



# National Survey of Children with Special Health Care Needs (NS-CSHCN), 2001

## Guide to Topics & Questions Asked

### **SECTION 1: 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 (**S\_UNDR18**)
2. Child's sex (**C2q03**)
3. Child's race/ethnicity (**C10q01 – CW10q03**)
4. CSHCN Screener questions:
  - Does child need or use more medical care, mental health or educational services than is usual for most children of the same age? (**FACCT2**)
  - Does child currently need or use medicine prescribed by a doctor? (**FACCT1**)
  - Is child limited in any way in his/her ability to do the things most children of the same age can do? (**FACCT3**)
  - Does child need or get special therapy such as physical, occupational, or speech therapy? (**FACCT4**)
  - Does child have any kind of emotional, developmental or behavioral problem for which he/she needs treatment or counseling? (**FACCT5**)

*If YES one or more of the five screening questions above, then two follow up questions are asked:*

Follow up questions:

**Question A:** Is this because of a medical, behavioral, or other health condition?

**Question B:** Has this condition lasted or is it expected to last for at least 12 months?

**NOTE:** *Child qualifies as having a special health care need if at least one of the screening questions AND both follow up questions (A & B) are answered "YES"*

After the initial screening is completed, a single CSHCN is randomly selected from households having one or more children identified as having special health needs. A total of 750 Children with Special Health Care Needs interviews are conducted in each state.

The selected CSHCN is the focus of the interview questions in Section 2 through Section 11A below. The parent or guardian who is most familiar with the selected child's health and health care answers the questions.

### **SECTION 2: Respondent Information**

1. Respondent's relationship to the [CHILD'S NAME] (**C2q04\_A**)
2. Respondent's educational level (**CW10q04**)
3. Mother's educational level (if respondent is not mother) (**CW10q04\_A**)

### **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? — If so, how much limitation does child experience? **(C3q02 – C3q03)**
2. Parent-rated severity of [CHILD'S NAME]'s health conditions or problems (0 – 10 rating scale) **(C3q10)**
3. Do [CHILD'S NAME]'s health care needs change all the time, change once in awhile or are usually stable? **(C3q11)**
4. Does [CHILD'S NAME] receive Early Intervention Services? (children 2 years old and younger) **(C3q12)**
5. Does [CHILD'S NAME] receive Special Education Services? (children over 2 years old) **(C3q13)**
6. If school age, number of school days missed during the past 12 months because of illness or injury? **(C3q14)**

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

1. Is there a place you usually go when [CHILD'S NAME] is sick or you need advice? — If YES, what kind of place? If NO, what kind of place do you most often go and is it the same place [CHILD'S NAME] goes for routine preventive care? **(C4q0A – C4q0B)**
2. What kind of place does [CHILD'S NAME] go for routine preventive care? **(C4q01 – C4q02)**
3. Do you have one person you think of as [CHILD'S NAME]'s personal doctor or nurse? — If YES, what type of health provider is he/she? **(C4q02A – C4q02B)**
4. In past 12 months, have you delayed or gone without health care for [CHILD'S NAME]? **(C4q03)**
  - If YES, respondent is asked a list of questions about possible reasons for delaying or not get health care for [CHILD'S NAME] **(C4q04\_A – C4q04\_L)**
5. In the past 12 months, did [CHILD'S NAME] need any of the following: **(C4q05\_01 – C4q05\_14)**

a) preventive care	h) home health care
b) specialist care	i) eyeglasses or vision care
c) dental care	j) hearing aids or care
d) prescription medication	k) mobility aids
e) occupational, physical or speech therapy	l) medical supplies
f) mental health care or counseling	m) other medical equipment
g) substance abuse treatment	

  - If YES to any of the above — respondent is asked if child got all needed care. If the answer is NO — a follow up question about reasons for not receiving care is asked. **(C4q05\_01A – C4q05\_14A)**

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

6. In the past 12 months, did you or other family members need any of the following services because of [CHILD'S NAME]'s health:
  - a) professional help with care coordination (C4q060A)
  - b) respite care (C4q0601)
  - c) genetic counseling (C4q0602)
  - d) mental health care or counseling (C4q0603)
  - If YES to any of the above — respondent is asked if family got all the care that was needed. If answer is NO — a follow up question about reasons for not receiving care is asked. (C4q06X0AA – C4q06X03B)
7. In the past 12 months, how much of a problem was it to get a referral to a specialist for [CHILD'S NAME]? (C4q07)

## **SECTION 5: Care Coordination**

**NOTE:** Items 1 through 5 are only asked of respondents who reply YES to question C4q060a in Section 4 which asks if the family needed a professional to help coordinate child's care:

1. How often does a professional help you coordinate [CHILD'S NAME]'s care? (C5q02)
2. Is the care coordinator in [CHILD'S NAME]'s primary care provider's office? (C5q03)
3. Who does the professional care coordinator work for? (health insurance plan, maternal and child health program, other state agency, specialty or other doctor, other) (C5q03a)
4. How satisfied are you with the help you receive in coordinating [CHILD'S NAME]'s care? (C5q04)
5. How well do you think [CHILD'S NAME]'s health care providers communicate with each other? (C5q05)

**NOTE:** Items 6 through 7 are asked for all children.

6. How well do you think [CHILD'S NAME]'s health care providers communicate with his/her school, early intervention program, child care providers, or vocational rehabilitation program? (C5q06)
7. Have you heard of [name of respondent's state Title V program]? — If YES, does [CHILD'S NAME] get any health care services, care coordination, medications, equipment, or supplies through the Title V program? (C5q07 – C5q08)

## **SECTION 6: Satisfaction with Care — Family Centered Care — Transition**

In the past 12 months:

1. How many times did [CHILD'S NAME] visit a doctor or other health care provider? (C6q01)
2. How often did [CHILD'S NAME]'s doctors and other health care providers spend enough time with him/her? (C6q02)
3. How often did [CHILD'S NAME]'s doctors and other health care providers listen carefully to you? (C6q03)
4. How often were [CHILD'S NAME]'s doctors and other health care providers sensitive to your family's values and customs? (C6q04)
5. How often did you get the specific information you needed from [CHILD'S NAME]'s doctors and other health care providers? (C6q05)
6. 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)

**NOTE:** *Items 7 through 10 are asked for youth 13 – 17 yrs old.*

7. Have [CHILD'S NAME]'s doctors or other health care providers talked with you and [CHILD'S NAME] about how his/her needs might change as he/she becomes an adult? (C6q0A)
8. Has a plan for addressing these changing needs been developed with [CHILD'S NAME]'s doctors or other health care providers? (C6q0A\_A)
9. Have [CHILD'S NAME]'s doctors or other health care providers discussed having [CHILD'S NAME] eventually see a doctor who treats adults? (C6q0A\_B)
10. Has [CHILD'S NAME] received any vocational or career training to help him/her prepare for a job when he/she becomes an adult? (C6q0B)

**NOTE:** *Items 11 through 12 are asked for all children.*

11. Thinking about [CHILD'S NAME]'s health needs and the services he/she receives, how satisfied or dissatisfied are you with those services? (C6q0C)
12. Thinking about the services [CHILD'S NAME] needs, are those services organized in a way that makes them easy to use? (C6q0D)

## **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 used to determine if a child is insured at the time of the survey.*

- For children who are insured at the time of the survey, information about the type and source of coverage including private, employer-based, Medicaid, S-CHIP, other public insurance, military, native American, Title V, etc. derived from questions in this section is included in the publicly available data files.
- For children who are uninsured at the time of the survey, information about the length of time without insurance during the 12 months prior to survey is included in the publicly available data files.

## **SECTION 8: Adequacy of Health Care Coverage**

**NOTE:** *The following questions are only asked for those children who meet the criteria in Section 7 for being currently insured:*

1. Does [CHILD'S NAME]'s health insurance offer benefits that meet his/her needs? (C8q01\_A)
2. Are the costs not covered by [CHILD'S NAME]'s health insurance reasonable? (C8q01\_B)
3. Does the health insurance company allow [CHILD'S NAME] to see the health care providers he/she needs? (C8q01\_C)
4. In the past 12 months, have you called or written [CHILD'S NAME]'s health plan with a complaint or a problem? (C8q02)
5. Parent-rating of [CHILD'S NAME]'s health plan (0 – 10 rating scale) (C8q03)
6. If you could, would you switch health plans? (C8q04)
7. Do you have enough information about how [CHILD'S NAME]'s health plan works? (C8q05)
8. Do you believe [CHILD'S NAME]'s health plan is good for CSHCN? (C8q06)

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

1. During the past 12 months, how much has your family paid out-of-pocket for [CHILD'S NAME]'s health related needs? (C9q01 – C9q01A)
2. Do you or other family members provide home health care for [CHILD'S NAME]? — If YES, how many hours per week? (C9q02 – C9q03)
3. How many hours a week do you or other family members spend arranging or coordinating [CHILD'S NAME]'s care? (C9q04)
4. Has [CHILD'S NAME]'s health condition(s) caused financial problems for the family? (C9q05)
5. Have you or other family members cut down on hours worked to care for [CHILD'S NAME]? (C9q06)
6. Have you needed additional income to cover [CHILD'S NAME]'s medical expenses? (C9q07)
7. Have you or other family members stopped working because of [CHILD'S NAME]'s health condition(s)? (C9q10)

## **SECTION 10: Pretest Questions**

This section originally contained questions used during the pretest phases to help develop the final survey. These questions are not included in the final version of the National Survey of CSHCN.

## **SECTION 11: Household Income**

1. How many people in household? **(C11q01\_A)**
2. Total combined household income before taxes? **(C11q01)**
3. Does [CHILD'S NAME] receive Supplemental Security Income (SSI)? — If YES, is this for a disability? **(C11q12)**

**NOTE:** *Item 4 only asked for households with incomes below the 200% poverty level.*

4. 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)**

## **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.

## **SECTION 12: Medicaid/S-CHIP Knowledge and Experience**

The questions in this section are asked in each state for a small group of children identified as uninsured yet eligible for Medicaid and/or S-CHIP coverage – approximately 200 children per state overall, only 20 – 30 of which are likely to be CSHCN. The content focuses on respondents' familiarity and experience with their specific states' Medicaid and S-CHIP programs. Responses to questions in this section are not comparable for CSHCN and non-CSHCN at the state-level because of the small numbers of CSHCN represented.

## **SECTION 13: Utilization and Barriers to Care for Low-Income/Uninsured Children *without* Special Health Care Needs**

The questions in this section are asked in each state for a small group (approximately 200 per state) of non-CSHCN identified as being uninsured yet eligible for Medicaid and/or S-CHIP coverage. The questions asked are the same as those asked in the CSHCN-specific portion of the survey.