

2011 SURVEY OF PATHWAYS TO DIAGNOSIS AND SERVICES **An American Recovery and Reinvestment Act Project**

Sponsored by the National Institute of Mental Health, National Institutes of Health
Conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention

INTRODUCTION	2
ELIGIBILITY CONFIRMATION	3
INFORMED CONSENT	5
PARENTAL CONCERNS	6
DIAGNOSTIC EXPERIENCES.....	11
HEALTH CARE SERVICES	18
EDUCATIONAL SERVICES	25
UNMET NEEDS AND INSURANCE ADEQUACY.....	27
FUNCTIONING, STRENGTHS, AND DIFFICULTIES	28
WANDERING AND WANDERING PREVENTION.....	29
PARENTAL PERCEPTIONS	30
FAMILY AND DEMOGRAPHICS	31

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

NOTES: This questionnaire reflects the survey as administered. All questions have Don't Know (DK) and Refused (RF) as answer options, whether or not those choices are specifically included in this questionnaire.

Data users should not rely on the coding system reflected in this questionnaire. Data files from the survey use an alternative coding system, such as zero for No, six for Don't Know, seven for Refused, and other numeric codes for selected verbatim responses. Data users should refer to the assigned labels in the data files to verify the codes used for each question.

INTRODUCTION

INTRO Hello, my name is _____. I'm calling on behalf of the CDC's National Center for Health Statistics. 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. Are you this child's [RELATION]?

IF YES AND SPEAKING ON A LANDLINE, CATI WILL GO TO INTRO_3.

IF YES AND SPEAKING ON A CELL PHONE, CATI WILL GO TO QUESTIONS ABOUT RESPONDENT'S SAFETY BEFORE GOING TO INTRO_3.

IF NEW PERSON COMES TO PHONE, CATI WILL REPEAT INTRO_2.

IF PERSON HAS MOVED OR HAS NEW PHONE NUMBER, CATI WILL GO TO QUESTIONS THAT COLLECT LOCATING INFORMATION.

IF PERSON OR CHILD IS DECEASED, A POLITE EXIT SCRIPT IS READ.

IF PERSON IS UNKNOWN OR IF SOMEONE ANSWERING THE PHONE INDICATES THAT A BUSINESS HAS BEEN REACHED, AN EXIT SCRIPT IS READ.

OTHER ROUTES ARE SCRIPTED IF RESPONDENTS HANG UP DURING THE INTRODUCTION, REQUEST A COPY OF THE ADVANCE LETTER, OR INDICATE THAT THEY WILL CALL 800 LINE AFTER CHECKING SURVEY WEBSITE.

ELIGIBILITY CONFIRMATION

INTRO3. Thank you for previously completing the National Survey of Children with Special Health Care Needs. We appreciate your 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 learning and developmental conditions. This survey will provide information to researchers on how certain developmental conditions are diagnosed and treated. Some of the questions may seem like those you answered before. If you qualify for and complete this survey, we will pay you \$[MONEY_4/MONEY_5] for your time.

[IF PATHWAYS_INCENT_FLAG=2 AND PATHWAYS_LTR_FLAG=2, THEN FILL MONEY_5; ELSE FILL MONEY_4]

COND_ We are calling you because you previously said that a doctor or other health care provider
CONFIRM once told you that your child had:

[IF K2Q35A=1 ADD "autism or an autism spectrum disorder"
IF K2Q37A=1 ADD "an intellectual disability or mental retardation"
IF K2Q36A=1 ADD "a developmental delay that affected [IF SCSEX=1 THEN FILL
"his"; ELSE IF SCSEX=2 THEN FILL "her"] ability to learn"

IF MORE THAN ONE OF THESE ITEMS = 1, THEN ADD "and" BETWEEN EACH
ADDITIONAL STATEMENT.

Is that correct?

- (1) YES, CONTINUE [GO TO AGE]
- (2) CHILD DOES NOT HAVE CONDITION(S)
- (77) DON'T KNOW
- (99) REFUSED

COND_CHK. I am going to read you a list of conditions. 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.*

Has a doctor or other health care provider ever told you that your child had...

COND_A Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder?

COND_B Any developmental delay that affects [his/her] ability to learn?

COND_C Intellectual disability or mental retardation?

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

IF COND_A=1 OR COND_B=1 OR COND_C=1 THEN GO TO AGE; ELSE GO TO COND_EXIT

COND_EXIT Those are all the questions I have. You and your child are not eligible for this follow-up survey. I'd like to thank you on behalf of the CDC's National Center for Health Statistics for the time and effort you've spent answering these questions.

TERMINATE

AGE When we last spoke, your child was [NS-CSHCN AGE IN MONTHS OR YEARS]. How old is [he/she] now?

RECORD VALUE: _____

AGE1 (1) MONTHS
(2) YEARS

IF CHILD IS NOT 6-17 YEARS OLD GO TO AGE_EXIT

AGE_EXIT We are only interviewing parents whose child is 6 to 17 years old. I'd like to thank you on behalf of the CDC's National Center for Health Statistics for the time and effort you've spent answering these questions.

TERMINATE

INHOUSE Is [SC] still living with you?

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

INHOUSE_EXIT

We are only interviewing parents if the child still resides in their household. 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.

TERMINATE

SC_NAME I can continue to refer to your child as [FILL REFNAME1 IF VALUE WAS PROVIDED IN NSCSHCN, OR FILL AGEID FROM PATHWAYS IF REFNAME1 IS BLANK], or if you prefer, you could give me another name to refer to your child as for this survey.

(1) CONTINUE TO USE AGE REFERENCE [GO TO CONSENT]
(2) USE NAME [GO TO SELECTION1_NAME_A]

SC_NAME_A ENTER NAME/INITIALS: _____ [GO TO CONSENT]
(99) REFUSED [GO TO CONSENT]

INFORMED CONSENT

CONSENT Before we continue, I'd like you to know that taking part in this research is voluntary. You may choose not to answer any question you don't wish to answer, or end the interview at any time with no impact on the benefits you may receive. We are required by Federal law to develop and follow strict procedures to protect the confidentiality of your information and use your answers only for statistical research. I can describe these laws if you wish. In appreciation for your time, we will send you \$[MONEY_4/MONEY_5]. 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.

[IF PATHWAYS_INCENT_FLAG=2 AND PATHWAYS_LTR_FLAG=2, THEN FILL MONEY_5; ELSE FILL MONEY_4]

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

PARENTAL CONCERNS

PC1 I would like to ask you a little about [SC's] early development. How old was [SC] when you first wondered if there might be something not quite right with [his/her] development?

RECORD VALUE_____ [IF 0, GO TO PC5; ELSE GO TO PC1_A]

RECORD AGE IN MONTHS FOR 0 TO 35 MONTHS. IF 2 YEARS OR OLDER AND MONTHS NOT GIVEN, RECORD AGE IN YEARS 2 TO 17.

(44) CONCERNS PRESENT BEFORE CHILD/PARENT ENTERED FAMILY [GO TO PC5]

(55) CONDITION PRESENT SINCE BIRTH [GO TO PC5]

(66) RESPONDENT NEVER NOTICED/WAS NEVER CONCERNED [GO TO DXINTRO]

(77) DON'T KNOW [GO TO PC3]

(99) REFUSED [GO TO PC3]

PC1_A (1) YEARS
(2) MONTHS

PC2_INTRO There are many reasons why a parent might be concerned about a child's development. I am going to read you a list of behaviors that can cause a parent to be concerned. I want you to think about the concerns you had when [SC] was [FILL AGE FROM PC1 AND PC1_A]. For each behavior that I read, please tell me if this was one of the reasons you were concerned about [his/her] development at that time.

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

READ THIS STEM FOR ALL QUESTIONS IN PC2:

When [he/she] was [FILL AGE FROM PC1], were you concerned that [he/she]...

PC2_A Had medical problems such as seizures, lack of physical growth, or stomach problems

PC2_B Didn't make eye contact when talking or playing with others?

PC2_C Didn't respond when called or didn't respond to sounds?

PC2_D Didn't seem to understand nonverbal communication, such as understanding what you meant by the tone of voice you used or your facial expressions or other body language cues?

PC2_E Had behavioral difficulties such as sleeping or eating problems, high activity level, wandering, tantrums, aggressive or destructive behavior?

PC2_F Had problems with coordination or gross motor skills such walking?

IF AGE AT PC1 < 6 MONTHS, SKIP TO PC3. ELSE ASK PC2_G.

PC2_G Talked later than usual for most children?

IF AGE AT PC1 < 9 MONTHS, SKIP TO PC3. ELSE ASK PC2_H.

When [he/she] was [FILL AGE FROM PC1], were you concerned that [he/she]...

- PC2_H Was not talking at all?
- PC2_I Did not talk as well as other children that were the same age?
- PC2_J Some speech skills that [he/she] had already developed were lost?
- PC2_K Didn't seem to understand what you or other adults said to [him/her]?

IF AGE AT PC1 < 12 MONTHS, SKIP TO PC3. ELSE ASK PC2_L.

- PC2_L Had problems with fine motor skills such as using scissors or drawing with crayons?
- PC2_M Had difficulty playing or interacting with others, or played alone "in [his/her] own world"?
- PC2_N Insisted on sameness or had difficulties with change?
- PC2_O Had difficulty learning new skills such as toilet training or getting dressed?
- PC2_P Had difficulty learning new things such as the alphabet or numbers?
- PC2_Q Had unusual gestures or movements such as hand-flapping, toe-walking, or self-spinning?

HELP TEXT FOR ALL QUESTIONS IN PC2: CODE "NO" IF RESPONDENT INDICATES THAT THE CHILD DID NOT HAVE THAT PROBLEM AT THAT AGE.

- PC3 Were you the first person who had the concern that something didn't seem right with [SC]'s development?

- (1) YES [GO TO PC5]
- (2) NO [GO TO PC4]
- (77) DON'T KNOW [GO TO PC5]
- (99) REFUSED [GO TO PC5]

- PC4 Who first had the concern that something didn't seem right with [SC]'s development?

- (1) MOTHER
- (2) FATHER
- (3) FAMILY MEMBER/RELATIVE
- (4) A DOCTOR OR OTHER HEALTH CARE PROVIDER
- (5) A TEACHER
- (6) THE SCHOOL COUNSELOR OR NURSE
- (7) FAMILY FRIEND
- (8) OTHER [GO TO PC4_OTHER]
- (77) DON'T KNOW
- (99) REFUSED

- PC4_OTHER RECORD VERBATIM RESPONSE

PC5 Did you *ever* talk to a doctor or health care provider about your concerns?

- (1) YES
- (2) NO [GO TO PC8]
- (77) DON'T KNOW [GO TO PC8]
- (99) REFUSED [GO TO PC8]

PC6 How old was [SC] when you first talked to a doctor or health care provider about your concerns?

RECORD VALUE _____

RECORD AGE IN MONTHS FOR 0 TO 35 MONTHS. IF 2 YEARS OR OLDER AND MONTHS NOT GIVEN, RECORD AGE IN YEARS.

PC6_A (1) MONTHS
(2) YEARS

PC7_A How did that doctor or health care provider respond to your concern?

INTERVIEWER INSTRUCTION: READ EACH RESPONSE OPTION 1 - 7 TO THE RESPONDENT AND PROMPT FOR A YES OR NO ANSWER FOR EACH. MARK ALL THAT APPLY.

REPEAT QUESTION STEM AS NEEDED.

- (1) Did they conduct developmental tests?
- (2) Did they make a referral to a specialist; such as a developmental pediatrician, child psychologist, occupational, or speech therapist?
- (3) Did they suggest that you discuss the concern with the school?
- (4) Did they say nothing was wrong, the behavior was normal?
- (5) Did they say it was too early to tell if anything was wrong?
- (6) Did they say that your child might "grow out of it?"
- (7) Did they do or say anything else? [GO TO PC7A_OTHER]
- (77) DON'T KNOW
- (99) REFUSED

PC7A_OTHER RECORD VERBATIM RESPONSE

PC7_B *ASK ONLY IF PC6 IS LESS THAN 6 YEARS OF AGE. OTHERWISE, SKIP TO PC8.*

Did the doctor or health care provider have you fill out a questionnaire about specific concerns or observations you may have had about [SC]'s development, communication, or social behaviors?

- (1) YES
- (2) NO [GO TO PC7_G]
- (77) DON'T KNOW [GO TO PC7_G]
- (99) REFUSED [GO TO PC7_G]

PC7_C *ASK ONLY IF PC6 IS LESS THAN 24 MONTHS OF AGE. OTHERWISE, SKIP TO PC7_E*

Did this questionnaire ask about your concerns or observations about how [SC] talks or makes speech sounds?

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

PC7_D Did this questionnaire ask about your concerns or observations about how [SC] interacts with you and others?

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

[AFTER PC7_D IS COMPLETED, ALL SKIP TO PC7_G]

PC7_E Did this questionnaire ask about your concerns or observations about words and phrases [SC] uses and understands?

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

PC7_F Did this questionnaire ask about your concerns or observations about how [SC] behaves and gets along with you and others?

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

PC7_G Sometimes doctors or other health care providers try to learn how a child is developing by having them do certain tasks. This is called a developmental screening or assessment. Did the doctor or health care provider tell you that they were carrying out a developmental screening or assessment of [SC]?

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

PC7_H *ASK ONLY IF PC6 IS AT LEAST 12 MONTHS OF AGE. OTHERWISE, SKIP TO PC8*

Did the doctor or health care provider have [SC] perform certain tasks such as picking up small objects or stacking blocks or throwing a ball or recognizing different colors?

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

PC8 Did you *ever* talk to a teacher, school nurse, school counselor, or other school professional about your concerns with [SC]’s development?

- (1) YES [GO TO PC9]
- (2) NO [GO TO PC11]
- (77) DON’T KNOW [GO TO PC11]
- (99) REFUSED [GO TO PC11]

PC9 How old was [SC] when you first talked to a teacher, school nurse, school counselor, or other school professional about your concerns?

RECORD VALUE _____

RECORD AGE IN MONTHS FOR 0 TO 35 MONTHS. IF 2 YEARS OR OLDER AND MONTHS NOT GIVEN, RECORD AGE IN YEARS.

PC9_A (1) MONTHS
(2) YEARS

PC10 How did that school professional respond to your concern?

INTERVIEWER INSTRUCTION: READ EACH RESPONSE OPTION 1 - 8 TO THE RESPONDENT AND PROMPT FOR A YES OR NO ANSWER FOR EACH. MARK ALL THAT APPLY.

REPEAT QUESTION STEM AS NEEDED.

- (1) Did they conduct developmental tests?
- (2) Did they make a referral to an in-school specialist?
- (3) Did they make a referral to a specialist outside the school system; such as developmental pediatrician, child psychologist, occupational or speech therapist?
- (4) Did they suggest that you discuss the concern with the child’s doctor?
- (5) Did they say nothing was wrong, the behavior was normal?
- (6) Did they say it was too early to tell if anything was wrong?
- (7) Did they say that your child might “grow out of it?”
- (8) Did they do or say anything else? [GO TO PC10_OTHER]
- (77) DON’T KNOW
- (99) REFUSED

PC10_OTHER RECORD VERBATIM RESPONSE

PC11 *ASK ONLY IF PC5 IS 2, 77, OR 99 AND IF PC8 IS 2, 77, OR 99. OTHERWISE, GO TO DXINTRO.*

Just to confirm, did you ask for advice about your concerns from any professional such as a doctor, health care provider, teacher, or counselor?

- (1) YES [GO BACK TO PC5]
- (2) NO
- (77) DON’T KNOW
- (99) REFUSED

DIAGNOSTIC EXPERIENCES

DXINTRO Now I would like to ask you about certain conditions that a doctor or other health care provider told you that [SC] had. In our previous interview, you reported that a doctor or other health care provider said, at some point, that [SC] had:

[IF K2Q35A=1 OR COND_A=1 ADD "autism or autism spectrum disorder"
IF K2Q36A=1 OR COND_B=1 ADD "a developmental delay that affects [IF SCSEX=1
THEN FILL "his"; ELSE IF SCSEX=2 THEN FILL "her"] ability to
learn"
IF K2Q37A=1 OR COND_C=1 ADD "an intellectual disability or mental retardation"
IF K2Q31A=1 ADD "Attention Deficit Disorder or Attention Deficit Hyperactivity
Disorder"
IF K2Q32A=1 ADD "depression"
IF K2Q33A=1 ADD "anxiety problems"
IF K2Q34A=1 ADD "behavioral or conduct problems"

IF MORE THAN ONE OF THESE ITEMS = 1, THEN ADD "and" BETWEEN EACH
ADDITIONAL STATEMENT.

IF MORE THAN ONE, ADD: I'm going to ask you some questions about each of these
conditions separately. Let's start with [FILL CONDITION NAME].

*BEGIN A LOOP TO BE ASKED FOR EACH CONDITION IDENTIFIED BY PARENT. USE THE
FOLLOWING TEXT FOR CONDITION FILLS:*

[Autism or ASD] (AUT)	[Depression] (DEP)
[Developmental delay] (DEV)	[Anxiety problems] (ANX)
[Intellectual disability] (INT)	[Behavioral or conduct problems] (BEH)
[ADD or ADHD] (ADD)	

DE_X1 [ONLY ASK IF AUT, DEV, OR INT]

What type of doctor or other health care provider *first* told you that [SC] had [CONDITION]?

HELP TEXT: Who was the first to tell you?

HELP TEXT: IF R SAYS CONDITION NEVER EXISTED OR R 'JUST KNEW', PROBE FOR ANOTHER ANSWER. CODE AS 66 IF R CONTINUES TO SAY THAT CONDITION NEVER EXISTED OR "JUST KNEW."

- (1) PEDIATRICIAN OR OTHER GENERAL PEDIATRIC HEALTH CARE PROVIDER (SUCH AS NURSE PRACTITIONER OR PHYSICIAN'S ASSISTANT IN PEDIATRIC CLINIC)
- (2) ANOTHER TYPE OF GENERAL HEALTH CARE PROVIDER (SUCH AS FAMILY PRACTICE DOCTOR OR NURSE PRACTITIONER OR PHYSICIAN'S ASSISTANT IN GENERAL PRACTICE)
- (3) A SPECIALIST PEDIATRICIAN SUCH AS A DEVELOPMENTAL PEDIATRICIAN
- (4) SCHOOL PSYCHOLOGIST / COUNSELOR
- (5) OTHER PSYCHOLOGIST (NON-SCHOOL)
- (6) PSYCHIATRIST (MEDICAL DOCTOR)
- (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) OTHER [GO TO DE_X1_OTHER]
- (44) TEAM OF PROFESSIONALS/MULTIDISCIPLINARY TEAM
- (66) NO ONE HAS EVER TOLD ME MY CHILD HAS THIS CONDITION [IF 66, GO TO END OF LOOP]
- (77) DON'T KNOW
- (99) REFUSED

DE_X1_OTHER RECORD VERBATIM RESPONSE

DE_X2 How old was [SC] when you were first told that [he/she] had [CONDITION]?

RECORD VALUE _____

- (66) NO ONE EVER TOLD ME THAT MY CHILD HAD THAT CONDITION [IF 66, GO TO END OF LOOP]
- (77) DON'T KNOW
- (99) REFUSED.

ASK FOR AGE IN MONTHS IF CHILD WAS 2 YEARS OR LESS. RECORD AGE IN MONTHS FOR 0 TO 35 MONTHS AND YEARS FOR 2 TO 17 YEARS.

DE_X2A (1) MONTHS
(2) YEARS

DE_X3 [ONLY ASK IF AUT, DEV, OR INT]

Did *any other* doctor, health care provider, or school professional also tell you that [SC] had [CONDITION]?

- (1) YES [GO TO DE_X4]
- (2) NO [GO TO DE_X5A]
- (77) DK [GO TO DE_X5A]
- (99) RF [GO TO DE_X5A]

DE_X4 [ONLY ASK IF AUT, DEV, OR INT]

Who was that? (*MARK ALL THAT APPLY*)

(READ AS NECESSARY: What types of other doctors, health care providers, or school professionals told you that [SC] had [CONDITION]?)

INTERVIEWER PROMPT: Was there anyone else?

- (1) PEDIATRICIAN OR OTHER GENERAL PEDIATRIC HEALTH CARE PROVIDER (SUCH AS NURSE PRACTITIONER OR PHYSICIAN'S ASSISTANT IN PEDIATRIC CLINIC)
- (2) ANOTHER TYPE OF GENERAL HEALTH CARE PROVIDER (SUCH AS FAMILY PRACTICE DOCTOR OR NURSE PRACTITIONER OR PHYSICIAN'S ASSISTANT IN GENERAL PRACTICE)
- (3) A SPECIALIST PEDIATRICIAN SUCH AS A DEVELOPMENTAL PEDIATRICIAN
- (4) SCHOOL PSYCHOLOGIST / COUNSELOR
- (5) OTHER PSYCHOLOGIST (NON-SCHOOL)
- (6) PSYCHIATRIST (MEDICAL DOCTOR)
- (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) OTHER [GO TO DE_X4_OTHER]
- (12) TEACHER
- (77) DON'T KNOW
- (99) REFUSED

DE_X4_OTHER RECORD VERBATIM RESPONSE

DE_X8 [ONLY ASK IF AUT, DEV, OR INT]

How old was [SC] when you were first told that [he/she] did *not* have [CONDITION]?

RECORD VALUE _____

INTERVIEWER NOTE:
 ASK FOR AGE IN MONTHS IF CHILD WAS 2 YEARS OR LESS. RECORD AGE IN MONTHS FOR 0 TO 35 MONTHS AND YEARS FOR 2 TO 17 YEARS.
 ENTER 77 FOR DON'T KNOW AND 99 FOR REFUSED.

DE_X8A (1) MONTHS
 (2) YEARS

DE_X9 When you were told that [he/she] did not have [CONDITION], were you told that [SC] had some other developmental, learning, emotional, or mental health condition?

(1) YES [GO TO DE_X10]
 (2) NO [GO TO DE_X11]
 (77) DON'T KNOW [GO TO DE_X11]
 (99) REFUSED [GO TO DE_X11]

DE_X10 What conditions were you told that [SC] had?

RECORD VERBATIM RESPONSE

DE_X11 To the best of your knowledge, does [SC] currently have [CONDITION]?

(1) YES [GO TO END OF LOOP]
 (2) NO [GO TO DE_X12]
 (77) DON'T KNOW [GO TO END OF LOOP]
 (99) REFUSED [GO TO END OF LOOP]

DE_X12 To the best of your knowledge, did [SC] *ever* have [CONDITION]?

(1) YES [GO TO DE_X13_INTRO]
 (2) NO [GO TO DE_X15A]
 (77) DON'T KNOW [GO TO DE_X15A]
 (99) REFUSED [GO TO DE_X15A]

DE_X13_
INTRO

I am going to read a list of reasons why [SC] may no longer have [CONDITION]. For each reason, please tell me if it applies to [SC].

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

DE_X13A
DE_X13B
DE_X13C
DE_X13D

Treatment helped the condition go away
The condition seemed to go away on its own
The behaviors or symptoms changed
A doctor or health care provider changed the diagnosis

DE_X14

Are there any other reasons why you think [SC] may no longer have [CONDITION]?

(1) YES [GO TO DE_X14A] (2) NO
(77) DON'T KNOW (99) REFUSED

[GO TO END OF LOOP IF NO/DK/RF.]

DE_X14_
OTHER

RECORD VERBATIM RESPONSE [THEN GO TO END OF LOOP]

DE_X15_
INTRO

I am going to read a list of reasons why a doctor, health care provider, or school professional may have told you that [SC] had a condition that [he/she] never had. For each reason, please tell me if it applies to [SC].

DE_X15A
DE_X15B
DE_X15C

With more information, the diagnosis was changed
The diagnosis was given so that [SC] could receive needed services
You disagree with the doctor or other health provider about his or her opinion that [SC] had [CONDITION].

READ AS NECESSARY: This statement relates to whether a doctor, health care provider, or school professional may have told you that [SC] had a condition that [he/she] never had.

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

DE_X16

Are there any other reasons why a doctor or other health care provider may have told you that [SC] had a condition that [he/she] never had?

(1) YES [GO TO DE_X16A] (2) NO
(77) DON'T KNOW (99) REFUSED

[END LOOP IF NO/DK/RF.]

DE_X16A RECORD VERBATIM RESPONSE

END OF LOOP. RETURN TO #1 FOR EACH ADDITIONAL CONDITION. SKIP TO DE17 AFTER THIS SECTION HAS BEEN COMPLETED FOR ALL CONDITIONS.

DE17 Did [SC] ever get a genetic screening to confirm a diagnosis or so that you could learn more about [his/her] conditions?

- (1) YES [GO TO DE18]
- (2) NO [GO TO HCS_INTRO]
- (77) DON'T KNOW [GO TO HCS_INTRO]
- (99) REFUSED [GO TO HCS_INTRO]

DE18 Did the genetic screening confirm or reveal any specific genetic or chromosomal condition?

- (1) YES [GO TO DE19]
- (2) NO [GO TO HCS_INTRO]
- (77) DON'T KNOW [GO TO HCS_INTRO]
- (99) REFUSED [GO TO HCS_INTRO]

DE19 What genetic or chromosomal condition did it confirm or reveal?

RECORD VERBATIM RESPONSE

HEALTH CARE SERVICES

HCS1_INTRO Children with learning and developmental conditions receive many different services to meet their needs. I am going to read a list of possible services. For each one, please tell me whether or not [SC] *ever* used this service to meet [his/her] developmental needs, even if [he/she] is not using the service now.

HELP TEXT: Development refers to your child's physical, social, and emotional growth and learning. Developmental needs are whatever is necessary to support your child's development.

HCS1_A Has [SC] *ever* used Behavioral intervention or modification services to meet [his/her] developmental needs?

INTERVIEWER NOTE: INCLUDES DISCRETE TRIAL TRAINING AND OTHER METHODS OF APPLIED BEHAVIOR ANALYSIS (ABA)

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

HCS1_B Has [SC] *ever* used Sensory integration therapy to meet [his/her] developmental needs?

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

HCS1_C Has [SC] *ever* used Cognitive based therapy to meet [his/her] developmental needs?

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

(READ AS NECESSARY: Has [SC] *ever* used this service to meet [his/her] developmental needs?)

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

HCS1_D School-based occupational therapy?

HCS1_E Other occupational therapy?

HCS1_F School-based physical therapy?

HCS1_G Other physical therapy?

HCS1_H School-based social skills training?

HCS1_I Other social skills training?

HCS1_J School-based speech or language therapy?

HCS1_K Other speech or language therapy?

BEGIN LOOP TO BE ASKED FOR EACH SERVICE IDENTIFIED BY PARENT

THE "X" IN HCS1_X_1 SHOULD BE REPLACED WITH A-L BASED ON SERVICES SELECTED BY R

HCS1_X_1A How old was [SC] when [he/she] first started using [SERVICE]?

RECORD VALUE _____

(77) DON'T KNOW (99) REFUSED

RECORD AGE IN MONTHS FOR 0 TO 35 MONTHS. IF 2 YEARS OR OLDER AND MONTHS NOT GIVEN, RECORD AGE IN YEARS 2 TO 17.

HCS1_X_1B (1) MONTHS
(2) YEARS

HCS1_X_2 Does [SC] currently use [SERVICE] on a regular basis?

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

HCS1_X_3A About how often does [SC] use [SERVICE]?

RECORD VALUE _____

(77) DON'T KNOW [GO TO END OF LOOP]
(99) REFUSED [GO TO END OF LOOP]

RECORD NUMBER OF TIMES AND PERIOD (PER DAY, PER WEEK, PER MONTH, OR PER YEAR).

HCS1_X_3B (1) PER DAY (2) PER WEEK (3) PER MONTH (4) PER YEAR

HCS1_X_4A When [SC] uses [SERVICE], about how long does each session last?

RECORD VALUE _____

RECORD NUMBER AND UNIT OF MEASUREMENT (MINUTES OR HOURS).

HCS1_X_4B (1) MINUTES
(2) HOURS

END OF LOOP. RETURN TO HCS1_X_1 FOR EACH ADDITIONAL SERVICE.

HCS2_INTRO Children with learning and developmental conditions work with many different types of service providers to meet their needs. I am going to read a list of possible providers that [SC] may have worked with at school, at home, at an office, or in a clinic. For each one, please tell me whether or not [SC] *ever* worked with this type of provider to meet [his/her] developmental needs, even if [he/she] is not working with this provider now.

HELP TEXT: Development refers to your child's physical, social, and emotional growth and learning. Developmental needs are whatever is necessary to support your child's development.

(READ AS NECESSARY: Has [SC] *ever* worked with ... to meet [his/her] developmental needs?)

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

HCS2_A	Has [SC] <i>ever</i> worked with an audiologist to meet [his/her] developmental needs?
HCS2_B	Has [SC] <i>ever</i> worked with a developmental pediatrician to meet [his/her] developmental needs?
HCS2_C	Has [SC] <i>ever</i> worked with a neurologist to meet [his/her] developmental needs?
HCS2_D	A nutritionist?
HCS2_E	An at home or long-term nurse?
HCS2_F	A psychiatrist?
HCS2_G	A psychologist or psychotherapist?
HCS2_H	A social worker?

BEGIN LOOP TO BE ASKED FOR EACH PROVIDER IDENTIFIED BY PARENT

THE "X" IN HCS2_X_1A SHOULD BE REPLACED WITH A-H BASED ON PROVIDERS SELECTED

HCS2_X_1A How old was [SC] when [he/she] first started working with [PROVIDER]?

RECORD VALUE _____

(77) DON'T KNOW (99) REFUSED

RECORD AGE IN MONTHS FOR 0 TO 23 MONTHS. IF 2 YEARS OR OLDER AND MONTHS NOT GIVEN, RECORD AGE IN YEARS.

HCS2_X_1B (1) MONTHS
(2) YEARS

HCS2_X_2 Does [SC] *currently* work with [PROVIDER] on a regular basis?

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

[END LOOP IF NO/DK/RF]

HCS2_X_3A About how often does [SC] work with [PROVIDER]?

RECORD VALUE _____

(77) DON'T KNOW [GO TO END OF LOOP]
(99) REFUSED [GO TO END OF LOOP]

RECORD NUMBER OF TIMES AND PERIOD (PER DAY, PER WEEK, PER MONTH, OR PER YEAR).

HCS2_X_3B (1) PER DAY (2) PER WEEK (3) PER MONTH (4) PER YEAR

HCS2_X_4A When [SC] works with [PROVIDER], about how long does each session last?

RECORD VALUE _____

RECORD NUMBER AND UNIT OF MEASUREMENT (MINUTES OR HOURS)

HCS2_X_4B (1) MINUTES
(2) HOURS

END OF LOOP. RETURN TO HCS2_X_1 FOR EACH ADDITIONAL PROVIDER.

HCS3_INTRO Children with learning and developmental conditions sometimes take medications to meet their needs. I am going to read a list of medication types. For each one, please tell me whether or not [SC] *ever* used this type of medication *to meet [his/her] developmental needs*, even if [he/she] is not taking this medication now.

HELP TEXT: Development refers to your child's physical, social, and emotional growth and learning. Developmental needs are whatever is necessary to support your child's development.

INTERVIEWER NOTE: DO NOT READ EXAMPLES OF MEDICATIONS. THESE ARE LISTED TO ASSIST YOU IN IDENTIFYING POSSIBLE EXAMPLES OF EACH MEDICATION TYPE.

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

HCS3_A Has [SC] *ever* used stimulant medications to meet [his/her] developmental needs?
INTERVIEWER HELP: ADDERALL, CONCERTA, DEXEDRINE, RITALIN

HCS3_B Has [SC] *ever* used anti-depressant medications to meet [his/her] developmental needs?
INTERVIEWER HELP: ANAFRANIL, LUVOX, PROZAC, WELLBUTRIN, ZOLOFT

HCS3_C Has [SC] *ever* used anti-anxiety or mood stabilizing medications to meet [his/her] developmental needs?
INTERVIEWER HELP: LITHIUM, VALIUM, XANAX

(READ AS NECESSARY: Has [SC] *ever* used ... to meet [his/her] developmental needs?)

HCS3_D Anti-seizure medications?
INTERVIEWER HELP: DEPAKOTE, LAMICTAL, TEGRETOL, TOPAMAX

HCS3_E Anti-psychotic medications?
INTERVIEWER HELP: ABILIFY, CLOZARIL, GEODON, HALDOL, RISPERDAL, ZYPREXA

HCS3_F Sleep medications?
INTERVIEWER HELP: ATARAX, CATAPRES, TENEX

HCS3_G SILENT PROMPT: RECORD VERBATIM ANY OTHER TYPES OF MEDICATION RESPONDENT REPORTS THAT DO NOT MATCH WITH A CATEGORY ABOVE.

RECORD VERBATIM RESPONSE

BEGIN LOOP TO BE ASKED FOR EACH MEDICATION TYPE IDENTIFIED BY PARENT

*THE "X" IN HCS3_X1 SHOULD BE REPLACED WITH A-F BASED ON MEDICATION TYPES
SELECTED BY R IF HCS3_X = 1.*

HCS3_X_1A How old was [SC] when [he/she] first started taking [MEDICATION TYPE]?

RECORD VALUE _____

RECORD AGE IN MONTHS FOR 0 TO 23 MONTHS. IF 2 YEARS OR OLDER AND
MONTHS NOT GIVEN, RECORD AGE IN YEARS.

HCS3_X_1B (1) MONTHS
(2) YEARS

HCS3_X_2 Does [SC] *currently* take [MEDICATION TYPE] on a regular basis?

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

END OF LOOP. RETURN TO HCS3_X1 FOR EACH ADDITIONAL MEDICATION TYPE.

HCS4

Alternative health care can include acupuncture, chiropractic care, relaxation therapies, herbal supplements, and others. Some therapies involve seeing a practitioner, while others can be done on your own.

Has [SC] *ever* used any type of alternative health care or treatment to meet [his/her] developmental needs?

HELP TEXT: Development refers to your child's physical, social, and emotional growth and learning. Developmental needs are whatever is necessary to support your child's development.

HELP TEXT: RESPONDENTS SHOULD INCLUDE ANY ALTERNATIVE CARE OR THERAPIES USED FOR THE CHILD'S CONDITIONS. IF THE RESPONDENT CONSIDERS THE HEALTH CARE TO BE ALTERNATIVE, IT SHOULD BE INCLUDED. DO NOT TRY TO DETERMINE IF ANY PARTICULAR TYPE OF TREATMENT IS AN "ALTERNATIVE" TREATMENT.

READ IF NECESSARY: Generally, alternative care and treatments are those not typically provided in conventional medical care settings. Examples of relaxation therapies include biofeedback, deep breathing exercises, and yoga. Examples of herbal supplements include any non-vitamin and non-mineral supplement, as well as homeopathic treatments. Other examples of alternative health care could include chelation therapy, energy healing therapy, hypnosis, massage, naturopathy, and use of traditional healers such as an espiritista or a Native American medicine man.

- (1) YES [GO TO HCS5]
- (2) NO [GO TO ES1]
- (77) DON'T KNOW [GO TO ES1]
- (99) REFUSED [GO TO ES1]

HCS5

Does [SC] currently use any type of alternative health care or treatment to meet [his/her] developmental needs?

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

ES9 At any time before [SC] was 3 years old, did [he/she] receive services from a program called Early Intervention Services? Children receiving these services often have an Individualized Family Service Plan.

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

ES10 Were you *ever* told that [SC] was *not* eligible for Early Intervention Services?

(1) YES [GO TO ES11]
(2) NO [GO TO INS1]
(77) DON'T KNOW [GO TO INS1]
(99) REFUSED [GO TO INS1]

ES11 Why were you told that [SC] was *not* eligible for Early Intervention Services?
(*MARK ALL THAT APPLY*)

INTERVIEWER PROMPT: Are there any others?

(1) CHILD'S LEVEL OF FUNCTIONING WAS NOT LOW ENOUGH
(2) INCOME WAS TOO HIGH
(3) DID NOT LIVE IN THE RIGHT LOCATION
(4) SERVICES WOULD NOT BE APPROPRIATE FOR CHILD
(5) PARENT COULD NOT OR WOULD NOT DEVOTE ENOUGH TIME FOR IT
(6) OTHER [GO TO ES11_OTHER]
(77) DON'T KNOW
(99) REFUSED

ES11_OTHER RECORD VERBATIM RESPONSE

UNMET NEEDS AND INSURANCE ADEQUACY

INS1 During the past 12 months, did [SC] receive all the treatments and services necessary to meet [his/her] developmental needs?

HELP TEXT: Development refers to your child’s physical, social, and emotional growth and learning. Developmental needs are whatever is necessary to support your child’s development.

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

INS2 During the past 12 months, did [SC] see all the service providers needed to care for [his/her] developmental needs?

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

INS3 Does [SC] have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?

(1) YES [GO TO INS4] (2) NO [GO TO INS6]
(77) DK [GO TO INS6] (99) RF [GO TO INS6]

INS4 Are there treatments, services, or service providers that [SC] needs that are not covered by [his/her] health insurance?

(1) YES [GO TO INS5] (2) NO [GO TO INS6]
(77) DK [GO TO INS6] (99) RF [GO TO INS6]

INS5 What treatments, services, or service providers are not covered by [his/her] health insurance? (*MARK ALL THAT APPLY*)

INTERVIEWER PROMPT: Are there any others?

- (1) SPEECH OR LANGUAGE THERAPY
- (2) OCCUPATIONAL THERAPY
- (3) BEHAVIORAL MANAGEMENT SERVICES
- (4) PSYCHOLOGICAL SERVICES
- (5) MEDICATIONS / PHARMACY SERVICES
- (6) OTHER [GO TO INS5_OTHER]
- (77) DON’T KNOW
- (99) REFUSED

INS5_OTHER RECORD VERBATIM RESPONSE

INS6 *ASK INS6 ONLY IF CHILD WAS EVER DIAGNOSED WITH AUTISM. OTHERWISE, SKIP TO FSD1.*

Has [SC] ever received Medicaid-reimbursed services for autism?

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

FUNCTIONING, STRENGTHS, AND DIFFICULTIES

FSD1_INTRO I am going to read a list of activities that [SC] may be able to do independently, may be able to do with help, or may not be able to do. For each one, please tell me how capable [he/she] is when doing the following activities?

Would you say [SC] can do this by [himself/herself], can do with help, cannot do, or never tried?

- (1) CAN DO INDEPENDENTLY
- (2) CAN DO WITH HELP
- (3) CANNOT DO
- (4) NEVER TRIED
- (77) DON'T KNOW
- (99) REFUSED

FSD1_A Is [SC] able to go the bathroom by [himself/herself]?

FSD1_B Is [SC] able to feed [himself/herself]?

FSD1_C Is [SC] able to dress [himself/herself]?

(READ AS NECESSARY: Is [SC] able to [FSD1_X]? Would you say [SC] can do this by [himself/herself], can do with help, cannot do, or never tried?)

FSD1_D Ask for things [he/she] needs or wants?

FSD1_E Provide [his/her] name, address, and phone number if asked?

FSD1_F Spend time with friends?

IF AGE < 12 YEARS, SKIP TO FSD5_INTRO.

FSD1_G Cook or prepare meals?

FSD1_H Manage money?

FSD1_I Get around by driving, public transportation, biking, or walking?

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FSD5_INTRO I am going to read a list of items that describe children. For each item, please tell me if it has been not true, somewhat true, or certainly true for [SC] during the past *six* months.

(1) NOT TRUE (2) SOMEWHAT TRUE (3) CERTAINLY TRUE
(77) DON'T KNOW (99) REFUSED

FSD5_A [He/She] is generally well behaved, usually does what adults request.
FSD5_B [He/She] has many worries, or often seems worried.
FSD5_C [He/She] is often unhappy, depressed, or tearful.
FSD5_D [He/She] gets along better with adults than with other children/youth.
FSD5_E [He/She] has good attention span, sees chores or homework through to the end.

WANDERING AND WANDERING PREVENTION

WWP1_INTRO Some children with learning and developmental conditions are likely to wander off and become so lost that it is necessary to search for them. I am going to read a list of places. Please tell me if [SC] wandered off or became lost from any of these places within the past year, even if it occurred just once.

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

WWP1_A Within the past year has [SC] wandered off or became lost from your home?
WWP1_B Within the past year has [SC] wandered off or became lost from someone else's home such as a relative, friend, neighbor, or babysitter?
WWP1_C Within the past year has [SC] wandered off or became lost from school, day care, or summer camp?

(READ AS NECESSARY: Has [SC] wandered off or became lost in the following place within the past year?)

WWP1_D From a store, restaurant, playground, campsite, or any other public place?

WWP2 Have you added fences, gates, locks, alarms, or other barriers to your home in an effort to prevent [SC] from wandering off or becoming lost?

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

WWP3 Within the past year, has [SC] worn a tracking device to help you find [him/her] if [he/she] wandered off?

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

PARENTAL PERCEPTIONS

PP1_INTRO I am going to read you a few statements about [SC]'s teachers and then about [SC]'s doctors. Please tell me how much you agree or disagree with each of these statements.

PP1_A The teachers and other professionals at [SC]'s school are able to meet [his/her] needs.

PP1_B I am satisfied with the services that [SC] receives from teachers and other school professionals.

PP1_C The doctors and other health care providers that [SC] sees are able to meet [his/her] needs.

PP1_D I am satisfied with the services that [SC] receives from doctors and other health care providers.

Would you say you definitely agree, somewhat agree, somewhat disagree, or definitely disagree?

(1) DEFINITELY AGREE

(2) SOMEWHAT AGREE

(3) SOMEWHAT DISAGREE

(4) DEFINITELY DISAGREE

(77) DON'T KNOW

(99) REFUSED

HELP TEXT: DON'T PROBE FOR DON'T KNOW. DON'T KNOW IS A VALID ANSWER.

PP2_INTRO Now, please tell me how much you agree or disagree with each of these statements about [SC]'s learning and developmental conditions.

PP2_A [SC]'s condition is likely to be lifelong rather than temporary.

PP2_B The problems related to [SC]'s condition can be prevented or decreased with treatment.

PP2_C I have the power to change [SC]'s condition.

PP2_D [S.C]'s condition is a mystery to me.

PP2_E [SC]'s symptoms come and go.

PP2_F When I think about [SC]'s condition I get upset.

PP2_G I think [SC]'s condition is genetic or hereditary.

PP2_H I think [SC]'s condition was caused by something [he/she] was exposed to in utero, that is, before [he/she] was born.

PP2_I I think [SC]'s condition was caused by something [he/she] was exposed to after [he/she] was born.

Would you say you definitely agree, somewhat agree, somewhat disagree, or definitely disagree?

(1) DEFINITELY AGREE

(2) SOMEWHAT AGREE

(3) SOMEWHAT DISAGREE

(4) DEFINITELY DISAGREE

(77) DON'T KNOW

(99) REFUSED

HELP TEXT: DON'T PROBE FOR DON'T KNOW. DON'T KNOW IS A VALID ANSWER.

PP3 Has [SC] experienced any accident, injury, or illness that you feel has had an effect on [his/her] behavior or development?

HELP TEXT: DON'T PROBE FOR DON'T KNOW. DON'T KNOW IS A VALID ANSWER.

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

FAMILY AND DEMOGRAPHICS

DEMO1 How many biological brothers or sisters does [SC] have?

INTERVIEWER NOTE: COUNT SHOULD INCLUDE HALF-SIBLINGS

RECORD VALUE _____

(77) DON'T KNOW (99) REFUSED

SKIP TO DEMO7 IF ZERO/DK/RF. SKIP TO DEMO4 IF 2 OR MORE. SKIP TO DEMO2 IF 1.

DEMO2 Is this brother or sister older, younger, or the same age?

(1) OLDER
(2) YOUNGER
(3) SAME AGE
(77) DON'T KNOW
(99) REFUSED

DEMO3 Has a doctor or other health care provider *ever* told you that this brother or sister had...

DEMO3_A Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder?

DEMO3_B Any developmental delay that affects [his/her] ability to learn?

DEMO3_C Intellectual disability or mental retardation?

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

[SKIP TO DEMO7]

DEMO4 How many of [SC]'s biological brothers and sisters are older than [he/she] is?

RECORD VALUE _____

(77) DON'T KNOW (99) REFUSED

RECORD VALUE. IF VALUE EQUAL TO VALUE FROM DEMO1, FILL "0" FOR DEMO5 AND SKIP TO DEMO6. IF DK/RF, FILL SAME VALUE FOR DEMO5 AND SKIP TO DEMO6.

DEMO5 How many are younger than [he/she] is?

RECORD VALUE _____

(77) DON'T KNOW

(99) REFUSED

BEGIN LOOP AND REPEAT FOR EACH OF THREE CONDITIONS:

- a. Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder?
- b. Any developmental delay that affects [his/her] ability to learn?
- c. Intellectual disability or mental retardation?

DEMO6_X_1 Has a doctor or other health care provider *ever* told you that any of [SC]'s biological brothers or sisters had [CONDITION]?

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

[END LOOP IF NO/DK/RF]

DEMO6_X_2 How many of [SC]'s biological brothers or sisters have been diagnosed with [CONDITION]?

RECORD VALUE _____

IF DK/RF, THEN END LOOP

ELSE IF VALUE IS EQUAL TO VALUE IN DEMO1 THEN END LOOP.

ELSE IF VALUE IN DEMO4 OR VALUE IN DEMO5 IS ZERO, THEN END LOOP.

ELSE IF VALUE IS GREATER THAN ONE, THEN SKIP TO DEMO6_X_4.

DEMO6_X_3 Is this brother or sister older than [SC]?

- (1) OLDER
- (2) YOUNGER
- (3) SAME AGE
- (4) DON'T KNOW
- (1) REFUSED

[END LOOP]

DEMO6_X_4 How many of these brothers or sisters are older than [SC]?

RECORD VALUE _____

END OF LOOP. RETURN TO DEMO6_X_1 FOR EACH ADDITIONAL CONDITION.

DEMO7 My next questions are about [SC]'s biological parents. [Are you / Is [his/her] biological mother] of Hispanic, Latino, or Spanish origin?

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

DEMO8 [Are you / Is [his/her] biological father] of Hispanic, Latino, or Spanish origin?

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

DEMO9 *ASK ONLY IF RESPONDENT IS NOT THE BIOLOGICAL MOTHER OR BIOLOGICAL FATHER. OTHERWISE, SKIP TO DEMO10.*

And are you of Hispanic, Latino, or Spanish origin?

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

DEMO10 Please choose one or more of the following categories to describe (your / [SC]'s biological mother's) race. (Are you / Is she) White, Black or African American, American Indian, Alaska Native, Asian, Native Hawaiian, or other Pacific Islander?

- (1) WHITE/CAUCASIAN
- (2) BLACK/AFRICAN AMERICAN
- (3) AMERICAN INDIAN/NATIVE AMERICAN
- (4) ALASKA NATIVE
- (5) ASIAN
- (6) NATIVE HAWAIIAN
- (7) PACIFIC ISLANDER
- (8) OTHER [GO TO DEMO10_OTHER]
- (77) DON'T KNOW
- (99) REFUSED

DEMO10_OTHER RECORD VERBATIM RESPONSE

DEMO11 And how about (you / [SC]'s biological father)?

- (1) WHITE/CAUCASIAN
- (2) BLACK/AFRICAN AMERICAN
- (3) AMERICAN INDIAN/NATIVE AMERICAN
- (4) ALASKA NATIVE
- (5) ASIAN
- (6) NATIVE HAWAIIAN
- (7) PACIFIC ISLANDER
- (8) OTHER [GO TO DEMO11_OTHER]
- (77) DON'T KNOW
- (99) REFUSED

DEMO11_OTHER RECORD VERBATIM RESPONSE

DEMO12 *ASK ONLY IF RESPONDENT IS NOT THE BIOLOGICAL MOTHER OR BIOLOGICAL FATHER. OTHERWISE, SKIP TO DEMO13A.*

And how about you?

(READ AS NECESSARY: Are you White, Black or African American, American Indian, Alaska Native, Asian, Native Hawaiian, or other Pacific Islander?)

- (1) WHITE / CAUCASIAN
- (2) BLACK/ AFRICAN AMERICAN
- (3) AMERICAN INDIAN / NATIVE AMERICAN
- (4) ALASKA NATIVE
- (5) ASIAN
- (6) NATIVE HAWAIIAN
- (7) PACIFIC ISLANDER
- (8) OTHER [GO TO DEMO12_OTHER]
- (77) DON'T KNOW
- (99) REFUSED

DEMO12_OTHER RECORD VERBATIM RESPONSE

DEMO13A How old [are you / is [SC]'s biological mother]?

RECORD VALUE IN YEARS _____ [GO TO DEMO14A]

- (666) DECEASED [GO TO DEMO13B]
- (777) DON'T KNOW [GO TO DEMO13B]
- (999) REFUSED [GO TO DEMO13B]

DEMO13B How old was [SC]'s biological mother when [SC] was born?

RECORD VALUE IN YEARS _____

DEMO14A How old [are you / is [SC]'s biological father]?

RECORD VALUE IN YEARS _____ [GO TO DEMO15]

- (666) DECEASED [GO TO DEMO14B]
- (777) DON'T KNOW [GO TO DEMO14B]
- (999) REFUSED [GO TO DEMO14B]

DEMO14B How old was [SC]'s biological father when [SC] was born?

RECORD VALUE IN YEARS _____

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

DEMO15A *ASK ONLY IF RESPONDENT IS NOT THE BIOLOGICAL MOTHER OR BIOLOGICAL FATHER. OTHERWISE, SKIP TO SAQ.*

And how old are you?

RECORD VALUE IN YEARS _____

(77) DON'T KNOW

(99) REFUSED

DEMO15B_
MDY

What is [S.C.]'s date of birth?

ENTER 77 FOR DON'T KNOW AND 99 FOR REFUSED

MM/DD/YYYY: __ / __ / ____

SAQ_OFFER Those are all the questions I have. Before I go, I'd like to make you aware of the next component of the survey. We would like to mail you a paper questionnaire that asks you a few questions about your child's behaviors. Participation in the survey is voluntary, and you will receive a payment of \$[MONEY_6] for your participation. We will send you the questionnaire along with a self-addressed, stamped return envelope. All you will need to do is fill out the questionnaire, put it in the envelope, and drop it in the mail.

READ IF NECESSARY: You may have seen or filled out this questionnaire before at a doctor's office.

(1) CONTINUE

(99) RESPONDENT REFUSES

ADDRESS I'll need your mailing address so we can send you \$[MONEY_4/MONEY_5] as a token of our appreciation for taking the time to answer our questions [IF SAQ NE 99 THEN FILL: "and to send you the paper questionnaire"].

GO TO AC_NAME AND PROCEED THROUGH ADDRESS COLLECTION OR VERIFICATION

(1) ADDRESS CORRECT AND CONFIRMED

(99) REFUSED TO GIVE/CORRECT ADDRESS

CLOSING 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 [NUMBER]. If you have questions about your rights as a survey participant, you may call the chairman of the Research Ethics Review Board at [NUMBER]. Thank you again.