

Attachment A:
2014 NS-DATA
Telephone Questionnaire

NATIONAL SURVEY OF THE DIAGNOSIS AND TREATMENT OF ATTENTION DEFICIT HYPERACTIVITY DISORDER AND TOURETTE SYNDROME

The following public burden estimate statement will be available as a CATI screen:

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, "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 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?

(1) YES, SPEAKING WITH THAT PERSON, RECORDING OK <IF RDD_NCELL_CCELL=1 THEN GO TO S1; IF RDD_NCELL_CCELL=2, 3 THEN GO TO S_WARM>

(2) YES, SPEAKING WITH THAT PERSON, REFUSED RECORDING <IF RDD_NCELL_CCELL=1 THEN GO TO S1; IF RDD_NCELL_CCELL=2, 3 THEN GO TO S_WARM>

(3) YES, NEW PERSON COMES TO PHONE <GO TO INTRO2>

- (4) NO, NOT AVAILABLE NOW <SET GCB AND TERMINATE>
- (5) NO, PERSON HAS MOVED OR HAS NEW PHONE NUMBER <GO TO LOC_A>
- (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 <GO TO MOVED>

R_TYPE IF INTRO_1=1 OR INTRO_1=2 AND INTRO_2=1 THEN DISPLAY,

INTERVIEWER INTRUCTION: DID THE RESPONDENT INDICATE HIS/HER RELATIONSHIP TO SC? 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 SC

If RDD_NCCELL_CCELL=1, GO TO S1; ELSE IF RDD_NCCELL_CCELL=2,3 GO TO S_WARM

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 [GO TO S1]
- (2) R UNABLE TO CONTINUE [GO TO S_ATTEN]
- (3) NOT A CELL PHONE [GO TO S1]

S_ATTEN For your safety, we will call you back at another time.

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

- (1) CALL BACK ANOTHER TIME
- (2) CALL BACK AT ANOTHER NUMBER REQUESTED
- (3) WRONG TIME ZONE FOR CELL PHONE [GO TO CELL_TZ_1]
- (4) GO BACK TO S_WARM

CELL_TZ_1 In what time zone would you like to be called?

- (1) ATLANTIC TIME [Change TZ variable to 58 and GO TO CB1]
- (2) EASTERN STANDARD TIME [Change TZ variable to 62 and GO TO CB1]
- (3) CENTRAL STANDARD TIME [Change TZ variable to 65 and GO TO CB1]
- (4) STANDARD MOUNTAIN TIME [Change TZ variable to 69 and GO TO CB1]

- (5) US STANDARD MOUNTAIN TIME (ARIZONA) [Change TZ variable to 68 & GO TO CB1]
- (6) PACIFIC STANDARD TIME [Change TZ variable to 70 and GO TO CB1]
- (7) ALASKAN STANDARD TIME [Change TZ variable to 71 and GO TO CB1]
- (8) HAWAIIAN STANDARD TIME [Change TZ variable to 72 and GO TO CB1]
- (10) Go Back to INTRO_1 [GO TO INTRO_1 ELSE GO TO N_INTRO1]
- (12) RESPONDENT DOESN'T KNOW/KEEP OLD TIME ZONE [GO TO CB1]

S1 Am I speaking to someone [IF RDD_NCCELL_CCELL=1 "who lives in this household"] who is over 17 years old?

IF THE RESPONDENT SAYS NO: ASK TO SPEAK WITH SOMEONE OVER 17 WHO LIVES IN THE HOUSEHOLD.

- (1) YES [GO TO INTRO3]
- (2) NEW PERSON COMES TO PHONE [GO TO INTRO2]
- (3) NO, NOT AVAILABLE NOW [SET GCB AND TERMINATE]

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?

UNKNOWN_EXIT Thank you for your time. Have a nice day.

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 ___-___-_____

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 [GO TO LOC_D]
- (2) NO [GO TO LOC_F]
- (77) DON'T KNOW [GO TO LOC_F]
- (99) REFUSED [GO TO LOC_F]

LOC_D What is that telephone number?

RECORD NUMBER ____ - ____ - _____

- (77) DON'T KNOW
- (99) REFUSED

IF NUMBER RECORDED, SET NEWPHONE2_FLAG=1
SKIP TO LOC_F IF NONE/DK/RF.

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?

RECORD VERBATIM RESPONSE

- (77) DON'T KNOW
- (99) REFUSED

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?

IF INTRO_1= 7 OR INTRO_2=7, OR R_TYPE=1, AUTOMATICALLY FILL
LOC_TYPE=2 AND SKIP LOC_TYPE.

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

ON NEXT CALL, FOLLOW INTRO PATH IF LOC_TYPE=1; FOLLOW
NEWINTRO PATH IF LOC_TYPE=2,77,99

LOC_G What is your name?

RECORD VERBATIM RESPONSE. 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.

(77) DON'T KNOW
(99) REFUSED

GO TO LOC_EXIT

LOC_EXIT Thank you for providing contact information for [S.C.]'s caregiver. We will
attempt to contact [him/her] as soon as possible to discuss this important survey.
Thank you for your time and have a nice day.

SET CALLING RULES TO IMMEDIATELY DIAL THE NUMBER ENTERED
AT LOC_AA; SET RDD_NCCELL_CCELL=(1 OR 2 BASED ON LOC_B).
SET CALLING RULES TO TRY THE NUMBER ENTERED AT LOC_D IF
LOC_AA IS NOT SUCCESSFUL.

IF CASE IS ORIGINAL RESPONDENT (LOC_TYPE=1) AT NEW NUMBER, CALL NEW
NUMBER AND GO TO INTRO1; IF CASE IS NEW RESPONDENT (LOC_TYPE=2), CALL
NEW NUMBER AND GO TO NEWINTRO_1.

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 [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. For quality assurance, this call may be monitored or recorded. 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, RECORDING OK <IF
RDD_NCCELL_CCELL=1 THEN GO TO S1; IF RDD_NCCELL_CCELL=2, 3
THEN GO TO S_WARM; CONTINUE TO NEWINTRO_2>
(2) YES, SPEAKING WITH THAT PERSON, REFUSED RECORDING <IF
RDD_NCCELL_CCELL=1 THEN GO TO S1; IF RDD_NCCELL_CCELL=2, 3
THEN GO TO S_WARM; CONTINUE TO NEWINTRO_2>

- (3) YES, NEW PERSON COMES TO PHONE <REPEAT NEWINTRO_1>
- (4) NO, NOT AVAILABLE NOW <SET GCB AND TERMINATE>
- (5) HOW DID YOU GET MY NUMBER? <GO TO NEWINTRO_2>
- (6) NO, PERSON HAS MOVED OR HAS NEW PHONE NUMBER <GO TO LOC_A>
- (7) DO NOT KNOW THIS PERSON <GO TO UNKNOWN>
- (8) NO, PERSON IS DECEASED <GO TO DECEASEDP>
- (9) NO, CHILD IS DECEASED <GO TO DECEASED>
- (10) CHILD NO LONGER LIVES IN HOUSE WITH R <GO TO MOVED>

NEWINTRO_2. In [INTERVIEW MONTH AND YEAR], 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 re-contacted 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, or with another parent or guardian of the child. 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 <GO TO LOC_A>
- (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 <GO TO MOVED>

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

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?

- (1) YES <GO TO LOC_A>
- (2) NO [TERMINATE]

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 [TERMINATE]

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 [TERMINATE]

INTRO_2 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). 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, or with another parent or guardian of the child. For quality assurance, this call may be monitored or recorded. Is this person available?

- (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 <REPEAT INTRO2>
- (3) NO, NOT AVAILABLE NOW <SET GCB AND TERMINATE>
- (5) NO, PERSON HAS MOVED OR HAS NEW PHONE NUMBER <GO TO LOC_A>
- (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 <GO TO MOVED>

NEWINTRO3. IF TS_SAMPLED=1 DISPLAY:

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.

ELSE IF TS_SAMPLED=0 AND ADHD_SAMPLED=1 DISPLAY:

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.

[GO TO KNOW]

KNOW IF R_TYPE=1, SKIP TO COND_CONFIRM
Are you knowledgeable about the child's health?
(1) YES, <GO TO COND_CONFIRM>
(2) NO

FOLLOWK Is there a knowledgeable parent or guardian available?
(1) YES <GO TO INTRO2>
(2) NO [TERMINATE]

INTRO3. IF TS_SAMPLED=1 DISPLAY:
[IF R_TYPE=1 THEN DISPLAY: 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.

ELSE IF TS_SAMPLED=0 AND ADHD_SAMPLED=1 DISPLAY:
[IF R_TYPE=1 THEN DISPLAY: 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.

[GO TO KNOW]

COND_CONFIRM We are calling you because you or another parent or guardian of the child 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) CONTINUE
- (2) CHILD DOES NOT HAVE CONDITION(S)
- (77) DON'T KNOW
- (99) REFUSED

ALL GO TO COND_CHK

COND_CHK [IF COND_CONFIRM=1 DISPLAY:
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...
Attention Deficit Hyperactivity Disorder or ADHD, or Attention Deficit Disorder
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 <FLAG FOR TS MODULE (TS_ELIG=1) AND GO TO AGE>
- (2) NO <IF COND_A=01 GO TO AGE, ELSE GO TO COND_EXIT>
- (77) DON'T KNOW < IF COND_A=01 GO TO AGE, ELSE GO TO
COND_EXIT>
- (99) REFUSED < IF COND_A=01 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 Centers for Disease Control and Prevention for the time and effort you've spent answering these questions.

AGE When we originally spoke with your household, [child] was [NSCH AGE IN MONTHS OR YEARS]. How old is [he/she] now?

RECORD VALUE: _____

RECORD AGE IN YEARS.

IF CHILD IS 18 YEARS OR OLDER GO TO AGE_EXIT

AGE_EXIT We are only interviewing parents or guardians whose child is under 18 years old. I'd like to thank you on behalf of the Centers for Disease Control and Prevention for the time and effort you've spent answering these questions.

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 [GO TO CONSENT]
- (2) NO [GO TO MOVED2]
- (77) DON'T KNOW [GO TO MOVED2]
- (99) REFUSED [GO TO MOVED2]

CONSENT Based on your responses, you are eligible to complete a survey on [SC]'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. [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]. 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: 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

Tourette Syndrome Questionnaire

[If TS module is not flagged (TS_ELIG=0) skip to ADHD_A1_2, ELSE start at TS_A1_2]

A. Diagnosis

A1. Previous Tourette Syndrome Diagnosis

TS_A1_2 Thank you for confirming that a doctor or other health care provider once told you that [SC] had Tourette Syndrome. The first set of questions will ask about [SC]'s Tourette Syndrome diagnosis.

How old was [child] when you were first told by a doctor or other health care provider that he/she had Tourette Syndrome?

Record Value: _____

TS_A1_2a. (1) Years
(2) Months

TS_A1_3. What type of doctor or other health care provider first told you that [child] had Tourette Syndrome?

- (1) Pediatrician or other general pediatric healthcare provider (such as nurse practitioner or physician's assistant in pediatric clinic)
- (2) Another type of general health care provider (such as a family practice doctor or nurse practitioner or physician's assistant in general practice)
- (3) Specialist pediatrician, such as a developmental or developmental behavioral pediatrician
- (4) School psychologist/counselor
- (5) A clinical psychologist or another psychologist outside of the school
- (6) Psychiatrist (medical doctor or nurse practitioner in a mental health setting)
- (7) Neurologist
- (8) School nurse
- (9) Physical, occupational, speech or other therapist
- (10) A specialist doctor (other than a developmental pediatrician, psychiatrist, or neurologist)
- (11) Team of professionals/multidisciplinary team
- (12) Other (Specify): _____
- (66) No health care provider has ever told me my child has this condition

TS_A1_4. How many doctors or other health care providers saw [child] about tics before he/she was diagnosed with Tourette Syndrome?
____ (Number)

TS_A1_5. Now I would like you to think about the time before [child]'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. Some common tics are eye blinking; facial movements; shoulder shrugging; coughing; throat clearing; sniffing; humming; making animal noises like barking, and other sounds or verbalizations. Tics can be suppressed for short periods of time, but eventually come out. Tics come and go and often change over time.

Who first noticed that [child] had tics? Was it:

- (1) You 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 school, or
- (4) Someone else?

TS_A1_6. How old was [child] when someone first noticed that he/she had tics?

Record Value: _____

- TS_A1_6a.
- (1) Years
 - (2) Months

TS_A1_7. What type of tics did [child] have when someone first noticed he/she had tics? Were they motor tics, vocal or phonic tics, or some other kind of tics?

- (1) Motor tic
- (2) Vocal or phonic tic
- (3) Both
- (4) Other

TS_A1_8. Do you believe that [child's] tics were caused by a stressful life event?

- (1) Yes
- (2) No

TS_A1_9. Do you believe that [child'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).

- (1) Yes
- (2) No

TS_A1_10. How old was [child] when you first asked a doctor or other health care provider for help because of the tics?

Record Value: _____

TS_A1_10a. (1) Years
(2) Months

A2. Current Tourette Syndrome and Severity

TS_A2_1. Does [child] currently have Tourette Syndrome?

- (1) Yes
- (2) No (Go to TS_A2_3)

TS_A2_2. Would you describe his/her Tourette Syndrome as mild, moderate, or severe?

- (1) Mild
- (2) Moderate
- (3) Severe

TS_A2_3. When the symptoms were at their worst, how would you describe [child]'s Tourette Syndrome? Would you describe it as mild, moderate, or severe?

- (1) Mild
- (2) Moderate
- (3) Severe

TS_A2_4. When the symptoms were at their worst, were the tics noticeable to strangers?

- (1) Yes
- (2) No

TS_A2_5. When the symptoms were at their worst, did the tics interfere with [child]'s ability to do things other children could do?

- (1) Yes
- (2) No

TS_A2_6. How old was [child] when the Tourette Syndrome was at its worst?

HELP TEXT: IF R GIVES AN AGE RANGE, ASK HIM/HER TO CHOOSE THE AGE WHEN THE TICS WERE THE WORST.

Record Value: _____

- TS_A2_6a. (1) Years
(2) Months

IF CHILD CURRENTLY HAS TS [TS_A2_1 = YES, DK, RF], SKIP TO B1_1.

TS_A2_7. Did treatment help [child's] tics go away or did the tics seem to go away on their own?

HELP TEXT: 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
- (2) Tics went away on their own

(3) Child never had tics (Go to TS_B1_1)

TS_A2_8. Does [child] currently have tics?
(1) Yes
(2) No

B. Co-occurring Disorders

TS_B1_1. Has a doctor or health care provider ever told you that [child] had:

(READ/ANSWER EACH OPTION)

- (1) Oppositional defiant disorder or ODD
- (2) Conduct disorder
- (3) Autism Spectrum Disorder or Pervasive Developmental Disorder
- (4) A sleep disorder
- (5) An intellectual disability
- (6) A learning disorder
- (7) A language disorder
- (8) Obsessive compulsive disorder or OCD
- (9) Post-traumatic stress disorder or PTSD
- (10) Another anxiety disorder, such as generalized anxiety disorder, panic disorder, or a phobia
- (11) Bipolar disorder
- (12) Intermittent explosive disorder
- (13) Another mood disorder, such as depression, major depressive disorder or dysthymic disorder
- (14) An eating disorder, such as anorexia or bulimia
- (15) Substance use disorder

IF NONE OF B1_1-B1_15 ARE YES, THEN SKIP TO C.

TS_B1_2. Does [child] currently have [loop through list for each YES answer]?

- (1) Yes
- (2) No

C. Tourette Syndrome Treatment

C1. Medication

TS_C1_1. Has [child] ever taken medication for Tourette Syndrome?
(1) Yes (Go to TS_C1_2)
(2) No (Go to TS_C3_1)

TS_C1_2. At what age did [child] first start taking Tourette Syndrome medication?
_____ Record age in years

[IF CHILD DOES NOT CURRENTLY HAVE TS [TS_A2_1 = NO], SKIP TO TS_C1_5]

TS_C1_3. Is [child] currently taking medication for Tourette Syndrome?
(1) Yes
(2) No (Go to TS_C1_5)

TS_C1_4. What medications does [child] currently take for Tourette Syndrome?

PROBE: Does (he/she) take any other medications for Tourette Syndrome?

- | | |
|---|--|
| (1) Abilify, Abilify Maintena, Abilify Discmelt | (25) Kemstro |
| (2) Apo-Metoclop | (26) Klonopin, Klonopin Wafer |
| (3) Apokyn | (27) Levetiracetam |
| (4) Apomorphine | (28) Lioresal |
| (5) Aricept, Aricept ODT | (29) Marinol |
| (6) Aripiprazole | (30) Metoclopramide, Metoclopramide Hydrochloride Injection, Metoclopramide Omega, Nu-Metoclopramide, PMS-Metoclopramide |
| (7) Baclofen | (31) Mirapex, Mirapex ER |
| (8) Botulinum toxin, Botox | (32) NAC |
| (9) Clonazepam | (33) Neurobloc |
| (10) Clonidine, Clonidine ER | (34) Nexiclon |
| (11) Catapres, Catapres-TTS | (35) Olanzapine |
| (12) Deltanyne | (36) Ondansetron |
| (13) Donepezil | (37) Orap |
| (14) Dronabinol | (38) Pergolide |
| (15) Duraclon | (39) Permax |
| (16) Dysport | (40) Permitil |
| (17) Fluphenazine | (41) Pimozide |
| (18) Gablofen | (42) Pramipexole |
| (19) Geodon | (43) Prolixin, Prolixin Decanoate, Prolixin Enanthate |
| (20) Guanfacine | (44) Quetiapine |
| (21) Haloperidol, Haldol, Haldol Decanoate | (45) Requip |
| (22) Intuniv | |
| (23) Kapvay | |
| (24) Keppra, Keppra XR | |

- | | |
|---|---|
| (46) Risperidone, Risperdal, Risperdal
Consta, Risperdal M-Tab | (55) Xenazine |
| (47) Ropinirole | (56) Ziprasidone |
| (48) Sativex | (57) Zofran |
| (49) Seroquel, Seroquel XR | (58) Zyprexa, Zyprexa Zydis, Zyprexa
Relprevv, Zyprexa Intramuscular |
| (50) Tenex | (59) OTHER [GO TO
TS_C1_4_VERBATIM] |
| (51) Tetrabenazine | (60) NOT CURRENTLY TAKING
MEDICATION |
| (52) Tetrahydrocannabinol, Δ-9-THC | |
| (53) Topamax, Topamax Sprinkle | |
| (54) Topiramate, Topiragen | |
| | (77) DON'T KNOW |

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 [SC]’s medication so we may record the name of it.”

TS_C1_4_VERBATIM. Enter other medication.

_____ ENTER TEXT

TS_C1_5. Has [child] ever experienced any of the following side effects of a Tourette Syndrome medication?

TS_C1_5a. Weight gain
(1) Yes (2) No

TS_C1_5b. Being physically slowed down or sluggish, such as moving slowly
(1) Yes (2) No

TS_C1_5c. Being mentally slowed down or sluggish, for example, thinking slowly or being less attentive
(1) Yes (2) No

TS_C1_5d. Sleep problems or insomnia, such as trouble getting to sleep or staying asleep
(1) Yes (2) No

TS_C1_5e. Body twisting, squirming, or other new body movements, not including tics
(1) Yes (2) No

TS_C1_5f. Has [child] experienced any other side effects?
(1) Yes (2) No

TS_C1_5fa. Enter other side effect.
_____ ENTER TEXT

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

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.

C2. Medication Adherence

TS_C2_1. Who usually makes sure [child] 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

TS_C2_2. In the past 12 months, was there a time when [child] resisted taking [his/her] Tourette Syndrome medication?

- (1) Yes
- (2) No

C3. 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]

Has [child] ever received any of the following for treating Tourette Syndrome?

- TS_C3_1. Comprehensive behavioral intervention for tics (CBIT) or habit reversal therapy?
(If yes, go to TS_C3_1a, else go to TS_C3_2)
(1) Yes (2) No
- TS_C3_2. School-based behavioral treatment, support, or accommodation?
(If yes, go to TS_C3_2a, else go to TS_C3_3)
(1) Yes (2) No
- TS_C3_3. Behavioral treatment based outside of school?
(If yes, go to TS_C3_3a, else go to TS_C3_4)
(1) Yes (2) No
- TS_C3_4. Other treatment
(1) Yes (2) No (If yes, go to TS_C3_4a, else go to C3_11)
- TS_C3_4a. Enter other treatment.

_____ Enter text (Go to C3_4aa)

[IF CHILD DOES NOT CURRENTLY HAVE TS [TS_A2_1=NO], SKIP TO C3_11]

- TS_C3_1a. Is [child] currently receiving comprehensive behavioral intervention for tics (CBIT) or habit reversal therapy for Tourette Syndrome?
(1) Yes (Go to TS_C3_1b)
(2) No (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?
(1) Psychologist
(2) Social worker
(3) Occupational therapist
(4) Psychiatrist
(5) Neurologist
(6) Physical therapist
(7) Pediatrician
(8) Physician's assistant
(9) Another type of health care provider
(10) Another type of professional

TS_C3_2a. Is [child] currently receiving school-based behavioral treatment, support, or accommodation for Tourette Syndrome?
(1) Yes (Go to TS_C3_3)
(2) No (Go to TS_C3_3)

TS_C3_3a. Is [child] currently receiving behavioral treatment based outside of school for Tourette Syndrome?
(1) Yes (Go to TS_C3_4)
(2) No (Go to TS_C3_4)

TS_C3_4aa. Is [child] currently receiving [other treatment] to treat Tourette Syndrome?
(1) Yes
(2) No

C3_11. 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 TS_C4_1)

C3_12. Is it an IEP, a 504 plan, or something else?
(1) IEP
(2) 504
(3) Something else (specify)

C3_12a. _____(specify)

C4. Treatment Barriers and Satisfaction

IF CHILD DOES NOT CURRENTLY HAVE TS [TS_A2_1=NO], SKIP TO TS_D2_1]

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_2)
- (2) No (Go to TS_C4_4)

TS_C4_2a. What treatment was [child] unable to get? Was it medication?

- (1) Yes
- (2) No

TS_C4_2b. Comprehensive behavioral intervention for tics (CBIT) or habit reversal therapy?

- (1) Yes
- (2) No

TS_C4_2c. School-based behavioral treatment, support, or accommodation?

- (1) Yes
- (2) No

TS_C4_2d. Behavioral treatment based outside of school?

- (1) Yes
- (2) No

TS_C4_2e. Some other treatment outside of school?

- (1) Yes
- (2) No

TS_C4_2ea. What was it? (specify)

_____ Enter text

IF TS_C4_2b = NO, DK, RF, THEN SKIP TO TS_C4_4.

TS_C4_3. Why was [child] unable to get comprehensive behavioral intervention for tics or habit reversal therapy?

- (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
- (7) Family issues: Child or other family members did not want the treatment/service
- (8) Other (specify): _____ Enter text

TS_C4_4. Overall, how satisfied are you with [child]'s Tourette Syndrome treatment and management?

- (1) Very satisfied
- (2) Somewhat satisfied
- (3) Somewhat dissatisfied
- (4) Very dissatisfied

D. Performance

Now I'd like to ask you about [child]'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.

TS_D2_1. How would you describe [child]'s overall school performance? Would you say:
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent

TS_D2_2. How about reading? Would you say:
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent

TS_D2_3. Writing?
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent

TS_D2_4. Mathematics?
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent

TS_D2_5. How would you describe [child]'s relationship with [his/her] parents? Would you say:
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent

TS_D2_6. How about relationships with siblings?
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent
(6) Child does not have siblings

TS_D2_7. Relationships with peers?
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent

TS_D2_8. How would you describe [child]'s participation in organized activities such as teams? Would you say:
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent

TS_D2_9. How would you describe [child]'s handwriting, that is, his/her ability to form letters and numbers that are clear and can be recognized? Would you say:
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent

E. Academic Health and Discipline

TS_E1. Overall, would you consider [child] an [READ RESPONSES]:

- (1) A student
- (2) B student
- (3) C student
- (4) D student, or
- (5) F Student?

TS_E2. What kind of school is [child] currently enrolled in? Is it a public school, private school, or home-school?

- (1) Public
- (2) Private
- (3) Home-Schooled
- (4) [Child] is not enrolled in school

TS_E3. Since starting kindergarten, has [he/she] repeated any grades?

- (1) Yes
- (2) No (Go to TS_E5)

TS_E4. Which grade or grades did [he/she] repeat? [Mark all that apply.]

- (1) Kindergarten
- (2) 1st grade
- (3) 2nd grade
- (4) 3rd grade
- (5) 4th grade
- (6) 5th grade
- (7) 6th grade
- (8) 7th grade
- (9) 8th grade
- (10) 9th grade
- (11) 10th grade
- (12) 11th grade
- (13) 12th grade

TS_E5. Has [child] ever been expelled or asked not to return to a childcare center, preschool, or school?

- (1) Yes
- (2) No (Go to TS_E_7)

TS_E6. In what grade or grades was [child] expelled or asked not to return to school?

- (1) Childcare (birth through age 2)
- (2) Preschool (3 through age 5)
- (3) Kindergarten
- (4) 1st grade
- (5) 2nd grade
- (6) 3rd grade
- (7) 4th grade
- (8) 5th grade
- (9) 6th grade
- (10) 7th grade
- (11) 8th grade
- (12) 9th grade
- (13) 10th grade
- (14) 11th grade
- (15) 12th grade

TS_E_7. Has your child ever been treated differently because of his/her tics, for example, being bullied or discriminated against, or treated rudely?

- (1) Yes (Go to TS_E_7a)
- (2) No (Go to TS_E_8)

TS_E_7a. Who has discriminated against or bullied the child? Were they:
(check all that apply)

- (1) Siblings,
- (2) Other children,
- (3) Business owners or employees,
- (4) Teachers,
- (5) Family members,
- (6) Or some other adults?

IF CHILD DOES NOT CURRENTLY HAVE TICS [TS_A2_7 = 3 or TS_A2_8 = NO], THEN
GO TO TS_F_1.

TS_E_8. Sometimes certain things seem to make tics better or worse. Do any of the following seem to make [child]'s tics better or worse?

TS_E_8a. Do major transitions like starting a new school or moving into a new class seem to make [child]'s tics better or worse, or is there no impact?

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

TS_E_8b. Do minor transitions like switching activities or changing locations seem to make [child]'s tics better or worse, or is there no impact?

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

TS_E_8c. Does being tired seem to make tics better or worse, or is there no impact?

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

TS_E_8d. Talking about tics.

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

TS_E_8e. Doing homework.

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

TS_E_8f. Playing music or singing.

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

TS_E_8g. Exercising or doing an individual sport, like running or swimming

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

TS_E_8h. Playing team sports, like soccer, baseball or volleyball

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

TS_E_8i. Listening to music

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

TS_E_8j. Reading for pleasure

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

TS_E_8k. Watching TV

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

TS_E_8l. Playing video games or other computer games

(1) Better activity (2) Worse (3) Depends (4) No impact (5) My child doesn't do that

F. Family Impact of Tourette Syndrome

- TS_F1_1. Has [child]'s Tourette syndrome caused financial problems for your family?
(1) Yes
(2) No
- TS_F1_2. Have you or other family members stopped working because of [child]'s Tourette syndrome?
(1) Yes
(2) No
- 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 [child]'s Tourette syndrome?
(1) Yes
(2) No
- TS_F1_4. Have you or other family members avoided changing jobs because of concerns about maintaining health insurance for [child]?
(1) Yes
(2) No

G. ACS Questions

TS_G1_1. How well does [child] speak English? (for children 5 or older)

- (1) Very well
- (2) Well
- (3) Not Well
- (4) Not at All

TS_G1_2. Is [child] deaf or have serious difficulty hearing?

- (1) Yes
- (2) No

TS_G1_3. Is [child] blind or have serious difficulty seeing, even when wearing glasses?

- (1) Yes
- (2) No

TS_G1_4. Because of a physical, mental or emotional condition, does [child] have serious difficulty concentrating, remembering, or making decisions?

- (1) Yes
- (2) No

TS_G1_5. Does [child] have serious difficulty walking or climbing stairs? (for children 5 or older)

- (1) Yes
- (2) No

TS_G1_6. Does [child] have difficulty dressing or bathing? (for children 5 or older)

- (1) Yes
- (2) No

TS_G1_7. Because of a physical, mental or emotional condition, does [child] have difficulty doing errands alone such as visiting a doctor's office or shopping? (for children 15 and older)

- (1) Yes
- (2) No

H. Household and Demographics

TS_H_INTRO Thank you for your answers. Now I have a few more general questions about [S.C.] and your household.

TS_H1_Q01 Including the adults and all the children, how many people live in this household?
ENTER 77 FOR DON'T KNOW AND 99 FOR REFUSED
ENTER NUMBER: _____

TS_H1_Q02 I have that you are [S.C.]'s [FILL FROM K1Q02]. Is that correct?
(01) YES [GO TO TS_H1_Q2_CHK]
(02) NO [GO TO TS_H1_Q2_CHK]
(77) DON'T KNOW [GO TO TS_H1_Q2_CHK]
(99) REFUSED [GO TO TS_H1_Q2_CHK]

TS_H1_Q03 IF K1Q02=77, 99 OR TS_H1_Q02=02, 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 TS_H1_Q02=01 AND K1Q02=01 THEN DISPLAY:
Are you [S.C.]'s biological, adoptive, step, or foster mother?

IF TS_H1_Q02=01 AND K1Q02=02 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 = DK/RF, 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?

PARENT

- | | |
|-------------------------------|-------------------------------|
| (01) BIOLOGICAL MOTHER | (06) BIOLOGICAL FATHER |
| (02) STEP MOTHER | (07) STEP FATHER |
| (03) FOSTER MOTHER | (08) FOSTER FATHER |
| (04) ADOPTIVE MOTHER | (09) ADOPTIVE FATHER |
| (05) MOTHER, but TYPE REFUSED | (10) FATHER, but TYPE REFUSED |

OLDER RELATIVES OR GUARDIANS

- | | |
|------------------|----------------------|
| (11) GRANDMOTHER | (14) UNCLE |
| (12) GRANDFATHER | (15) FEMALE GUARDIAN |
| (13) AUNT | (16) MALE GUARDIAN |

OTHER RELATIVES

- (17) SISTER
- (18) BROTHER
- (19) COUSIN

- (20) IN-LAW OF ANY TYPE
- (21) [S.C.]’S CHILD, SON, OR DAUGHTER
- (22) OTHER RELATIVE / FAMILY MEMBER

OTHER NON-RELATIVES

- (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_CONF I am now going to list all the people that live in your household.

I have that [LIST OF RELATIONSHIPS ROSTERED] live in this household with [S.C.].

Is this a correct list of everyone living in your household?

- (1) CONFIRMED - THIS LIST IS CORRECT
- (2) NOT CORRECT - RETURN TO TS_H1_Q01 AND START AGAIN

TS_H1_Q04_WARNING Earlier you told me that there are [VALUE FROM TS_H1_Q01] people living in your household. However, based on the relationships you just gave, I have [COUNT OF RELATIONSHIPS INCLUDING R & SC] people living in your household. Let's re-confirm your answers.

- (1) RETURN TO RE-CONFIRM ANSWERS [GO TO TS_H1_Q01]
USE RARELY:
- (2) ISSUE CANNOT BE RESOLVED - CONTINUE ON [GO TO TS_H1_Q03_ADOPT]

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_Q01_CONF 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 [SKIP TO TS_H2_Q04]
- (2) NOT CORRECT - CHILD HAS INSURANCE - RETURN TO TS_H2_Q01 AND ENTER CORRECT RESPONSE [SKIP TO TS_H2_Q01]

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 state-sponsored Children's Health Insurance Program 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_Q01_CONF Just to confirm that I entered it correctly, the total income of all family members was [AMOUNT FROM TS_H3_Q01]. Is that correct?

- (1) YES > GO TO TS_ADDRESS_CONF
- (2) NO > GO TO TS_H3_Q01

TS_H3_Q02

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 [GO TO TS_H3_Q05]
- (77) DON'T KNOW [GO TO TS_ADDRESS_CONF]
- (99) REFUSED [GO TO TS_ADDRESS_CONF]

TS_H3_Q03

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 TS_H3_Q01= (8, 9) GO TO TS_H3_Q04; ELSE GO TO TS_ADDRESS_CONF]
- (77) DON'T KNOW [GO TO TS_ADDRESS_CONF]
- (99) REFUSED [GO TO TS_ADDRESS_CONF]

TS_H3_Q04

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 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 TS_ADDRESS_CONF]
- (2) [FILL: Poverty threshold for household of size TS_H3_Q01] OR MORE [GO TO TS_ADDRESS_CONF]
- (77) DON'T KNOW [GO TO TS_ADDRESS_CONF]
- (99) REFUSED [GO TO TS_ADDRESS_CONF]

TS_H3_Q05

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 TS_ADDRESS_CONF]
- (77) DON'T KNOW [GO TO TS_ADDRESS_CONF]
- (99) REFUSED [GO TO TS_ADDRESS_CONF]

TS_H3_Q06

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

TS Medication Follow-Up

CPGOGETMED_TS

IF ADHD_ELIG=0 AND TS_C1_4= 77 GO TO GOGETMED. ELSE GO TO ADDRESS CONFIRMATION

GOGETMED_TS

Earlier you told me that [S.C.] has taken medication for TS in the past week, however you did not know the name of the medication. Before we finish the interview, can you please take a moment to get [S.C.]'s medication so we may record the name of the medication?

READ IF NECESSARY: If [S.C.] takes more than one medication for TS, please get all the medications so we can record each name.

(1) YES **[SKIP TO GOGETMED_CNFM]**
(99) REFUSED **[GO TO ADDRESS CONFIRMATION]**

GOGETMED_CNFM

READ AS NECESSARY: Please read the name of each medication that [S.C.] takes for TS.

READ AS NECESSARY: Thank you for taking the time to get the medication.

INTERVIEWER INSTRUCTIONS: MARK ALL THAT APPLY AMONG 1-18. DO NOT READ LIST.

- (1) Abilify, Abilify Maintena, Abilify Discmelt
- (2) Apo-Metoclop
- (3) Apokyn
- (4) Apomorphine
- (5) Aricept, Aricept ODT
- (6) Aripiprazole
- (7) Baclofen
- (8) Botulinum toxin, Botox
- (9) Clonazepam
- (10) Clonidine, Clonidine ER
- (11) Catapres, Catapres-TTS
- (12) Deltanyne
- (13) Donepezil
- (14) Dronabinol
- (15) Duraclon
- (16) Dysport

- (17) Fluphenazine
- (18) Gablofen
- (19) Geodon
- (20) Guanfacine
- (21) Haloperidol, Haldol, Haldol Decanoate
- (22) Intuniv
- (23) Kapvay
- (24) Keppra, Keppra XR
- (25) Kemstro
- (26) Klonopin, Klonopin Wafer
- (27) Levetiracetam
- (28) Lioresal
- (29) Marinol
- (30) Metoclopramide, Metoclopramide Hydrochloride Injection, Metoclopramide
Omega, Nu-Metoclopramide, PMS-Metoclopramide
- (31) Mirapex, Mirapex ER
- (32) NAC
- (33) Neurobloc
- (34) Nexiclon
- (35) Olanzapine
- (36) Ondansetron
- (37) Orap
- (38) Pergolide
- (39) Permax
- (40) Permitil
- (41) Pimozide
- (42) Pramipexole
- (43) Prolixin, Prolixin Decanoate, Prolixin Enanthate
- (44) Quetiapine
- (45) Requip
- (46) Risperidone, Risperdal, Risperdal Consta, Risperdal M-Tab
- (47) Ropinirole
- (48) Sativex
- (49) Seroquel, Seroquel XR
- (50) Tenex
- (51) Tetrabenazine
- (52) Tetrahydrocannabinol, Δ -9-THC
- (53) Topamax, Topamax Sprinkle
- (54) Topiramate, Topiragen
- (55) Xenazine
- (56) Ziprasidone
- (57) Zofran
- (58) Zyprexa, Zyprexa Zydis, Zyprexa Relprevv, Zyprexa Intramuscular
- (59) OTHER [GO TO GOGETMED_TS_VERBATIM]
- (60) NOT CURRENTLY TAKING MEDICATION
- (77) DON'T KNOW

(99) REFUSED

GOGETMED_TS_VERBATIM

ENTER OTHER MEDICATION. IF MORE THAN ONE MEDICATION IS
GIVEN ENTER ALL MEDICATIONS ON ONE LINE.

_____ENTER TEXT

[TIMESTAMP_GOGET_END]

Address Confirmation

TS_ADDRESS_CONF

IF (NSDATA_INCENT_FLAG = 2 OR NSDATA_PASSIVE in (1,2))AND
NSDATA_LETTER_FLG=2 THEN FILL MONEY_2; ELSE FILL MONEY_1

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.

GO TO AC_NAME AND PROCEED THROUGH ADDRESS COLLECTION OR
VERIFICATION

(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 [SC] 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 [SC] and ADHD. The survey will
take approximately [MINUTES] minutes, and we will send you an additional \$20 for
your time, for a total of \$[40/45]. 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.

(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.

(1) CONTINUE

ADHD Questionnaire

A. Diagnosis

A1. Previous ADHD Diagnoses

ADHD_A1_2.

Thank you for confirming that a doctor or other health care provider once told you that [SC] had ADHD. The next set of questions will ask about [SC]'s ADHD diagnosis.

How old was [child] when you were first told by a doctor or other health care provider that he/she had ADHD?

Record Value: _____

ADHD_A1_2a. (1) Years
 (2) Months

ADHD_A1_3. What type of doctor or other health care provider first told you that [child] had ADHD?

- (1) Pediatrician or other general pediatric healthcare provider (such as nurse practitioner or physician's assistant in pediatric clinic)
- (2) Another type of general health care provider (such as a family practice doctor or nurse practitioner or physician's assistant in general practice)
- (3) Specialist pediatrician, such as a developmental or developmental behavioral pediatrician
- (4) School psychologist/counselor
- (5) A clinical psychologist or another psychologist outside of the school
- (6) Psychiatrist (medical doctor or nurse practitioner in a mental health setting)
- (7) Neurologist (or nurse practitioner in a neurology clinic)
- (8) School nurse
- (9) Physical, occupational, speech or other therapist
- (10) A specialist doctor (other than a developmental pediatrician, psychiatrist, or neurologist)
- (11) Team of professionals/multidisciplinary team
- (12) Other (Specify): _____
- (66) No health care provider has ever told me my child has this condition

ADHD_A1_4. Did any other doctor, health care provider, or school professional also tell you that [child] had ADHD?

- (1) Yes (Go to ADHD_A1_5)
- (2) No (Go to ADHD_A1_6)

ADHD_A1_5. Who was that? (Mark all that apply)

(Read as necessary: What types of other doctors, health care providers, or school professionals told you that [child] had ADHD?) INTERVIEWER PROMPT: Was there anyone else?

- (1) Pediatrician or other general pediatric healthcare provider (such as nurse practitioner or physician's assistant in pediatric clinic)
- (2) Another type of general health care provider (such as a family practice doctor or nurse practitioner or physician's assistant in general practice)
- (3) Specialist pediatrician, such as a developmental or developmental behavioral pediatrician
- (4) School nurse, school psychologist or school counselor
- (5) A clinical psychologist or another psychologist outside of the school
- (6) Psychiatrist (medical doctor or nurse practitioner in a mental health setting)
- (7) Neurologist
- (8) Physical, occupational, speech or other therapist
- (9) A specialist doctor (other than a developmental pediatrician, psychiatrist, or neurologist)
- (10) Social worker
- (11) Teacher or daycare provider
- (12) A school administrator, such as a principal or vice-principal
- (13) Team of professionals/multidisciplinary team
- (14) Other (specify): _____

ADHD_A1_6. Now I'd like you to think about the time before {child}'s ADHD diagnosis. Who was first concerned with [child's] behavior, attention, or performance? Was it:

- (1) You 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 school, or
- (4) Someone else?

ADHD_A1_7. How old was [child] when [FILL RESPONSE FROM A1_6] was first concerned with his/her behavior, attention, or performance?

Record Value: _____

- ADHD_A1_7a. (1) Years
(2) Months

Before [child] received an ADHD diagnosis, were you or other people concerned about...

- ADHD_A1_8a. [Child's] behavior at home, such as completing chores or getting along with parents?
(1) Yes (2) No

ADHD_A1_8b. [Child's] 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

ADHD_A1_8c. [Child's] school performance, such as grades or test scores, or completing assignments?
(1) Yes (2) No

ADHD_A1_8d. [Child's] relationships with other children, such as playing together, or making or keeping friends?
(1) Yes (2) No

A2. Diagnostic Context

ADHD_A2_INTRO Now I'd like you to think about the time when [child] 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_1. Different health and school professionals are sometimes involved in conducting an ADHD assessment. Who was involved in conducting [child]'s ADHD assessment?

ADHD_A2_1a. Were medical doctors involved?
(1) Yes (2) No

ADHD_A2_1b. Were school psychologists or school counselors involved?
(1) Yes (2) No

ADHD_A2_1c. Were teachers or other education staff involved?
(1) Yes (2) No

ADHD_A2_1d. How about clinical psychologists or other psychologists not at your child's school?

INTERVIEWER NOTE: INCLUDE THOSE OUTSIDE OF THE SCHOOL EVEN IF REFERRED TO BY THE SCHOOL.

(1) Yes (2) No

ADHD_A2_1e. Were any other health care professionals involved?
(1) Yes (Who else was involved?: _____)
(2) No

ADHD_A2_2. 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?

ADHD_A2_2a. A rating scale or checklist about the child's behavior
(1) Yes (2) No

ADHD_A2_2b. A conversation with you about the child's behavior
(1) Yes (2) No

ADHD_A2_2c. A series of tests to better understand how the child learns, reads, understands and processes information, also known as neuropsychological testing

INTERVIEWER NOTE: ALSO INCLUDE CONTINUOUS PERFORMANCE TESTS

(1) Yes (2) No

ADHD_A2_2d. Medical tests, such as an EEG, CT scan, MRI, or blood tests to test for lead exposure

(1) Yes (2) No

ADHD_A2_3. Did the doctor, health care provider, or school professional who diagnosed [child] with ADHD collect information from:

ADHD_A2_3a. [Child]?

(1) Yes (2) No

ADHD_A2_3b. Other family members?

(1) Yes (2) No

ADHD_A2_3c. [Child]'s school teachers or other school staff?

(1) Yes (2) No

ADHD_A2_3d. Childcare provider, such as a daycare teacher, nanny, or babysitter?

INTERVIEWER NOTE: MAY ALSO BE REFERRED TO AS AN EARLY CHILDHOOD EDUCATOR.

(1) Yes (2) No

ADHD_A2_3e. Other community members, such as a coach, music or dance teacher, religious leader, scout leader, or other group leader?

(1) Yes (2) No

ADHD_A2_4. Did the doctor, health care provider, or school professional who diagnosed [child] with ADHD ever observe the child in their classroom or at daycare?

(1) Yes

(2) No

ADHD_A2_5. How involved were you in [child]'s ADHD assessment?

(1) Very involved

(2) Somewhat involved

(3) Not very involved

(4) Not at all involved

A3. Current ADHD and Severity

ADHD_A3_1. Does [child] currently have ADHD?

- (1) Yes
- (2) No (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

ADHD_A3_3. When the symptoms were at their worst, how would you describe [child]'s ADHD? Would you describe it as mild, moderate, or severe?

- (1) Mild
- (2) Moderate
- (3) Severe

A4. Ever but not Current ADHD

IF CHILD CURRENTLY HAS ADHD [ADHD_A3_1 = YES, DK, RF], GO TO ADHD_B1_1.

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 [child].

ADHD_A4_1a. Condition seemed to go away on its own as the child got older
(1) Yes
(2) No

ADHD_A4_1b. Treatment helped the condition to go away
(1) Yes
(2) No

ADHD_A4_1c. A doctor or health care provider changed the diagnosis
(1) Yes
(2) No

ADHD_A4_1d. Is there another reason that you think [child] no longer has ADHD?
(1) Yes
(2) No

ADHD_A4_1da. Specify _____

IF ADHD_A4_1C = NO, DK, RF, THEN GO TO ADHD_B1_1.

ADHD_A4_2. What was the diagnosis changed to?
(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

A4_2a. Specify _____

B. Co-occurring Disorders

[SKIP THIS SECTION IF THE TS MODULE WAS COMPLETED. GO TO ADHD_C1_1]

ADHD_B1_1. Has a doctor or health care provider ever told you that [child] had:

(READ/ANSWER EACH OPTION)

- (1) Oppositional defiant disorder or ODD
- (2) Conduct disorder
- (3) Autism Spectrum Disorder or Pervasive Developmental Disorder
- (4) A sleep disorder
- (5) An intellectual disability
- (6) A learning disorder
- (7) A language disorder
- (8) Obsessive compulsive disorder or OCD
- (9) Post-traumatic stress disorder or PTSD
- (10) Another anxiety disorder, such as generalized anxiety disorder, panic disorder, or a phobia
- (11) Bipolar disorder
- (12) Intermittent explosive disorder
- (13) Another mood disorder, such as depression, major depressive disorder or dysthymic disorder
- (14) An eating disorder, such as anorexia or bulimia
- (15) Substance use disorder

IF NONE OF ADHD_B1_1- ADHD_B1_15 ARE YES, THEN SKIP TO ADHD_B1_3.

ADHD_B1_2. Does [child] currently have [loop through B1_1 list for each YES answer]?

- (1) Yes
- (2) No

ADHD_B1_3. 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; making animal noises like barking, and other sounds or verbalizations. Tics can be suppressed for short periods of time, but eventually come out. Tics come and go and often change over time. Has [child] ever had tics?

- (1) Yes (Go to B1_4)
- (2) No (Go to C1_1)

ADHD_B1_4. Does [child] currently have tics?

- (1) Yes
- (2) No

C. ADHD Treatment

C1. Medication

ADHD_C1_1. Has [child] ever taken medication for ADHD?

(1) Yes

(2) No (Go to ADHD_C3)

ADHD_C1_2. At what age did [child] first start taking ADHD medication?

_____ Record age in years

[IF CHILD DOES NOT CURRENTLY HAVE ADHD [ADHD_A3_1 = NO], SKIP TO
ADHD_C1_5]

ADHD_C1_3. Is [child] currently taking medication for ADHD?

(3) Yes

(4) No (Go to ADHD_C1_5)

ADHD_C1_4. What medications does [child] currently take for ADHD?

PROBE: Does (he/she) take any other medications for ADHD?

- (1) ABILIFY, ARIPIPRAZOLE
- (2) AMPHETAMINE (am-FET-a-meen)
- (3) ADDERALL (ADD-ur-all)
- (4) ADDERALL XR
- (5) BUPROPRION, WELLBUTRIN
- (6) CELEXA, CITALOPRAM (si-TAL-o-pram)
- (7) CLONIDINE, KAPVAY
- (8) CONCERTA
- (9) DEXEDRINE, DEXEDRINE SPANSULE, DEXTROSTAT, DEXTRO-AMPHETAMINE
- (10) DEXMETHYLPHENIDATE
- (11) FLUOXETINE (floo-ox-e-teen)
- (12) FOCALIN
- (13) FOCALIN XR
- (14) GUANFACINE, INTUNIV, TENEX
- (15) METADATE, METADATE CD
- (16) METHYLIN
- (17) METHYLPHENIDATE
- (18) METHYLPHENIDATE PATCH (DAYTRANA)
- (19) QUILLIVANT
- (20) PROZAC
- (21) RISPERDAL, RISPERIDONE, RISPERIDOL
- (22) RITALIN
- (23) RITALIN LA, RITALIN SR
- (24) SERTRALINE (SER-tra-leen)
- (25) STRATTERA, ATOMOXETINE (AT-oh-mox-e-teen)
- (26) VYVANSE, LISDEXAMFETAMINE (lis-dex-am-FET-a-meen)
- (27) ZOLOFT
- (28) OTHER [GO TO ADHD_C1_4_VERBATIM]
- (1) NOT CURRENTLY TAKING MEDICATION
- (77) DON'T KNOW
- (99) REFUSED

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 [SC]'s medication so we may record the name of it."

ADHD_C1_4_VERBATIM. Enter other medication.

_____ ENTER TEXT

ADHD_C1_5. Has [child] ever experienced any of the following side effects of an ADHD medication?

ADHD_C1_5a. Headache
(1) Yes (2) No

ADHD_C1_5b. Stomach problems, such as stomachache, nausea, vomiting, or loss of appetite
(1) Yes (2) No

ADHD_C1_5c. Weight gain
(1) Yes (2) No

ADHD_C1_5d. Weight loss
(1) Yes (2) No

ADHD_C1_5e. Slowed growth
(1) Yes (2) No

ADHD_C1_5f. Acting dazed or “out of it,” including long periods of staring, having a glassy-eyed appearance, or being slow to respond
(1) Yes (2) No

ADHD_C1_5g. Change in personality or mood

HELP TEXT: EXAMPLES OF CHANGE IN PERSONALITY OR MOOD INCLUDE: IRRITABILITY; INCREASED ANXIETY OR AGITATION; EXTREME SADNESS OR UNUSUAL CRYING; DULL, TIRED OR LISTLESS BEHAVIOR; BECOMING SOCIALLY WITHDRAWN; AND DECREASED INTERACTION WITH OTHERS.

(1) Yes (2) No

ADHD_C1_5h. Sleep problems/insomnia, such as trouble getting to sleep, staying asleep
(1) Yes (2) No

ADHD_C1_5i. Repetitive movements, tics, jerking, twitching, eye blinking
(1) Yes (2) No

ADHD_C1_5j. Feeling shaky or jittery
(1) Yes (2) No

ADHD_C1_5k. Increased blood pressure or heart rate
(1) Yes (2) No

ADHD_C1_5l. Has [child] experienced any other side effects?
(1) Yes (2) No

ADHD_C1_5la. Enter other side effect.
_____ ENTER TEXT

IF ANY ADHD_C1_5A- ADHD_C1_5L = YES, THEN GO TO ADHD_C1_6.

ELSE, IF CHILD IS CURRENTLY TAKING MEDS (ADHD_C1_3 = YES), GO TO ADHD_C1_7.

IF CHILD IS NOT CURRENTLY TAKING MEDS (ADHD_C1_3 = NO, DK, RF), GO TO ADHD_C3_1.

ADHD_C1_6. Were these side effects troublesome enough to stop taking the medication?
(1) YES
(2) NO

IF CHILD IS CURRENTLY TAKING MEDS (ADHD_C1_3 = YES), GO TO ADHD_C1_7.
IF CHILD IS NOT CURRENTLY TAKING MEDS (ADHD_C1_3 = NO, DK, RF), GO TO ADHD_C3_1.

ADHD_C1_7. Other than medications for ADHD, how many other medications is [child] currently taking for difficulties with his/her emotions, concentration, or behavior?
_____ (enter number)

ADHD_C1_8. In past 12 months, about how many times did [child] see a health care provider about his/her ADHD medication?

HELP TEXT: INCLUDE MEDICATION-FOCUSED VISITS AND OTHER VISITS (WELL-CHILD OR SICK VISITS) WHERE MEDICATIONS MAY HAVE BEEN DISCUSSED AS WELL.

_____ (enter number)

ADHD_C1_9. What type of doctor or other health care provider currently manages [child's] ADHD medication?

HELP TEXT: "MANAGES" MEANS DOING THINGS LIKE INCREASING OR DECREASING THE DOSAGES OF MEDICATIONS OR CHANGING MEDICATIONS.

- (1) Pediatrician or other general pediatric healthcare provider (such as nurse practitioner or physician's assistant in pediatric clinic)
- (2) Another type of general health care provider (such as a family practice doctor or nurse practitioner or physician's assistant in general practice)
- (3) Specialist pediatrician, such as a developmental or developmental behavioral pediatrician
- (4) A clinical psychologist or another psychologist
- (5) Psychiatrist (medical doctor or nurse practitioner in a mental health setting)
- (6) Neurologist (or nurse practitioner in a neurology clinic)
- (7) A specialist doctor (other than a developmental pediatrician, psychiatrist, or neurologist)
- (8) Other (Specify): _____

ADHD_C1_10. In a regular school week, how much does [child]'s medication help [child] with schoolwork and academics? Would you say:

- (1) Not at all
- (2) A little
- (3) Some
- (4) A lot

ADHD_C1_11. In a regular school week, how much does [child]'s medication help [child] with his/her classroom and home behavior? Would you say:

- (1) Not at all
- (2) A little
- (3) Some
- (4) A lot

ADHD_C1_12. In a regular school week, how much does [child]'s medication help [child] with his/her interactions with friends and adults? Would you say:

- (1) Not at all
- (2) A little
- (3) Some
- (4) A lot

C2. Medication Adherence

ADHD_C2_1. I want you to think about [child's] last school week. How many of the five days in the most recent school week did [child] take medication for ADHD?
_____ (enter number)

ADHD_C2_2. Now I want you to think about last weekend. How many of the two days in the last weekend did [child] take medication for ADHD?
_____ (enter number)

ADHD_C2_3. On a typical school day, when does [child] usually take medication for ADHD? Is it before school, during school, or after school?
(Mark all that apply)
(1) Before school
(2) During school
(3) After school

ADHD_C2_4. Does [child] take regularly scheduled breaks from his/her ADHD medication, such as on weekends or over the summer?

HELP TEXT: REGULARLY SCHEDULED BREAKS ARE SOMETIMES REFERRED TO AS A "DRUG HOLIDAY."

- (1) Yes
- (2) No

ADHD_C2_6. Who usually makes sure [child] takes his/her ADHD medication?
(1) A parent or guardian
(2) Another family member
(3) Someone at school
(4) A babysitter or nanny
(5) The child
(6) Other

ADHD_C2_7. In the past 12 months, was there a time when [child] resisted taking [his/her] ADHD medication? Please do not include times when [child] resisted due to physical reasons such as being unable to swallow a pill.

- (1) Yes
- (2) No

ADHD_C2_8. To the best of your knowledge, has [child]'s ADHD medication ever been taken or used by someone else, including a family member?
(1) Yes
(2) No

C3. Other Treatment

Has [child] ever received any of the following for treating ADHD or for treating difficulties with his/her emotions, concentration, or behavior?

ADHD_C3_1. School-based educational support, intervention, or accommodation, such as tutoring, extra help from teacher, preferential seating, or extra time to complete work
(If yes, go to ADHD_C3_1a, else go to ADHD_C3_2)
(1) Yes (2) No

ADHD_C3_2. Classroom management, such as reward systems, behavioral modification, or a daily report card
(If yes, go to ADHD_C3_2a, else go to ADHD_C3_3)
(1) Yes (2) No

ADHD_C3_3. Peer interventions, such as peer tutoring or the Good Behavior Game
(If yes, go to ADHD_C3_3a, else go to ADHD_C3_4)
(1) Yes (2) No

ADHD_C3_4. Social skills training, such as support in how to interact with others
(If yes, go to ADHD_C3_4a, else go to ADHD_C3_5)
(1) Yes (2) No

ADHD_C3_5. Cognitive Behavioral Therapy

READ AS 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.

(If yes, go to ADHD_C3_5a, else go to ADHD_C3_6)
(1) Yes (2) No

ADHD_C3_6. Dietary supplements, herbal supplements, and other non-prescription medications
(If yes, go to ADHD_C3_6a, else go to ADHD_C3_7)
(1) Yes (2) No

ADHD_C3_7. EEG neurofeedback or other kinds of biofeedback
(If yes, go to ADHD_C3_7a, else go to ADHD_C3_8)
(1) Yes (2) No

ADHD_C3_8. Other treatment)
(If yes, go to ADHD_C3_8a, else go to ADHD_C3_11)
(1) Yes (2) No

ADHD_C3_8a. Enter other treatment.
_____ Enter text (Go to ADHD_C3_8aa)

ALLOW THREE "OTHER" TREATMENTS

ADHD_C3_1a. Is [child] currently receiving school-based educational support, intervention, or accommodation?

- (1) Yes (Go to ADHD_C3_2)
- (2) No (Go to ADHD_C3_2)

ADHD_C3_2a. Is [child] currently receiving treatment through classroom management?

- (1) Yes (Go to ADHD_C3_3)
- (2) No (Go to ADHD_C3_3)

ADHD_C3_3a. Is [child] currently receiving treatment through peer interventions?

- (1) Yes (Go to ADHD_C3_4)
- (2) No (Go to ADHD_C3_4)

ADHD_C3_4a. Is [child] currently receiving social skills training?

- (1) Yes (Go to ADHD_C3_5)
- (2) No (Go to ADHD_C3_5)

ADHD_C3_5a. Is [child] currently receiving cognitive behavioral therapy?

- (1) Yes (Go to ADHD_C3_6)
- (2) No (Go to ADHD_C3_6)

ADHD_C3_6a. Is [child] currently receiving dietary supplements, herbal supplements, or non-prescription medications for ADHD?

- (1) Yes (Go to ADHD_C3_7)
- (2) No (Go to ADHD_C3_7)

ADHD_C3_7a. Is [child] currently receiving EEG neurofeedback or other kinds of biofeedback for ADHD?

- (1) Yes (Go to ADHD_C3_8)
- (2) No (Go to ADHD_C3_8)

ADHD_C3_8aa. Is [child] currently receiving [other treatment] for ADHD?

LOOP FOR EACH TREATMENTS PROVIDED IN ADHD_C3_8a (UP TO THREE)

- (1) Yes
- (2) No

[SKIP ADHD_C3_11 AND ADHD_C3_12 IF THE TS MODULE WAS COMPLETED. GO TO ADHD_C4_1.]

ADHD_C3_11. 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)

ADHD_C3_12. Is it an IEP, a 504 plan, or something else?

(1) IEP

(2) 504

(3) Something else (specify): _____

C4. Treatment Barriers and Satisfaction

[SKIP TO ADHD_C5_1 IF CHILD NO LONGER HAS ADHD (ADHD_A3_1=NO)]

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_2)
- (2) No (Go to ADHD_C4_4)

ADHD_C4_2. What treatment was [child] unable to get? Was it:

ADHD_C4_2a. Medication?
(1) Yes (2) No

ADHD_C4_2b. School-based behavioral treatment, support, or accommodation?
(1) Yes (2) No

ADHD_C4_2c. Behavioral treatment based outside of school?
(1) Yes (2) No

ADHD_C4_2d. Some other treatment outside of school? What was it? (specify)
(1) Yes (2) No

ADHD_C4_2da. Enter other treatment
_____ Enter text

IF ADHD_C4_2A = NO, THEN GO TO ADHD_C4_3B.

ADHD_C4_3a. Why was [child] unable to get medication?

- (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
- (7) Family issues: Child or other family members did not want the treatment/service
- (8) Other (specify): _____ Enter text

IF ADHD_C4_2B = NO, THEN GO TO ADHD_C4_3C.

ADHD_C4_3b. Why was [child] unable to get school-based behavioral treatment, intervention, or accommodation?

- (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
- (7) Family issues: Child or other family members did not want the treatment/service
- (8) Other (specify): _____ Enter text

IF ADHD_C4_3C = NO, THEN GO TO ADHD_C4_4.

ADHD_C4_3c. Why was [child] unable to get behavioral treatment based outside of school?

- (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
- (7) Family issues: Child or other family members did not want the treatment/service
- (8) Other (specify): _____ Enter text

SKIP TO SECTION C5 IF NOT CURRENT ADHD (ADHD_A3_1=NO)

ADHD_C4_4. Overall, how satisfied are you with [child]'s ADHD treatment and management?

- (1) Very satisfied
- (2) Somewhat satisfied
- (3) Somewhat dissatisfied
- (4) Very dissatisfied

C5. 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 [child's] ADHD?

- (1) Yes (Go to ADHD_C5_2)
- (2) No (Go to ADHD_C5_3)

ADHD_C5_2. Are you currently receiving parent training to help you manage [child's] ADHD?

- (1) Yes
- (2) No

ADHD_C5_3. Did you ever need parent training that you were unable to get?

- (1) Yes
- (2) No

D. DSM-V ADHD Symptoms and Performance/Impairment

D1. Vanderbilt ADHD-18

Now I'd like to ask you about [child]'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, [IF CURRENTLY TAKING MEDICATION, DISPLAY "when he/she is **not** taking medication for ADHD."]

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.

For each behavior, tell me how frequently you see this behavior from [child]: Never, Occasionally, Often, or Very Often.

(0) Never (1) Occasionally (2) Often (3) Very Often

- ADHD_D1_1. Does not pay attention to details or makes careless mistakes, such as in homework
- ADHD_D1_2. Has difficulty sustaining attention to tasks or activities
- ADHD_D1_3. Does not seem to listen when spoken to directly
- ADHD_D1_4. Does not follow through on instruction and fails to finish schoolwork (not due to oppositional behavior or failure to understand)
- ADHD_D1_5. Has difficulty organizing tasks and activities
- ADHD_D1_6. Avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort
- ADHD_D1_7. Loses things necessary for tasks or activities (school assignments, pencils, or books)
- ADHD_D1_8. Is easily distracted by extraneous stimuli
- ADHD_D1_9. Is forgetful in daily activities
- ADHD_D1_10. Fidgets with hands or feet or squirms in seat
- ADHD_D1_11. Leaves seat when remaining seated is expected
- ADHD_D1_12. Runs about or climbs excessively in situations when remaining seated is expected
- ADHD_D1_13. Has difficulty playing or engaging in leisure activities quietly
- ADHD_D1_14. Is "on the go" or often acts as if "driven by a motor"
- ADHD_D1_15. Talks too much
- ADHD_D1_16. Blurts out answers before questions have been completed
- ADHD_D1_17. Has difficulty waiting his or her turn
- ADHD_D1_18. Interrupts or intrudes on others (butts into conversations or games)

D2. Performance

[SKIP TO ADHD_E7 IF TS MODULE WAS COMPLETED.]

- ADHD_D2_1. How would you describe [child]'s overall school performance? Would you say:
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent
- ADHD_D2_2. How about reading? Would you say:
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent
- ADHD_D2_3. Writing?
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent
- ADHD_D2_4. Mathematics?
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent
- ADHD_D2_5. How would you describe [child]'s relationship with [his/her] parents? Would you say:
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent
- ADHD_D2_6. How about relationships with siblings?
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent
(6) Child does not have siblings
- ADHD_D2_7. Relationships with peers?
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent
- ADHD_D2_8. How would you describe [child]'s participation in organized activities such as teams? Would you say:
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent
- ADHD_D2_9. How would you describe [child]'s handwriting, that is, his/her ability to form letters and numbers that are clear and can be recognized? Would you say:
(1) Problematic (2) Somewhat of a problem (3) Average (4) Above Average (5) Excellent

E. Academic Health and Discipline

ADHD_E1. Overall, would you consider [child] an [READ RESONSES]:

HELP TEXT: A = EXCEPTIONAL; B = ABOVE AVERAGE; C = AVERAGE; D = BELOW AVERAGE; F = FAILING

- (6) A student
- (7) B student
- (8) C student
- (9) D student, or
- (10) F Student?

ADHD_E2. What kind of school is [child] currently enrolled in? Is it a public school, private school, or home-school?

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.

- (1) Public
- (2) Private
- (3) Home-schooled
- (4) [Child] is not enrolled in school

ADHD_E3. Since starting kindergarten, has [he/she] repeated any grades?

- (1) Yes
- (2) No (Go to F5)

ADHD_E4. Which grade or grades did [he/she] repeat? [Mark all that apply.]

- (14) Kindergarten
- (15) 1st grade
- (16) 2nd grade
- (17) 3rd grade
- (18) 4th grade
- (19) 5th grade
- (20) 6th grade
- (21) 7th grade
- (22) 8th grade
- (23) 9th grade
- (24) 10th grade
- (25) 11th grade
- (26) 12th grade

ADHD_E5. Has [child] ever been expelled or asked not to return to a childcare center, preschool, or school?

- (1) Yes

- (2) No (Go to ADHD_E7)

ADHD_E6. In what grade or grades was [child] expelled or asked not to return to school?
[CHECK ALL THAT APPLY]

INTERVIEW INSTRUCTION: DO NOT READ RESPONSE OPTIONS

- (16) Childcare (birth through age 2)
- (17) Preschool (3 through age 5)
- (18) Kindergarten
- (19) 1st grade
- (20) 2nd grade
- (21) 3rd grade
- (22) 4th grade
- (23) 5th grade
- (24) 6th grade
- (25) 7th grade
- (26) 8th grade
- (27) 9th grade
- (28) 10th grade
- (29) 11th grade
- (30) 12th grade

ADHD_E7. Has [child] ever had to appear in court for something he/she had done?

- (1) Yes
- (2) No

F. Family Impact of ADHD

- ADHD_F1_1. Has [child]'s ADHD caused financial problems for your family?
(1) Yes
(2) No
- ADHD_F1_2. Have you or other family members stopped working because of [child]'s ADHD?
(1) Yes
(2) No
- ADHD_F1_3. [IF ADHD_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 [child]'s ADHD?
(1) Yes
(2) No
- ADHD_F1_4. Have you or other family members avoided changing jobs because of concerns about maintaining health insurance for [child]?
(1) Yes
(2) No

G. ACS Questions

[SKIP TO ADHD_ADDRESS_CONF IF TS MODULE WAS COMPLETED.]

ADHD_G1_1. How well does [child] speak English? (for children 5 or older)

- (1) Very well
- (2) Well
- (3) Not Well
- (4) Not at All

ADHD_G1_2. Is [child] deaf or have serious difficulty hearing?

- (1) Yes
- (2) No

ADHD_G1_3. Is [child] blind or have serious difficulty seeing, even when wearing glasses?

- (1) Yes
- (2) No

ADHD_G1_4. Because of a physical, mental or emotional condition, does [child] have serious difficulty concentrating, remembering, or making decisions?

- (1) Yes
- (2) No

ADHD_G1_5. Does [child] have serious difficulty walking or climbing stairs? (for children 5 or older)

- (1) Yes
- (2) No

ADHD_G1_6. Does [child] have difficulty dressing or bathing? (for children 5 or older)

- (1) Yes
- (2) No

ADHD_G1_7. Because of a physical, mental or emotional condition, does [child] have difficulty doing errands alone such as visiting a doctor's office or shopping? (for children 15 and older)

- (1) Yes
- (2) No

H. Household and Demographics

[SKIP THIS SECTION IF TS MODULE WAS COMPLETED AND FILL RESPONSES FROM TS QUESTIONS.]

ADHD _H_INTRO Thank you for your answers. Now I have a few more general questions about [S.C.] and your household.

ADHD _H1_Q01 Including the adults and all the children, how many people live in this household?

ENTER 77 FOR DON'T KNOW AND 99 FOR REFUSED
ENTER NUMBER: _____

ADHD _H1_Q02 I have that you are [S.C.]'s [FILL FROM K1Q02]. Is that correct?

- (01) YES [GO TO ADHD _H1_Q2_CHK]
- (02) NO [GO TO ADHD _H1_Q2_CHK]
- (77) DON'T KNOW [GO TO ADHD _H1_Q2_CHK]
- (99) REFUSED [GO TO ADHD _H1_Q2_CHK]

ADHD _H1_Q03 IF K1Q02=77, 99 OR ADHD _H1_Q02=02, 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=01 AND K1Q02=01 THEN DISPLAY:
Are you [S.C.]'s biological, adoptive, step, or foster mother?

IF ADHD _H1_Q02=01 AND K1Q02=02 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

ADHD_H1_Q04 IF ADHD_H1_Q01= 2 THEN SKIP TO ADHD_H1_Q04_CONF

IF ADHD_H1_Q01 = DK/RF, 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 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.]? *[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?

PARENT

(01) BIOLOGICAL MOTHER
FATHER

(02) STEP MOTHER

(03) FOSTER MOTHER

(04) ADOPTIVE MOTHER

(05) MOTHER, but TYPE REFUSED
REFUSED

(06) BIOLOGICAL

(07) STEP FATHER

(08) FOSTER FATHER

(09) ADOPTIVE FATHER

(10) FATHER, but TYPE

OLDER RELATIVES OR GUARDIANS

(11) GRANDMOTHER

(12) GRANDFATHER

(13) AUNT

(14) UNCLE

(15) FEMALE GUARDIAN

(16) MALE GUARDIAN

OTHER RELATIVES

- (17) SISTER
- (18) BROTHER
- (19) COUSIN
- (20) IN-LAW OF ANY TYPE
- (21) [S.C.]'S CHILD, SON, OR DAUGHTER
- (22) OTHER RELATIVE / FAMILY MEMBER

OTHER NON-RELATIVES

- (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_Q04_CONF I am now going to list all the people that live in your household.

I have that [LIST OF RELATIONSHIPS ROSTERED] live in this household with [S.C.].

Is this a correct list of everyone living in your household?

- (1) CONFIRMED - THIS LIST IS CORRECT
- (2) NOT CORRECT - RETURN TO ADHD_H1_Q01 AND START AGAIN

ADHD_H1_Q04_WARNING

Earlier you told me that there are [VALUE FROM ADHD_H1_Q01] people living in your household. However, based on the relationships you just gave, I have [COUNT OF RELATIONSHIPS INCLUDING R & SC] people living in your household. Let's re-confirm your answers.

- (1) RETURN TO RE-CONFIRM ANSWERS [GO TO ADHD_H1_Q01] USE RARELY:
- (2) ISSUE CANNOT BE RESOLVED - CONTINUE ON [GO TO ADHD_H1_Q03_ADOPT]

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_Q02
- (99) REFUSED > SKIP TO ADHD_H2_Q02

ADHD_H2_Q01_CONF 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 [SKIP TO ADHD_H2_Q04]
- (2) NOT CORRECT - CHILD HAS INSURANCE - RETURN TO ADHD_H2_Q01 AND ENTER CORRECT RESPONSE [SKIP TO ADHD_H2_Q01]

ADHD_H2_02

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_Q03

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

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 [GO TO ADHD_H3_Q01_CONF]:

- [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_Q01_CONF Just to confirm that I entered it correctly, the total income of all family members was [AMOUNT FROM ADHD_H3_Q01]. Is that correct?

- (1) YES > GO TO TS_ADDRESS_CONF
- (2) NO > GO TO TS_H3_Q01

ADHD_H3_Q02

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 [GO TO ADHD_H3_Q05]
- (77) DON'T KNOW [GO TO ADHD_ADDRESS_CONF]
- (99) REFUSED [GO TO ADHD_ADDRESS_CONF]

ADHD_H3_Q03

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 ADHD_H1_Q01= (8, 9) GO TO ADHD_H3_Q04; ELSE GO TO ADHD_ADDRESS_CONF]
- (77) DON'T KNOW [GO TO ADHD_ADDRESS_CONF]
- (99) REFUSED [GO TO ADHD_ADDRESS_CONF]

ADHD_H3_Q04

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 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 ADHD_ADDRESS_CONF]
- (2) [FILL: Poverty threshold for household of size ADHD_H1_Q01] OR MORE [GO TO ADHD_ADDRESS_CONF]
- (77) DON'T KNOW [GO TO ADHD_ADDRESS_CONF]
- (99) REFUSED [GO TO ADHD_ADDRESS_CONF]

ADHD_H3_Q05

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 ADHD_ADDRESS_CONF]
- (77) DON'T KNOW [GO TO ADHD_ADDRESS_CONF]
- (99) REFUSED [GO TO ADHD_ADDRESS_CONF]

ADHD_H3_Q06

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

ADHD Medication Follow-Up

CPGOGETMED_ADHD

IF TS_ELIG=1 AND TS_C1_4= 77 GO TO GOGETMED_TS. IF TS_ELIG=0 AND ADHD_C1_4=77 GO TO GOGETMED_ADHD. ELSE GO TO ADDRESS CONFIRMATION

GOGETMED_TS

Earlier you told me that [S.C.] has taken medication for [TS AND/OR ADHD] in the past week, however you did not know the name of the medication. Before we finish the interview, can you please take a moment to get [S.C.]'s medication so we may record the name of the medication?

READ IF NECESSARY: If [S.C.] takes more than one medication for [TS AND/OR ADHD], please get all the medications so we can record each name.

(1) YES **[SKIP TO GOGETMED_CNFM]**
(99) REFUSED **[GO TO ADDRESS CONFIRMATION]**

GOGETMED_CNFM

READ AS NECESSARY: Please read the name of each medication that [S.C.] takes for TS.

READ AS NECESSARY: Thank you for taking the time to get the medication.

INTERVIEWER INSTRUCTIONS: MARK ALL THAT APPLY AMONG 1-18. DO NOT READ LIST.

- (1) Abilify, Abilify Maintena, Abilify Discmelt
- (2) Apo-Metoclop
- (3) Apokyn
- (4) Apomorphine
- (5) Aricept, Aricept ODT
- (6) Aripiprazole
- (7) Baclofen
- (8) Botulinum toxin, Botox
- (9) Clonazepam
- (10) Clonidine, Clonidine ER
- (11) Catapres, Catapres-TTS
- (12) Deltanyne
- (13) Donepezil
- (14) Dronabinol
- (15) Duraclon

- (16) Dysport
- (17) Fluphenazine
- (18) Gablofen
- (19) Geodon
- (20) Guanfacine
- (21) Haloperidol, Haldol, Haldol Decanoate
- (22) Intuniv
- (23) Kapvay
- (24) Keppra, Keppra XR
- (25) Kemstro
- (26) Klonopin, Klonopin Wafer
- (27) Levetiracetam
- (28) Lioresal
- (29) Marinol
- (30) Metoclopramide, Metoclopramide Hydrochloride Injection, Metoclopramide
Omega, Nu-Metoclopramide, PMS-Metoclopramide
- (31) Mirapex, Mirapex ER
- (32) NAC
- (33) Neurobloc
- (34) Nexiclon
- (35) Olanzapine
- (36) Ondansetron
- (37) Orap
- (38) Pergolide
- (39) Permax
- (40) Permitil
- (41) Pimozide
- (42) Pramipexole
- (43) Prolixin, Prolixin Decanoate, Prolixin Enanthate
- (44) Quetiapine
- (45) Requip
- (46) Risperidone, Risperdal, Risperdal Consta, Risperdal M-Tab
- (47) Ropinirole
- (48) Sativex
- (49) Seroquel, Seroquel XR
- (50) Tenex
- (51) Tetrabenazine
- (52) Tetrahydrocannabinol, Δ -9-THC
- (53) Topamax, Topamax Sprinkle
- (54) Topiramate, Topiragen
- (55) Xenazine
- (56) Ziprasidone
- (57) Zofran
- (58) Zyprexa, Zyprexa Zydis, Zyprexa Relprevv, Zyprexa Intramuscular
- (59) OTHER [GO TO GOGETMED_TS_VERBATIM]
- (60) NOT CURRENTLY TAKING MEDICATION

- (77) DON'T KNOW
- (99) REFUSED

GOGETMED_TS_VERBATIM

ENTER OTHER MEDICATION. IF MORE THAN ONE MEDICATION IS GIVEN ENTER ALL MEDICATIONS ON ONE LINE.

_____ ENTER TEXT

GOGETMED_ADHD

Earlier you told me that [S.C.] has taken medication for ADHD in the past week, however you did not know the name of the medication. Before we finish the interview, can you please take a moment to get [S.C.]'s medication so we may record the name of the medication?

READ IF NECESSARY: If [S.C.] takes more than one medication for ADHD, please get all the medications so we can record each name.

- (1) YES **[SKIP TO GOGETMED_CNFM]**
- (99) REFUSED **[GO TO ADDRESS CONFIRMATION]**

GOGETMED_ADHD_CNFM

READ AS NECESSARY: Please read the name of each medication that [S.C.] takes for ADHD.

READ AS NECESSARY: Thank you for taking the time to get the medication.

INTERVIEWER INSTRUCTIONS: MARK ALL THAT APPLY AMONG 1-18. DO NOT READ LIST.

- (1) ABILIFY, ARIPIPRAZOLE
- (2) AMPHETAMINE (am-FET-a-meen)
- (3) ADDERALL (ADD-ur-all)
- (4) ADDERALL XR
- (5) BUPROPRION, WELLBUTRIN
- (6) CELEXA, CITALOPRAM (si-TAL-o-pram)
- (7) CLONIDINE, KAPVAY
- (8) CONCERTA
- (9) DEXEDRINE, DEXEDRINE SPANSULE, DEXTROSTAT, DEXTRO-AMPHETAMINE
- (10) DEXMETHYLPHENIDATE
- (11) FLUOXETINE (floo-ox-e-teen)
- (12) FOCALIN
- (13) FOCALIN XR

- (14) GUANFACINE, INTUNIV, TENEX
- (15) METADATE, METADATE CD
- (16) METHYLIN
- (17) METHYLPHENIDATE
- (18) METHYLPHENIDATE PATCH (DAYTRANA)
- (19) QUILLIVANT
- (20) PROZAC
- (21) RISPERDAL, RISPERIDONE, RISPERIDOL
- (22) RITALIN
- (23) RITALIN LA, RITALIN SR
- (24) SERTRALINE (SER-tra-leen)
- (25) STRATTERA, ATOMOXETINE (AT-oh-mox-e-teen)
- (26) VYVANSE, LISDEXAMFETAMINE (lis-dex-am-FET-a-meen)
- (27) ZOLOFT
- (28) OTHER (Specify): _____[GO TO ADHD_C1_4_VERBATIM]
- (66) NOT CURRENTLY TAKING MEDICATION
- (77) DON'T KNOW
- (66) (99) REFUSED

GOGETMED_ADHD_VERBATIM

ENTER OTHER MEDICATION. IF MORE THAN ONE MEDICATION IS GIVEN ENTER ALL MEDICATIONS ON ONE LINE.

_____ ENTER TEXT

[TIMESTAMP_GOGET_END]

ADHD Address Confirmation

ADHD_ADDRESS_CONF IF (NSDATA_INCENT_FLAG = 2 OR NSDATA_PASSIVE in (1,2))AND NSDATA_LETTER_FLG = 2 AND TS_END=1 THEN FILL MONEY_4 = \$45;

ELSE IF (NSDATA_INCENT_FLAG=1 OR NSDATA_PASSIVE=0) AND TS_END=1 FILL MONEY_3 = \$40;

ELSE IF (NSDATA_INCENT_FLAG = 2 OR NSDATA_PASSIVE in (1,2))AND NSDATA_LETTER_FLG = 2 AND TS_END=0 THEN FILL MONEY_2 = \$25;

ELSE FILL MONEY_1= \$20;

Those are all the questions I have.

[IF TS_ELIG=0 DISPLAY: Before I go, I'll need your mailing address so we can send you \$ [MONEY_1 / MONEY_2/MONEY_3/MONEY_4] as a token of our appreciation for taking the time to answer our questions.

[IF TS_ELIG=1 DISPLAY: I would like to again confirm your mailing address to ensure you receive \$ [MONEY_1 / MONEY_2/MONEY_3/MONEY_4] 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.

NSDATA_END_TIME

CALLBACK AND ANSWERING MACHINE SCRIPTS

INTRO_CB USE INTRO_CB ONLY IF INTRO3=1, 2, 77, OR 99; ELSE USE INTRO1

Hello, my name is _____. I'm calling on behalf of the CDC's National Center for Health Statistics [(NSDATA_INCENT_FLAG = 2 AND NSDATA_LTR_FLAG = 1 THEN, "to follow up on a letter that was sent to your home"/ ELSE NO FILL]. Earlier, we contacted your household to participate in a survey about children with ADHD or Tourette Syndrome. I'm calling back to continue the interview. For quality assurance, this call may be monitored or recorded. May I please speak with [SC]'s [RELATION]?

(IF NAME WAS GIVEN FOR APPOINTMENT, ASK FOR THAT PERSON.)

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, RECORDING OK <IF RDD_NCCELL_CCELL=1 THEN GO TO INTRO3; IF RDD_NCCELL_CCELL=2,3 THEN GO TO S_WARM>
- (2) YES, SPEAKING WITH THAT PERSON, RECORDING REFUSED <IRDD_NCCELL_CCELL=1 THEN GO TO INTRO3; IF RDD_NCCELL_CCELL=2,3 THEN GO TO S_WARM>
- (3) YES, NEW PERSON COMES TO PHONE <REPEAT INTRO_CB>
- (4) NO, NOT AVAILABLE NOW <SET GCB AND TERMINATE>
- (5) TERMINATE INTERVIEW => GO TO T1
- (6) NO, PERSON HAS MOVED OR HAS NEW PHONE NUMBER <IF RDD_NCCELL_CCELL=1 THEN GO TO LOC_A; ELSE IF RDD_NCCELL_CCELL=2,3 THEN GO TO S_WARM>
- (7) NO, PERSON IS DECEASED <GO TO DECEASED>
- (8) NO, CHILD IS DECEASED <GO TO DECEASED>

REMIND1 I want to remind you that we will be asking questions about [SC] for the rest of this interview, and we will send you \$[MONEY] for completing the interview.

FOR ALL CASES THAT HAVE NOT YET MADE CONTACT WITH A LIVE PERSON IN NS-DATA:

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 APPROPRIATE: "to follow up on a letter that was sent to your home"]. 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, or a knowledge parent or guardian

to complete a survey on children with specific special health care needs. If you would like to participate right away, please call our toll-free number, at [NUMBER]. In appreciation for your time, we will send you [MONEY AMOUNT] in cash once the interview is completed. Again, our toll-free number is [NUMBER]. Thank you.

FOR ALL CASES IN THE NS-DATA INTERVIEW:

MSG_NSDATA (PLEASE READ SLOWLY AND CLEARLY.) Hello. I'm calling on behalf of the CDC's National Center for Health Statistics [(NS_DATA_INCENT_FLAG = 2 OR NS_DATA_PASSIVE = 1 or 2) AND NS_DATA_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 with specific special health care needs. I'm calling back to continue the interview (IF INCENTIVE CASE, DISPLAY: "In appreciation for your time, we will send you \$[MONEY_4/MONEY_5] for completing the interview."). Thank you.

FOR SCHEDULED NSDATA APPTS WHERE RESPONDENT DOES NOT ANSWER PHONE:

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 with specific special health care needs. 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 [NUMBER]. In appreciation for your time, we will send you \$[MONEY] for completing the interview. Thank you.