



# National Survey of Children with Special Health Care Needs (NS-CSHCN), 2005 - 2006

## Guide to Topics & Questions Asked

### SECTION 1: NIS/SLAITS Eligibility and Screeners

1. How many children between the ages of 12 months and 3 years old are living or staying in your household? (**S\_NUMB**)
2. How many people less than 18 years old live in this household? (**S\_UNDR18**)

### SECTION 2: Initial Household Screening for Special Health Care Needs

*The parent or guardian who is the most familiar with the health and health care situations of the children in the household answers the following questions for each child in the household under 18 years old:*

1. Child's age (**C2Q01B**)
2. Child's sex (**C2Q03**)
3. CSHCN Screener questions:
  - Does child currently need or use medicine prescribed by a doctor, other than vitamins? (**CSHCN1**)
    - Is [his/her] need for prescription medicine because of ANY medical, behavioral or other health condition? (**CSHCN1\_A**)
    - Is this a condition that has lasted or is expected to last 12 months or longer? (**CSHCN1\_B**)
  - Does child need or use more medical care, mental health or educational services than is usual for most children of the same age? (**CSHCN2**)
    - Is [his/her] need for medical care, mental health, or educational services because of ANY medical, behavioral or other health condition? (**CSHCN2\_A**)
    - Is this a condition that has lasted or is expected to last 12 months or longer? (**CSHCN2\_B**)
  - Is child limited or prevented in any way in [his/her] ability to do the things most children of the same age can do? (**CSHCN3**)
    - Is [his/her]'s limitation in abilities because of ANY medical, behavioral or other health condition? (**CSHCN3\_A**)
    - Is this a condition that has lasted or is expected to last 12 months or longer? (**CSHCN3\_B**)
  - Does child need or get special therapy such as physical, occupational, or speech therapy? (**CSHCN4**)
    - Is [his/her] need for special therapy because of ANY medical, behavioral or other health condition? (**CSHCN4\_A**)
    - Is this a condition that has lasted or is expected to last 12 months or longer? (**CSHCN4\_B**)
  - Does child have any kind of emotional, developmental or behavioral problem for which he/she needs treatment or counseling? (**CSHCN5**)
    - Has [his/her]'s emotional, developmental, or behavioral problem lasted or expected to last for 12 months or longer? (**CSHCN5\_A**)
4. Child's race/ethnicity (**CW10Q01, CW10Q02**)

## **SECTION 2: Initial Household Screening for Special Health Care Needs (continued)**

### **Respondent Information**

5. What is the highest level of school that anyone in the household has completed or the highest degree anyone in the household has received? **(CW10Q04)**
6. What is the primary language spoken in your home? **(C2Q05)**
7. Respondent's relationship to the [CHILD'S NAME] **(C2Q04)**

## **SECTION 3: Child Health and Functional Status**

1. How often does [CHILD'S NAME]'s health condition affect [his/her] ability to do age-appropriate things? **(C3Q02)**
  - If so, how much limitation does child experience? **(C3Q03)**
2. Do [CHILD'S NAME]'s health care needs change all the time, change once in awhile or are usually stable? **(C3Q11)**
3. Without glasses or contact lenses, would you say [he/she] experiences any difficulty seeing? **(S3Q01)**
  - Does [CHILD'S NAME] wear glasses or contact lenses? **(S3Q01A)**
  - Does [CHILD'S NAME] have any difficulty seeing even when wearing glasses or contact lenses? **(S3Q01B)**
4. Without hearing aids, would you say [he/she] experiences any difficulty hearing? **(S3Q02)**
  - Does [CHILD'S NAME] use a hearing aid? **(S3Q02A)**
  - Does [CHILD'S NAME] have any difficulty hearing even when using a hearing aid? **(S3Q02B)**
5. Would you say [he/she] experiences any difficulty with any of the following:
  - Breathing or other respiratory problems, such as wheezing or shortness of breath? **(S3Q03)**
  - Swallowing, digesting food, or metabolism? **(S3Q04)**
  - Blood circulation? **(S3Q05)**
  - Repeated or chronic physical pain, including headaches? **(S3Q06)**
6. Compared to other children [his/her] age, would you say he/she experiences any difficulty with any of the following:
  - Taking care of [himself/herself], for example, doing things like eating, dressing and bathing? **(S3Q07)**
  - Coordination or moving around **(S3Q08)**
  - Using [his/her] hands **(S3Q09)**
  - Learning, understanding, or paying attention? **(S3Q10)**
  - Speaking, communicating, or being understood? **(S3Q11)**
  - With feeling anxious or depressed? **(S3Q12)**
  - With behavior problems, such as acting-out, fighting, bullying, or arguing? **(S3Q13)**
  - Making and keeping friends? **(S3Q14)**

### SECTION 3: Child Health and Functional Status *(continued)*

7. Overall, how would you rate the severity of the difficulties caused by [CHILD'S NAME]'s health problems? **(C3Q10)**
8. You reported that [CHILD'S NAME] does not experience any difficulty in any of the areas just mentioned. In your opinion, would you say this is because [CHILD'S NAME]'s health problems are being treated and are under control? **(S3Q15)**
9. To the best of your knowledge, does [CHILD'S NAME] currently have any of the following conditions?
  - Asthma? **(S3Q16)**
  - Attention Deficit Disorder or Attention Deficit Hyperactive Disorder (ADD or ADHD)? **(S3Q17)**
  - Autism or Autism Spectrum Disorder (ASD)? **(S3Q18)**
  - Down Syndrome? **(S3Q19)**
  - Mental retardation or developmental delay? **(S3Q20)**
  - Depression, anxiety, an eating disorder, or other emotional problems? **(S3Q21)**
  - Diabetes? **(S3Q22)**
    - Does [CHILD'S NAME] use insulin? **(S3Q22A)**
  - A heart problem, including congenital heart disease? **(S3Q23)**
  - Blood problems such as anemia or sickle cell disease? Please do not include Sickle Cell Trait. **(S3Q25)**
  - Cystic Fibrosis? **(S3Q26)**
  - Cerebral Palsy? **(S3Q27)**
  - Muscular Dystrophy? **(S3Q28)**
  - Epilepsy or other seizure disorder? **(S3Q29)**
  - Migraine or frequent headaches? **(S3Q30)**
  - Arthritis or other joint problems? **(S3Q32)**
  - Allergies? **(S3Q31)**
    - Food allergies? **(S3Q31\_A)**
10. If school age, number of school days missed during the past 12 months because of illness or injury? **(C3Q14)**
11. During the past 12 months, how many times did [CHILD'S NAME] visit a hospital emergency room? **(C6Q00)**
12. During the past 12 months, how many times did [CHILD'S NAME] visit a doctor or other health care provider? **(C6Q01)**

### SECTION 4: Access to Care — Use of Services and Unmet Needs

1. Is there a place [CHILD'S NAME] usually goes when [he/she] is sick or you need advice about [his/her] health? **(C4Q0A)**
  - What kind of place? **(C4Q0B INDEX – asked only for children with a usual source of care)**
  - Is there a place that [CHILD'S NAME] usually goes when [he/she] needs routine preventive care, such as a physical exam or a well-child check-up? **(C4Q0D- asked only for children without a usual source of care)**
2. Is the [place selected in C4Q0B] that [CHILD'S NAME] goes to when [he/she] is sick the same place [CHILD'S NAME] usually goes for routine preventive care? **(C4Q01 – asked only for a YES response to C4Q0D)**
  - What kind of place does [CHILD'S NAME] go for routine preventive care? **(C4Q02 INDEX – asked only for a NO response to C4Q01)**

**SECTION 4: Access to Care – Use of Services and Unmet Needs (continued)**

3. Do you have one or more persons you think of as [CHILD'S NAME]'s personal doctor or nurse? **(C4Q02A)**
  - Who is this person? **(C4Q02B INDEX – asked only for children who have a personal doctor or nurse)**
4. In past 12 months, have you delayed or gone without health care for [CHILD'S NAME]? **(C4Q03)**
  - Why did you delay or not get health care for [CHILD'S NAME]? **(C4Q04\_A – C4Q04\_L INDEX– asked only for respondents who delayed health care)**
5. In the past 12 months was there any time when [CHILD'S NAME] needed the following services:

	<b>Needed Services?</b>	<b>Received all needed care?</b>	<b>Reasons for not receiving care?</b>	<b>Received any care?</b>
• Routine preventive care:	<b>(C4Q05_X01)</b>	<b>(C4Q05X01A)</b>	<b>(C4Q0501B)</b>	<b>(C4Q05X01C)</b>
• Specialty care:	<b>(C4Q05_X02)</b>	<b>(C4Q05X02A)</b>	<b>(C4Q0502B)</b>	<b>(C4Q05X02C)</b>
• Preventive dental care:	<b>(C4Q05_X031)</b>	<b>(C4Q05X031A)</b>	<b>(C4Q05031B)</b>	<b>(C4Q05X031C)</b>
• Other dental care:	<b>(C4Q05_X032)</b>	<b>(C4Q05X032A)</b>	<b>(C4Q05032B)</b>	<b>(C4Q05X032C)</b>
• Prescription medications:	<b>(C4Q05_X04)</b>	<b>(C4Q05X04A)</b>	<b>(C4Q0504B)</b>	<b>(C4Q05X04C)</b>
• Physical, Occupational, or Speech Therapy:	<b>(C4Q05_X05)</b>	<b>(C4Q05X05A)</b>	<b>(C4Q0505B)</b>	<b>(C4Q05X05C)</b>
• Mental health care or counseling:	<b>(C4Q05_X06)</b>	<b>(C4Q05X06A)</b>	<b>(C4Q0506B)</b>	<b>(C4Q05X06C)</b>
• Substance abuse treatment or counseling:	<b>(C4Q05_X07)</b>	<b>(C4Q05X07A)</b>	<b>(C4Q0507B)</b>	<b>(C4Q05X07C)</b>
• Home health care:	<b>C4Q05_X08)</b>	<b>(C4Q05X08A)</b>	---	<b>(C4Q05X08C)</b>
• Eyeglasses or vision care:	<b>C4Q05_X09)</b>	<b>(C4Q05X09A)</b>	---	<b>(C4Q05X09C)</b>
• Hearing aids or hearing care:	<b>(C4Q05_X10)</b>	<b>(C4Q05X10A)</b>	---	<b>(C4Q05X10C)</b>
• Mobility aids or devices:	<b>(C4Q05_X11)</b>	<b>(C4Q05X11A)</b>	---	<b>(C4Q05X11C)</b>
• Communication aids or devices:	<b>(C4Q05_X12)</b>	<b>(C4Q05X12A)</b>	---	<b>(C4Q05X12C)</b>
• Medical supplies:	<b>(C4Q05_X13)</b>	<b>(C4Q05X13A)</b>	---	<b>(C4Q05X13C)</b>
• Durable medical equipment:	<b>(C4Q05_X14)</b>	<b>(C4Q05X14A)</b>	---	<b>(C4Q05X14C)</b>

6. In the past 12 months was there any time when you or other family members needed the following services:

	<b>Family needed services?</b>	<b>Family received all needed care?</b>	<b>Reasons for not receiving care?</b>	<b>Family received any care?</b>
• Respite care	<b>(C4Q06_X01)</b>	<b>(C4Q06X01A)</b>	<b>(C4Q0601B)</b>	<b>(C4Q06X01C)</b>
• Genetic counseling	<b>(C4Q06_X02)</b>	<b>(C4Q06X02A)</b>	<b>(C4Q0602B)</b>	<b>(C4Q06X02C)</b>
• Mental health care or counseling	<b>(C4Q06_X03)</b>	<b>(C4Q06X03A)</b>	<b>(C4Q0603B)</b>	<b>(C4Q06X03C)</b>

7. Does [CHILD'S NAME] receive Early Intervention Services? **(C3Q12 – children ages 2 and younger only)**
8. Does [CHILD'S NAME] receive Special Education Services? **(C3Q13 – children ages 2 and older only)**

## SECTION 5: Care Coordination

1. During the past 12 months, did [CHILD'S NAME] need a referral to see any doctors or receive any services? **(C5Q11)**
  - Was getting referrals a big problem, a small problem, or not a problem? **(C4Q07 – only children with YES to needing a referral)**
2. Does anyone help you arrange or coordinate [CHILD'S NAME]'s care among the different doctors or services that he/she uses? **(C5Q12 – only children who responded YES to two or more of questions C4Q05X01A-C4Q05X14A, C4Q05X01C-C4Q05X14C, C5Q01, C3Q12, or C3Q13)**
  - Does a doctor or someone in a doctor's office provide this help arranging or coordinating [CHILD'S NAME]'s care? **(C5Q13 – only children with YES to help coordinating care)**
  - Who does provide help arranging or coordinating [CHILD'S NAME]'s care? **(C5Q14 INDEX – only children with NO to help coordinating care)**
3. Is there anyone else who helps arrange or coordinate [CHILD'S NAME]'s care? **(C5Q15)**
  - Who is this person? **(C5Q16 INDEX – only children with YES to others helping to coordinate care)**
4. During the past 12 months, have you felt that you could have used extra help arranging or coordinating [CHILD'S NAME]'s care among these different health care providers or services? **(C5Q17)**
  - How often did you get as much help as you wanted with arranging or coordinating [CHILD'S NAME]'s care? **(C5Q09 – only children with YES to extra help with coordinating care)**
5. Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among [CHILD'S NAME]'s doctors and other health care providers? **(C5Q10)**
6. Do [CHILD'S NAME]'s doctors or other health care providers need to communicate with [his/her] school, early intervention program, child care providers, vocational education or rehabilitation program? **(C5Q05)**
  - Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with that communication? **(C5Q06 – only children with YES to doctors communicating with school)**

## SECTION 6A: Family Centered Care

### In the past 12 months:

1. How often did [CHILD'S NAME]'s doctors and other health care providers spend enough time with [him/her]? **(C6Q02 - asked of respondents whose children visited a doctor or health care provider in the last 12 months)**
2. How often did [CHILD'S NAME]'s doctors and other health care providers listen carefully to you? **(C6Q03- asked of respondents whose children visited a doctor or health care provider in the last 12 months)**
3. How often were [CHILD'S NAME]'s doctors and other health care providers sensitive to your family's values and customs? **(C6Q04- asked of respondents whose children visited a doctor or health care provider in the last 12 months)**
4. How often did you get the specific information you needed from [CHILD'S NAME]'s doctors and other health care providers? **(C6Q05- asked of respondents whose children visited a doctor or health care provider in the last 12 months)**
5. How often did [CHILD'S NAME]'s doctors and other health care providers help you feel like a partner in his or her care? **(C6Q06- asked of respondents whose children visited a doctor or health care provider in the last 12 months)**
6. During the past 12 months, did you [or CHILD'S NAME] need an interpreter to help speak with [his/her] doctors or other health care providers? **(S5Q13 – based on respondent's answer to C2Q05 which asks about the household's primary spoken language)**
  - When you [or CHILD'S NAME] needed an interpreter, how often were you able to get someone other than a family member to help you speak with [his/her] doctors or other health care providers? **(S5Q13A – asked of respondents who needed an interpreter to help speak with the doctor)**

## SECTION 6B: Transition Issues

7. Do any of [CHILD'S NAME]'s doctors or other health care providers treat only children? **(C6Q07 – ages 12-17 only)**
  - Have they talked with you about having [CHILD'S NAME] eventually see doctors or other health care providers who treat adults? **(C6Q0A\_B – only children with YES to providers only treating children)**
  - Would a discussion about doctors who treat adults have been helpful to you? **(C6Q0A\_C – only children with NO to providers only treating children)**
8. Have [CHILD'S NAME]'s doctors or other health care providers talked with you or [CHILD'S NAME] about [his/her] health care needs as he/she becomes an adult? **(C6Q0A – ages 12-17 only)**
  - Would a discussion about [CHILD'S NAME]'s health care needs have been helpful? **(C6Q0A\_D – only children with NO to providers talking about transition to adulthood)**
9. Eligibility for health insurance often changes as children reach adulthood. Has anyone discussed with you how to obtain or keep some type of health insurance coverage as [CHILD'S NAME] becomes an adult? **(C6Q0A\_E – ages 12-17 only)**
  - Would a discussion about health insurance have been helpful to you? **(C6Q0A\_F – only children with NO to a discussion about health insurance coverage)**
10. How often do [CHILD'S NAME]'s doctors or other health care providers encourage [him/her] to take responsibility for [his/her] health care needs? **(C6Q08 – children ages 5-17 only)**

## SECTION 6C: Ease of Service Use

11. Thinking about [CHILD'S NAME]'s health needs and all the services that he/she needs, have you had any difficulties trying to use these services during the past 12 months? **(C6Q0D)**
  - Did you have any difficulties for any of the following reasons **(C6Q0E INDEX – only children with difficulties trying to use services)**
12. Thinking about [CHILD'S NAME]'s health needs and the services he/she receives, how satisfied or dissatisfied are you with those services? **(C6Q0C)**

## SECTION 7: Health Insurance

This section asks an extensive series of questions about [CHILD'S NAME]'s health insurance status and source(s) of coverage. Responses to these questions are considered confidential, but are used to determine if a child is insured at the time of the survey. The following variables are released in the public use dataset.

- How many CSHCN were without insurance at the time of the survey?
- How many CSHCN were without insurance at some point in the past year?
- How many CSHCN have private or public insurance?

## SECTION 8: Adequacy of Health Care Coverage

1. Does [CHILD'S NAME]'s health insurance offer benefits or cover services that meet [his/her] needs? **(C8Q01\_A – only children with current insurance)**
2. Are the costs not covered by [CHILD'S NAME]'s health insurance reasonable? **(C8Q01\_B – only children with current insurance)**
3. Does [CHILD'S NAME] health insurance company allow [him/her] to see the health care providers he/she needs? **(C8Q01\_C – only children with current insurance)**

## **SECTION 9: Impact on the Family**

1. During the past 12 months, would you say that the family paid more than \$500, \$250-%500, less than \$250 or nothing for [CHILD'S NAME]'s medical care? **(C9Q01)**
  - Would you say that the family paid more than \$5,000, \$1,000 to \$5,000, or less than \$1,000 for [CHILD'S NAME]'s medical care? **(C9Q01A – asked only for children paying more than \$500 for medical care)**
2. Do you or other family members provide health care at home for [CHILD'S NAME]? **(C9Q02)**
  - How many hours per week? **(C9Q03 – asked only for children whose family members provide health care at home)**
3. How many hours a week do you or other family members spend arranging or coordinating [CHILD'S NAME]'s care? **(C9Q04)**
4. Have [CHILD'S NAME]'s health condition(s) caused financial problems for your family? **(C9Q05)**
5. Have you or other family members stopped working because of [CHILD'S NAME]'s health condition(s)? **(C9Q10)**
6. Have you or other family members cut down on the hours you work because of [CHILD'S NAME]'s health? **(C9Q06)**
7. Have you needed additional income to cover [CHILD'S NAME]'s medical expenses? **(C9Q07)**

## **SECTION 10: Family Composition**

**NOTE:** Responses to the other questions in this section are considered confidential, and are used to create a single derived variable on family composition available with the public use data set.

- Please tell me how many people live in this household, including all children and anyone who normally lives here even if they are not here now, like someone who is away traveling or in the hospital **(C11Q01\_A)**

## **SECTION 11: Household Income**

1. Does [CHILD'S NAME] receive Supplemental Security Income (SSI)? **(C11Q12)**
  - Is this for a disability? **(C11Q13 – asked for children who received supplemental security income)**
2. At any time during the last 12 months, did anyone in the household receive any cash assistance from a state or county welfare program? **(C11Q11 – asked only for households below the 200% poverty level)**

## **SECTION 11A: Telephone Line and Household Information**

The questions in this section ask about zip code and number of telephone lines in the household. This information is used to mathematically weight the sample so it more accurately represents all families, including those without telephones. The questions in this section were not released due to confidentiality.