**Attachment 2: SPDS telephone interview questionnaire**

**Survey of pathways to diagnosis and services (The “Pathways Survey”)**

**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](mailto: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 04/30/11

**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.*

INTRO1. Hello, my name is \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_. I’m calling on behalf of 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 child’s [RELATION] again. Is [he/she/this person] available?

(1) Yes, speaking with that person <GO TO INTRO3>

(2) Yes, new person comes to phone <GO TO INTRO2>

(3) No, not available now <SCHEDULE AND TERMINATE>

(4) No, parent has moved <GO TO LOC\_A>

(5) Do not know this person <TERMINATE>

(6) No, parent is deceased <GO TO DECEASED>

(7) No, child is deceased <GO TO DECEASED>

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

1. CONTINUE [IF INTRO1=4 THE GO TO LOC\_A; ELSE GO TO INTRO3]
2. R UNABLE TO CONTINUE [GO TO S\_ATTN]
3. NOT A CELL PHONE [GO TO S1]

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

1. CALL BACK ANOTHER TIME [GO TO CB1]
2. CALL BACK AT ANOTHER NUMBER REQUESTED [GO TO CB1N\_WARNING]
3. WRONG TIME ZONE FOR CELL PHONE [GO TO CELL\_TZ\_1]
4. GO BACK TO S\_WARM

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

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]

(99) Refused to continue/ hung up [TERMINATE, SET ITS=41]

LOC\_A What is their new telephone number?

CONTINUE/ NONE/ DK / RF

RECORD NUMBER. SKIP TO LOC\_F IF NONE/DK/RF.

LOC\_B. Is that a landline or cell phone number?

LANDLINE / CELLULAR / DK / RF

LOC\_C. Does this person have any other number where (he/she) might be reached?

YES/NO/DK/RF [SKIP TO LOC\_F IF NO/DK/RF]

LOC\_D. What is that telephone number?

RECORD NUMBER. SKIP TO LOC\_F IF NONE/DK/RF.

LOC\_E. Is that a landline or cellular telephone number?

LANDLINE / CELLULAR / DK / RF

LOC\_F. What is (his/her) name?

RECORD VERBATIM RESPONSE, THEN TERMINATE.

GO TO LOCATE\_EXIT

LOC\_EXIT Thank you for providing contact information for [SC]’s [RELATION]. 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.

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

INTRO2. Hello, my name is \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_. I’m calling on behalf of 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]?

(1) Yes, speaking with that person <GO TO INTRO3>

(2) Yes, new person comes to phone <REPEAT INTRO2>

(3) No, not available now <SCHEDULE AND TERMINATE>

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 the parents and guardians of children who have or have had learning and developmental conditions. If you qualify for and complete this survey, we will pay you $[MONEY\_4/MONEY\_5] for your time.

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:

[autism or an autism spectrum disorder]; [and]

[intellectual disability or mental retardation]; [and]

[developmental delay that affected (his/her) ability to learn].

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

Is that correct?

YES/NO/DK/RF [SKIP TO AGE IF YES.]

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.

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?

YES/NO/DK/RF FOR EACH ITEM.

IF ALL ITEMS ARE NO/DK/RF, THEN GO TO COND\_EXIT; ELSE GO TO AGE

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 CDC’s National Center for Health Statistics for the time and effort you’ve spent answering these questions.

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

RECORD VALUE: \_\_\_\_\_\_\_\_\_\_

RECORD AGE IN MONTHS FOR 0 TO 23 MONTHS. IF 2 YEARS OR OLDER AND MONTHS NOT GIVEN, RECORD AGE IN 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 CDC’s National Center for Health Statistics for the time and effort you’ve spent answering these questions.

INHOUSE. Is [SC] still living with you?

YES/NO/DK/RF [IF YES GO TO CONSENT]

TERMINATE IF NO/DK/RF

INHOUSE\_

EXIT We are only interviewing parents if the child still resides in their household. I’d like to thank you on behalf of CDC’s National Center for Health Statistics for the time and effort you’ve spent answering these questions.

SC\_NAME I can continue to refer to your child as [AGEID] for the rest of the interview, or if you prefer, you could give me a first name or initials.

ENTER NAME/INITIALS: \_\_\_\_\_\_\_\_\_\_

CONSENT I would like to ask you some more questions about [SC]’s learning and development. 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\_AMOUNT]. The survey will take about a half hour. In order to review my work, my supervisor may record and listen as I ask the questions. I'd like to continue now unless you have any questions.

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. 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 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

**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

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

INCLUDE CODES FOR “SINCE BIRTH” AND “PARENT NEVER CONCERNED.”

IF PARENT NEVER CONCERNED, SKIP TO NEXT SECTION.

PC2 I am going to read a list of behaviors that might have given you concern about [his/her] development at that time. For each behavior, please tell me if it gave you concern when [SC] was [FILL AGE FROM PC1].

HELP TEXT: CODE “NO” IF RESPONDENT INDICATES THAT THE CHILD DID NOT HAVE THAT PROBLEM AT THAT AGE.

Did it give you concern when [he/she] was [FILL AGE FROM PC1] and …

a. Talked later than is usual for most children

b. Was not talking at all

c. Did not talk as well as other children that were the same age

d. Some speech skills that (he/she) had already developed were lost

e. Didn’t seem to understand what you or other adults said to (him/her)

f. Didn’t respond when called or didn’t respond to sounds

g. 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

h. Didn’t make eye contact when talking or playing with others

i. Had difficulty playing or interacting with others, or played alone “in (his/her) own world”

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

k. Insisted on sameness or had difficulties with change

l. Had problems with coordination or gross motor skills such walking

m. Had problems with fine motor skills such as using scissors or drawing with crayons

n. Had difficulty learning new skills such as toilet training or getting dressed

o. Had difficulty learning new things such as the alphabet or numbers

p. Had unusual gestures or movements such as hand-flapping, toe-walking, or self-spinning

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

YES/NO/DK/RF FOR EACH ITEM

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

YES/NO/DK/RF [SKIP TO PC5 IF YES/DK/RF]

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 councilor or nurse
7. Family friend
8. Other [RECORD VERBATIM RESPONSE]

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

YES/NO/DK/RF [SKIP TO PC8 IF NO/DK/RF]

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

PC7\_A How did that doctor or health care provider respond to your concern? *(MARK ALL THAT APPLY)*

INTERVIEWER PROMPT: Was there anything else?

1. Conducted developmental tests
2. Made a referral to a specialist (such as developmental pediatrician, child psychologist, occupational or speech therapist)
3. Suggested that the parent discuss the concern with the school
4. Said nothing was wrong / the behavior was normal
5. Said it was too early to tell if anything is wrong
6. Said that the child might “grow out of it”
7. 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?

YES/NO/DK/RF [SKIP TO PC7\_G IF NO/DK/RF]

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?

YES/NO/DK/RF

PC7\_D Did this questionnaire ask about your concerns or observations about how [SC] interacts with you and others?

YES/NO/DK/RF [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?

YES/NO/DK/RF

PC7\_F Did this questionnaire ask about your concerns or observations about how [SC] behaves and gets along with you and others?

YES/NO/DK/RF

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]?

YES/NO/DK/RF

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?

YES/NO/DK/RF

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

YES/NO/DK/RF [GO TO PC11 IF NO/DK/RF]

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

RECORD VALUE \_\_\_\_\_\_\_\_\_\_

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

PC10 How did that school professional respond to your concern? *(Mark all that apply)*

INTERVIEWER PROMPT: Was there anything else?

1. Conducted developmental tests
2. Made a referral to an in-school specialist
3. Made a referral to a specialist outside the school system (such as developmental pediatrician, child psychologist, occupational or speech therapist)
4. Suggested that the parent discuss the concern with the child’s doctor
5. Said the behavior was normal
6. Said it was too early to tell if anything is wrong
7. Said that the child might “grow out of it”
8. Other [RECORD VERBATIM RESPONSE]

PC11 *ASK ONLY IF PC5 IS NO, DK, OR RF AND IF PC8 IS NO, DK, OR RF. OTHERWISE, SKIP TO NEXT SECTION.*

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

YES/NO/DK/RF [GO BACK TO PC5 IF YES]

**DIAGNOSTIC EXPERIENCE**

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:

[Autism or autism spectrum disorder]

[Developmental delay that affects his/her ability to learn]

[Intellectual disability or mental retardation]

[Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder]

[Depression]

[Anxiety problems]

[Behavioral or conduct problems]

IF MORE THAN ONE, ADD: Let’s start with [CONDITION]. WHEN BEGINNING LOOP FOR EACH SUBSEQUENT CONDITION, ADD: Now, I would like to ask some questions about [CONDITION].

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

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 [RECORD VERBATIM RESPONSE]
12. Wasn’t told by a doctor or other health care professional

DE\_X2 How old was [SC] when you were first told that [he/she] had [CONDITION]?

RECORD VALUE \_\_\_\_\_\_\_\_\_\_

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

DE\_X3 Did any other doctor, health care provider, or school professional also tell you that [SC] had [CONDITION]?

YES/NO/DK/RF [GO TO DE\_X5A IF NO/DK/RF]

DE\_X4 What types of other doctors, health care providers, or school professionals told you that [SC] had [CONDITION]? *(Mark all that apply)*

INTERVIEWER PROMPT: Was there anything else?

USE SAME LIST OF DOCTORS AND HEALTH CARE PROVIDERS AS FOR DE\_X1

DE\_X5A *ASK ONLY WHEN LOOP IS CONCERNED WITH AUTISM OR ASD. OTHERWISE, SKIP TO DEX\_6.*

Did the doctors, health care providers, or school professionals ever tell you that [SC] had any of the following autism spectrum disorders?

a. Asperger’s Disorder

b. Pervasive Developmental Disorder

c. Autistic Disorder

YES/NO/DK/RF FOR EACH ITEM

DE\_X6 Since you were first told that [he/she] had [CONDITION], has a doctor, health care provider, or school professional ever told you that [SC] did *not* have [CONDITION]?

YES/NO/DK/RF [GO TO DE\_X11 IF NO/DK/RF]

DE\_X7 What types of doctors, health care providers, or school professionals ever told you that [SC] did *not* have [CONDITION]? *(MARK ALL THAT APPLY)*

INTERVIEWER PROMPT: Was there anything else?

USE SAME LIST OF DOCTORS AND HEALTH CARE PROVIDERS AS FOR DE\_X1

DE\_X8 How old was [SC] when you were first told that [he/she] did *not* have [CONDITION]?

RECORD VALUE \_\_\_\_\_\_\_\_\_\_

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

YES/NO/DK/RF [GO TO DE\_X11 IF NO/DK/RF]

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]?

YES/NO/DK/RF [END LOOP IF YES/DK/RF]

DE\_X12 To the best of your knowledge, did [SC] ever have [CONDITION]?

YES/NO/DK/RF [GO TO DE\_X15 IF NO/DK/RF ]

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].

DE\_X13A a. Treatment helped the condition go away

b. The condition seemed to go away on its own

c. The behaviors or symptoms changed

d. A doctor or health care provider changed the diagnosis

YES/NO/DK/RF FOR EACH ITEM

DE\_X14 Are there any other reasons why you think [SC] may no longer have [CONDITION]?

YES/NO/DK/RF

[END LOOP IF NO/DK/RF. RECORD VERBATIM RESPONSE IF YES, THEN END LOOP.]

DE\_X15A 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].

a. With more information, the diagnosis was changed

b. The diagnosis was given so that [SC] could receive needed services

c. You disagree with the doctor or other health provider about his or her opinion that [SC] had [CONDITION].

YES/NO/DK/RF FOR EACH ITEM

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?

YES/NO/DK/RF

[END LOOP IF NO/DK/RF. RECORD VERBATIM RESPONSE IF YES, THEN END LOOP.]

*END OF LOOP.* RETURN TO DE\_X1 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?

YES/NO/DK/RF [SKIP TO NEXT SECTION IF NO/DK/RF]

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

YES/NO/DK/RF [SKIP TO NEXT SECTION IF NO/DK/RF]

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.

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. Behavioral intervention or modification services?

*NOTE: Includes discrete trial training and other methods of Applied Behavior Analysis (ABA)*

b. Sensory integration therapy?

c. Cognitive based therapy?

d. School-based occupational therapy?

e. Other occupational therapy?

f. School-based physical therapy?

g. Other physical therapy?

h. School-based social skills training?

i. Other social skills training?

j. School-based speech or language therapy?

k. Other speech or language therapy?

l. Vision services?

YES/NO/DK/RF FOR EACH ITEM

*BEGIN LOOP TO BE ASKED FOR EACH SERVICE IDENTIFIED BY PARENT*

HCS1\_X\_1A How old was [SC] when [he/she] first started using [SERVICE]?

RECORD VALUE \_\_\_\_\_\_\_\_\_\_

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

HCS1\_X\_2 Does [SC] *currently* use [SERVICE] on a regular basis?

YES/NO/DK/RF [END LOOP IF NO/DK/RF]

HCS1\_X\_3A About how often does [SC] use [SERVICE]?

RECORD VALUE \_\_\_\_\_\_\_\_\_\_

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

*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.

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.

HCS2 An audiologist?

b. A developmental pediatrician?

c. A neurologist?

d. A nutritionist?

e. An at home or long-term nurse?

f. A psychiatrist?

g. A psychologist or psychotherapist?

h. A social worker?

YES/NO/DK/RF FOR EACH ITEM

*BEGIN LOOP TO BE ASKED FOR EACH PROVIDER IDENTIFIED BY PARENT*

HCS2\_X\_1A How old was [SC] when [he/she] first started working with [PROVIDER]?

RECORD VALUE \_\_\_\_\_\_\_\_\_\_

RECORD AGE IN MONTHS FOR 0 TO 23 MONTHS. IF 2 YEARS OR OLDER AND

HCS2\_X\_2 Does [SC] *currently* work with [PROVIDER] on a regular basis?

YES/NO/DK/RF [END LOOP IF NO/DK/RF]

HCS2\_X\_3A About how often does [SC] work with [PROVIDER]?

RECORD VALUE \_\_\_\_\_\_\_\_\_\_

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

*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.

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.

HCS3\_A Stimulant medications?

*EXAMPLES: Adderall, Concerta, Dexedrine, Ritalin*

HCS3\_B Anti-depressant medications?

*EXAMPLES: Anafranil, Luvox, Prozac, Wellbutrin, Zoloft*

HCS3\_C Anti-anxiety or mood stabilizing medications?

*EXAMPLES: Lithium, Valium, Xanax*

HCS3\_D Anti-seizure medications?

*EXAMPLES: Depakote, Lamictal, Tegretol, Topamax*

HCS3\_E Anti-psychotic medications?

*EXAMPLES: Abilify, Clozaril, Geodon, Haldol, Risperdal, Zyprexa*

HCS3\_F Sleep medications?

*EXAMPLES: Atarax, Catapres, Tenex*

YES/NO/DK/RF FOR EACH ITEM

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

HCS3\_X1. How old was [SC] when (he/she) first started taking [RX TYPE]?

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

HCS3\_X3. Does [SC] *currently* take [RX TYPE] on a regular basis?

YES/NO/DK/RF [END LOOP IF NO/DK/RF]

*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.

YES/NO/DK/RF [SKIP TO NEXT SECTION IF NO/DK/RF]

HCS5 Does [SC] *currently* use any type of alternative health care or treatment to meet [his/her] developmental needs?

YES/NO/DK/RF

**EDUCATIONAL SERVICES**

ES1 What kind of school is [SC] currently enrolled in? Is it a public school, private school, or home-school?

(1) Public

(2) Private

(3) Home-schooled [SKIP TO NEXT SECTION]

(4) [SC] is not enrolled in school [SKIP TO NEXT SECTION]

ES2 Does [SC] spend at least part of [his/her] school day in a resource room or special education classroom?

YES/NO/DK/RF

ES3 Does [SC] have a one to one aide or a shadow for at least part of [his/her] school day?

YES/NO/DK/RF

ES4 Does [SC] receive any other academic support inside school because of [his/her] developmental needs?

YES/NO/DK/RF

ES5 Does [SC] receive tutoring outside school because of [his/her] developmental needs?

YES/NO/DK/RF

ES6 Does [SC] have a written intervention plan called an Individualized Education Program or IEP?

YES/NO/DK/RF [GO TO ES9 IF NO/DK/RF]

ES7 What special education disability category is identified in [SC]’s IEP? *(MARK ALL THAT APPLY)*

INTERVIEWER PROMPT: Are there any others?

(01) Autism

(02) Emotional behavioral disabilities

(03) Hearing impairments

(04) Intellectual disability or mental retardation

(05) Learning disabilities

(06) Orthopedic impairment,

(07) Significant developmental delay

(08) Speech/language impairments

(09) Traumatic brain injury

(10) Visual impairments

(11) Other health impairment

ES8 Does [SC]’s IEP address all of your concerns about [his/her] development and education?

YES/NO/DK/RF

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.

YES/NO/DK/RF

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

YES/NO/DK/RF [IF NO/DK/RF, SKIP TO NEXT SECTION.]

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 [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.

.

YES/NO/DK/RF

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

YES/NO/DK/RF

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

YES/NO/DK/RF [GO TO INS6 IF NO/DK/RF]

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

YES/NO/DK/RF [GO TO INS6 IF NO/DK/RF]

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 [RECORD VERBATIM RESPONSE]

CP\_INS6 *ASK INS6 ONLY IF CHILD WAS EVER DIAGNOSED WITH AUTISM. OTHERWISE, SKIP TO FSD1.*

INS6 Has [SC] ever received Medicaid-reimbursed services for autism?

YES/NO/DK/RF

**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?

FSD1 How capable is [SC] at…

a. Going to the bathroom by (himself/herself)

b. Feeding (himself/herself)

c. Dressing (himself/herself)

d. Asking for things (he/she) needs or wants

e. Providing (his/her) name, address, and phone number if asked

f. Spending time with friends [IF AGE < 12 YEARS, SKIP TO #2.]

g. Cooking or preparing meals

h. Managing money

i. Getting around by driving, public transportation, biking, or walking

Would you say: can do independently, can do with help, cannot do, or never tried?

(1) CAN DO INDEPENDENTLY

(2) CAN DO WITH HELP

(3) CANNOT DO

(4) NEVER TRIED

DK/RF

*The following statements are included here for legal reasons. The items contained in FDS2 are from the Children’s Social Behavior Questionnaire (CSBQ), developed by the Department of Psychiatry, University Medical Center Groningen, University of Groningen, The Netherlands. The full Children’s Social Behavior Questionnaire is included in the SPDS mail questionnaire. These items were selected based on the result of a factor analysis of the full questionnaire by the original developers (Hartman et al., 2006, Journal of Autism and Developmental Disorders). Researchers should use caution when interpreting results from just these few selected items.*

FSD2\_INTRO I am going to read several descriptions of children’s behaviors. For each one, please tell me the extent to which the description applies to [SC] during the last two months. There are three answer choices. Please answer “clearly or often” if the description clearly applies or if the behavior occurs regularly. Please answer “sometimes or somewhat” if the description applies only slightly or if the behavior occurs infrequently. Please answer “does not apply” if the description does not apply to your child or the behavior does not occur.

FSD2 a. (He/She) takes things literally, for example, does not understand certain expressions

b. (He/She) flaps arms or hands when excited

c. (He/She) makes little eye contact.

d. (He/She) has little or no need for contact with others

e. (He/She) smells or constantly feels objects

f. (He/She) does things without realizing the aim, for example, constantly has to be reminded to finish things

g. (He/She) quickly gets angry

h. (He/She) remains clammed up in new situations or if change occurs

Would you say: clearly or often, sometimes or somewhat, or does not apply?

CLEARLY OR OFTEN / SOMETIMES OR SOMEWHAT / DOES NOT APPLY / DK / RF

*The following statements are included here for legal reasons. The items contained in FSD5 are included in this survey with permission. The SDQ questions are copyrighted by Robert Goodman, Ph.D., FRCPSYCH, MRCP. State and local agencies may use these questions without charge and without seeking separate permission provided the wording is not modified, all the questions are retained, and Dr. Goodman's copyright is acknowledged.*

FSD5\_INTRO I am going to read another 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.

FSD5 a. (He/She) is generally well behaved, usually does what adults request.

b. (He/She) has many worries, or often seems worried.

c. (He/She) is often unhappy, depressed, or tearful.

d. (He/She) gets along better with adults than with other [children/youth].

e. (He/She) has good attention span, sees chores or homework through to the end.

(1) NOT TRUE

(2) SOMEWHAT TRUE

(3) CERTAINLY TRUE

DK/ REF

**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.

WWP1 Within the past year has [SC] wandered off or became lost…

From your home?

b. From someone else’s home such as a relative, friend, neighbor, or babysitter?

c. From school, day care, or summer camp?

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

YES/NO/DK/RF

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?

YES/NO/DK/RF

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

YES/NO/DK/RF

**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.

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

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

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

(6) DON’T KNOW

(7) REFUSED

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.

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

c. I have the power to change [SC]’s condition.

d. [SC]’s condition is a mystery to me.

e. [SC]’s symptoms can come and go.

f. When I think about [SC]’s condition I get upset.

g. I think [SC]’s condition is genetic or hereditary.

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

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

(6) DON’T KNOW

(7) REFUSED

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

YES/NO/DK/RF

**FAMILY AND DEMOGRAPHICS**

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

INTERVIEWER NOTE: Count should include half-siblings

RECORD VALUE \_\_\_\_\_\_\_\_\_\_

SKIP TO DEMO10 IF ZERO/DK/RF. SKIP TO DEMO4 IF 2+. SKIP TO DEMO2 IF 1.

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

OLDER/YOUNGER/SAME/DK/RF

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

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?

YES/NO/DK/RF FOR EACH ITEM [THEN SKIP TO DEMO10]

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

RECORD VALUE \_\_\_\_\_\_\_\_\_\_

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 \_\_\_\_\_\_\_\_\_\_

*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]?

YES/NO/DK/RF [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 SKIP TO DEMO6\_X\_4 IF VALUE IS GREATER THAN ONE.

DEMO6\_X\_3 Is this brother or sister older than [SC]?

OLDER/YOUNGER/SAME/DK/RF [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?

YES/NO/DK/RF

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

YES/NO/DK/RF

DEMO9 *ASK ONLY IF RESPONDENT IS NOT THE BIOLOGICAL MOTHER OR BIOLOGICAL FATHER. OTHERWISE, SKIP TO DEMO13.*

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

YES/NO/DK/RF

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 [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 [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 [RECORD VERBATIM RESPONSE]

DEMO13A How old (are you / is [SC]’s biological mother)?

RECORD VALUE IN YEARS \_\_\_\_\_\_\_\_\_\_ [GO TO DEMO14A]

(XX) DECEASED [GO TO DEMO13B]

(6) DON’T KNOW [GO TO DEMO13B]

(7) 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 \_\_\_\_\_\_\_\_\_\_

(XX) DECEASED [GO TO DEMO13B]

(6) DON’T KNOW [GO TO DEMO13B]

(7) REFUSED [GO TO DEMO13B]

INCLUDE CODES FOR “DECEASED.” IF BIOLOGICAL FATHER IS DECEASED, ASK DEMO14B. OTHERWISE, SKIP TO DEMO15.

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

RECORD VALUE IN YEARS \_\_\_\_\_\_\_\_\_\_

DEMO15 *ASK ONLY IF RESPONDENT IS NOT THE BIOLOGICAL MOTHER OR BIOLOGICAL FATHER. OTHERWISE, SKIP TO SAQ\_OFFER.*

And how old are you?

RECORD VALUE IN YEARS \_\_\_\_\_\_\_\_\_\_

SAQ\_OFFER Those are all the questions I have. 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 more questions about your child’s behaviors. Participation in the survey is voluntary, and you will receive a payment of [MONEY AMOUNT] 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.

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 OFFER NE 99 THEN FILL: “and to send you the paper questionnaire”].

RECORD NAME AND 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.