social Supports" for NSCNC or Section 5, "Symptoms and Performance/Impairment" for NSDATA.

## Case Disposition at Close of Data Collection

#### **NSCNC**

Data collection for NSCNC started April 2, 2013, and ended August 12, 2013, resulting in a total of 1,298 full or partial NSCNC interviews. Partially completed interviews that were complete through the end of the "Child Well-Being, Child Care, and School" section were considered to be full interviews. In addition to full NSCNC interview completes, there were a total of 206 NLNPCG module completes,

11

including 180 households that completed the NLNPCG module and 26 households that both completed the NLNPCG module and provided contact information for the child's current caregiver that enabled an NSCNC interview to also be completed for that household. In all, 1,478 households responded with at least one completed interview, either NSCNC (n=1,272), NLNPCG (n=180), or both (n=26). A total of 1,584 cases were pending (i.e., not a full or partial NSCNC complete) at the end of data collection. The largest group of pending cases comprised those for which a known household was reached but the residency of the child could not be confirmed (16.6% of the initial sample). See Table C for more information about the final dispositions of all sampled NSCNC cases. Table D shows final dispositions for the subset of sampled cases that were eligible for the NLNPCG module.

Table C. Final dispositions of NSCNC sample

Description	Frequency	Percent
Total	2,882	100.0
NSCNC complete	1,290	44.8
NSCNC partial complete	8	0.3
NSCNC complete (full and partial)	1,298	45.1
Known household, child's residency not		
confirmed	479	16.6
No response to all contact attempts	372	12.9
Answering machine	264	9.2
Nonworking phone number	213	7.4
Known eligible child, no interview completed	166	5.7
Ineligible for NSCNC and NLNPCG	63	2.0
Ineligible for NSCNC only	4	0.1
Known household, child found	14	0.5
Nonresidential phone number	13	0.5

NOTE: NSCNC is National Survey of Children in Nonparental Care, and NLNPCG is no longer nonparental caregiver.

SOURCES: NCHS, National Survey of Children in Nonparental Care, 2013, and National Survey of Children's Health, 2011–2012.

Table D. Final disposition of cases eligible for NLNPCG module

Description	Frequency	Percent
Total	2,882	100.0
Not eligible NLNPCG complete, NSCNC incomplete NLNPCG complete, NSCNC complete NLNPCG eligbile but not complete	2,594 180 26 82	90.0 6.2 0.9 2.9

NOTE: NLNPCG is no longer nonparental caregiver, and NSCNC is National Survey of Children in Nonparental Care.

SOURCES: NCHS, National Survey of Children in Nonparental Care, 2013, and National Survey of Children's Health, 2011–2012.

#### **NSDATA**

Data collection for NSDATA started January 22, 2014, and ended June 25, 2014, resulting in a total of 3,018 NSDATA interviews—2,903 ADHD module completes, 42 TS module completes, and 73 that completed both the ADHD and TS modules. The survey module administered depended on the condition reported at NSDATA screening (i.e., respondents could complete the ADHD module, the TS module, or both modules). When both modules were completed, the TS module was administered first. These counts include partially completed interviews, as defined by interview completion through the end of the ADHD Treatment section in the ADHD module, or the TS Treatment section in the TS module.

A total of 3,068 ADHD cases were pending (i.e., not a full or partial complete) at the end of data collection. The largest group of pending cases comprised those ADHD cases for which an answering machine was reached (13.7% of the initial ADHD sample). See Table E for more information about the final dispositions of sampled NSDATA cases in the ADHD sample.

A total of 84 TS cases were pending (i.e., not a full or partial complete) at the end of data collection. The largest group of pending cases also comprised those TS cases for which

Table E. Final dispositions of ADHD sample on public data file

Description	Frequency	Percent
Total	6,034	100.0
Full completed interview <sup>1</sup>	2,945	48.8
Partial completed interview <sup>1</sup>	21	0.3
Completed interviews (full and partial)	2,966	49.1
Eligible respondent, no interview completed	195	3.2
Condition and age eligible, residency ineligible	53	0.9
Condition eligible, age ineligible	209	3.5
Condition ineligible	154	2.6
Condition and age eligible, unknown residency eligibility Condition eligible, unknown age and residency	5	0.1
eligibility	_	-
NSCH respondent found, no interview completed	209	3.5
Deceased	5	0.1
Verified household, unknown if have NSCH respondent	765	12.7
Answering machine	825	13.7
No response to all contact attempts	268	4.4
Nonresidential phone number	17	0.3
Disconnected phone number	363	6.0

<sup>-</sup> Quantity zero.

NOTES: Final dispositions are shown of sampled cases that were eligible for the ADHD module as identified in the National Survey of Children's Health (NSCH) interview. TS sampled cases that screened in the ADHD module of the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, but were not part of the ADHD sample, are excluded from this table (n=10).

SOURCES: NCHS, National Survey of Children's Health, 2011–2012, and National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, 2014.

<sup>&</sup>lt;sup>1</sup>Includes cases that completed both the attention-deficit/hyperactivity disorder (ADHD) and Tourette syndrome (TS) modules.

Table F. Final dispositions of TS sample on data file

Description	Frequency	Percent
Total	162	100.0
Full completed interview <sup>1</sup>	78	48.1
Partial completed interview <sup>1</sup>	_	_
Completed interviews (full and partial)	78	48.1
Eligible respondent, no interview completed	_	_
Condition and age eligible, residency ineligible	_	_
Condition eligible, age ineligible	4	2.5
Condition ineligible	29	17.9
Condition and age eligible, unknown residency eligibility	-	_
Condition eligible, unknown age and residency eligibility	_	_
NSCH respondent found	9	5.6
Deceased	_	_
Verified household, unknown if have NSCH		
respondent	14	8.6
Answering machine	16	9.9
No response to all contact attempts	5	3.1
Nonresidential phone number	_	-
Disconnected phone number	7	4.3

<sup>-</sup> Quantity zero.

NOTES: Final dispositions are shown of sampled cases that were eligible for the TS module as identified in the National Survey of Children's Health (NSCH) interview. ADHD sampled cases that screened in the TS module of the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, but were not part of the TS sample, are excluded from this table. (n = 37).

SOURCES: NCHS, National Survey of Children's Health, 2011–2012, and National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, 2014.

an answering machine was reached (9.9% of the initial TS sample). See Table F for more information about the final dispositions of sampled NSDATA cases in the TS sample.

#### **Response Rates**

Response rates provide one measure of the potential for nonresponse bias—that is, the possibility that the sample interviewed differs from the actual population in some meaningful way. As described earlier, both NSCNC-eligible and NSDATA-eligible respondents were sampled from the 2011–2012 NSCH and then recontacted to conduct the NSCNC or NSDATA interview. Thus, the overall NSCNC or NSDATA response rate can be divided into two components: 1) response from the 2011–2012 NSCH, and 2) response from the follow-up interview for NSCNC or NSDATA.

In the 2011–2012 NSCH, the combined landline and cell-phone sample response rate was 23.0%, while the landline response rate was 38.2% and the cell-phone response rate was 15.5% (9). Table G provides the unweighted and weighted contact rates, interview completion rates, and cumulative response rates for the NSCNC follow-up survey, by sample type. Table H provides the unweighted and weighted contact rates, interview completion rates, and cumulative response rates for the NSDATA follow-up survey, by sample type.

The contact rate was calculated as the number of cases who were contacted divided by the total number of sample cases. The interview completion rate was calculated as the number of cases completing the NSCNC or NSDATA interview

Table G. NSCNC component rates, by sample type

Sample type	Total sample released	Unweighted contact rate	Weighted contact rate	Total sample released, minus ineligible	Unweighted phone interview completion rate	Weighted phone interview completion rate	Unweighted culmulative response rate	Weighted culmulative response rate
		Percent				Perc	ent	
Combined	2,882	70.4	64.0	2,819	74.5	71.2	52.4	45.6
Landline	2,054	70.7	62.1	2,003	75.6	72.5	53.5	45.0
Cell	828	69.4	66.1	816	71.8	69.9	49.9	46.2

NOTE: NSCNC is National Survey of Children in Nonparental Care.

SOURCES: NCHS, National Survey of Children in Nonparental Care, 2013, and National Survey of Children's Health, 2011–2012.

Table H. NSDATA component rates, by sample type

Sample type	Total sample released	Unweighted contact rate	Weighted contact rate	Total sample released, minus ineligible	Unweighted phone interview completion rate	Weighted phone interview completion rate	Unweighted culmulative response rate	Weighted culmulative response rate
		Percent				Percent		
Combined Landline Cell	6,034 3,913 2,121	62.9 63.4 62.1	58.4 60.5 56.4	5,613 3,603 2,010	84.0 84.1 83.8	80.8 83.7 78.1	52.8 53.3 52.0	47.2 50.6 44.0

NOTES: This table includes only cases sampled for attention-deficit/hyperactivity disorder (ADHD). NSDATA is National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome.

SOURCES: NCHS, National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, 2014, and National Survey of Children's Health, 2011–2012.

<sup>&</sup>lt;sup>1</sup>Includes cases that completed both the attention-deficit/hyperactivity disorder (ADHD) and Tourette syndrome (TS) modules.

divided by the total number of contacted cases minus the number of children found to be ineligible (e.g., age of child is at least 18 years) at the time of NSCNC or NSDATA. The cumulative response rate is the response rate. It is calculated by multiplying the contact rate by the interview completion rate.

Calculation of the NSDATA response rate was limited to children who were identified as ever being diagnosed with ADHD in NSCH. Children who were sampled for TS in NSCH were excluded from these calculations due to the small sample size and different weighting scheme. Moreover, this calculation counted only completed interviews from cases sampled for the ADHD module. When cases sampled for ADHD completed only the TS module and not the ADHD module, these were not counted as completed interviews for purposes of response rate calculation. Similarly, cases sampled for TS that went on to complete only the ADHD module after confirming an ADHD diagnosis during NSDATA were excluded from response rate calculation.

The overall response rates, incorporating nonresponse from both NSCH and NSCNC or NSDATA, are derived by multiplying the NSCH rate by the corresponding (landline, cell, or combined) NSCNC or NSDATA rate. Table J displays the NSCNC overall response rates by sample type, while Table K displays the NSDATA overall response rate by sample type.

Table J. NSCNC overall response rates, by sample type

Sample type	Cumulative response rate	NSCH	Overall response rate
Combined	52.4	23.0	12
Landline	53.5	38.2	20
Cell	49.9	15.5	8

NOTES: NSCNC is National Survey of Children in Nonparental Care and NSCH is National Survey of Children's Health. The NSCNC overall response rate is NSCH response rate times NSCNC response rate.

SOURCES: NCHS, National Survey of Children's Health, 2011–2012, and National Survey of Children in Nonparental Care, 2013.

Table K. NSDATA ADHD sample overall response rates, by sample type

Sample type	Cumulative response rate	NSCH	Overall response rate
Combined	47.2	23.0	11
Landline	50.6	38.2	19
Cell	44.0	15.5	7

NOTES: NSDATA is National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, ADHD is attention-deficit/hyperactivity disorder, and NSCH is National Survey of Children's Health. The NSDATA ADHD sample overall response rate is NSCH response rate times NSDATA ADHD sample response rate.

SOURCES: NCHS, National Survey of Children's Health, 2011–2012, and National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, 2014.

#### **Efforts to Maximize Response Rates**

Both surveys included efforts to encourage respondent participation by informing respondents of the importance of the surveys, offering incentives, and allowing respondents to call a toll-free number at their convenience. The toll-free number allowed respondents to participate immediately, ask questions regarding the survey, or obtain additional survey-related information.

Additionally, advance letters, refusal conversion efforts, and translated questionnaires were used to help improve response rates. NCHS worked with data collection contractor NORC to conduct ongoing assessments of the data collection instrument, data collection procedures, and calling rules.

Both surveys also monitored response rates throughout the data collection period. In response to findings of certain nonresponse patterns, both surveys implemented incentive models targeted at these nonresponsive subpopulations. A portion of interviewers were trained refusal converters who attempted to convert nonrespondents by targeting the case-specific source of the refusal based on the case history. More detailed descriptions regarding the incentive models, the process by which cases were offered an incentive, and response rates follow.

#### Incentive Effort for NSCNC

This section explains how token payments, additional refusal conversion incentives, and thank you letters were distributed for NSCNC. Respondent payment distribution is divided into the following three subsections: standard payment, refusal conversion incentives, and token payment refusal cases.

#### Standard payment

Once it was confirmed that interviewers had located the NSCH respondent or another parent or guardian of the sampled child, a \$10 payment was offered to respondents for completing the NSCNC interview. The \$10 offer was also mentioned during informed consent. If it was determined that the sampled child no longer lived with the respondent and the respondent was eligible for the NLNPCG module, a \$10 token payment was also sent upon completion of the module. The \$10 payment was sent in cash and was included with a thank you letter that can be found in Appendix VI.

#### **Refusal conversion incentives**

NSCNC protocols were designed to encourage participation by informing respondents of the survey's importance, offering them a token payment as thanks for their participation, and allowing them to call a toll-free number at their convenience to obtain more information about the survey or participate immediately. However, some respondents still initially refused participation. Beyond the general refusal aversion efforts made by the telephone interviewing staff, NORC employed an additional refusal conversion technique: a \$5

incentive payment. Refusals included cases where either 1) the respondent refused participation twice (soft refusals) or 2) had the equivalent combination of refusals and instances of "hung up during introduction" or HUDI.

In accordance with NORC's standard operating procedure, refusal conversion incentives were not offered to hostile refusals or cases that requested, "take me off the list," or TMOL. Table M reflects the total number of NSCNC cases that became incentive eligible due to refusals. Only 74 of the cases sampled for NSCNC, or 2.5%, became incentive eligible as a result of two refusals. Of these 74 cases, 17.6% went on to complete the NSCNC interview.

Table M. NSCNC incentive-eligible cases

Characteristic	Overall
Total cases sampled for NSCNC	2,882
Number of completed cases Incentive-eligible cases Incentive-eligible cases completed Percentage of incentive-eligible cases completed	1,290 74 13 17.6

NOTES: Incentive-eligible cases are those with two refusals, not including hostile or "take me off the list" refusals. NSCNC is National Survey of Children in Nonparental Care.

SOURCE: NCHS, National Survey of Children in Nonparental Care, 2013.

#### **Special incentive cases**

For NSCNC, a special group of cases fitting a different set of criteria were also considered incentive eligible. This group of cases included those who were not already considered incentive eligible through active refusals and for whom all contact attempts resulted in no contact. In addition, only cases for which addresses were available were identified and sent a refusal conversion letter.

NORC ultimately mailed letters and \$5 incentives to 298 of these special cases. Of the 298 cases, 21.8% fully completed the telephone interview and 3 cases partially completed it.

#### Incentive Effort for NSDATA

Similar to NSCNC, monetary incentives were offered for participation in the NSDATA survey in two ways—a standard incentive offered up front to all sampled cases (\$20), and a refusal conversion incentive sent to households following active refusals and other special situations (\$5). Respondents of children screened as having both ADHD and TS were offered double the standard incentive (\$40) if both interviews were completed. Special situations included cases with an available address that were not already considered incentive eligible through active refusals and for whom all contact attempts resulted in no contact. Letters with a \$5 incentive offering were mailed to 677 cases in this special situation, of which 26.3% (n = 178) fully completed the telephone interview, with 3 cases partially completing the interview.

Table N reflects the total number of NSDATA cases that became incentive eligible due to active refusals. About 16% of the cases sampled for NSDATA became incentive eligible. Of these cases, one-third (n = 340) went on to complete the NSDATA interview.

Table N. NSDATA incentive-eligible cases

Characteristic	Overall
Total cases sampled for NSDATA	6,102
Number of completed cases Incentive-eligible cases Incentive-eligible cases completed Percentage of incentive-eligible cases completed	3,018 1,022 340 33.3

NOTES: Incentive-eligible cases are those with two refusals, not including hostile or "take me off the list" refusals. Completed cases include those that completed the attention-deficit/hyperactivity disorder (ADHD) module only, the Tourette syndrome (TS) module only, and both the ADHD and TS modules.

SOURCE: NCHS, National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, 2014.

#### **Locating Respondents**

Numerous locating tactics were explored as an essential part of data collection due to the follow-up nature of both surveys. Locating efforts consisted of several stages: a) identifying cases that qualified for locating, b) generating leads using Accurint and Internet databases, and c) dialing leads to identify the correct household.

NORC performed various locating activities on the NSCNC sample after first dialing cases through the CATI system. Dialing the cases first allowed interviewers to determine if the number sampled from NSCH continued to be the correct number by which the previous respondent could be contacted. The NSCNC locating effort consisted of first identifying cases for locating, followed by locating activities—categorized into three steps, or tiers—which were conducted until an eligible NSCNC respondent was located, or until the case was deemed unlocatable.

The NSCH sample was approximately 1 year older by the time data collection for NSDATA began. Thus, before locating began, a vendor batch service was used. The vendor, Accurint, attempted to find updated phone numbers for the NSCH respondents. These new phone number leads were then dialed as part of the first step of locating. The NSDATA locating effort consisted of first identifying cases for locating, after which locating activities were conducted until the original NSCH respondent or current caregiver was located, or until the case was deemed unlocatable. For most cases deemed unlocatable, a different locator made a second attempt at locating them.

#### **Identifying Cases Qualified for Locating**

NORC began locating activities 2 weeks into the data collection effort for NSCNC and approximately 1 month into the data collection effort for NSDATA. Initial call attempts yielded a number of cases for which NORC staff were unable to proceed with the original phone number for various reasons:

- The number no longer reached the NSCH respondent or an eligible NSCNC/NSDATA respondent.
- The number was nonworking.
- The number was working but no contact was made.

**NSCNC**—Of the 2,882 cases sampled for NSCNC, 1,146 were identified as requiring locating activities (39.8%). Of these cases, an eligible NSCNC respondent was located for 542 cases, or 47.3% of the cases sent to locating. Of the cases located, 156 went on to complete the full NSCNC interview (28.8%).

**NSDATA**—Of the 6,102 cases sampled for NSDATA, 2,957 were identified for locating (48.5%). Of these cases, an eligible NSDATA respondent was located for 1,977 cases, or 66.9% of the cases sent to locating. Of the cases located, 703 went on to complete the full NSDATA interview (35.6%).

#### **Accurint Database Searches**

If a respondent was not located through the free Internet search sites, the case was then moved into the Accurint locating queue. Accurint is a locating vendor that maintains a database of public records. Specially trained NORC employees with knowledge of Accurint would conduct a search for the NSCH respondent or other eligible NSCNC or NSDATA respondent. The method of searching was very similar to that of the free websites and included:

- First and last name with address.
- First initial and last name in a specific city and state.
- Last name in a specific city and state.
- Reverse telephone number search.
- Reverse address search.

Throughout the locating process, trained supervisors reviewed pending cases for completeness in search protocols. If all required searches were not completed and the case was identified as unlocatable, the case was sent for further work with instructions from the supervisor. If all protocols were followed and no further leads could be identified, indicating that the NSCH respondent could not be found, the case was finalized as unlocatable. Only a supervisor had permission to finalize a case in this manner. Of the 1,146 NSCNC cases sent to locating, 604 were considered unlocatable at the close of data collection (52.7%). Of the 2,957 NSDATA cases sent to locating, 980 were considered unlocatable at the close of data collection (33.1%).

#### **Locating Protocol**

Cases being located were updated based on phone number information returned from the locating batch services. Those cases were then delivered to the telephone interviewers and dialed. Appropriate status codes were assigned to each case upon dialing.

While dialing leads, locators used one of the following introductions:

"Hello. My name is \_\_\_\_\_\_, and I'm calling from

NORC at the University of Chicago. I'm trying to locate [NSCH respondent]. Does [he/she] live here?"

or

"Hello. My name is \_\_\_\_\_\_\_\_, and I'm calling from NORC at the University of Chicago. We are conducting an important follow-up survey on children's health and would like to speak with [NSCH respondent]."

If the NSCH respondent name was not known, the locator filled [NSCH respondent] with the relationship of the respondent to the child along with the age and sex of the NSCH child.

After the introduction, locators followed a process that guided them through the different scenarios encountered during locating:

- If the respondent was confirmed and available, the locator immediately attempted to complete the interview.
- Appointments were scheduled to call back households that were confirmed to be the target household but the respondent was unavailable.
- If the respondent did not live in the household but the informant knew the respondent, locators probed to obtain new address and phone information.

If the informant refused to give out the information, the locator left the project's toll-free number and asked that it be passed along to the respondent. Throughout location efforts, locators were careful not to mention sensitive information such as adoption (NSCNC) or mental health conditions (NSDATA) until the respondent was confirmed as the appropriate respondent. This was done to prevent the accidental disclosure of information to any person in the household unaware of such information.

#### **Quality Control**

#### **Quality Control of Interviewing**

Telephone center supervisors were available to the interviewing staff at all times to resolve any questions or concerns about a case. Supervisors regularly observed the data collection process to monitor interviewers informally. In addition, supervisory staff used remote telephone- and computer-monitoring technology to evaluate whether

interviewers performed according to project specifications. This formal monitoring was conducted to ensure that: introductory materials were properly read, item wording and sequence of the questionnaire were followed correctly, respondent questions were answered properly, and any vague responses were properly probed. Computer monitoring also allowed supervisors to determine whether answers were entered accurately into the CATI system.

To avoid bias in selecting whom to monitor, the CATI monitoring system automatically selected which interviewers to monitor and gave newly trained interviewers, those with the fewest monitoring sessions, and those with the weakest performance reviews the highest priority for selection. Experienced interviewers were prioritized for monitoring based on the length of time since their last monitoring session and recent monitoring scores. Each interviewer was typically monitored at least once a week; however, some were monitored more often.

#### **Data Quality Control**

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

#### **Data Files**

Because the structure of the data files and the ability to link public-use files to the public-use NSCH file differ between NSCNC and NSDATA, the data files for the two surveys are described separately. Certain aspects of the data files that do not differ between NSCNC and NSDATA are described first, followed by NSCNC specifics and then NSDATA specifics.

#### **Editing**

The CATI system used for both NSCNC and NSDATA was designed to perform edits as an interviewer enters data into the computer system. To prevent interview error, the CATI system was developed to include range checks and consistency checks. If an interviewer entered a value that was "out of range," a warning screen would appear, instructing the interviewer that the data would not be accepted and that he or she would have to enter a different answer (and possibly re-ask the question). As a result, the CATI system helped to correct respondent error during the interview (e.g., a respondent saying two children lived in the household but providing only one child's age) and to identify and correct data-entry error by interviewers (e.g.,

a child being reported to have seen a doctor 4 times in the past year, but the interviewer attempting to enter 444 times). To the extent possible without making the CATI system overly complicated, out-of-range and inconsistent responses resulted in a warning screen for the benefit of the interviewer, who was trained to correct errors as they occurred. These messages were designed primarily to prevent data entry errors and respondent errors and not to challenge respondents who gave logically inconsistent responses. Logically inconsistent responses given by the respondent were left inconsistent.

Variables in the public data sets with an "R" appended to the variable name indicate that some kind of additional editing has occurred between data collection and data release, such as collapsing or top-coding of categories. New variables derived from other variables were given new variable names. Specific variables of these types (i.e., variables that do not appear in the questionnaires) are listed in the survey-specific sections that follow.

# Coding of Verbatim Answers Into Question Responses

For some questions in the NSCNC or NSDATA interviews, respondents occasionally provided a response that did not match any predetermined answer category. If this occurred, the interviewer chose "other" and typed in the exact response provided by the respondent. At the end of the data collection period, an attempt was made to recode the verbatim responses into existing response categories where appropriate. When necessary, new response categories were added to the data file to capture the verbatim responses. However, when a verbatim response was unique (i.e., did not match any existing response category or other verbatim response), the response remained coded as "other." Both the original verbatim response and the original response to the root question were maintained in the raw variables. Variables in the public-use data files include the back-coded responses.

Specific variables that received this back-coding are listed in the survey-specific sections that follow.

#### **Missing Data**

Missing data are not desirable when doing analyses and are often ignored completely. However, it can be very helpful to know why data are missing. The SAS data files for NSCNC and NSDATA include special missing value codes for analysts who may wish to differentiate between different types of missing values. The following key provides a description of the various codes that were used to represent missing data in the file.

**(.L) Legitimate skip**—Variable is missing due to valid questionnaire paths based on a previous answer to a root

question. Legitimate skip coding applies to all cases, even those that partially completed the interview.

**(.P) Partially completed interview**—Variable is missing because the respondent ended the call after completing the Child Well-Being, Child Care, and School section (for NSCNC) or the Treatment section (for NSDATA) but before completing the full interview.

**(.M) Missing in error**— Variable is missing due to interviewer or system errors. In cases of interviewer error, the interviewer may have deleted the data by accident or never entered the response. In cases of system error, the data may not have been collected or saved properly after the interviewer entered it in the CATI system.

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

Data missing because the respondent did not know the answer or refused to provide the answer have been treated differently. Rather than assigning a missing value to these records, a numeric code was used to identify these responses. Typically, unknown answers are coded as "6," "96," or "996." Refused responses are coded as "7," "97," or "997." However, the codes may be different for specific variables; therefore, analysts are encouraged to consult the data documentation and frequency lists to identify the correct codes for each variable. Failure to do so may result in inappropriate calculations, especially for variables measured using ordinal, interval, or ratio scales.

#### Edits to Protect Confidentiality

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

The specific steps taken to protect confidentiality in the NSCNC and NSDATA public data files are described in the following survey-specific sections.

#### **Data Files—NSCNC**

The NSCNC public-use Interview File contains data for all households that completed an NSCNC interview during a

5-month data collection period from April through August 2013. A total of 1,298 records are contained in the Interview File

In addition to the Interview File, two other public-use files are available: 1) a Screener File containing information on all 1,778 households that were recontacted and for which the child's then-current status (living with the same caregiver or not) was determined, and 2) an NLNPCG module file, containing data from a special short module of questions that were asked when it was determined that the child no longer lived with the NSCH caregiver. These files and the overlap between them are detailed below.

A total of 1,778 households were contacted, and it was determined whether the child still lived with the NSCH caregiver. The Screener File containing records for these households can be used to estimate the prevalence of children in nonparental care remaining in that care 1–2 years later. It also can be stratified by demographic variables from NSCH that have been appended to the data records, such as the age, sex, and race and ethnicity of the child, and household income relative to poverty level.

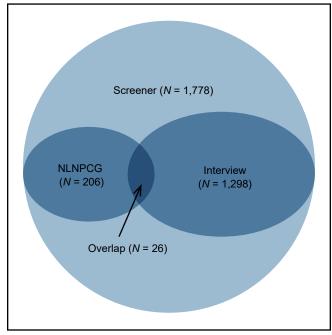
For those recontacted cases reporting that the child no longer lived in the NSCH caregiver's household, the NLNPCG module was administered with the original caregiver, and then attempts were made to reach the child's new caregiver's household to complete the full NSCNC detailed interview. Of the 1,778 screener records, 206 households completed the NLNPCG module. The NLNPCG File contains data from the NLNPCG module questions, plus the demographic variables from NSCH that were appended to the NLNPCG Screener File. This file can be used to analyze characteristics of entry into and exit from nonparental care.

Regardless of whether the child still lived with the original caregiver, an attempt was made to complete the detailed NSCNC interview with the current caregiver. The 1,298 records in the Interview File are a subset of the 1,778 screener records. For 26 of the 206 NLNPCG module cases, the new caregiver was contacted and the NSCNC interview was completed. The remaining 1,272 interview cases consisted exclusively of children still living with the NSCH caregiver.

Figure 2 shows the overlap of these files graphically (not to scale). The Screener File and Interview File are available for download at the NCHS website (https://www.cdc.gov/nchs/slaits/nscnc.htm). Because of the small sample size and resulting limited analytic utility of the NLNPCG File, it is being made available only under a data use agreement upon request (contact slaits@cdc.gov to request this file).

Because of the existence of administrative records of children in foster care, it was not desirable to release the state identifier on the public NSCNC data files. Because the state identifier is included on the public NSCH data file, it was necessary to release public NSCNC files that cannot be linked back to the public NSCH file by suppressing, perturbing, or

Figure 2. Venn diagram showing overlap of NSCNC Screener File, NLNPCG module file, and Interview File



NOTE: NSCNC is National Survey of Children in Nonparental Care, and NLNPCG is no longer nonparental caregiver. SOURCE: NCHS, National Survey of Children in Nonparental Care, 2013.

masking NSCNC data elements that could be matched to corresponding NSCH data elements. Analysts interested in using the raw, unperturbed NSCNC data, or linked NSCH and NSCNC data, are encouraged to submit a proposal to access nonpublic data via the NCHS Research Data Center (RDC) at: https://www.cdc.gov/rdc/index.htm.

State is a sample design variable indicating sampling strata within the landline and cell-phone sampling frames; thus, it was necessary to design a collapsed stratum identifier for the public files. The original strata included 102 levels (50 states and Washington, D.C., with landline and cell-phone samples for each). These 102 levels were rank-ordered by average sampling weight and then collapsed to 20 levels with 5 or 6 original strata per collapsed stratum. Collapsing strata with similar average sampling weights results in a design structure not much different from the original uncollapsed structure.

The resulting collapsed stratum variable COL\_STRATA should be used for analyses of NSCNC public data. The primary sampling unit (PSU) identifier is NSCNCHH S for analyses of the Screener or NLNPCG Files, and NSCNCHH I for analyses of the Interview File.

#### **Coding of Verbatim Answers Into Question** Responses

Variables that included an "other-specify" verbatim response were examined on a record-by-record basis to determine if any verbatim responses could be backfilled into existing response categories, as variant versions of those same responses, or if enough verbatim responses of certain types existed to support creating new categories, which could be filled with these responses. ASPE, NCHS, and NORC staff worked together to make these decisions. NSCNC variables requiring back-coding are shown in Table O. Public-use variables based on these variables include the back-coded responses and new categories, if applicable. Analysts interested in working with the original, raw data before back-coding and new-response category coding are encouraged to submit a proposal to access nonpublic data via NCHS RDC at: https://www.cdc.gov/rdc/index.htm.

#### **Edits to Protect Confidentiality**

Edits made to protect the confidentiality of the NSCNC respondents are described in the following sections.

#### Geography

No geographic identifiers exist on the NSCNC public files. Although the state identifier is included in the NSCH publicuse file, NSCNC public data cannot be linked to NSCH public data.

#### Race

The child's race and ethnicity is included on the NSCNC public files, but race and ethnicity of the child's (absent) mother, the child's (absent) father, and the NSCNC respondent have been suppressed. For most cases, the child's parents' and caregiver's race and ethnicity would match those of the child; for the remaining cases, including such detail could reveal rare and observable combinations of races or ethnicities or both. Thus, variables P2, P3, P19, P20, D3, and D4 have been deleted from the public NSCNC Interview File. Furthermore, the child's race and ethnicity are restricted to four categories for public data: Hispanic, non-Hispanic white only, non-Hispanic black only, and non-Hispanic other (includes multiple races).

#### **Top-coded variables**

The following variables were top-coded to mask extreme values:

H1R: H1 top-coded: Number of adults in the household (topcoded to three or more).

H2R: H2 top-coded: Number of children in the household (four or more).

H14 RCM: H14 standardized to months since and top-coded: Time since child began living with caregiver (120 months or

L5R: L5 top-coded: Number of child's biological siblings (four or more).

Table O. NSCNC variables requiring back-coding

Variable	Question text		
NSCNC interview variables			
C7	Who do you think [S.C.] will live with after you?		
C10	What discouraged you from seeking custody or guardianship of [S.C.] or prevented you from making such a plan?		
C13	What discouraged you from wanting to adopt [S.C.] or prevented you from making such a plan?		
D9 and D10	What is your/[spouse's/partner's] current employment status?		
F5	From whom do you receive payments?		
F7	Why didn't you receive Temporary Assistance for Needy Families (TANF), that is, welfare payments, for [S.C.]?		
H9_1 and H9_2	What is your/[spouse's/partner's] relationship to [S.C.]?		
L1_1	Just before coming to live with you, where did [S.C.] live?		
L4	When [S.C.] was not living with you for a month or more, did [he/she] ever spend time living with [his/her] mother, [his/her] father, [his/her] grandparent(s), an aunt or uncle, other relatives, a foster home, a group home, or a residential treatment center or hospital?		
P5 and P23	Why [doesn't/didn't] [S.C.] live with [his/her] [mother/father] [now/previously]?		
P6	Why didn't [S.C.] live with [his/her] mother originally?		
P24	Why didn't [S.C.] live with [his/her] father originally?		
D4	Respondent's race		
S2_1	Is that health insurance provided through your current employer, former employer, union, Medicare, Medicaid, or some other source?		
NLNPCG module variables			
N2	What is the reason [S.C.] is no longer living with you?		
N3	With whom did [S.C.] live immediately after leaving your household?		
N_L1_1	Just before coming to live with you, where did [S.C.] live?		
 N_P5	When you were caring for [S.C.] and [S.C.] was living with you, why didn't [he/she] live with [his/her] mother?		
N_P23	When you were caring for [S.C.] and [S.C.] was living with you, why didn't [he/she] live with [his/her] father?		

NOTES: S.C. is sampled child's name. NSCNC is National Survey of Children in Nonparental Care. NLNPCG is no longer nonparental caregiver.

SOURCE: NCHS, National Survey of Children in Nonparental Care, 2013.

L6R: L6 top-coded: Number of siblings now living with current caregiver (three or more).

C6R: C6 top-coded: How long caregiver thinks child will live with caregiver (120 months or more).

N1R (NLNPCG Module): Number of months since child stopped living with caregiver (13 or more).

#### **Collapsed variables**

The following variables have been collapsed to coarsen the data:

AGE\_CNCR: Age at time of NSCNC in single years has been collapsed to eight categories: 1–3, 4–5, 6–7, 8–9, 10–11, 12–13, 14–15, and 16–17.

H6R: H6 collapsed: Caregiver's marital status was collapsed such that widowed, divorced, and separated are grouped as "formerly married."

D1R: D1 collapsed: Respondent's birth year was collapsed into the following categories: before 1940, 1940–1944, 1945–1949, 1950–1954, 1955–1959, 1960–1964, 1965–1969, and 1970 and beyond.

D2R: D2 collapsed: Respondent's spouse's birth year (same categories as D1R).

P4R: P4 collapsed: Mother's educational attainment has been collapsed to less than high school, high school or equivalent, and more than high school.

P21R: P21 collapsed: Father's educational attainment has been collapsed to less than high school, high school or equivalent, and more than high school.

H13R: H13 collapsed: Categories 3, 4, 5, and 6 have been collapsed into new category 3 "other."

#### **Combined pretest variables**

The 56 pretest cases were retained in the final data file. Because of the potential disclosure risk posed by knowledge of the date of interview, and the narrow date range for pretest interviews, the status of pretest case compared with nonpretest case is suppressed in the public data. Releasing variables in pretest format, or releasing final variables with pretest cases missing, might reveal which cases are pretest cases. Some variable pairs in the pretest questionnaire were replaced with single questions in the final questionnaire, and pretest cases were coded to the new variables based on responses to the original question pairs, as described in Appendix V.

L7R: L7 for nonpretest cases; combination of pretest versions of L7 and L8 for pretest cases.

P9R: P9 for nonpretest cases; combination of pretest versions of P9 and P10 for pretest cases.

P11R: P11 for nonpretest cases; combination of pretest versions of P11 and P12 for pretest cases.

P27R: P27 for nonpretest cases; combination of pretest versions of P27 and P28 for pretest cases.

P29R: P29 for nonpretest cases; combination of pretest versions of P29 and P30 for pretest cases.

P36R: P36 for nonpretest cases; combination of pretest versions of P13 and P31 for pretest cases.

DEPRESSED: This derived variable is based on the Kessler K6 scale of serious psychological distress (16,17) for the 56 pretest cases and on the Patient Health Questionnaire—2 (PHQ—2) depression scale (18) for the remaining NSCNC interview cases (Appendix V).

#### **Deleted variables**

The following variables have been deleted from the public NSCNC data files in their original form due to disclosure risk. In some instances, a coarsened, top-coded, or otherwise perturbed formatted variable was created to take its place, while others were deleted entirely. Analysts interested in using these suppressed variables should contact NCHS RDC (https://www.cdc.gov/rdc/index.htm) for more information on how to access nonpublic NCHS data.

H4: This variable captures whether the child was living with a parent at time of NSCNC, either via reunification with a biological parent or adoption by a nonparental caregiver; it is represented in the public-use file by derived variable PARENT.

H5: This variable captures whether the parent respondent was the mother or father.

H9\_1: This variable captures the relationship of the respondent to the child (information from H9\_1 was used to derive CAREGIVER CNC).

H9\_2: This variable captures the relationship of the respondent's spouse to the child (information from H9\_2 was used to derive CAREGIVER\_CNC).

N5: This variable, which was asked only if the respondent was the father of the child, asked where the child's mother lived.

N6: This variable, which was asked only if the respondent was the mother of the child, asked where the child's father lived.

L4X06: This dummy variable response category indicated that children who lived apart from the caregiver temporarily were living in a foster home.

P5X02: This dummy variable response category indicated that the child didn't live with the mother because she had been detained or deported for immigration violations.

P5X13: This dummy variable response category indicated that the child didn't live with the mother because she had died.

P23X02: This dummy variable response category indicated that the child didn't live with the father because he had been detained or deported for immigration violations.

P23X13: This dummy variable response category indicated that the child didn't live with the father because he had died.

C13X05: This dummy variable response category indicated that the respondent did not adopt the child because the child's race and ethnicity differed from that of the respondent's family.

R13NEW\_1-R13NEW\_2: These are the PHQ-2 items used to code derived variable DEPRESSED for nonpretest cases. DEPRESSED is included in the public NSCNC Interview File.

S4: This variable confirmed the response to the previous question that the child did not have health insurance coverage.

S18 through S23: These questions captured the total income of the household, or whether the total income was above or below certain thresholds, and is represented in the public data by the derived variable POVLEVEL1 5.

D1: This variable captured the year of the respondent's birth and is represented in the public data by the collapsed variable D1R.

D2: This variable captured the year of the respondent's spouse's birth and is represented in the public data by the collapsed variable D2R.

D3: This variable indicates whether the respondent is of Hispanic ethnicity.

D4: This variable indicates the respondent's race.

D11: This variable indicates the respondent's education level and is represented in the public data by derived variable HIGHEDUC.

D12: This variable indicates the respondent's spouse's education level and is represented in the public data by derived variable HIGHEDUC.

D13: This variable indicates whether the respondent was born in the United States.

D14: This variable indicates whether the respondent's spouse was born in the United States.

PRETEST: This derived variable indicates which cases were pretest cases.

RTYPE: This derived variable indicates the type of respondent (i.e., NSCH respondent, child's parent, or not the NSCH respondent but a nonparental caregiver). This variable is derived from information collected during screening and item H4.

LAG\_CNC: This derived variable indicates the number of days between completion of the NSCH interview and completion of the NSCNC interview.

LAG\_NLN: This derived variable indicates the number of days between NSCH completion and NLNPCG completion.

LAG\_NLNSTATUS: This derived variable indicates the number of days between the NSCH interview and when the NLNPCG status was determined.

Note: All pretest-version variables that were deleted for the final questionnaire are available in nonpublic data files for the 56 pretest cases, but they have been dropped from the public NSCNC data files.

#### **Derived Variables**

Derived variables that were deleted from the public NSCNC data files are listed above in the "Deleted variables" section and not listed here again. Derived variables included in the public data files follow:

DEPRESSED: This variable is based on the Kessler K6 scale of serious psychological distress (16,17) for the 56 pretest cases and on the PHQ–2 depression scale (18) for the remaining NSCNC interview cases (Appendix V).

HISP\_RACER: This variable is based on NSCH variables HISPANIC and RACER and includes codes for Hispanic, non-Hispanic white only, non-Hispanic black only, and non-Hispanic other (includes multiple races).

SEX: This variable is based on NSCH variable K1Q01 and includes codes for male and female.

PARENT: This derived variable indicates whether a parent currently lived in the household at NSCNC interview and whether the respondent was the parent. This variable is derived from items H4, P5X15, and P23X15.

H14\_RCM: This variable combines responses from H14\_MDY, H14\_1, and H14\_2, and standardizes all responses to months, top-coded to 120 months or more.

POVLEVEL1\_5: This variable combines responses from S18 through S23 with information on the number of people in the household to derive household poverty level based on HHS poverty guidelines (Appendix VII).

HIGHEDUC: This variable combines responses from D11 and D12 to code the highest educational level in the household (respondent or respondent's spouse, whichever is highest).

TYPEINS: This variable combines responses from S3\_1 and S5 to indicate type of insurance, using three categories: public, nonpublic, and uninsured.

#### **Dummy Variables**

Variables that allowed for multiple responses needed a separate dummy variable for each response to capture the full response. The following variables are represented in the public NSCNC data file by dummy variables as shown in the following list.

L4: Responses are represented by dummy variables L4X01, L4X02, L4X03, L4X04, L4X05, L4X07, L4X08, and L4X09.

P5: Responses are represented by dummy variables P5X01, P5X03, P5X04, P5X05, P5X06, P5X07, P5X08, P5X09, P5X10, P5X11, P5X12, P5X14, and P5X15.

P6: Responses are represented by dummy variables P6X01, P6X02, P6X03, P6X04, P6X05, P6X06, P6X07, P6X08, P6X09, P6X10, P6X11, P6X12, P5X13, and P5X14.

P23: Responses are represented by dummy variables P23X01, P23X03, P23X04, P23X05, P23X06, P23X07, P23X08, P23X09, P23X10, P23X11, P23X12, P23X14, and P23X15.

P24: Responses are represented by dummy variables P24X01, P24X02, P24X03, P24X04, P24X05, P24X06, P24X07, P24X08, P24X09, P24X10, P24X11, P24X12, and P24X13.

F1: Responses are represented by dummy variables F1X01, F1X02, F1X03, and F1X04.

F5: Responses are represented by dummy variables F5X01, F5X02, F5X03, F5X04, F5X05, F5X06, F5X07, and F5X08.

F12: Responses are represented by dummy variables F12X01, F12X02, F12X03, and F12X04.

F7: Responses are represented by dummy variables F7X01, F7X02, F7X03, F7X04, F7X05, F7X06, and F7X07.

C7: Responses are represented by dummy variables C7X01, C7X02, C7X03, C7X04, C7X05, C7X06, C7X07, C7X08, and C7X09.

C10: Responses are represented by dummy variables C10X01, C10X02, C10X03, C10X04, C10X05, C10X06, C10X07, C10X08, C10X09, C10X10, C10X11, and C10X12.

C13: Responses are represented by dummy variables C13X01, C13X02, C13X03, C13X04, C13X06, C13X07, C13X08, C13X09, C13X10, C13X11, C13X12, and C13X13.

WB4: Responses are represented by dummy variables WB4X01, WB4X02, WB4X03, WB4X04, WB4X05, WB4X06, WB4X07, WB4X08, WB4X09, WB4X10, WB4X11, and WB4X12.

S8: Responses are represented by dummy variables S8X01, S8X02, S8X03, S8X04, S8X05, S8X06, S8X07, S8X08, S8X09, S8X10, S8X11, S8X12, S8X13, and S8X14.

S2\_1: Responses are represented by dummy variables S2\_1X01, S2\_1X02, S2\_1X03, S2\_1X04, S2\_1X05, and S2\_1X06.

#### **Additional Data Notes**

Cleaning of the variable that identifies whether a parent currently lives in the household with the child (H4) resulted in the need to set a number of variables in various sections (where applicable) to missing in error, because this variable drives skip logic throughout the instrument.

22

- 1. A system error in the instrument during early production resulted in 56 cases skipping H18 in error when H4 = 2.
- Two instrument skip logic errors affected cases that reported the selected child's mother or father as deceased in the "Parents: Characteristics and Interaction With Child" section of the survey. Details surrounding the skip errors, along with the resulting data loss, are:
  - For cases that reported the mother to be deceased (or don't know/refused) at P1\_1 (P1\_1 = 2, 6, 7), the instrument progressed directly to P18, incorrectly skipping over P6. As a result, 104 cases are missing a value at P6 in error.
  - The second skip logic error involved cases that reported the father to be deceased at P18 (P18 = 2)—such cases should then receive P21 and P22, and then skip to P24. A total of 33 cases skipped directly to P25, and P24 was set to .M.

#### Data Files—NSDATA

The data files for NSDATA are constructed from the ADHD and TS modules. Data from 2,966 households where the ADHD module was completed were released publicly with some variables suppressed, coarsened, or otherwise perturbed but with most of the ADHD module variables included, as well as a few demographic characteristics measured at NSCH appended to the data records and linkable to the public NSCH file. This public file, unlike NSCNC, does not convey heightened disclosure risk due to including the state identifier and, therefore, can be linked back to the public NSCH file, enabling analysis of public NSDATA records with NSCH variables appended.

Data from the 115 households where the TS module was completed, however, did not receive the same treatment. Because TS is a much rarer and more observable condition than ADHD, the disclosure risk for a similar public file for the TS module would have been much higher than for the ADHD module, especially given that NSCH includes the state identifier on the public file. Thus, analysis of the TS module data can occur only through NCHS RDC.

Because no data have ever been available on a national sample regarding the diagnosis and treatment of TS, researchers interested in analyzing the TS data in RDC have very little prior research to guide their analysis plans. Recognizing that the lack of a public TS file could discourage researchers seeking to estimate a proposed project's feasibility, a pre-RDC file has been prepared that is available under a Data Use Agreement (see https://www.cdc.gov/nchs/data/slaits/TS\_DUF\_Agreement.pdf) to researchers who plan to analyze the TS sample in RDC. The pre-RDC file has been perturbed and stripped of all potentially identifying variables, including geography, child sex, age, race, ethnicity, household structure, income, sample design

variables, and any variables that could be used to match to variables in NSCH. With this file, potential analysts can check frequency distributions on outcome variables of interest to determine if their project is feasible prior to submitting an RDC proposal. Users interested in accessing the pre-RDC file must first complete and sign the Data Use Agreement, which describes the specific protections in place that meet NCHS confidentiality standards for data users. Each data user who will have direct access to the pre-RDC file must sign the agreement.

# **Coding of Verbatim Answers Into Question Responses**

Variables that included an "other-specify" verbatim response were examined on a record-by-record basis to determine if any verbatim responses could be backfilled into existing response categories (as variant versions of those same responses), or if there were enough verbatim responses of certain types to support creating new categories that could be filled with these responses. NCBDDD, NCHS, and NORC staff worked together to make these decisions. NSDATA variables requiring back-coding are shown in Tables P (for variables in the ADHD public file) and Q (for variables in the TS Pre-RDC file). Public-use variables based on these variables include back-coded responses and new categories, if applicable. Analysts interested in working with the original, raw data before back-coding and new response-category coding are encouraged to submit a proposal to access nonpublic data via NCHS RDC at: https://www.cdc.gov/rdc/index.htm.

#### **Edits to Protect Confidentiality**

Edits made to protect the confidentiality of NSDATA respondents are described in the following sections.

#### Geography

The state identifier is included in the NSDATA public files as a sample design variable indicating the sampling strata within landline and cell-phone sampling frames. Because the state identifier is also included on the NSCH 2011–2012 public-use data files, and the NSDATA public file is linkable to the NSCH public file, suppressing the state identifier in the NSDATA public file was unnecessary. No other geographic identifiers appear in the public NSDATA file.

Note that although the state identifier is included on the NSDATA public file due to its utility as a sample design variable, the file is not representative at the state level, and analysts should not use the file to prepare state-specific estimates. The weights have been calibrated to be representative at the national level only.

#### Race and ethnicity

The NSDATA questionnaire did not include new questions on race and ethnicity. Rather, the original NSCH variables were

Table P. NSDATA ADHD module variables requiring back-coding

Variable	Question text		
ADHD_A1_1_NEW ADHD_A1_3_NEW ADHD_A2_1E ADHD_A4_1CA ADHD_A4_1D ADHD_C1_9_NEW ADHD_C1_5L ADHD_C3_8_VA ADHD_C3_8_VB	What type of doctor or other health provider FIRST told you that [S.C] had ADHD? Who else diagnosed [S.C.] with ADHD? What other health care professionals were involved in conducting [S.C]'s ADHD assessment? What was [S.C.]'s ADHD diagnosis changed to? Is there another reason you think [S.C.] no longer has ADHD? What type of doctor or other health care provider currently manages [S.C.]'s ADHD medication? Due to ADHD medication, what other side effects has [S.C.] experienced? What other treatment has [S.C.] received? What other treatment has [S.C.] received?		
ADHD_C3_8_VC ADHD_C4_2AA ADHD_C4_2BA ADHD_C4_2CA	What other treatment has [S.C.] received? Why was [S.C.] unable to get medication? Why couldn't [S.C.] get school-based behavioral treatment, intervention, or accommodation? Why couldn't [S.C.] get behavioral treatment based outside of school?		

NOTE: NSDATA is National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, ADHD is attention-deficit/hyperactivity disorder, and S.C. is sampled child's name.

SOURCE: NCHS, National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, 2014.

Table Q. NSDATA TS module variables requiring back-coding

Variable	Question text
TS_A1_1_NEW TS_C1_5L TS_C4_2BA	What type of doctor or other health provider FIRST told you that [S.C] had TS? Due to TS medication, what other side effects has [S.C.] experienced? Why couldn't [S.C.] get comprehensive behavioral intervention?

NOTE: NSDATA is National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, TS is Tourette syndrome, and S.C. is sampled child's name.

SOURCE: NCHS, National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, 2014.

appended to the NSDATA records. Although NSCH asked about race categories including Asian, American Indian or Alaska Native, and Native Hawaiian or Pacific Islander, as well as detail on specific combinations of multiple races, a child's race and ethnicity in NSDATA is restricted to three categories for the public data: white, black, or other. Whether the child was of Hispanic or Latino origin is also included in the public data file.

# Top-coded, bottom-coded, and collapsed variables

The following variables were top-coded to mask extreme values. The value of the highest code is given in parentheses:

ADHD\_A1\_AGE\_STD: Age child was diagnosed with ADHD (age 14 years and over).

ADHD\_A1\_4\_AGE\_STD: Age of concern about child's behavior, attention, or performance (age 13 and over).

ADHD\_C1\_2\_STD: Age child started ADHD medication (age 15 and over).

ADHD\_C1\_7: Number of non-ADHD medications for emotions, concentration, or behaviors (4 or more).

ADHD\_C1\_8: Times child saw health care provider about medication management (13 or more).

ADHD\_H1\_Q01: Number of people living in the household (6 or more).

TS\_A1\_2: Number of doctors seen before child was diagnosed with Tourette syndrome (5 or more).

TS\_A1\_4\_AGE\_STD: Age when someone first noticed child's tics (age 12 and over).

TS\_A1\_5D\_STD: Age when family asked a doctor for help with child's tics (age 12 and over).

TS\_A2\_6\_STD: Age when Tourette syndrome was at its worst (age 12 and over).

TS\_C1\_2\_STD: Age child first started taking medication for Tourette syndrome (age 12 and over).

The following variables were bottom-coded to mask extreme values. The value of the lowest code is given in parentheses:

ADHD\_A1\_AGE\_STD: Age child was diagnosed with ADHD (age 1 year and under).

ADHD\_C1\_2\_STD: Age child started ADHD medication (age 2 years and under).

TS\_A1\_4\_AGE\_STD: Age when someone first noticed child's tics (age 1 year and under).

TS\_A1\_5D\_STD: Age when family asked a doctor for help with child's tics (age 1 year and under).

The following variables were collapsed to mask extreme values. The values of the collapsed categories are given in parentheses:

AGE\_NSDATAR: Age at time of NSDATA interview (age 7 and under, 8–9, 10–11, 12–13, 14–15, and 16–17).

ADHD\_C2\_1: Number of days in recent school week child took medication for ADHD (1–2 days).

#### **Deleted variables**

The following variables have been deleted from the public ADHD data file in their original form due to disclosure risk. Analysts interested in using these suppressed variables should contact NCHS RDC for more information on how to access nonpublic NCHS data (see https://www.cdc.gov/rdc/index.htm).

ADHD\_B1\_1\_12, ADHD\_B1\_1\_14, and ADHD\_B1\_1\_15: These three variables capture whether the child had ever been diagnosed with intermittent explosive disorder, an eating disorder (e.g., anorexia or bulimia), or a substance use disorder. Children with any of these conditions are captured in the derived variable ADHD\_B1\_1\_16 (see the following "Derived Variables" section for more information about this and any other referenced derived variables).

ADHD\_B1\_2\_12, ADHD\_B1\_2\_14, and ADHD\_B1\_2\_15: These three variables indicate if the child was currently diagnosed with intermittent explosive disorder, an eating disorder (e.g., anorexia or bulimia), or a substance use disorder. Children currently diagnosed with any of these conditions are captured in the derived variable ADHD\_B1\_2\_16.

ADHD\_A4\_1CA\_X11 and ADHD\_A4\_1CA\_X12: These two variables indicate whether the child's original ADHD diagnosis had changed to schizophrenia or schizoaffective disorder, or a personality disorder (e.g., borderline personality disorder). Children whose ADHD was changed to either of these disorders are captured in ADHD\_A4\_1CA\_X14.

ADHD\_E4\_X01-ADHD\_E4\_X13: These 13 variables capture what specific grades or programs the child had repeated (childcare, preschool, kindergarten, and 1st-12th grades). Information from these variables was used to derive ADHD\_E4R and MULT REPEATS.

ADHD\_E6\_X01-ADHD\_E6\_X13: These 13 variables indicate specific grades or programs from which the child had been expelled (childcare, preschool, kindergarten, and 1st-12th grades). Information from these variables was used to derive ADHD\_E6R and MULT\_EXPELS.

ADHD\_E7: This variable indicates whether the child ever had to appear in court for something he or she had done.

ADHD\_H1\_Q03: This variable captures the relationship between the child and the NSDATA respondent. Information from ADHD\_H1\_Q03 was used to derive ADHD\_RELATION.

ADHD\_H1\_Q03\_ADOPT: This variable captures whether the NSDATA respondent had legally adopted the child.

ADHD\_H2\_STATE: This question asked what state the child lived in at the time of the NSDATA interview; it has been recoded as STATE.

ADHD\_H2\_Q01 and ADHD\_H2\_Q02: These two variables indicate whether the child had any kind of health care coverage, including if the coverage was Medicaid or Children's Health Insurance Program. Information from these two variables was used to derive TYPEINS.

ADHD\_H2\_Q03 and ADHD\_H2\_Q04: These two variables capture if the child was not covered by any health insurance in the past 12 months and if there was any time in the past 12 months that the child had health insurance coverage. Information from these two variables was used to derive CONTINS.

ADHD\_H3\_Q01-ADHD\_H3\_Q06: These six variables contain elements of family income, including a cascade of questions based on federal poverty level or monetary brackets if the NSDATA respondent cannot provide a numeric answer. Information from these variables was used to derive POVLEVEL1\_4.

ADHD\_C1\_4\_NEW\_X01—ADHD\_C1\_4\_NEW\_X91: These 91 variables represent the specific medication the child currently takes for ADHD (captured in question ADHD\_C1\_4\_NEW). Information from these variables was used to derive ADHD\_MEDS\_CLASS\_1—ADHD\_MEDS\_CLASS\_10.

ADHD\_C3\_8\_VA-ADHD\_C3\_8\_VC: These three variables capture up to three other treatments the child ever received.

ADHD\_C3\_8A-ADHD\_C3\_8C: These three variables subsequently indicate whether the child was currently receiving up to three other treatments identified in ADHD\_C3\_8\_VA-ADHD\_C3\_8\_VC.

A series of variables that captured the child's age at the time of a given event has been deleted and replaced with a standardized version for the public data file. Each original age variable was broken into two indicators, the first capturing a number, and the second capturing whether that number was in months or years. The deleted age variables include:

ADHD\_A1\_AGE and ADHD\_A1\_AGE\_MY: Replaced with ADHD\_A1\_AGE\_STD.

ADHD\_A1\_4\_AGE and ADHD\_A1\_4\_AGE\_MY: Replaced with ADHD\_A1\_4\_AGE\_STD.

ADHD\_C1\_2 and ADHD\_C1\_2\_MY: Replaced with ADHD\_C1\_2\_STD.

#### **Deleted variables from TS DUF file**

TS\_E6\_X01-TS\_E6\_X13: These 13 variables indicate specific grades or programs from which the child had been expelled (childcare, preschool, kindergarten, and 1st-12th grades).

Information from these variables was used to derive TS\_E6R and MULT\_EXPELS.

TS\_C1\_4\_NEW\_X01-TS\_C1\_4\_NEW\_X91: These 91 variables represent the specific medication the child currently takes for TS (captured in question TS\_C1\_4\_NEW). Information from these variables was used to derive TS\_MEDS\_CLASS\_1—TS\_MEDS\_CLASS\_10.

The deleted age variables include:

TS\_A1\_4\_AGE and TS\_A1\_4\_AGE\_MY: Replaced with TS\_ A1\_4\_AGE\_STD.

TS\_A1\_5D and TS\_A1\_5D\_MY: Replaced with TS\_A1\_5D\_ STD.

TS A2 6 and TS A2 6 MY: Replaced with TS A2 6 STD.

TS\_C1\_2 and TS\_C1\_2\_MY: Replaced with TS\_C1\_2\_STD.

#### **Derived Variables**

#### **ADHD** file derived variables

ADHD\_A2\_1F: This back-coded variable (from ADHD\_A2\_1E) captures whether the child had a speech, language, or occupational therapist involved in his or her ADHD assessment (from back-code).

ADHD\_A1\_3\_NEW\_X17: This back-coded variable (from ADHD\_A1\_3) captures whether a teacher had also said the child had ADHD.

ADHD\_A1\_3\_NEW\_X18: This back-coded variable (from ADHD\_A1\_3) captures whether other school professionals or a team of school professionals had also said the child had ADHD.

ADHD\_A1\_3\_NEW\_X19: This back-coded variable (from ADHD\_A1\_3) captures whether an unspecified doctor had also said the child had ADHD.

ADHD\_A4\_1CA\_X14: This variable indicates whether the sampled child's original ADHD diagnosis had changed to schizophrenia or schizoaffective disorder, or a personality disorder (e.g., borderline personality disorder).

ADHD\_A4\_1E: This back-coded variable (from ADHD\_A4\_1D) captures whether the child no longer has ADHD because the child never had the condition or was misdiagnosed.

ADHD\_A4\_1F: This back-coded variable (from ADHD\_A4\_1D) captures whether the child no longer has ADHD because environmental or structural changes helped the condition to go away.

ADHD\_B1\_1\_16: This variable indicates whether the sampled child had ever been diagnosed with intermittent explosive disorder, an eating disorder (e.g., anorexia or bulimia), or a substance use disorder.

ADHD\_B1\_2\_16: This variable indicates whether the sampled child currently has intermittent explosive disorder,

an eating disorder (e.g., anorexia or bulimia), or a substance use disorder.

ADHD\_MEDS: This variable identifies whether the sampled child currently has ADHD and whether the child is taking ADHD medication.

ADHD\_MEDS\_CLASS\_1: This back-coded variable (from ADHD\_C1\_4\_NEW) identifies whether the child currently takes an anticonvulsant or mood stabilizer for ADHD.

ADHD\_MEDS\_CLASS\_2: This back-coded variable (from ADHD\_C1\_4\_NEW) identifies whether the child currently takes an antidepressant for ADHD.

ADHD\_MEDS\_CLASS\_3: This back-coded variable (from ADHD\_C1\_4\_NEW) identifies whether the child currently takes an antiemetic for ADHD.

ADHD\_MEDS\_CLASS\_4: This back-coded variable (from ADHD\_C1\_4\_NEW) identifies whether the child currently takes an antiparkinsonian for ADHD.

ADHD\_MEDS\_CLASS\_5: This back-coded variable (from ADHD\_C1\_4\_NEW) identifies whether the child currently takes an antipsychotic for ADHD.

ADHD\_MEDS\_CLASS\_6: This back-coded variable (from ADHD\_C1\_4\_NEW) identifies whether the child currently takes an anxiolytic for ADHD.

ADHD\_MEDS\_CLASS\_7: This back-coded variable (from ADHD\_C1\_4\_NEW) identifies whether the child currently takes a central nervous system agent for ADHD.

ADHD\_MEDS\_CLASS\_8: This back-coded variable (from ADHD\_C1\_4\_NEW) identifies whether the child currently takes a central nervous system stimulant for ADHD.

ADHD\_MEDS\_CLASS\_9: This back-coded variable (from ADHD\_C1\_4\_NEW) identifies whether the child currently takes a musculoskeletal agent for ADHD.

ADHD\_MEDS\_CLASS\_10: This back-coded variable (from ADHD\_C1\_4\_NEW) identifies whether the child currently takes some other medication agent for ADHD.

ADHD\_C1\_5M: This back-coded variable (from ADHD\_C1\_5L) captures whether the child has ever experienced the side effect of loss of appetite from an ADHD medication.

ADHD\_C1\_5N: This back-coded variable (from ADHD\_C1\_5L) captures whether the child has ever experienced the side effect of an allergic reaction from an ADHD medication.

ADHD\_C1\_50: This back-coded variable (from ADHD\_C1\_5L) captures whether the child has ever experienced the side effect of fatigue or drowsiness from an ADHD medication.

ADHD\_C1\_5P: This back-coded variable (from ADHD\_C1\_5L) captures whether the child has ever experienced the side effect of constipation or diarrhea from an ADHD medication.

ADHD\_C1\_5Q: This back-coded variable (from ADHD\_C1\_5L) captures whether the child has ever experienced the side effect of dizziness or decreased blood pressure from an ADHD medication.

ADHD\_C1\_5R: This back-coded variable (from ADHD\_C1\_5L) captures whether the child has ever experienced the side effect of skin picking or hair pulling from an ADHD medication.

ADHD\_C1\_5S: This back-coded variable (from ADHD\_C1\_5L) captures whether the child has ever experienced the side effect of suicidal ideation or self-harm from an ADHD medication.

ADHD\_C1\_5T: This back-coded variable (from ADHD\_C1\_5L) captures whether the child has ever experienced the side effect of other appetite changes from an ADHD medication.

ADHD\_C3\_8\_X01: This back-coded variable (from ADHD\_C3\_8A) captures whether the child is currently receiving any other treatment for ADHD or for other difficulties with emotions, concentration, or behavior through other psychological therapy or counseling.

ADHD\_C3\_8\_X02: This back-coded variable (from ADHD\_C3\_8A) captures whether the child is currently receiving any other treatment for ADHD or for other difficulties with emotions, concentration, or behavior through behavioral therapy.

ADHD\_C3\_8\_X03: This back-coded variable (from ADHD\_C3\_8A) captures whether the child is currently receiving any other treatment for ADHD or for other difficulties with emotions, concentration, or behavior through physical, speech, or occupational therapy.

ADHD\_C3\_8\_X04: This back-coded variable (from ADHD\_C3\_8A) captures whether the child is currently receiving any other treatment for ADHD or for other difficulties with emotions, concentration, or behavior through alternative and complementary therapies or dietary changes.

ADHD\_C3\_8\_X05: This back-coded variable (from ADHD\_C3\_8A) captures whether the child is currently receiving any other treatment for ADHD or for other difficulties with emotions, concentration, or behavior through other medication.

ADHD\_C3\_8\_X06: This back-coded variable (from ADHD\_C3\_8A) captures whether the child is currently receiving any other treatment for ADHD or for other difficulties with emotions, concentration, or behavior through other unspecified treatment.

ADHD\_E4R: This variable was derived from ADHD\_E3 and indicates the most recent grade repeated based on the highest repeated grade. Categories include no grades, kindergarten, elementary school, middle school, and high school.

MULT\_REPEATS: This variable was derived from ADHD\_E3 if multiple grades were repeated.

ADHD\_E6R: This variable was derived from ADHD\_E6 and indicates the most recent grade from which the child was expelled or asked not to return to school based on the highest expelled grade. Categories include no grades, kindergarten, elementary school, middle school, and high school.

MULT\_EXPELS: This variable was derived from ADHD\_E6 if the child was expelled from multiple grades.

ADHD\_RELATION: This variable was derived from ADHD\_H1\_Q02 and ADHD\_H1\_Q03, where the respondent is asked their relationship to the child, including whether he or she was the respondent at the time of NSCH. Categories include mother, father, grandparent, and other.

TYPEINS: This variable was derived from questions ADHD\_H2\_Q01 and ADHD\_H2\_Q02, where the respondent is asked if the child is currently covered by any type of health insurance, including whether it is public or private. Categories include public, private, and uninsured.

CONTINS: This variable was derived from question ADHD\_ H2\_Q04 and indicates whether there was any time over the past 12 months that the child was not covered by any health insurance.

POVLEVEL1\_4: This variable is based on total household members (ADHD\_H1\_Q01) and the total household income value (ADHD\_H3\_Q01). If data for either of these components are missing, refused, or had a "don't know" response, this variable is assigned a missing value. Once an income-to-household size measure was computed, it was compared with HHS federal poverty guidelines (Appendix VII) and collapsed into four categories: below 100% of federal poverty level (FPL); at or above 100% FPL but below 200% of FPL; at or above 200% FPL but below 400% of FPL; and at or above 400% of FPL.

STATE: This variable, based on sampling state, is updated to reflect the state the respondent provided in ADHD\_H2\_STATE if the telephone number had migrated to a household in a different state.

SAMPLE: This variable indicates the telephone sample type (i.e., landline or cell phone).

SEX: This variable, based on NSCH variable K1Q01, specifies the child's sex.

HISPANIC: This variable, based on NSCH variable K11Q01, specifies whether the child is of Hispanic or Latino descent.

RACER: This variable, based on NSCH variable K11Q02, specifies the race of the child among three categories: white, black, or other or multiracial.

### TS file derived variables

TS\_MEDS: This variable identifies whether the sampled child currently has TS and whether the child is taking TS medication.

TS\_MEDS\_CLASS\_1: This back-coded variable (from TS\_C1\_4\_NEW) identifies whether the child currently takes an anticonvulsant or mood stabilizer for TS.

TS \_MEDS\_CLASS\_2: This back-coded variable (from TS\_C1\_4\_NEW) identifies whether the child currently takes an antidepressant for TS.

TS \_MEDS\_CLASS\_3: This back-coded variable (from TS\_C1\_4\_NEW) identifies whether the child currently takes an antiemetic for TS.

TS \_MEDS\_CLASS\_4: This back-coded variable (from TS\_C1\_4\_NEW) identifies whether the child currently takes an antiparkinsonian for TS.

TS \_MEDS\_CLASS\_5: This back-coded variable (from TS\_C1\_4\_NEW) identifies whether the child currently takes an antipsychotic for TS.

TS \_MEDS\_CLASS\_6: This back-coded variable (from TS\_C1\_4\_NEW) identifies whether the child currently takes an anxiolytic for TS.

TS \_MEDS\_CLASS\_7: This back-coded variable (from TS\_C1\_4\_NEW) identifies whether the child currently takes a central nervous system agent for TS.

TS \_MEDS\_CLASS\_8: This back-coded variable (from TS\_C1\_4\_NEW) identifies whether the child currently takes a central nervous system stimulant for TS.

TS \_MEDS\_CLASS\_9: This back-coded variable (from TS\_C1\_4\_NEW) identifies whether the child currently takes a musculoskeletal agent for TS.

TS \_MEDS\_CLASS\_10: This back-coded variable (from TS\_C1\_4\_NEW) identifies whether the child currently takes some other medication agent for TS.

TS\_E6R: This variable was derived from TS\_E6, and indicates the most recent grade from which the child was expelled or asked not to return to school, based on the highest expelled grade. Categories include no grades, kindergarten, elementary school, middle school, and high school.

MULT\_EXPELS: This variable was derived from TS\_E6 if the child was expelled from multiple grades.

# **Dummy Variables**

Variables that allowed for multiple responses needed a separate dummy variable for each response so as to capture the full response. The following variables are represented in the public NSDATA ADHD module data file by dummy variables as shown in the following list.

ADHD\_A1\_3\_NEW: Responses are represented by dummy variables ADHD\_A1\_3\_NEW\_X01, ADHD\_A1\_3\_NEW\_X02, ADHD\_A1\_3\_NEW\_X03, ADHD\_A1\_3\_NEW\_X04, ADHD\_A1\_3\_NEW\_X05, ADHD\_A1\_3\_NEW\_X06, ADHD\_A1\_3\_NEW\_X07, ADHD\_A1\_3\_NEW\_X08, ADHD\_A1\_3\_NEW\_X09, ADHD\_A1\_3\_NEW\_X10, ADHD\_A1\_3\_NEW\_X11, ADHD\_A1\_3\_NEW\_X12, ADHD\_A1\_3\_NEW\_X13, ADHD\_A1\_3\_NEW\_X14, ADHD\_A1\_3\_NEW\_X15, ADHD\_A1\_3\_NEW\_X16, ADHD\_A1\_3\_NEW\_X17, ADHD\_A1\_3\_NEW\_X18, and ADHD\_A1\_3\_NEW\_X19.

ADHD\_A4\_1CA: Responses are represented by dummy variables ADHD\_A4\_1CA\_X01, ADHD\_A4\_1CA\_X02, ADHD\_A4\_1CA\_X03, ADHD\_A4\_1CA\_X04, ADHD\_A4\_1CA\_X05, ADHD\_A4\_1CA\_X06, ADHD\_A4\_1CA\_X07, ADHD\_A4\_1CA\_X08, ADHD\_A4\_1CA\_X09, ADHD\_A4\_1CA\_X10, ADHD\_A4\_1CA\_X13, and ADHD\_A4\_1CA\_X14.

ADHD\_C2\_3: Responses are represented by dummy variables ADHD\_C2\_3\_X01, ADHD\_C2\_3\_X02, and ADHD\_C2\_3\_X03.

ADHD\_C4\_2AA: Responses are represented by dummy variables ADHD\_C4\_2AA\_X01, ADHD\_C4\_2AA\_X02, ADHD\_C4\_2AA\_X03, ADHD\_C4\_2AA\_X04, ADHD\_C4\_2AA\_X05, ADHD\_C4\_2AA\_X06, ADHD\_C4\_2AA\_X07, and ADHD\_C4\_2AA\_X08.

ADHD\_C4\_2BA: Responses are represented by dummy variables ADHD\_C4\_2BA\_X01, ADHD\_C4\_2BA\_X02, ADHD\_C4\_2BA\_X03, ADHD\_C4\_2BA\_X04, ADHD\_C4\_2BA\_X05, ADHD\_C4\_2BA\_X06, ADHD\_C4\_2BA\_X07, ADHD\_C4\_2BA\_X08, and ADHD\_C4\_2BA\_X09.

ADHD\_C4\_2CA: Responses are represented by dummy variables ADHD\_C4\_2CA\_X01, ADHD\_C4\_2CA\_X02, ADHD\_C4\_2CA\_X03, ADHD\_C4\_2CA\_X04, ADHD\_C4\_2CA\_X05, ADHD\_C4\_2CA\_X06, ADHD\_C4\_2CA\_X07, and ADHD\_C4\_2CA\_X08.

TS\_C4\_2BA: Responses are represented by dummy variables TS\_C4\_2BA\_X01, TS\_C4\_2BA\_X02, TS\_C4\_2BA\_X03, TS\_C4\_2BA\_X04, TS\_C4\_2BA\_X05, TS\_C4\_2BA\_X06, TS\_C4\_2BA\_X07, and TS\_C4\_2BA\_X08.

TS\_E\_7A: Responses are represented by dummy variables TS\_E7A\_X01, TS\_E7A\_X02, TS\_E7A\_X03, TS\_E7A\_X04, TS\_E7A\_X05, and TS\_E7A\_X06.

# Weighting and Estimation Procedures

This section provides a nontechnical overview of the weighting procedures for the NSCNC and NSDATA samples. A more detailed and technical description can be found in Appendixes I (for NSCNC) and II (for NSDATA).

# **NSCNC Weights**

The NSCNC weighting scheme involved the following steps:

- 1. Base sampling weights
- 2. Adjustment for unlocatable eligible children
- Adjustment for incomplete Residency Eligibility Screener
- 4. Raking adjustment of Residency Screener weights
- 5. Adjustment for nonresponse to the NLNPCG module
- Poststratification adjustment of NLNPCG module weights (final NLNPCG module weight)
- Adjustment for incomplete Age or Residency Eligibility Screener
- 8. Adjustment for age-ineligible NSCH 16-year-olds
- 9. Adjustment for nonresponse to the NSCNC interview
- 10. Raking adjustment of child weights (final NSCNC weight)

Each individual weighting step is described below. More detail is provided in Appendix I.

# Step 1: Base sampling weights

Sample cases were selected from children identified in the 2011–2012 National Survey of Children's Health (NSCH). The sample eligibility criteria for NSCNC were that the child had been reported to be living with a nonparental caregiver and under age 17 years at the time of NSCH. Because the sample came directly from those who completed the NSCH interview, the base weights were the final child weights from the NSCH weighting process.

# Step 2: Adjustment for unlocatable eligible children

Some NSCH households could not be contacted for NSCNC. At step 2, an adjustment was made to account for the cases for which the original NSCH household was not contacted.

# Step 3: Adjustment for incomplete Residency Eligibility Screener

Among the contacted households, the NSCNC Residency Eligibility Screener was incomplete for some children. For such cases, it was not known if the eligible child previously found through NSCH was still eligible. To compensate for this, the weights of the children with completed NSCNC Residency Eligibility Screeners were adjusted.

# **Step 4: Raking adjustment of Residency Screener** weights

The residency screener weights were adjusted such that the sum of the weights agreed with the control totals in various categories of sex, age, race and ethnicity, census region, caregiver type, and education in the household. All raking dimensions were obtained by summing the final 2011–2012 NSCH weights for all NSCNC-eligible cases. Control totals for the 2011–2012 NSCH were obtained from the 2011 American Community Survey data.

# Step 5: Adjustment for nonresponse to the NLNPCG module

A portion of the children identified in NSCH no longer lived at the household that was contacted. These special cases went through a separate module, but not all eligible respondents completed the module. The raked residency screener weight assigned to a household responding to the NLNPCG module was adjusted for the nonresponse of other NLNPCG screened and eligible households.

Note that this step applied only to cases that were deemed eligible for the NLNPCG module.

# Step 6: Poststratification adjustment of NLNPCG module weights

The NLNPCG module nonresponse weights were adjusted such that the sum of the weights agreed with the totals of eligible cases in categories of caregiver type.

Note that this step applied only to cases that were deemed eligible for the NLNPCG module. This step produced the final weight for tabulations associated with the NLNPCG module.

# Step 7: Adjustment for incomplete Age or Residency Eligibility Screener

Among the contacted households, the NSCNC age and residency eligibility screeners were incomplete for some children. For such cases, it was not known if the eligible child previously found through NSCH was still eligible. To compensate for this, the weights of the children with completed NSCNC eligibility screeners were adjusted.

# Step 8: Adjustment for age-ineligible NSCH 16-year-olds

Among the sampled cases where the child was aged 16 years at the time of the NSCH interview, a portion of the cases were aged 18 or over at the time of the NSCNC interview and, thus, were not eligible to be interviewed. The weights of the NSCNC children who were aged 16 years at the time of NSCH and still under age 18 at the time of the NSCNC interview were adjusted to compensate for the cases that had aged out of NSCNC eligibility.

# Step 9: Adjustment for nonresponse to the NSCNC interview

Not all eligible children for the NSCNC interview completed the interview. The weight from the previous step associated with cases that completed an NSCNC interview was adjusted for the interview nonresponse of other NSCNC screened and eligible children.

# Step 10: Raking adjustment of child weights

The NSCNC interview nonresponse weights were adjusted such that the sum of the weights agreed with the control totals in various categories of sex, age, race and ethnicity, census region, caregiver type, and education in the household. The raked child weight was the final weight for all NSCNC interview tabulations.

# **NSDATA ADHD Weights**

Because the ADHD and TS samples were weighted separately, the methodology used for each is described separately. The ADHD weighting scheme involved the following steps:

- 1. Base sampling weights
- 2. Adjustment for noncontacted eligible children
- Adjustment for incomplete Condition Eligibility Screener
- 4. Adjustment for condition-ineligible cases
- Adjustment for incomplete Age and Residency Eligibility Screeners
- 6. Adjustment for age-ineligible NSCH 15-year-olds
- 7. Adjustment for nonresponse to the NSDATA interview
- 8. Raking adjustment of child weights

Each individual weighting step is described below. More detail is provided in Appendix II.

### Step 1: Base sampling weights

Sample cases were selected from children identified in the 2011–2012 National Survey of Children's Health (NSCH). The sample eligibility criteria for NSDATA were that the child had ever been diagnosed with ADHD, and was under age 16 at the time of NSCH. Because the sample comes directly from those who completed the NSCH interview, the base weights were the final child weights from the NSCH weighting process.

Cases where the child was not originally deemed to have ADHD but was found to have ADHD through the NSDATA screener were kept on the data file for ADHD but have a missing weight for each step in the ADHD weighting process.

# Step 2: Adjustment for noncontacted eligible children

At the next step, an adjustment to the contacted cases was necessary to account for the cases for which the original NSCH household was not contacted.

# Step 3: Adjustment for incomplete Condition Eligibility Screener

Among the contacted households, the NSDATA Residency Eligibility Screener was incomplete for some children. For such cases, it was not known if the eligible child previously found through NSCH was still living in the household. To compensate for this, the weights of the children with completed NSDATA Residency Eligibility Screeners were adjusted.

# Step 4: Adjustment for condition-ineligible cases

A portion of the ADHD module-eligible children identified in NSCH no longer had that condition at NSDATA data collection. The weights of the NSDATA condition-eligible children were adjusted to compensate for these cases that were no longer condition-eligible.

# Step 5: Adjustment for incomplete Age and Residency Eligibility Screeners

Among the contacted households, the NSDATA Age and Residency Eligibility Screeners were incomplete for some children. For such cases, it was not known if the eligible child previously found through NSCH was still eligible. To compensate for this, the weights of the children with completed NSDATA Age and Residency Eligibility Screeners were adjusted.

# Step 6: Adjustment for age-ineligible NSCH 15-year-olds

Among the sampled cases for which the child was aged 15 years at the time of the NSCH interview, a portion of the children were aged 18 or over at the time of the NSDATA interview and were not interviewed. The weights of the NSDATA eligible children who were aged 15 at the time of NSCH were adjusted to compensate for these cases that aged out of the interview.

# Step 7: Adjustment for nonresponse to the NSDATA interview

Not all households eligible for the NSDATA interview completed the interview. The age-ineligible weight associated with cases that completed an NSDATA interview was adjusted for the interview nonresponse of other NSDATA screened and eligible children.

### Step 8: Raking adjustment of child weights

The NSDATA interview nonresponse weights were adjusted such that the sum of the weights agreed with the control totals in various categories of sex, age, race and ethnicity, census region, and household education. All raking dimensions were obtained by summing the final 2011–2012 NSCH weights for all NSDATA ADHD-eligible cases. Control

totals for the 2011–2012 NSCH were obtained from the 2011 American Community Survey data. The raked child weight is the final weight for all NSDATA telephone interview tabulations using the ADHD sample.

# Weighting Methodology for TS Sample

The next sections describe the final weighting scheme for the TS sample:

- 1. Base sampling weights
- 2. Raking adjustment of child weights

Each individual weighting step is described below; more detail is provided in Appendix II.

# Step 1: Base sampling weights

Sample cases were selected from children identified in the 2011–2012 NSCH. The sample eligibility criteria for NSDATA were that the child had been reported to have TS and was under age 16 years at the time of NSCH. Because the sample comes directly from those who completed the NSCH interview, the base weights were the final child weights from the NSCH weighting process.

## Step 2: Raking adjustment of child weights

The NSDATA base weights were adjusted such that the sum of the weights agreed with the control totals in various categories of age, sex, race and ethnicity, and household education. All raking dimensions were obtained by summing the final 2011–2012 NSCH weights for all NSDATA TS-eligible cases. Control totals for the 2011–2012 NSCH were obtained from the 2011 American Community Survey data. The raked child weights are the final weight for all NSDATA telephone interview tabulations using the TS sample.

# **Quality Control**

NORC staff compared the formulas for the weights and adjustments developed by the lead statistician with the actual weights and adjustments constructed by the statistical programmer. An independent check was performed on the programmer's implementation of the statistician's weighting specifications.

# Imputation of Relevant Variables

Because both NSCNC and NSDATA cases are a subset of 2011–2012 NSCH cases, most variables that need to be imputed in the respective weighting processes used imputed values from the 2011–2012 NSCH. Given the breadth of variables used for adjustment cells across all steps, hot-deck imputation was applied if additional variables were needed to be imputed, while using all eligible cases as potential donors for imputation.

# **Estimation and Hypothesis Testing**

Data were obtained through a complex sample design involving clustering of children within households, stratification of households within states, and separate sampling frames for landline and cell-phone numbers. To produce estimates that are representative of children nationally, sample weights must be used. These sample weights account for the unequal probability of selection of each household and child, and they include adjustments for multiple-telephone households, unit nonresponse, and noncoverage of nontelephone households, as well as adjustments to known population control totals. NSCNC estimates based on the sample weights generalize to the U.S. population of children in nonparental care who were aged 0-16 years in 2011-2012. NSDATA ADHD estimates based on the sample weights generalize to the U.S. population of children who had ever been diagnosed with ADHD and who were aged 2-15 in 2011-2012. Estimates do not generalize to the populations of parents of children in nonparental care or parents of children diagnosed with ADHD, nor do the estimates generalize to the populations of providers of children in nonparental care or diagnosed with ADHD. Due to the small size of the TS sample, NSDATA TS weighted estimates are considered to be unreliable and may not generalize to the U.S. population of children who had ever been diagnosed with TS and who were aged 2-15 in 2011-2012.

# **Variables Used for Variance Estimation**

The sample design of NSCNC and NSDATA is complex, and the interview records have unequal weights, so statistical software that assumes simple random sampling will most often compute standard errors that are too low. Tests of statistical hypotheses may suggest statistically significant differences or associations that are misleading. Computer programs are available that provide the capability of variance estimation for complex sample designs (e.g., SUDAAN, Stata, and WesVar). To provide the user with the capability to estimate the complex sample variance for NSCNC and NSDATA data, stratum and PSU identifiers have been provided on the data files. These variables and the sampling weights are necessary to properly calculate variances.

The NSCNC sample size of 1,298 and the NSDATA sample size for the ADHD module of 2,966 for the public data file are considerably smaller than the NSCH sample size of 95,677. Both are too small to allow for reliable estimates at the state level. The NSCNC public data file does not contain a state variable given the disclosure risk (see the previous "Data Files" section for more information). Although state is included on the public data file for the NSDATA ADHD module, it is provided only because it is necessary to identify the stratum. The weights are not representative at the state level, and analysts should avoid using the state identifier to

subset the state for state-specific estimates, which will not be accurate.

For both surveys, households were sampled within states, and the unique household identifier is called IDNUMR. The overall number of persons in these surveys is sufficient for many statistical inference purposes. However, analyses of some rare responses and analyses of subclasses can lead to estimates that are unreliable. Small sample size used in the variance calculations may produce unstable estimates of the variances. Consequently, these analyses require that the data user pay particular attention to the variability of estimates of means, proportions, and totals.

# Variance Estimation Using SUDAAN or Stata

Standard errors of estimates from NSCNC or NSDATA can be obtained using the Taylor series approximation, available in software such as SUDAAN, SAS, and Stata. The collapsed stratum variable COL\_STRATA should be used for analyses of NSCNC public data. The PSU identifier is NSCNCHH\_S for analyses of the Screener or NLNPCG Files, and NSCNCHH\_I for analyses of the Interview File. For NSDATA analyses, the stratum should be identified by the variables STATE and SAMPLE, and PSU should be identified by the variable IDNUMR.

The simplifying assumption that households have been sampled with replacement allows most complex survey sample design computer programs to calculate standard errors straightforwardly. This method requires no recoding of design variables but is statistically less efficient (and, therefore, more conservative) than some other methods, because the household unit is treated as being sampled with replacement within the stratum unit. For SUDAAN, the data file needs to be sorted by stratum, sample type, and PSU. The default number of design variables to be included in the NEST statement is two; because three such variables exist, the PSULEV statement is included to indicate that PSU is the third variable on the list. However, for the NSCNC public files, stratum and sample type have been collapsed into the single variable COL STRATA. The following SUDAAN design statements are used for analyses of the NSCNC Screener File:

```
PROC... DESIGN = WR;

NEST COL_STRATA NSCNCHH_S;

WEIGHT RES_SCR_WT;
```

The following Stata design statement is used for analyses of the NSCNC Screener File:

```
svyset [pweight=RES_SCR_WT] strata(COL_STRATA)
psu(NSCNCHH S)
```

The following SUDAAN design statements are used for analyses of the NSCNC Interview File:

```
PROC... DESIGN = WR;
```

```
NEST COL_STRATA NSCNCHH_I; WEIGHT FINAL WT;
```

The following Stata design statement is used for analyses of the NSCNC Interview File:

```
svyset [pweight=FINAL_WT] strata(COL_STRATA)
psu(NSCNCHH_I)
```

The following SUDAAN design statements are used for analyses of NSDATA:

```
PROC... DESIGN = WR;

NEST STATE SAMPLE IDNUMR / PSULEV = 3;

WEIGHT WEIGHT_ADHD;
```

Because Stata allows for only a single strata variable, STATE and SAMPLE should first be combined into a single variable with (51 x 2 = 102) levels, in this instance called STRATACROSS, which can be formed through the command: EGEN STRATACROSS = GROUP (STATE SAMPLE).

For Stata, the following design statement is used:

```
svyset [pweight=WEIGHT_ADHD] strata(STRATACROSS)
psu(IDNUMR)
```

Other variance estimation procedures are also applicable to NSCH. Specifically, the jackknife method with replicate weights and the bootstrap resampling method with replicate weights can also be used (via software such as WesVar) to obtain standard errors that fully reflect the impact of the weighting adjustments.

### Variance Estimation for Data Subsets

Many analyses of survey data will focus on specific population subgroups, such as children in foster care living in poverty or children with ADHD living in poverty. Some analysts will, therefore, be tempted to delete all records outside of the domain of interest to work with smaller data files and run computer jobs more quickly. This procedure of keeping only selected records and listwise deleting other records is called subsetting the data. Subsetted data that are appropriately weighted can be used to generate correct point estimates (e.g., estimates of population subgroup frequencies or means), but many software packages that analyze complex survey data will incorrectly compute standard errors for subsetted data. When complex survey data are subsetted, the sample design structure is often compromised, because the complete design information is not available. Subsetting the data can delete important design information needed for variance estimation (e.g., deleting all records for certain subgroups may result in entire PSUs being removed from the design structure). Typically, the standard errors for subsetted data will be inflated, resulting in a higher probability of type II error (i.e., failing to detect significant differences that do in fact exist). SUDAAN has a SUBPOPN option that allows the user to target specific subpopulations for analysis while retaining the full unsubsetted data set that includes the full sample design information, and Stata has a similar option called SUBPOP. Analysts interested in specific population subgroups should use these subpopulation options rather than subsetting the data sets.

# **Guidelines for Data Use**

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

Any published material derived from the data should acknowledge NCHS as the original source. The suggested citation is either "Data Source: National Center for Health Statistics, 2013 National Survey of Children in Nonparental Care" or "Data Source: National Center for Health Statistics, 2014 National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome," depending on which data set was used. This citation should appear at the bottom of all tables and figures. Published material derived from the data should also include a disclaimer that credits any analyses, interpretations, or conclusions reached to the author and not to NCHS, which is responsible only for the initial data. Consumers who wish to publish a technical description of the data should make a reasonable effort to ensure that the description is not inconsistent with that published by NCHS.

CIPSEA and the Public Health Service Act (Section 308d) provide that these data collected by NCHS may be used only for the purpose of health statistical reporting and analysis. Any effort to determine the identity of any reported case is prohibited by these laws. NCHS takes extraordinary measures to assure that the identity of survey subjects cannot be disclosed. All direct identifiers, as well as any characteristics that might lead to identification, have been omitted from the data set. Any intentional identification or disclosure of a person or establishment violates the assurances of confidentiality given to the providers of the information.

Therefore, users must:

- Use the data in this data set for statistical reporting and analysis only.
- Make no use of the identity of any person discovered, inadvertently or otherwise, and advise the Director, NCHS, of any such discovery by calling 301–458–4500.
- Not link this data set with individually identifiable data from any other NCHS or non-NCHS data sets.

Use of the data set signifies users' agreement to comply with the above-stated statutory-based requirements.

# **Further Information**

Data users can obtain the latest information about SLAITS by periodically checking the SLAITS website at http://www.cdc.gov/nchs/slaits.htm. This site features downloadable

data files and documentation for SLAITS modules, as well as important information about any modifications and updates to data or documentation. Data users will also find current contact information if they have any additional questions. Data users with questions may also send e-mail to slaits@cdc.gov.

For more information on CDC, contact CDC's Information Contact Center (CDC–INFO) in English or Spanish by calling (800) CDC–INFO (or 800–232–4636) or by e-mailing cdcinfo@cdc.gov. Persons with hearing impairment may contact CDC–INFO with a TTY machine at (888) 232–6348. The CDC–INFO fax machine line is (770) 488–4760. Note, however, that CDC–INFO cannot respond to questions about individual medical cases, provide second medical opinions, or make specific recommendations regarding therapy. These issues should be addressed directly with personal health care providers.

# References

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# Appendix I. Technical Description for Weighting the National Survey of Children in Nonparental Care

This appendix summarizes the methodology used for weighting the National Survey of Children in Nonparental Care (NSCNC) sample. The weighting scheme involved the following steps:

- 1. Base sampling weights
- 2. Adjustment for unlocatable eligible children
- 3. Adjustment for incomplete Residency Eligibility Screener
- 4. Raking adjustment of Residency Screener weights
- 5. Adjustment for nonresponse to the no longer nonparental caregiver (NLNPCG) module
- Poststratification adjustment of NLNPCG module weights (final NLNPCG module weight)
- Adjustment for incomplete Age and Residency Eligibility Screeners
- 8. Adjustment for age-ineligible NSCH 16-year-olds
- 9. Adjustment for nonresponse to the NSCNC interview
- Raking adjustment of child weights (final NSCNC weight)
   Each individual weighting step is detailed below.

# **Step 1: Base Sampling Weights**

The sample was selected from children identified in the 2011–2012 National Survey of Children's Health (NSCH). The sample eligibility criteria for NSCNC were that the child had been reported to be living with a nonparental caregiver and under age 17. Because the sample came directly from those who completed the NSCH interview, the base weights were the final child weights from the NSCH weighting process. The base weight for the *k*-th child in the sample was defined by

$$W_{1k} = W_{NSCH,k}$$
 where 
$$W_{NSCH,k} = Final \ child \ weight \ of \ the \ k-th \ child \ from \ the \ NSCNC-eligible \ NSCH \ completed \ interviews.$$

Cases where either the respondent or child was determined to be deceased during screening were dropped from the weighting process at this step.

# Step 2: Adjustment for Unlocatable Eligible Children

At the next step, an adjustment was necessary to account for the cases for which the original NSCH household was not contacted. To make the adjustment, a number of adjustment cells were formed by controlling for known covariates. The adjusted weights were computed as:

$$W_{2k} = \frac{W_{1k}}{R_{2\ell}} \quad \text{if } k \in A, \ell$$

= 0 otherwise

where

$$R_{2\ell} = \frac{\sum_{k \in A} \delta_{2k\ell} W_{1k}}{\sum_{k \in S} \delta_{2k\ell} W_{1k}}$$

A = The set of contacted telephone numbers

 $\delta_{2k\ell}$  = 1 if the k-th child was in the  $\ell$ -th cell

and

= 0 otherwise.

Adjustment cells ( $\ell$ ) for the sample were defined by the child's age at time of interview (ages 0–15 and 16); age of oldest adult in the household (under 50 and 50 and over); housing tenure (own and other); and whether the child was in foster care. Adjustment cells were collapsed where the number of cases was small (less than 20).

# Step 3: Adjustment for Incomplete Residency Eligibility Screener

Among the contacted households, the NSCNC Residency Eligibility Screener was incomplete for some children. For such cases, it was not known if the eligible child previously found through NSCH was still eligible. To compensate for this, the weights of the children with completed NSCNC Residency Eligibility Screeners were adjusted. The adjusted weight for the *k*-th child was

$$W_{3k}$$
 =  $\frac{W_{2k}}{R_{3\ell}}$  if  $k \in B, \ell$  and = 0 otherwise

where

$$R_{3\ell} = \frac{\displaystyle\sum_{k \in B} \delta_{3k\ell} W_{2k}}{\displaystyle\sum_{k \in A} \delta_{3k\ell} W_{2k}}$$

$$B = \text{The subset of children in } A \text{ that completed the NSCNC Residency Eligibility Screener}$$

$$\delta_{3k\ell} = \text{1 if the } k\text{-th child was in the } \ell\text{-th cell}$$
and
$$= \text{0} \text{ otherwise.}$$

Adjustment cells ( $\ell$ ) for the sample were defined by the same variables used in step 2: child's age at time of interview (ages 0–15 and 16); age of oldest adult (under 50 and 50 and over); housing tenure (own and other); and whether the child was in foster care. Adjustment cells were collapsed where the number of cases was small (less than 20).

# **Step 4: Raking Adjustment of Residency Screener Weights**

The residency screener weights were adjusted such that the sum of the weights agreed with the control totals in various categories of the following margins:

- Number of male and female NSCNC eligible children in three age groups based on age at time of NSCH interview: 0-5 years, 6-11, and 12-16
- Number of NSCNC eligible children of various racial and ethnic backgrounds: Hispanic, non-Hispanic African American, and children of all other backgrounds including non-Hispanic white and multiple-race children
- Number of NSCNC eligible children in the census region
- Number of NSCNC by caregiver type: grandparents only, grandparents plus others, and others
- Number of NSCNC eligible children in households where the highest reported education of parents was high school or less or more than high school

These totals were based on the NSCNC eligible final child weights from NSCH. The categories of raking dimensions were collapsed where the number of cases was small (less than 20) or if any difficulty occurred in raking convergence.

The raked weight for the k-th child from the t-th indication was

$$W_{4k} = R_{4k} W_{3k}$$

where

At this point, the weights were checked for extreme raking adjustment factors, and extreme adjustment factors were truncated. The raking adjustment was rerun after the treatment of weights with extreme adjustment factors.

# **Step 5: Adjustment for Nonresponse to NLNPCG Module**

A portion of the children identified in NSCH no longer lived at the household that was contacted. These special cases went through a separate module, but not all eligible respondents completed the module. The raked residency screener weight assigned to a household responding to the NLNPCG module was adjusted for the nonresponse of other NLNPCG screened and eligible households. The adjustment was made by forming nonresponse adjustment cells ( $\ell$ ). The adjusted weight for the k-th household was

$$W_{5k}$$
 =  $\frac{W_{4k}}{R_{5\ell}}$  if  $k \in D, \ell$   
and = 0 otherwise

where

$$R_{5\ell}$$
 =  $\frac{\sum_{k \in D} \delta_{5k\ell} W_{4k}}{\sum_{k \in C} \delta_{5k\ell} W_{4k}}$   
 $C$  = The subset of children in  $B$  that were eligible for the NLNPCG

D = The subset of children in C that completed the NLNPCG module

 $\delta_{{\rm S}k\ell}$  = 1 if the k-th child was in the  $\ell$ -th adjustment cell

0 otherwise.

Adjustment cells ( $\ell$ ) for the sample were defined by level of effort to complete the NSCH interview (no refusals or at least one refusal). Adjustment cells were collapsed where

the number of cases was small (less than 20).

and

Note that this step applied only to cases that were deemed eligible for the NLNPCG module.

36

# **Step 6: Poststratification Adjustment of NLNPCG Module Weights**

The NLNPCG module nonresponse weights were adjusted such that the sum of the weights agreed with the control totals in categories of the following variable:

Number of children by caregiver type: Grandparents only, grandparents plus others, and others.

These totals were based on the NLNPCG eligible raked screener weights from step 4 above. The categories were collapsed where the number of cases was small (less than 20).

The poststratified weight for the k-th child from the t-th indication was

$$W_{6k} = R_{6k} W_{5k}$$

where

 $R_{6k}$  = The poststratification adjustment factor for the k-th child.

Note that this step applied only to cases that were deemed eligible for the NLNPCG module. This was the final weight for tabulations associated with the NLNPCG module.

# **Step 7: Adjustment for Incomplete Age and Residency Eligibility Screeners**

Among the contacted households, the NSCNC Age and Residency Eligibility Screeners were incomplete for some children. For such cases, it was not known if the eligible child previously found through NSCH was still eligible. To compensate for this, the weights of the children with completed NSCNC eligibility screeners were adjusted. The adjusted weight for the k-th child was

$$W_{7k}$$
 =  $\frac{W_{4k}}{R_{7\ell}}$  if  $k \in E$ ,  $\ell$  and = 0 otherwise

where

$$R_{7\ell}$$
 =  $\frac{\sum_{k \in E} \delta_{7k\ell} W_{4k}}{\sum_{k \in B} \delta_{7k\ell} W_{4k}}$ 
 $E$  = The subset of children in  $B$  that completed the NSCNC Age and Residency Eligibility Screeners

 $\delta_{7k\ell}$  = 1 if the  $k$ -th child was in the  $\ell$ -th cell and = 0 otherwise.

Adjustment cells ( $\ell$ ) for the sample were defined by child's age at time of interview (ages 0–15 and 16); age of oldest adult (under 50 and 50 and over); housing tenure (own and other); and whether the child was in foster care. Adjustment cells were collapsed where the number of cases was small (less than 20).

# Step 8: Adjustment for Age-ineligible NSCH 16-year-olds

Among the sampled cases where the child was aged 16 at the time of the NSCH interview, a portion of the cases were aged 18 or over at the time of the NSCNC interview and, thus, were not eligible to be interviewed. The weights of the NSCNC children who were aged 16 at the time of NSCH and still under age 18 at the time of the NSCNC interview were adjusted to compensate for the cases that had aged out of NSCNC eligibility. The adjusted weight for the *k*-th child was

$$W_{8k}$$
 =  $\frac{W_{7k}}{R_{8\ell}}$  if  $k \in F$ ,  $\ell$  and = 0 otherwise

where

$$R_{8\ell}$$
 
$$\sum_{k \in E} \delta_{8k\ell} W_{7k}$$
 
$$\sum_{k \in E} \delta_{8k\ell} W_{7k}$$
 
$$F = \text{The subset of children in } E \text{ that completed the NSCNC Age and Residency Eligibility Screeners}$$

$$\delta_{8k\ell}$$
 = 1 if the  $k$ -th child was in the  $\ell$ -th cell

and were still age eligible

and

0 otherwise.

Adjustment cells ( $\ell$ ) for the sample were based on age only. Cases where the child was aged 0–15 at the time of the NSCH interview had an adjustment factor of 1, because this was only an issue related to cases that were aged 16 at the time of the NSCH interview.

# **Step 9: Adjustment for Nonresponse to the NSCNC Interview**

Not all eligible children for the NSCNC interview completed the interview. The weight from the previous step associated with cases that completed an NSCNC interview was adjusted for the interview nonresponse of other NSCNC screened and eligible children. The adjustment was made by forming nonresponse adjustment cells ( $\ell$ ). The adjusted weight for the k-th child was

$$W_{9k}$$
 =  $\dfrac{W_{8k}}{R_{9\ell}}$  if  $k \in G, \ell$  and = 0 otherwise

where

$$R_{9\ell}$$
 =  $\dfrac{\displaystyle\sum_{k\in G} \delta_{9k\ell} W_{8k}}{\displaystyle\sum_{k\in F} \delta_{9k\ell} W_{8k}}$    
  $G$  = The subset of children in  $F$  that completed the NSCNC interview  $\delta_{9k\ell}$  = 1 if the  $k$ -th child was in the  $\ell$ -th adjustment cell and = 0 otherwise.

Adjustment cells  $(\ell)$  for the sample were defined by highest education level attained by a member of the household and metropolitan statistical area status. Adjustment cells were collapsed where the number of cases was small (less than 20).

# Step 10: Raking Adjustment of Child Weights

The NSCNC interview nonresponse weights were adjusted such that the sum of the weights agreed with the control totals in various categories of the following variables:

- Number of male and female NSCNC eligible children in three age groups based on age at time of NSCH interview: 0-5 years, 6-11, and 12-16
- Number of NSCNC eligible children of various racial and ethnic backgrounds: Hispanic, non-Hispanic African American, and children of all other backgrounds including non-Hispanic white and multiple-race children
- Number of NSCNC eligible children in the census region
- Number of NSCNC eligible children by caregiver type: grandparents only, grandparents plus others, and others
- Number of NSCNC eligible children in households where the highest reported education of parents was high school or less or more than high school

These totals were based on the NSCNC eligible final child weights from the NSCH survey. The categories of raking dimensions were collapsed where the number of cases was small (less than 20) or if any difficulty occurred in raking convergence.

The raked weight for the *k*-th child from the *t*-th indication was

$$W_{10k} = R_{10k} W_{9k}$$

where

$$R_{10k}$$
 = The raking adjustment factor for the  $k$ -th child.

At this point, the weights were checked for extreme raking adjustment factors, and the weights with extreme adjustment factors were truncated. The raking adjustment was rerun after the treatment of weights with extreme adjustment factors. The raked child weight was the final weight for all NSCNC interview tabulations.

# Appendix II. Technical Description for Weighting the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome

This appendix summarizes the methodology used for weighting the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome (NSDATA). Because the attention-deficit/hyperactivity disorder (ADHD) and Tourette syndrome (TS) samples were weighted separately, the methodology used for each is described separately below.

# **Weighting Methodology for ADHD Sample**

The weighting scheme for ADHD involved the following steps:

- 1. Base sampling weights
- 2. Adjustment for noncontacted eligible children
- 3. Adjustment for incomplete Condition Eligibility Screener
- 4. Adjustment for condition-ineligible cases
- Adjustment for incomplete Age and Residency Eligibility Screeners
- 6. Adjustment for age-ineligible NSCH 15-year-olds
- 7. Adjustment for nonresponse to the NSDATA interview
- 8. Raking adjustment of child weights

Each individual weighting step is detailed below.

# **Step 1: Base Sampling Weights**

Sample cases were selected from children identified in the 2011–2012 National Survey of Children's Health (NSCH). The sample eligibility criteria for NSDATA were that the child had ever been diagnosed with ADHD and was under age 16. Because the sample comes directly from those who completed the NSCH interview, the base weights were the final child weights from the NSCH weighting process. The base weight for the *k*-th child in the sample was defined by

$$W_{1k}$$
 =  $W_{NSCH,k}$ 

where

 $W_{NSCH,k}$  = Final child weight of the k-th child from the NSDATA eligible NSCH completed interviews.

Cases where the child was not originally deemed to have ADHD but was found to have ADHD through the NSDATA screener were kept on the data file for ADHD but have a missing weight for each step in the ADHD weighting process.

# Step 2: Adjustment for Noncontacted Eligible Children

At the next step, an adjustment to the contacted cases was necessary to account for the cases for which the original NSCH household was not contacted. For making the adjustment, a number of adjustment cells were formed by controlling for known covariates. The adjusted weights were computed as:

$$W_{2k}$$
 =  $\frac{W_{1k}}{R_{2\ell}}$  if  $k \in A, \ell$ 

0 otherwise

where

$$R_{2\ell} = \frac{\sum_{k \in A} \delta_{2k\ell} W_{1k}}{\sum_{k \in S} \delta_{2k\ell} W_{1k}}$$

A = The set of contacted telephone numbers

 $\delta_{2k\ell}$  = 1 if the k-th child is in the  $\ell$ -th cell and

= 0 otherwise.

Adjustment cells ( $\ell$ ) for the sample were defined by housing tenure (own and other); age of oldest adult (under 50 and 50 and over); and income range (\$0–\$19,999, \$20,000–\$59,999, and \$60,000 and more). Adjustment cells were collapsed where the number of cases was small (less than 20). Cases where either the respondent or child was determined to be deceased during screening were dropped from the weighting process at this step.

# Step 3: Adjustment for Incomplete Condition Eligibility Screener

Among the contacted households, the NSDATA Residency Eligibility Screener was incomplete for some children. For such cases, it was not known if the eligible child previously found through NSCH was still living in the household. To compensate for this, the weights of the children with completed NSDATA Residency Eligibility Screeners were adjusted. The adjusted weight for the *k*-th child was

$$W_{3k}$$
 =  $\frac{W_{2k}}{R_{3\ell}}$  if  $k \in B, \ell$   
and = 0 otherwise

where

$$R_{3\ell} = \frac{\displaystyle\sum_{k \in B} \delta_{3k\ell} W_{2k}}{\displaystyle\sum_{k \in A} \delta_{3k\ell} W_{2k}}$$

$$B = \text{The subset of children in } A \text{ who completed the NSDATA } Condition Eligibility Screener}$$

$$\delta_{3k\ell} = \text{1 if the } k\text{-th child is in the } \ell\text{-th cell}$$
and

0 otherwise.

Adjustment cells ( $\ell$ ) for the sample were defined by income range (\$0-\$19,999, \$20,000-\$59,999, and \$60,000 and more); age of oldest adult (under 50 and 50 and over); and whether the child had special health care needs. Adjustment cells were collapsed where the number of cases was small (less than 20).

# **Step 4: Adjustment for Conditionineligible Cases**

A portion of the ADHD module-eligible children identified in NSCH no longer had that condition at NSDATA data collection. The weights of the NSDATA condition-eligible children were adjusted to compensate for these cases that were no longer condition eligible. The adjusted weight for the *k*-th child was

$$W_{4k}$$
 =  $\frac{vV_{3k}}{R_{4\ell}}$  if  $k \in C$ ,  $\ell$  and = 0 otherwise

where

$$R_{4\ell} = \frac{\sum_{k \in C} \delta_{4k\ell} W_{3k}}{\sum_{k \in R} \delta_{4k\ell} W_{3k}}$$

$$C$$
 = The subset of children in  $B$  who were condition eligible 
$$\delta_{4k\ell} = 1 \text{ if the } k\text{-th child is in the } \ell\text{-th adjustment cell}$$
 and 
$$= 0 \text{ otherwise.}$$

Adjustment cells ( $\ell$ ) for the sample were defined by special health care needs (yes or no); reported general health of the child (excellent or very good, and other); and highest level of education attained by parent or caregiver (less than high school, high school, and more than high school). Adjustment cells were collapsed where the number of cases was small (less than 20).

# **Step 5: Adjustment for Incomplete Age and Residency Eligibility Screeners**

Among the contacted households, the NSDATA Age and Residency Eligibility Screeners were incomplete for some children. For such cases, it was not known if the eligible child previously found through NSCH was still eligible. To compensate for this, the weights of the children with completed NSDATA Age and Residency Eligibility Screeners were adjusted. The adjusted weight for the *k*-th child was

$$W_{5k}$$
 =  $\frac{W_{4k}}{R_{5\ell}}$  if  $k \in D, \ell$   
and = 0 otherwise

where

$$R_{5\ell} = \frac{\displaystyle\sum_{k \in D} \delta_{5k\ell} W_{4k}}{\displaystyle\sum_{k \in C} \delta_{5k\ell} W_{4k}}$$

$$D = \text{The subset of children in $C$ who completed the NSDATA Age and Residency Eligibility Screeners}$$

$$\delta_{5k\ell} = \text{1 if the $k$-th child is in the $\ell$-th cell and}$$

$$= \text{0 otherwise.}$$

Adjustment cells  $(\ell)$  for the sample were defined by sex (male or female) and reported general health of child (excellent or very good, and other). Adjustment cells were collapsed where the number of cases was small (less than 20). Cases that were deemed ineligible due to the child no longer living in the household (i.e., residency ineligible) were dropped after this step.

# Step 6: Adjustment for Age-ineligible NSCH 15-year-olds

Among the sampled cases for which the child was aged 15 at the time of the NSCH interview, a portion of the children were aged 18 or over at the time of the NSDATA interview and were not interviewed. The weights of the NSDATA eligible children who were aged 15 at the time of NSCH were adjusted to compensate for these cases that aged out of the interview. The adjusted weight for the *k*-th child was

$$W_{6k}$$
 =  $\frac{W_{5k}}{R_{6\ell}}$  if  $k \in E, \ell$  and = 0 otherwise

where

$$R_{6\ell} = \frac{\sum_{k \in \mathcal{E}} \delta_{6k\ell} W_{5k}}{\sum_{k \in \mathcal{D}} \delta_{6k\ell} W_{5k}}$$

E = The subset of children in D
who completed the NSDATA Age
and Residency Eligibility
Screeners and were still age and
residency eligible

 $\delta_{6k\ell}$  = 1 if the k-th child is in the  $\ell$ -th cell and

= 0 otherwise.

Adjustment cells ( $\ell$ ) for the sample were based on age only. Cases where the child was aged 0–14 years at the time of the NSCH interview had an adjustment factor of 1, because this was an issue related only to cases that were aged 15 at the time of NSCH interview.

# **Step 7: Adjustment for Nonresponse to the NSDATA Interview**

Not all households eligible for the NSDATA interview completed the interview. The weight from the previous step associated with cases that completed an NSDATA interview was adjusted for the interview nonresponse of other NSDATA screened and eligible children. The adjustment was made by forming nonresponse adjustment cells ( $\ell$ ). The adjusted weight for the k-th child was

$$W_{7k}$$
 =  $\frac{W_{6k}}{R_{7\ell}}$  if  $k \in F$ ,  $\ell$  and = 0 otherwise

where

$$R_{7\ell} = \frac{\sum_{k \in F} \delta_{7k\ell} W_{6k}}{\sum_{k \in E} \delta_{7k\ell} W_{6k}}$$

F = The subset of children in E who completed the NSDATA interview  $\delta_{7k\ell}$  = 1 if the k-th child is in the  $\ell$ -th adjustment cell and

0 otherwise.

Adjustment cells ( $\ell$ ) for the sample were defined by telephone status (cell phone-only/mostly and other); special health care needs status (yes or no); and housing tenure (own and other). Adjustment cells were collapsed where the number of cases was small (less than 20).

# Step 8: Raking Adjustment of Child Weights

The NSDATA interview nonresponse weights were adjusted such that the sum of the weights agreed with the control totals in various categories of the following margins:

- Number of male and female NSDATA eligible children in three age groups based on age at time of NSCH interview: Male: aged 2–9, 10–12, and 13–15, and Female: aged 2–9, 10–12, and 13–15
- Number of NSDATA eligible children of various racial and ethnic backgrounds: Hispanic, non-Hispanic African American, and children of all other backgrounds including non-Hispanic white and multiple-race children
- Number of NSDATA eligible children in the census region
- Number of NSDATA eligible children in households where the highest reported education of parents is high school or less, or more than high school

These totals were based on the final child weights from the NSCH survey for NSDATA-eligible children. The categories of raking dimensions were collapsed where the number of cases was small (less than 20) or if there was any difficulty in raking convergence.

The raked weight for the *k*-th child from the *t*-th indication was expressed as

$$W_{8k} = R_{8k} W_{7k}$$

where

 $R_{8k}$  is the raking adjustment factor for the k-th child.

At this point, the weights were checked for extreme raking adjustment factors, and the weights with extreme adjustment factors were truncated. The raking adjustment was rerun after the treatment of weights with extreme adjustment factors. The raked child weight is the final weight for all NSDATA telephone interview tabulations using the ADHD sample.

# Weighting Methodology for TS Sample

The next two sections describe the final weighting scheme for the TS sample.

- 1. Base sampling weights
- 2. Raking adjustment of child weights

Each individual weighting step is detailed below.

# **Step 1: Base Sampling Weights**

Sample cases were selected from children identified in the 2011–2012 National Survey of Children's Health (NSCH). The sample eligibility criteria for NSDATA were that the child had been reported to have Tourette syndrome (TS) and was under age 16. Because the sample comes directly from those who completed the NSCH interview, the base weights were the final child weights from the NSCH weighting process. The base weight for the *k*-th child in the sample was defined by

$$W_{TS-1k} = W_{NSCH,k}$$

where

 $W_{NSCH,k}$  = Final child weight of the k-th child from the NSDATA eligible

NSCH completed interviews.

# Step 2: Raking Adjustment of Child Weights

The NSDATA base weights were adjusted such that the sum of the weights agreed with the control totals in various categories of the following margins:

- Number of NSDATA eligible children in three age groups based on age at time of NSCH interview: ages 2–9, 10–12, and 13–15
- Number of NSDATA eligible children by sex, male or female
- Number of NSDATA eligible children of various racial and ethnic backgrounds: non-Hispanic white and other
- Number of NSDATA eligible children in households where the highest reported education of parents is high school or less, or more than high school

These totals were based on the final child weights from the NSCH survey for NSDATA TS-eligible children. The categories of raking dimensions were collapsed where the number of cases was small (less than 20) or if there was any difficulty in raking convergence.

The raked weight for the *k*-th child from the *t*-th indication can be expressed as

$$W_{\tau\varsigma-2k} = R_{\tau\varsigma-2k}W_{\tau\varsigma-1k}$$

where

 $R_{TS-2k}$  = The raking adjustment factor for the k-th child.

At this point, the weights were checked for extreme raking adjustment factors, and the weights with extreme adjustment factors were truncated. The raking adjustment was rerun after the treatment of weights with extreme adjustment factors. The raked child weights are the final weight for all NSDATA telephone interview tabulations using the TS sample.

# Appendix III. NSCNC Questionnaire

# 2013 National Survey of Children in Nonparental Care

Sponsored by the Assistant Secretary for Planning and Evaluation

Conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention

Introduction, Eligibility Confirmation, and Informed Consent
NLNPCG Module
Household Structure
Living Arrangement
Parents: Characteristics and Interaction With Child
Financial Support
Caregiver Preparation, Long-Term Planning, and Legal Custody
Caregiver and Child Interactions, Relationship, and Monitoring and Supervision
Child Well-Being, Child Care, and School
Caregiver Well-Being, Caregiver Physical and Mental Health, and Social Supports
Services and Supports
Demographics
Callback and Refusal Conversion Scripts 125

# NATIONAL SURVEY OF CHILDREN IN NONPARENTAL CARE (NSCNC)

### The following public burden estimate statement will be available as a CATI screen (H4):

According to the Paperwork Reduction Act (PRA) of 1995, no persons are required to respond to a collection of information unless such collection displays a valid OMB control number. The valid OMB control number for this information collection is 0920-0406. The time required to complete this information collection is estimated to average 30 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have any comments about the accuracy of the time estimate(s) or suggestions for improving this form please write to: CDC Reports Clearance Officer, 1600 Clifton Road, MS-D74, Atlanta, GA 30333; call 404-639-4794; or send an email to omb@cdc.gov.

Data collection conducted under contract to the CDC by NORC at the University of Chicago.

Form approved OMB No. 0920-0406 Exp. Date 04/30/14

**Assurance of Confidentiality**. All information which would permit identification of any individual, a practice, or an establishment will be held confidential, will be used for statistical purposes 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 the 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).

NOTE: ALL QUESTIONS HAVE DON'T KNOW (DK) AND REFUSED (RF) AS ANSWER OPTIONS, WHETHER OR NOT THOSE CHOICES ARE SPECIFICALLY INCLUDED IN THIS QUESTIONNAIRE.

NOTE: WHEN FILLING [INTERVIEW DATE] IN INTRO\_1 AND INTRO\_2, USE MONTH AND YEAR ONLY

INTRO 1

Hello, my name is \_\_\_\_\_\_\_. I'm calling on behalf of the CDC's National Center for Health Statistics (IF RECEIVED ADVANCE LETTER (ADVLTR=1), "to follow up on a letter that was sent to your home"/ ELSE NO FILL). In [INTERVIEW DATE], we conducted a telephone survey on children's health with an adult at this phone number about a [Male/Female] child who would now be about [ESTIMATED AGE] years old. The person we spoke with told us [he was/she was/they were] the child's [RELATION]. We are interested in speaking with this child's [RELATION] again, or with a parent or guardian who is currently living with the child. Is this person available?

HELP TEXT: COMPLETE THE INTERVIEW WITH THE ORIGINAL NSCH RESPONDENT ONLY IF HE/SHE IS THE CURRENT CAREGIVER OF S.C. IF NOT, THEN ONLY ASK THE ORIGINAL RESPONDENT THE LOCATING QUESTIONS AND THE 9 QUESTIONS IN THE NLNPCG SECTION BUT COMPLETE THE FULL INTERVIEW WITH THE CURRENT PARENT/GUARDIAN/CAREGIVER OF SC.

- (1) YES, SPEAKING WITH THAT PERSON < IF RDD\_NCCELL\_CCELL=1 THEN GO TO INTRO3; IF RDD\_NCCELL\_CCELL=2, 3 THEN GO TO S\_WARM>
- (2) YES, NEW PERSON COMES TO PHONE < GO TO INTRO 2>
- (3) NO, NOT AVAILABLE NOW <SET GCB AND TERMINATE>
- (4) TERMINATE THE INTERVIEW <GO TO T1>
- (5) NO, PERSON HAS MOVED OR HAS NEW PHONE NUMBER <IF

  RDD\_NCCELL\_CCELL=1 THEN GO TO LOC\_A; IF RDD\_NCCELL\_CCELL=2, 3

  THEN GO TO S WARM>
- (6) DO NOT KNOW THIS PERSON *<GO TO UNKNOWN>*
- (7) NO, PERSON IS DECEASED < GO TO DECEASEDP>
- (8) NO, CHILD IS DECEASED < GO TO DECEASED>
- (9) CHILD NO LONGER LIVES IN HOUSE WITH R < IF RDD\_NCCELL\_CCELL=1 THEN GO TO MOVED; IF RDD\_NCCELL\_CCELL=2, 3 THEN GO TO S\_WARM>
- (11) CONFIRM BUSINESS < GO TO SALZ >
- (12) ANSWERING MACHINE < IF MESSAGE IS TO BE LEFT THEN GO TO SASERV, ELSE HANG UP AND SET ITS =35>
- (15) SUPERVISOR REVIEW (RAISE YOUR HAND TO GET PERMISSION BEFORE USING THIS CODE) *SET ITS =31>*

# R TYPE IF INTRO\_1=1 OR INTRO\_1=2 AND INTRO\_2=1 THEN DISPLAY,

INTERVIEWER INSTRUCTION: DID THE RESPONDENT INDICATE HIS/HER RELATIONSHIP TO S.C.? IF NOT, ASK RESPONDENT: Are you the child's [RELATION]?

- (1) YES CHILD'S [RELATION] (NSCH RESPONDENT)
- (2) NO OTHER PARENT OR GUARDIAN CURRENTLY LIVING WITH S.C.

# S\_WARM If you are currently driving a car or doing any activity that requires your full attention I need to call you back at a later time.

- (1) CONTINUE <IF INTRO\_1 = 1 THEN GO TO INTRO\_3; ELSE IF INTRO\_1 = 5 THEN GO TO LOC\_A; ELSE IF INTRO\_1=9 THEN GO TO MOVED>
- (2) R UNABLE TO CONTINUE < GO TO S ATTN>
- (3) NOT A CELL PHONE <IF INTRO\_1 = 1 THEN GO TO INTRO\_3; ELSE IF INTRO\_1 = 5 THEN GO TO LOC\_A; ELSE IF INTRO\_1 = 9 THEN GO TO MOVED>

# S\_ATTN For your safety, we will call you back at another time.

INTERVIEWER INSTRUCTION: EVEN IF THE RESPONDENT IS USING A HANDS-FREE DEVICE WHILE DRIVING, YOU MUST END THE CALL.

(1) CALL BACK ANOTHER TIME <GO TO CB1> (2) CALL BACK AT ANOTHER NUMBER REQUESTED <GO TO CB1N WARNING> (3) WRONG TIME ZONE FOR CELL PHONE *<GO TO CELL TZ 1>* (4) GO BACK TO S WARM UNKNOWN Do you know anyone who would be able to tell us how to get in contact with this child's current caregiver or guardian? INTERVIEWER INSTRUCTION: IF INFORMATION IS PROVIDED, ENTER IT IN A DETAILED CALL NOTE. (1) YES <GO TO UNKNOWN EXIT> (2) NO <GO TO UNKNOWN EXIT> UNKNOWN EXIT Thank you for your time. Have a nice day. **TERMINATE AND SET ITS=71** LOC A What is their new telephone number? (1) CONTINUE – R CAN PROVIDE A NEW NUMBER (2) NONE (77) DON'T KNOW (99) REFUSED SKIP TO LOC\_F IF NONE/DK/RF. LOC AA RECORD NUMBER - -IF NUMBER RECORDED, SET NEWPHONE1\_FLAG=1. LOC B Is that a landline or cell phone number? (1) LANDLINE (2) CELLULAR (77) DON'T KNOW (99) REFUSED LOC C Does this person have any other number where they might be reached?

(1) YES  $\langle GO \ TO \ LOC \ D \rangle$ 

	(2) NO < <i>GO TO LOC_F</i> > (77) DON'T KNOW < <i>GO TO LOC_F</i> > (99) REFUSED < <i>GO TO LOC_F</i> >
LOC_D	What is that telephone number?
	(1) CONTINUE - R CAN PROVIDE A NEW NUMBER (2) NONE (77) DON'T KNOW (99) REFUSED
	SKIP TO LOC_F IF NONE/DK/RF.
LOC_DD	RECORD NUMBER
	IF NUMBER RECORDED, SET NEWPHONE2_FLAG=1
LOC_E	Is that a landline or cellular telephone number?
	(1) LANDLINE (2) CELLULAR (77) DON'T KNOW (99) REFUSED
LOC_F	What is their name?
	(1) CONTINUE - R CAN PROVIDE A NAME (77) DON'T KNOW [GO TO LOC_TYPE] (99) REFUSED [GO TO LOC_TYPE]
LOC_FF	RECORD VERBATIM RESPONSE
LOC_TYPE	IF INTRO_1= 7 OR INTRO_2=7, OR R_TYPE=1, AUTOMATICALLY FILL LOC_TYPE=2 AND SKIP LOC_TYPE.
	IF LOC_A IN (2,77,99) AND LOC_F IN (77,99) THEN SKIP TO LOC_G; ELSE, DISPLAY
	Is the contact information you are providing for the child's [RELATION] or for a different caregiver or guardian?

- (1) CHILD'S [RELATION]
- (2) NEW CAREGIVER/ GUARDIAN
- (77) DON'T KNOW
- (99) REFUSED

LOC G What is your name?

INTERVIEWER INSTRUCTION: IF R ASKS WHY THEIR NAME IS NEEDED, INDICATE THAT WE WILL PROBABLY NEED TO EXPLAIN WHO REFERRED US TO THE CHILD'S CURRENT CAREGIVER. IF R IS UNCOMFORTABLE, GET FIRST NAME ONLY.

- (1) CONTINUE R CAN PROVIDE A NAME
- (77) DON'T KNOW < GO TO LOC EXIT>
- (99) REFUSED < GO TO LOC EXIT>

LOC GG RECORD VERBATIM RESPONSE

LOC\_EXIT IF (LOC\_A NOT IN (2,77,99) OR LOC\_D NOT IN (2,77,99) OR LOC\_F NOT IN (2,77,99)) THEN DISPLAY,

Thank you for providing contact information for [S.C.]'s caregiver. We will attempt to contact this person as soon as possible to discuss this important survey.

ELSE, IF (LOC\_A IN (2,77,99) AND LOC\_F IN (2,77,99)) AND (INTRO\_1=9 OR INTRO\_2=9 OR ELIG\_ = 2, 77, 99) DO NOT DISPLAY AND GO TO NLNPCG

ELSE, IF (LOC\_A IN (2,77,99) AND LOC\_F IN (2,77,99)) AND (INTRO\_1=5 OR INTRO\_2=5 ) DO NOT DISPLAY AND GO TO LOC\_EXIT2

LOC EXIT2 Thank you for your time and have a nice day.

IF PHONE NUMBER PROVIDED (i.e., LOC\_AA NE MISSING OR LOC DD NE MISSING), SET ITS=73.

SET CALLING RULES TO IMMEDIATELY DIAL THE NUMBER ENTERED AT LOC\_AA; SET RDD\_NCCELL\_CCELL=(1 OR 2 BASED ON LOC\_B); ON NEXT DIAL, IF LOC\_TYPE=1 THEN GO TO INTRO\_1; ELSE IF LOC\_TYPE=2, 77 OR 99 THEN GO TO NEWINTRO\_1.

IF NO PHONE NUMBER PROVIDED (i.e., LOC\_A IN (2,77,99)), BUT NAME PROVIDED (LOC\_FF NE MISSING), TERMINATE AND SET ITS=71.

# NEWINTRO\_1

Hello, my name is \_\_\_\_\_\_\_\_. I'm calling on behalf of the CDC's National Center for Health Statistics. We are trying to reach a current parent or guardian of [FILL: [CHILD NAME] IF AVAILABLE, "a [male/female] child" IF NAME NOT AVAILABLE] who is now approximately [ESTIMATED AGE] years old. [FILL: [ORIGINAL RESPONDENT NAME] IF AVAILABLE, "[His/Her] previous caregiver" IF NAME NOT AVAILABLE] told us that [FILL: [NEW CAREGIVER NAME] (IF NAME AVAILABLE) OR "this person" IF NAME NOT AVAILABLE] could be reached at this telephone number. Is [FILL: [NEW CAREGIVER NAME] IF NAME AVAILABLE OR "this child's current parent or guardian" IF NAME NOT AVAILABLE] available?

- (1) YES, SPEAKING WITH THAT PERSON < GO TO NEWINTRO 2>
- (2) YES, NEW PERSON COMES TO PHONE < REPEAT NEWINTRO 1>
- (3) NO, NOT AVAILABLE NOW *SET GCB AND TERMINATE>*
- (4) HOW DID YOU GET MY NUMBER? < GO TO NEWINTRO 2>
- (5) NO, PERSON HAS MOVED OR HAS NEW PHONE NUMBER <IF

  RDD\_NCCELL\_CCELL=1 THEN GO TO LOC\_A; IF RDD\_NCCELL\_CCELL=2, 3

  THEN GO TO S WARM>
- (6) DO NOT KNOW THIS PERSON <GO TO UNKNOWN>
- (7) NO, PERSON IS DECEASED <GO TO DECEASEDP>
- (8) NO, CHILD IS DECEASED <GO TO DECEASED>
- (9) CHILD NO LONGER LIVES IN HOUSE WITH R < IF RDD\_NCCELL\_CCELL=1
  THEN GO TO MOVED; IF RDD\_NCCELL\_CCELL=2, 3 THEN GO TO S\_WARM>
- (11) CONFIRM BUSINESS < GO TO SALZ >
- (12) ANSWERING MACHINE < IF MESSAGE IS TO BE LEFT THEN GO TO SASERY, ELSE HANG UP AND SET ITS =35>
- (15) SUPERVISOR REVIEW (RAISE YOUR HAND TO GET PERMISSION BEFORE USING THIS CODE) < SET ITS = 3I>

### NEWINTRO 2

In [INTERVIEW DATE], we conducted a telephone survey on children's health with an adult about [FILL CHILD'S NAME, OR: a [Male/Female] child who would now be about [ESTIMATED AGE] years old]. The person we spoke with

told us [he was/she was/they were] the child's caregiver. We recently recontacted that person's household and were told that someone at this telephone number is now providing care for the child. We are interested in speaking with the child's current caregiver. Is this person available?

- (1) YES, SPEAKING WITH THAT PERSON < GO TO NEWINTRO 3>
- (2) YES, NEW PERSON COMES TO PHONE < REPEAT NEWINTRO 1>
- (3) NO, NOT AVAILABLE NOW *SET GCB AND TERMINATE*>
- (5) NO, PERSON HAS MOVED OR HAS NEW PHONE NUMBER <IF RDD\_NCCELL\_CCELL=1 THEN GO TO LOC\_A; IF RDD\_NCCELL\_CCELL=2, 3 THEN GO TO S WARM>
- (6) DO NOT KNOW THIS PERSON *<GO TO UNKNOWN>*
- (7) NO, PERSON IS DECEASED <GO TO DECEASEDP>
- (8) NO, CHILD IS DECEASED < GO TO DECEASED>
- (9) CHILD NO LONGER LIVES IN HOUSE WITH R < IF RDD\_NCCELL\_CCELL=1 THEN GO TO MOVED; IF RDD\_NCCELL\_CCELL=2, 3 THEN GO TO S\_WARM>
- (11) CONFIRM BUSINESS < GO TO SALZ >
- (12) ANSWERING MACHINE < IF MESSAGE IS TO BE LEFT THEN GO TO SASERV, ELSE HANG UP AND SET ITS =35>
- (15) SUPERVISOR REVIEW (RAISE YOUR HAND TO GET PERMISSION BEFORE USING THIS CODE) <*SET ITS* = 31>

### **DECEASED**

I'm sorry to hear that. I do not need to continue. Thank you, and please accept my condolences. Goodbye.

### [TERMINATE AND SET ITS=82]

### **DECEASEDP**

I'm sorry to hear that, please accept my condolences. Would you be able to tell us how to get in contact with this child's current caregiver or guardian?

INTERVIEWER INSTRUCTION: IF R ANSWERS "NO" SAY "Thank you for your time. Have a nice day."

- (1) YES  $\langle GO \ TO \ LOC \ A \rangle$
- (2) NO <TERMINATE AND SET ITS=74>
- (3) I AM THAT PERSON < GO TO NEWINTRO 3>

# MOVED

We are interested in speaking with a parent or guardian of the child who is currently living with the child. Would you be able to tell us how to get in contact with this person?

(1) YES < GO TO LOC\_A> (2) NO < GO TO NLNPCG>

### MOVED2

Would you be able to tell us how to get in contact with a parent or guardian of the child who is currently living with the child?

(1) YES < GO TO LOC\_A> (2) NO < GO TO NLNPCG>

### INTRO 2

Hello, my name is \_\_\_\_\_\_\_. I'm calling on behalf of the CDC's National Center for Health Statistics (IF RECEIVED ADVANCE LETTER (ADVLTR=1), "to follow up on a letter that was sent to your home"/ ELSE NO FILL). In [INTERVIEW DATE], we conducted a telephone survey on children's health with an adult at this phone number about a [Male/Female] child who would now be about [ESTIMATED AGE] years old. The person we spoke with told us [he was/she was/they were] the child's [RELATION]. We are interested in speaking with this person again, or with a parent or guardian who is currently living with the child. Is this person available?

- (1) YES, SPEAKING WITH THAT PERSON < IF RDD\_NCCELL\_CCELL=1 THEN GO TO INTRO 3; IF RDD NCCELL CCELL=2, 3 THEN GO TO S WARM>
- (2) YES, NEW PERSON COMES TO PHONE < REPEAT INTRO 2>
- (3) NO, NOT AVAILABLE NOW < SET GCB AND TERMINATE>
- (5) NO, PERSON HAS MOVED OR HAS NEW PHONE NUMBER <IF

  RDD\_NCCELL\_CCELL=1 THEN GO TO LOC\_A; IF RDD\_NCCELL\_CCELL=2, 3

  THEN GO TO S WARM>
- (6) DO NOT KNOW THIS PERSON < GO TO UNKNOWN>
- (7) NO, PERSON IS DECEASED < GO TO DECEASEDP>
- (8) NO, CHILD IS DECEASED < GO TO DECEASED>
- (9) CHILD NO LONGER LIVES IN HOUSE WITH R < IF RDD\_NCCELL\_CCELL=1 THEN GO TO MOVED; IF RDD\_NCCELL\_CCELL=2, 3 THEN GO TO S\_WARM>
- (11) CONFIRM BUSINESS *<GO TO SALZ>*
- (12) ANSWERING MACHINE < IF MESSAGE IS TO BE LEFT THEN GO TO SASERV, ELSE HANG UP AND SET ITS =35>

### NEWINTRO 3

The CDC's National Center for Health Statistics is re-contacting caregivers and guardians of children who were living apart from their parents. This survey will help researchers to understand the living situations of these children and the problems they and their caregivers may have receiving needed services. If you qualify for and complete this survey, as a token of appreciation we will send you \$[MONEY\_1/MONEY\_2] for your time.

(1) CONTINUE  $\langle GO\ TO\ ELIG \rangle$ 

### INTRO 3

Thank you for previously completing the National Survey of Children's Health. We appreciate your household's participation in this important survey.

The CDC's National Center for Health Statistics is re-contacting caregivers and guardians of children who were living apart from their parents. This survey will help researchers to understand the living situations of these children and the problems they and their caregivers may have receiving needed services. If you

qualify for and complete this survey, as a token of appreciation we will send you \$[MONEY 1/MONEY 2] for your time.

(1) CONTINUE <GO TO ELIG >

### ELIG

We are interested in speaking with a parent or guardian of the child who is currently living with the child. Does the child live with you now?

- (1) YES  $\langle GO \ TO \ AGE \rangle$
- (2) NO  $\langle GO \ TO \ MOVED2 \rangle$
- (77) DON'T KNOW < GO TO MOVED2>
- (99) REFUSED <GO TO MOVED2>

### AGE

When we last spoke, your child was [AGEYR\_CHILD]. How old is [he/she] now?

ENTER AGE IN YEARS: \_\_\_\_

ENTER 77 FOR DON'T KNOW AND 99 FOR REFUSED

CURRENT AGE CANNOT BE LESS THAN EST\_AGE.

# IF AGE LE 17 OR AGE IN (77, 99) GO TO CONSENT; ELSE, GO TO AGE\_EXIT

# AGE\_EXIT

We are only interviewing parents or guardians whose child is less than 18 years old. I'd like to thank you on behalf of the CDC's National Center for Health Statistics for the time and effort you've spent answering these questions. Have a good day.

### TERMINATE AND SET ITS=76

### **NLNPCG**

I only have a few additional questions for you.

**READ IF NECESSARY:** You do not qualify for the full survey today because you are no longer caring for [S.C.]. We would, however, like to ask you a few questions about being a former caregiver of [S.C.].

(1) CONTINUE

### **CONSENT**

Before we continue, I'd like you to know that taking part in this research is voluntary. You may choose not to answer any question you don't wish to answer, or end the interview at any time with no impact on the benefits you may receive. We are required by Federal law to develop and follow strict procedures to protect

the confidentiality of your information and use your answers only for statistical research. I can describe these laws if you wish. [FILL: IF INTRO1=9 OR INTRO2=9 OR ELIG NE 1, LEAVE BLANK; ELSE FILL: In appreciation for your time, we will send you \$[MONEY\_1/MONEY\_2]. The survey will take about a half hour.] In order to review my work, this call will be recorded and my supervisor may listen as I ask the questions. I'd like to continue now unless you have any questions.

**READ IF NECESSARY:** If you are receiving government benefits, your participation in this survey will not change whether or not you receive the benefits. If you are not receiving benefits, participation will not change your eligibility for any benefits.

READ IF NECESSARY: The Public Health Service Act is Title 42 of the US Code, Section 242k. The collection of information in this survey is authorized by Section 306 of this Act. Through the National Center for Health Statistics, the confidentiality of your responses is assured by Section 308d of this Act and by the Confidential Information Protection and Statistical Efficiency Act. Would you like me to read the Confidential Information Protection provisions to you?

IF RESPONDENT WOULD LIKE TO HEAR PROVISIONS, 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 NCHS employees or agents. By law, every employee of the National Center for Health Statistics, N-O-R-C at the University of Chicago, and their agents and contractors 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.

- (1) CONTINUE, RECORDING ACCEPTABLE
- (2) CONTINUE, DO NOT RECORD

IF INTRO\_1=9 OR INTRO\_2=9 OR ELIG NE 1 THEN GO TO NLNPCGSTART, ELSE GO TO H1.

### **NLNPCGSTART**

(THESE 9 QUESTIONS ARE ASKED OF FORMER CAREGIVERS NO LONGER CARING FOR THE CHILD AND THE INTERVIEW THEN TERMINATES)

N\_L1 Just before coming to live with you, where did [S.C.] live? [SELECT ONLY ONE]

INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS THEY MOVED INTO [S.C.]'S HOUSEHOLD, RATHER THAN [S.C.] COMING TO LIVE WITH THEM, CODE "RESPONDENT MOVED INTO [S.C.]'S HOUSEHOLD."

INTERVIEWER INSTRUCTION: IF [S.C.] HAS LIVED WITH RESPONDENT SINCE BIRTH, CODE "[S.C.] HAS LIVED WITH RESPONDENT SINCE BIRTH"

- (1) WITH [HIS/HER] BIRTH PARENT(S)
- (2) WITH [HIS/HER] ADOPTIVE PARENT(S)
- (3) WITH OTHER MEMBERS OF [HIS/HER] BIRTH FAMILY, ANOTHER RELATIVE
- (4) WITH ANOTHER FOSTER PARENT
- (5) IN A GROUP HOME IN FOSTER CARE SYSTEM, THAT IS, A HOME WITH 4 FOSTER CHILDREN OR MORE
- (6) IN A RESIDENTIAL TREATMENT FACILITY, THAT IS, A FACILITY WHERE A NUMBER OF CHILDREN AND YOUTH LIVE
- (7) SOMEONE ELSE NOT MENTIONED (SPECIFY) [SKIP TO N L1 VERBATIM]
- (8) RESPONDENT MOVED INTO [S.C.]'S HOUSEHOLD
- (9) [S.C.] HAS LIVED WITH RESPONDENT SINCE BIRTH
- (77) DON'T KNOW
- (99) REFUSED

# ALL EXCEPT 7 SKIP TO N\_H14

DECORD VERDATIM DECRONCE

N_LI_VERBATIM	RECORD VERBATIWI RESPONSE
N_H14	When did [S.C.] start living with you on a regular basis, without [his/her] parent or parents?
	READ IF NECESSARY: Do you know the year? READ IF NECESSARY: Do you know the month?
	RECORD DATE/_/

ENTER 55/55/5555 FOR SINCE BIRTH [SKIP TO N\_H16]
ENTER 66/66/6666 TO RECORD LENGTH OF TIME (MONTHS OR YEARS) [SKIP TO N\_H14\_1]
ENTER 77/77/7777 FOR DON'T KNOW [SKIP TO N\_H16]
ENTER 99/99/9999 FOR REFUSED [SKIP TO N\_H16]

N H14 1 RECORD VALUE

ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

N\_H14\_2 (1) YEARS

(2) MONTHS

IF  $N_H14_2 = 1$  AND  $N_H14_1 > [AGE*12]$ , OR

IF  $N_H14_2 = 2$  AND  $N_H14_1 > [AGE]$ ,

THEN [DISPLAY WARNING TEXT]

ELSE, [SKIP TO N H16]

WARNING: ANSWER IS GREATER THAN CURRENT AGE OF CHILD. PLEASE CORRECT.

N\_H16 Did anyone from child protective services or a foster care agency help arrange for you to care for [S.C.]?

(1) YES

(2) NO

(77) DON'T KNOW

(99) REFUSED

N1 How many months ago did [S.C.] stop living with you?

INTERVIEWER INSTRUCTION: IF LESS THAN A MONTH, ENTER ZERO.

RECORD VALUE

ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

N2 What is the reason [S.C.] is no longer living with you? [MARK ALL THAT

APPLY]

### **CUSTODY**

- (1) YOU HAD LEGAL CUSTODY AGREEMENT THAT THE CHILD WOULD LIVE ELSEWHERE
- (2) YOU VOLUNTARILY GAVE UP CUSTODY
- (3) YOU HAD AN INFORMAL AGREEMENT THAT SOMEONE ELSE WOULD TAKE CARE OF THE CHILD
- (4) CHILD PROTECTIVE SERVICES, ANOTHER AGENCY, OR THE COURT REMOVED THE CHILD FROM YOUR HOME

### CURRENT LIVING ARRANGEMENT

- (5) TOO MUCH CONFLICT BETWEEN THE CHILD AND OTHER CHILDREN IN THE HOUSEHOLD
- (6) SPOUSE/PARTNER WANTED THE CHILD TO MOVE
- (7) COULD NOT HANDLE/MANAGE THE CHILD
- (8) CHILD WENT TO LIVE WITH PARENT/REUNIFIED

### **HEALTH AND SAFETY**

- (9) YOU HAD HEALTH PROBLEMS
- (10) THE CHILD HAD HEALTH PROBLEMS
- (11) FELT CHILD WAS UNSAFE IN YOUR NEIGHBORHOOD
- (12) FAMILY EMERGENCY

### **CHILD'S DECISION**

- (13) THE CHILD CHOSE TO LIVE WITH DIFFERENT CAREGIVERS
- (14) CHILD WANTED TO LIVE BY HIM/HERSELF
- (15) CHILD WANTED TO LIVE WITH GIRLFRIEND/BOYFRIEND OR ROOMMATES/ FRIENDS
- (16) CHILD RAN AWAY

### **OTHER**

- (17) CHILD WENT AWAY TO SCHOOL
- (18) FINANCIAL PROBLEMS/COULD NOT AFFORD THE COST OF CARING FOR THE CHILD
- (19) CHILD WAS PLACED IN JUVENILE DETENTION CENTER/INCARCERATED
- (20) OTHER (SPECIFY) [SKIP TO N2 VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

N2_VERBATIM	RECORD VERBATIM RESPONSE
N3	With whom did [S.C.] live immediately after leaving your household?
	(1) WITH [HIS/HER] BIRTH PARENTS (2) WITH [HIS/HER] ADOPTIVE PARENTS (3) WITH OTHER MEMBERS OF [HIS/HER] BIRTH OR ADOPTIVE FAMILY, ANOTHER RELATIVE (4) WITH A FOSTER PARENT

FOSTER CHILDREN OR MORE (6) IN A RESIDENTIAL TREATMENT FACILITY, THAT IS, A FACILITY WHERE A NUMBER OF CHILDREN AND YOUTH LIVE (7) IN A JUVENILE DETENTION CENTER OR PRISON (8) ON HIS/HER OWN (9) WITH GIRLFRIEND/BOYFRIEND, OR WITH ROOMMATES/FRIENDS (10) SOMEONE ELSE NOT MENTIONED (SPECIFY) [SKIP TO N3 VERBATIM] (77) DON'T KNOW (99) REFUSED N3 VERBATIM RECORD VERBATIM RESPONSE N4 Did you agree with the decision to change [SC]'s living arrangement? (1) YES (2) NO (77) DON'T KNOW (99) REFUSED N P5 When you were caring for [S.C.] and [S.C.] was living with you, why didn't [he/she] live with [her/his] mother? [MARK ALL THAT APPLY] (1) MOTHER IN JAIL (2) MOTHER DETAINED/DEPORTED FOR IMMIGRATION VIOLATIONS (3) MOTHER WAS NOT A GOOD MOTHER/WAS ABUSIVE/MISTREATED CHILD (4) CHILD REMOVED BY CHILD PROTECTIVE SERVICES (5) MOTHER IS SICK (6) MOTHER TOO BUSY/WORK SCHEDULE TOO DEMANDING (7) MOTHER HAS PROBLEMS WITH HUSBAND/BOYFRIEND (8) MOTHER HAS FINANCIAL PROBLEMS/CAN'T AFFORD TO KEEP CHILD (9) MOTHER HAS DRUG/ALCOHOL PROBLEMS (10) MOTHER DOESN'T WANT TO CARE FOR CHILD/GAVE CHILD UP (11) MOTHER THINKS CURRENT CARETAKER CAN DO A BETTER JOB (12) MOTHER'S NEIGHBORHOOD NOT GOOD FOR RAISING CHILDREN (13) MOTHER DECEASED (14) OTHER (SPECIFY) [SKIP TO N P5 VERBATIM] (77) DON'T KNOW (99) REFUSED N P5 VERBATIM RECORD VERBATIM RESPONSE N P23 When you were caring for [S.C.] and [S.C.] was living with you, why didn't

(5) IN A GROUP HOME IN FOSTER CARE SYSTEM, THAT IS, A HOME WITH 4

[he/she] live with [her/his] father? [MARK ALL THAT APPLY]

- (1) FATHER IN JAIL
- (2) FATHER DETAINED/DEPORTED FOR IMMIGRATION VIOLATIONS
- (3) FATHER WAS NOT A GOOD FATHER/WAS ABUSIVE/MISTREATED CHILD
- (4) CHILD REMOVED BY CHILD PROTECTIVE SERVICES
- (5) FATHER IS SICK
- (6) FATHER TOO BUSY/WORK SCHEDULE TOO DEMANDING
- (7) FATHER HAS PROBLEMS WITH WIFE/GIRLFRIEND
- (8) FATHER HAS FINANCIAL PROBLEMS/CAN'T AFFORD TO KEEP CHILD
- (9) FATHER HAS DRUG/ALCOHOL PROBLEMS
- (10) FATHER DOESN'T WANT TO CARE FOR CHILD/GAVE CHILD UP
- (11) FATHER THINKS CURRENT CARETAKER CAN DO A BETTER JOB
- (12) FATHER'S NEIGHBORHOOD NOT GOOD FOR RAISING CHILDREN
- (13) FATHER DECEASED
- (14) OTHER (SPECIFY) [SKIP TO N\_P23\_VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

N P23 VERBATIM RECORD VERBATIM RESPONSE	
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### NLNPCG END

Those are all the questions I have. I'd like to thank you on behalf of the CDC's National Center for Health Statistics for the time and effort you've spent answering these questions. If you have any questions about this survey, you may call my supervisor toll-free at 1-877-346-9982. If you have questions about your rights as a survey participant, you may call the chairman of the Research Ethics Review Board at 1-800-223-8118. We would like to send you \$10 in appreciation for your time. I will need to collect your name and address information so that we can mail it to you.

[INTERVIEWER INSTRUCTION: COLLECT NAME AND FULL ADDRESS IN FOOTPRINTS BEFORE HITTING ENTER]

Thank you again and have a nice day.

IF NLNPCG MODULE COMPLETE AND NO LOCATING INFORMATION WAS COLLECTED AT LOC\_A (2,77,99) AND LOC\_D (2,77,99) AND LOC\_F IN (2,77,99) OR MOVED/MOVED2 = 2 THEN TERMINATE AND SET ITS=65

IF NLNPCG MODULE COMPLETE AND LOCATING INFORMATION WAS COLLECTED AT LOC\_A=1 OR LOC\_D=1 OR LOC\_F=1 OR MOVED/MOVED2 = 1 THEN TERMINATE AND SET ITS=66

IF ITS=66 THEN SET CALLING RULES TO IMMEDIATELY DIAL THE NUMBER ENTERED AT LOC\_AA; SET RDD\_NCCELL\_CCELL=(1 OR 2 BASED ON LOC\_B) AND GO TO NEWINTRO\_1.

SET CALLING RULES TO TRY THE NUMBER ENTERED AT LOC\_DD IF LOC AA IS NOT SUCCESSFUL AND GO TO NEWINTRO 1.

IF BREAKOFF OCCURS IN NLNPCG MODULE AND NO LOCATING INFORMATION WAS COLLECTED AT LOC\_A (2,77,99) AND LOC\_D (2,77,99) AND LOC\_F IN (2,77,99) OR MOVED/MOVED2 = 2 THEN TERMINATE AND SET ITS=54. DO NOT SEND CASE FOR LOCATING.

IF BREAKOFF OCCURS IN NLNPCG MODULE AND LOCATING INFORMATION WAS COLLECTED AT LOC\_A=1 OR LOC\_D=1 OR LOC\_F=1 OR MOVED/MOVED2 = 1 THEN TERMINATE AND SET ITS=56. SEND CASE FOR LOCATING.

# **HOUSEHOLD STRUCTURE, HOUSING (H)**

H1\_INTRO I can continue to refer to your child as [your N year old] for the rest of the interview, or if you prefer, you could give me a first name or initials.

(01) CONTINUE TO USE AGE REFERENCE [GO TO H1]

(02) USE NAME [GO TO SC\_NAME]

[SKIP TO H1 IF NAME OF S.C. ALREADY GATHERED AT SCNAME OR SELECTION1 NAME A]

SC\_NAME ENTER NAME/INITIALS: \_\_\_\_\_ [GO TO H1]

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**Universe: All** 

How many adults age 18 or older live in this household?

INTERVIEWER INSTRUCTION: EACH PERSON IN THE HOUSEHOLD MUST BE A CURRENT RESIDENT OF THE HOUSEHOLD. CHILDREN WHO ONLY LIVE PART-TIME IN THE HOUSEHOLD BECAUSE OF CUSTODY ISSUES SHOULD BE INCLUDED IF THEY ARE STAYING THERE WHEN CONTACT WITH THE HOUSEHOLD IS MADE.

A CURRENT RESIDENCE IS DEFINED AS A PLACE WHERE THE PERSON IS STAYING FOR MORE THAN TWO MONTHS AT THE TIME OF THE SURVEY CONTACT. IF A PERSON HAS NO PLACE WHERE HE OR SHE USUALLY STAYS, THE PERSON SHOULD BE CONSIDERED A CURRENT RESIDENT REGARDLESS OF THE LENGTH OF THE CURRENT STAY.

PERSONS AWAY FROM THEIR RESIDENCE FOR TWO MONTHS OR LESS, WHETHER TRAVELING OR IN THE HOSPITAL, ARE CONSIDERED "IN RESIDENCE." PERSONS AWAY FROM THEIR RESIDENCE FOR MORE THAN TWO MONTHS ARE CONSIDERED "NOT IN RESIDENCE" UNLESS THE PERSON IS AWAY AT SCHOOL (I.E., BOARDING SCHOOL, MILITARY ACADEMY, PREP SCHOOL, ETC.).

RECORD NUMBER OF PEOPLE:
RESPONSE MUST BE GREATER THAN 0

ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

### H2

**Universe: All** 

How many children age 17 or younger live in this household?

INTERVIEWER INSTRUCTION: EACH PERSON IN THE HOUSEHOLD MUST BE A CURRENT RESIDENT OF THE HOUSEHOLD. CHILDREN WHO ONLY LIVE PART-TIME IN THE HOUSEHOLD BECAUSE OF CUSTODY ISSUES SHOULD BE INCLUDED IF THEY ARE STAYING THERE WHEN CONTACT WITH THE HOUSEHOLD IS MADE.

A CURRENT RESIDENCE IS DEFINED AS A PLACE WHERE THE PERSON IS STAYING FOR MORE THAN TWO MONTHS AT THE TIME OF THE SURVEY CONTACT. IF A PERSON HAS NO PLACE WHERE HE OR SHE USUALLY STAYS, THE PERSON SHOULD BE CONSIDERED A CURRENT RESIDENT REGARDLESS OF THE LENGTH OF THE CURRENT STAY.

PERSONS AWAY FROM THEIR RESIDENCE FOR TWO MONTHS OR LESS, WHETHER TRAVELING OR IN THE HOSPITAL, ARE CONSIDERED "IN RESIDENCE." PERSONS AWAY FROM THEIR RESIDENCE FOR MORE THAN TWO MONTHS ARE CONSIDERED "NOT IN RESIDENCE" UNLESS THE PERSON IS AWAY AT SCHOOL (I.E., BOARDING SCHOOL, MILITARY ACADEMY, PREP SCHOOL, ETC.).

RECORD NUMBER OF PEOPLE:
RESPONSE MUST BE GREATER THAN 0

ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

### **H4**

**Universe: All** 

IF INTRO\_1=1, FILL= "when we last spoke with you." ELSE FILL "When we last spoke with someone in your household."

[When we last spoke with you/When we last spoke with someone in your household], [S.C.] did not have any parents living in the household with [him/her]. Does [S.C.] have any parents living in your household now?

**READ IF NECESSARY:** During the NSCH interview, the respondent reported that [S.C.] did not have a mother or father of any type living in the household with [S.C.].

(1) NO [GO TO H6]

- (2) YES, RESPONDENT IS THE CHILD'S PARENT (BIOLOGICAL, STEP, OR ADOPTIVE PARENT WHO ADOPTED THE CHILD BEFORE THE NSCH SURVEY) (3) RESPONDENT IS NOT A BIOLOGICAL OR ADOPTIVE PARENT, BUT A BIOLOGICAL OR ADOPTIVE PARENT LIVES IN THE HOUSEHOLD [GO TO H6] (4) RESPONDENT IS CAREGIVER WHO ADOPTED THE CHILD **SINCE** THE NSCH SURVEY [GO TO H6]
- (77) DON'T KNOW [GO TO H6]
- (99) REFUSED [GO TO H6]

### **H5**

Universe: Respondents who are parents

INTERVIEWER INSTRUCTION: IF NOT OBVIOUS, ASK WHETHER THE PARENT IS THE CHILD'S MOTHER OR FATHER. ELSE, CODE THE APPROPRIATE RESPONSE WITHOUT ASKING.

- (1) MOTHER
- (2) FATHER
- (77) DON'T KNOW
- (99) REFUSED

### **H6**

Universe: All

Are you married, widowed, divorced, separated or never married?

- (1) MARRIED
- (2) WIDOWED [GO TO H8]
- (3) DIVORCED [GO TO H8]
- (4) SEPARATED [GO TO H8]
- (5) NEVER MARRIED [GO TO H8]
- (77) DON'T KNOW [GO TO H8]
- (99) REFUSED [GO TO H8]

### H7

Universe: All married Rs

Does your spouse currently live with you?

- (1) YES [GO TO H9]
- (2) NO [GO TO H9]
- (77) DON'T KNOW [GO TO H9]
- (99) REFUSED [GO TO H9]

### H8

Universe: Rs who are not married and not currently living with spouse

Are you currently living with a boyfriend, girlfriend, or partner?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# H9 1

Universe: All except parents

# IF H4=2, THEN GO TO H13

What is your relationship to [S.C.]? [MARK ALL THAT APPLY]

**READ IF NECESSARY**: Are you related on the mother's side of [S.C.'s] family or on the father's side of the family? If not related, how do you know [S.C.]?

INTERVIEWER INSTRUCTION: IF CARETAKER IS BOTH A RELATIVE AND A FOSTER PARENT, CODE BOTH. IF CARETAKER IS BOTH A FRIEND OF THE FAMILY AND A FOSTER PARENT, CODE BOTH.

INTERVIEWER INSTRUCTION: IF R IS ADOPTIVE PARENT, PROBE FOR ANOTHER PREVIOUS RELATIONSHIP AND CODE BOTH.

- (1) MATERNAL GRANDPARENT
- (2) PATERNAL GRANDPARENT
- (3) GREAT GRANDPARENT
- (4) AUNT/UNCLE
- (5) SIBLING
- (6) OTHER RELATIVE
- (7) STEP-PARENT
- (8) FOSTER PARENT
- (9) FRIEND OF CHILD'S MOTHER OR FATHER
- (10) OTHER FAMILY FRIEND, INCLUDING THOSE NOT SURE IF FRIEND OF MOTHER OR FATHER
- (11) ADOPTIVE PARENT (MUST CODE ANOTHER)
- (12) OTHER (SPECIFY) [SKIP TO H9\_1\_VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

H9	1	VERBATIM	RECORD	VERBATIM RESPONSE	

#### H9 2

Universe: All except parents

IF H6=1 OR H8=1 ASK H9 2; ELSE GO TO H10

IF H6=1 THEN ASK: What is your spouse's relationship to [S.C.]? [MARK ALL THAT APPLY]

IF H6 NE 1 AND H8=1 What is your partner's relationship to [S.C.]? [MARK ALL THAT APPLY]

READ IF NECESSARY: Is your [IF H6=1 THEN FILL "spouse"; IF H6 NE 1 AND H8=1 THEN FILL "partner"] related on the mother's side of [S.C.]'s family or on the father's side of the family? If not related, how does he/she know [S.C.]?

INTERVIEWER INSTRUCTION: IF CARETAKER IS BOTH A RELATIVE AND A FOSTER PARENT, CODE BOTH. IF CARETAKER IS BOTH A FRIEND OF THE FAMILY AND A FOSTER PARENT, CODE BOTH.

INTERVIEWER INSTRUCTION: IF SPOUSE/PARTNER IS ADOPTIVE PARENT, PROBE FOR ANOTHER PREVIOUS RELATIONSHIP AND CODE BOTH.

- (1) MATERNAL GRANDPARENT
- (2) PATERNAL GRANDPARENT
- (3) GREAT GRANDPARENT
- (4) AUNT/UNCLE
- (5) SIBLING
- (6) OTHER RELATIVE
- (7) STEP-PARENT
- (8) FOSTER PARENT
- (9) FRIEND OF CHILD'S MOTHER OR FATHER
- (10) OTHER FAMILY FRIEND, INCLUDING THOSE NOT SURE IF FRIEND OF MOTHER OR FATHER
- (11) ADOPTIVE PARENT (MUST CODE ANOTHER)
- (12) OTHER (SPECIFY) [SKIP TO H9 2 VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

H9 2 VERBATIM RECORD VERBATIM RESPONSE	
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Universe: All except parents

# IF H4=2 SKIP TO H13

IF H4 NE 2, AND H6=1 THEN ASK: Have you and/or your spouse legally adopted [S.C.]?

IF H4 NE 2, AND H6 NE 1 and H8=1 THEN ASK: Have you and/or your partner legally adopted [S.C.]?

IF H4 NE 2, AND H6 NE 1 and H8 NE 1 THEN ASK: Have you legally adopted [S.C.]?

INTERVIEWER INSTRUCTION: IF RESPONDENT IS PARENT AND ANSWERS HE/SHE IS THE BIOLOGICAL PARENT CODE '2'.

- (1) YES (R AND/OR SPOUSE/PARTNER IS LEGAL ADOPTIVE PARENT) [GO TO H13]
- (2) NO (NEITHER R NOR SPOUSE/PARTNER IS LEGAL ADOPTIVE PARENT)
- (77) DON'T KNOW
- (99) REFUSED

# H11

# Universe: All except parents

IF H6=1 THEN ASK: Did you or your spouse know [S.C.] before you began caring for [him/her]?

IF H6 NE 1 and H8=1 THEN ASK: Did you or your partner know [S.C.] before you began caring for [him/her]?

IF H6 NE 1 and H8 NE 1 THEN ASK: Did you know [S.C.] before you began caring for [him/her]?

- (1) YES (R OR SPOUSE/PARTNER KNEW CHILD PREVIOUSLY)
- (2) NO (NEITHER R NOR SPOUSE/PARTNER KNEW CHILD)
- (77) DON'T KNOW
- (99) REFUSED

# Universe: All except parents

IF H6=1 THEN ASK: Since [S.C.] has been living in your household, have you or your spouse ever been officially a foster parent to [him/her]?

IF H6 NE 1 and H8=1 THEN ASK: Since [S.C.] has been living in your household, have you or your partner ever been officially a foster parent to [him/her]?

IF H6 NE 1 and H8 NE 1 THEN ASK: Since [S.C.] has been living in your household, have you ever been officially a foster parent to [him/her]?

READ IF NECESSARY: IF R ASKS WHAT WE MEAN BY "OFFICALLY A FOSTER PARENT" SAY: Foster parents have to complete an application process called a home study, including a home inspection by the child protective services agency. Often to become a foster parent, you also have to participate and complete training.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### H13

#### **Universe: All**

What is your current housing situation? Please stop me when I read the statement that describes your situation. Do you own your own home, rent your own apartment or house, live with family or friends who rent and you contribute part of the rent, live with family or friends who rent but you do not pay rent, or live in a house or condo owned by another family member? [SELECT ONLY ONE]

- (1) OWN YOUR OWN HOME
- (2) RENT YOUR OWN APARTMENT OR HOUSE
- (3) LIVE WITH FAMILY OR FRIENDS WHO RENT AND YOU CONTRIBUTE PART OF THE RENT
- (4) LIVE WITH FAMILY OR FRIENDS WHO RENT BUT YOU DO NOT PAY RENT
- (5) LIVE IN A HOUSE OR CONDO OWNED BY ANOTHER FAMILY MEMBER
- (6) OTHER
- (77) DON'T KNOW
- (99) REFUSED

**Universe: All** 

# H14 MDY

IF RESPONDENT IS A PARENT (H4=2), ASK: Now, I'd like to ask you some questions about [S.C.]. Thinking about the time when you and [S.C.] weren't living together, when was it that [S.C.] stopped living with you on a regular basis?

ELSE, ASK: Now, I'd like to ask you some questions about [S.C.]. When did [S.C.] start living with you on a regular basis, without [his/her] parent or parents?

READ IF NECESSARY: Do you know the year? READ IF NECESSARY: Do you know the month?

RECORD DATE / /

ENTER 55/55/5555 FOR SINCE BIRTH [SKIP TO H16]

ENTER 66/66/6666 TO RECORD LENGTH OF TIME (MONTHS OR YEARS) [SKIP

TO H14\_1]

ENTER 77/77/7777 FOR DON'T KNOW [SKIP TO H15] ENTER 99/99/9999 FOR REFUSED [SKIP TO H15]

# H14 1 RECORD VALUE

ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

# H14 2 (1) YEARS

(2) MONTHS

IF  $H14_2 = 1$  AND  $H14_1 > [AGE*12]$ , OR

IF H14 2 = 2 AND H14 1 > [AGE],

THEN [DISPLAY WARNING TEXT]

ELSE, [SKIP TO H16]

WARNING: ANSWER IS GREATER THAN CURRENT AGE OF CHILD. PLEASE CORRECT.

# H15

Universe: All respondents who don't know the year and month in H14

IF AGE < 4 THEN ASK: About how long ago do you think it was? Was it a year ago or less, or two or three years ago?

IF AGE >= 4 THEN ASK: About how long ago do you think it was? Was it a year ago or less, or two or three years ago, or four or five years ago?

IF AGE >= 6 THEN ASK: About how long ago do you think it was? Was it a year ago or less, or two or three years ago, or four or five years ago, or six or seven years ago?

IF AGE >= 8 THEN ASK: About how long ago do you think it was? Was it a year ago or less, or two or three years ago, or four or five years ago, or six or seven years ago, or eight or nine years ago?

IF AGE >= 10 THEN ASK: About how long ago do you think it was? Was it a year ago or less, or two or three years ago, or four or five years ago, or six or seven years ago, or eight or nine years ago, or 10 or more years ago?

- (1) A YEAR AGO OR LESS
- (2) A YEAR AGO
- (3) TWO OR THREE YEARS AGO
- (4) FOUR OR FIVE YEARS AGO
- (5) SIX OR SEVEN YEARS AGO
- (6) EIGHT OR NINE YEARS AGO
- (7) 10 OR MORE YEARS AGO
- (77) DON'T KNOW
- (99) REFUSED

#### H16

**Universe: All except parents** 

# IF H4=2, THEN GO TO H18

Did anyone from child protective services or a foster care agency help arrange for you to care for [S.C.]?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# H17

# **Universe: All except parents**

When the arrangement was made for you to care for [S.C.], did a court or judge make you responsible for the care of [S.C.]?

- (1) YES
- (2) NO

- (77) DON'T KNOW
- (99) REFUSED

**Universe: All** 

To your knowledge, has [S.C.] ever had an open child protective services case?

**READ IF NECESSARY:** Has a child protective services or social services worker ever visited [S.C.] on a regular basis?

READ IF NECESSARY: Child protective services is the agency designated (in most States) to receive and investigate reports that a child has been abused or neglected. This agency may be part of the larger social services agency. When the agency finds that abuse or neglect has occurred or is at risk of occurring, it will typically open a case and provide intervention and treatment services to the child and family involved.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# H19

Universe: All except parents

IF H4=2, THEN GO TO N5

As part of the process of [S.C.] coming to live with you, did someone from the child protective services agency visit your home?

INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS THEY MOVED INTO [S.C.]'S HOUSEHOLD, RATHER THAN [S.C.] COMING TO LIVE WITH THEM, READ: Please think about the process of you coming to live with [S.C.].

READ IF NECESSARY: It may have been someone from your state or county's child welfare agency, department of social services, or department of human resources.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

Universe: All except parents

GO TO L1\_1

As part of the process of [S.C.] coming to live with you, were you required to undergo a local, state, or federal criminal background check?

INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS THEY MOVED INTO [S.C.]'S HOUSEHOLD, RATHER THAN [S.C.] COMING TO LIVE WITH THEM, READ: Please think about the process of you coming to live with [S.C.].

**READ IF NECESSARY:** Did you have to get fingerprinted?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# N5

**Universe: Fathers** 

IF H5=1, THEN GO TO N6; ELSE IF H5 IN [6,7] THEN GO TO L1

Does [S.C.]'s mother live with you and [S.C.] in this household, or somewhere else?

**READ IF NECESSARY:** If [S.C.] has had more than one person who has been a legal mother, please consider the individual who was the child's legal guardian, either biological or adoptive, when we last interviewed someone in your household on [INTERVIEW DATE].

- (1) IN THIS HOUSEHOLD [GO TO L1 1]
- (2) SOMEWHERE ELSE [GO TO L1\_1]
- (3) DON'T KNOW WHO MOTHER IS, OR DON'T KNOW ANYTHING ABOUT THE MOTHER [GO TO L1 1]
- (4) MOTHER IS DECEASED
- (77) DON'T KNOW [GO TO L1\_1]
- (99) REFUSED [GO TO L1 1]

# **N6**

**Universe: Mothers** 

Does [S.C.]'s father live with you and [S.C.] in this household, or somewhere else?

**READ IF NECESSARY:** If [S.C.] has had more than one person who has been a legal father, please consider the individual who was the child's legal guardian, either biological or adoptive, when we last interviewed someone in your household on [INTERVIEW DATE].

- (1) IN THIS HOUSEHOLD
- (2) SOMEWHERE ELSE
- (3) DON'T KNOW WHO FATHER IS, OR DON'T KNOW ANYTHING ABOUT FATHER
- (4) FATHER IS DECEASED
- (77) DON'T KNOW
- (99) REFUSED

# LIVING ARRANGEMENT (L)

L1 1

**Universe: All except parents** 

IF H4=2, THEN GO TO L2

# IF H14\_DAY=55 AND H14\_MONTH=55 AND H14\_YEAR=5555, FILL L1\_1= 9 AND SKIP L1 1

Just before coming to live with you, where did [S.C.] live? [SELECT ONLY ONE]

INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS THEY MOVED INTO [S.C.]'S HOUSEHOLD, RATHER THAN [S.C.] COMING TO LIVE WITH THEM, CODE "RESPONDENT MOVED INTO [S.C.]'S HOUSEHOLD."

INTERVIEWER INSTRUCTION: IF [S.C.] HAS LIVED WITH RESPONDENT SINCE BIRTH, CODE "[S.C.] HAS LIVED WITH RESPONDENT SINCE BIRTH"

- (1) WITH [HIS/HER] BIRTH PARENT(S)
- (2) WITH [HIS/HER] ADOPTIVE PARENT(S)
- (3) WITH OTHER MEMBERS OF [HIS/HER] BIRTH FAMILY, ANOTHER RELATIVE
- (4) WITH ANOTHER FOSTER PARENT
- (5) IN A GROUP HOME IN FOSTER CARE SYSTEM, THAT IS, A HOME WITH 4 FOSTER CHILDREN OR MORE
- (6) IN A RESIDENTIAL TREATMENT FACILITY, THAT IS, A FACILITY WHERE A NUMBER OF CHILDREN AND YOUTH LIVE
- (7) SOMEONE ELSE NOT MENTIONED (SPECIFY) [SKIP TO L1 VERBATIM]
- (8) RESPONDENT MOVED INTO [S.C.]'S HOUSEHOLD
- (9) [S.C.] HAS LIVED WITH RESPONDENT SINCE BIRTH
- (77) DON'T KNOW
- (99) REFUSED

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RECORD VERBATIM RESPONSE

**L2** 

**Universe: All** 

How much of the time does [S.C.] live with you? Is it all or most of the time, weekdays only, about half of the time, weekends only, or less than all of these?

(1) ALL OR MOST OF THE TIME

NATIONAL SURVEY OF CHILDREN IN NONPARENTAL CARE (NSCNC)

- (2) WEEKDAYS ONLY
- (3) ABOUT HALF OF THE TIME
- (4) WEEKENDS ONLY
- (5) LESS THAN OTHER OPTIONS GIVEN
- (77) DON'T KNOW
- (99) REFUSED

# **L3**

Universe: All except parents

IF H4=2 THEN GO TO L5

Since [S.C.] began living with you, has there been any time lasting a month or more when [S.C.] did not live with you?

INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS THEY MOVED INTO [S.C.]'S HOUSEHOLD, RATHER THAN [S.C.] COMING TO LIVE WITH THEM, READ: "Please think about when you came to live with [S.C.]."

- (1) YES
- (2) NO [GO TO L5]
- (77) DON'T KNOW [GO TO L5]
- (99) REFUSED [GO TO L5]

# **L4**

Universe: All except parents; where R has lived apart from [SC] for one month or more since [SC] came to live with them

# IF H4=2 THEN GO TO L5

When [S.C.] was not living with you for a month or more, did [he/she] ever spend time living with [his/her] mother, [his/her] father, [his/her] grandparent(s), an aunt or uncle, other relatives, a foster home, a group home, or a residential treatment center or hospital? [MARK ALL THAT APPLY]

- (1) [HIS/HER] MOTHER
- (2) [HIS/HER] FATHER
- (3) [HIS/HER] GRANDPARENT(S)
- (4) [HIS/HER] AUNT/UNCLE
- (5) OTHER RELATIVES
- (6) FOSTER HOME
- (7) GROUP HOME
- (8) RESIDENTIAL TREATMENT CENTER OR HOSPITAL
- (9) OTHER (SPECIFY) [SKIP TO L4 VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

L4 VERBATIM	RECORD VERBATIM R	RESPONSE	

L5
Universe: All
IF L5=0, THEN GO TO P1_1

How many biological or adoptive brother or sisters does [S.C.] have?

INTERVIEWER INSTRUCTION: INCLUDE STEP AND HALF BROTHERS AND SISTERS.

ENTER NUMBER OF SIBLINGS:

- (66) [S.C.] HAS SIBLING(S), BUT DON'T KNOW HOW MANY
- (77) DON'T KNOW IF [S.C.] HAS ANY SIBLINGS [GO TO P1 1]
- (99) REFUSED [GO TO P1\_1]

L5\_CONF Just to confirm, I entered that [S.C.] has [fill response from L5] siblings. Is this correct?

- (1) CONFIRMED CHILD HAS [fill response from L5] SIBLINGS
- (2) NOT CORRECT CHILD DOES NOT HAVE [fill response from L5] SIBLINGS RETURN TO L5 AND ENTER CORRECT RESPONSE

#### **L6**

Universe: [SC] has any siblings

# IF L6 > L5 AND L6 NOT = [77, 99] GO TO L6 CONF ELSE SKIP TO L7

How many of these siblings are living with you now?

ENTER NUMBER OF CHILDREN: \_\_\_\_\_

- (77) DON'T KNOW
- (99) REFUSED

L6\_CONF Just to confirm, I entered that [fill response from L6] siblings are living with you now. Is this correct?

- (1) CONFIRMED CHILD HAS [fill response from L6] SIBLINGS
- (2) NOT CORRECT CHILD DOES NOT HAVE [fill response from L6] SIBLINGS RETURN TO L6 AND ENTER CORRECT RESPONSE

# **L7**

Universe: All except parents; where [SC] has non-residential siblings

IF L5=L6 OR H4=2, THEN GO TO P1\_1

During the past 12 months, about how often did [S.C.] have contact with [his/her] siblings that don't live with you, either in person or by talking on the telephone, texting, email, or connecting on Facebook or other social media?

INTERVIEWER INSTRUCTION: READ RESPONSE OPTIONS IF NECESSARY

- (1) NOT AT ALL
- (2) ONCE OR TWICE A YEAR
- (3) SEVERAL TIMES A YEAR
- (4) 1-3 TIMES A MONTH
- (5) ABOUT ONCE A WEEK
- (6) SEVERAL TIMES A WEEK/EVERYDAY
- (77) DON'T KNOW
- (99) REFUSED

# PARENTS: CHARACTERISTICS AND INTERACTION WITH CHILD (P)

#### P1 1

Universe: All except parents

# IF H4=2 THEN GO TO P4

I'd like to ask you a few questions about [S.C.]'s mother.

IF RESPONDENT HAS ADOPTED CHILD SINCE THE TIME OF THE NSCH INTERVIEW (H10=1), ASK: Is [S.C.]'s previous legal mother currently living?

**READ IF NECESSARY:** By previous legal mother, we mean [S.C.]'s legal guardian, either biological or adoptive, before you adopted [him/her].

ELSE ASK: Is [S.C.]'s mother currently living?

**READ IF NECESSARY:** By mother, we mean the child's most recent legal guardian, either biological or adoptive.

- (1) YES
- (2) NO
- (3) DON'T KNOW WHO MOTHER IS, OR DON'T KNOW ANYTHING ABOUT THE MOTHER [GO TO P5]
- (77) DON'T KNOW
- (99) REFUSED

#### **P4**

Universe: All except Rs who don't know who mother is or don't know anything about her IF N5=3 THEN GO TO P5

IF R IS CHILD'S PARENT WHO IS MOTHER (H5=1), ASK: What is the highest grade or year of school you completed?

ELSE ASK: What is the highest grade or year of school [S.C.]'s mother completed?

- (1) 8th GRADE OR LESS
- (2) 9th-12th GRADE NO DIPLOMA
- (3) HIGH SCHOOL GRADUATE OR GED COMPLETED
- (4) COMPLETED A VOCATIONAL, TRADE, OR BUSINESS SCHOOL PROGRAM
- (5) SOME COLLEGE CREDIT BUT NO DEGREE

NATIONAL SURVEY OF CHILDREN IN NONPARENTAL CARE (NSCNC)

- (6) ASSOCIATE DEGREE (AA, AS)
- (7) BACHELOR'S DEGREE (BA, BS, AB)
- (8) MASTER'S DEGREE (MA, MS, MSW, MBA)
- (9) DOCTORATE (PhD, EdD) or PROFESSIONAL DEGREE (MD, DDS, DVM, JD)
- (77) DON'T KNOW
- (99) REFUSED

# **P5**

Universe: All except current non-parental caregivers who reported that mother is deceased

#### IF P1 1=2 THEN GO TO P6

IF R IS CHILD'S MOTHER (H5=1), ASK: Why weren't you living with [S.C.] previously? [MARK ALL THAT APPLY]

ELSE, IF R IS CHILD'S FATHER (H5=2), ASK: Why wasn't [S.C.] living with [his/her] mother previously? [MARK ALL THAT APPLY]

ELSE, IF MOTHER IS NOT DECEASED (P1\_1 = 1,3,77,99) ASK: Why doesn't [S.C.] live with [his/her] mother now? [MARK ALL THAT APPLY]

- (1) MOTHER IN JAIL
- (2) MOTHER DETAINED/DEPORTED FOR IMMIGRATION VIOLATIONS
- (3) MOTHER WAS NOT A GOOD MOTHER/WAS ABUSIVE/MISTREATED CHILD
- (4) CHILD REMOVED BY CHILD PROTECTIVE SERVICES
- (5) MOTHER IS SICK OR MENTALLY ILL
- (6) MOTHER TOO BUSY/WORK SCHEDULE TOO DEMANDING
- (7) MOTHER HAS PROBLEMS WITH HUSBAND/BOYFRIEND
- (8) MOTHER HAS FINANCIAL PROBLEMS/CAN'T AFFORD TO KEEP CHILD
- (9) MOTHER HAS DRUG/ALCOHOL PROBLEMS
- (10) MOTHER DOESN'T WANT TO CARE FOR CHILD/GAVE CHILD UP
- (11) MOTHER THINKS CURRENT CARETAKER CAN DO A BETTER JOB
- (12) MOTHER'S NEIGHBORHOOD NOT GOOD FOR RAISING CHILDREN
- (14) OTHER [SKIP TO P5 VERBATIM]
- (15) MOTHER DOES LIVE WITH [S.C.] NOW
- (77) DON'T KNOW
- (99) REFUSED

P5 VERBATIM	RECORD VERBATIM RESPONSE	

# P6 NEW1

Universe: All except parents and current non-parental caregivers who reported that mother is deceased

# IF H4=2 THEN GO TO P18

Was there a different reason why [S.C.] didn't live with [his/her] mother originally?

- (1) YES THERE WAS A DIFFERENT REASON [GO TO P6]
- (2) NO THE SAME REASON [GO TO P7]
- (77) DON'T KNOW [GO TO P7]
- (99) REFUSED [GO TO P7]

# **P6**

**Universe: All except parents** 

IF H4=2 THEN GO TO P18

Why didn't [S.C.] live with [his/her] mother originally? [MARK ALL THAT APPLY]

- (1) MOTHER IN JAIL
- (2) MOTHER DETAINED/DEPORTED FOR IMMIGRATION VIOLATIONS
- (3) MOTHER WAS NOT A GOOD MOTHER/WAS ABUSIVE/MISTREATED CHILD
- (4) CHILD REMOVED BY CHILD PROTECTIVE SERVICES
- (5) MOTHER WAS SICK OR MENTALLY ILL
- (6) MOTHER TOO BUSY/WORK SCHEDULE TOO DEMANDING
- (7) MOTHER HAS PROBLEMS WITH HUSBAND/BOYFRIEND
- (8) MOTHER HAS FINANCIAL PROBLEMS/CAN'T AFFORD TO KEEP CHILD
- (9) MOTHER HAS DRUG/ALCOHOL PROBLEMS
- (10) MOTHER DOESN'T WANT TO CARE FOR CHILD/GAVE CHILD UP
- (11) MOTHER THINKS CURRENT CARETAKER CAN DO A BETTER JOB
- (12) MOTHER'S NEIGHBORHOOD NOT GOOD FOR RAISING CHILDREN
- (13) MOTHER DECEASED
- (15) OTHER (SPECIFY) [SKIP TO P6 VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

P6\_VERBATIM

RECORD VERBATIM RESPONSE

**P7** 

Universe: All except parents, Rs who do not know who mother is or don't know anything about her, and [S.C.]'s mother is deceased or mother is in jail

Is [S.C.]'s mother currently living in a hospital, in an institution or residential treatment facility, or in jail, prison or a detention center, or none of these?

INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS 'REHAB' CODE '2'.

- (1) IN THE HOSPITAL
- (2) IN AN INSTITUTION OR RESIDENTIAL TREATMENT FACILITY
- (3) IN JAIL, PRISON OR DETENTION CENTER
- (4) NONE OF THE ABOVE
- (77) DON'T KNOW
- (99) REFUSED

# **P8**

Universe: All except parents, Rs who do not know who mother is or don't know anything about her, and [S.C.]'s mother is deceased

During the past 12 months how often has [S.C.] seen [his/her] mother?

- (1) NOT AT ALL
- (2) ONCE OR TWICE A YEAR
- (3) SEVERAL TIMES A YEAR
- (4) 1-3 TIMES A MONTH
- (5) ABOUT ONCE A WEEK
- (6) SEVERAL TIMES A WEEK
- (77) DON'T KNOW
- (99) REFUSED

# **P9**

Universe: All except parents, Rs who do not know who mother is or don't know anything about her, and [S.C.]'s mother is deceased

During the past 12 months, about how often did [S.C.] have contact with [his/her] mother by talking on the telephone, texting, email, connecting on Facebook or other social media, or by receiving a card, letter or package from [his/her] mother?

- (1) NOT AT ALL
- (2) ONCE OR TWICE A YEAR
- (3) SEVERAL TIMES A YEAR
- (4) 1-3 TIMES A MONTH
- (5) ABOUT ONCE A WEEK
- (6) SEVERAL TIMES A WEEK
- (7) DON'T KNOW EXACT FREQUENCY BUT KNOW [S.C.] AND MOTHER CONNECT
- (77) DON'T KNOW
- (99) REFUSED

#### P11

Universe: All except parents, Rs who do not know who mother is or don't know anything about her, and [S.C.]'s mother is deceased

During the past 12 months, has [S.C.]'s mother ever cared for [him/her] during the day or overnight?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### P14

Universe: All except parents, Rs who do not know who mother is or don't know anything about her, and [S.C.]'s mother is deceased

When there are decisions to make about [S.C.]'s school or day care arrangements, how often do you talk it over with [S.C.]'s mother first? Is it all the time, most of the time, about half the time, sometimes, or never?

- (1) ALL THE TIME
- (2) MOST OF THE TIME
- (3) ABOUT HALF THE TIME
- (4) SOMETIMES
- (5) NEVER
- (77) DON'T KNOW
- (99) REFUSED

#### P15

Universe: All except parents, Rs who do not know who mother is or don't know anything about her, and [S.C.]'s mother is deceased

When there are decisions to make about [S.C.]'s health or health care, how often do you talk it over with [S.C.]'s mother first? Is it all the time, most of the time, about half the time, sometimes, or never?

- (1) ALL THE TIME
- (2) MOST OF THE TIME
- (3) ABOUT HALF THE TIME
- (4) SOMETIMES
- (5) NEVER
- (77) DON'T KNOW
- (99) REFUSED

# **END MOTHER SERIES**

# START FATHER SERIES

#### P18

**Universe: All except parents** 

IF H4=2, THEN GO TO P21

I'd like to ask you a few questions about [S.C.]'s father.

IF RESPONDENT HAS ADOPTED CHILD SINCE THE TIME OF THE NSCH INTERVIEW (H10=1), ASK: Is [S.C.]'s previous legal father currently living?

**READ IF NECESSARY:** By previous legal father, we mean the child's most recent legal guardian, either biological or adoptive, before you adopted [him/her].

ELSE ASK: Is [S.C.]'s father currently living?

**READ IF NECESSARY:** By father, we mean [S.C.]'s most recent legal guardian, either biological or adoptive.

- (1) YES
- (2) NO
- (3) DON'T KNOW WHO FATHER IS, OR DON'T KNOW ANYTHING ABOUT FATHER [GO TO P23]
- (77) DON'T KNOW
- (99) REFUSED

# P21

Universe: All except Rs who don't know who father is or don't know anything about him

IF N6=3 THEN GO TO P23

IF R IS [S.C.]'S PARENT WHO IS FATHER, ASK: What is the highest grade or year of school you completed?

ELSE ASK: What is the highest grade or year of school [S.C.]'s father completed?

- (1) 8th GRADE OR LESS
- (2) 9th-12th GRADE NO DIPLOMA
- (3) HIGH SCHOOL GRADUATE OR GED COMPLETED
- (4) COMPLETED A VOCATIONAL, TRADE, OR BUSINESS SCHOOL PROGRAM
- (5) SOME COLLEGE CREDIT BUT NO DEGREE
- (6) ASSOCIATE DEGREE (AA, AS)
- (7) BACHELOR'S DEGREE (BA, BS, AB)

- (8) MASTER'S DEGREE (MA, MS, MSW, MBA)
- (9) DOCTORATE (PhD, EdD) or PROFESSIONAL DEGREE (MD, DDS, DVM, JD)
- (77) DON'T KNOW
- (99) REFUSED

#### P22

Universe: All except fathers and Rs who don't know who father is or don't know anything about him

#### IF H5=2 THEN GO TO P23

IF FATHER IS DECEASED (P18 =1) THEN ASK: Had legal paternity been established? That is, had the father signed a document identifying himself as [S.C.]'s father or had a court or administrative agency, such as the child support agency, established the child's father as his legal father?

ELSE ASK: Has legal paternity been established? That is, has the father signed a document identifying himself as [S.C.]'s father or has a court or administrative agency, such as the child support agency, established the child's father as his legal father?

HELP TEXT: Code 'YES' is father signed the birth certificate.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### P23

Universe: All except current non-parental caregivers who reported that father is deceased IF P18=2 THEN GO TO P24 NEW1

IF R IS CHILD'S FATHER (H5=2), ASK: Why weren't you living with [S.C.] previously? [MARK ALL THAT APPLY]

ELSE, IF R IS CHILD'S MOTHER (H5=1), ASK: Why wasn't [S.C.] living with [his/her] father previously? [MARK ALL THAT APPLY]

ELSE, IF FATHER IS NOT DECEASED (P18 = 1,3,77,99) ASK: Why doesn't [S.C.] live with [his/her] father now? [MARK ALL THAT APPLY]

- (1) FATHER IN JAIL
- (2) FATHER DETAINED/DEPORTED FOR IMMIGRATION VIOLATIONS
- (3) FATHER WAS NOT A GOOD FATHER/WAS ABUSIVE/MISTREATED CHILD

- (4) CHILD REMOVED BY CHILD PROTECTIVE SERVICES
- (5) FATHER IS SICK OR MENTALLY ILL
- (6) FATHER TOO BUSY/WORK SCHEDULE TOO DEMANDING
- (7) FATHER HAS PROBLEMS WITH WIFE/GIRLFRIEND
- (8) FATHER HAS FINANCIAL PROBLEMS/CAN'T AFFORD TO KEEP CHILD
- (9) FATHER HAS DRUG/ALCOHOL PROBLEMS
- (10) FATHER DOESN'T WANT TO CARE FOR CHILD/GAVE CHILD UP
- (11) FATHER THINKS CURRENT CARETAKER CAN DO A BETTER JOB
- (12) FATHER'S NEIGHBORHOOD NOT GOOD FOR RAISING CHILDREN
- (14) OTHER (SPECIFY) [SKIP TO P23\_VERBATIM]
- (15) FATHER DOES LIVE WITH [S.C.] NOW
- (77) DON'T KNOW
- (99) REFUSED

RECORD VERBATIM RESPONS
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**P24** 

Universe: All except parents

# **IF H4=2 THEN GO TO C5**

P24 NEW1

Was there a different reason why [S.C.] didn't live with [his/her] father originally?

- (1) YES THERE WAS A DIFFERENT REASON [GO TO P24]
- (2) NO THE SAME REASON [GO TO P25]
- (77) DON'T KNOW [GO TO P25]
- (99) REFUSED [GO TO P25]

P24 Why didn't [S.C.] live with [his/her] father originally? [MARK ALL THAT APPLY]

- (1) FATHER IN JAIL
- (2) FATHER DETAINED/DEPORTED FOR IMMIGRATION VIOLATIONS
- (3) FATHER WAS NOT A GOOD FATHER/WAS ABUSIVE/MISTREATED CHILD
- (4) CHILD REMOVED BY CHILD PROTECTIVE SERVICES
- (5) FATHER WAS SICK OR MENTALLY ILL
- (6) FATHER TOO BUSY/WORK SCHEDULE TOO DEMANDING
- (7) FATHER HAS PROBLEMS WITH WIFE/GIRLFRIEND
- (8) FATHER HAS FINANCIAL PROBLEMS/CAN'T AFFORD TO KEEP CHILD
- (9) FATHER HAS DRUG/ALCOHOL PROBLEMS
- (10) FATHER DOESN'T WANT TO CARE FOR CHILD/GAVE CHILD UP
- (11) FATHER THINKS CURRENT CARETAKER CAN DO A BETTER JOB
- (12) FATHER'S NEIGHBORHOOD NOT GOOD FOR RAISING CHILDREN
- (13) SAME REASON THAT CHILD DOESN'T LIVE WITH FATHER NOW

- (14) OTHER (SPECIFY) [SKIP TO P24 VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

P24 VERBATIM RECORD VERBATIM RESPONSE \_\_\_\_\_

# P25

Universe: All except parents, Rs who do not know who father is or don't know anything about him, [SC]'s father is deceased, or father is in jail.

IF P18 IN [1, 99] AND P23=15 THEN GO TO P29

IF P23=1 THEN GO TO P26

Is [S.C.]'s father currently living in a hospital, in an institution or residential treatment facility, or in jail, prison or a detention center, none of these?

INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS 'REHAB' CODE '2'.

- (1) IN THE HOSPITAL
- (2) IN AN INSTITUTION OR RESIDENTIAL TREATMENT FACILITY
- (3) IN JAIL, PRISON OR DETENTION CENTER
- (4) NONE OF THE ABOVE
- (77) DON'T KNOW
- (99) REFUSED

#### **P26**

Universe: All except parents, Rs who do not know who father is or don't know anything about him, and [S.C.]'s father is deceased

During the past 12 months how often has [S.C.] seen [his/her] father?

- (1) NOT AT ALL
- (2) ONCE A YEAR OR TWICE A YEAR
- (3) SEVERAL TIMES A YEAR
- (4) 1-3 TIMES A MONTH
- (5) ABOUT ONCE A WEEK
- (6) SEVERAL TIMES A WEEK/EVERYDAY
- (77) DON'T KNOW
- (99) REFUSED

#### **P27**

Universe: All except parents, Rs who do not know who father is or don't know anything about him, and [S.C.]'s father is deceased

During the past 12 months, about how often did [S.C.] have contact with [his/her] father by talking on the telephone, texting, email, connecting on Facebook or other social media, or by receiving a card, letter or package from [his/her] father?

- (1) NOT AT ALL
- (2) ONCE OR TWICE A YEAR
- (3) SEVERAL TIMES A YEAR
- (4) 1-3 TIMES A MONTH
- (5) ABOUT ONCE A WEEK
- (6) SEVERAL TIMES A WEEK/EVERYDAY
- (7) DON'T KNOW EXACT FREQUENCY BUT KNOW [S.C.] AND FATHER CONNECT
- (77) DON'T KNOW
- (99) REFUSED

# **P29**

Universe: All except parents, Rs who do not know who father is or don't know anything about him, and [S.C.]'s father is deceased

During the past 12 months, has [S.C.]'s father ever cared for [him/her] during the day or overnight?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# P32

Universe: All except parents, Rs who do not know who father is or don't know anything about him, and [S.C.]'s father is deceased

When there are decisions to make about [S.C.]'s school or day care arrangements, how often do you talk it over with [S.C.]'s father first? Is it all the time, most of the time, about half the time, sometimes, or never?

- (1) ALL THE TIME
- (2) MOST OF THE TIME
- (3) ABOUT HALF THE TIME

- (4) SOMETIMES
- (5) NEVER
- (77) DON'T KNOW
- (99) REFUSED

#### P33

Universe: All except parents, Rs who do not know who father is or don't know anything about him, and [S.C.]'s father is deceased

When there are decisions to make about [S.C.]'s health or health care, how often do you talk it over with [S.C.]'s father first? Is it all the time, most of the time, about half the time, sometimes, or never?

- (1) ALL THE TIME
- (2) MOST OF THE TIME
- (3) ABOUT HALF THE TIME
- (4) SOMETIMES
- (5) NEVER
- (77) DON'T KNOW
- (99) REFUSED

#### P36

Universe: ONLY ASK IF AT LEAST ONE PARENT IS LIVING (IF P1 1=1 OR P18=1)

ONLY ASK IF AT LEAST ONE PARENT IS LIVING (IF P1 1=1 OR P18=1)

IF P1\_1 NE 1 AND P18=1 THEN ASK: "How well do you get along with [S.C.]'s father? Would you say get along very well, get along somewhat well, don't get along very well, or don't get along at all?

IF P1\_1=1 AND P18 NE 1 THEN ASK: "How well do you get along with [S.C.]'s mother? Would you say get along very well, get along somewhat well, don't get along very well, or don't get along at all?

ELSE IF P1\_1 AND P18=1 ASK: How well do you get along with [S.C.]'s parents? Would you say get along very well, get along somewhat well, don't get along very well, or don't get along at all?

# **END FATHER SERIES**

# FINANCIAL SUPPORT (F)

#### **F1**

# Universe: All except parents

Next, I'd like to ask some questions about child support from [S.C.]'s parent or parents. Have child support payments for [S.C.] ever been agreed to informally, agreed to in writing, awarded to you by a court or judge, or do you not have an agreement of any kind? [MARK ALL THAT APPLY]

INTERVIEWER INSTRUCTION: CODE 4 CANNOT BE CODED WITH ANY OTHER.

- (1) YES, AGREED TO INFORMALLY
- (2) YES, AGREED TO IN WRITING
- (3) YES, AWARDED BY A COURT OR JUDGE
- (4) NO AGREEMENT [GO TO F3]
- (77) DON'T KNOW [GO TO F3]
- (99) REFUSED [GO TO F3]

#### F3

# Universe: All except parents; where there is no child support agreement

Have you ever contacted a child support enforcement office, a department of social services, welfare office, or any government agency to find out about child support for [S.C.]?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### F4

# Universe: All except parents

In the past 12 months, did you receive any payment for taking care of [S.C.]? Please include foster care or adoption assistance payments, social security survivor benefits, payments from Temporary Assistance for Needy Families (TANF) or welfare, as well as child support payments from a parent.

- (1) YES
- (2) NO [GO TO F10]
- (77) DON'T KNOW [GO TO F10]
- (99) REFUSED [GO TO F10]

# **F5**

Universe: All except parents; where any payment is received for caring for [S.C.]

From whom do you receive payments? [MARK ALL THAT APPLY]

- (1) CHILD'S MOTHER
- (2) CHILD'S FATHER
- (3) FOSTER CARE OR ADOPTION PAYMENT/STIPEND
- (4) TEMPORARY ASSISTANCE FOR NEEDY FAMILIES (TANF) / WELFARE
- (5) SOCIAL SECURITY FOR CHILD
- (6) UNSPECIFIED GOVERNMENT SOURCE
- (7) FRIENDS OR RELATIVES
- (8) OTHER (SPECIFY) [SKIP TO F5\_VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

#### F5 VERBATIM

RECORD VERBATIM RESPONSE

#### F10

Universe: All except parents; where R receives child support payments from [S.C.]'s mother and/or father

# IF F5 NE [1, 2], THEN GO TO F11

IF F5 = 1 AND 2, THEN ASK: Do [S.C.]'s parents give you a regular amount of money each month or just money once in a while to help out?

IF F5 = 1, THEN ASK: Does [S.C.]'s mother give you a regular amount of money each month or just money once in a while to help out?

IF F5 = 2, THEN ASK: Does [S.C.]'s father give you a regular amount of money each month or just money once in a while to help out?

- (1) REGULAR AMOUNT
- (2) MONEY ONCE IN A WHILE
- (77) DON'T KNOW
- (99) REFUSED

# F11

# Universe: All except parents

Do you receive any non-monetary support from [S.C.]'s parents or your friends or other relatives for taking care of [S.C.]? Non-monetary support may include diapers, formula, food, clothes, or bedding.

**READ IF NECESSARY**: Relatives could include relatives of the child or your own relatives.

- (1) YES
- (2) NO [GO TO F6]
- (77) DON'T KNOW [GO TO F6]
- (99) REFUSED [GO TO F6]

#### F12

Universe: All except parents; where R receives non-monetary support from [S.C.]'s parents or friends or other relatives

Who do you receive the non-monetary supports from? [MARK ALL THAT APPLY]

- (1) CHILD'S MOTHER
- (2) CHILD'S FATHER
- (3) FRIENDS OR RELATIVES
- (4) CHURCH OR OTHER GROUP
- (77) DON'T KNOW
- (99) REFUSED

# **F6**

# Universe: All except parents

IF F5=4, THEN ASK: Did you apply for the TANF or welfare payments for [S.C.]?

IF F5 NE 4, THEN ASK: Have you ever applied for TANF or welfare payments on behalf of [S.C.]?

- (1) YES
- (2) NO [GO TO F9]
- (77) DON'T KNOW [GO TO F9]
- (99) REFUSED [GO TO F9]

#### **F7**

Universe: All except parents; where R does not receive TANF

IF F5=4, THEN GO TO F9

Why didn't you receive Temporary Assistance for Needy Families (TANF), that is, welfare payments, for [S.C.]? [MARK ALL THAT APPLY]

INTERVIEWER INSTRUCTION: PROBE "Any other reason?"

HELP TEXT: "NOT ELIGIBLE" CAN BE DUE TO INCOME, RELATIONSHIP TO CHILD, OR OTHER REASONS.

- (1) NOT ELIGIBLE
- (2) ASSISTANCE NOT AVAILABLE
- (3) PUT ON WAITLIST
- (4) DISCOURAGED/GAVE UP/ TOO MUCH HASSLE
- (5) DECIDED DIDN'T WANT/NEED HELP FROM GOVERNMENT
- (6) DIDN'T KNOW ASSISTANCE WAS AVAILABLE
- (7) OTHER (SPECIFY) [SKIP TO F7\_VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

# F7 VERBATIM

RECORD VERBATIM RESPONSE

Universe: All except parents; where R received TANF/welfare payments and R did not apply for TANF/welfare payments

IF F5 NE 4, THEN GO TO C1

Was [S.C.] already receiving TANF or welfare benefits before coming to live with you?

INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS THEY MOVED INTO [S.C.]'S HOUSEHOLD, RATHER THAN [S.C.] COMING TO LIVE WITH THEM, READ: Please think about when you came to live with [S.C.].

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# CAREGIVER PREPARATION, LONG TERM PLANNING, LEGAL CUSTODY (C)

#### C1

# Universe: All except parents

Now I'd like to ask some questions about how prepared you were to care for [S.C.] and any plans you may have for the future.

Overall, how well prepared were you to care for [S.C.] when [he/she] first came to live with you? Would you say you were very well prepared, somewhat prepared, not very well prepared, or not at all prepared?

INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS THEY MOVED INTO [S.C.]'S HOUSEHOLD, RATHER THAN [S.C.] COMING TO LIVE WITH THEM, READ: Please think about when you came to live with [S.C.].

- (1) VERY WELL PREPARED
- (2) SOMEWHAT PREPARED
- (3) NOT VERY WELL PREPARED
- (4) NOT AT ALL PREPARED
- (77) DON'T KNOW
- (99) REFUSED

#### C<sub>2</sub>

# Universe: All except parents

I am going to ask you about specific services or items you may have needed at the time [S.C.] first came to live with you. I'd like you to tell me how easy or difficult each item or service was to obtain.

INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS THEY MOVED INTO [S.C.]'S HOUSEHOLD, RATHER THAN [S.C.] COMING TO LIVE WITH THEM, READ: Please think about when you came to live with [S.C.].\

(1) CONTINUE

C2A Please tell me how easy or difficult it was to obtain...

Child care for [S.C.]

Would you say it was very easy, somewhat easy, somewhat difficult, very difficult, or you never needed it for [S.C.]?

# INTERVIEWER INSTRUCTION: CODE "VERY DIFFICULT" IF RESPONDENT CANNOT GET SERVICE.

- (1) VERY EASY
- (2) SOMEWHAT EASY
- (3) SOMEWHAT DIFFICULT
- (4) VERY DIFFICULT
- (5) NEVER NEEDED FOR [S.C.]
- (6) DIDN'T KNOW ABOUT THIS SERVICE OR NEVER TRIED TO GET IT
- (77) DON'T KNOW
- (99) REFUSED

C2B Please tell me how easy or difficult it was to obtain...

Clothing for [S.C.]?

Would you say it was very easy, somewhat easy, somewhat difficult, very difficult, or you never needed it for [S.C.]?

INTERVIEWER INSTRUCTION: CODE "VERY DIFFICULT" IF RESPONDENT CANNOT GET SERVICE.

- (1) VERY EASY
- (2) SOMEWHAT EASY
- (3) SOMEWHAT DIFFICULT
- (4) VERY DIFFICULT
- (5) NEVER NEEDED FOR [S.C.]
- (6) DIDN'T KNOW ABOUT THIS SERVICE OR NEVER TRIED TO GET IT
- (77) DON'T KNOW
- (99) REFUSED

C2C Please tell me how easy or difficult it was to obtain...

A bed or other furniture for [S.C.]

Would you say it was very easy, somewhat easy, somewhat difficult, very difficult, or you never needed it for [S.C.]?

INTERVIEWER INSTRUCTION: CODE "VERY DIFFICULT" IF RESPONDENT CANNOT GET SERVICE.

- (1) VERY EASY
- (2) SOMEWHAT EASY
- (3) SOMEWHAT DIFFICULT
- (4) VERY DIFFICULT
- (5) NEVER NEEDED FOR [S.C.]
- (6) DIDN'T KNOW ABOUT THIS SERVICE OR NEVER TRIED TO GET IT

(77) DON'T KNOW

(99) REFUSED

C2D (READ IF NECESSARY: Please tell me how easy or difficult it was to obtain...)

Legal assistance

**READ IF NECESSARY:** Would you say it was very easy, somewhat easy, somewhat difficult, very difficult, or you never needed it for [S.C.]?

HELP TEXT: LEGAL ASSISTANCE IS HELP OR ADVICE PROVIDED BY AN ATTORNEY.

INTERVIEWER INSTRUCTION: CODE "VERY DIFFICULT" IF RESPONDENT CANNOT GET SERVICE.

- (1) VERY EASY
- (2) SOMEWHAT EASY
- (3) SOMEWHAT DIFFICULT
- (4) VERY DIFFICULT
- (5) NEVER NEEDED FOR [S.C.]
- (6) DIDN'T KNOW ABOUT THIS SERVICE OR NEVER TRIED TO GET IT
- (77) DON'T KNOW
- (99) REFUSED

C2E (READ IF NECESSARY: Please tell me how easy or difficult it was to obtain...)

Food from a pantry or food bank

**READ IF NECESSARY:** Would you say it was very easy, somewhat easy, somewhat difficult, very difficult, or you never needed it for [S.C.]?

INTERVIEWER INSTRUCTION: CODE "VERY DIFFICULT" IF RESPONDENT CANNOT GET SERVICE.

- (1) VERY EASY
- (2) SOMEWHAT EASY
- (3) SOMEWHAT DIFFICULT
- (4) VERY DIFFICULT
- (5) NEVER NEEDED FOR [S.C.]
- (6) DIDN'T KNOW ABOUT THIS SERVICE OR NEVER TRIED TO GET IT
- (77) DON'T KNOW
- (99) REFUSED

C2F (READ IF NECESSARY: Please tell me how easy or difficult it was to find ...)

A parent or grandparent support group

**READ IF NECESSARY:** Would you say it was very easy, somewhat easy, somewhat difficult, very difficult, or you never needed it for [S.C.]?

INTERVIEWER INSTRUCTION: A GRANDPARENT SUPPORT GROUP IS A GROUP OF GRANDPARENTS WHO MEET TOGETHER TO SHARE THEIR EXPERIENCES AND ADVICE ABOUT RAISING THEIR GRANDCHILDREN.

INTERVIEWER INSTRUCTION: CODE "VERY DIFFICULT" IF RESPONDENT CANNOT GET SERVICE.

- (1) VERY EASY
- (2) SOMEWHAT EASY
- (3) SOMEWHAT DIFFICULT
- (4) VERY DIFFICULT
- (5) NEVER NEEDED FOR [S.C.]
- (6) DIDN'T KNOW ABOUT THIS SERVICE OR NEVER TRIED TO GET IT
- (77) DON'T KNOW
- (99) REFUSED

C2G (READ IF NECESSARY: Please tell me how easy or difficult it was to obtain...)

Transportation assistance

**READ IF NECESSARY:** Would you say it was very easy, somewhat easy, somewhat difficult, very difficult, or you never needed it for [S.C.]?

INTERVIEWER INSTRUCTION: CODE "VERY DIFFICULT" IF RESPONDENT CANNOT GET SERVICE.

- (1) VERY EASY
- (2) SOMEWHAT EASY
- (3) SOMEWHAT DIFFICULT
- (4) VERY DIFFICULT
- (5) NEVER NEEDED FOR [S.C.]
- (6) DIDN'T KNOW ABOUT THIS SERVICE OR NEVER TRIED TO GET IT
- (77) DON'T KNOW
- (99) REFUSED

C2H (READ IF NECESSARY: Please tell me how easy or difficult it was to obtain...)

Help obtaining public assistance such as food stamps, Medicaid, Social Security, or TANF

**READ IF NECESSARY:** Would you say it was very easy, somewhat easy, somewhat difficult, very difficult, or you never needed it for [S.C.]?

**HELP TEXT**: TANF stands for Temporary Assistance for Needy Families.

# INTERVIEWER INSTRUCTION: CODE "VERY DIFFICULT" IF RESPONDENT CANNOT GET SERVICE.

- (1) VERY EASY
- (2) SOMEWHAT EASY
- (3) SOMEWHAT DIFFICULT
- (4) VERY DIFFICULT
- (5) NEVER NEEDED FOR [S.C.]
- (6) DIDN'T KNOW ABOUT THIS SERVICE OR NEVER TRIED TO GET IT
- (77) DON'T KNOW
- (99) REFUSED
- C2K (READ IF NECESSARY: Please tell me how easy or difficult it was to obtain...)

Information about the school system

**READ IF NECESSARY:** Would you say it was very easy, somewhat easy, somewhat difficult, very difficult, or you never needed it for [S.C.]?

INTERVIEWER INSTRUCTION: CODE "VERY DIFFICULT" IF RESPONDENT CANNOT GET SERVICE.

- (1) VERY EASY
- (2) SOMEWHAT EASY
- (3) SOMEWHAT DIFFICULT
- (4) VERY DIFFICULT
- (5) NEVER NEEDED FOR [S.C.]
- (6) DIDN'T KNOW ABOUT THIS SERVICE OR NEVER TRIED TO GET IT
- (77) DON'T KNOW
- (99) REFUSED
- C2L (READ IF NECESSARY: Please tell me how easy or difficult it was to obtain...)

Information about adoption, guardianship, or custody

**READ IF NECESSARY:** Would you say it was very easy, somewhat easy, somewhat difficult, very difficult, or you never needed it for [S.C.]?

INTERVIEWER INSTRUCTION: CODE "VERY DIFFICULT" IF RESPONDENT CANNOT GET SERVICE.

- (1) VERY EASY
- (2) SOMEWHAT EASY
- (3) SOMEWHAT DIFFICULT
- (4) VERY DIFFICULT
- (5) NEVER NEEDED FOR [S.C.]
- (6) DIDN'T KNOW ABOUT THIS SERVICE OR NEVER TRIED TO GET IT
- (77) DON'T KNOW
- (99) REFUSED

#### **C5**

**Universe: All** 

Do you think that [S.C.] will live with you until [he/she] grows up?

- (1) YES [GO TO C8]
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **C6**

Universe: All; where R thinks [S.C.] won't live with R until [S.C.] grows up or R doesn't know or refuses to answer if [S.C.] will live with R until [S.C.] grows up

How much longer do you think [S.C.] will stay with you?

**READ IF NECESSARY:** Your best estimate is fine.

INTERVIEWER INSTRUCTION: CODE ONE OF TWO WAYS: MONTHS OR YEARS

ENTER NUMBER

ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

C6 1 CHOOSE MONTHS OR YEARS

- (1) GAVE NUMBER OF MONTHS
- (2) GAVE NUMBER OF YEARS

# **C7**

Universe: All; where R thinks [S.C.] won't live with R until [S.C.] grows up or R doesn't know or refuses to answer if [S.C.] will live with R until [S.C.] grows up

Who do you think [S.C.] will live with after you? [MARK ALL THAT APPLY]

- (1) MOTHER
- (2) FATHER
- (3) MOTHER AND FATHER
- (4) OTHER RELATIVE OF CHILD
- (5) FRIEND
- (6) FOSTER PARENT/FAMILY
- (7) ADOPTIVE PARENT/FAMILY

- (8) INDEPENDENTLY BY [HIMSELF/HERSELF] OR WITH ROOMMATES OR SPOUSE/PARTNER
- (9) OTHER (SPECIFY) [SKIP TO C7\_VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

# C7\_VERBATIM RECORD VERBATIM RESPONSE \_\_\_\_\_

**C8** 

Universe: All except parents, and Rs who have adopted [S.C.]

**IF H4=2 OR H10 = 1, THEN GO TO CC1** 

Do you have a formal or legal agreement about custody or guardianship for [S.C.]?

READ IF NECESSARY: Custody refers to the legal right to make decisions about children, including where they live. Parents have legal custody of their children unless they voluntarily give custody to someone else or a court takes this right away and gives it to someone else. For instance, a court may give legal custody to a relative or to a child welfare agency.

- (1) YES [GO TO C11]
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

**C9** 

Universe: All except parents, and Rs who have adopted [S.C.]; where R does not have custody/guardianship of [S.C.]

Are you currently trying or planning to seek legal custody of [S.C.] or become [S.C.]'s legal guardian?

READ IF NECESSARY: Legal custody or guardianship means that the parental responsibility and legal authority for [S.C.] have been transferred to you, with the intention that you plan to provide permanent care for [S.C.]. This can be done without terminating the parental rights of the child's parents. If [S.C.] was in foster care, then establishing custody or guardianship would have ended [his/her] involvement in the child welfare system, allowing you to make important decisions on the child's behalf, and establishing you as a long-term caregiver for the child.

- (1) YES [GO TO C11]
- (2) NO

- (77) DON'T KNOW [GO TO C11]
- (99) REFUSED [GO TO C11]

# C10

Universe: All except parents, and Rs who have adopted [S.C.]; where R is not seeking or not planning to seek custody or guardianship of [S.C.]

What discouraged you from seeking custody or guardianship of [S.C.] or prevented you from making such a plan? [MARK ALL THAT APPLY]

- (1) CHILD HAS DISABILITIES/HEALTH PROBLEMS THAT RESPONDENT MAY NOT BE ABLE TO HANDLE IN A LONG-TERM SITUATION
- (2) PROBLEMS BETWEEN CHILD AND OTHER FAMILY MEMBERS
- (3) PROCESS SEEMED TOO COMPLICATED/DIFFICULT
- (4) FINANCIAL CONCERNS
- (5) RESPONDENT'S HEALTH OR AGE
- (6) CHILD'S PARENTS DISCOURAGED IT
- (7) COURT REFUSED TO GRANT CUSTODY/GUARDIANSHIP
- (8) ATTORNEY OR SOCIAL WORKER RECOMMENDED AGAINST
- (9) CHILD'S AGE/CHILD TOO OLD
- (10) CHILD'S BEHAVIOR PROBLEMS OR JUVENILE JUSTICE SYSTEM INVOLVEMENT
- (11) NO DISCOURAGING FACTORS
- (12) OTHER, SPECIFY [SKIP TO C10\_VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

C10 VERBATIM	RECORD VERBATIM RESPONSE	

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Universe: All except parents, and Rs who have adopted [S.C.]

# IF H4=3 THEN GO TO CC1

Have you ever considered legally adopting [S.C.] if [he/she] cannot return to [his/her] parents?

**READ IF NECESSARY:** By adoption, I mean the court process through which a child would become a full and permanent legal member of your family. Although a child could maintain contact with their birth family, the parents' rights have to be terminated or relinquished for an adoption to be finalized.

- (1) YES
- (2) NO [GO TO C13]
- (77) DON'T KNOW
- (99) REFUSED

#### C12

# Universe: All except parents, and Rs who have adopted [S.C.]

Are you currently planning to adopt [S.C.]?

- (1) YES [GO TO CC1]
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### C13

Universe: All except parents; where R has not adopted [S.C.] and is not currently planning to adopt [S.C.]

What discouraged you from wanting to adopt [S.C.] or prevented you from making such a plan? [MARK ALL THAT APPLY]

#### **BIOLOGICAL FAMILY ISSUES:**

- (1) CHILD STILL EMOTIONALLY ATTACHED TO BIOLOGICAL PARENT(S)
- (2) BIOLOGICAL PARENT HAS NOT RELINQUISHED RIGHTS, OR RIGHTS HAVE NOT BEEN TERMINATED BY COURT
- (3) CHILD'S PARENTS DISCOURAGED IT
- (4) PROBLEMS BETWEEN CHILD AND OTHER MEMBERS OF RESPONDENT'S FAMILY

#### **CHILD ISSUES:**

- (5) CHILD'S RACE/ETHNICITY DIFFERS FROM RESPONDENT'S FAMILY
- (6) CHILD'S AGE/CHILD TOO OLD

#### **HEALTH ISSUES:**

- (7) CHILD HAS DISABILITIES/HEALTH PROBLEMS THAT RESPONDENT MAY NOT BE ABLE TO HANDLE IN A LONG-TERM SITUATION
- (8) RESPONDENT'S HEALTH OR AGE
- (9) CHILD'S BEHAVIOR PROBLEMS/JUVENILE JUSTICE SYSTEM INVOLVEMENT

#### FINANCIAL ISSUES:

(10) FINANCIAL CONCERNS

#### OTHER:

- (11) PROCESS SEEMED TOO COMPLICATED/DIFFICULT
- (12) NO DISCOURAGING FACTORS
- (13) OTHER, SPECIFY [SKIP TO C13\_VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

C13 V	/ERBATIM	RECORD	VERBATIM RESPONSE	
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## CAREGIVER AND CHILD INTERACTIONS, RELATIONSHIP, MONITORING AND SUPERVISION (CC)

CC1

**Universe: All** 

How would you describe your relationship to [S.C.]? Would you say very warm and close, somewhat warm and close, somewhat distant, or very distant? Please describe your relationship as it exists now.

- (1) VERY WARM AND CLOSE
- (2) SOMEWHAT WARM AND CLOSE
- (3) SOMEWHAT DISTANT
- (4) VERY DISTANT
- (77) DON'T KNOW
- (99) REFUSED

## CHILD WELL-BEING, CHILD CARE, AND SCHOOL (WB)

#### WB2

**Universe: All** 

Now I want to ask about mental health care [S.C.] may have received during the last 12 months. Mental health professionals include psychiatrists, psychologists, psychiatric nurses, and clinical social workers. During the past 12 months, has [S.C.] received any treatment or counseling from a mental health professional?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## WB3

Universe: All where [S.C.] is age 5 or older

## IF AGE <5, THEN GO TO WB8

How easy or difficult was it to enroll [S.C.] in school? Would you say it was very easy, somewhat easy, somewhat difficult, or very difficult?

- (1) VERY EASY [GO TO WB6]
- (2) SOMEWHAT EASY
- (3) SOMEWHAT DIFFICULT
- (4) VERY DIFFICULT
- (5) NOT EVER HAD TO ENROLL IN SCHOOL [GO TO WB6]
- (77) DON'T KNOW
- (99) REFUSED

#### WB4

Universe: All where [S.C.] is age 5 or older and respondent ever enrolled child in school but did not report that doing so was very easy

What difficulties did you face in enrolling [S.C.] in school? [MARK ALL THAT APPLY]

- (1) LACK OF TRANSPORTATION
- (2) LACK OF IMMUNIZATION AND MEDICAL RECORDS
- (3) LACK OF SCHOOL RECORDS
- (4) LACK OF GUARDIANSHIP OR CUSTODY OF CHILD
- (5) LACK OF PROOF OF CHILD'S RESIDENCY

- (6) LACK OF BIRTH CERTIFICATE
- (7) SCHOOL FEES
- (8) CHILD'S LEARNING OR BEHAVIORAL ISSUES
- (9) DID NOT KNOW WHOM TO CALL OR WHERE TO GO TO ENROLL CHILD
- (10) SCHOOL CREDIT ACCRUAL/COURSEWORK NOT CONSISTENT IN

DIFFERENT SCHOOLS CHILD HAS ATTENDED

- (11) OTHER (SPECIFY) [SKIP TO WB4 VERBATIM]
- (12) NO DIFFICULTIES
- (77) DON'T KNOW
- (99) REFUSED

WB4 VERBATIM

RECORD VERBATIM RESPONSE

#### WB6

Universe: All except parents; where child is age 5 or older and was enrolled in school (or homeschooled) during last school year

How would you describe [S.C.]'s school performance in reading and writing? Would you say that it is excellent, very good, good, fair, or poor?

- (1) EXCELLENT
- (2) VERY GOOD
- (3) GOOD
- (4) FAIR
- (5) POOR
- (6) CHILD NOT ENROLLED IN SCHOOL/HOMESCHOOLED
- (77) DON'T KNOW
- (99) REFUSED

#### WB7

Universe: All except parents; where child is age 5 or older and was enrolled in school (or homeschooled) at during last school year

How would you describe [S.C.]'s school performance in math? Would you say that it is excellent, very good, good, fair, or poor?

- (1) EXCELLENT
- (2) VERY GOOD
- (3) GOOD
- (4) FAIR
- (5) POOR
- (6) CHILD NOT ENROLLED IN SCHOOL/HOMESCHOOLED
- (77) DON'T KNOW
- (99) REFUSED

#### **WB6.2**

## Universe: All except parents; where child age is 5 or more

How well does [S.C.] speak English?

- (1) VERY WELL
- (2) WELL
- (3) NOT WELL
- (4) NOT AT ALL
- (77) DON'T KNOW
- (99) REFUSED

#### WB8

Universe: All except parents; where child age is 0 to 12

## IF AGE >12, THEN GO TO WB9

We'd like to know how [S.C.] spent [his/her] time when [he/she] was not with you during the last month. I'm going to read a list of different kinds of programs children attend and different kinds of people who care for children. I'd like you to tell me which ones you used for [S.C.], at least once a week during the last month.

INTERVIEWER INSTRUCTION: TYPE OF CHILD CARE USED FOR [S.C.] AT LEAST ONCE A WEEK DURING THE LAST MONTH.

<ENTER>

## WB8A [IF AGE > 5, GO TO WB8C]

First, did [S.C.] attend Head Start?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### WB8B

Other than Head Start, what about a nursery school, a preschool, a prekindergarten, or a day care center? Please do not include child care or babysitting in someone else's home.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## WB8C [IF AGE < 2 THEN GO TO WB8D]

IF S.C. IS 2 TO 5 YEARS OLD ASK: A program that provided before- or after-school care?

IF S.C. IS 6 TO 12 YEARS OLD ASK: First, did [S.C.] attend a program that provided before- or after-school care?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## WB8D Did [S.C.] have child care or babysitting in your home by someone other than

[you/you or your spouse/partner]?

- (1) YES
- (2) NO [GO TO WB8H]
- (77) DON'T KNOW [GO TO WB8H] (99) REFUSED [GO TO WB8H]
- WB8H What about child care or babysitting in someone else's home?
  - (1) YES
  - (2) NO [GO TO WB9]
  - (77) DON'T KNOW [GO TO WB9]
  - (99) REFUSED [GO TO WB9]

#### WB9

Universe: All except parents; where [S.C.] age 5 or older at time R began caring for [S.C.] IF [CHILD AGE – (LENGTH OF TIME IN YEARS BETWEEN CURRENT DATE AND DATE WHEN [S.C.] BEGAN LIVING WITH R) < 5 YEARS] OR H4=2, THEN GO TO R1.

Did [S.C.] change schools as a result of coming to live with you?

INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS THEY MOVED INTO [SC]'S HOUSEHOLD, RATHER THAN [SC] COMING TO LIVE WITH THEM, READ: Please think about the time when you came to live with SC.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## **WB10**

#### **Universe: All**

Is [S.C.] deaf or does [he/she] have serious difficulty hearing?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## **WB11**

#### **Universe: All**

Is [S.C.] blind or does [he/she] have serious difficulty seeing, even when wearing glasses?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## WB12

## Universe: All; where child age is 5 or more

Because of a physical, mental or emotional condition, does [S.C.] have serious difficulty concentrating, remembering, or making decisions?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### **WB13**

## Universe: All; where child age is 5 or more

Does [S.C.] have serious difficulty walking or climbing stairs?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## **WB14**

## Universe: All; where child age is 5 or more

Does [S.C.] have difficulty dressing or bathing?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## **WB15**

## Universe: All; where child age is 15 or more

Because of a physical, mental or emotional condition, does [S.C.] have difficulty doing errands alone such as visiting a doctor's office or shopping?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## CAREGIVER WELL-BEING, CAREGIVER PHYSICAL AND MENTAL HEALTH, SOCIAL SUPPORTS (R)

#### R1 1

## **Universe: All**

Now I'm going to ask you some questions about your health and supports you may receive.

Would you say that, in general, your health is excellent, very good, good, fair, or poor?

- (1) EXCELLENT
- (2) VERY GOOD
- (3) GOOD
- (4) FAIR
- (5) POOR
- (77) DON'T KNOW
- (99) REFUSED

## R2 1

## Universe: Married or cohabiting Rs

## IF H6 NE 1 AND H8 NE 1, THEN GO TO R3 1

Would you say that, in general, your [spouse's/partner's] health is excellent, very good, good, fair, or poor?

- (1) EXCELLENT
- (2) VERY GOOD
- (3) GOOD
- (4) FAIR
- (5) POOR
- (77) DON'T KNOW
- (99) REFUSED

## R3 1

## **Universe: All**

Would you say that, in general, your mental and emotional health is excellent, very good, good, fair, or poor?

(1) EXCELLENT

- (2) VERY GOOD
- (3) GOOD
- (4) FAIR
- (5) POOR
- (77) DON'T KNOW
- (99) REFUSED

#### R4 1

Universe: Married or cohabiting Rs

## IF H6 NE 1 AND H8 NE 1, THEN GO TO R5

Would you say that, in general, your [spouse's/partner's] mental and emotional health is excellent, very good, good, fair, or poor?

- (1) EXCELLENT
- (2) VERY GOOD
- (3) GOOD
- (4) FAIR
- (5) POOR
- (77) DON'T KNOW
- (99) REFUSED

#### **R5**

**Universe: All** 

Do you have a physical health condition that limits the amount or kind of work or activities that you can do in or outside the household?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **R6**

Universe: Married or cohabiting Rs

## IF H6 NE 1 AND H8 NE 1, THEN GO TO R11

Does your [spouse/partner] have a physical health condition that limits the amount or kind of work or activities that they can do in or outside the household?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **R11**

#### **Universe: All**

Now I will read you a number of statements. Some of the statements describe how a parent or caregiver may feel about parenting, raising children, or their family life more generally. Other statements describe how a parent or caregiver who is receiving services or considering receiving services may feel about his or her situation. For each statement, please tell me whether you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree.

I often feel tired, worn out, or exhausted from raising a family.

Would you say you strongly agree, somewhat agree, somewhat disagree, or strongly disagree?

- (1) STRONGLY AGREE
- (2) SOMEWHAT AGREE
- (3) SOMEWHAT DISAGREE
- (4) STRONGLY DISAGREE
- (77) DON'T KNOW
- (99) REFUSED

## **R14**

## **Universe: All**

R14A When problems arise with [S.C.], I handle them pretty well.

Would you say you strongly agree, somewhat agree, somewhat disagree, or strongly disagree?

- (1) STRONGLY AGREE
- (2) SOMEWHAT AGREE
- (3) SOMEWHAT DISAGREE
- (4) STRONGLY DISAGREE
- (77) DON'T KNOW
- (99) REFUSED

When I need help with problems in my family, I am able to ask for help from others.

**READ IF NECESSARY:** Would you say you strongly agree, somewhat agree, somewhat disagree, or strongly disagree?

- (1) STRONGLY AGREE
- (2) SOMEWHAT AGREE
- (3) SOMEWHAT DISAGREE
- (4) STRONGLY DISAGREE
- (77) DON'T KNOW
- (99) REFUSED
- R14I I have a good understanding of [S.C.]'s feelings and problems.

**READ IF NECESSARY:** Would you say you strongly agree, somewhat agree, somewhat disagree, or strongly disagree?

- (1) STRONGLY AGREE
- (2) SOMEWHAT AGREE
- (3) SOMEWHAT DISAGREE
- (4) STRONGLY DISAGREE
- (77) DON'T KNOW
- (99) REFUSED
- R14J I have a good understanding of the services available in my community to help my family.

**READ IF NECESSARY:** Would you say you strongly agree, somewhat agree, somewhat disagree, or strongly disagree?

- (1) STRONGLY AGREE
- (2) SOMEWHAT AGREE
- (3) SOMEWHAT DISAGREE
- (4) STRONGLY DISAGREE
- (77) DON'T KNOW
- (99) REFUSED

## R13NEW 1

**Universe: All** 

Over the past two weeks, how often have you been bothered by any of the following problems?

Little interest or pleasure in doing things

Would you say not at all, several days, more than half the days or nearly every day?

- (1) NOT AT ALL
- (2) SEVERAL DAYS
- (3) MORE THAN HALF THE DAYS
- (4) NEARLY EVERY DAY
- (77) DON'T KNOW
- (99) REFUSED

## R13NEW 2

**Universe: All** 

**READ IF NECESSARY:** Over the past two weeks, how often have you been bothered by any of the following problems?

Feeling down, depressed, or hopeless

Would you say not at all, several days, more than half the days or nearly every day?

- (1) NOT AT ALL
- (2) SEVERAL DAYS
- (3) MORE THAN HALF THE DAYS
- (4) NEARLY EVERY DAY
- (77) DON'T KNOW
- (99) REFUSED

## **SERVICES AND SUPPORTS (S)**

#### S3 1

#### **Universe: All**

Now I have some questions about health insurance and other services and supports. Does [S.C.] have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?

- (1) YES [GO TO S5]
- (2) NO
- (77) DON'T KNOW [GO TO S5]
- (99) REFUSED [GO TO S5]

#### **S4**

## Universe: All; where R indicates [S.C.] has no health coverage

Just to confirm, I entered that [S.C.] is not covered by any type of health insurance. Is this correct?

- (1) CONFIRMED CHILD IS NOT COVERED BY ANY TYPE OF HEALTH INSURANCE [GO TO S7]
- (2) NOT CORRECT CHILD HAS INSURANCE RETURN TO S3 AND ENTER CORRECT RESPONSE
- (77) DON' KNOW [GO TO S5]

#### **S5**

Universe: All; where R indicates [S.C.] has health coverage or R doesn't know/refuses to answer whether [S.C.] has health coverage

IF S3\_1 = 1 THEN FILL "Is that coverage" ELSE, fill "Is [he/she] insured by."

[Is that coverage/Is [he/she] insured by] Medicaid or the Children's Health Insurance Program, CHIP? In [FILL NAME OF STATE FROM NSCH PRELOAD], the program is sometimes called [FILL MEDICAID NAME, CHIP NAME].

READ IF NECESSARY: CHIP, also known as S-CHIP, is a type of state-sponsored health insurance coverage that a child may have. The name of the plan varies from state-to-state.

(1) YES [GO TO S6]

- (2) NO [GO TO S6]
- (3) R DOESN'T LIVE IN THE STATE MENTIONED IN THE QUESTION
- (77) DON'T KNOW [GO TO S6]
- (99) REFUSED [GO TO S6]

## **S6**

Universe: All; where R indicates that [S.C.] has health coverage

## IF S3 1 NE 1, THEN GO TO S7

During the past 12 months, was there any time when [S.C.] was not covered by ANY health insurance?

- (1) YES [GO TO S8]
- (2) NO [GO TO S1 1]
- (77) DON'T KNOW [GO TO S1\_1]
- (99) REFUSED [GO TO S1 1]

#### **S7**

Universe: All; where R indicates that [S.C.] does not have health coverage

## **IF S3\_1 NE 2, THEN GO TO S1\_1**

During the past 12 months, was there any time when [S.C.] had health care coverage?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **S8**

Universe: All; where R indicates that [S.C.] does not currently have health coverage or lacked coverage at any point in prior 12 months

IF S3\_1=2, FILL "is." ELSE IF S6=1 FILL "was."

What are the reasons why [S.C.] [is/was] not covered by insurance? [MARK ALL THAT APPLY]

#### **COST**

(1) COST IS TOO HIGH

#### **ELIGIBILITY**

(2) INSURER REFUSES TO COVER / PREEXISTING CONDITION

- (3) CHILD NOT ELIGIBLE FOR INSURANCE THROUGH R OR R'S SPOUSE/PARTNER'S EMPLOYER PROVIDED INSURANCE BECAUSE OF CUSTODY ISSUES
- (4) R IS NOT ELIGIBLE FOR COVERAGE THROUGH OWN EMPLOYMENT OR THAT OF SPOUSE/PARTNER'S EMPLOYMENT
- (5) CHILD NOT ELIGIBLE FOR SOME OTHER REASON

### APPLICATION PROCESS

- (6) HAVE APPLIED NOW JUST WAITING
- (7) INTEND TO APPLY BUT JUST HAVEN'T DONE SO
- (8) DON'T KNOW WHERE OR HOW TO APPLY
- (9) APPLICATION PROCESS TOO DIFFICULT, TAKES TOO MUCH TIME

#### **OTHER**

- (10) R'S EMPLOYER AND SPOUSE/PARTNER'S EMPLOYER DO NOT OFFER INSURANCE
- (11) DO NOT LIKE DOCTORS / MEDICAL STAFF / CLINIC IN HEALTH PLAN AVAILABLE TO CHILD
- (12) CHILD DOES NOT NEED INSURANCE / DOES NOT GET SICK
- (13) EXPECT TO HAVE INSURANCE FROM ANOTHER SOURCE SOON
- (14) OTHER
- (77) DON'T KNOW
- (99) REFUSED

#### S1 1

## **Universe: All**

At this time, do *you* have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid or Medicare?

- (1) YES
- (2) NO [GO TO S9]
- (77) DON'T KNOW [GO TO S9]
- (99) REFUSED [GO TO S9]

## S2 1

## Universe: Rs with health coverage

Is that health insurance provided through your current employer, former employer, union, Medicare, Medicaid, or some other source? [MARK ALL THAT APPLY]

**READ IF NECESSARY**: Please think about your insurance or your spouse's insurance.

NATIONAL SURVEY OF CHILDREN IN NONPARENTAL CARE (NSCNC)

- (1) CURRENT EMPLOYER
- (2) FORMER EMPLOYER
- (3) UNION
- (4) MEDICARE
- (5) MEDICAID
- (6) SOME OTHER SOURCE [SPECIFY] [SKIP TO S2 1 VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

S2	1	VERBATIM	RECORD VERBAT	TIM RESPONSE

**S9** 

**Universe: All** 

In addition to earnings from work, families often receive other sources of income and supports, from the government, from private institutions or from their own savings. I would like to ask you a few questions about all sources of income and supports currently received by members of your household other than earnings from work.

Does anybody in your household receive Social Security retirement benefits or payments to survivors from the U.S. government?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

**S10** 

**Universe: All** 

Does anybody in your household receive Social Security disability benefits, or SSDI?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

**S11** 

Universe: All

Does anybody in your household receive veterans' benefits?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## **S12**

**Universe: All** 

How about Food Stamps?

- (1) YES
- (2) NO [GO TO S14]
- (77) DON'T KNOW [GO TO S14]
- (99) REFUSED [GO TO S14]

## **S13**

Universe: All except parents; where R's household receives food stamps

IF H4=2, THEN GO TO S14

Are the Food Stamps received as a result of your caring for [S.C.]?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## **S14**

Universe: All; where child is 6 years old or younger

IF AGE > 6, THEN GO TO S15

Does [S.C.] receive Women, Infants, and Children (WIC) Program benefits?

HELP TEXT: WIC STANDS FOR WOMEN, INFANTS, AND CHILDREN (WIC) PROGRAM.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **S15**

**Universe: All** 

Does [S.C.] get free or reduced price meals while at child care or in school?

**READ IF NECESSARY:** "Free or reduced price meals" are paid or partially paid for by a government program or agency. Do not include meals that are covered by tuition you pay for school.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **S17**

Universe: All; where child uses any form of child care

IF [IF WB8A= [2, 77, 99] AND WB8B=[2, 77, 99] AND WB8C=[2, 77, 99] AND WB8D=[2, 77, 99] AND WB8H=[2, 77, 99]], THEN GO TO S18

In addition to any child care for [S.C.] that you paid for, were any of [his/her] regular child care arrangements last month free or at a reduced fee or cost?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **S18**

**Universe: All** 

When answering this next question, please remember to include your income PLUS the income of all family members living in this household.

What is your best estimate of the total income of all family members from all sources, before taxes, in 2012?

INTERVIEWER INSTRUCTION: ENTER '999,995' IF THE REPORTED INCOME IS GREATER THAN \$999,995.

RECORD INCOME AMOUNT [GO TO S18\_CONF]: \_\_\_\_\_INCOME GREATER THAN \$999,995 [GO TO D1] 999995

## INTERVIEWER INSTRUCTION: ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

S18\_CONF

CATI INSTRUCTION: IF S18=77,99 GO TO INCOME CASCADE (S19) Just to confirm that I entered it correctly, the total income of all family members was [AMOUNT FROM S18]. Is that correct?

- (1) YES > GO TO D1
- (2) NO > GO TO S18

## **S19**

Universe: Respondents who don't know or refuse to report income initially

Was your total family income from all sources less than \$50,000 or \$50,000 or more?

- (1) LESS THAN \$50,000
- (2) \$50,000 OR MORE [G0 TO S22]
- (77) DON'T KNOW [G0 TO D1]
- (99) REFUSED [G0 TO D1]

## **S20**

Universe: Respondents who don't know or refuse to report income initially, then report income of less than \$50,000

Was your total family income from all sources less than \$35,000 or \$35,000 or more?

- (1) LESS THAN \$35,000
- (2) \$35,000 OR MORE [IF H1 + H2 = (8, 9) GO TO S21; ELSE GO TO D1]
- (77) DON'T KNOW [GO TO D1]
- (99) REFUSED [GO TO D1]

#### **S21**

Universe: Respondents who don't know or refuse to report income initially, then report income of less than \$35,000 or report an income of \$35,000-\$50,000 for a family with 8-9 family members

Was your total family income from all sources less than [FILL: Poverty threshold for household of size H1 + H2] or [FILL: Poverty threshold for household of size H1 + H2] or more?

- (1) LESS THAN [FILL: Poverty threshold for household of size H1 + H2] [GO TO D1]
- (2) [FILL: Poverty threshold for household of size H1 + H2] OR MORE [GO TO D1]

- (77) DON'T KNOW [GO TO D1]
- (99) REFUSED [GO TO D1]

## **S22**

Universe: Respondents who don't know or refuse to report income initially, then report income of at least \$50,000

Was your total family income from all sources less than \$100,000 or \$100,000 or more?

- (1) LESS THAN \$100,000
- (2) \$100,000 OR MORE [GO TO D1]
- (77) DON'T KNOW [GO TO D1]
- (99) REFUSED [GO TO D1]

## **S23**

Universe: Respondents who don't know or refuse to report income initially, then report income of less than \$100,000

Was your total family income from all sources less than \$75,000 or \$75,000 or more?

- (1) LESS THAN \$75,000
- (2) \$75,000 OR MORE
- (77) DON'T KNOW
- (99) REFUSED

## **DEMOGRAPHICS (D)**

#### D1

**Universe: All** 

IF H4=2, H6=1 THEN ASK: Now I'm going to ask a few final questions about you and your spouse. What year were you born?

IF H4=2, H6 NE 1 and H8=1 THEN ASK: Now I'm going to ask a few final questions about you and your partner. What year were you born?

IF H4=2, H6 NE 1 and H8 NE 1 THEN ASK: Now I'm going to ask a few final questions about you. What year were you born?

YEAR:

ENTER 7777 FOR DON'T KNOW ENTER 9999 FOR REFUSED

#### D2

Universe: All; where R has spouse/partner

IF H6 NE 1 AND H8 NE 1, THEN GO TO D3

What year was your [spouse/partner] born?

YEAR:

ENTER 7777 FOR DON'T KNOW ENTER 9999 FOR REFUSED

#### **D3**

**Universe: All** 

IF H5=1 (R is mom) AND P2 NE MISSING, THEN FILL D3 WITH P2 – SKIP

Are you of Hispanic or Latino origin?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **D4**

**Universe: All** 

## IF H5=1 (R is mom) AND P3 NE MISSING, THEN FILL D4 WITH P3 - SKIP

Please choose one or more of the following categories to describe your race. Are you White, Black or African American, American Indian, Alaska Native, Asian, or Native Hawaiian or other Pacific Islander? [MARK ALL THAT APPLY]

- (1) WHITE
- (2) BLACK/AFRICAN AMERICAN
- (3) AMERICAN INDIAN/NATIVE AMERICAN
- (4) ALASKA NATIVE
- (5) ASIAN
- (6) NATIVE HAWAIIAN
- (7) PACIFIC ISLANDER
- (8) OTHER (SPECIFY) [SKIP TO D4\_VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

## D4 VERBATIM

RECORD VERBATIM RESPONSE

#### **D5**

**Universe: All** 

Compared to yourself, is [S.C.] a different race or ethnicity or from a different culture?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## **D9**

**Universe: All** 

What is your current employment status?

INTERVIEWER INSTRUCTIONS:

RECORD AS STUDENT ONLY IF THERE IS NO FULL- OR PART-TIME EMPLOYMENT.

'SEMI-RETIRED' SHOULD BE CODED AS 'EMPLOYED PART-TIME'.

'SELF-EMPLOYED' SHOULD BE CODED AS 'EMPLOYED FULL-TIME' OR 'EMPLOYED PART-TIME' DEPENDING ON HOW MUCH THEY WORK.

- (1) EMPLOYED FULL-TIME (MORE THAN 30 HOURS PER WEEK)
- (2) EMPLOYED PART-TIME (30 HOURS PER WEEK OR LESS)
- (3) NOT WORKING--ON VACATION
- (4) NOT WORKING--ON TEMPORARY LAYOFF OR STRIKE
- (5) NOT WORKING BUT LOOKING FOR WORK
- (6) HOMEMAKER/TAKING CARE OF HOME OR FAMILY
- (7) RETIRED
- (8) STUDENT
- (9) DISABLED
- (10) OTHER (SPECIFY) [SKIP TO D9 VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

**D10** 

Universe: All Rs with a spouse or partner

IF H6 NE 1 AND H8 NE 1, THEN GO TO D11

What is your [spouse's/partner's] current employment status?

#### **INTERVIEWER INSTRUCTIONS:**

RECORD AS STUDENT ONLY IF THERE IS NO FULL- OR PART-TIME EMPLOYMENT.

'SEMI-RETIRED' SHOULD BE CODED AS 'EMPLOYED PART-TIME'.

'SELF-EMPLOYED' SHOULD BE CODED AS 'EMPLOYED FULL-TIME' OR 'EMPLOYED PART-TIME' DEPENDING ON HOW MUCH THEY WORK.

- (1) EMPLOYED FULL-TIME (MORE THAN 30 HOURS PER WEEK)
- (2) EMPLOYED PART-TIME (30 HOURS PER WEEK OR LESS)
- (3) NOT WORKING--ON VACATION
- (4) NOT WORKING--ON TEMPORARY LAYOFF OR STRIKE
- (5) NOT WORKING BUT LOOKING FOR WORK
- (6) HOMEMAKER/TAKING CARE OF HOME OR FAMILY
- (7) RETIRED
- (8) STUDENT

- (9) DISABLED
- (10) OTHER (SPECIFY) [SKIP TO D10\_VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

D10 VERBATIM RECORD VERBATIM RESPONSE

**Universe: All** 

IF NSCNC RESPONDENT IS SAME PERSON WHO RESPONDED TO NSCH, FILL INFO FROM NSCH VARIABLE K11Q20 IF R WAS FOSTER MOTHER (i.e., IF NSCH VARIABLE C10Q02A=3), ELSE FROM NSCH VARIABLE K11Q21 IF R WAS FOSTER FATHER (i.e., IF NSCH VARIABLE C10Q02A=8), ELSE FROM K11Q22.

ELSE, ASK: What is the highest degree or year of school you have completed?

- (1) 8th GRADE OR LESS
- (2) 9th-12th GRADE NO DIPLOMA
- (3) HIGH SCHOOL GRADUATE OR GED COMPLETED
- (4) COMPLETED A VOCATIONAL, TRADE, OR BUSINESS SCHOOL PROGRAM
- (5) SOME COLLEGE CREDIT BUT NO DEGREE
- (6) ASSOCIATE DEGREE (AA, AS)
- (7) BACHELOR'S DEGREE (BA, BS, AB)
- (8) MASTER'S DEGREE (MA, MS, MSW, MBA)
- (9) DOCTORATE (PhD, EdD) or PROFESSIONAL DEGREE (MD, DDS, DVM, JD)
- (77) DON'T KNOW
- (99) REFUSED

#### D12

Universe: All; where R has spouse/partner

## IF H6 NE 1 AND H8 NE 1, THEN GO TO D13

What is the highest grade or year of school your [spouse/partner] has completed?

- (1) 8th GRADE OR LESS
- (2) 9th-12th GRADE NO DIPLOMA
- (3) HIGH SCHOOL GRADUATE OR GED COMPLETED
- (4) COMPLETED A VOCATIONAL, TRADE, OR BUSINESS SCHOOL PROGRAM
- (5) SOME COLLEGE CREDIT BUT NO DEGREE
- (6) ASSOCIATE DEGREE (AA, AS)
- (7) BACHELOR'S DEGREE (BA, BS, AB)
- (8) MASTER'S DEGREE (MA, MS, MSW, MBA)
- (9) DOCTORATE (PhD, EdD) or PROFESSIONAL DEGREE (MD, DDS, DVM, JD)
- (77) DON'T KNOW
- (99) REFUSED

#### D13

## **Universe: All**

Were you born in the United States?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **D14**

Universe: All Rs with a spouse or partner

## **IF H6=1 OR H8=1 THEN GO TO D15**

Was your [spouse/partner] born in the United States?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

ADDRESS INTRO IF (NSCNC INCENT FLAG = 2 OR NSCNC PASSIVE in (1,2)) AND NSCNC LETTER FLG = 2 THEN FILL MONEY 2 = \$15; ELSE FILL MONEY 1 = \$10

> Those are all the questions I have. Before I go, I'll need to confirm your mailing address so we can send you \$[MONEY 1/MONEY 2] as a token of our appreciation for taking the time to answer these questions.

<GET/CONFIRM ADDRESS and GO TO NSCNC END>

## NSCNC END

I'd like to thank you on behalf of the CDC's National Center for Health Statistics for the time and effort you've spent answering these questions. If you have any questions about this survey, you may call my supervisor toll-free at 1-877-346-9982. If you have questions about your rights as a survey participant, you may call the chairman of the Research Ethics Review Board at 1-800-223-8118. Thank you again.

## CALLBACK AND REFUSAL CONVERSION SCRIPTS

INTRO\_CB

USE INTRO\_CB ONLY IF INTRO\_3=1 OR NEWINTRO\_3=1; ELSE USE INTRO\_1 OR NEWINTRO\_1

Hello, my name is \_\_\_\_\_. I'm calling on behalf of the CDC's National Center for Health Statistics (IF ADVANCE LETTER SENT (ADVLTR=1), "to follow up on a letter that was sent to your home"/ ELSE NO FILL). We are re-contacting caregivers and guardians of children who were living apart from their parents. Earlier, we contacted your household to participate in a survey about the living situations of these children and the problems they and their caregivers may have with receiving needed services. I'm calling back to continue the interview. May I speak with the person who started this interview?

INTERVIEWER INSTRUCTION: IF NAME WAS GIVEN FOR APPOINTMENT, ASK FOR THAT PERSON.

INTERVIEWER INSTRUCTION: CONFIRM THAT YOU ARE SPEAKING WITH THE SAME PERSON WHO STARTED THE INTERVIEW. THE PERSON WHO STARTED THE INTERVIEW MUST COMPLETE THIS INTERVIEW.

- (1) YES, SPEAKING WITH THAT PERSON <IF RDD\_NCCELL\_CCELL=1 THEN GO TO INTRO 3; IF RDD NCCELL CCELL=2, 3 THEN GO TO S WARM>
- (2) YES, NEW PERSON COMES TO PHONE <GO TO INTRO\_2>
- (3) NO, NOT AVAILABLE NOW <SET GCB AND TERMINATE>
- (4) TERMINATE THE INTERVIEW <GO TO T1>
- (8) NO, CHILD IS DECEASED <GO TO DECEASED>
- (10) CELL PHONE
- (11) CONFIRM BUSINESS <GO TO SALZ >
- (12) ANSWERING MACHINE < IF MESSAGE IS TO BE LEFT THEN GO TO SASERV, ELSE HANG UP AND SET ITS =35>
- (15) SUPERVISOR REVIEW (RAISE YOUR HAND TO GET PERMISSION BEFORE USING THIS CODE) <SET ITS =31>

REMIND1

I want to remind you that we will be asking questions about [S.C.] for the rest of this interview, and we will send you \$[MONEY\_1/MONEY\_2] for completing the interview.

MSG FIRST

PLEASE READ SLOWLY AND CLEARLY.) Hello, my name is

\_\_\_\_\_\_\_. I'm calling on behalf of the CDC's National Center for
Health Statistics (IF ADVANCE LETTER SENT (ADVLTR=1), "to follow up on
a letter that was sent to your home"/ ELSE NO FILL). On [INTERVIEW DATE],
we conducted a telephone survey on children's health with an adult at this phone
number about a [Male/Female] child who would now be about [ESTIMATED
AGE] years old. The person we spoke with told us [he was/she was/they were] the
child's [RELATION]. We are interested in speaking with this person again. If
you would like to participate immediately, please call our toll-free number, 1-877346-9982. In appreciation for your time, we will send you \$10 in cash once the
interview is completed. Again, our toll-free number is 1-877-346-9982. Thank
you.

MSG\_NSCNC

(PLEASE READ SLOWLY AND CLEARLY.) Hello. I'm calling on behalf of the CDC's National Center for Health Statistics [(NSCNC\_INCENT\_FLAG = 2 OR NSCNC\_PASSIVE = 1 or 2) AND NSCNC\_LTR\_FLAG = 1 THEN, "to follow up on a letter that was sent to your home"/ ELSE NO FILL]. We recently contacted you and began a survey on children who were living apart from their parents. I'm calling back to continue the survey. In appreciation for your time, we will send you \$[MONEY 1/MONEY 2] for completing the interview.

MSG Y APPT

(PLEASE READ SLOWLY AND CLEARLY.) Hello. I am calling on behalf of the CDC's National Center for Health Statistics regarding a survey about children who were living apart from their parents. I'm sorry that we've missed you. When we spoke previously about this important study, you requested that we call you back at this time. We'll try to contact you again soon but please feel free to return our call anytime at 1-877-346-9982. In appreciation for your time, we will send you \$[MONEY 1/MONEY 2] for completing the interview. Thank you.

# Appendix IV. NSDATA Questionnaire

## 2014 National Survey of the Diagnosis and Treatment of Attention-Deficit/Hyperactivity Disorder and Tourette Syndrome

Sponsored by the National Center on Birth Defects and Developmental Disabilities

Conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention

Eligibility Confirmation	31
	,
Informed Consent	32
Tourette Syndrome Module	33
Diagnosis	33
Co-occurring Disorders	38
Treatment	47
Symptoms and Performance/Impairment	
Academic Health and Discipline	
Family Impact	69
American Community Survey Questions	
Household and Demographics	
Attention-Deficit/Hyperactivity Module	78
Diagnosis	
Co-occurring Disorders	
Treatment	
Symptoms and Performance/Impairment	
Academic Health and Discipline	
Family Impact	
American Community Survey Questions	
Household and Demographics	

All information which would permit identification of any individual, a practice, or an establishment will be held confidential, will be used for statistical purposes 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 the 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).

According to the Paperwork Reduction Act (PRA) of 1995, no persons are required to respond to a collection of information unless such collection displays a valid OMB control number. The valid OMB control number for this information collection is 0920-0406. The time required to complete this information collection is estimated to average 30 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have any comments about the accuracy of the time estimate(s) or suggestions for improving this form please write to: CDC Reports Clearance Officer, 1600 Clifton Road, MS-D74, Atlanta, GA 30333; call 404-639-4794; or send an email to <a href="mailto:omb@cdc.gov">omb@cdc.gov</a>.

Data collection conducted under contract to the CDC by NORC at the University of Chicago.

#### *NOTES*:

This questionnaire reflects the survey as administered. All questions have Don't Know (DK) and Refused (RF) as answer options, whether or not those choices are specifically included in this questionnaire.

Data users should not rely on the coding system reflected in this questionnaire. Data files from the survey use an alternative coding system, such as zero for No, six for Don't Know, seven for Refused, and other numeric codes for selected verbatim responses. Data users should refer to the assigned labels in the data files to verify the codes used for each question.

## **INTRODUCTION**

**INTRO** 

Hello, my name is \_\_\_\_\_\_\_. I'm calling on behalf of the CDC's National Center for Health Statistics [IF RECEIVED ADVANCE LETTER, "to follow up on a letter that was sent to your home"/ ELSE NO FILL]. In [INTERVIEW DATE], we conducted a telephone survey on children's health with an adult at this phone number about a [Male/Female] child who would now be about [ESTIMATED AGE] years old. The person we spoke with told us [he was/she was/they were] the child's [RELATION]. We are interested in speaking with this child's [RELATION] again, or with another parent or guardian of the child. For quality assurance, this call may be monitored or recorded. Is this person available?

IF YES AND SPEAKING ON A LANDLINE, CATI WILL GO TO INTRO\_3.

IF YES AND SPEAKING ON A CELL PHONE, CATI WILL GO TO QUESTIONS ABOUT RESPONDENT'S SAFETY BEFORE GOING TO INTRO\_3.

IF NEW PERSON COMES TO PHONE, CATI WILL REPEAT INTRO. NEW PERSON IS ALSO ASKED IF THEY ARE KNOWLEDGABLE ABOUT THE CHILD'S HEALTH.

IF PERSON HAS MOVED OR HAS NEW PHONE NUMBER, CATI WILL GO TO QUESTIONS THAT COLLECT LOCATING INFORMATION.

IF PERSON OR CHILD IS DECEASED, A POLITE EXIT SCRIPT IS READ.

IF PERSON IS UNKNOWN OR IF SOMEONE ANSWERING THE PHONE INDICATES THAT A BUSINESS HAS BEEN REACHED, AN EXIT SCRIPT IS READ.

## **ELIGIBILITY CONFIRMATION**

INTRO\_3 Thank you for previously completing the National Survey of Children's Health. We appreciate your household's participation in this important survey.

The CDC's National Center for Health Statistics is re-contacting parents and guardians of children who have or have had Attention Deficit Hyperactivity Disorder, Attention Deficit Disorder, or Tourette syndrome. This survey will help researchers to understand the medical needs of these children and the problems they and their families may have receiving needed services. If you qualify for and complete this survey, as a token of appreciation we will send you \$[MONEY] for your time.

## COND CONFIRM

We are calling you because you previously said that a doctor or health care provider once told you that your child had either Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder, that is, ADD or ADHD, or Tourette syndrome.

Is that correct?

- (1) YES, CONTINUE
- (2) CHILD DOES NOT HAVE CONDITION(S)
- (77) DON'T KNOW
- (99) REFUSED
- COND\_CHK I would like to confirm this information with you today before we continue. For each condition, please tell me if a doctor or other health care provider ever told you that your child had the condition, even if [he/she] does not have the condition now.
- COND\_A Has a doctor or other health care provider ever told you that your child had ADHD or ADD?
  - (1) YES [FLAG FOR ADHD MODULE (ADHD ELIG=1)]
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED
- COND\_B Has a doctor or other health care provider ever told you that your child had Tourette syndrome?
  - (1) YES [IF SPANISH=0 FLAG FOR TS MODULE (TS\_ELIG=1) AND GO TO AGE ELSE IF COND\_A=1 GO TO AGE, ELSE GO TO COND\_EXIT]
  - (2) NO [IF COND A=1 GO TO AGE, ELSE GO TO COND EXIT]
  - (77) DON'T KNOW [IF COND\_A=1 GO TO AGE, ELSE GO TO COND EXIT]
  - (99) REFUSED [IF COND A=1 GO TO AGE, ELSE GO TO COND\_EXIT]

COND EXIT

Those are all the questions I have. You and your child are not eligible for this follow-up survey. I'd like to thank you on behalf of the CDC's National Center for Health Statistics for the time and effort you've spent answering these questions.

AGE When we last spoke, your child was [AGEYR\_CHILD] years old. How old is [he/she] now?

RECORD VALUE:

IF CHILD IS NOT UNDER 18, GO TO AGE EXIT

AGE\_EXIT We are only interviewing parents or guardians whose child is less than 18 years

old. I'd like to thank you on behalf of the CDC's National Center for Health Statistics for the time and effort you've spent answering these questions. Have a

good day.

**TERMINATE** 

ELIG We are interested in speaking with a parent or guardian of the child who is currently living with the child. Does the child live with you now?

IF YES GO TO CONSENT. IF CHILD IS NOT CURRENTLY LIVING IN HOUSEHOLD, RESPONDENT SHOULD BE ASKED LOCATING

QUESTIONS IF APPROPRIATE.

### **INFORMED CONSENT**

#### CONSENT

Based on your responses, you are eligible to complete a survey on [S.C.]'s experience with [IF TS\_ELIG=1 THEN DISPLAY "Tourette syndrome"; IF TS\_ELIG=0 AND ADHD\_ELIG=1 THEN DISPLAY "ADHD."]

Before we continue, I'd like you to know that taking part in this research is voluntary. You may choose not to answer any question you don't wish to answer, or end the interview at any time with no impact on the benefits you may receive. We are required by Federal law to develop and follow strict procedures to protect the confidentiality of your information and use your answers only for statistical research. I can describe these laws if you wish. In appreciation for your time, we will send you \$[MONEY\_1/MONEY\_2]. The survey will take about a half hour. I'd like to continue now unless you have any questions.

READ IF NECESSARY: The Public Health Service Act is Title 42 of the US Code, Section 242k. The collection of information in this survey is authorized by Section 306 of this Act. Through the National Center for Health Statistics, the confidentiality of your responses is assured by Section 308d of this Act and by the Confidential Information Protection and Statistical Efficiency Act. Would you like me to read the Confidential Information Protection provisions to you?

IF RESPONDENT WOULD LIKE TO HEAR PROVISIONS, 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 NCHS employees or agents. By law, every employee of the National Center for Health Statistics, N-O-R-C at the University of Chicago, and their agents and contractors 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. [IF TS MODULE IS NOT FLAGGED (TS\_ELIG=0) SKIP TO ADHD\_A1\_AGE AFTER NAME\_PROMPT]

## NAME PROMPT

In the last survey, your child was referred to as [IF REF\_NAME1 NOT BLANK USE REF\_NAME1, ELSE USE AGE]. I can continue to do so or can refer to them as something else if you'd like.

- (1) CONTINUE TO USE CURRENT REFERENCE [GO TO TS A1 AGE]
- (2) USE SOMETHING ELSE [GO TO NAME PROMPT NEW]

#### NAME PROMPT NEW

How would you like me to refer to your [S.C.] for the remainder of the interview? RECORD VERBATIM RESPONSE

## TOURETTE SYNDROME MODULE

## **DIAGNOSIS**

## PREVIOUS TOURETTE SYNDROME DIAGNOSIS

TS A1 AGE

Thank you for confirming that a doctor or other health care provider once told you that [S.C.] had Tourette syndrome. The first set of questions will ask about [S.C.]'s Tourette syndrome diagnosis.

How old was [S.C.] when you were first told by a doctor or other health care provider that [he/she] had Tourette syndrome?

SKIP TO TS A1 1 NEW, ELSE GO TO TS A1 AGE MY

TS A1 AGE MY

- (1) YEARS
- (2) MONTHS

## TS\_A1\_1\_NEW

What type of doctor or other health care provider FIRST told you that [S.C.] had Tourette syndrome?

- (1) DEVELOPMENTAL OR BEHAVIORAL PEDIATRICIAN
- (2) FAMILY PRACTICE DOCTOR
- (3) NEUROLOGIST
- (4) NURSE PRACTITIONER
- (5) OCCUPATIONAL THERAPIST
- (6) PEDIATRICIAN (GENERAL)
- (7) PHYSICAL THERAPIST
- (8) PHYSICIAN'S ASSISTANT
- (9) PSYCHIATRIST
- (10) PSYCHOLOGIST OUTSIDE OF SCHOOL
- (11) SCHOOL COUNSELOR
- (12) SCHOOL NURSE
- (13) SCHOOL PSYCHOLOGIST
- (14) SPEECH THERAPIST
- (15) TEAM OF PROFESSIONALS/MULTIDISCIPLINARY TEAM
- (16) OTHER [GO TO TS\_A1\_1\_ VERBATIM\_NEW]
- (66) NO HEALTH CARE PROVIDER HAS EVER TOLD ME MY CHILD HAS THIS CONDITION
- (77) DON'T KNOW
- (99) REFUSED

TS_A1_1_VERBATIM_NEW	
RECORD VERBATIM RESPONSE	

TS\_A1\_2 Besides the doctor or other health care provider that first told you that [S.C.] had TS, how many doctors or other healthcare providers saw did [S.C.] see about [his/her] tics before [he/she] was diagnosed with Tourette syndrome?

RECORD VALUE: \_\_\_\_ ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

## TS A1 3 INTRO

Now I would like you to think about the time before [S.C.]'s Tourette syndrome diagnosis, when [he/she] first had tics. As you probably know, tics are usually sudden, brief, rapid and repetitive movements or sounds.

READ IF NECESSARY: Some common tics are eye blinking; facial movements; shoulder shrugging; coughing; throat clearing; sniffing; humming; barking, and blurting out words. Tics can be suppressed for short periods of time, but eventually come out. Tics come and go and often change over time.

- TS\_A1\_3 Who first noticed that [S.C.] had tics? Was it you or another family member, someone at your child's school or daycare, a doctor or health care professional not at your child's school or someone else?
  - (1) RESPONDENT OR ANOTHER FAMILY MEMBER
  - (2) SOMEONE AT YOUR CHILD'S SCHOOL OR DAYCARE
  - (3) A DOCTOR OR OTHER HEALTH CARE PROFESSIONAL NOT AT YOUR CHILD'S
  - (4) SOMEONE ELSE
  - (77) DON'T KNOW
  - (99) REFUSED

## TS A1 4 AGE

How old was [S.C.] when someone first noticed that [S.C.] had tics?

RECORD VALUE: \_\_\_\_ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

## TS\_A1\_4\_AGE\_MY

- (1) YEARS
- (2) MONTHS
- TS\_A1\_5A What type of tics did [S.C.] have when someone first noticed [he/she] had tics? Were they motor tics, vocal or phonic tics, or some other kind of tics?

READ IF NECESSARY: Motor tics include movements such as eye-blinking and shoulder shrugging. Vocal or phonic tics are noises that the child makes such as humming, making animal noises, or blurting out words.

- (1) MOTOR TIC
- (2) VOCAL OR PHONIC TIC
- (3) BOTH
- (4) OTHER
- (77) DON'T KNOW
- (99) REFUSED
- TS A1 5B Do you believe that [S.C.]'s tics were caused by a stressful life event?

INTERVIEWER INSTRUCTION: DO NOT PROBE "DON'T KNOW" RESPONSES FOR THIS QUESTION

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS A1 5C Do you believe that [S.C.]'s tics were caused by an infection such as strep throat?

READ IF NECESSARY: For example, parents may believe that tics are the result of Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (PANDAS).

INTERVIEWER INSTRUCTION: DO NOT PROBE "DON'T KNOW" RESPONSES FOR THIS QUESTION

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_A1\_5D How old was [S.C.] when you first asked a doctor or other health care provider for help because of the tics?

**RECORD VALUE:** 

ENTER 77 FOR DON'T KNOW [GO TO TS\_A2\_1] ENTER 99 FOR REFUSED [GO TO TS\_A2\_1]

TS A1 5D MY

- (1) YEARS
- (2) MONTHS

## CURRENT TOURETTE SYNDROME AND SEVERITY

TS\_A2\_1 Does [S.C.] currently have Tourette syndrome?

- (1) YES [GO TO TS A2 2] (2) NO [GO TO TS A2 3] (77) DON'T KNOW [GO TO TS A2 3] (99) REFUSED [GO TO TS A2 3] Would you describe [his/her] Tourette syndrome as mild, moderate, or severe? TS\_A2\_2 (1) MILD (2) MODERATE (3) SEVERE (77) DON'T KNOW (99) REFUSED TS A2 3 When the symptoms were at their worst, how would you describe [S.C.]'s Tourette syndrome? Would you describe it as mild, moderate, or severe? (1) MILD (2) MODERATE (3) SEVERE (77) DON'T KNOW (99) REFUSED When the symptoms were at their worst, were the tics noticeable to strangers? TS A2 4 (1) YES (2) NO (77) DON'T KNOW (99) REFUSED When the symptoms were at their worst, did the tics interfere with [S.C.]'s ability TS A2 5 to do things other children could do? (1) YES (2) NO (77) DON'T KNOW (99) REFUSED
- TS A2 6 How old was [S.C.] when the Tourette syndrome was at its worst?

INTERVIEWER INSTRUCTION: IF RESPONDENT GIVES AN AGE RANGE, ASK THEM TO CHOOSE SINGLE AGE.

RECORD VALUE: \_\_\_\_ ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

TS\_A2\_6\_MY

- (1) YEARS
- (2) MONTHS

IF CHILD CURRENTLY HAS TS [TS\_A2\_1 = YES, DK, RF], SKIP TO B1\_1. ELSE ASK TS A2 7

TS\_A2\_7 Did treatment help [S.C.]'s tics go away or did the tics seem to go away on their own?

INTERVIEWER INSTRUCTION: CODE "3" ONLY IF R SAYS THAT THE CHILD NEVER HAD TICS. OPTIONS "1" AND "2" CAN BE USED EVEN IF SOME TICS WENT AWAY AND SOME REMAIN.

- (1) TREATMENT HELPED TICS GO AWAY [GO TO TS A2 8]
- (2) TICS WENT AWAY ON THEIR OWN [GO TO TS A2 8]
- (3) CHILD NEVER HAD TICS [GO TO TS\_B1\_1\_INTRO]
- (77) DON'T KNOW [GO TO TS\_A2\_8]
- (99) REFUSED [GO TO TS A2 8]
- TS\_A2\_8 Does [S.C.] currently have tics?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED

#### **CO-OCCURRING DISORDERS**

TS B1 INTRO

Now I'm going to ask you about other conditions your child might have been diagnosed with by a doctor or other healthcare provider.

TS\_B1\_1\_1 Has a doctor or health care provider ever told you that [S.C.] had oppositional defiant disorder or ODD?

HELP TEXT: Oppositional defiant disorder is an ongoing pattern of defiant and hostile behavior that interferes with a child's life and daily activities.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_B1\_1\_2 Has a doctor or health care provider ever told you that [S.C.] had conduct disorder?

HELP TEXT: Children with conduct disorder may be aggressive to people or animals, destroy property, steal, and violate rules.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_B1\_1\_3 Has a doctor or health care provider ever told you that [S.C.] had Autism Spectrum Disorder or Pervasive Developmental Disorder?

HELP TEXT: Children with autism spectrum disorder have delays in language, communication, and social skills. They often have an intense interest in a single subject or topic. Children with pervasive developmental disorder have severe and persistent delays in language, communication, and social skills.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

TS\_B1\_1\_4 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

A sleep disorder?

HELP TEXT: Sleep apnea, insomnia, and narcolepsy are examples of sleep disorders.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_B1\_1\_5 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had....

An intellectual disability?

HELP TEXT: Children with intellectual disabilities learn and develop more slowly than a typical child. Intellectual disability can include mental retardation or Down syndrome.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_B1\_1\_6 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

A learning disorder?

HELP TEXT: Dyslexia and mathematical learning disabilities are examples of learning disorders.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

TS\_B1\_1\_7 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

A language disorder?

HELP TEXT: Children with language disorders have trouble getting their meaning or message across to others, or understanding the message coming from others, or both. Stuttering and communication disorders are examples of a language disorder.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_B1\_1\_8 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Obsessive compulsive disorder or OCD?

HELP TEXT: Children with OCD feel the need to check things repeatedly, or have certain thoughts or perform routines and rituals over and over.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_B1\_1\_9 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Post-traumatic stress disorder or PTSD?

HELP TEXT: Children with PTSD develop this disorder after experiencing a traumatic event. Due to the emotional distress, children with PTSD continue to feel stressed and afraid even after the danger is over.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

TS\_B1\_1\_10 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Another anxiety disorder, such as generalized anxiety disorder, panic disorder, or a phobia?

HELP TEXT: Anxiety is a feeling of constant worrying. Children with severe anxiety problems may be diagnosed as having anxiety disorders.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_B1\_1\_11 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Bipolar disorder?

HELP TEXT: Bipolar disorder is a mood disorder where a person experiences periods of depression and periods of being extremely happy or being cross or irritable.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_B1\_1\_12 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Intermittent explosive disorder?

HELP TEXT: Intermittent explosive disorder is a behavioral disorder characterized by extreme expression of anger, often to the point of uncontrollable rage that is disproportionate to the situation at hand.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

TS\_B1\_1\_13 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Another mood disorder, such as depression, or major depressive disorder

HELP TEXT: Depression is an illness that involves the body, mood, and thoughts. It is marked by persistent sadness or an anxious or empty mood. It affects how a child feels, and the way a child eats, sleeps, and functions.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_B1\_1\_14 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

An eating disorder, such as anorexia or bulimia?

HELP TEXT: Children with eating disorders exhibit extreme emotions, attitudes, and behaviors about weight and food issues.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_B1\_1\_15 READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Substance use disorder?

HELP TEXT: Substance abuse is the frequent use of substances such as drugs that can be physically dangerous and can potentially lead to legal problems and frequent social or interpersonal problems.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

IF NONE OF B1 1 1-B1 1 15 ARE YES, THEN SKIP TO SECTION C

### TS B1 2 1 [IF TS B1 1 1=1 ASK, ELSE SKIP TO TS B1 2 2]

Earlier you told me that [S.C.] has been diagnosed with oppositional defiant disorder or ODD.

Does [S.C.] currently have oppositional defiant disorder or ODD?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## TS\_B1\_2\_2 [IF TS\_B1\_1\_2=1 ASK, ELSE SKIP TO TS\_B1\_2\_3]

Earlier you told me that [S.C.] has been diagnosed with conduct disorder.

Does [S.C.] currently have conduct disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## TS B1 2 3 [IF TS B1 1 3=1 ASK, ELSE SKIP TO TS B1 2 4]

Earlier you told me that [S.C.] has been diagnosed with Autism Spectrum Disorder or Pervasive Developmental Disorder.

Does [S.C.] currently have Autism Spectrum Disorder or Pervasive Developmental Disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### TS B1 2 4 [IF TS B1 1 4=1 ASK, ELSE SKIP TO TS B1 2 5]

Earlier you told me that [S.C.] has been diagnosed with a sleep disorder.

Does [S.C.] currently have a sleep disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### TS B1 2 5 [IF TS B1 1 5=1 ASK, ELSE SKIP TO TS B1 2 6]

Earlier you told me that [S.C.] has been diagnosed with an intellectual disorder.

Does [S.C.] currently have an intellectual disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## TS\_B1\_2\_6 [IF TS\_B1\_1\_6=1 ASK, ELSE SKIP TO TS\_B1\_2\_7]

Earlier you told me that [S.C.] has been diagnosed with a learning disorder.

Does [S.C.] currently have a learning disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## TS B1 2 7 [IF TS B1 1 7=1 ASK, ELSE SKIP TO TS B1 2 8]

Earlier you told me that [S.C.] has been diagnosed with a language disorder.

Does [S.C.] currently have a language disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## TS B1 2 8 [IF TS B1 1 8=1 ASK, ELSE SKIP TO TS B1 2 9]

Earlier you told me that [S.C.] has been diagnosed with obsessive compulsive disorder or OCD.

Does [S.C.] currently have obsessive compulsive disorder or OCD?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## TS\_B1\_2\_9 [IF TS\_B1\_1\_9=1 ASK, ELSE SKIP TO TS\_B1\_2\_10]

Earlier you told me that [S.C.] has been diagnosed with post-traumatic stress disorder or PTSD.

Does [S.C.] currently have post-traumatic stress disorder or PTSD?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## TS B1 2 10 [IF TS B1 1 10=1 ASK, ELSE SKIP TO TS B1 2 11]

Earlier you told me that [S.C.] has been diagnosed with another anxiety disorder, such as generalized anxiety disorder, panic disorder, or a phobia.

Does [S.C.] currently have another anxiety disorder, such as generalized anxiety disorder, panic disorder, or a phobia?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## TS B1 2 11 [IF TS B1 1 11=1 ASK, ELSE SKIP TO TS B1 2 12]

Earlier you told me that [S.C.] has been diagnosed with bipolar disorder.

Does [S.C.] currently have bipolar disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## TS B1 2 12 [IF TS B1 1 12=1 ASK, ELSE SKIP TO TS B1 2 13]

Earlier you told me that [S.C.] has been diagnosed with intermittent explosive disorder.

Does [S.C.] currently have intermittent explosive disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## TS B1 2 13 [IF TS B1 1 13=1 ASK, ELSE SKIP TO TS B1 2 14]

Earlier you told me that [S.C.] has been diagnosed with another mood disorder, such as depression, or major depressive disorder.

Does [S.C.] currently have another mood disorder, such as depression, or major depressive disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# TS\_B1\_2\_14 [IF TS\_B1\_1\_14=1 ASK, ELSE SKIP TO TS\_B1\_2\_15]

Earlier you told me that [S.C.] has been diagnosed with an eating disorder, such as anorexia or bulimia.

Does [S.C.] currently have an eating disorder, such as anorexia or bulimia?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# TS\_B1\_2\_15 [IF TS\_B1\_1\_15=1 ASK, ELSE SKIP TO TS\_C1\_INTRO]

Earlier you told me that [S.C.] has been diagnosed with substance use disorder.

Does [S.C.] currently have substance use disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **TREATMENT**

#### **MEDICATION**

TS C1 INTRO

I will now be asking you some questions about medications [S.C.] may be taking for [his/her] Tourette syndrome.

- TS C1 1 Has [S.C.] ever taken medication for Tourette syndrome?
  - (1) YES [Go to TS\_C1\_2]
  - (2) NO [Go to TS\_C3\_1]
  - (77) DON'T KNOW [Go to TS C3 1]
  - (99) REFUSED [Go to TS C3 1]
- TS\_C1\_2 At what age did [S.C.] first start taking Tourette syndrome medication?

**RECORD VALUE:** 

ENTER 77 FOR DON'T KNOW [GO TO TS\_C1\_5]

ENTER 99 FOR REFUSED [GO TO TS C1 5]

TS C1 2 MY

- (1) YEARS
- (2) MONTHS

[IF CHILD DOES NOT CURRENTLY HAVE TS [TS\_A2\_1 = (2) NO], SKIP TO TS C1 5]

- TS C1 3 Is [S.C.] currently taking medication for Tourette syndrome?
  - (1) YES [Go to TS C1 4]
  - (2) NO [Go to TS C1 5]
  - (77) DON'T KNOW [Go to TS C1 5]
  - (99) REFUSED [Go to TS C1 5]

#### TS C1 4 NEW

What medications does [S.C.] currently take for Tourette syndrome?

[SELECT ALL THAT APPLY]

PROBE: Does [he/she] take any other medications for TS?

NOTE TO INTERVIEWER: IF R SAYS "DON'T KNOW" SAY: That's okay. At the end of the interview I'll ask that you take a moment to get [S.C.]'s medication so we may record the name of it.

- (1) ABILIFY, ABILIFY MAINTENA, ABILIFY DISCMELT
- (2) ADDERALL (ADD-UR-ALL)
- (3) ADDERALL XR
- (4) AMPHETAMINE (AM-FET-A-MEEN)
- (5) APO-METOCLOP

- (6) APOKYN
- (7) APOMORPHINE
- (8) ARICEPT, ARICEPT ODT
- (9) ARIPIPRAZOLE
- (10) ATOMOXETINE (AT-OH-MOX-E-TEEN)
- (11) BUPROPRION
- (12) BACLOFEN
- (13) BOTULINUM TOXIN, BOTOX
- (14) CATAPRES, CATAPRES-TTS
- (15) CELEXA
- (16) CITALOPRAM (SI-TAL-O-PRAM)
- (17) CLONAZEPAM
- (18) CLONIDINE, CLONIDINE ER
- (19) CONCERTA
- (20) DELTANYNE
- (21) DEXEDRINE, DEXEDRINE SPANSULE
- (22) DEXTROSTAT, DEXTRO-AMPHETAMINE
- (23) DEXMETHYLPHENIDATE
- (24) DONEPEZIL
- (25) DRONABINOL
- (26) DURACLON
- (27) DYSPORT
- (28) FLUOXETINE (FLOO-OX-E-TEEN)
- (29) FLUPHENAZINE
- (30) FOCALIN
- (31) FOCALIN XR
- (32) GABLOFEN
- (33) GEODON
- (34) GUANFACINE,
- (35) HALOPERIDOL, HALDOL, HALDOL DECANOATE
- (36) INTUNIV
- (37) KAPVAY
- (38) KEPPRA, KEPPRA XR
- (39) KEMSTRO
- (40) KLONOPIN, KLONOPIN WAFER
- (41) LEVETIRACETAM
- (42) LIORESAL
- (43) LISDEXAMFETAMINE (LIS-DEX-AM-FET-A-MEEN)
- (44) MARINOL
- (45) METADATE, METADATE CD
- (46) METHYLIN
- (47) METHYLPHENIDATE
- (48) METHYLPHENIDATE PATCH (DAYTRANA)
- (49) METOCLOPRAMIDE, METOCLOPRAMIDE HYDROCHLORIDE INJECTION, METOCLOPRAMIDE OMEGA
- (50) MIRAPEX, MIRAPEX ER
- (51) NAC
- (52) NEUROBLOC
- (53) NEXICLON

- (54) NU-METOCLOPRAMIDE
- (55) OLANZAPINE
- (56) ONDANSETRON
- (57) ORAP
- (58) PERGOLIDE
- (59) PERMAX
- (60) PERMITIL
- (61) PIMOZIDE
- (62) PMS-METOCLOPRAMIDE
- (63) PRAMIPEXOLE
- (64) PROLIXIN, PROLIXIN DECANOATE, PROLIXIN ENANTHATE
- (65) PROZAC
- (67) QUETIAPINE
- (68) QUILLIVANT
- (69) REQUIP
- (70) RISPERDAL, RISPERDAL CONSTA, RISPERDAL M-TAB, RISPERIDONE, RISPERIDOL
- (71) RITALIN
- (72) RITALIN LA, RITALIN SR
- (73) ROPINIROLE
- (74) SATIVEX
- (75) SEROQUEL, SEROQUEL XR
- (76) SERTRALINE (SER-TRA-LEEN)
- (78) STRATTERA
- (79) TENEX
- (80) TETRABENAZINE
- (81) TETRAHYDROCANNABINOL, Δ DELTA-9-THC
- (82) TOPAMAX, TOPAMAX SPRINKLE
- (83) TOPIRAMATE, TOPIRAGEN
- (84) VYVANSE
- (85) WELLBUTRIN
- (86) XENAZINE
- (87) ZIPRASIDONE
- (88) ZOFRAN
- (89) ZOLOFT
- (90) ZYPREXA, ZYPREXA ZYDIS, ZYPREXA RELPREVV, ZYPREXA INTRAMUSCULAR
- (91) OTHER [GO TO TS C1 4 VERBATIM]
- (666) NOT CURRENTLY TAKING MEDICATION (GO TO TS C2 1]
- (777) DON'T KNOW [GO TO TS C2 1]
- (999) REFUSED [GO TO TS C2 1]

TS C1 4 VERBATIM
RECORD VERBATIM RESPONSE

## TS C1 5 INTRO

I will now be asking you about any side effects to the Tourette syndrome medication that [S.C.] may have experienced. Please think about side effects from medications that [S.C.] has ever taken for Tourette syndrome, even if [he/she] does not currently take them now.

TS\_C1\_5A Due to Tourette syndrome medication, has [S.C.] ever experienced weight gain?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the TS medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_C1\_5B Due to Tourette syndrome medication, has [S.C.] experienced being physically slowed down or sluggish, such as moving slowly?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the TS medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_C1\_5C Due to Tourette syndrome medication, has [S.C.] experienced being mentally slowed down or sluggish, for example, thinking slowly or being less attentive?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the TS medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

TS\_C1\_5D READ IF NECESSARY: Due to Tourette syndrome medication, has [S.C.] experienced...

Sleep problems or insomnia, such as trouble getting to sleep or staying asleep?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the TS medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_C1\_5E READ IF NECESSARY: Due to Tourette syndrome medication, has [S.C.] experienced...

Body twisting, squirming, or other new body movements, not including tics?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the TS medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_C1\_5F Due to Tourette syndrome medication, has [S.C.] experienced ever experienced any other side effects?
  - (1) YES [GO TO TS\_C1\_5F\_VERBATIM]
  - (2) NO [C
- [GO TO TS C1 6]
  - (77) DON'T KNOW [GO TO TS\_C1\_6]
  - (99) REFUSED [GO TO TS C1 6]
- TS C1 5F VERBATIM

RECORD VERBATIM RESPONSE

IF ANY TS\_C1\_5A-TS\_C1\_5F = YES, THEN GO TO TS\_C1\_6. ELSE, IF CHILD IS CURRENTLY TAKING MEDS (TS\_C1\_3 = YES), GO TO TS\_C2\_1. IF CHILD IS NOT CURRENTLY TAKING MEDS (TS\_C1\_3 = NO, DK, RF), GO TO TS\_C3\_1.

- TS C1 6 Were these side effects troublesome enough to stop taking the medication?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED

IF CHILD IS CURRENTLY TAKING MEDS (TS\_C1\_3 = YES), GO TO TS C2 1.

IF CHILD IS NOT CURRENTLY TAKING MEDS (TS\_C1\_3 = NO, DK, RF), GO TO TS C3 1.

#### MEDICATION ADHERENCE

- TS\_C2\_1 Who usually makes sure [S.C.] takes [his/her] Tourette syndrome medication?
  - (1) A PARENT OR GUARDIAN
  - (2) ANOTHER FAMILY MEMBER
  - (3) SOMEONE AT SCHOOL
  - (4) A BABYSITTER OR NANNY
  - (5) THE CHILD
  - (6) OTHER PERSON
  - (77) DON'T KNOW
  - (99) REFUSED
- TS\_C2\_2 In the past 12 months, was there a time when [S.C.] resisted taking [his/her] Tourette syndrome medication?

READ IF NECESSARY: Do not include resistance solely due to physical reasons such as being unable to swallow a pill.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### OTHER TREATMENT

[FOR QUESTIONS TS\_C3\_1-TS\_C3\_4, DO NOT SKIP TO CORRESPONDING CURRENT QUESTIONS IF CHILD DOES NOT CURRENTLY HAVE TS [TS\_A2\_1=NO], PROCEED TO C3\_11 AFTER TS\_C3\_4]

TS C3 INTRO

Now I will be asking you about other treatments for Tourette syndrome.

TS_C3_1	Has [S.C.] ever received comprehensive behavioral intervention for tics (CBIT) or habit reversal therapy for Tourette syndrome?
	(1) YES [IF TS_A2_1=1 GO TO TS_C3_1A; ELSE IF TS_A2_1=2, 77, 99 GO TO TS_C3_2] (2) NO [GO TO TS_C3_2] (77) DON'T KNOW [GO TO TS_C3_2] (99) REFUSED [GO TO TS C3_2]
TS_C3_1A	
	(1) YES [GO TO TS_C3_1B] (2) NO [GO TO TS_C3_2] (77) DON'T KNOW [GO TO TS_C3_2] (99) REFUSED [GO TO TS_C3_2]
TS_C3_1B	What type of health care provider is providing the comprehensive behavioral intervention for tics (CBIT) or habit reversal therapy?
	<ol> <li>PSYCHOLOGIST</li> <li>SOCIAL WORKER</li> <li>OCCUPATIONAL THERAPIST</li> <li>PSYCHIATRIST</li> <li>NEUROLOGIST</li> <li>PHYSICAL THERAPIST</li> <li>PEDIATRICIAN</li> <li>PHYSICIAN'S ASSISTANT</li> <li>OTHER [GO TO TS_C3_1B_VERBATIM]</li> <li>DON'T KNOW</li> <li>REFUSED</li> </ol>
TS_C3_1B_	VERBATIM RECORD VERBATIM RESPONSE
TS_C3_2	Has [S.C.] ever received school-based behavioral treatment, support, or accommodation for Tourette syndrome?
	READ IF NECESSARY: Do not include CBIT or habit reversal therapy.
	(1) YES [GO TO TS_C3_2A] (2) NO [GO TO TS_C3_3] (77) DON'T KNOW [GO TO TS_C3_3] (99) REFUSED [GO TO TS_C3_3]

TS_C3_2A	Is [S.C.] currently receiving school-based behavioral treatment, support, or accommodation for Tourette syndrome?
	(1) YES (2) NO (77) DON'T KNOW (99) REFUSED
TS_C3_3	Has [S.C.] ever received behavioral treatment based outside of school for Tourette syndrome?
	(1) YES [GO TO TS_C3_3A] (2) NO [GO TO TS_C3_4] (77) DON'T KNOW [GO TO TS_C3_4] (99) REFUSED [GO TO TS_C3_4]
TS_C3_3A	Is [S.C.] currently receiving behavior treatment based outside of school for Tourette syndrome?
	(1) YES (2) NO (77) DON'T KNOW (99) REFUSED
TS_C3_4	Has [S.C.] ever received any other treatment for Tourette syndrome?
	(1) YES [GO TO TS_C3_4_VERBATIM] (2) NO [GO TO TS_C3_5] (77) DON'T KNOW [GO TO TS_C3_5] (99) REFUSED [GO TO TS_C3_5]
TS_C3_4_VE	RBATIM RECORD VERBATIM RESPONSE
TS_C3_4A	Is [S.C.] currently receiving [other treatment] for Tourette syndrome?
	(1) YES (2) NO (77) DON'T KNOW (99) REFUSED

- TS\_C3\_5 Does the child currently have a formal educational plan, such as an Individualized Education Program, also called an IEP or a 504 plan?
  - (1) YES [GO TO TS\_C6]
  - (2) NO [GO TO TS C4 INTRO]
  - (77) DON'T KNOW [GO TO TS C4 INTRO]
  - (99) REFUSED [GO TO TS\_C4\_INTRO]
- TS\_C3\_6 Which one is it, an IEP or a 504 plan?
  - (1) IEP
  - (2) 504
  - (3) SOMETHING ELSE [GO TO TS\_C3\_6\_VERBATIM]
  - (4) BOTH IEP AND 504 PLAN
  - (77) DON'T KNOW
  - (99) REFUSED

#### TS C3 6 VERBATIM

RECORD VERBATIM RESPONSE

#### TREATMENT BARRIERS AND SATISFACTION

IF CHILD DOES NOT CURRENTLY HAVE TS [TS\_A2\_1=NO], SKIP TO TS\_D1\_1 ELSE ASK]

TS C4 INTRO

I will now ask you about your satisfaction with [S.C.]'s treatment and any treatment barriers you may have experienced.

- TS\_C4\_1 In the past 12 months, did your child need a Tourette syndrome treatment that he/she was unable to get?
  - (1) YES [GO TO TS C4 2A]
  - (2) NO [GO TO TS\_C4\_3]
  - (77) DON'T KNOW [GO TO TS C4 3]
  - (99) REFUSED [GO TO TS\_C4\_3]
- TS C4 2A Was the treatment [S.C.] needed but couldn't get....

Medication?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

TS\_C4\_2B Was the treatment [S.C.] needed but couldn't get...

Comprehensive behavioral intervention for tics (CBIT) or habit reversal therapy?

- (1) YES [GO TO TS C4 2BA]
- (2) NO [GO TO TS C4 2C]
- (77) DON'T KNOW [GO TO TS C4 2C]
- (99) REFUSED [GO TO TS C4 2C]
- TS\_C4\_2BA Why couldn't [S.C.] get comprehensive behavioral intervention for tics (CBIT) or habit reversal therapy? [SELECT ALL THAT APPLY]
  - (1) COST WAS TOO MUCH
  - (2) NOT AVAILABLE IN CHILD'S AREA OR SCHOOL
  - (3) WAITING LISTS, BACKLOGS, DRUG SHORTAGES OR OTHER DELAYS
  - (4) CHILD WAS NOT ELIGIBLE FOR THE TREATMENT/SERVICE
  - (5) PARENT/DOCTOR/SCHOOL DID NOT KNOW ABOUT TREATMENT OR HAD TROUBLE GETTING INFORMATION NEEDED
  - (6) DOCTOR/SCHOOL REFUSED TO PROVIDE TREATMENT OR DID NOT FOLLOW THROUGH
  - (7) CHILD OR OTHER FAMILY MEMBER DID NOT WANT TREATMENT/SERVICE
  - (8) OTHER [GO TO TS\_C4\_2BA\_VERBATIM]
  - (77) DON'T KNOW
  - (99) REFUSED

#### TS C4 2BA VERBATIM

RECORD VERBATIM RESPONSE

TS C4 2C Was the treatment [S.C.] needed but couldn't get...

School-based behavioral treatment, support or accommodation?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS C4 2D Was the treatment [S.C.] needed but couldn't get...

Behavioral treatment outside of school?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

- TS\_C4\_2E Were there any other types of treatment that [S.C.] needed but could not get?
  - (1) YES [GO TO TS\_C4\_2E\_VERBATIM]
  - (2) NO  $[GO TO TS\_C4\_3]$
  - (77) DON'T KNOW [GO TO TS C4 3]
  - (99) REFUSED [GO TO TS\_C4\_3]
- TS\_C4\_2E\_VERBATIM

RECORD VERBATIM RESPONSE

- TS\_C4\_3 Overall, how satisfied are you with [S.C.]'s Tourette syndrome treatment and management? Would you say you are very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied?
  - (1) VERY SATISFIED
  - (2) SOMEWHAT SATISFIED
  - (3) SOMEWHAT DISSATISFIED
  - (4) VERY DISSATISFIED
  - (77) DON'T KNOW
  - (99) REFUSED

#### SYMPTOMS AND PERFORMANCE/IMPAIRMENT

### TS D1 INTRO

Next I would like you to think about [S.C.]'s behavior and performance. When answering, please think about your child's behaviors in the past 6 months when he is not taking any medication for Tourette syndrome, ADHD, or any other medication for other difficulties with his emotions, concentration or behavior. For each question, please say whether [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent.

READ IF NECESSARY: If the child is always on medication think about even the short times when the child is not on medication such as early in the morning or when a dose is missed.

TS D1 1 How would you describe [S.C.]'s overall school performance?

Would you say that [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (6) CHILD NOT YET IN SCHOOL, PRESCHOOL OR DAYCARE
- (77) DON'T KNOW
- (99) REFUSED
- TS\_D1\_2 How would you describe [S.C.]'s performance in reading?

Would you say [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

INTERVIEWER INSTRUCTION: IF RESPONDENT STATES THAT CHILD DOES NOT READ YET, READ: Please consider what you this is appropriate for the age of your child.

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

## TS\_D1\_3 How would you describe [S.C.]'s performance writing?

Would you say [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

INTERVIEWER INSTRUCTION: IF RESPONDENT STATES THAT CHILD DOES NOT READ YET, READ: Please consider what you this is appropriate for the age of your child.

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

## TS\_D1\_4 How would you describe [S.C.]'s performance mathematics?

READ IF NECESSARY: Would you say [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

INTERVIEWER INSTRUCTION: IF RESPONDENT STATES THAT CHILD DOES NOT DO MATH YET, READ: Please consider what you this is appropriate for the age of your child.

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

TS\_D1\_5 How would you describe [S.C.]'s relationship with [his/her] parents, caregivers or guardians?

READ IF NECESSARY: Would you say [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent?

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED
- TS D1 6 How would you describe [S.C.]'s relationships with siblings?

READ IF NECESSARY: Would you say [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent?

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (6) CHILD DOES NOT HAVE SIBLINGS
- (77) DON'T KNOW
- (99) REFUSED
- TS D1 7 How would you describe [S.C.]'s relationships with peers?

READ IF NECESSARY: Would you say [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent?

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

TS\_D1\_8 How would you describe [S.C.]'s participation in organized activities such as teams?

READ IF NECESSARY: Would you say [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

INTERVIEWER INSTRUCTION: IF RESPONDENT STATES THAT CHILD DOES NOT PARTICIPATE IN ORGANIZED ACTIVITIES YET, READ: Please consider what you this is appropriate for the age of your child.

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (6) CHILD DOES NOT PARTICIPATE IN ORGANIZED ACTIVITIES
- (77) DON'T KNOW
- (99) REFUSED
- TS\_D1\_9 How would you describe [S.C.]'s handwriting, that is, his/her ability to form letters and numbers that are clear and can be recognized?

READ IF NECESSARY: Would you say [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

INTERVIEWER INSTRUCTION: IF RESPONDENT STATES THAT CHILD DOES NOT WRITE YET, READ: Please consider what you this is appropriate for the age of your child.

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

### **ACADEMIC HEALTH AND DISCIPLINE**

TS\_E\_INTRO

I'd now like to ask you a few questions about [S.C.]'s school experience.

TS\_E1 What kind of school is [S.C.] currently enrolled in? Is it a public school, private school, or is [S.C.] home-schooled?

INTERVIEWER INSTRUCTION: IF THE CHILD WAS ENROLLED IN MORE THAN ONE TYPE OF SCHOOL DURING THE CURRENT OR LAST SCHOOL YEAR, ASK THE TYPE OF SCHOOLS THAT THE CHILD HAS MOST RECENTLY ATTENDED.

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

INTERVIEWER INSTRUCTION: CODE CHARTER SCHOOLS AS "PUBLIC".

- (1) PUBLIC
- (2) PRIVATE
- (3) HOME-SCHOOLED
- (4) [S.C.] IS NOT ENROLLED IN SCHOOL
- (77) DON'T KNOW
- (99) REFUSED
- TS\_E1\_1 Is the school that [S.C.] is enrolled in a specialty school for children with learning and behavior differences?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED
- TS\_E2 Overall, would you consider [S.C.] an [READ RESPONSES]:

HELP TEXT: SCHOOL INCLUDES PRESCHOOL, DAYCARE AND HOME-SCHOOLING.

READ IF NECESSARY: Please use the following guideline:

- A = Exceptional
- B = Above average
- C = Average
- D = Below average
- F = Failing

- (1) A STUDENT
- (2) B STUDENT
- (3) C STUDENT
- (4) D STUDENT
- (5) F STUDENT
- (6) CHILD NOT ENROLLED IN ANY SCHOOLING
- (77) DON'T KNOW
- (99) REFUSED
- TS\_E3 Since starting kindergarten, has [he/she] repeated any grades?
  - (1) YES [GO TO TS\_E4]
  - (2) NO  $[GO TO TS\_E5]$
  - (3) CHILD HAS NOT YET ENTERED KINDERGARTEN [GO TO TS\_E5]
  - (77) DON'T KNOW [GO TO TS E5]
  - (99) REFUSED [GO TO TS E5]
- TS E4 Which grade or grades did [he/she] repeat? [SELECT ALL THAT APPLY]
  - (1) KINDERGARTEN
  - (2) 1<sup>ST</sup> GRADE
  - (3) 2<sup>ND</sup> GRADE
  - (4) 3<sup>RD</sup> GRADE
  - (5) 4<sup>TH</sup> GRADE
  - (6)  $5^{TH}$  GRADE
  - (7) 6<sup>TH</sup> GRADE
  - (8)  $7^{TH}$  GRADE
  - (9) 8<sup>TH</sup> GRADE
  - (10) 9<sup>TH</sup> GRADE
  - (11)  $10^{TH}$  GRADE
  - (12)  $11^{TH}$  GRADE
  - (13)  $12^{TH}$  GRADE
  - (77) DON'T KNOW
  - (99) REFUSED
- TS\_E5 Has [S.C.] ever been expelled or asked not to return to a childcare center, preschool, or school?
  - (1) YES [GO TO TS E 6]
  - (2) NO [GO TO TS E 7]
  - (77) DON'T KNOW [GO TO TS\_E\_7]
  - (99) REFUSED [GO TO TS E 7]

- TS E6 In what grade or grades was [S.C.] expelled or asked not to return to school? [SELECT ALL THAT APPLY]
  - (1) CHILDCARE (BIRTH THROUGH AGE 2)
  - (2) PRESCHOOL (AGE 3 TO AGE 5)
  - (3) KINDERGARTEN
  - (4) 1<sup>ST</sup> GRADE
  - (5) 2<sup>ND</sup> GRADE
  - (6) 3<sup>RD</sup> GRADE
  - (7) 4<sup>TH</sup> GRADE
  - (8) 5<sup>TH</sup> GRADE
  - (9)  $6^{TH}$  GRADE
  - (10) 7<sup>TH</sup> GRADE
  - (11) 8<sup>TH</sup> GRADE
  - (12) 9<sup>TH</sup> GRADE

  - $(13) 10^{TH} GRADE$ (14) 11<sup>TH</sup> GRADE
  - (15)  $12^{TH}$  GRADE

  - (77) DON'T KNOW
  - (99) REFUSED
- Has your child ever been treated differently because of [his/her] tics, for example, TS E 7 being bullied or discriminated against, or treated rudely?
  - (1) YES [GO TO TS E 7A]
  - (2) NO [GO TO TS E 8]
  - (77) DON'T KNOW [GO TO TS E 8]
  - (99) REFUSED [GO TO TS E 8]
- Who has discriminated against or bullied the child? Were they siblings, other TS E 7A children, business owners or employees, teachers, family members or some other adults? [SELECT ALL THAT APPLY]
  - (1) SIBLINGS
  - (2) OTHER CHILDREN
  - (3) BUSINESS OWNERS OR EMPLOYEES
  - (4) TEACHERS
  - (5) FAMILY MEMBERS
  - (6) SOME OTHER ADULTS
  - (77) DON'T KNOW
  - (99) REFUSED

IF CHILD DOES NOT CURRENTLY HAVE TICS [TS A2 7 = 3 or TS A2 8 = NO], THEN GO TO TS F 1.

Sometimes certain things seem to make tics better or worse. Please tell me if the following activities make [S.C.]'s tics better, worse or if they have no impact.

- TS\_E\_8A Do major transitions like starting a new school or moving into a new class seem to make [S.C.]'s tics better or worse, or is there no impact?
  - (1) BETTER
  - (2) WORSE
  - (3) DEPENDS
  - (4) NO IMPACT
  - (5) NOT APPLICABLE
  - (77) DON'T KNOW
  - (99) REFUSED
- TS\_E\_8B Do minor transitions like switching activities or changing locations seem to make [S.C.]'s tics better or worse, or is there no impact?
  - (1) BETTER
  - (2) WORSE
  - (3) DEPENDS
  - (4) NO IMPACT
  - (5) NOT APPLICABLE
  - (77) DON'T KNOW
  - (99) REFUSED
- TS\_E\_8C Does being tired seem to make tics better or worse, or is there no impact?
  - (1) BETTER
  - (2) WORSE
  - (3) DEPENDS
  - (4) NO IMPACT
  - (5) NOT APPLICABLE
  - (77) DON'T KNOW
  - (99) REFUSED
- TS\_E\_8D READ IF NECESSARY: Please tell me if the following activity makes [S.C.]'s tics better, worse or if it has no impact.

Talking about tics.

- (1) BETTER
- (2) WORSE
- (3) DEPENDS
- (4) NO IMPACT
- (5) CHILD DOES NOT DO THAT ACTIVITY
- (77) DON'T KNOW
- (99) REFUSED

TS\_E\_8E READ IF NECESSARY: Please tell me if the following activity makes [S.C.]'s tics better, worse or if it has no impact.

Doing homework.

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

- (1) BETTER
- (2) WORSE
- (3) DEPENDS
- (4) NO IMPACT
- (5) CHILD DOES NOT DO THAT ACTIVITY/CHILD NOT IN SCHOOL
- (77) DON'T KNOW
- (99) REFUSED
- TS\_E\_8F READ IF NECESSARY: Please tell me if the following activity makes [S.C.]'s tics better, worse or if it has no impact.

Playing music or singing.

- (1) BETTER
- (2) WORSE
- (3) DEPENDS
- (4) NO IMPACT
- (5) CHILD DOES NOT DO THAT ACTIVITY
- (77) DON'T KNOW
- (99) REFUSED
- TS\_E\_8G READ IF NECESSARY: Please tell me if the following activity makes [S.C.]'s tics better, worse or if it has no impact.

Exercising or doing an individual sport, like running or swimming.

- (1) BETTER
- (2) WORSE
- (3) DEPENDS
- (4) NO IMPACT
- (5) CHILD DOES NOT DO THAT ACTIVITY
- (77) DON'T KNOW
- (99) REFUSED

TS\_E\_8H READ IF NECESSARY: Please tell me if the following activity makes [S.C.]'s tics better, worse or if it has no impact.

Playing team sports, like soccer, baseball or volleyball.

- (1) BETTER
- (2) WORSE
- (3) DEPENDS
- (4) NO IMPACT
- (5) CHILD DOES NOT DO THAT ACTIVITY
- (77) DON'T KNOW
- (99) REFUSED
- TS\_E8IJ READ IF NECESSARY: Please tell me if following activity makes [S.C.]'s tics better, worse or if it has no impact.

Other quiet hobbies, such as listening to music or reading for pleasure.

- (1) BETTER
- (2) WORSE
- (3) DEPENDS
- (4) NO IMPACT
- (5) CHILD DOES NOT DO THAT ACTIVITY
- (77) DON'T KNOW
- (99) REFUSED
- TS\_E\_8K READ IF NECESSARY: Please tell me if the following activity makes [S.C.]'s tics better, worse or if it has no impact.

Watching TV.

- (1) BETTER
- (2) WORSE
- (3) DEPENDS
- (4) NO IMPACT
- (5) CHILD DOES NOT DO THAT ACTIVITY
- (77) DON'T KNOW
- (99) REFUSED

TS\_E\_8L READ IF NECESSARY: Please tell me if the following activity makes [S.C.]'s tics better, worse or if it has no impact.

Playing video games or other computer games.

- (1) BETTER
- (2) WORSE
- (3) DEPENDS
- (4) NO IMPACT
- (5) CHILD DOES NOT DO THAT ACTIVITY
- (77) DON'T KNOW
- (99) REFUSED

## **FAMILY IMPACT**

TS F INTRO

Now I'd like to ask you about [S.C.] and your family.

- TS F1 1 Has [S.C.]'s Tourette syndrome caused financial problems for your family?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED
- TS\_F1\_2 Have you or other family members stopped working because of [S.C.]'s Tourette syndrome?

HELP TEXT: CODE 2 IF NO ONE IN HOUSEHOLD WORKS

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_F1\_3 [IF TS\_F1\_2 = 1, THEN READ: Not including the family members who stopped working,] Have you or other family members cut down on the hours you work because of [S.C.]'s Tourette syndrome?

HELP TEXT: CODE 2 IF NO ONE IN HOUSEHOLD WORKS

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS\_F1\_4 Have you or other family members avoided changing jobs because of concerns about maintaining health insurance for [S.C.]?

HELP TEXT: CODE 2 IF NO ONE IN HOUSEHOLD WORKS

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **AMERICAN COMMUNITY SURVEY QUESTIONS**

#### TS G INTRO

Now I have a few more general questions about [S.C.] and your household. These questions may seem similar to other questions I have previously asked.

- TS\_G1\_1 How well does [S.C.] speak English? Would you say very well, well, not well or not at all?
  - (1) VERY WELL
  - (2) WELL
  - (3) NOT WELL
  - (4) NOT AT ALL
  - (77) DON'T KNOW
  - (99) REFUSED
- TS G1 2 Is [S.C.] deaf or have serious difficulty hearing?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED
- TS\_G1\_3 Is [S.C.] blind or have serious difficulty seeing, even when wearing glasses?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED
- TS\_G1\_4 Because of a physical, mental or emotional condition, does [S.C.] have serious difficulty concentrating, remembering, or making decisions?

HELP TEXT: ANY PHYSICAL, MENTAL OR EMOTIONAL CONDITION (INCLUDING TS) CAN BE CONSIDERED.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- TS G1 5 Does [S.C.] have serious difficulty walking or climbing stairs?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED

- TS G1 6 Does [S.C.] have difficulty dressing or bathing?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED
- TS G1 7 [IF AGE < 15 SKIP TO TS H1 Q01]

Because of a physical, mental or emotional condition, does [S.C.] have difficulty doing errands alone such as visiting a doctor's office or shopping?

HELP TEXT: ANY PHYSICAL, MENTAL OR EMOTIONAL CONDITION (INCLUDING TS) CAN BE CONSIDERED

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### **HOUSEHOLD AND DEMOGRAPHICS**

TS\_H1\_Q01 Including the adults and all the children, how many people live in this household?

RECORD VALUE:

TS H1 Q02 I have that you are [S.C.]'s [FILL FROM RELATION]. Is that correct?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

TS\_H1\_Q03 IF TS\_H1\_Q02=2, 77, 99 OR IF R\_TYPE=2, 77, 99 THEN DISPLAY: What is your relationship to [S.C.]?

IF TS\_H1\_Q02=1 AND C10Q02A=1 THEN DISPLAY: Are you [S.C.]'s biological, adoptive, step, or foster mother?

IF TS\_H1\_Q02=1 AND C10Q02A=2 THEN DISPLAY: Are you [S.C.]'s biological, adoptive, step, or foster father?

- (1) BIOLOGICAL MOTHER
- (2) STEP MOTHER
- (3) FOSTER MOTHER
- (4) ADOPTIVE MOTHER
- (5) MOTHER, but TYPE REFUSED
- (6) BIOLOGICAL FATHER
- (7) STEP FATHER
- (8) FOSTER FATHER
- (9) ADOPTIVE FATHER
- (10) FATHER, but TYPE REFUSED
- (11) GRANDMOTHER
- (12) GRANDFATHER
- (13) AUNT
- (14) UNCLE
- (15) FEMALE GUARDIAN
- (16) MALE GUARDIAN
- (17) SISTER (BIOLOGICAL, STEP, FOSTER, HALF, ADOPTIVE)
- (18) BROTHER (BIOLOGICAL, STEP, FOSTER, HALF, ADOPTIVE)
- (19) COUSIN
- (20) IN-LAW OF ANY TYPE
- (22) OTHER RELATIVE / FAMILY MEMBER
- (23) PARENT'S BOYFRIEND / MALE PARTNER
- (24) PARENT'S GIRLFRIEND / FEMALE PARTNER
- (25) PARENT'S PARTNER, but SEX REFUSED
- (26) OTHER NON-RELATIVE OR FRIEND
- (77) DON'T KNOW
- (99) REFUSED

# TS \_H1\_Q04 IF TS\_H1\_Q01= 2 THEN SKIP TO TS\_H1\_Q04\_CONF

### IF TS H1 Q01 = 77 or 99, THEN READ:

For the other people that live in your household with you and [S.C.], what is their relationship to [S.C.]? [MARK ALL THAT APPLY]

### IF TS H1 Q01>2, THEN READ:

In addition to you and [S.C.], I have that [FILL: TS\_H1\_Q01 - 2] [other person lives/other people live] in your household. What is their relationship to [S.C.]? [MARK ALL THAT APPLY]

IF R RESPONDS "Mother" or "Father," YOU MUST PROBE: Is that [S.C.]'s biological, step, foster, or adoptive mother/father?

IF R RESPONDS "Partner," PROBE: Is the partner male or female?

- (1) BIOLOGICAL MOTHER
- (2) STEP MOTHER
- (3) FOSTER MOTHER
- (4) ADOPTIVE MOTHER
- (5) MOTHER, but TYPE REFUSED
- (6) BIOLOGICAL FATHER
- (7) STEP FATHER
- (8) FOSTER FATHER
- (9) ADOPTIVE FATHER
- (10) FATHER, but TYPE REFUSED
- (11) GRANDMOTHER
- (12) GRANDFATHER
- (13) AUNT
- (14) UNCLE
- (15) FEMALE GUARDIAN
- (16) MALE GUARDIAN
- (17) SISTER (BIOLOGICAL, STEP, FOSTER, HALF, ADOPTIVE)
- (18) BROTHER (BIOLOGICAL, STEP, FOSTER, HALF, ADOPTIVE)
- (19) COUSIN
- (20) IN-LAW OF ANY TYPE
- (22) OTHER RELATIVE / FAMILY MEMBER
- (23) PARENT'S BOYFRIEND / MALE PARTNER
- (24) PARENT'S GIRLFRIEND / FEMALE PARTNER
- (25) PARENT'S PARTNER, but SEX REFUSED
- (26) OTHER NON-RELATIVE OR FRIEND
- (77) DON'T KNOW
- (99) REFUSED

### TS H1 Q03 ADOPT

Have you legally adopted [S.C.]?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### TS H2 INTRO

The next questions are about health insurance.

### TS H2 STATE

Because many health insurance programs are state specific, can you please tell me what state you live in?

# \_\_\_\_\_ ENTER STATE (DROP DOWN MENU)

TS\_H2\_Q01 Does [S.C.] have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?

READ IF NECESSARY: Medicaid refers to a medical assistance program that provides health care coverage to low-income and disabled persons. The Medicaid program is a joint federal-state program that is administered by the states. HMO is Health Maintenance Organization.

- (1) YES [SKIP TO TS H2 Q02]
- (2) NO [SKIP TO TS H2 Q01 CONF]
- (77) DON'T KNOW [SKIP TO TS H2 Q02]
- (99) REFUSED [SKIP TO TS H2 Q02]
- TS\_H2\_Q02 IF TS\_H2\_Q01 = 1 THEN FILL "Is that coverage". ELSE, FILL "Is [he/she] insured by] Medicaid or the Children's Health Insurance Program, or CHIP? [IF IAP=095, DISPLAY "In this area," ELSE DISPLAY "In this state,"] the program is sometimes called [FILL MEDICAID NAME, CHIP NAME].

READ IF NECESSARY: CHIP, also known as S-CHIP, is a type of state-sponsored health insurance coverage that a child may have. The name of the plan varies from state-to-state. CATI WILL AUTOMATICALLY FILL IN THE NAMES FOR YOU.

READ IF R MENTIONS THAT HE/SHE DOES NOT LIVE IN THE STATE MENTIONED IN THE QUESTION: Please think about the Medicaid or statesponsored Children's Health Insurance Program specific to the state in which you live.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

TS\_H2\_03 IF [(TS\_H2\_Q01 = 77, or 99) AND (TS\_H2\_Q02 = 2, 77, or 99)], SKIP TO TS\_H2\_Q04; ELSE, ASK

(IF AGE>1, "During the past 12 months", ELSE "Since [his/her] birth"), was there any time when [he/she] was not covered by ANY health insurance?

- (1) YES [SKIP TO TS\_H3\_Q01]
- (2) NO [SKIP TO TS H3 Q01]
- (77) DON'T KNOW [SKIP TO TS H3 Q01]
- (99) REFUSED [SKIP TO TS\_H3\_Q01]
- TS\_H2\_Q04 (IF AGE>1, "During the past 12 months", ELSE "Since [his/her] birth"), was there any time when [he/she] had health care coverage?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED
- TS H3 Q01 Now I am going to ask you a few questions about your income.

When answering this next question, please remember to include your income PLUS the income of all family members living in this household.

What is your best estimate of the total income of all family members from all sources, before taxes, in [FILL: last calendar year in 4 digit format]?

INTERVIEWER INSTRUCTION: ENTER '999,995' IF THE REPORTED INCOME IS GREATER THAN \$999,995.

INTERVIEWER INSTRUCTION: ENTER 77 FOR DON'T KNOW AND 99 FOR REFUSED

RECORD INCOME AMOUNT [GO TO TS H3 Q01 CONF]:

[INCOME GREATER THAN \$999,995 [GO TO TS ADDRESS CONF]

- (77) DON'T KNOW [GO TO TS H3 Q02]
- (99) REFUSED [GO TO TS H3 Q02]
- TS\_H3\_Q02 For the purposes of this survey, it is important to get at least a range for the total income received by all members of your household in 2013. Was your total family income from all sources less than \$50,000 or \$50,000 or more?
  - (1) LESS THAN \$50,000
  - (2) \$50,000 OR MORE [GO TO TS H3 Q05]
  - (77) DON'T KNOW [GO TO CPGOGETMED TS]
  - (99) REFUSED [GO TO CPGOGETMED TS]

- TS\_H3\_Q03 Was your total family income from all sources less than \$35,000 or \$35,000 or more?
  - (1) LESS THAN \$35,000
  - (2) \$35,000 OR MORE [IF TS\_H3\_Q01= (8, 9) GO TO TS\_H3\_Q04; ELSE GO TO CPGOGETMED TS]
  - (77) DON'T KNOW [GO TO CPGOGETMED TS]
  - (99) REFUSED [GO TO CPGOGETMED TS]
- TS\_H3\_Q04 Was your total family income from all sources less than [FILL: Poverty threshold for household of size TS\_H3\_Q01] or [FILL: Poverty threshold for household of size TS\_H3\_Q01] or more?
  - (1) LESS THAN [FILL: Poverty threshold for household of size TS\_H3\_Q01] [GO TO CPGOGETMED TS]
  - (2) [FILL: Poverty threshold for household of size TS\_H3\_Q01] OR MORE [GO TO CPGOGETMED TS]
  - (77) DON'T KNOW [GO TO CPGOGETMED TS]
  - (99) REFUSED [GO TO CPGOGETMED TS]
- TS\_H3\_Q05 Was your total family income from all sources less than \$100,000 or \$100,000 or more?
  - (1) LESS THAN \$100,000 [GO TO TS H3 Q06]
  - (2) \$100,000 OR MORE [GO TO CPGOGETMED TS]
  - (77) DON'T KNOW [GO TO CPGOGETMED TS]
  - (99) REFUSED [GO TO CPGOGETMED TS]
- TS\_H3\_06 Was your total family income from all sources less than \$75,000 or \$75,000 or more?
  - (1) LESS THAN \$75,000
  - (2) \$75,000 OR MORE
  - (77) DON'T KNOW
  - (99) REFUSED

IF RESPONDENT INDICATED NEEDING TO LOOK FOR MEDICATIONS EARLIER IN INTERVIEW THEY WERE GIVEN THE OPPORTUNITY (CPGOGETMED\_TS) TO GATHER THE MEDICATIONS TO ANSWER TS C1 4 NEW BEFORE CONCLUDING INTERVIEW.

#### TS ADDRESS CONF

IF ADHD ELIG=0 DISPLAY:

Those are all the questions I have.

[IF ADHD\_ELIG=0 DISPLAY: Before I go,] I will need your mailing address so we can send you \$ [MONEY\_1 / MONEY\_2] as a token of our appreciation for taking the time to answer our questions. Please note that your money will arrive in a standard white "Department of Health and Human Services" envelope.

(1) ADDRESS CORRECT AND CONFIRMED

(99) REFUSED TO GIVE/CONFIRM ADDRESS

IF ADHD\_ELIG=0, GO TO TS\_END; ELSE IF ADHD\_ELIG=1 GO TO ADHD TRANS

TS\_END Those are all the questions I have. You may be re-contacted in the future to participate in related studies. If you are contacted to participate in future surveys, you have the right to refuse. I'd like to thank you on behalf of the CDC's National Center for Health Statistics for the time and effort you've spent answering these questions. If you have any questions about this survey, you may call my supervisor toll-free at 1-877-346-9982. If you have questions about your rights as a survey participant, you may call the chairman of the Research Ethics Review Board at 1-800-223-8118. Thank you again.

### ADHD TRANS

Thank you for taking the time to answer those questions about [S.C.] and Tourette syndrome. Because you said that your child has also been diagnosed with ADHD, you are eligible to complete another set of questions about [S.C.] and ADHD. The survey will take approximately 20 minutes, and we will send you an additional \$20 for your time. We can continue with that survey now if you'd like, or we can schedule an appointment to complete the survey at a time that is convenient for you.

INTERVIEWER INSTRUCTION: IF RESPONDENT DOESN'T WANT TO CONTINUE BECAUSE OF TIME ESTIMATE: We really appreciate the time you have already spent with us on the phone. Is there a more convenient time for us to call you back?

- (1) CONTINUE WITH SURVEY NOW [SKIP TO ADHD\_CONSENT\_ABBREV]
- (2) SCHEDULE APPOINTMENT FOR ADHD [SCHEDULE APPT AND END CALL]
- (3) REFUSE TO DO ADHD SURVEY [SKIP TO TS END]

# ADHD CONSENT ABBREV

As before, you may choose not to answer any questions you don't wish to answer, or end the interview at any time with no impact on the benefits you may receive. I'd like to continue now unless you have any questions.

# ATTENTION-DEFICIT/HYPERACTIVITY DISORDER MODULE

# **DIAGNOSIS**

# PREVIOUS ADHD DIAGNOSIS

# ADHD A1 AGE

Thank you for confirming that a doctor or other health care provider once told you that [S.C.] had ADHD. The next set of questions will ask about [S.C.]'s ADHD diagnosis.

How old was [S.C.] when you were first told by a doctor or other health care provider that he/she had ADHD?

RECORD VALUE: \_\_\_\_ ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

### ADHD A1 AGE MY

- (1) YEARS
- (2) MONTHS

#### ADHD A1 1 NEW

What type of doctor or other health care provider FIRST told you that [S.C.] had ADHD?

- (1) DEVELOPMENTAL OR BEHAVIORAL PEDIATRICIAN
- (2) FAMILY PRACTICE DOCTOR
- (3) NEUROLOGIST
- (4) NURSE PRACTITIONER
- (5) OCCUPATIONAL THERAPIST
- (6) PEDIATRICIAN (GENERAL)
- (7) PHYSICAL THERAPIST
- (8) PHYSICIAN'S ASSISTANT
- (9) PSYCHIATRIST
- (10) PSYCHOLOGIST OUTSIDE OF SCHOOL
- (11) SCHOOL COUNSELOR
- (12) SCHOOL NURSE
- (13) SCHOOL PSYCHOLOGIST
- (14) SPEECH THERAPIST
- (15) TEAM OF PROFESSIONALS/MULTIDISCIPLINARY TEAM
- (16) OTHER [GO TO ADHD A1 1 VERBATIM NEW]
- (17) TEACHER
- (66) NO HEALTH CARE PROVIDER HAS EVER TOLD ME MY CHILD HAS THIS CONDITION
- (77) DON'T KNOW
- (99) REFUSED

ADHD_A1_1_VERBATIM_NEW RECORD VERBATIM RESPONSE
ADHD_A1_2 Besides the doctor or other health care provider that first told you that [S.C.] had ADHD, did any other doctor, health care provider, or school professional also tell you that [S.C.] had ADHD?
(1) YES [GO TO ADHD_A1_3] (2) NO [GO TO ADHD_A1_4] (77) DON'T KNOW [GO TO ADHD_A1_4] (99) REFUSED [GO TO ADHD_A1_4]
ADHD_A1_3_NEW Who was that? [SELECT ALL THAT APPLY]
READ IF NECESSARY: What types of other doctors, health care providers, or school professionals told you that [S.C.] had ADHD?
INTERVIEW PROMPT: Was there anyone else?
(1) DEVELOPMENTAL OR BEHAVIORAL PEDIATRICIAN (2) FAMILY PRACTICE DOCTOR (3) NEUROLOGIST (4) NURSE PRACTITIONER (5) OCCUPATIONAL THERAPIST (6) PEDIATRICIAN (GENERAL) (7) PHYSICAL THERAPIST (8) PHYSICIAN'S ASSISTANT (9) PSYCHIATRIST (10) PSYCHOLOGIST OUTSIDE OF SCHOOL (11) SCHOOL COUNSELOR (12) SCHOOL NURSE (13) SCHOOL PSYCHOLOGIST (14) SPEECH THERAPIST (15) TEAM OF PROFESSIONALS/MULTIDISCIPLINARY TEAM (16) OTHER [GO TO ADHD_A1_3_VERBATIM_NEW] (77) DON'T KNOW (99) REFUSED
ADHD_A1_3_VERBATIM_NEW RECORD VERBATIM RESPONSE

- ADHD\_A1\_4 Now I'd like you to think about the time before [S.C.]'s ADHD diagnosis. Who was FIRST person who was concerned with [child's] behavior, attention, or performance?
  - (1) YOU OR ANOTHER FAMILY MEMBER
  - (2) SOMEONE AT YOUR CHILD'S SCHOOL OR DAYCARE
  - (3) A DOCTOR OR HEALTHCARE PROFESSIONAL NOT AT CHILD'S SCHOOL
  - (4) SOMEONE ELSE
  - (77) DON'T KNOW
  - (99) REFUSED

# ADHD A1 4 AGE

How old was [S.C.] when [FILL RESPONSE FROM A1\_4] was first concerned with his/her behavior, attention, or performance?

RECORD VALUE: \_\_\_\_ ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

# ADHD\_A1\_4\_AGE\_MY

- (1) YEARS
- (2) MONTHS

### ADHD A1 5A

Before [S.C.] received an ADHD diagnosis, were you or other people concerned about...

Behavior at home, such as completing chores or getting along with parents

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### ADHD A1 5B

Before [S.C.] received an ADHD diagnosis, were you or other people concerned about...

Behavior at school or daycare, such as staying seated, listening to teachers, disrupting others, having tantrums or meltdowns, or paying attention in class.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD A1 5C

Before [S.C.] received an ADHD diagnosis, were you or other people concerned about...

School performance, such as grades or test scores, or completing assignments

HELP TEXT: School includes preschool or daycare.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD A1\_5D

Before [S.C.] received an ADHD diagnosis, were you or other people concerned about...

Relationships with other children, such as playing together, or making or keeping friends?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **DIAGNOSTIC CONTEXT**

#### ADHD A2 INTRO

Now I'd like you to think about the time when [S.C.] received an ADHD diagnosis. In order to determine whether a child has ADHD, a health care provider or school professional will ask whether the child has more problems with inattention, hyperactivity or impulsivity than other children of the same age.

### ADHD A2 1A

Different health and school professionals are sometimes involved in conducting an ADHD assessment. Who was involved in conducting [S.C.]'s ADHD assessment?

Were medical doctors involved?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

ADHD	$\Delta 2$	1B
$\Delta D \Pi L$	, ^_	- 112

Were school psychologists or school counselors involved?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD\_A2\_1C

Were teachers or other educational staff involved?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD A2 1D

Were clinical psychologists or other psychologists not at your school involved?

INTERVIEWER INSTRUCTIONS: INCLUDE PSYCHOLOGISTS AS OUTSIDE OF THE SCHOOL EVEN IF REFERRED TO BY SCHOOL.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD A2 1E

Were any other health care professionals involved?

- (1) YES [GO TO ADHD\_A2\_1E\_VERBATIM]
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD A2 1E VERBATIM

Who was that other person?

RECORD VERBATIM RESPONSE

### ADHD A2 2A

Doctors, health care providers, and school professionals have different ways to ask about symptoms of ADHD and their impact on the child. Do you recall your doctor, health care provider, or school professionals using any of the following methods with you or your child to assess for ADHD?

A rating scale or checklist about the child's behavior.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD A2\_2B

A conversation with you about the child's behavior.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD\_A2\_2C

A series of tests to better understand how the child learns, reads, understands and processes information, also known as neuropsychological testing

READ IF NECESSARY: Please include continuous performance tests.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD A2 2D

Medical tests, such as an EEG, CT scan, MRI, or blood tests to test for lead exposure

HELP TEXT: An EEG is recording of the brain's electrical activity along the scalp. A CT or CAT scan can provide a computed picture of an individual's brain. An MRI or magnetic resonance imaging can also provide a picture of an individual's brain.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD\_A2\_3A

Did the doctor, health care provider, or school professional who diagnosed [S.C.] with ADHD collect information from...

[S.C.] [himself/herself]?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD A2 3B

Did the doctor, health care provider, or school professional who diagnosed [S.C.] with ADHD collect information from...

Other family members?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD\_A2\_3C

Did the doctor, health care provider, or school professional who diagnosed [S.C.] with ADHD collect information from...

[S.C.]'s school teachers or other school staff?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD A2 3D

READ IF NECESSARY: Did the doctor, health care provider, or school professional who diagnosed [S.C.] with ADHD collect information from...

Childcare provider, such as a daycare teacher, nanny, or babysitter?

INTERVIEWER INSTRUCTION: MAY ALSO BE REFERRED TO AS AN EARLY CHILDHOOD EDUCATOR.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD A2 3E

READ IF NECESSARY: Did the doctor, health care provider, or school professional who diagnosed [S.C.] with ADHD collect information from...

Other community members, such as a coach, music or dance teacher, religious leader, scout leader, or other group leader?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- ADHD\_A2\_4 Did the doctor, health care provider, or school professional who diagnosed [S.C.] with ADHD ever observe the child in their classroom or at daycare?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED
- ADHD\_A2\_5 How involved were you in [S.C.]'s ADHD assessment? Were you very involved, somewhat involved, not very involved or not at all involved?
  - (1) VERY INVOLVED
  - (2) SOMEWHAT INVOLVED
  - (3) NOT VERY INVOLVED
  - (4) NOT AT ALL INVOLVED
  - (77) DON'T KNOW
  - (99) REFUSED

### **CURRENT ADHD AND SEVERITY**

- ADHD A3 1 Does [S.C.] currently have ADHD?
  - (1) YES
  - (2) NO [GO TO ADHD A3 3]
  - (77) DON'T KNOW [GO TO ADHD A3 3]
  - (99) REFUSED [GO TO ADHD A3 3]
- ADHD A3 2 Would you describe [his/her] ADHD as mild, moderate, or severe?
  - (1) MILD
  - (2) MODERATE
  - (3) SEVERE
  - (77) DON'T KNOW
  - (99) REFUSED

- ADHD\_A3\_3 When the symptoms were at their worst, how would you describe [S.C.]'s ADHD? Would you describe it as mild, moderate, or severe?
  - (1) MILD
  - (2) MODERATE
  - (3) SEVERE
  - (77) DON'T KNOW
  - (99) REFUSED

### EVER BUT NOT CURRENT ADHD

IF CHILD CURRENTLY HAS ADHD [ADHD\_A3\_1 = 1, 77, 99], GO TO ADHD B1 INTRO.

I am going to read a list of reasons why a child may no longer have ADHD. For each reason, please tell me if it applies to [S.C.].

# ADHD\_A4\_1A

Condition seemed to go away on its own as the child outgrew the ADHD.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD A4 1B

Treatment helped the condition to go away.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD\_A4\_1C

A doctor or health care provider changed the diagnosis.

- (1) YES [GO TO ADHD A4 1CA]
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD A4 1D

Is there another reason that you think [S.C.] no longer has ADHD?

- (1) YES [GO TO ADHD A4 1D VERBATIM]
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD A4 1D VERBATIM RECORD VERBATIM RESPONSE IF ADHD A4 1C = NO, DK, RF, THEN GO TO ADHD B1 INTRO. ADHD A4 1CA What was the diagnosis changed to? [SELECT ALL THAT APPLY] (1) OPPOSITIONAL DEFIANT DISORDER OR ODD (2) CONDUCT DISORDER (3) ANXIETY (4) DEPRESSION (5) BIPOLAR DISORDER (6) INTERMITTENT EXPLOSIVE DISORDER (7) LEARNING DISABILITY (8) LANGUAGE DISORDER (9) SLEEP DISORDER OR SLEEP APNEA (10) SUBSTANCE USE DISORDER (11) SCHIZOPHRENIA OR SCHIZOAFFECTIVE DISORDER (12) A PERSONALITY DISORDER, SUCH AS BORDERLINE PERSONALITY DISORDER (13) PERVASIVE DEVELOPMENTAL DISORDER OR AN AUTISM SPECTRUM DISORDER (14) OTHER [GO TO ADHD A4 1CA VERBATIM] (66) ADHD DIAGNOSIS REMOVED – NOT CHANGED TO ANOTHER DISORDER [GO TO ADHD A4 1D] (77) DON'T KNOW (99) REFUSED ADHD A4 1CA VERBATIM RECORD VERBATIM RESPONSE\_\_\_\_\_

### **CO-OCCURRING DISORDERS**

[SKIP THIS SECTION IF THE TS MODULE WAS COMPLETED. GO TO ADHD\_C1\_INTRO]

### ADHD B1 INTRO

Now I'm going to ask you about other conditions your child might have been diagnosed with by a doctor or other healthcare provider.

### ADHD B1 1 1

Has a doctor or health care provider ever told you that [S.C.] had oppositional defiant disorder or ODD?

HELP TEXT: Oppositional defiant disorder is an ongoing pattern of defiant and hostile behavior that interferes with a child's life and daily activities.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD B1 1 2

Has a doctor or health care provider ever told you that [S.C.] had conduct disorder?

HELP TEXT: Children with conduct disorder may be aggressive to people or animals, destroy property, steal, and violate rules.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD \_B1\_1\_3

Has a doctor or health care provider ever told you that [S.C.] had Autism Spectrum Disorder Or Pervasive Developmental Disorder?

HELP TEXT: Children with autism spectrum disorder have delays in language, communication, and social skills. They often have an intense interest in a single subject or topic. Children with pervasive developmental disorder have severe and persistent delays in language, communication, and social skills.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had a...

Sleep disorder?

HELP TEXT: Sleep apnea, insomnia, and narcolepsy are examples of sleep disorders.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 1 5

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

An intellectual disability?

HELP TEXT: Children with intellectual disabilities learn and develop more slowly than a typical child. Intellectual disability can include mental retardation or Down syndrome.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 1 6

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had a...

Learning disorder?

HELP TEXT: Dyslexia and mathematical learning disabilities are examples of learning disorders.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

A language disorder?

HELP TEXT: Children with language disorders have trouble getting their meaning or message across to others, or understanding the message coming from others, or both. Stuttering and communication disorders are examples of a language disorder.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD B1 1 8

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Obsessive compulsive disorder or OCD?

HELP TEXT: Children with OCD feel the need to check things repeatedly, or have certain thoughts or perform routines and rituals over and over.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 1 9

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had ...

Post-traumatic stress disorder or PTSD?

HELP TEXT: Children with PTSD develop this disorder after experiencing a traumatic event. Due to the emotional distress, children with PTSD continue to feel stressed and afraid even after the danger is over.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Another anxiety disorder, such as generalized anxiety disorder, panic disorder, or a phobia?

HELP TEXT: Anxiety is a feeling of constant worrying. Children with severe anxiety problems may be diagnosed as having anxiety disorders.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD B1\_1\_11

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had ...

Bipolar disorder?

HELP TEXT: Bipolar disorder is a mood disorder where a person experiences periods of depression and periods of being extremely happy or being cross or irritable.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 1 12

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Intermittent explosive disorder?

HELP TEXT: Intermittent explosive disorder is a behavioral disorder characterized by extreme expression of anger, often to the point of uncontrollable rage, that are disproportionate to the situation at hand.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Another mood disorder, such as depression or major depressive disorder?

HELP TEXT: Depression is an illness that involves the body, mood, and thoughts. It is marked by persistent sadness or an anxious or empty mood. It affects how a child feels, and the way a child eats, sleeps, and functions.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD B1 1 14

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

An eating disorder, such as anorexia or bulimia?

HELP TEXT: Children with eating disorders exhibit extreme emotions, attitudes, and behaviors about weight and food issues.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 1 15

READ IF NECESSARY: Has a doctor or health care provider ever told you that [S.C.] had...

Substance use disorder?

HELP TEXT: Substance abuse is the frequent use of substances such as drugs that can be physically dangerous and can potentially lead to legal problems and frequent social or interpersonal problems.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

IF NONE OF B1\_1\_1-B1\_1\_15 ARE YES, THEN SKIP TO SECTION ADHD B2.

# ADHD\_B1\_2\_1

[IF ADHD\_B1\_1\_1=1 ASK, ELSE SKIP TO ADHD\_B1\_2\_2] Earlier you told me that [S.C.] has been diagnosed with oppositional defiant disorder or ODD.

Does [S.C.] currently have oppositional defiant disorder or ODD?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 2

[IF ADHD\_B1\_1\_2=1 ASK, ELSE SKIP TO ADHD\_B1\_2\_3] Earlier you told me that [S.C.] has been diagnosed with conduct disorder.

Does [S.C.] currently have conduct disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 3

[IF ADHD\_B1\_1\_3=1 ASK, ELSE SKIP TO ADHD\_B1\_2\_4] Earlier you told me that [S.C.] has been diagnosed with Autism Spectrum Disorder or Pervasive Developmental Disorder.

Does [S.C.] currently have Autism Spectrum Disorder or Pervasive Developmental Disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 4

[IF ADHD\_B1\_1\_4=1 ASK, ELSE SKIP TO ADHD\_B1\_2\_5] Earlier you told me that [S.C.] has been diagnosed with a sleep disorder.

Does [S.C.] currently have a sleep disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD\_B1\_2\_5

[IF ADHD B1 1 5=1 ASK, ELSE SKIP TO ADHD B1 2 6]

Earlier you told me that [S.C.] has been diagnosed with an intellectual disorder.

Does [S.C.] currently have an intellectual disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 6

[IF ADHD\_B1\_1\_6=1 ASK, ELSE SKIP TO ADHD\_B1\_2\_7]

Earlier you told me that [S.C.] has been diagnosed with a learning disorder.

Does [S.C.] currently have a learning disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD B1 2 7

[IF ADHD\_B1\_1\_7=1 ASK, ELSE SKIP TO ADHD B1 2 8]

Earlier you told me that [S.C.] has been diagnosed with a language disorder.

Does [S.C.] currently have a language disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 8

[IF ADHD B1 1 8=1 ASK, ELSE SKIP TO ADHD B1 2 9]

Earlier you told me that [S.C.] has been diagnosed with obsessive compulsive disorder or OCD.

Does [S.C.] currently have obsessive compulsive disorder or OCD?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 9

[IF ADHD B1 1 9=1 ASK, ELSE SKIP TO ADHD B1 2 10]

Earlier you told me that [S.C.] has been diagnosed with post-traumatic stress disorder or PTSD.

Does [S.C.] currently have post-traumatic stress disorder or PTSD?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 10

[IF ADHD\_B1\_1\_10=1 ASK, ELSE SKIP TO ADHD\_B1\_2\_11]

Earlier you told me that [S.C.] has been diagnosed with another anxiety disorder, such as generalized anxiety disorder, panic disorder, or a phobia.

Does [S.C.] currently have another anxiety disorder, such as generalized anxiety disorder, panic disorder, or a phobia?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 11

[IF ADHD B1 1 11=1 ASK, ELSE SKIP TO ADHD B1 2 12]

Earlier you told me that [S.C.] has been diagnosed with bipolar disorder.

Does [S.C.] currently have bipolar disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 12

[IF ADHD B1 1 12=1 ASK, ELSE SKIP TO ADHD B1 2 13]

Earlier you told me that [S.C.] has been diagnosed with intermittent explosive disorder.

Does [S.C.] currently have intermittent explosive disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 13

# [IF ADHD B1 1 13=1 ASK, ELSE SKIP TO ADHD B1 2 14]

Earlier you told me that [S.C.] has been diagnosed with another mood disorder, such as depression, or major depressive disorder.

Does [S.C.] currently have another mood disorder, such as depression, or major depressive disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 14

### [IF ADHD\_B1\_1\_14=1ASK, ELSE SKIP TO ADHD\_B1\_2\_15]

Earlier you told me that [S.C.] has been diagnosed with an eating disorder, such as anorexia or bulimia.

Does [S.C.] currently have an eating disorder, such as anorexia, or bulimia?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B1 2 15

### [IF ADHD B1 1 15=1 ASK, ELSE SKIP TO ADHD B2]

Earlier you told me that [S.C.] has been diagnosed with substance use disorder.

Does [S.C.] currently have substance use disorder?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD B2 Now I have a question about tics.

Tics are usually sudden, brief, rapid and repetitive movements or sounds. Some common tics are eye blinking; facial movements; shoulder shrugging; coughing; throat clearing; sniffing; humming; barking, and blurting out words. Tics can be suppressed for short periods of time, but eventually come out. Tics come and go and often change over time. Has [S.C.] ever had tics?

- (1) YES [GO TO B3]
- (2) NO [GO TO C1 INTRO]
- (77) DON'T KNOW [GO TO C1 INTRO]
- (99) REFUSED [GO TO C1 INTRO]

# ADHD B3 Does [S.C.] currently have tics?

- (1) YES (2) NO
- (77) DON'T KNOW (99) REFUSED

### **TREATMENT**

#### **MEDICATION**

ADHD C1 INTRO

I will now be asking you some questions about medications [S.C.] may be taking.

ADHD C1 1 Has [S.C.] ever taken medication for ADHD?

- (1) YES
- (2) NO [GO TO ADHD\_C3]
- (77) DON'T KNOW [GO TO ADHD C3]
- (99) REFUSED [GO TO ADHD\_C3]

ADHD\_C1\_2 At what age did [S.C.] first start taking ADHD medication?

RECORD VALUE: \_\_\_\_ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

ADHD C1 2 MY

- (1) YEARS
- (2) MONTHS

[IF CHILD DOES NOT CURRENTLY HAVE ADHD [ADHD\_A3\_1 = NO], SKIP TO ADHD C1 5]

ADHD C1 3 Is [S.C.] currently taking medication for ADHD?

- (1) YES
- (2) NO [GO TO ADHD C1]
- (77) DON'T KNOW [GO TO ADHD C1 5]
- (99) REFUSED [GO TO ADHD C1 5]

### ADHD C1 4 NEW

What medications does [S.C.] currently take for ADHD? [SELECT ALL THAT APPLY]

PROBE: Does (he/she) take any other medications for ADHD?

INTERVIEWER INSTRUCTION: IF R SAYS "DON'T KNOW" SAY: "That's okay. At the end of the interview I'll ask that you take a moment to get [S.C.]'s medication so we may record the name of it."

- (1) ABILIFY, ABILIFY MAINTENA, ABILIFY DISCMELT
- (2) ADDERALL (ADD-UR-ALL)
- (3) ADDERALL XR
- (4) AMPHETAMINE (AM-FET-A-MEEN)
- (5) APO-METOCLOP
- (6) APOKYN

- (7) APOMORPHINE
- (8) ARICEPT, ARICEPT ODT
- (9) ARIPIPRAZOLE
- (10) ATOMOXETINE (AT-OH-MOX-E-TEEN)
- (11) BUPROPRION
- (12) BACLOFEN
- (13) BOTULINUM TOXIN, BOTOX
- (14) CATAPRES, CATAPRES-TTS
- (15) CELEXA
- (16) CITALOPRAM (SI-TAL-O-PRAM)
- (17) CLONAZEPAM
- (18) CLONIDINE, CLONIDINE ER
- (19) CONCERTA
- (20) DELTANYNE
- (21) DEXEDRINE, DEXEDRINE SPANSULE
- (22) DEXTROSTAT, DEXTRO-AMPHETAMINE
- (23) DEXMETHYLPHENIDATE
- (24) DONEPEZIL
- (25) DRONABINOL
- (26) DURACLON
- (27) DYSPORT
- (28) FLUOXETINE (FLOO-OX-E-TEEN)
- (29) FLUPHENAZINE
- (30) FOCALIN
- (31) FOCALIN XR
- (32) GABLOFEN
- (33) GEODON
- (34) GUANFACINE,
- (35) HALOPERIDOL, HALDOL, HALDOL DECANOATE
- (36) INTUNIV
- (37) KAPVAY
- (38) KEPPRA, KEPPRA XR
- (39) KEMSTRO
- (40) KLONOPIN, KLONOPIN WAFER
- (41) LEVETIRACETAM
- (42) LIORESAL
- (43) LISDEXAMFETAMINE (LIS-DEX-AM-FET-A-MEEN)
- (44) MARINOL
- (45) METADATE, METADATE CD
- (46) METHYLIN
- (47) METHYLPHENIDATE
- (48) METHYLPHENIDATE PATCH (DAYTRANA)
- (49) METOCLOPRAMIDE, METOCLOPRAMIDE HYDROCHLORIDE INJECTION, METOCLOPRAMIDE OMEGA
- (50) MIRAPEX, MIRAPEX ER
- (51) NAC
- (52) NEUROBLOC
- (53) NEXICLON
- (54) NU-METOCLOPRAMIDE

- (55) OLANZAPINE
- (56) ONDANSETRON
- (57) ORAP
- (58) PERGOLIDE
- (59) PERMAX
- (60) PERMITIL
- (61) PIMOZIDE
- (62) PMS-METOCLOPRAMIDE
- (63) PRAMIPEXOLE
- (64) PROLIXIN, PROLIXIN DECANOATE, PROLIXIN ENANTHATE
- (65) PROZAC
- (67) QUETIAPINE
- (68) QUILLIVANT
- (69) REQUIP
- (70) RISPERDAL, RISPERDAL CONSTA, RISPERDAL M-TAB, RISPERIDONE, RISPERIDOL
- (71) RITALIN
- (72) RITALIN LA, RITALIN SR
- (73) ROPINIROLE
- (74) SATIVEX
- (75) SEROQUEL, SEROQUEL XR
- (76) SERTRALINE (SER-TRA-LEEN)
- (78) STRATTERA
- (79) TENEX
- (80) TETRABENAZINE
- (81) TETRAHYDROCANNABINOL, Δ DELTA-9-THC
- (82) TOPAMAX, TOPAMAX SPRINKLE
- (83) TOPIRAMATE, TOPIRAGEN
- (84) VYVANSE
- (85) WELLBUTRIN
- (86) XENAZINE
- (87) ZIPRASIDONE
- (88) ZOFRAN
- (89) ZOLOFT
- (90) ZYPREXA, ZYPREXA ZYDIS, ZYPREXA RELPREVV, ZYPREXA INTRAMUSCULAR
- (91) OTHER [GO TO ADHD C1 4 VERBATIM]
- (666) NOT CURRENTLY TAKING MEDICATION [GO TO ADHD C2 1]
- (777) DON'T KNOW [GO TO ADHD C2 1]
- (999) REFUSED [GO TO ADHD C2 1]

# [IF TS\_END=1 THEN DISPLAY:

INTERVIEWER INSTRUCTION: MEDICATIONS THAT WERE REPORTED BY R IN THE TOURETTE SURVEY CAN BE CODED HERE AGAIN IF THEY ARE ALSO USED TO TREAT ADHD. ALLOW R TO OFFER THIS INFORMATION; DO NOT PROBE.

# ADHD\_C1\_4\_VERBATIM RECORD VERBATIM RESPONSE

# ADHD C1 5 INTRO

I will now be asking you about any side effects to the ADHD medication that [S.C.] may have experienced. Please think about side effects from medications that [S.C.] has ever taken for ADHD, even if [he/she] does not currently take them now.

# ADHD C1 5A

Due to ADHD medication has [S.C.] experienced headaches?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD C1 5B

Has [S.C.] experienced stomach problems, such as stomachache, nausea, or vomiting?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD C1 5C

Has [S.C.] experienced weight gain?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD C1 5D

READ IF NECESSARY: Due to ADHD medication has [S.C.] ever experienced...

Weight loss?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD C1\_5E

READ IF NECESSARY: Due to ADHD medication has [S.C.] ever experienced...

Slowed growth?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD C1 5F

READ IF NECESSARY: Due to ADHD medication has [S.C.] ever experienced...

Acting dazed, including long periods of staring, having a glassy-eyed appearance, or being slow to respond?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD C1 5G

READ IF NECESSARY: Due to ADHD medication has [S.C.] ever experienced...

Change in personality or mood?

HELP TEXT: Examples include irritability, increased anxiety or agitation, extreme sadness or unusual crying, dull, tired, listless behavior, change in personality, socially withdrawn or decreased interaction with others.

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD C1 5H

READ IF NECESSARY: Due to ADHD medication has [S.C.] ever experienced...

Sleep problems/insomnia, such as trouble getting to sleep, staying asleep?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD C1 5I

READ IF NECESSARY: Due to ADHD medication has [S.C.] ever experienced...

Repetitive movements, tics, jerking, twitching, eye blinking?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD\_C1\_5J

READ IF NECESSARY: Due to ADHD medication has [S.C.] ever experienced...

Feeling shaky or jittery?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD C1 5K

READ IF NECESSARY: Due to ADHD medication has [S.C.] ever experienced... Increased blood pressure or heart rate?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD C1 5L

READ IF NECESSARY: Due to ADHD medication has [S.C.] ever experienced... Any other side effects?

READ IF NECESSARY: Remember, we are asking if the child has experienced this symptom as a side effect of the ADHD medication.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

# ADHD C1 5L VERBATIM

RECORD VERBATIM RESPONSE

IF ANY ADHD\_C1\_5A- ADHD\_C1\_5L = 1, THEN GO TO ADHD\_C1\_6. ELSE, IF CHILD IS CURRENTLY TAKING MEDS (ADHD\_C1\_3 = 1), GO TO ADHD\_C1\_7.

IF CHILD IS NOT CURRENTLY TAKING MEDS (ADHD\_C1\_3 = 2, 77, 99), GO TO ADHD C3 1.

ADHD\_C1\_6 Were these side effects troublesome enough to stop taking the medication?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

IF CHILD IS CURRENTLY TAKING MEDS (ADHD\_C1\_3 = 1), GO TO ADHD\_C1\_7.

IF CHILD IS NOT CURRENTLY TAKING MEDS (ADHD\_C1\_3 = 2, 77, 99), GO TO ADHD C3 1.

ADHD\_C1\_7 Other than medications for ADHD, how many other medications is [S.C.] currently taking for difficulties with [his/her] emotions, concentration, or behavior? [IF TS\_ELIG=1 DISPLAY: Please include medication [S.C.] currently takes for Tourette syndrome.]

RECORD VALUE: \_\_\_\_ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

ADHD\_C1\_8 In past 12 months, about how many times did [S.C.] see a health care provider about his/her ADHD medication?

READ IF NECESSARY: Include both medication-focused visits or other visits (well or sick visits) where medication may have been discussed as well.

INTERVIEWER INSTRUCTIONS: ENTER 77 FOR DON'T KNOW AND 99 FOR REFUSED

RECORD VALUE: \_\_\_\_ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED

### ADHD C1 9 NEW

What type of doctor or other health care provider currently manages [S.C.]'s ADHD medication?

READ IF NECESSARY: Managed means doing things like increasing or decreasing dosages of a medication or changing medications.

- (1) DEVELOPMENTAL OR BEHAVIORAL PEDIATRICIAN
- (2) FAMILY PRACTICE DOCTOR
- (3) NEUROLOGIST
- (4) NURSE PRACTITIONER
- (5) PEDIATRICIAN (GENERAL)

- (6) PHYSICIAN'S ASSISTANT
- (7) PSYCHIATRIST
- (8) TEAM OF MEDICAL PROFESSIONALS
- (9) OTHER [GO TO ADHD C1 9 NEW VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

# ADHD C1 9 NEW VERBATIM

RECORD VERBATIM RESPONSE

ADHD\_C1\_10 In a regular school week, how much does [S.C.]'s medication help [S.C.] with schoolwork and academics? Would you say not at all, a little, some or a lot?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

HELP TEXT: REGULAR SCHOOL WEEK REFERS TO MONDAY THROUGH FRIDAY.

- (1) NOT AT ALL
- (2) A LITTLE
- (3) SOME
- (4) A LOT
- (77) DON'T KNOW
- (99) REFUSED

#### ADHD C1 11

In a regular school week, how much does [S.C.]'s medication help [S.C.] with [his/her] classroom and home behavior? Would you say not at all, a little, some or a lot?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

HELP TEXT: REGULAR SCHOOL WEEK REFERS TO MONDAY THROUGH FRIDAY.

- (1) NOT AT ALL
- (2) A LITTLE
- (3) SOME
- (4) A LOT
- (77) DON'T KNOW
- (99) REFUSED

### ADHD C1 12

In a regular school week, how much does [S.C.]'s medication help [S.C.] with [his/her] interactions with friends and adults? Would you say not at all, a little, some or a lot?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

HELP TEXT: REGULAR SCHOOL WEEK REFERS TO MONDAY THROUGH FRIDAY.

- (1) NOT AT ALL
- (2) A LITTLE
- (3) SOME
- (4) A LOT
- (77) DON'T KNOW
- (99) REFUSED

#### MEDICATION ADHERENCE

ADHD C2 1 I want you to think about [S.C.]'s last school week.

How many of the five days in the most recent school week did [S.C.] take medication for ADHD?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

HELP TEXT: REGULAR SCHOOL WEEK REFERS TO MONDAY THROUGH FRIDAY.

RECORD	VALUE:	
--------	--------	--

ADHD C2 2 Now I want you to think about last weekend, which would be last Saturday and Sunday.

How many of the two days in the last weekend did [S.C.] take medication for ADHD?

NEXAMED VALUE.	RECORD	VALUE:	
----------------	--------	--------	--

ADHD\_C2\_3 On a typical school day, when does [S.C.] usually take medication for ADHD? Is it before school, during school, or after school? [SELECT ALL THAT APPLY]

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

- (1) BEFORE SCHOOL
- (2) DURING SCHOOL
- (3) AFTER SCHOOL
- (77) DON'T KNOW
- (99) REFUSED

- ADHD\_C2\_4 Does [S.C.] take regularly scheduled breaks from [his/her] ADHD medication, such as on weekends or over the summer? This is sometimes referred to as a drug-holiday.
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED
- ADHD C2 5 Who usually makes sure [S.C.] takes [his/her] ADHD medication?

READ IF RESPONDENT SAYS MULTIPLE PEOPLE: Who does it most often?

- (1) A PARENT OR GUARDIAN
- (2) ANOTHER FAMILY MEMBER
- (3) SOMEONE AT SCHOOL
- (4) A BABYSITTER OR NANNY
- (5) THE CHILD
- (6) OTHER PERSON
- (77) DON'T KNOW
- (99) REFUSED
- ADHD\_C2\_6 In the past 12 months, was there a time when [S.C.] resisted taking [his/her] ADHD medication?

READ IF NECESSARY: Do not include resistance solely due to physical reasons such as being unable to swallow a pill.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- ADHD\_C2\_7 To the best of your knowledge, has [S.C.]'s ADHD medication ever been taken or used by someone else, including a family member?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED

#### **OTHER TREATMENT**

#### ADHD C3 INTRO

Now I will be asking you about other treatments for ADHD or difficulties with [S.C.]'s emotions, concentration, or behavior.

ADHD\_C3\_1 Has [S.C.] ever received school-based educational support, intervention, or accommodation, such as tutoring, extra help from a teacher, preferential seating, extra time to complete work or being enrolled in special education?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

HELP TEXT: IF CHILD HAS NEVER BEEN ENROLLED IN A SCHOOL, PRESCHOOL, OR DAYCARE, CHOOSE "NO".

- (1) YES [GO TO ADHD\_C3\_1A] (2) NO [GO TO ADHD\_C3\_2] (77) DON'T KNOW [GO TO ADHD\_C3\_2]
- (77) DON'T KNOW [GO TO ADHD\_C3\_2]
- (99) REFUSED [GO TO ADHD\_C3\_2]

## ADHD\_C3\_1A

Is [S.C.] currently receiving school-based educational support, intervention, or accommodation?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- ADHD\_C3\_2 Has [S.C.] ever received classroom management, such as reward systems, behavioral modification, or a daily report card?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

HELP TEXT: IF CHILD HAS NEVER BEEN ENROLLED IN A SCHOOL, PRESCHOOL, OR DAYCARE, CHOOSE "NO".

- (1) YES [GO TO ADHD\_C3\_2A] (2) NO [GO TO ADHD\_C3\_3] (77) DON'T KNOW [GO TO ADHD\_C3\_3]
- (99) REFUSED [GO TO ADHD C3 3]

#### ADHD C3 2A

Is [S.C.] currently receiving treatment through classroom management?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

ADHD\_C3\_3 Has [S.C.] ever received peer interventions, such as peer tutoring or the Good Behavior Game?

READ IF NECESSARY: The Good Behavior game is an approach that teachers use to manage classrooms and that rewards children for appropriate behaviors during class time.

HELP TEXT: IF CHILD HAS NEVER BEEN ENROLLED IN A SCHOOL, PRESCHOOL, OR DAYCARE, CHOOSE "NO".

- (1) YES [GO TO ADHD\_C3\_3A] (2) NO [GO TO ADHD\_C3\_4] (77) DON'T KNOW [GO TO ADHD\_C3\_4] (99) REFUSED [GO TO ADHD C3\_4]
- ADHD\_C3\_3A

s [S.C.] currently receiving treatment through peer interventions?

- (1) YES
- (2) NO
- (77) DON'T KNOW (99) REFUSED
- ADHD\_C3\_4 Has [S.C.] ever received social skills training, such as support in how to interact with others?
  - (1) YES [GO TO ADHD\_C3\_4A]
  - (2) NO [GO TO ADHD C3 5]
  - (77) DON'T KNOW [GO TO ADHD C3 5]
  - (99) REFUSED [GO TO ADHD C3 5]

#### ADHD C3 4A

Is [S.C.] currently receiving social skills training?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- ADHD C3 5 Has [S.C.] ever received Cognitive Behavioral Therapy also known as CBT?

READ IF NECESSARY: Cognitive-behavioral therapy, or CBT, is a type of therapy that aims to change negative emotions and behaviors through various techniques used by a trained psychologist or counselor.

(1) YES [GO TO ADHD\_C3\_5A] (2) NO [GO TO ADHD\_C3\_6] (77) DON'T KNOW [GO TO ADHD\_C3\_6] (99) REFUSED [GO TO ADHD\_C3\_6]

## ADHD C3 5A

Is [S.C.] currently receiving cognitive behavioral therapy?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- ADHD\_C3\_6 Has [S.C.] ever received dietary supplements, herbal supplements, and other non-prescription medications for ADHD or for other difficulties with [his/her] emotions, concentration or behavior?
  - (1) YES [GO TO ADHD\_C3\_6A] (2) NO [GO TO ADHD\_C3\_7]
  - (77) DON'T KNOW [GO TO ADHD\_C3\_7]
  - (99) REFUSED [GO TO ADHD\_C3\_7]

#### ADHD C3 6A

Is [S.C.] currently receiving dietary supplements, herbal supplements, or non-prescription medications for ADHD or for other difficulties with [his/her] emotions, concentration or behavior?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- ADHD C3 7 Has [S.C.] ever received EEG neurofeedback or other kinds of biofeedback?

HELP TEXT: An EEG is recording of the brain's electrical activity along the scalp.

- (1) YES [GO TO ADHD\_C3\_7A]
- (2) NO [GO TO ADHD C3 8]
- (77) DON'T KNOW [GO TO ADHD C3 8]
- (99) REFUSED [GO TO ADHD C3 8]

#### ADHD C3 7A

Is [S.C.] currently receiving EEG neurofeedback or other kinds of biofeedback for ADHD?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

ADHD_C3_8	8 Has [S.C.] ever received <i>any</i> other treatment for ADHD or for other difficulties with [his/her] emotions, concentration or behavior?	
	(1) YES [GO TO ADHD_C3_VA] (2) NO [GO TO ADHD_C3_9] (77) DON'T KNOW [GO TO ADHD_C3_9] (99) REFUSED [GO TO ADHD_C3_9]	
ADHD_C3_8	_VA What other treatment has [S.C.] received?	
	INTERVIEWER INSTRUCTION: PROBE UP TO THREE OTHER TREATMENTS. YOU MUST ENTER SOMETHING INTO EACH FIELD.	
	ENTER 66 IF THERE ARE NO TREATMENTS ENTER 77 FOR DON'T KNOW ENTER 99 FOR REFUSED	
	RECORD VERBATIM RESPONSE	
ADHD_C3_8	_VB What other treatment has [S.C.] received?	
	RECORD VERBATIM RESPONSE	
ADHD_C3_8	_VC What other treatment has [S.C.] received?	
	RECORD VERBATIM RESPONSE	
ADHD_C3_8	A Is [S.C.] currently receiving [other treatment from ADHD_C3_8_VA] for ADHD or for other difficulties with [his/her] emotions, concentration or behavior?	
	(1) YES (2) NO (77) DON'T KNOW (99) REFUSED	
ADHD_C3_8	B [IF ADHD_C3_VB=66, 77, 99 SKIP TO ADHD_C3_8C] Is [S.C.] currently receiving [other treatment from ADHD_C3_8_VB] for ADHD or for other difficulties with [his/her] emotions, concentration or behavior?	
	(1) YES (2) NO (77) DON'T KNOW (99) REFUSED	

## ADHD\_C3\_8C

[IF ADHD C3 VC=66, 77, 99 SKIP TO ADHD C3 9]

Is [S.C.] currently receiving [other treatment from ADHD\_C3\_8\_VC] for ADHD or for other difficulties with [his/her] emotions, concentration or behavior?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

[SKIP ADHD\_C3\_9 AND ADHD\_C3\_10 IF THE TS MODULE WAS COMPLETED. GO TO ADHD\_C4\_1]

- ADHD\_C3\_9 Does the child currently have a formal educational plan, such as an Individualized Education Program, also called an IEP, or a 504 plan?
  - (1) YES
  - (2) NO [GO TO ADHD C4]
  - (77) DON'T KNOW [GO TO ADHD C4]
  - (99) REFUSED [GO TO ADHD\_C4]
- ADHD\_C3\_10 Is it an IEP, a 504 plan, or something else?
  - (1) IEP
  - (2) 504 PLAN
  - (3) SOMETHING ELSE [GO TO ADHD CE 10 VERBATIM]
  - (4) BOTH IEP AND 504 PLAN
  - (77) DON'T KNOW
  - (99) REFUSED

#### TREATMENT BARRIERS AND SATISFACTION

[SKIP TO ADHD\_C5\_1 IF CHILD NO LONGER HAS ADHD (ADHD\_A3\_1=NO)]

ADHD\_C4\_INTRO

I will now ask you about your satisfaction with [S.C.]'s treatment and any treatment barriers you may have experienced.

- ADHD\_C4\_1 In the past 12 months, did your child need an ADHD treatment that [he/she] was unable to get?
  - (1) YES [GO TO ADHD\_C4\_2A]
  - (2) NO [GO TO ADHD C4 3]
  - (77) DON'T KNOW [GO TO ADHD C4 3]
  - (99) REFUSED [GO TO ADHD C4 3]

## ADHD C4 2A

Was the treatment [S.C.] needed but couldn't get ...

Medication?

- (1) YES [GO TO ADHD C4 2AA]
- (2) NO

[GO TO ADHD C4 2B]

- (77) DON'T KNOW [GO TO ADHD C4 2B]
- (99) REFUSED [GO TO ADHD C4 2B]

## ADHD C4 2AA

Why was [S.C.] unable to get medication? [SELECT ALL THAT APPLY]

- (1) COST: THERE WERE ISSUES RELATED TO COST OR INSURANCE
- (2) AVAILABILITY: THE TREATMENT/SERVICE WAS NOT AVAILABLE IN CHILD'S AREA/SCHOOL
- (3) DELAYS: THERE WERE WAITING LISTS, BACKLOGS, DRUG SHORTAGES, OR OTHER DELAYS
- (4) ELIGIBILITY: CHILD WAS NOT ELIGIBLE FOR THE TREATMENT/SERVICE
- (5) INFORMATION: PARENT/DOCTOR/SCHOOL DID NOT KNOW ABOUT TREATMENT/SERVICE OR HAD TROUBLE GETTING INFORMATION NEEDED
- (6) PROVIDER ISSUES: DOCTOR/SCHOOL REFUSED TO PROVIDE TREATMENT/SERVICE OR DID NOT FOLLOW THROUGH OR CHILD DOES NOT CURRENTLY HAVE A PROVIDER
- (7) FAMILY ISSUES: CHILD OR OTHER FAMILY MEMBERS DID NOT WANT THE TREATMENT/SERVICE
- (8) OTHER [GO TO ADHD C4 2AA VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

#### ADHD C4 2AA VERBATIM

RECORD VERBATIM RESPONSE

#### ADHD C4 2B

Was the treatment [S.C.] needed but couldn't get ...

School-based behavioral treatment, support, or accommodation?

INTERVIEWER INSTRUCTION: IF CHILD IS NOT ENROLLED IN SCHOOL, PRESCHOOL OR DAYCARE, CHOOSE "NO".

- (1) YES [GO TO ADHD\_C4\_2BA]
- (2) NO [GO TO ADHD C4 2C]
- (77) DON'T KNOW [GO TO ADHD C4 2C]
- (99) REFUSED [GO TO ADHD C4 2C]

#### ADHD C4 2BA

Why couldn't [S.C.] get school-based behavioral treatment, intervention, or accommodation? [SELECT ALL THAT APPLY]

- (1) COST: THERE WERE ISSUES RELATED TO COST OR INSURANCE
- (2) AVAILABILITY: THE TREATMENT/SERVICE WAS NOT AVAILABLE IN CHILD'S AREA/SCHOOL
- (3) DELAYS: THERE WERE WAITING LISTS, BACKLOGS, DRUG SHORTAGES, OR OTHER DELAYS
- (4) ELIGIBILITY: CHILD WAS NOT ELIGIBLE FOR THE TREATMENT/SERVICE
- (5) INFORMATION: PARENT/DOCTOR/SCHOOL DID NOT KNOW ABOUT TREATMENT/SERVICE OR HAD TROUBLE GETTING INFORMATION NEEDED
- (6) PROVIDER ISSUES: DOCTOR/SCHOOL REFUSED TO PROVIDE TREATMENT/SERVICE OR DID NOT FOLLOW THROUGH OR CHILD DOES NOT CURRENTLY HAVE A PROVIDER
- (7) FAMILY ISSUES: CHILD OR OTHER FAMILY MEMBERS DID NOT WANT THE TREATMENT/SERVICE
- (8) CHILD NOT YET IN SCHOOL
- (9) OTHER [GO TO ADHD C4 2BA VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

### ADHD C4 2BA VERBATIM

RECORD VERBATIM RESPONSE

#### ADHD C4 2C

Was the treatment [S.C.] needed but couldn't get...

Behavioral treatment based outside of school?

- (1) YES [GO TO ADHD C4 2CA]
- (2) NO [GO TO ADHD C4 2D]
- (77) DON'T KNOW [GO TO ADHD C4 2D]
- (99) REFUSED [GO TO ADHD C4 2D]

#### ADHD C4 2CA

Why couldn't [S.C.] get behavioral treatment based outside of school? [SELECT ALL THAT APPLY]

- (1) COST: THERE WERE ISSUES RELATED TO COST OR INSURANCE
- (2) AVAILABILITY: THE TREATMENT/SERVICE WAS NOT AVAILABLE IN CHILD'S AREA/SCHOOL
- (3) DELAYS: THERE WERE WAITING LISTS, BACKLOGS, DRUG SHORTAGES, OR OTHER DELAYS
- (4) ELIGIBILITY: CHILD WAS NOT ELIGIBLE FOR THE TREATMENT/SERVICE
- (5) INFORMATION: PARENT/DOCTOR/SCHOOL DID NOT KNOW ABOUT TREATMENT/SERVICE OR HAD TROUBLE GETTING INFORMATION NEEDED

- (6) PROVIDER ISSUES: DOCTOR/SCHOOL REFUSED TO PROVIDE TREATMENT/SERVICE OR DID NOT FOLLOW THROUGH OR CHILD DOES NOT CURRENTLY HAVE A PROVIDER
- (7) FAMILY ISSUES: CHILD OR OTHER FAMILY MEMBERS DID NOT WANT THE TREATMENT/SERVICE
- (8) OTHER GO TO ADHD C4 2CA VERBATIM]
- (77) DON'T KNOW
- (99) REFUSED

ADHD	C4	2CA	VERB.	ATIM

RECORD VERBATIM RESPONSE

ADHD\_C4\_2D

Was the treatment [S.C.] needed but couldn't get some other treatment outside of school?

- (1) YES [GO TO ADHD C4 2D VERBATIM]
- (2) NO [GO TO ADHD C4 3]
- (77) DON'T KNOW [GO TO AGO TO ADHD\_C4\_3]
- (99) REFUSED [GO TO GO TO ADHD\_C4\_3]

#### ADHD C4 2D VERBATIM

RECORD VERBATIM RESPONSE \_\_\_\_\_

SKIP TO SECTION C5 IF NOT CURRENT ADHD (ADHD A3 1=NO)

- ADHD\_C4\_3 Overall, how satisfied are you with [S.C.]'s ADHD treatment and management? Would you say you are very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied?
  - (1) VERY SATISFIED
  - (2) SOMEWHAT SATISFIED
  - (3) SOMEWHAT DISSATISFIED
  - (4) VERY DISSATISFIED
  - (77) DON'T KNOW
  - (99) REFUSED

#### PARENT TRAINING

ADHD\_C5\_1 Parent training includes formal classes or informal coaching to support your child's behavior at home. Have you ever received parent training to help you manage [S.C.]'s ADHD?

HELP TEXT: Do not include self-training, such as internet research that the parent or guardian does on his/her own.

```
(1) YES [GO TO ADHD_C5_2]
(2) NO [GO TO ADHD_C5_3]
(77) DON'T KNOW [GO TO ADHD_C5_3]
(99) REFUSED [GO TO ADHD C5_3]
```

ADHD\_C5\_2 Are you currently receiving parent training to help you manage [S.C.]'s ADHD?

```
(1) YES [GO TO ADHD_C5_3]
(2) NO [GO TO ADHD_C5_3]
(77) DON'T KNOW [GO TO ADHD_C5_3]
(99) REFUSED [GO TO ADHD C5_3]
```

ADHD\_C5\_3 Did you ever need parent training that you were unable to get?

```
(1) YES [GO TO ADHD_D1_INTRO]
(2) NO [GO TO ADHD_D1_INTRO]
(77) DON'T KNOW [GO TO ADHD_D1_INTRO]
(99) REFUSED [GO TO ADHD_D1_INTRO]
```

## **SYMPTOMS AND PERFORMANCE/IMPAIRMENT**

#### **VANDERBILT ADHD-18**

#### ADHD D1 INTRO

Now I'd like to ask you about [S.C.]'s behavior and performance. Each rating should be considered in the context of what is appropriate for the age of your child. When answering, please think about your child's behaviors in the past 6 months when [he/she] is not taking medication for ADHD. [IF TS\_END=1 DISPLAY ", Tourette syndrome,"] or any other medication for other difficulties with [his/her] emotions, concentration or behavior.

For each behavior, please tell me how frequently the behavior happens: Never, Occasionally, Often, or Very Often.

READ IF NECESSARY: If the child is always on medication, think about even the short times when the child is not on medication, such as early in the mornings or when a dose is missed.

ADHD D1 1 Does not pay attention to details or makes careless mistakes, such as in homework.

Would you say this behavior happens never, occasionally, often or very often?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

HELP TEXT: IF RESPONDENT STATES THAT CHILD IS NOT IN SCHOOL, ASK R TO THINK ABOUT SCENARIOS IN WHICH CHILD MAY NOT PAY ATTENTION OR MAY MAKE CARELESS MISTAKES.

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

ADHD D1 2 Had difficulty sustaining attention to tasks or activities.

Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

## ADHD D1 3 Does not seem to listen when spoken to directly.

Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

## ADHD\_D1\_4 Does not follow through on instruction and fails to finish schoolwork (not due to oppositional behavior or failure to understand).

READ IF NECESSARY: Would you say this behavior happens never, occasionally, often or very often?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE

HELP TEXT: IF RESPONDENT STATES THAT CHILD IS NOT IN SCHOOL, ASK R TO THINK ABOUT SCENARIOS IN WHICH CHILD MAY NOT FOLLOW INSTRUCTIONS OR MAY FAIL TO FINISH A TASK.

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

## ADHD D1 5 Has difficulty organizing tasks and activities

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

ADHD D1 6 Avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort.

READ IF NECESSARY: Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

ADHD D1 7 Loses things necessary for tasks or activities (school assignments, pencils, or books).

READ IF NECESSARY: Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

ADHD D1 8 Is easily distracted by extraneous stimuli.

READ IF NECESSARY: Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

ADHD D1 9 Is forgetful in daily activities.

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

## ADHD D1 10

Fidgets with hands or feet or squirms in seat.

READ IF NECESSARY: Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

## ADHD\_D1\_11

Leaves seat when remaining seated is expected

READ IF NECESSARY: Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

## ADHD D1 12

Runs about or climbs excessively in situations when remaining seated is expected

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

## ADHD D1 13

Has difficulty playing or engaging in leisure activities quietly

READ IF NECESSARY: Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

## ADHD\_D1\_14

Is "on the go" or often acts as if "driven by a motor".

READ IF NECESSARY: Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

## ADHD D1 15

Talks too much.

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

## ADHD\_D1\_16

Blurts out answers before questions have been completed.

READ IF NECESSARY: Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

### ADHD D1 17

Has difficulty waiting [his/her] turn.

READ IF NECESSARY: Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

## ADHD D1 18

Interrupts or intrudes on others (butts into conversations or games).

READ IF NECESSARY: Would you say this behavior happens never, occasionally, often or very often?

- (1) NEVER
- (2) OCCASIONALLY
- (3) OFTEN
- (4) VERY OFTEN
- (77) DON'T KNOW
- (99) REFUSED

#### **PERFORMANCE**

IF TS END=1, SKIP TO ADHD E7, ELSE ASK

#### ADHD D2A INTRO

Next I would like you to think about [S.C.]'s academic performance.

Just as a reminder, please think about your child's behaviors in the past 6 months when he/she is not taking medication for ADHD or any other medication for other difficulties with [his/her] emotions, concentration or behavior.

For each question, please say whether [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent.

READ IF NECESSARY: If the child is always on medication, think about even the short times when the child is not on medication, such as early in the mornings or when a dose is missed.

## ADHD D2A 1

How would you describe [S.C.]'s overall school performance? Would you say that [S.C.]'s performance is problematic, somewhat problematic, average, above average, or excellent?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

### ADHD D2A 2

How would you describe [S.C.]'s performance in reading? Would you say that [S.C.]'s performance is problematic, somewhat problematic, average, above average, or excellent?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

INTERVIEWER INSTRUCTION: IF RESPONDENT STATES THAT CHILD DOES NOT READ YET, READ: Please consider what you this is appropriate for the age of your child.

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

#### ADHD D2A 3

How would you describe [S.C.]'s performance in mathematics? Would you say that [S.C.]'s performance is problematic, somewhat problematic, average, above average, or excellent?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

INTERVIEWER INSTRUCTION: IF RESPONDENT STATES THAT CHILD DOES NOT DO MATH YET, READ: Please consider what you this is appropriate for the age of your child.

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

## ADHD D2A 4

How would you describe [S.C.]'s performance in writing?

READ IF NECESSARY: Would you say [S.C.]'s performance is problematic, somewhat problematic, average, above average or excellent?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

INTERVIEWER INSTRUCTION: IF RESPONDENT STATES THAT CHILD DOES NOT WRITE YET, READ: Please consider what you this is appropriate for the age of your child.

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

#### ADHD D2B INTRO

Next I would like you to think about [S.C.]'s relationships. For each question, please say whether [S.C.]'s relationship is problematic, somewhat problematic, average, above average or excellent.

## ADHD D2B 1

How would you describe [S.C.]'s relationship with [his/her] parents, caregivers, or guardians? Would you say [S.C.]'s relationship is problematic, somewhat problematic, average, above average or excellent?

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

## ADHD\_D2B\_2

How about relationships with siblings? Would you say [S.C.]'s relationship is problematic, somewhat problematic, average, above average or excellent?

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (6) CHILD DOES NOT HAVE SIBLINGS
- (77) DON'T KNOW
- (99) REFUSED

## ADHD D2B 3

How would you describe [S.C.]'s relationship with peers? Would you say [S.C.]'s relationship is problematic, somewhat problematic, average, above average or excellent?

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

## ADHD D2B 4

How would you describe [S.C.]'s participation in organized activities such as teams?

READ IF NECESSARY: Would you say [S.C.]'s relationship is problematic, somewhat problematic, average, above average or excellent?

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (6) CHILD DOES NOT PARTICIPATE IN ORGANIZED ACTIVITIES
- (77) DON'T KNOW
- (99) REFUSED

## ADHD D2C 1

How would you describe [S.C.]'s handwriting, that is, [his/her] ability to form letters and numbers that are clear and can be recognized?

READ IF NECESSARY: Would you say [S.C.]'s handwriting is problematic, somewhat problematic, average, above average or excellent?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

INTERVIEWER INSTRUCTION: IF RESPONDENT STATES THAT CHILD DOES NOT WRITE YET, READ: Please consider what you this is appropriate for the age of your child.

- (1) PROBLEMATIC
- (2) SOMEWHAT PROBLEMATIC
- (3) AVERAGE
- (4) ABOVE AVERAGE
- (5) EXCELLENT
- (77) DON'T KNOW
- (99) REFUSED

## **ACADEMIC HEALTH AND DISCIPLINE**

ADHD E INTRO

I'd now like to ask you a few questions about [S.C.]'s school experience.

ADHD\_E1 What kind of school is [S.C.] currently enrolled in? Is it a public school, a private school, or is [S.C.] home-schooled?

INTERVIEWER INSTRUCTION: IF THE CHILD WAS ENROLLED IN MORE THAN ONE TYPE OF SCHOOL DURING THE CURRENT OR LAST SCHOOL YEAR, ASK THE TYPE OF SCHOOL THAT THE CHILD HAS MOST RECENTLY ATTENDED.

HELP TEXT: SCHOOL INCLUDES PRESCHOOL OR DAYCARE.

INTERVIEWER INSTRUCTION: CODE CHARTER SCHOOLS AS "PUBLIC".

(1) PUBLIC	[GO TO ADHD_E1_1]
(2) PRIVATE	[GO TO ADHD_E1_1]
(3) HOME-SCHOOLED	[GO TO ADHD_E2]
(4) [S.C.] IS NOT ENROLLED IN SCHOOL	[GO TO ADHD_E2]
(77) DON'T KNOW	[GO TO ADHD_E2]
(99) REFUSED	[GO TO ADHD_E2]

- ADHD\_E1\_1 Is the school that [S.C.] is enrolled in a specialty school for children with learning and behavior differences?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED
- ADHD\_E2 Overall, would you consider [S.C.] an A student, B student, C student, D student, or F student?

HELP TEXT: SCHOOL INCLUDES PRESCHOOL, DAYCARE AND HOME-SCHOOLING.

READ IF NECESSARY: Please use the following guideline:

- A = Exceptional
- B = Above average
- C = Average
- D = Below average
- F = Failing

- (1) A STUDENT
- (2) B STUDENT
- (3) C STUDENT
- (4) D STUDENT
- (5) F STUDENT
- (77) DON'T KNOW
- (99) REFUSED
- ADHD E3 Since starting kindergarten, has [he/she] repeated any grades?
  - (1) YES
  - [GO TO ADHD E5] (2) NO
  - (3) CHILD HAS NOT YET ENTERED KINDERGARTEN [GO TO ADHD E5].
  - (77) DON'T KNOW [GO TO ADHD E5]
  - (99) REFUSED [GO TO ADHD E5]
- Which grade or grades did [he/she] repeat? [SELECT ALL THAT APPLY] ADHD E4
  - (1) KINDERGARTEN
  - (2) 1<sup>ST</sup> GRADE
  - (3) 2<sup>ND</sup> GRADE
  - (4) 3<sup>RD</sup> GRADE
  - (5) 4<sup>TH</sup> GRADE
  - (6) 5<sup>TH</sup> GRADE
  - (7) 6<sup>TH</sup> GRADE
  - (8) 7<sup>TH</sup> GRADE
  - (9) 8<sup>TH</sup> GRADE

  - (10) 9<sup>TH</sup> GRADE
  - $(11) 10^{TH} GRADE$
  - $(12) 11^{TH} GRADE$
  - (13)  $12^{TH}$  GRADE
  - (77) DON'T KNOW
  - (99) REFUSED
- ADHD E5 Has [S.C.] ever been expelled or asked not to return to a childcare center, preschool, or school?
  - (1) YES [GO TO ADHD E6]
  - [GO TO ADHD E7] (2) NO
  - (77) DON'T KNOW [GO TO ADHD E7]
  - [GO TO ADHD E7] (99) REFUSED

## ADHD\_E6 In what grade or grades was [S.C.] expelled or asked not to return to school? [SELECT ALL THAT APPLY]

- (1) CHILDCARE (BIRTH TO AGE 2)
- (2) PRESCHOOL (AGE 3 TO AGE 5)
- (3) KINDERGARTEN
- (4) 1<sup>ST</sup> GRADE
- (5) 2<sup>ND</sup> GRADE
- (6)  $3^{RD}$  GRADE
- (7) 4<sup>TH</sup> GRADE
- (8) 5<sup>TH</sup> GRADE
- (9) 6<sup>TH</sup> GRADE
- (10) 7<sup>TH</sup> GRADE
- (11) 8<sup>TH</sup> GRADE
- (12) 9<sup>TH</sup> GRADE
- (13)  $10^{TH}$  GRADE
- (14) 11<sup>TH</sup> GRADE
- (15)  $12^{TH}$  GRADE
- (77) DON'T KNOW
- (99) REFUSED
- ADHD E7 Has [S.C.] ever had to appear in court for something [he/she] had done?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED

## **FAMILY IMPACT**

## ADHD F INTRO

Now I'd like to ask you about [S.C.] and your family.

- ADHD F1 1 Has [S.C.]'s ADHD caused financial problems for your family?
  - (1) YES
  - (2) NO
  - (77) DON'T KNOW
  - (99) REFUSED
- ADHD\_F1\_2 Have you or other family members stopped working because of [S.C.]'s ADHD?

HELP TEXT: CODE 2 IF NO ONE IN HOUSEHOLD WORKS.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- ADHD\_F1\_3 [IF ADHD\_F1\_2 = 1, THEN DISPLAY: Not including the family members who stopped working...] Have you or other family members cut down on the hours you work because of [S.C.]'s ADHD?

HELP TEXT: CODE 2 IF NO ONE IN HOUSEHOLD WORKS

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED
- ADHD\_F1\_4 Have you or other family members avoided changing jobs because of concerns about maintaining health insurance for [S.C.]?

HELP TEXT: CODE 2 IF NO ONE IN HOUSEHOLD WORKS

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### **AMERICAN COMMUNITY SURVEY QUESTIONS**

[IF TS END=1 SKIP TO ADHD H1 Q01 CHK, ELSE ASK:]

#### ADHD G INTRO

Thank you for your answers. Now I have a few more general questions about [S.C.] and your household. These questions may seem similar to other questions I have previously asked.

ADHD G1 1 How well does [S.C.] speak English?

- (1) VERY WELL
- (2) WELL
- (3) NOT WELL
- (4) NOT AT ALL
- (77) DON'T KNOW
- (99) REFUSED

ADHD G1 2 Is [S.C.] deaf or have serious difficulty hearing?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

ADHD G1 3 Is [S.C.] blind or have serious difficulty seeing, even when wearing glasses?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

ADHD\_G1\_4 Because of a physical, mental or emotional condition, does [S.C.] have serious difficulty concentrating, remembering, or making decisions?

HELP TEXT: ANY PHYSICAL, MENTAL OR EMOTIONAL CONDITION (INCLUDING ADHD) CAN BE CONSIDERED.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

ADHD G1 5 Does [S.C.] have serious difficulty walking or climbing stairs?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

ADHD\_G1\_6 Does [S.C.] have difficulty dressing or bathing?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

[IF AGE < 15 SKIP TO ADHD\_H1\_Q01]

ADHD\_G1\_7 Because of a physical, mental or emotional condition, does [S.C.] have difficulty doing errands alone such as visiting a doctor's office or shopping?

HELP TEXT: ANY PHYSICAL, MENTAL OR EMOTIONAL CONDITION (INCLUDING ADHD) CAN BE CONSIDERED.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

#### HOUSEHOLD AND DEMOGRAPHICS

ADHD H1 Q01

Including the adults and all the children, how many people live in this household? RECORD VALUE:

ADHD H1 Q02

IF TS\_END=1 THEN DISPLAY: Just to confirm once again,] I have that you are [S.C.]'s [FILL FROM RELATION]. Is that correct?

READ IF NECESSARY: I have to re-ask this question for statistical reasons

READ IF NECESSARY: We want to ensure we have your relationship with the child correct.

- (1) YES [GO TO ADHD H1\_Q2\_CHK]
- (2) NO [GO TO ADHD H1\_Q3]
- (77) DON'T KNOW [GO TO ADHD H1\_Q3]
- (99) REFUSED [GO TO ADHD H1 Q3]

ADHD H1 Q03

IF ADHD H1 Q02=2, 77, 99 OR IF R TYPE=2, 77, 99 THEN DISPLAY:

What is your relationship to [S.C.]?

IF R RESPONDS "Mother" or "Father," YOU MUST PROBE: Are you [S.C.]'s biological, step, foster, or adoptive mother/father?

IF R RESPONDS "Parent's Partner," PROBE IF NOT SURE: Are you male or female?

IF ADHD \_H1\_Q02=1 AND C10Q02A=1,2, 3,4,5 THEN DISPLAY: Are you [S.C.]'s biological, adoptive, step, or foster mother?

IF ADHD \_H1\_Q02=1 AND C10Q02A =6,7,8,9,10 THEN DISPLAY: Are you [S.C.]'s biological, adoptive, step, or foster father?

- (1) BIOLOGICAL MOTHER
- (2) STEP MOTHER
- (3) FOSTER MOTHER
- (4) ADOPTIVE MOTHER
- (5) MOTHER, but TYPE REFUSED
- (6) BIOLOGICAL FATHER
- (7) STEP FATHER
- (8) FOSTER FATHER
- (9) ADOPTIVE FATHER
- (10) FATHER, but TYPE REFUSED
- (11) GRANDMOTHER
- (12) GRANDFATHER
- (13) AUNT

- (14) UNCLE
- (15) FEMALE GUARDIAN
- (16) MALE GUARDIAN
- (17) SISTER (BIOLOGICAL, STEP, FOSTER, HALF, ADOPTIVE)
- (18) BROTHER (BIOLOGICAL, STEP, FOSTER, HALF, ADOPTIVE)
- (19) COUSIN
- (20) IN-LAW OF ANY TYPE
- (22) OTHER RELATIVE / FAMILY MEMBER
- (23) PARENT'S BOYFRIEND / MALE PARTNER
- (24) PARENT'S GIRLFRIEND / FEMALE PARTNER
- (25) PARENT'S PARTNER, but SEX REFUSED
- (26) OTHER NON-RELATIVE OR FRIEND
- (77) DON'T KNOW
- (99) REFUSED

IF TS\_END=1 FILL ADHD\_H1\_Q4 WITH TS\_H1\_Q4 AND GO TO CPGOGETMED ADHD, ELSE GO TO ADHD H1 Q04.

## ADHD H1 Q04

IF ADHD \_H1\_Q01= 2 THEN SKIP TO ADHD \_H1\_Q04\_CONF

IF ADHD \_H1\_Q01 = 77, 99, THEN READ: For the other people that live in your household with you and [S.C.], what is their relationship to [S.C.]? [SELECT ALL THAT APPLY]

IF ADHD \_H1\_Q01 > 2, THEN READ: In addition to you and [S.C.], I have that [FILL: ADHD \_H1\_Q01 - 2] [other person lives/other people live] in your household. What is their relationship to [S.C.]? [SELECT ALL THAT APPLY]

IF R RESPONDS "Mother" or "Father," YOU MUST PROBE: Is that [S.C.]'s biological, step, foster, or adoptive mother/father?

IF R RESPONDS "Partner," PROBE: Is the partner male or female?

- (1) BIOLOGICAL MOTHER
- (2) STEP MOTHER
- (3) FOSTER MOTHER
- (4) ADOPTIVE MOTHER
- (5) MOTHER, but TYPE REFUSED
- (6) BIOLOGICAL FATHER
- (7) STEP FATHER
- (8) FOSTER FATHER
- (9) ADOPTIVE FATHER
- (10) FATHER, but TYPE REFUSED
- (11) GRANDMOTHER
- (12) GRANDFATHER
- (13) AUNT
- (14) UNCLE
- (15) FEMALE GUARDIAN

- (16) MALE GUARDIAN
- (17) SISTER (BIOLOGICAL, STEP, FOSTER, HALF, ADOPTIVE)
- (18) BROTHER (BIOLOGICAL, STEP, FOSTER, HALF, ADOPTIVE)
- (19) COUSIN
- (20) IN-LAW OF ANY TYPE
- (22) OTHER RELATIVE / FAMILY MEMBER
- (23) PARENT'S BOYFRIEND / MALE PARTNER
- (24) PARENT'S GIRLFRIEND / FEMALE PARTNER
- (25) PARENT'S PARTNER, but SEX REFUSED
- (26) OTHER NON-RELATIVE OR FRIEND
- (77) DON'T KNOW
- (99) REFUSED

#### ADHD H1 Q03 ADOPT

Have you legally adopted [S.C.]?

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

### ADHD H2 INTRO

The next questions are about health insurance.

#### ADHD H2 STATE

Because many health insurance programs are state specific, can you please tell me what state you live in?

ENTER STATE (DROP DOWN MENU)

#### ADHD H2 Q01

Does [S.C.] have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?

READ IF NECESSARY: Medicaid refers to a medical assistance program that provides health care coverage to low-income and disabled persons. The Medicaid program is a joint federal-state program that is administered by the states. HMO is Health Maintenance Organization.

- (1) YES [SKIP TO ADHD H2 Q02]
- (2) NO [SKIP TO ADHD H2 Q01 CONF]
- (77) DON'T KNOW [SKIP TO ADHD H2 Q01 CONF]
- (99) REFUSED [SKIP TO ADHD H2 Q01 CONF]

#### ADHD H2 Q02

IF ADHD\_H2\_Q01=1 THEN FILL "Is that coverage". ELSE, FILL "Is [he/she] insured by] Medicaid or the Children's Health Insurance Program, or CHIP? In this state, the program is sometimes called [FILL MEDICAID NAME, CHIP NAME].

READ IF NECESSARY: CHIP, also known as S-CHIP, is a type of state-sponsored health insurance coverage that a child may have. The name of the plan varies from state-to-state. CATI WILL AUTOMATICALLY FILL IN THE NAMES FOR YOU.

READ IF R MENTIONS THAT HE/SHE DOES NOT LIVE IN THE STATE MENTIONED IN THE QUESTION: Please think about the Medicaid or state-sponsored Children's Health Insurance Program specific to the state in which you live.

- (1) YES
- (2) NO
- (77) DON'T KNOW
- (99) REFUSED

## ADHD H2 03

IF [(ADHD\_H2\_Q01 = 77, or 99) AND (ADHD\_H2\_Q02 = 2, 77, or 99)], SKIP TO ADHD H2 Q04; ELSE, ASK

[IF AGE>1 "During the past 12 months", ELSE "Since [his/her] birth"], was there any time when [he/she] was not covered by ANY health insurance?

- (1) YES [SKIP TO ADHD\_H3\_Q01] (2) NO [SKIP TO ADHD\_H3\_Q01] (77) DON'T KNOW [SKIP TO ADHD\_H3\_Q01] (99) REFUSED [SKIP TO ADHD\_H3\_Q01]
- ADHD H2 Q04

[IF AGE>1, "During the past 12 months", ELSE "Since [his/her] birth"], was there any time when [he/she] had health care coverage?

(1) YES [SKIP TO ADHD\_H3\_Q01] (2) NO [SKIP TO ADHD\_H3\_Q01] (77) DON'T KNOW [SKIP TO ADHD\_H3\_Q01] (99) REFUSED [SKIP TO ADHD\_H3\_Q01]

#### ADHD H3 Q01

Now I am going to ask you a few questions about your income.

When answering this next question, please remember to include your income PLUS the income of all family members living in this household.

What is your best estimate of the total income of all family members from all sources, before taxes, in [FILL: last calendar year in 4 digit format]?

INTERVIEWER INSTRUCTION: ENTER '999,995' IF THE REPORTED INCOME IS GREATER THAN \$999,995.

INTERVIEWER INSTRUCTION: ENTER 77 FOR DON'T KNOW AND 99 FOR REFUSED

RECORD INCOME AMOUNT: \_\_\_\_\_\_ [INCOME GREATER THAN \$999,995 [GO TO ADHD ADDRESS CONF]

(77) DON'T KNOW [GO TO ADHD\_H3\_Q02]

(99) REFUSED [GO TO ADHD\_H3\_Q02]

### ADHD H3 Q02

For the purposes of this survey, it is important to get at least a range for the total income received by all members of your household in 2013. Was your total family income from all sources less than \$50,000 or \$50,000 or more?

- (1) LESS THAN \$50,000
- (2) \$50,000 OR MORE [GO TO ADHD H3 Q05]
- (77) DON'T KNOW [GO TO CPGOGETMED ADHD]
- (99) REFUSED [GO TO CPGOGETMED\_ADHD]

### ADHD H3 Q03

Was your total family income from all sources less than \$35,000 or \$35,000 or more?

- (1) LESS THAN \$35,000
- (2) \$35,000 OR MORE [IF ADHD \_H1\_Q01= (8, 9) GO TO ADHD\_H3\_Q04; ELSE GO TO CPGOGETMED ADHD]
- (77) DON'T KNOW [GO TO CPGOGETMED ADHD]
- (99) REFUSED [GO TO CPGOGETMED ADHD]

#### ADHD H3 Q04

Was your total family income from all sources less than [FILL: Poverty threshold for household of size ADHD \_H1\_Q01] or [FILL: Poverty threshold for household of size ADHD \_H1\_Q01] or more?

- (1) LESS THAN [FILL: Poverty threshold for household of size ADHD H1\_Q01] [GO TO CPGOGETMED ADHD]
- (2) [FILL: Poverty threshold for household of size ADHD \_H1\_Q01] OR MORE [GO TO CPGOGETMED ADHD]
- (77) DON'T KNOW [GO TO CPGOGETMED ADHD]
- (99) REFUSED [GO TO CPGOGETMED ADHD]

#### ADHD H3 Q05

Was your total family income from all sources less than \$100,000 or \$100,000 or more?

(1) LESS THAN \$100,000 [GO TO ADHD H3 Q06]

(2) \$100,000 OR MORE [GO TO CPGOGETMED\_ADHD] (77) DON'T KNOW [GO TO CPGOGETMED\_ADHD] (99) REFUSED [GO TO CPGOGETMED\_ADHD]

## ADHD H3 Q06

Was your total family income from all sources less than \$75,000 or \$75,000 or more?

(1) LESS THAN \$75,000 [GO TO CPGOGETMED\_ADHD]
(2) \$75,000 OR MORE [GO TO CPGOGETMED\_ADHD]
(77) DON'T KNOW [GO TO CPGOGETMED\_ADHD]
(99) REFUSED [GO TO CPGOGETMED ADHD]

IF RESPONDENT INDICATED NEEDING TO LOOK FOR MEDICATIONS EARLIER IN INTERVIEW THEY WERE GIVEN THE OPPORTUNITY (CPGOGETMED\_ADHD) TO GATHER THE MEDICATIONS TO ANSWER ADHD\_C1\_4\_NEW BEFORE CONCLUDING INTERVIEW.

## ADHD ADDRESS CONF

#### TEXT 1:

[IF TS\_END=0 DISPLAY: Those are all the questions I have. Before I go, I'll need your mailing address so we can send you \$ [25 / 20] as a token of our appreciation for taking the time to answer our questions.]

#### TEXT 2:

[IF TS\_END=1 DISPLAY: Those are all the questions I have. Before I go, I'll need your mailing address so we can send you an additional \$20, for a total of \$[45 / 40] as a token of our appreciation for taking the time to answer our questions.]

GO TO AC\_NAME AND PROCEED THROUGH ADDRESS COLLECTION OR VERIFICATION

- (1) ADDRESS CORRECT AND CONFIRMED
- (99) REFUSED TO GIVE/CONFIRM ADDRESS
- ADHD\_END Those are all the questions I have. You may be re-contacted in the future to participate in related studies. If you are contacted to participate in future surveys, you have the right to refuse. I'd like to thank you on behalf of the CDC's National Center for Health Statistics for the time and effort you've spent answering these questions. If you have any questions about this survey, you may call my supervisor toll-free at 1-877-346-9982. If you have questions about your rights as a survey participant, you may call the chairman of the Research Ethics Review Board at 1-800-223-8118. Thank you again.

# Appendix V. NSCNC Pretest

The National Survey of Children in Nonparental Care (NSCNC) pretest occurred April 2–4, 2013, resulting in 56 completed pretest interviews. National Center for Health Statistics and NORC at the University of Chicago staff held a debriefing meeting April 4, 2013, during which observations from interview monitoring, as well as feedback from the interviewer debriefing session, were discussed, and questionnaire changes were suggested. The questionnaire changes, which were finalized April 4–11, 2013, included questionnaire modifications, deletions, and additions.

Original timing estimates for the NSCNC interview length, derived from computer-assisted telephone interview (CATI) programmer testing, indicated that the timing was roughly comparable to the desired interview length of 30 minutes. Thus, only minor deletions were anticipated to reach that target. However, the pretest indicated a considerably longer average interview length than anticipated: 43 minutes, 10 seconds. This may have been due to the particularities of this sample and the salience of the survey topic to the respondents—most of the respondents were grandparents who were caring for their grandchildren, and many seemed very interested in sharing their stories about that caregiving. Thus, many responses tended to be long, greatly increasing average interview length.

Because the available funding for data collection did not permit longer interviews, and response rates suffer when potential respondents are informed of long interview length when consent is requested, it was critical to shorten the interview length to an average 30 minutes. Given that the ratio of observed interview length to desired interview length was 1.4, applying that ratio to the number of questions in the survey indicated a need to delete about 63 questions.

Questions that seemed to cause significant delays in interviews, because they were cognitively difficult for respondents to answer or for interviewers to process, were deleted first, as well as questions that had potential issues regarding their validity (based on suspicions of socially desirable answers or interviewer perceptions obtained via interviewer debriefing). Questions that showed limited variability in response options or limited analytic utility for other reasons were deleted next. Third, questions that were redundant with other items were eliminated and, in some cases, separate questions that measured different aspects of the same topic were combined into single questions. In one case, a previously validated six-item measure of serious psychological distress, the Kessler 6 (K6) scale (16,17), was replaced with an alternate, the previously validated two-item measure of depression, the Patient Health Questionnaire-2 (PHQ-2) (18). Finally, a few deletions were made based on prioritizing the data needs of the U.S. Department of Health

and Human Services' Office of the Assistant Secretary for Planning and Evaluation. In making such priority-based decisions, items that were similar to items measured in the original NSCH data collection (except for living arrangements, caregiver health and insurance, and household income, which could have changed between interviews) were given lower priority for retention.

## Combining Pretest Question Pairs Into New Combined Variables

As mentioned above, as part of the effort to reduce average interview time by deleting questions, some new questions were derived by combining pairs of questions into single questions. Because the pretest cases were retained in the final data file, this meant creating new codes from the deleted pretest variable pairs that would correspond to the code on the new combined variable for the 56 pretest cases. This section describes the rules for combining responses on the original question pairs into corresponding responses on the final question versions.

Original questions L7 and L8 were combined into a single question, L7. The original questions asked how often in the previous 12 months the sampled child had seen (L7) or talked on the telephone, texted, e-mailed, or connected on Facebook or other social media (L8) with his or her sibling(s) who didn't live with the respondent. New variable L7 asked,

During the past 12 months, about how often did [S.C.] have contact with [his/her] siblings that don't live with you, either in person or by talking on the telephone, texting, email, or connecting on Facebook or other social media?

- (1) NOT AT ALL
- (2) ONCE OR TWICE A YEAR
- (3) SEVERAL TIMES A YEAR
- (4) 1-3 TIMES A MONTH
- (5) ABOUT ONCE A WEEK
- (6) SEVERAL TIMES A WEEK/EVERYDAY

DON'T KNOW (DK), REFUSED (RF)

Original L7 and L8 responses are treated as "either/or" in final variable L7. Thus,

If value is missing (DK, RF, or .M) on both L7 and L8, assign missing value to new L7 (assign .M if missing types differ across L7 and L8).

If value is missing on L7 or L8, and valid on the other, assign the valid value to new L7.

If value is "not at all" for both L7 and L8, assign "not at all" to new L7.

Otherwise, assign the highest valid value between L7 and L8 to the new L7.

Original questions P9 and P10 were combined into a single question, P9. The original questions asked how often in the previous 12 months the sampled child had talked on the telephone, texted, e-mailed, or connected on Facebook or other social media with (P9), or received a card, letter, or package from (P10) his or her mother who didn't live with the respondent. New variable P9 asked:

During the past 12 months, about how often did [S.C.] have contact with [his/her] mother by talking on the telephone, texting, email, connecting on Facebook or other social media, or by receiving a card, letter or package from [his/her] mother?

- (1) NOT AT ALL
- (2) ONCE OR TWICE A YEAR
- (3) SEVERAL TIMES A YEAR
- (4) 1-3 TIMES A MONTH
- (5) ABOUT ONCE A WEEK
- (6) SEVERAL TIMES A WEEK
- (7) DON'T KNOW EXACT FREQUENCY BUT KNOW [S.C.] AND MOTHER CONNECT

DON'T KNOW (DK), REFUSED (RF)

Combining P9 and P10 into new P9 follows the same pattern as for combining L7 and L8 into L7, except that there is an additional code for P9 and P10: Response (7) "DK exact frequency, but know they connect." Thus,

If values are missing (DK, RF, or .M) on both P9 and P10, assign missing value to new P9 (assign .M if missing types differ across P9 and P10).

If value is missing on P9 or P10 and valid on the other, assign the valid value to new P9.

If value is "not at all" for both P9 and P10, assign "not at all" to new P9.

If value is 7 for both P9 and P10, assign 7 to new P9.

If value is 7 for either P9 or P10 and any valid value 1–6 on the other, assign the valid value to new P9.

Otherwise, assign the highest valid value 1–6 between P9 and P10 to new P9.

Original questions P11 and P12 were combined into a single question, P11. The original questions asked whether in the previous 12 months the sampled child's mother had ever cared for him or her during the day (P11) or overnight (P12).

New variable P11 asked:

During the past 12 months, has [S.C.]'s mother ever cared for [him/her] during the day or overnight?

- (1) YES
- (2) NO

DON'T KNOW (DK), REFUSED (RF)

Original P11 and P12 responses are treated as "either/or" in final variable P11. Thus,

If values are missing (DK, RF, or .M) for both P11 and P12, assign missing value to new P11 (assign .M if missing types differ across P11 and P12).

If value is missing on either P11 or P12 and valid on the other, assign the valid value to new P11.

If value is "no" for both P11 and P12, assign "no" to new P11.

Otherwise, if value is "Yes" for either P11 or P12, assign "yes" to new P11.

Pretest variables P27 and P28 were combined into new variable P27. These variables are exactly analogous to variables P9 and P10 discussed above, except that they ask about contact with the child's father rather than the child's mother. The coding of new variable P27 from the original pretest variables follows the same pattern as for P9 and P10.

Pretest variables P29 and P30 were combined into new variable P29. These variables are exactly analogous to variables P11 and P12 discussed above, except that they ask about the child's father caring for the child rather than the child's mother caring for the child. The coding of new variable P29 from the original pretest variables follows the same pattern as for P11 and P12.

Original questions P13 and P31, concerning how well the NSCNC respondent gets along with the sampled child's mother (P13) and father (P31), were combined into a single question, P36:

How well do you get along with [S.C.]'s [FILL depending on who is alive: mother/father/parents]?

- (1) GET ALONG VERY WELL
- (2) GET ALONG SOMEWHAT WELL
- (3) DON'T GET ALONG VERY WELL
- (4) DON'T GET ALONG AT ALL

DON'T KNOW (DK), REFUSED (RF)

In order to combine P13 and P31:

If P1\_1 NE 1 AND P18 = 1 (i.e., if sampled child's father is alive and sampled child's mother is not alive), then assign the value of P31 to P36.

If P1\_1 = 1 AND P18 NE 1 (i.e., if sampled child's mother is alive and sampled child's father is not alive), then assign the value of P13 to P36.

- ELSE If P1\_1 AND P18 = 1 (i.e., both parents are alive), then assign as follows to apply to both parents:
  - If values are missing (DK, RF, or .M) on both P13 and P31, then assign missing value to P36 (assign .M if missing types differ across P13 and P31).
  - If value is missing on P13 or P31 and valid on the other, then assign the valid value to P36.
  - If values of P13 and P31 are the same and that value is 1, 2, 3, or 4, then assign that value to P36.
  - Otherwise, see Table I for the codes to assign on P36 with two valid, but different, values on P13 and P31.

Table I. Rules for combining valid values of P13 and P31 into new variable P36

Combination of variables <sup>1</sup>	Value for combined variable P36
1 and 2	2
1 and 3	2
1 and 4	2
2 and 3	3
2 and 4	3
3 and 4	3

<sup>&</sup>lt;sup>1</sup>Regardless of which is P13 and which is P31.

SOURCE: NCHS, National Survey of Children in Nonparental Care, 2013.

DEPRESSED: This derived variable is based on K6 for the 56 pretest cases, and on PHQ–2 for the rest of the NSCNC Interview cases (16–18). PHQ–2 scores range from 0–6, with a score of 3 or higher indicating depression (18). K6 scores of 10 or more are used to identify serious psychological distress (16,17). An examination of the distributions of pretest cases and nonpretest cases screened as having or not having depression, based on various score cutoffs, indicated that a K6 score of 13 or more would most closely approximate the distribution of depressed or not depressed among the pretest cases, as seen among the nonpretest cases when using PHQ–2 with a score of 3 or more as the cutoff. Therefore, for pretest cases, a K6 score of 13 or more was coded as "depressed," while for the nonpretest cases, a PHQ–2 score of 3 or more was also coded as "depressed."

In addition to these questionnaire deletions and variable combinations, a number of small changes were made to improve questionnaire flow or reduce respondent or interviewer confusion. The next section summarizes these changes made following the pretest.

## Summary of Changes Made Following NSCNC Pretest

Questionnaire modifications are:

- 1. Skip Logic change at P4
  - IF N5 = 3 THEN GO TO P5
- 2. Skip Logic change at P21
  - IF N6 = 3 THEN GO TO P22
- 3. Skip F9 if H14\_MDY = "Since Birth"
- 4. Skip Logic at P7 update
  - IF P5 = 1 THEN GO TO P8
- 5. Skip logic at P25 update
  - IF P23 = 1 THEN GO TO P26
- 6. Skip logic change at L1\_1 when H14\_MDY = "Since Birth"
- 7. L5\_CONF Question Text Edit for "Siblings" if L5 = 1 "Sibling" else "siblings"
- 8. Skip logic change skip C8 only when (H4 = 2 or H10 = 1) and go to CC1
- 9. P26 = 2 Response Option Update from (2) ABOUT ONCE A YEAR to P26 = (2) ONCE OR TWICE A YEAR
- 10. Skip logic at WB9 if H4 = 2, or if the child has been living with the respondent for less than 5 years
- 11. Remove D15, R21A, and R21B from instrument
- 12. New response category for N\_H14 which is "55 55 5555" for "since birth"
- 13. Original R11 question text deleted and now combined with R14 question text; R11 moved to R14 position
- 14. Change order of F10, F11, and F12
- 15. Add HELP TEXT for C2D
- 16. P7 and P25—addition of "INTERVIEWER INSTRUCTION" as well as additional skip logic
- 17. P1\_1 and P18—revision of "READ IF NECESSARY" text for both version of each question
- 18. Cut P2, P3, P5\_15, P13, P16, P17, P19, P20, P23\_15, P31, P34, and P35
- P5, P6, P23, and P24—add "... OR MENTALLY ILL" to response option 5
- P5 and P23—remove response option 13 (MOTHER/ FATHER DECEASED)
- 21. Addition of new questions—P6\_NEW1 and P24\_NEW1
- 22. P6 and P24—removal of response option 14
- 23. Addition of new question—P36 (same response options as P13/P31)

- 24. H10 should be skipped for parents (H4 = 2)
- 25. New questions—R13 NEW1 and R13 NEW2
- 26. Remove response option (3) NEITHER AGREE NOR DISAGREE for R14, R14A, R14F, R14I, and R14J
- 27. Add response option (12) NO DIFFICULTIES to WB4
- 28. Additional help text at C2D
  - HELP TEXT: LEGAL ASSISTANCE IS HELP OR ADVICE PROVIDED BY AN ATTORNEY.
- 29. Additional response option for questions C2A-N
  - (6) DIDN'T KNOW ABOUT THIS SERVICE OR NEVER TRIED TO GET IT
- 30. F4 question text revised
- 31. S1\_1, S2\_1, and S2\_VERBATIM were moved after TIMESTAMP\_SECTION\_92
- 32. New question text added to S3\_1
- 33. S5 STATE deleted
- 34. Skip logic for S6 = 2, 77, 99 changed from S9 to S1 1
- 35. If S3 NE 2, then go to S1\_1 instead of S
- 36. S1\_1 = 2, 77, 99 skip logic changed from S3 to S9
- S2\_1 is a "MARK ALL THAT APPLY" question and READ IF NECESSARY text added
  - READ IF NECESSARY: Please think about your insurance or your spouse's insurance.
- 38. D6, D7, and D8 deleted, skip from D5 to D9
- 39. P8 response option (2) ABOUT ONCE A YEAR to (2) ONCE OR TWICE A YEAR
- 40. Delete D5
- 41. Update skip logic at D6

» IF H4 = 2, THEN GO TO WB9

- 42. Add response option to WB6 and WB7
  - (6) CHILD NOT ENROLLED IN SCHOOL/HOME-SCHOOLED
- 43. H9 split into two questions and if H4 = 2 skip H9 and go to H13
- 44. F1 question text and response options edits
- 45. F5 and F7 response options text edits
- 46. F7 help text added
  - HELP TEXT: "NOT ELIGIBLE" CAN BE DUE TO INCOME, RELATIONSHIP TO CHILD, OR OTHER REASONS.
- 47. C2H new help text added
  - HELP TEXT: TANF stands for Temporary Assistance for Needy Families.

- 48. "MARK ALL THAT APPLY" instructions were added to C7, C10, and C13
- 49. "READ IF NECESSARY" help text has been added to S2\_1
  - READ IF NECESSARY: It can be you or your spouse's insurance.
- 50. A "Don't Know" response was included for S4
  - Just to confirm, I entered that [S.C.] is not covered by any type of health insurance. Is this correct?
    - (1) CONFIRMED—CHILD IS NOT COVERED BY ANY TYPE OF HEALTH INSURANCE [GO TO S7]
    - (2) NOT CORRECT—CHILD HAS INSURANCE—RETURN TO S3 AND ENTER CORRECT RESPONSE [GO TO S5]
    - (77) DON'T KNOW
- 51. Interviewer instructions were added for D9 and D10
  - RECORD AS STUDENT ONLY IF THERE IS NO FULL- OR PART-TIME EMPLOYMENT.
  - "SEMI-RETIRED" SHOULD BE CODED AS "EMPLOYED PART-TIME."
  - "SELF-EMPLOYED" SHOULD BE CODED AS "EMPLOYED FULL-TIME" OR "EMPLOYED PART-TIME" DEPENDING ON HOW MUCH THEY WORK.
- 52. S18\_CONF was revised so the interviewer could confirm with respondent that ALL members of household are being accounted for when answering this question
- 53. Interviewer instruction text was added at P7 and P25
  - INTERVIEWER INSTRUCTION: IF RESPONDENT SAYS "REHAB" CODE "2."
- 54. P5/P23 and P6/P24 response options were updated
  - Response option (13) MOTHER DECEASED was deleted at P5
  - "OR MENTALLY ILL" was added to response option (5)
     MOTHER IS SICK for P5, P6, P23, and P24
- 55. P29 and P30 questions have been combined
  - During the past 12 months, has [S.C.]'s father ever cared for [him/her] during the day or overnight?
- 56. P11 and P12 questions have been combined
  - During the past 12 months, has [S.C.]'s mother ever cared for [him/her] during the day or overnight?
- 57. P27 and P28 questions have been combined
  - During the past 12 months, about how often did [S.C.]
    have contact with [his/her] father by talking on the
    telephone, texting, email, connecting on Facebook or
    other social media, or by receiving a card, letter or
    package from [his/her] father?
- 58. P9 and P10 questions have been combined
  - During the past 12 months, about how often did [S.C.] have contact with [his/her] mother by talking on the

- telephone, texting, email, connecting on Facebook or other social media, or by receiving a card, letter or package from [his/her] mother?
- 59. A total of 65 questions throughout the survey have been cut due to various reasons, including: the question was hard to process, of lower priority, of limited utility and validity, or considered redundant
  - P2 (S.C.'s mom's ethnicity)
  - P3 (S.C.'s mom's race)
  - P5\_15 (Why S.C. mom not caregiver)
  - P13 (How well respondent gets along with S.C.'s mom)
  - P16 (Respondent ever ask S.C. mom to spend more time)
  - P17 (Respondent ever refused S.C. mom visit)
  - P19 (S.C.'s dad's ethnicity)
  - P20 (S.C.'s dad's race)
  - P23 15 (Why S.C. dad not caregiver)
  - P31 (How well respondent gets along with S.C.'s dad)
  - P34 (Respondent ever ask S.C. dad to spend more time)
  - P35 (Respondent ever refused S.C. dad visit)
  - F2 (Child support agreement w/mom or dad)
  - F8 (How heard about TANF)
  - C2I (Ease obtain educ re: child special needs)
  - C2J (Ease obtain educ re: legal issues)
  - C2M (Ease obtain info re: medical care)
  - C2N (Ease obtain overview of programs/services)
  - C3 (Where learn about services)
  - C4 (How much respondent knew regarding child background)
  - CC2A (Supervision: where child is)
  - CC2B (Supervision: who child is with)
  - CC2C (Supervision: child arrives at home)
  - CC2D (Supervision: child finished homework)
  - CC2E (Supervision: control child's free time)
  - CC2F (Supervision: child's money)
  - CC2G (Supervision: child does chores)
  - CC2H (Supervision: child without sitter)
  - WB1 (How S.C. feels re: living with respondent)
  - WB8E (Child care: sitter related to respondent)
  - WB8F (Child care: sitter related to spouse)
  - WB8G (Child care: sitter lives with respondent)
  - WB8I (Child care: other home sitter related to S.C.)
  - WB8J (Child care: other home sitter related to respondent/spouse)
  - R7 (How it's going caring for S.C.)
  - R8A (Getting help: someone to watch S.C.)

- R8B (Getting help: a ride to the doctor)
- R8C (Getting help: family/friends check on sick S.C.)
- R8D (Getting help: someone to talk w/re: problems)
- R8E (Getting help: family/friends lend cash)
- R9 (R feels trapped by parenting responsibility)
- R10 (Caring for S.C. more work than pleasure)
- R12 (Respondent self-rating caregiver quality)
- R13A (Depression scale: sad)
- R13B (Depression scale: nervous)
- R13C (Depression scale: restless/fidgety)
- R13D (Depression scale: hopeless)
- R13E (Depression scale: everything an effort)
- R13F (Depression scale: worthless)
- R14B (Confident can help S.C. grow)
- R14C (Know steps when receiving poor services)
- R14D (Family life is under control)
- R14E (Tell pros my thoughts re: services)
- · R14G (I try to find needed services)
- R14H (Focus on good as well as problems)
- S5\_STATE (Confirm state to fill insurance program name)
- S16 (Paying lower rent due to subsidy)
- D8 (S.C. transracial with respondent's spouse)
- R21A (Verbatim most challenging re: care for S.C.)
- R21B (Verbatim most rewarding re: care for S.C.)
- 60. L7 and L8 guestions have been combined
  - During the past 12 months, about how often did [S.C.] have contact with [his/her] siblings that don't live with you, either in person or by talking on the telephone, texting, email, or connecting on Facebook or other social media?
- 61. Response options at C13 were reordered and included bold subheadings for ease of reading
- 62. The skip logic at C8 was updated to account for cases that responded H10 = 1
- 63. Question text changes and interviewer instructions were made at C2F
  - (READ IF NECESSARY: Please tell me how easy or difficult it was to find ...)

A parent or grandparent support group

READ IF NECESSARY: Would you say it was very easy, somewhat easy, somewhat difficult, very difficult, or you never needed it for [S.C.]?

INTERVIEWER INSTRUCTION: A GRANDPARENT SUPPORT GROUP IS A GROUP OF GRANDPARENTS WHO MEET TOGETHER TO SHARE THEIR EXPERIENCES AND ADVICE ABOUT RAISING THEIR GRANDCHILDREN.

- 64. Response option "SINCE BIRTH" was added at H14
- 65. The skip logic at C11 was updated to account for cases where H4 = 3 to skip this question and go to question CC1
- P1\_1 and P18 question text was updated and a READ IF NECESSARY text was added
  - I'd like to ask you a few questions about [S.C.]'s father. IF RESPONDENT HAS ADOPTED CHILD SINCE THE TIME OF THE NSCH INTERVIEW (H10 = 1), ASK: Is [S.C.]'s previous legal father currently living?
  - READ IF NECESSARY: By previous legal father, we mean the child's most recent legal guardian, either biological or adoptive, before you adopted [him/her].
- 67. Response option 2 was updated for questions L7 and L8 from "ABOUT ONCE A YEAR" to "ONCE OR TWICE A YEAR"
- 68. Response options for question H13 were reordered, and the question text was updated to reflect that change
- 69. Response options for H4 were modified
  - [When we last spoke with you/When we last spoke with someone in your household], [S.C.] did not have any parents living in the household with [him/her].
     Does [S.C.] have any parents living in your household now?
    - (1) NO [GO TO H6]
    - (2) YES, RESPONDENT IS THE CHILD'S PARENT (BIOLOGICAL, STEP, OR ADOPTIVE PARENT WHO ADOPTED THE CHILD BEFORE THE NSCH SURVEY)
    - (3) RESPONDENT IS NOT A BIOLOGICAL OR ADOPTIVE PARENT, BUT A BIOLOGICAL OR ADOPTIVE PARENT LIVES IN THE HOUSEHOLD [GO TO H6]
    - (4) RESPONDENT IS CAREGIVER WHO ADOPTED THE CHILD SINCE THE NSCH SURVEY [GO TO H6]
    - (77) DON'T KNOW [GO TO H6]
    - (99) REFUSED [GO TO H6]
- 70. Response options for H4 were modified
- 71. READ IF NECESSARY text added to CONSENT variable
  - READ IF NECESSARY: If you are receiving government benefits, your participation in this survey will not change whether or not you receive the benefits. If you are not receiving benefits, participation will not change your eligibility for any benefits.

# Appendix VI. NSCNC and NSDATA Respondent Letters

The letters sent to sampled households are included in this appendix. Advance letters were sent prior to calling to encourage response. Thank you letters were sent after interview completion to accompany incentive payments. Refusal conversion letters were sent to encourage response among households that had passively refused.

National Survey of Children in Nonparental Care (NSCNC) letters are listed first, followed by National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome (NSDATA) letters:

NSCNC Advance letter
NSCNC \$10 Thank You letter
NSCNC \$15 Thank You letter
NSCNC Refusal Conversion letter
NSDATA Advance letter
NSDATA \$20 Thank You letter
NSDATA \$25 Thank You letter
NSDATA \$40 Thank You letter
NSDATA \$45 Thank You letter
NSDATA Refusal Conversion letter



Public Health Service Centers for Disease Control and Prevention

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

Dear Caregiver,

Thank you for your help!

Your household recently participated in the National Survey of Children's Health over the telephone. Based on the answers you provided during this survey, your household is eligible for an important survey on children who live apart from their parents. Information about the child in your care will help the U.S. Department of Health and Human Services develop programs to promote the health and well-being of these children and their caregivers in your state and throughout the United States.

In the next few weeks, the National Center for Health Statistics (NCHS), part of the Centers for Disease Control and Prevention (CDC), will call your household and ask to talk to the same caregiver who completed the previous telephone survey, or another parent or guardian of the child who currently lives with the child. The survey will take about half an hour to complete.

#### In appreciation for your continued time and effort, we will send you \$10 once the survey is complete.

Participation is voluntary. We hope you will share this important information about the child in your care by phone when an interviewer calls to ask you to take part in the study. If you do, you can choose not to answer any questions you do not wish to answer. All information collected for this study is confidential and protected by federal law. The back of this letter provides answers to some questions you may have and ways to get more information about the survey.

To learn more about the study or to take part right away, call **1-877-346-9982**, toll-free. You can also visit the study's website for additional study information – <u>www.cdc.gov/nchs/slaits.htm</u>.

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

Sincerely,

Edward J. Sondik, Ph.D.

Edffel

Director, National Center for Health Statistics Centers for Disease Control and Prevention

If you prefer to use TTY

Please call the AT&T Relay Service at 1-800-855-2880 and request that

1-877-259-4326 be called. The call is toll-free.

#### National Survey of Children in Nonparental Care

#### **Frequently Asked Questions**

#### What is the purpose of this study?

The purpose of this study is to better understand the living situations of children living apart from their parents. This study also aims to describe the types of services and supports that children in these households use, and to identify any problems they have in getting the care they need. Another important goal of this survey is to learn about the difficulties facing the caregivers of these children in enrolling the child in school and obtaining health insurance coverage and other services for the child. This study is authorized by Section 306 of the Public Health Service Act and funded by the U.S. Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation

#### Why do I qualify for this study?

Your household participated in a telephone survey about the health and health care of children. Based on the answers provided in this survey, a child in your household *was identified as living in a household with no biological, adoptive or step parents*. If we are contacting your household in error, we would greatly appreciate talking to a parent or guardian so we can confirm that your household should not be a part of this study.

#### How will you protect my privacy?

We are bound by law to maintain strict confidentiality standards. Your identifiable information and the child's identifiable information will never be associated with any published information from this study.

If you would like more information about the confidentiality of the research or the federal laws that ensure the protection of your information, including the Public Health Service Act and the Confidential Information Protection and Statistical Efficiency Act, these are described in detail at:

http://www.cdc.gov/nchs/about/policy/confidentiality.htm. If you want to know more about your rights as a study participant you may call **1-800-223-8118**, toll-free. This is the number for the Research Ethics Review Board at NCHS. You will be asked to leave a message and say you are calling about Protocol 2013-03.

#### How will this information be used?

The Department of Health and Human Services will use this information to identify problems that affect children in nonparental care and their caregivers and to develop programs to promote the health and well-being of these children. The federal government will also use this information to learn about the types of support services that these children need.

You may visit <a href="http://www.cdc.gov/nchs/slaits.htm">http://www.cdc.gov/nchs/slaits.htm</a> to find general information about the study.

#### Is there a toll-free number to learn more?

To learn more about the study or to take part right away, call **1-877-346-9982**, toll-free. The National Center for Health Statistics has hired NORC at the University of Chicago to conduct the survey. You can call NORC's toll-free number to take part in the study right away, learn more about the study, and hear what you will be asked.



Public Health Service Centers for Disease Control and Prevention

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

#### Dear Caregiver:

Thank you for your participation in the National Survey of Children in Nonparental Care. The information that you provided about the child in your care will help the Department of Health and Human Services develop programs to promote the health of children living apart from their parents in your state and throughout the United States.

In appreciation for the time and effort you spent answering our questions, we are enclosing \$10.

If you would like more information about the National Survey of Children in Nonparental Care, you can visit the study's web site at <a href="www.cdc.gov/nchs/slaits.htm">www.cdc.gov/nchs/slaits.htm</a> or call the toll-free telephone number for the study at 1-877-346-9982.

Thank you again for your help with this important research.

Sincerely,

Edward J. Sondik, Ph.D.

Edflet

Director, National Center for Health Statistics Centers for Disease Control and Prevention



Public Health Service Centers for Disease Control and Prevention

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

#### Dear Caregiver:

Thank you for your participation in the National Survey of Children in Nonparental Care. The information that you provided about the child in your care will help the Department of Health and Human Services develop programs to promote the health of children living apart from their parents in your state and throughout the United States.

In appreciation for the time and effort you spent answering our questions, we are enclosing \$15.

If you would like more information about the National Survey of Children in Nonparental Care, you can visit the study's web site at <a href="www.cdc.gov/nchs/slaits.htm">www.cdc.gov/nchs/slaits.htm</a> or call the toll-free telephone number for the study at 1-877-346-9982.

Thank you again for your help with this important research.

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Director, National Center for Health Statistics Centers for Disease Control and Prevention



Public Health Service Centers for Disease Control and Prevention

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

Dear Caregiver,

The CDC needs your help!

Recently, your family was asked to participate in the National Survey of Children in Nonparental Care. We hope you will reconsider our request. Information about the child in your care and others will help the Department of Health and Human Services develop programs to promote the health of children living apart from their parents in your state and throughout the United States.

In appreciation for your time and effort, we have enclosed \$5. As promised, we will send you an additional \$10 once the survey is complete.

We hope you will share this important information with us by telephone when an interviewer calls to ask you to participate in the study. If you would like to participate immediately, please call the toll-free telephone number 1-877-346-9982.

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

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

Sincerely,

Edward J. Sondik, Ph.D.

Edflet

Director, National Center for Health Statistics Centers for Disease Control and Prevention

#### Why is this study being conducted?

The Department of Health and Human Services is committed to improving children's health and well-being. State and federal health authorities are depending on the results of this study to help them understand how best to meet children's needs.

#### How do I know that my information will remain private?

By law, all information that you provide is kept confidential. The collection of information in this survey is authorized by Section 306 of the Public Health Service Act. The Public Health Service Act is Volume 42 of the US Code, Section 242k. The confidentiality of your responses is assured by Section 308(d) of this Act.

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

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

#### How can I find out more about this survey?

If you have any questions about this research study, please call 1-877-346-9982.

If your questions are about your rights as a participant in this research study, you may also call the office of the Institutional Review Board at the National Center for Health Statistics, toll free, at 1-800-223-8118. Please leave a brief message with your name and phone number. Say that you are calling about Protocol #2013-03. Your call will be returned as soon as possible.

#### **NSDATA Advance Letter**



#### **DEPARTMENT OF HEALTH & HUMAN SERVICES**

Public Health Service
Centers for Disease Control and Prevention

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

Dear Parent or Guardian,

Thank you for your help!

Your household participated in the 2011-2012 National Survey of Children's Health over the telephone. Based on the answers you provided during this survey, your household is eligible for an important survey on children who have ever been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) or Tourette Syndrome (TS). Information about the child in your care will help the U.S. Department of Health and Human Services develop programs to promote the health and well-being of these children and their caregivers in your state and throughout the United States.

In the next few weeks, the National Center for Health Statistics (NCHS), part of the Centers for Disease Control and Prevention (CDC), will call your household and ask to talk to the same caregiver who completed the previous telephone survey, or another parent or guardian of the child who currently lives with the child. The survey will take about half an hour to complete.

#### In appreciation for your continued time and effort, we will send you \$20 once the survey is complete.

Participation is voluntary. We hope you will share this important information about your child by phone when an interviewer calls to ask you to take part in the study. If you do, you can choose not to answer any questions you do not wish to answer. All information collected for this study is confidential and protected by federal law. The back of this letter provides answers to some questions you may have and ways to get more information about the survey.

To learn more about the study or to take part right away, call 1-877-346-9982, toll-free. You can also visit the study's website for additional study information – <a href="https://www.cdc.gov/nchs/slaits.htm">www.cdc.gov/nchs/slaits.htm</a>.

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

Sincerely,

/Charles J. Rothwell/

Charles J. Rothwell, MBA, MS Director, National Center for Health Statistics Centers for Disease Control and Prevention

#### If you prefer to use TTY



Please call the AT&T Relay Service at 1-800-855-2880 and request that 1-877-259-4326 be called. The call is toll-free.

#### National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome

#### **Frequently Asked Questions**

#### What is the purpose of this study?

The purpose of this study is to obtain information necessary to improve the process by which children with ADHD or Tourette Syndrome (TS) are diagnosed and treated. This study also aims to describe the types of services and supports these children use, and to identify any problems they have in getting the care they need. People have very different experiences with their children's health and health care. In order to improve children's health and well-being overall, it is important that we learn about diagnosis and treatment. This study is authorized by Section 306 of the Public Health Service Act and funded by the National Center on Birth Defects and Developmental Disabilities.

#### Why do I qualify for this study?

Your household participated in a telephone survey about the health and health care of children. Based on the answers provided in this survey, a child in your household *has or had been diagnosed with* ADHD or TS. If we are contacting your household in error, we would greatly appreciate talking to a parent or guardian so we can confirm that your household should not be a part of this study.

#### How will you protect my privacy?

We are bound by law to maintain strict confidentiality standards. Your identifiable information and the child's identifiable information will <u>never</u> be associated with any published information from this study.

If you would like more information about the confidentiality of the research or the federal laws that ensure the protection of your information, including the Public Health Service Act and the Confidential Information Protection and Statistical Efficiency Act, these are described in detail at: <a href="http://www.cdc.gov/nchs/about/policy/confidentiality.htm">http://www.cdc.gov/nchs/about/policy/confidentiality.htm</a>.

If you want to know more about your rights as a study participant you may call 1-800-223-8118, toll-free. This is the number for the Research Ethics Review Board at NCHS. You will be asked to leave a message and say you are calling about Protocol 2014-02.

#### How will this information be used?

Maternal and child health agencies in your state will use this information to improve diagnosis and treatment of children with neurodevelopmental conditions. The federal government will also use this information to learn about the types of support services that states need for these children.

You may visit http://www.cdc.gov/nchs/slaits.htm to find general information about the study.

#### Is there a toll-free number to learn more?

To learn more about the study or to take part right away, call **1-877-346-9982**, toll-free. The National Center for Health Statistics has hired NORC at the University of Chicago to conduct the survey. You can call NORC's toll-free number to take part in the study right away, learn more about the study, and hear what you will be asked.



Public Health Service Centers for Disease Control and Prevention

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

Dear Parent or Guardian,

Thank you for your participation in a recent national survey. The information that you gave about your child will help the Centers for Disease Control and Prevention develop programs to promote the health of children with ADHD and Tourette Syndrome throughout the United States. In appreciation for the time and effort you spent answering our questions, we are enclosing \$20.

If you would like more information about the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, you can visit the study's web site at <a href="http://www.cdc.gov/nchs/slaits.htm">http://www.cdc.gov/nchs/slaits.htm</a> or call the toll-free telephone number for the study at 1-877-346-9982.

Thank you again for your help with this important research.

Sincerely,

/Charles J. Rothwell/



Public Health Service Centers for Disease Control and Prevention

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

Dear Parent or Guardian,

Thank you for your participation in a recent national survey. The information that you gave about your child will help the Centers for Disease Control and Prevention develop programs to promote the health of children with ADHD and Tourette Syndrome throughout the United States. In appreciation for the time and effort you spent answering our questions, we are enclosing \$25.

If you would like more information about the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, you can visit the study's web site at <a href="http://www.cdc.gov/nchs/slaits.htm">http://www.cdc.gov/nchs/slaits.htm</a> or call the toll-free telephone number for the study at 1-877-346-9982.

Thank you again for your help with this important research.

Sincerely,

/Charles J. Rothwell/



Public Health Service Centers for Disease Control and Prevention

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

Dear Parent or Guardian,

Thank you for your participation in a recent national survey. The information that you gave about your child will help the Centers for Disease Control and Prevention develop programs to promote the health of children with ADHD and Tourette Syndrome throughout the United States. In appreciation for the time and effort you spent answering our questions, we are enclosing \$40.

If you would like more information about the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, you can visit the study's web site at <a href="http://www.cdc.gov/nchs/slaits.htm">http://www.cdc.gov/nchs/slaits.htm</a> or call the toll-free telephone number for the study at 1-877-346-9982.

Thank you again for your help with this important research.

Sincerely,

/Charles J. Rothwell/



Public Health Service Centers for Disease Control and Prevention

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

Dear Parent or Guardian,

Thank you for your participation in a recent national survey. The information that you gave about your child will help the Centers for Disease Control and Prevention develop programs to promote the health of children with ADHD and Tourette Syndrome throughout the United States. In appreciation for the time and effort you spent answering our questions, we are enclosing \$45.

If you would like more information about the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, you can visit the study's web site at <a href="http://www.cdc.gov/nchs/slaits.htm">http://www.cdc.gov/nchs/slaits.htm</a> or call the toll-free telephone number for the study at 1-877-346-9982.

Thank you again for your help with this important research.

Sincerely,

/Charles J. Rothwell/



Public Health Service Centers for Disease Control and Prevention

National Center for Health Statistics 3311 Toledo Road Hyattsville, Maryland 20762

Dear Parent or Guardian,

The CDC needs your help!

Recently, your family was asked to participate in the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome. We hope you will reconsider our request. Information about the child in your care and others will help the Department of Health and Human Services develop programs to promote the health of children in your state and throughout the United States.

In appreciation for your time and effort, we have enclosed \$5. As promised, we will send you an additional \$20 once the survey is complete.

We hope you will share this important information with us by telephone when an interviewer calls to ask you to participate in the study. If you would like to participate immediately, please call the toll-free telephone number 1-877-346-9982.

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

Sincerely,

/Charles J. Rothwell/

#### Why is this study being conducted?

The Department of Health and Human Services is committed to improving children's health and well-being. State and federal health authorities are depending on the results of this study to help them understand how best to meet children's needs.

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

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

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If your questions are about your rights as a participant in this research study, you may also call the office of the Research Ethics Review Board at the National Center for Health Statistics, toll free, at 1-800-223-8118. Please leave a brief message with your name and phone number. Say that you are calling about Protocol # 2014-02. Your call will be returned as soon as possible.

### Appendix VII. Income Thresholds

The Services and Support section of the National Survey of Children in Nonparental Care (NSCNC) questionnaire contained questions that collected the NSCNC respondent's best estimate of the total income of all family members from all sources in the household. When respondents were unable to supply a specific dollar amount for household income, they were asked a series of questions that identified whether the household income was below, exactly at, or above certain income threshold amounts. This series of questions referenced the following income ranges:

- Less than \$35,000 or \$35,000 or more (item \$20)
- Less than \$50,000 or \$50,000 or more (item \$19)
- Less than \$75,000 or \$75,000 or more (item \$23)
- Less than \$100,000 or \$100,000 or more (item \$22)

If the respondent reported that their total family income was less than \$35,000, item \$21 was asked to obtain a more precise estimate of the respondent's total family income:

Was your total family income from all sources less than [FILL: Poverty threshold for household of size H1 + H2] or [FILL: Poverty threshold for household of size H1 + H2] or more?

Respondents would also receive item S21 if they reported that their total family income was \$35,000 or more but less than \$50,000 and their household size was eight or greater. The income reference value placed in item S21 was based on U.S. Department of Health and Human Services (HHS) federal poverty guidelines, which are produced annually and developed separately for the 48 contiguous states and the District of Columbia, Alaska, and Hawaii. In addition to the HHS federal poverty guidelines, item S21 also references two variables—the number of adults living in the household (item H1) and the number of children under age 18 living in the household (item H2).

For example, if a respondent lived in one of the 48 contiguous states and reported a household size of four persons earning less than \$35,000, the income reference fill at item S21 would be \$23,600. See Tables II–IV for the reference fill for various household sizes.

In the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome (NSDATA), the same procedure was used to collect household income data on both the attention-deficit/hyperactivity disorder (ADHD) and Tourette syndrome (TS) modules. The only difference was in the guideline reference year used. For NSDATA, 2013 guidelines (Tables II—IV) were used with interviews conducted during the NSDATA soft launch on January 22 and 23, 2014.

Table II. 2013 federal poverty guidelines for families in the 48 contiguous states and District of Columbia

	Household size	Poverty guideline <sup>1</sup>	Fill <sup>1</sup>
2		15,510	15,500
3		19,530	19,500
4		23,550	23,600
5		27,570	27,600
6		31,590	31,600
7		35,610	35,600
8		39,630	39,600
9		43,650	43,700
10		47,670	47,700
		•	•

<sup>&</sup>lt;sup>1</sup>U.S. dollars.

SOURCE: U.S. Department of Health and Human Services federal poverty guidelines, 2013.

Table III. 2013 federal poverty guidelines for families in Alaska

	Household size	Poverty guideline <sup>1</sup>	Fill <sup>1</sup>
2		19,380	19,400
3		24,410	24,400
4		29,440	29,400
5		34,470	34,500
6		39,500	39,500
7		44,530	44,500
8		49,560	49,600
9		54,590	54,600
10		59,620	59,600
		00,020	00,000

<sup>&</sup>lt;sup>1</sup>U.S. dollars.

SOURCE: U.S. Department of Health and Human Services federal poverty guidelines, 2013.

Table IV. 2013 federal poverty guidelines for families in Hawaii

Н	ousehold size	Poverty guideline <sup>1</sup>	Fill <sup>1</sup>
2		17,850	17,900
3		22,470	22,500
4		26,510	26,500
5		31,710	31,700
6		36,330	36,300
7		40,950	41,000
8		45,570	45,600
9		50,190	50,200
10		54,810	54,800

<sup>&</sup>lt;sup>1</sup>U.S. dollars.

SOURCE: U.S. Department of Health and Human Services federal poverty quidelines, 2013.

The 2014 guidelines (Tables V–VII) were used for main launch interviews conducted from February 17 through June 25, 2014.

Table V. 2014 federal poverty guidelines for families in the 48 contiguous states and District of Columbia

	Household size	Poverty guideline <sup>1</sup>	Fill <sup>1</sup>
2		15,730	15,700
3		19,790	19,800
4		23,850	23,900
5		27,910	27,900
6		31,970	32,000
7		36,030	36,000
8		40,090	40,100
9		44,150	44,200
10		48,210	48,200

<sup>&</sup>lt;sup>1</sup>U.S. dollars.

SOURCE: U.S. Department of Health and Human Services federal poverty guidelines, 2014.

Table VI. 2014 federal poverty guidelines for families in Alaska

	Household size	Poverty guideline <sup>1</sup>	Fill <sup>1</sup>
2		19,660	19,700
3		24,740	24,700
4		29,820	29,800
5		34,900	34,900
6		39,980	40,000
7		45,060	45,100
8		50,140	50,100
9		55,220	55,200
10		60,300	60,300

<sup>&</sup>lt;sup>1</sup>U.S. dollars.

SOURCE: U.S. Department of Health and Human Services federal poverty guidelines, 2014.

Table VII. 2014 federal poverty guidelines for families in Hawaii

	Household size	Poverty guideline <sup>1</sup>	Fill <sup>1</sup>
2		18,090	18,100
3		22,760	22,800
4		27,430	27,400
5		32,100	32,100
6		36,770	36,800
7		41,440	41,400
8		46,110	46,100
9		50,780	50,800
10		55,450	55,500

<sup>&</sup>lt;sup>1</sup>U.S. dollars.

SOURCE: U.S. Department of Health and Human Services federal poverty guidelines, 2014.

# Appendix VIII. Medicaid and Children's Health Insurance Program Text Fills

In the Services and Support section of the National Survey of Children in Nonparental Care (NSCNC) questionnaire, question S5 fills state-specific Medicaid and Children's Health Insurance Program (CHIP) names based on the respondent's state, as reported in National Survey of Children's Health (NSCH). Item S5, shown below, was administered only when respondents reported that the sampled child was covered by any type of health care coverage at S3\_1:

S5: [Is that coverage/Is [he/she] insured by] Medicaid or the Children's Health Insurance Program, CHIP? In [fill name of state reported in NSCH], the program is sometimes called [FILL MEDICAID NAME, CHIP NAME].

Similarly, in the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome (NSDATA) questionnaire, separate questions on the attention-deficit/hyperactivity disorder (ADHD) and Tourette syndrome (TS) modules each referenced state-specific Medicaid and CHIP program names:

ADHD\_H2\_Q02: IF ADHD\_H2\_Q01=1 THEN FILL "Is that coverage." ELSE, FILL "Is [he/she] insured by] Medicaid or the Children's Health Insurance Program, or CHIP? In this state, the program is sometimes called [FILL MEDICAID NAME, CHIP NAME].

TS\_H2\_Q02: IF TS\_H2\_Q01=1 THEN FILL "Is that coverage". ELSE, FILL "Is [he/she] insured by] Medicaid or the Children's Health Insurance Program, or CHIP? [IF IAP=095, DISPLAY "In this area," ELSE DISPLAY "In this state," the program is sometimes called [FILL MEDICAID NAME, CHIP NAME].

The state-specific Medicaid and CHIP program names used for both NSCNC and NSDATA fills are shown in Table VIII. States could be divided into two classes depending on how they named the expanded or created programs that use Title XXI funds. In 2011–2012, 26 states had distinct Medicaid and CHIP (known as State CHIP or S-CHIP prior to 2011) programs and used different names for each type of program. The remaining 24 states, as well as the District of Columbia, had distinct Medicaid and CHIP programs but used the same (or substantially similar) name for both programs.

Because a single question was asked about both Medicaid and CHIP, survey analysts will not be able to distinguish between Medicaid and CHIP coverage in analyses. Analysts may be required to report on public insurance only.

Table VIII. State-specific program names for Medicaid and CHIP

State	Type of program	Category <sup>1</sup>	Name used with Medicaid questions	Name used with CHIP questions	Name used with combination questions
Alabama	Separate	А	Patient 1st Program or SOBRA	ALL Kids	
Alaska	Medicaid expansion	С			Denali KidCare
Arizona	Separate	А	Arizona Health Care Cost Containment System (AHCCCS) or SOBRA	KidsCare	
Arkansas	Combination	С			ARKids
California	Combination	Α	Medi-Cal	Healthy Families	•••
Colorado	Separate	Α		Child Health Plan Plus (CHP+)	
Connecticut	Separate	С			HUSKY Health or Medical Assistance
Delaware	Combination	Α	Diamond State Health Plan	Delaware Healthy Children Program	

See footnotes at end of table.

Table VIII. State-specific program names for Medicaid and CHIP—Con.

State	Type of program	Category <sup>1</sup>	Name used with Medicaid questions	Name used with CHIP questions	Name used with combination questions
District of Columbia	Medicaid expansion	С			DC Healthy Families or Medical Assistance
Florida	Combination	А		Florida KidCare, which includes Healthy Kids and MediKids	
Georgia	Separate	А	Right from the Start	PeachCare for Kids	
Hawaii	Medicaid expansion	С			Hawaii QUEST
Idaho	Combination	А	Medical Assistance	Idaho Children's Health Insurance Program (CHIP)	
Illinois	Combination	С			All Kids or Medical Assistance
Indiana	Combination	С			Hoosier Healthwise
Iowa	Combination	А	Medical Assistance	Healthy and Well Kids in Iowa (HAWK-I)	
Kansas	Separate	С			HealthWave or Kansas Medical Assistance Program (KMAP)
Kentucky	Combination	С			KyHealth Choices or Family Choices or Kentucky Children's Health Insurance Program (KCHIP)
Louisiana	Combination	А		Louisiana Children's Health Insurance Program (LaCHIP)	
Maine	Combination	С			MaineCare
Maryland	Combination	A	Maryland Medical Assistance	Maryland Children's Health Program (MCHP)	
Massachusetts	Combination	С			MassHealth
Michigan	Combination	А	Healthy Kids or Medical Assistance	MIChild	
Minnesota	Combination	С		•••	Medical Assistance or MinnesotaCare
Mississippi	Separate	A	Medical Assistance	Mississippi Children's Health Insurance Program (CHIP)	
Missouri	Combination	C	•••	•••	MO HealthNet for Kids
Montana	Separate	C			Healthy Montana Kids
Nebraska	Medicaid expansion	С	•••		Kids Connection or Medical Assistance
Nevada	Separate	Α	Child Health Assurance Program (CHAP)	Nevada Check Up	
New Hampshire	Combination	Α	Healthy Kids Gold	Healthy Kids Silver	
New Jersey	Combination	С			NJ FamilyCare
New Mexico	Medicaid expansion	С			New Mexico SALUD! or New MexiKids/New MexiTeens
New York	Separate	Α		Child Health Plus	•••
North Carolina	Separate	А		Health Choice for Children	
North Dakota	Combination	A	•••	Healthy Steps	II. III. O
Ohio	Medicaid expansion	С			Healthy Start and Healthy Families
Oklahoma	Combination	С		•••	SoonerCare

Table VIII. State-specific program names for Medicaid and CHIP—Con.

State	Type of program	Category <sup>1</sup>	Name used with Medicaid questions	Name used with CHIP questions	Name used with combination questions
Oregon	Separate	С			Oregon Healthy Kids or Oregon Health Plan
Pennsylvania	Separate	А		Pennsylvania Children's Health Insurance Program (CHIP)	
Rhode Island	Combination	С			RIteCare or Rhode Island Medical Assistance Program
South Carolina	Combination	С			Healthy Connections Kids or Partners for Healthy Children
South Dakota	Combination	А	Medical Assistance	South Dakota Children's Health Insurance Program (CHIP)	
Tennessee	Combination	Α	TennCare	Tennessee CoverKids	
Texas	Separate	А	Children's Medicaid	Texas Children's Health Insurance Program (CHIP)	
Utah	Separate	А		Utah Children's Health Insurance Program (CHIP)	
Vermont	Separate	Α		Dr. Dynasaur	
Virginia	Combination	С		•••	FAMIS
Washington	Separate	С		•••	Apple Health for Kids or Basic Health Plus
West Virginia	Separate	А	Medical Assistance	West Virginia Children's Health Insurance Program (WVCHIP)	
Wisconsin	Combination	С			BadgerCare Plus or Medical Assistance or Healthy Start
Wyoming	Separate	А	EqualityCare	Wyoming Kid Care or Kid Care CHIP	

SOURCE: Centers for Medicare & Medicaid Services.

<sup>...</sup> Category not applicable.

¹States in category A had distinct programs for Medicaid and Children's Health Insurance Program (CHIP) and used different names for each type of program. States in category C also had distinct programs for Medicaid and CHIP but used the same (or substantially similar) name for both programs. For all cases, a single question about public insurance coverage was asked using the program name(s).

# Appendix IX. NSCNC Nonresponse Bias Analysis

As previously described, the overall response rate for the National Survey of Children in Nonparental Care (NSCNC) was 12.1%. Nonresponse to NSCNC occurred in two stages: nonresponse to the 2011–2012 National Survey of Children's Health (NSCH), and nonresponse to the follow-up NSCNC interview. All of the nonrespondents in the second stage had already completed NSCH, and as a result, a great deal of information was known about these nonrespondents. This has two main implications: First, it was possible to conduct an extensive analysis of the potential for nonresponse bias resulting from the second stage of nonresponse, and second, it was possible to adjust the weights more precisely to correct for nonresponse bias (Appendix I).

Tables IX-XI present a comparison of NSCNC respondents and nonrespondents on selected NSCH data elements. All cases completed NSCH; they are differentiated by whether they responded in the second stage (i.e., whether they responded to NSCNC). For this analysis, NSCNC nonrespondents include all children in nonparental care from the original NSCH sampling frame who are not represented in the final NSCNC interview file, that is, 1) children who were excluded due to aging out of the sample (having reached age 18 before the NSCNC interview) or having moved and been unlocatable at the new address, 2) children from the NSCH guarter 1, 2011, sample who were excluded because of the long duration between interviews, as well as 3) children whose caregivers refused the NSCNC interview. All of these categories of nonresponse were corrected in weighting adjustmentsthe final interview sample is meant to represent the full population as identified in NSCH. The analysis will show whether the weighting adjustments do an adequate job of correcting for bias from all of these children having been excluded.

Table IX shows child-level demographic and health characteristics for NSCNC respondents and nonrespondents, Table X shows household-level socioeconomic and demographic characteristics, and Table XI compares response and nonresponse to NSCH data elements that are topically similar to the kinds of data collected in NSCNC. These tables demonstrate the existence of some significant differences between respondents and nonrespondents on many dimensions.

NSCNC nonrespondents were significantly less likely to be non-Hispanic white children than NSCNC respondents but were more likely to be uninsured (Table IX). In addition, NSCNC nonrespondents were significantly more likely to be from households with an income of \$10,000–\$19,999 and

three or more adults than NSCNC respondents, but were significantly less likely to be from households in the Midwest or households where English was the primary household language (Table X). Finally, NSCNC nonrespondents were significantly more likely than respondents to be children with foster parents, but less likely to be children whose caregivers were nonfoster grandparents (Table XI).

Table IX. Percentage of children in NSCNC, by demographic and health characteristics for respondents and nonrespondents

Child-level characteristic	NSCNC nonrespondents (n = 1,891)	NSCNC respondents (n = 1,298)
Age (years)	Weighted percent	(standard error)
0–5	24.1 (2.57)	25.2 (2.94)
6–11	34.8 (2.51)	34.9 (2.63)
12–16	41.1 (2.57)	39.9 (3.16)
Sex		
Male	50.3 (2.68)	48.2 (3.10)
Female	49.7 (2.68)	51.8 (3.10)
Race and ethnicity		
Non-Hispanic white	†32.7 (2.25)	42.8 (2.94)
Non-Hispanic black	36.3 (2.62)	32.5 (2.98)
Non-Hispanic other or multiracial	10.7 (1.40)	10 4 (1 50)
Hispanic	10.7 (1.49) 20.2 (2.58)	10.4 (1.53) 14.4 (3.02)
•	20.2 (2.30)	14.4 (0.02)
Overall health		
Excellent	41.7 (2.58)	46.6 (3.11)
Very good	34.4 (2.74)	32.6 (2.98)
Good Fair	19.3 (1.99)	16.8 (2.16)
Poor	3.5 (0.72) 1.2 (0.55)	3.1 (0.69) 0.8 (0.36)
Special health care needs	1.2 (0.00)	0.0 (0.00)
Yes	21.7 (0.56)	20.1 (2.00)
No	31.7 (2.56) 68.3 (2.56)	39.1 (3.08) 60.9 (3.08)
Received mental health care in previous year	00.0 (2.00)	00.3 (3.00)
Yes	20.8 (2.26)	18.9 (1.92)
No	79.2 (2.26)	81.1 (1.92)
Type of health insurance		
Public only	74.5 (2.37)	78.1 (2.41)
Any nonpublic	17.3 (1.84)	18.4 (2.25)
None	†8.2 (1.81)	3.5 (1.00)

<sup>†</sup> Estimate differs at the 0.05 level from that of respondents.

NOTE: NSCNC is National Survey of Children in Nonparental Care.

SOURCES: NCHS, National Survey of Children's Health, 2011–2012, and National Survey of Children in Nonparental Care, 2013.

266

Table X. Percentage of children in NSCNC, by household socioeconomic and demographic characteristics for respondents and nonrespondents

•		-
Household-level characteristic	NSCNC nonrespondents (n = 1,891)	NSCNC respondents (n = 1,298)
Total household income	Weighted percent	(standard error)
Less than \$10,000	13.8 (2.12)	13.6 (2.84)
\$10,000-\$19,999	†18.8 (2.09)	12.5 (1.75)
\$20,000–\$39,999	24.5 (1.99)	26.9 (2.53)
\$40,000–\$59,999	16.4 (1.92)	16.1 (2.01)
\$60,000 or more	26.5 (2.51)	30.9 (2.94)
Highest educational attainment		
Less than high school	26.6 (2.59)	22.4 (3.02)
High school or equivalent	30.2 (2.30)	33.1 (2.77)
More than high school	43.2 (2.64)	44.4 (3.06)
Number of adults		
One	25.0 (2.16)	22.4 (3.02)
Two	46.8 (2.66)	33.1 (2.77)
Three or more	†28.2 (2.68)	44.4 (3.06)
Number of children		
One	30.2 (2.16)	36.8 (2.71)
Two	30.2 (2.37)	30.9 (2.80)
Three or more	39.6 (2.79)	32.3 (3.32)
Primary household language		
English	†92.7 (1.73)	98.1 (0.76)
Not English	7.3 (1.73)	1.9 (0.76)
Census region		
Northeast	11.4 (1.55)	10.6 (1.93)
Midwest	†18.4 (1.71)	25.6 (2.66)
South	54.0 (2.66)	50.6 (3.09)
West	16.2 (2.44)	13.2 (1.44)
MSA status		
In MSA	74.0 (2.13)	75.0 (2.35)
Not in MSA	26.0 (2.13)	25.0 (2.35)

<sup>†</sup> Estimate differs at the 0.05 level from that of respondents.

NOTE: NSCNC is National Survey of Children in Nonparental Care, and MSA is metropolitan statistical area.

SOURCES: NCHS, National Survey of Children's Health, 2011–2012, and National Survey of Children in Nonparental Care, 2013.

Tables XII–XIV present estimates for the final NSCNC sample, weighted by the nonresponse-adjusted sampling weights, compared with estimates for the full pool of NSCH cases that were eligible for NSCNC (i.e., the NSCNC respondents and nonrespondents combined—the final NSCNC sample that would have been attained if no second-stage nonresponse existed). After the weighting adjustments described in Appendix I, estimates for NSCNC respondents are close enough to those from the original NSCH-eligible sample that the remaining differences are smaller than sampling error (i.e., not significantly different). Although this is to be expected for characteristics that were used to adjust the weights, such as age, sex, and race and ethnicity, it is also the case for characteristics that were not directly controlled in the adjustment of the sampling weights, presumably because

they are related to the variables that were controlled for in the weighting adjustment.

Of all the characteristics examined, a second-stage nonresponse bias of more than 4 percentage points was found for categories of only two variables: how well the caregiver and child share ideas or talk and the caregiver's mental health. However, none of these biases were greater than the sampling error associated with the estimates. Although this analysis does not necessarily demonstrate that no nonresponse bias derives from second-stage nonresponse, it does show that detectable bias was reduced to nonsignificance by weighting adjustments.

Table XI. Percentage of children in NSCNC, by NSCH characteristics similar to NSCNC data elements for respondents and nonrespondents

Characteristic	NSCNC nonrespondents (n = 1,891)	NSCNC respondents $(n = 1,298)$
Caregiver type	Weighted percent	(standard error)
Foster	†18.4 (2.06)	10.7 (1.76)
Nonfoster, grandparent only	†20.3 (2.01)	32.3 (2.93)
Nonfoster, grandparent and others	38.9 (2.64)	39.3 (2.94)
Nonfoster, not grandparents	22.4 (2.29)	17.7 (2.74)
Type of school		
Public	93.6 (1.50)	94.8 (0.93)
Private	5.1 (1.36)	4.1 (0.85)
Homeschooled Not enrolled	1.0 (0.64) 0.4 (0.26)	0.9 (0.34) 0.1 (0.09)
How well caregiver and child share ideas or talk	0.1 (0.20)	3.1 (0.00)
Very well	63.6 (2.88)	68.9 (2.97)
Somewhat well	28.4 (2.75)	24.6 (2.61)
Not very well	6.0 (1.52)	5.3 (1.78)
Not well at all	2.0 (0.71)	1.2 (0.48)
How well caregiver copes with parenting		
Very well	62.2 (2.67)	60.8 (2.88)
Somewhat well	35.8 (2.67)	36.9 (2.80)
Not very well	1.7 (0.45)	1.0 (0.30)
Not well at all	0.3 (0.12)	1.3 (0.94)
How often caregiver feels child is harder to care for than most children		
Never	54.3 (2.67)	53.5 (3.09)
Rarely	14.2 (1.73)	13.8 (1.75)
Sometimes	19.4 (2.34)	23.9 (2.81)
Usually Always	5.0 (0.92) 7.1 (1.26)	3.2 (0.70) 5.6 (1.43)
How often child does things that bother caregiver	( -1)	
Never	30.8 (2.51)	27.3 (2.75)
Rarely	23.6 (2.14)	25.2 (2.71)
Sometimes	37.8 (2.66)	40.9 (3.07)
Usually	3.6 (0.74)	3.4 (0.72)
Always	4.2 (0.94)	3.2 (1.27)
How often caregiver feels angry with child		
Never	29.4 (2.48)	28.2 (3.04)
Rarely	35.6 (2.65)	30.0 (2.52)
Sometimes	31.4 (2.38)	38.1 (3.07)
Usually Always	2.5 (0.66) 1.2 (0.53)	2.5 (0.92) 1.1 (0.92)
Caregiver has someone to turn to for emotional help with parenting	(* * * * )	(* * /
Yes	84.3 (1.83)	79.9 (2.91)
No	15.7 (1.83)	20.1 (2.91)
Caregiver's general health		
Excellent	14.2 (1.55)	15.5 (2.09)
Very good	32.8 (2.58)	29.0 (2.89)
Good	31.4 (2.61)	36.6 (3.06)
Fair	17.4 (1.92)	14.8 (2.13)
Poor	4.2 (0.86)	4.1 (0.88)

See footnotes at end of table.

Table XI. Percentage of children in NSCNC, by NSCH characteristics similar to NSCNC data elements for respondents and nonrespondents—Con.

Characteristic	NSCNC nonrespondents $(n = 1,891)$	NSCNC respondents (n = 1,298)
Caregiver's mental health		
Excellent	25.6 (2.34)	23.8 (2.43)
Very good	32.6 (2.52)	39.7 (3.06)
Good	32.0 (2.54)	29.1 (2.93)
Fair	8.7 (1.35)	7.0 (1.69)
Poor	1.1 (0.52)	0.3 (0.17)

<sup>†</sup> Estimate differs at the 0.05 level from that of respondents.

NOTE: NSCNC is National Survey of Children in Nonparental Care and NSCH is National Survey of Children's Health.

Table XII. Percentage of children in final NSCNC weighted sample and comparable population as estimated by NSCH, by demographic and health characteristics

Child-level characteristic	NSCH children in nonparental care (n = 3,189)	NSCNC children in nonparental care (n = 1,298)
Age (years)	Weighted percent (95% CI)	
0–5	24.5 (20.8-28.5)	24.6 (19.0-31.2)
6–11	34.9 (31.3–38.6)	35.0 (29.6–40.7)
12–16	40.7 (36.8–44.6)	40.4 (33.8–47.5)
Sex		
Male	49.5 (45.5-53.5)	49.2 (42.5-55.9)
Female	50.5 (46.5–54.5)	50.8 (44.1–57.5)
Race and ethnicity		
Non-Hispanic white	36.3 (32.9-39.9)	36.3 (31.0-42.0)
Non-Hispanic black	35.0 (31.2–39.0)	35.1 (29.2–41.4)
Non-Hispanic other or multiracial	10.6 (8.6-13.0)	9.9 (7.0-13.8)
Hispanic	18.1 (14.6–22.3)	18.7 (13.3–25.7)
Overall health		
Excellent	43.4 (39.6-47.4)	45.5 (39.0-52.2)
Very good	33.8 (29.9–37.9)	33.7 (27.6–40.4)
Good	18.4 (15.7–21.5)	17.2 (13.0–22.3)
Fair	3.3 (2.4–4.5)	2.8 (1.7–4.5)
Poor	1.1 (0.5–2.1)	0.8 (0.4–1.9)
Special health care needs		
Yes	34.4 (30.6-38.4)	38.1 (31.7-44.9)
No	65.6 (61.6–69.4)	61.9 (55.1–68.3)
Received mental health care in previous year		
Yes	20.1 (17.2–23.5)	18.2 (14.6–22.5)
No	79.9 (76.5–82.8)	81.8 (77.5–85.4)
Type of health insurance		
Public only	75.8 (72.2–79.1)	76.5 (69.7-82.1)
Any nonpublic	17.7 (15.1–20.7)	18.9 (14.0–25.1)
None	6.5 (4.5–9.4)	4.7 (2.2–9.7)

NOTES: NSCNC is National Survey of Children in Nonparental Care, NSCH is National Survey of Children's Health, and CI is confidence interval. Eligiblity for sampling was determined using the original NSCH sample.

Table XIII. Percentage of children in final NSCNC weighted sample and comparable population as estimated by NSCH, by household socioeconomic and demographic characteristics

Household-level characteristic	NSCH children in nonparental care (n = 3,189)	NSCNC children in nonparental care (n = 1,298)
Total household income	Weighted per	cent (95% CI)
ess than \$10,000	13.7 (10.7–17.4)	13.6 (8.9-20.3)
610,000–\$19,999	16.5 (13.8–19.7)	12.5 (9.3–16.6)
\$20,000–\$39,999	25.4 (22.4–28.6)	28.2 (22.9-34.3)
\$40,000–\$59,999	16.3 (13.7–19.3)	15.2 (11.6–19.7)
\$60,000 or more	28.1 (24.5–32.0)	30.4 (24.3–37.3)
Highest educational attainment		
ess than high school	25.1 (21.4-29.2)	22.8 (17.1-29.7)
ligh school or equivalent	31.2 (27.9–34.8)	32.9 (27.4–39.0)
Nore than high school	43.7 (39.8–47.6)	44.4 (37.7–51.3)
Number of adults		
One	26.3 (23.0-29.9)	28.2 (22.4-34.9)
Гwo	48.1 (44.1–52.1)	48.6 (41.8-55.4)
Three or more	25.6 (22.0–29.5)	23.2 (18.0–29.3)
Number of children		
One	32.6 (29.3-36.0)	32.4 (27.4-37.9)
wo	30.4 (27.0-34.1)	31.7 (26.1–37.8)
hree or more	37.0 (32.9–41.3)	35.9 (29.4–42.9)
Primary household language		
English	94.6 (91.8-96.5)	97.4 (93.8-99.0)
Not English	5.4 (3.5-8.2)	2.6 (1.0–6.2)
Census region		
Vortheast	11.1 (9.0-13.7)	11.4 (8.4–15.3)
Midwest	20.9 (18.2-24.0)	20.9 (17.1–25.3)
South	52.8 (48.8–56.7)	52.6 (47.5–57.6)
Vest	15.1 (12.2–18.7)	15.1 (12.8–17.7)
MSA status		
n MSA	74.4 (71.1–77.4)	76.9 (72.1–81.1)
Not in MSA	25.6 (22.6–28.9)	23.1 (19.0–27.9)

NOTE: NSCNC is National Survey of Children in Nonparental Care, NSCH is National Survey of Children's Health, CI is confidence interval, and MSA is metropolitan statistical area.

Table XIV. Percentage of children in final NSCNC weighted sample and comparable population as estimated by NSCH, by NSCH characteristics similar to NSCNC data elements

Characteristic	NSCH children in nonparental care (n = 3,189)	NSCNC children in nonparental care (n = 1,298)
Corogiver type		· · · · · · · · · · · · · · · · · · ·
Caregiver type		rcent (95% CI)
Foster	15.6 (13.0–18.7)	14.5 (10.4–19.8)
Nonfoster, grandparent only	24.6 (21.4–28.1)	25.7 (20.3–32.0)
Nonfoster, grandparent and others	39.1 (35.2–43.0)	38.0 (32.5–43.8)
Nonfoster, not grandparents	20.7 (17.5–24.4)	21.8 (16.0–28.9)
Type of school		
Public	94.0 (91.6-95.7)	94.4 (91.1-96.5)
Private	4.7 (3.2–6.9)	4.7 (2.7–8.0)
Homeschooled	1.0 (0.4–2.3)	0.8 (0.4–1.7)
Not enrolled	0.3 (0.1–1.0)	0.1 (0.0–0.4)
How well caregiver and childshare ideas or talk		
Very well	65.5 (61.1–69.6)	71.6 (65.4–77.0)
Somewhat well	27.0 (23.3–31.2)	23.2 (18.3–29.0)
Not very well	5.8 (3.9–8.5)	4.3 (2.2–8.3)
Not well at all	1.7 (1.0–3.0)	0.9 (0.4–1.8)
How well caregiver copes with parenting	( /	- ( )
Very well	61.7 (57.7–65.5)	62.7 (56.7–68.3)
Somewhat well		,
	36.2 (32.4–40.2)	35.3 (29.8–41.3)
Not very well	1.5 (1.0–2.2)	0.8 (0.4–1.4)
Not well at all	0.6 (0.2–1.8)	1.2 (0.3–5.0)
How often caregiver feels child is harder to care for than most children		
Never	54.0 (50.0-58.0)	54.3 (47.6–60.9)
Rarely	14.0 (11.7–16.7)	13.3 (9.9–17.5)
Sometimes	21.0 (17.6–24.7)	23.2 (17.9–29.5)
Usually	4.4 (3.3–5.8)	2.8 (1.9–4.2)
Always	6.6 (4.9–8.7)	6.4 (3.8–10.6)
How often child does things that bother caregiver		
Never	29.6 (26.0-33.4)	30.5 (24.4–37.3)
Rarely	24.2 (21.0–27.6)	24.1 (18.8–30.4)
Sometimes	38.9 (35.0–42.9)	39.4 (33.3–45.8)
Usually	3.6 (2.6–4.8)	3.2 (2.0–4.9)
Always	3.8 (2.6–5.6)	2.9 (1.3–6.1)
•	0.0 (2.0 0.0)	2.0 (1.0 0.1)
How often caregiver feels angry with child  Never	29.0 (25.3–32.9)	29.3 (22.9–36.5)
Rarely	33.6 (29.9–37.5)	30.0 (24.7–35.9)
Sometimes		'
	33.8 (30.2–37.6)	37.3 (31.0–44.1)
Usually Always	2.5 (1.6–3.8) 1.2 (0.5–2.6)	2.3 (1.2–4.4) 1.1 (0.2–5.2)
Caregiver has someone to turn to for	1.2 (0.0 2.0)	1.1 (0.2 0.2)
emotional help with parenting	00.7 (70.4.05.6)	70.0 (70.1.05.1)
Yes No	82.7 (79.4–85.6) 17.3 (14.4–20.6)	79.8 (73.1–85.1) 20.2 (14.9–26.9)
	17.5 (14.4-20.0)	20.2 (14.3-20.3)
Caregiver's general health	447/404 470	47.4 (40.4.00.4)
Excellent	14.7 (12.4–17.3)	17.1 (12.4–23.1)
Very good	31.5 (27.8–35.4)	28.3 (22.4–35.1)
Good	33.2 (29.4–37.3)	35.0 (28.8–41.7)
Fair	16.5 (13.8–19.5)	15.2 (11.4–20.0)
Poor	4.1 (3.1–5.6)	4.5 (2.7–7.4)

See footnotes at end of table.

Table XIV. Percentage of children in final NSCNC weighted sample and comparable population as estimated by NSCH, by NSCH characteristics similar to NSCNC data elements—Con.

Characteristic	NSCH children in nonparental care (n = 3,189)	NSCNC children in nonparental care (n = 1,298)
Caregiver's mental health		
Excellent	23.9 (21.7–28.5)	25.9 (20.4-32.2)
Very good	35.2 (31.4–39.1)	39.7 (33.2–46.6)
Good	30.9 (27.3–34.9)	27.6 (22.1–33.9)
Fair	8.1 (6.3–10.4)	6.5 (4.0–10.2)
Poor	0.9 (0.4–1.9)	0.3 (0.1–0.8)

NOTES: NSCNC is National Survey of Children in Nonparental Care, NSCH is National Survey of Children's Health, and CI is confidence interval. Eligiblity for sampling was determined using the original NSCH sample.

# Appendix X. NSDATA Nonresponse Bias Analysis

As with the analysis described in Appendix IX, the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome (NSDATA) nonresponse bias analysis makes use of National Survey of Children's Health (NSCH) variables that are available for all cases, NSDATA respondents and nonrespondents alike, to investigate the magnitude of the second-stage nonresponse to the follow-up survey.

NSDATA nonresponse bias analysis was limited to refer to the children who ever had ADHD in the 2011-2012 NSCH (i.e., only those who appear on the public file). The Tourette syndrome (TS) data did not include enough cases to adequately form adjustment cells for weighting adjustments, so it is not expected that the final TS weights adequately correct for any nonresponse bias that may be present in the TS module. Among NSCH children sampled for the NSDATA attention-deficit/hyperactivity disorder (ADHD) module, those who completed the ADHD module were considered respondents (i.e., completed interviews). All other cases that did not complete the NSDATA ADHD module were considered nonrespondents in this analysis. Those who were sampled for the NSDATA ADHD module but completed only the NSDATA TS module were also considered as nonrespondents in this analysis.

Tables XV-XVII present a comparison of ADHD module respondents and nonrespondents on selected NSCH data elements. As noted earlier, all cases in these tables completed NSCH; however, they are differentiated by whether they responded in the second stage (i.e., whether they responded to the ADHD module). Table XV presents childlevel demographics and health characteristics, Table XVI displays household-level socioeconomic and demographic characteristics, and Table XVII shows NSCH data elements that are topically similar to the kind of data collected in the NSDATA ADHD module. These tables demonstrate that significant differences exist between respondents and nonrespondents on some dimensions. Nonrespondent cases were more likely to be non-Hispanic black children, less likely to have special health care needs, and more likely to have public insurance (Table XV). In terms of household-level characteristics, nonrespondent cases were significantly more likely to live in lower-income households, in households where the educational attainment of any adult was at most high school or equivalent, and in households with one adult (Table XVI). Among the NSCH variables that are topically similar to data elements in the ADHD module, children in nonrespondent households were less likely to need or use more medical or educational services, to receive mental

health treatment, and to have more than one personal doctor or nurse (Table XVII).

Tables XVIII—XX present estimates for the final NSDATA ADHD sample, weighted by the final ADHD weights, compared with estimates for all NSCH children who had ever been diagnosed with ADHD. A limited number of eligible cases from NSCH were not released for data collection due to the age of that sample at the time of the NSDATA survey (quarter 1, 2011, cases). Other children were excluded because they had reached age 18 by the time of the NSDATA data collection.

Table XV. Percentage of children in NSDATA ADHD module, by demographic and health characteristics for respondents and nonrespondents

Child-level characteristic	NSDATA nonrespondents (n = 3,068)	NSDATA respondents (n = 2,966)
Age (years)	Weighted percentag	e (standard error)
2–9	35.7 (1.81)	32.9 (1.89)
10-12	29.5 (1.81)	34.2 (2.00)
13–15	34.8 (1.84)	32.9 (1.93)
Sex		
Male	69.0 (1.77)	71.3 (1.88)
Female	31.0 (1.77)	28.7 (1.88)
Race and ethnicity		
Hispanic	15.1 (1.70)	14.2 (2.03)
Non-Hispanic black	†16.7 (1.49)	12.1 (1.31)
Non-Hispanic other	68.3 (1.95)	73.7 (2.15)
Overall health		
Excellent	45.8 (1.92)	47.6 (2.05)
Very good	31.2 (1.74)	28.5 (1.78)
Good	17.2 (1.56)	16.1 (1.44)
Fair	4.5 (0.66)	6.2 (1.50)
Poor	1.2 (0.74)	1.7 (0.57)
Child has special health care needs		
Yes	†77.1 (1.51)	82.6 (1.52)
No	†22.9 (1.51)	17.4 (1.52)
Type of health insurance		
Public only	†57.2 (1.89)	41.7 (2.09)
Any nonpublic	†38.5 (1.84)	55.0 (2.09)
None	4.3 (0.80)	3.3 (0.88)

<sup>†</sup> Estimates differ at the 0.05 level from that of respondents.

NOTE: NSDATA is National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome and ADHD is attention-deficit/hyperactivity disorder

Table XVI. Percentage of children in NSDATA ADHD module, by household socioeconomic and demographic characteristics for respondents and nonrespondents

Household-level characteristic	NSDATA nonrespondents (n = 3,068)	NSDATA respondents (n = 2,966)
Total household income	Weighted percentag	e (standard error)
Less than \$10,000	†12.2 (1.30)	7.7 (1.21)
\$10,000–\$19,999	†15.0 (1.37)	7.8 (1.08)
\$20,000-\$39,999	21.5 (1.52)	20.0 (1.67)
\$40,000-\$59,999	16.6 (1.41)	17.3 (1.70)
\$60,000 or more	†34.8 (1.85)	47.2 (2.04)
Highest educational attainment		
Less than high school	†11.1 (1.22)	7.6 (1.21)
High school or equivalent	†30.1 (1.82)	19.3 (1.67)
More than high school	†58.9 (1.92)	73.1 (1.89)
Number of adults		
One	†22.5 (1.53)	18.1 (1.60)
Two	†58.5 (1.86)	64.0 (1.96)
Three or more	19.0 (1.45)	17.9 (1.50)
Number of children		
One	21.0 (1.29)	22.6 (1.32)
Two	39.8 (1.89)	36.1 (1.90)
Three or more	39.2 (1.96)	41.3 (2.17)
Primary household language		
English	95.4 (1.04)	95.8 (1.40)
Not English	4.6 (1.04)	4.2 (1.40)
Census region		
Northeast	14.3 (1.13)	15.6 (1.26)
Midwest	23.6 (1.29)	24.3 (1.38)
South	42.7 (1.76)	42.8 (1.96)
West	19.4 (1.91)	17.2 (1.83)
MSA status		
In MSA	79.8 (1.25)	82.6 (1.31)
Not in MSA	20.2 (1.25)	17.4 (1.31)

<sup>†</sup> Estimates differ at the 0.05 level from that of respondents.

NOTE: NSDATA is National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, ADHD is attention-deficit/hyperactivity disorder, and NSCH is National Survey of Children's Health.

SOURCES: NCHS, National Survey of Children's Health, 2011–2012, and National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, 2014.

Weighting adjustments described in Appendix II were designed to account for these types of nonresponse as well, and the analysis shows how well the weighting adjustments did in mitigating bias from all types of nonresponse.

NSDATA estimates for the ADHD module respondents, weighted by the final ADHD module weights, are close to the estimates for the full pool of NSDATA-eligible cases for most of the characteristics studied. Most comparisons are so close that the remaining difference is negligible. Although this is to be expected for the characteristics that were used to adjust the weights (e.g., age and sex of the child), it is also the case for some characteristics that were not directly controlled in the adjustment of the sampling weights,

presumably because they are related to the variables that were controlled for in the weighting adjustment. Although most of the differences found in Tables XVIII–XX are small, a small number of differences are statistically significant:

- Among the child-level characteristics in Table XVIII, compared with the NSCH estimate, the proportion of children with public insurance was underestimated by 2.7 percentage points, and the proportion of children with nonpublic insurance was overestimated by 3.1 percentage points in the NSDATA ADHD module.
- Among the household-level characteristics in Table XIX, the proportion of children in households with only one child was overestimated by 5.0 percentage points, the proportion of children in households with three or more children was underestimated by 3.4 percentage points, and the proportion of children living in a metropolitan statistical area was underestimated by 1.6 percentage points in the NSDATA ADHD module.
- Among the NSCH variables that are topically similar to the NSDATA ADHD module (Table XX), the proportion of children who have more than one person considered to be a personal doctor or nurse was overestimated by 3.2 percentage points, and the proportion of children with no personal doctor or nurse was underestimated by 2.7 percentage points.

This analysis shows that although differences exist between NSDATA ADHD module respondents and nonrespondents for some measures, weighting adjustments mitigated the differences such that only a few characteristics showed a difference larger than sampling error, and only one estimate was found with a bias larger than 4 percentage points.

Table XVII. Percentage of children in NSDATA ADHD module, by NSCH characteristics similar to NSDATA ADHD data elements for respondents and nonrespondents

Characteristic	NSDATA nonrespondents (n = 3,068)	NSDATA respondents (n = 2,966)
Taken any medication in past 12 months due to difficulties with emotions, concentration, or behavior	Weighted percentaç	ge (standard error)
Yes No	20.8 (2.73) 79.2 (2.73)	18.4 (2.20) 81.6 (2.20)
Needs or uses more medical care, mental health, or educational services than most children of same age		
Yes No	†50.4 (1.94) †49.6 (1.94)	57.6 (2.01) 42.4 (2.01)
Has written intervention plan		
Yes No	41.2 (1.86) 58.8 (1.86)	44.3 (2.04) 55.7 (2.04)
Received mental health treatment		
Yes No	†42.8 (1.90) †57.2 (1.90)	49.0 (2.07) 51.0 (2.07)
Number of times school contacted parents about any problems in school		
Never	31.3 (1.81)	33.3 (2.01)
One to six times Seven times or more	48.4 (2.04) 20.3 (1.65)	45.8 (2.11) 20.9 (1.87)
Needed health care but was delayed or did not receive		
Yes No	12.1 (1.14) 87.9 (1.14)	12.2 (1.34) 87.9 (1.34)
Has one or more persons thought of as personal doctor or nurse		
Yes, one person	54.7 (1.91)	55.1 (2.04)
Yes, more than one person No	†34.2 (1.71) †11.2 (1.46)	39.4 (1.95) 5.6 (1.25)
How much of a problem was it to get the care from the specialists that child needed?		
Big problem	13.4 (2.44)	15.5 (2.52)
Small problem Not a problem	16.9 (2.06) 69.8 (2.87)	16.8 (2.36) 67.7 (3.02)
Received therapy services to meet developmental needs		
Yes No	88.6 (2.27) 11.4 (2.27)	90.9 (2.07) 9.1 (2.07)
Ever told child has behavioral or conduct problems	, ,	( - /
Yes	29.3 (1.79)	29.2 (1.98)
No	70.7 (1.79)	70.8 (1.98)

 $<sup>\</sup>dagger$  Estimates differ at the 0.05 level from that of respondents.

NOTE: NSDATA is National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, ADHD is attention-deficit/hyperactivity disorder, and NSCH is National Survey of Children's Health.

Table XVIII. Percentage of children in final NSDATA ADHD module weighted sample and comparable population as estimated by NSCH, by demographic and health characteristics

Child-level characteristic	NSCH children with ADHD (n = 6,696)	NSDATA respondents (n = 2,966)
Age (years)	Weighted perce	entage (95% CI)
2–9	34.6 (32.1-37.1)	34.6 (31.5-37.6)
10–12	31.2 (28.7–33.7)	31.2 (28.3–34.1)
13–15	34.2 (31.8–36.7)	34.2 (31.2–37.3)
Sex		
Male	70.1 (67.7-72.4)	70.1 (67.2-73.0)
Female	29.9 (27.6–32.3)	29.9 (27.0–32.9)
Race and ethnicity		
Hispanic	15.2 (12.7-17.6)	15.2 (12.6-17.7)
Non-Hispanic black	14.8 (13.0–16.7)	14.8 (12.4–17.2)
Non-Hispanic other	70.0 (67.3–72.7)	70.0 (66.9–73.1)
Overall health		
Excellent	46.2 (43.6-48.8)	45.9 (42.8-49.1)
Very good	30.7 (28.3–33.1)	29.2 (26.4–32.1)
Good	16.4 (14.5–18.4)	17.9 (15.4–20.5)
Fair	5.2 (3.9–6.6)	5.3 (3.7–6.8)
Poor	1.5 (0.6–2.3)	1.7 (0.7–2.6)
Special health care needs		
Yes	79.7 (77.7–81.6)	79.8 (77.2–82.4)
No	20.3 (18.4–22.3)	20.2 (17.6–22.8)
Type of health insurance		
Public only	†49.4 (46.7–52.0)	46.7 (43.5-49.9)
Any nonpublic	†46.8 (44.2–49.4)	49.9 (46.7–53.0)
None	3.8 (2.8–4.9)	3.5 (2.2–4.7)

<sup>†</sup> Estimates differ at the 0.05 level from that of NSDATA respondents.

NOTE: NSDATA is National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, ADHD is attention-deficit/hyperactivity disorder, NSCH is National Survey of Children's Health, and CI is confidence interval.

Table XIX. Percentage of children in final NSDATA ADHD module weighted sample and comparable population as estimated by NSCH, by household socioeconomic and demographic characteristics

Household-level characteristic	NSCH children with ADHD (n = 6,696)	NSDATA respondents (n = 2,966)
Total household income	Weighted perce	entage (95% CI)
Less than \$10,000	9.8 (8.2-11.4)	9.6 (7.5-11.8)
\$10,000-\$19,999	11.4 (9.7–13.0)	11.9 (9.6–14.2)
\$20,000-\$39,999	21.0 (18.9–23.1)	21.6 (18.9–24.4)
\$40,000-\$59,999	16.6 (14.5–18.6)	16.4 (14.1–18.7)
\$60,000 or more	41.3 (38.7–43.8)	40.5 (37.5–43.5)
Highest educational attainment		
Less than high school	9.6 (8.0-11.2)	9.4 (7.3-11.6)
High school or equivalent	24.7 (22.4–27.0)	24.8 (21.9–27.8)
More than high school	65.7 (63.2–68.3)	65.7 (62.5–69.0)
Number of adults		
One	20.1 (18.0-22.1)	21.1 (18.3-23.8)
Two	61.3 (58.8–63.8)	60.2 (57.1–63.4)
Three or more	18.7 (16.7–20.6)	18.7 (16.3–21.1)
Number of children		
One	†21.6 (19.9–23.3)	26.6 (24.0-29.2)
Two	38.3 (35.8–40.9)	36.7 (33.6–39.7)
Three or more	†40.1 (37.3–42.8)	36.7 (33.5–39.9)
Primary household language		
English	95.5 (94.0-97.1)	96.4 (95.0-97.8)
Not English	4.5 (2.9–6.0)	3.6 (2.2–5.0)
Census region		
Northeast	15.6 (14.1-17.1)	15.6 (13.6-17.6)
Midwest	23.2 (21.7–24.8)	23.2 (21.1–25.3)
South	43.6 (41.3–45.8)	43.6 (40.9–46.2)
West	17.6 (15.2–20.0)	17.6 (15.6–19.6)
MSA status		
In MSA	†82.0 (80.4-83.7)	80.4 (78.0-82.8)
Not in MSA	†18.0 (16.3–19.6)	19.6 (17.2–22.0)

<sup>†</sup> Estimates differ at the 0.05 level from that of NSDATA respondents.

NOTE: NSDATA is National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, ADHD is attention-deficit/hyperactivity disorder, NSCH is National Survey of Children's Health, CI is confidence interval, and MSA is metropolitan statistical area.

Table XX. Percentage of children in final NSDATA ADHD module weighted sample and comparable population as estimated by NSCH, by NSCH characteristics similar to NSDATA ADHD data elements

Characteristic	NSCH children with ADHD $(n = 6,696)$	NSDATA respondents $(n = 2,966)$
Taken any medication in past 12 months due to difficulties with emotions, concentration, or behavior	Weighted percer	ntage (95% CI)
Yes No	19.5 (16.1–22.9) 80.5 (77.1–83.9)	19.5 (15.6–23.4) 80.5 (76.6–84.4)
Needs or uses more medical care, mental health, or educational services than most children of same age		
Yes	54.0 (51.4-56.6)	55.0 (51.8-58.1)
No	46.0 (43.4–48.6)	45.0 (41.9–48.2)
Has written intervention plan		
Yes	43.0 (40.4–45.6)	43.8 (40.6–46.9)
No	57.0 (54.4–59.6)	56.2 (53.1–59.4)
Received mental health treatment		
Yes	46.2 (43.6–48.9)	46.9 (43.7–50.0)
No	53.8 (51.1–56.4)	53.1 (50.0–56.3)
Number of times school contacted parents about any problems in school		
Never	32.0 (29.5–34.5)	32.0 (29.0–35.1)
One to six times Seven times or more	47.1 (44.4–49.8) 20.9 (18.5–23.2)	47.1 (43.8–50.4) 20.9 (18.1–23.7)
Needed health care but was delayed or did not receive	20.9 (10.3–23.2)	20.9 (10.1–23.7)
Yes	12.2 (10.5–13.9)	12.2 (10.2–14.3)
No	87.8 (86.1–89.5)	87.8 (85.7–89.8)
Has one or more persons thought of as personal doctor or nurse		
Yes, one person	55.0 (52.4-57.5)	54.4 (51.3-57.6)
Yes, more than one person	†36.7 (34.3–39.1)	39.9 (36.8–43.0)
No	†8.4 (6.6–10.1)	5.7 (4.1–7.2)
How much of a problem was it to get the care from the specialists that child needed?		
Big problem	14.3 (11.0–17.6)	15.2 (11.1–19.2)
Small problem Not a problem	16.6 (13.8–19.5) 69.1 (65.2–73.0)	17.3 (13.5–21.1) 67.5 (62.6–72.4)
·	09.1 (00.2–73.0)	01.3 (02.0-12.4)
Received therapy services to meet developmental needs		
Yes No	89.6 (86.8–92.4) 10.4 (7.6–13.3)	89.7 (85.9–93.5) 10.3 (6.5–14.1)
Ever told child has behavioral or conduct problems	10.4 (1.0-13.3)	10.5 (0.5–14.1)
Yes	29.3 (26.9–31.8)	29.3 (26.3–32.2)
No	70.7 (68.2–73.1)	70.8 (67.8–73.7)

<sup>†</sup> Estimates differ at the 0.05 level from that of NSDATA respondents.

NOTE: NSDATA is National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, ADHD is attention-deficit/hyperactivity disorder, NSCH is National Survey of Children's Health, and CI is confidence interval.

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