




**National Survey of Children with Special Health Care Needs (NS-CSHCN)
MCHB Core Outcomes**

Summary of key differences in measurement: 2001 to 2005-2006

 = Outcome comparable across survey years
 = Outcome not comparable across survey years



| MCHB Core Outcome | 2001 NS-CSHCN | 2005/06 NS-CSHCN | | Survey items used | Key differences to consider when comparing results across survey years |
|---|----------------------------|----------------------------|---|--|---|
| Outcome #1: CSHCN whose families are partners in decision making at all levels, and are satisfied with the services they receive | 57.5% 95% CI: 56.0-59.0 | 57.4% 95% CI: 56.5-58.2 |  | Satisfaction with health related services: C6Q0C Health care providers partner with families: C6Q06 | <p><u>No wording changes to these questions in 2005/06; same as 2001</u></p> <p><u>Position and ordering of question C6Q0C in survey changed substantially in 2005/06:</u> Question C6Q0C asks how satisfied parents are with services the child receives related to his/her health needs</p> <p>In 2001: question C6Q0C was added to Section 6 of the survey about half way through the data collection cycle. Consequently, 2001 estimates for Outcome #1 are based on only part of the sample.</p> <p>In 2005/06: question C6Q0C was moved to a different section in the survey (Section 6c) and is immediately preceded by a new question (C6Q0D) which asks whether parents encountered any difficulties when trying to use health related services needed by their child during past 12 months.</p> <p>In 2005/06: The six question family-centered care sequence that includes question C6Q06 was moved to a different section in the survey (Section 6a) and the satisfaction with and ease of service use questions are no longer asked in close proximity to the family centered care questions items.</p> <p>To meet threshold criteria for OUTCOME #1, a child must have responses of USUALLY or ALWAYS to question C6Q06 (partnership with health providers) AND a response of VERY SATISFIED to question C6Q0C about level of satisfaction with services child receives related to his/her health needs. Same scoring criteria used in 2001 and 2005/06.</p> |

Side by side comparison of NS-CSHCN interview questions used to measure **OUTCOME #1**

| 2001 NS-CSHCN | 2005/2006 NS-CSHCN |
|--|--|
| <p>Section 6. <u>SATISFACTION WITH CARE</u></p> <p>C6Q0C Thinking about (S.C.) 's health needs and the services (he/she) receives, how satisfied or dissatisfied are you with those services? Would you say very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied? (1) Very satisfied (2) Somewhat satisfied (3) Somewhat dissatisfied (4) Very dissatisfied</p> <p>C6Q06 In the past 12 months, how often did (S.C.)'s doctors or other health care providers help you feel like a partner in (his/her) care? Would you say: (1) Never (2) Sometimes (3) Usually (4) Always</p> | <p>Section 6C. EASE OF SERVICE USE</p> <p>C6Q0C Thinking about (S.C.)'s health needs and the services (he/she) receives, how satisfied or dissatisfied are you with those services? Would you say very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied? (1) Very satisfied (2) Somewhat satisfied (3) Somewhat dissatisfied (4) Very dissatisfied</p> <p>Section 6A. FAMILY CENTERED CARE</p> <p>C6Q06 During the past 12 months/ [WHEN S.C. IS YOUNGER THAN 12 MONTHS] Since (his/her) birth), how often did (S.C.)'s doctors or other health care providers help you feel like a partner in (his/her) care? Would you say never, sometimes, usually, or always? (1) Never (2) Sometimes (3) Usually (4) Always</p> |

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|--|---|--|--|---|--|
| <p>Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home</p> | <p style="text-align: center;">52.6% 95% CI: 51.7 -53.6</p> | <p style="text-align: center;">47.1% 95% CI: 46.3-48.0</p> | | <p>Personal doctor or nurse component: C4q02a</p> <p>Usual source of care component: C4q0a; C4q0b C4q01; C4q02 C4q0d (2005/06 only)</p> <p>Access to needed referrals component C4q07 C5q11 (2005/06 only) C4q05_02 (2001 only)</p> <p>Family-centered care component: C6q02;C6q03 C6q04; C6q05 C6q06 S5q13 (2005/06 only) S5q13a (2005/06 only)</p> <p>Care coordination component: C5q05; C5q06 2005/06 only: C5q12, C5q17; C5q09; C5q10 2001 only: C5q02, C4q06_0a; C4q06x0aa</p> | <p>The scoring algorithm for the medical home outcome has several steps and requires construction of five different medical home component indicators, which are then combined together to create an overall medical home composite measure for OUTCOME #2.</p> <p>The medical home composite measure is comprised of the following components:</p> <ol style="list-style-type: none"> 1. Personal doctor or nurse component 2. Usual source of care component 3. Access to needed referrals component 4. Family-centered care component 5. Care coordination component <p>In 2001, sixteen different survey questions were used to develop to scoring components and calculate the medical home composite measure.</p> <p>In 2005/06, due to improvements and additions to the questions for assessing the medical home concept, 21 different survey questions are used to calculate the individual components and medical home outcome composite measure.</p> <p>In some cases, wording and skip patterns changed substantially in even though a question retained the same item numbering across both years of the survey.</p> <p>A complete description of the survey content differences and scoring method is too lengthy to be addressed in this summary document. A technical manual with detailed information about the medical home scoring algorithm, including analytic programs in both SAS and SPSS will be available to interested users in March 2008. Please email: cahmi@ohsu.edu for more information.</p> |

Side by side comparison of NS-CSHCN interview questions used to measure **OUTCOME #2**

| 2001 NS-CSHCN | | 2005/2006 NS-CSHCN | |
|---------------------------------|--|---------------------------------|--|
| PERSONAL DOCTOR or NURSE | | PERSONAL DOCTOR or NURSE | |
| C4q02a | <p>A personal doctor or nurse is the health provider who knows (S.C.) best. Do you have ONE person that you think of as (S.C.)'s personal doctor or nurse?</p> <p>(1) YES (2) NO (6) DON'T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO C4Q03] [SKIP TO C4Q03] [SKIP TO C4Q03]</p> | C4Q02A | <p>A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant. Do you have one or more persons you think of as (S.C.)'s personal doctor or nurse?</p> <p>(1) YES, ONE PERSON (2) YES, MORE THAN ONE PERSON (3) NO (6) DON'T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO C4Q03] [SKIP TO C4Q03] [SKIP TO C4Q03]</p> |
| USUAL SOURCE OF CARE: | | USUAL SOURCE OF CARE: | |
| C4q0a | <p>Is there a place that (S.C.) USUALLY goes when (he/she) is sick or you need advice about (his/her) health?</p> <p>(1) YES (2) THERE IS NO PLACE (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO C4Q02] [SKIP TO C4Q02] [SKIP TO C4Q02]</p> | C4Q0A | <p>Is there a place that (S.C.) USUALLY goes when (he/she) is sick or you need advice about (his/her) health?</p> <p>(1) YES (2) THERE IS NO PLACE (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW (7) REFUSED</p> <p style="text-align: right;">[SKIP TO C4Q0D] [SKIP TO C4Q0D] [SKIP TO C4Q0D]</p> |
| If Yes: C4q0b | <p>Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?</p> <p>(01) DOCTOR'S OFFICE (02) HOSPITAL EMERGENCY ROOM (03) HOSPITAL OUTPATIENT DEPT (04) CLINIC OR HEALTH CENTER (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) (06) SOME OTHER PLACE (07) DOES NOT GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED</p> <p style="text-align: right;">[SKIP TO C4Q01] [SKIP TO C4Q01] [SKIP TO C4Q01] [SKIP TO C4Q01] [SKIP TO C4Q01] [SKIP TO C4Q02] [SKIP TO C4Q02] [SKIP TO C4Q02]</p> | If Yes: C4Q0B | <p>Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?</p> <p>(01) DOCTOR'S OFFICE (02) HOSPITAL EMERGENCY ROOM (03) HOSPITAL OUTPATIENT DEPARTMENT (04) CLINIC OR HEALTH CENTER (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) (06) FRIEND/ RELATIVE (07) MEXICO/OTHER LOCATIONS OUT OF US (08) SOME OTHER PLACE (09) DOES NOT GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED</p> <p style="text-align: right;">[SKIP TO C4Q0D] [SKIP TO C4Q0D] [SKIP TO C4Q0D] [SKIP TO C4Q0D] [SKIP TO C4Q0D] [SKIP TO C4Q0D] [SKIP TO C4Q0D] [SKIP TO C4Q0D] [SKIP TO C4Q0D] [SKIP TO C4Q0D]</p> |

| 2001 NS-CSHCN | | 2005/2006 NS-CSHCN | |
|------------------------------------|--|------------------------------------|--|
| | | C4Q0D | Is there a place that (S.C.) USUALLY goes when (he/she) needs routine preventive care, such as a physical examination or well-child check-up? (1) YES (2) THERE IS NO PLACE [SKIP TO C4Q02A] (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW [SKIP TO C4Q02A] (7) REFUSED [SKIP TO C4Q02A] |
| C4q01 | Is the [place selected in C4q0b] that (S.C.) goes to when (he/she) is sick the same place (S.C.) usually goes for routine preventive care? (1) YES [SKIP TO C4Q02A] (2) NO [SKIP TO C4Q02] (6) DON'T KNOW [SKIP TO C4Q02A] (7) REFUSED [SKIP TO C4Q02A] | If Yes: C4Q01 | Is the [place selected in C4Q0B] that (S.C.) goes when (he/she) is sick the same place (S.C.) usually goes for routine preventive care? (1) YES [SKIP TO C4Q02A] (2) NO (6) DON'T KNOW [SKIP TO C4Q02A] (7) REFUSED [SKIP TO C4Q02A] |
| C4q02 | What kind of place does (S.C.) go to most often when (he/she) needs routine preventive care? (01) DOES NOT GET PREVENTIVE CARE ANYWHERE (02) DOCTOR'S OFFICE (03) HOSPITAL EMERGENCY ROOM (04) HOSPITAL OUTPATIENT DEPARTMENT (05) CLINIC OR HEALTH CENTER (06) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) (07) SOME OTHER PLACE [SKIP TO C4Q02_1] (08) DOES NOT GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED | C4Q02 | What kind of place does (S.C.) go to most often when (he/she) needs routine preventive care? (01) DOCTOR'S OFFICE (02) HOSPITAL EMERGENCY ROOM (03) HOSPITAL OUTPATIENT DEPARTMENT (04) CLINIC OR HEALTH CENTER (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) (06) FRIEND/ RELATIVE (07) MEXICO/OTHER LOCATIONS OUT OF US (08) SOME OTHER PLACE [SKIP TO C4Q02_1] (09) DOES NOT GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED |
| ACCESS TO NEEDED REFERRALS: | | ACCESS TO NEEDED REFERRALS: | |
| C4q05_02 | During the past 12 months, was there any time when ("S" CHILD) needed care from a specialty doctor? (1) YES (2) NO [SKIP TO C4Q05_03] (6) DON'T KNOW [SKIP TO C4Q05_03] (7) REFUSED [SKIP TO C4Q05_03] | C5Q11 | During the past 12 months, did (S.C.) need a referral to see any doctors or receive any services? (1) YES [SKIP TO C4Q07] (2) NO [SKIP TO C5Q12] (6) DON'T KNOW [SKIP TO C5Q12] (7) REFUSED [SKIP TO C5Q12] |
| C4q07 | In the past 12 months, how much of a problem, if any, was it to get a referral to a specialist that your child needed to see? (1) Big problem (2) Small problem (3) Not a problem (4) Child did not go to see a specialist in the past 12 months (5) DID NOT NEED REFERRALS (6) DON'T KNOW (7) REFUSED | If Yes: C4Q07 | Was getting referrals a big problem, a small problem, or not a problem? (1) BIG PROBLEM (2) SMALL PROBLEM (3) NOT A PROBLEM (6) DON'T KNOW (7) REFUSED |

2001 NS-CSHCN**FAMILY CENTERED CARE**

- C6Q02** During the past 12 months, how often did (S.C.)'s doctors and other health care providers spend enough time with (him/her)?
(1) NEVER
(2) SOMETIMES
(3) USUALLY
(4) ALWAYS
(6) DON'T KNOW
(7) REFUSED
- C6Q03** During the past 12 months, how often did (S.C.)'s doctors and other health care providers listen carefully to you?
(1) NEVER
(2) SOMETIMES
(3) USUALLY
(4) ALWAYS
(6) DON'T KNOW
(7) REFUSED
- C6Q04** When (S.C.) is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs?
(1) NEVER
(2) SOMETIMES
(3) USUALLY
(4) ALWAYS
(6) DON'T KNOW
(7) REFUSED
- C6Q05** Information about a child's health care include things such as the causes of any health problems, how to care for a child now, and what changes to expect in the future. During the past 12 months, how often did you get the specific information you needed from (S.C.)'s doctors and other health care providers?
(1) NEVER
(2) SOMETIMES
(3) USUALLY
(4) ALWAYS
(6) DON'T KNOW
(7) REFUSED
- C6Q06** During the past 12 months, how often did (S.C.)'s doctors or other health care providers help you feel like a partner in (his/her) care?
(1) NEVER
(2) SOMETIMES
(3) USUALLY
(4) ALWAYS
(6) DON'T KNOW
(7) REFUSED

2005/2006 NS-CSHCN**FAMILY CENTERED CARE**



- C6Q02** During the past 12 months, how often did (S.C.)'s doctors and other health care providers spend enough time with (him/her)?
(1) NEVER
(2) SOMETIMES
(3) USUALLY
(4) ALWAYS
(6) DON'T KNOW
(7) REFUSED
- C6Q03** During the past 12 months, how often did (S.C.)'s doctors and other health care providers listen carefully to you?
(1) NEVER
(2) SOMETIMES
(3) USUALLY
(4) ALWAYS
(6) DON'T KNOW
(7) REFUSED
- C6Q04** When (S.C.) is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs?
(1) NEVER
(2) SOMETIMES
(3) USUALLY
(4) ALWAYS
(6) DON'T KNOW
(7) REFUSED
- C6Q05** Information about a child's health care include things such as the causes of any health problems, how to care for a child now, and what changes to expect in the future. During the past 12 months, how often did you get the specific information you needed from (S.C.)'s doctors and other health care providers?
(1) NEVER
(2) SOMETIMES
(3) USUALLY
(4) ALWAYS
(6) DON'T KNOW
(7) REFUSED
- C6Q06** During the past 12 months, how often did (S.C.)'s doctors or other health care providers help you feel like a partner in (his/her) care?
(1) NEVER
(2) SOMETIMES
(3) USUALLY
(4) ALWAYS
(6) DON'T KNOW
(7) REFUSED


| 2001 NS-CSHCN | | 2005/2006 NS-CSHCN | |
|--|--|--|--|
| | | S5Q13 An interpreter is someone who repeats what one person says in a language used by another person. During the past 12 months, did you (or S.C.) need an interpreter to help speak with (his/her) doctors or other health care providers? (1) YES [SKIP TO S5Q13A] (2) NO [SKIP TO C6Q07] (6) DON'T KNOW [SKIP TO C6Q07] (7) REFUSED [SKIP TO C6Q07] | |
| | | IF Yes: S5Q13a When you (or S.C.) 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? (1) NEVER (2) SOMETIMES (3) USUALLY (4) ALWAYS (6) DON'T KNOW | |
| CARE COORDINATION | | CARE COORDINATION | |
| C4q06_0a During the past 12 months, was there any time when you or other family members needed professional care coordination among different health care providers and services that the child uses? (1) YES (2) NO [SKIP TO C4Q06_01] (6) DON'T KNOW [SKIP TO C4Q06_01] (7) REFUSED [SKIP TO C4Q06_01] | | C5Q12 Does anyone help you arrange or coordinate (S.C.)'s care among the Different doctors or services that (he/she) uses? By "arrange or coordinate," I mean: Is there anyone who helps you make sure that (S.C.) gets all the health care and services (he/she) needs, that health care providers share information, and these services fit together and are paid for in a way that works for you? (1) YES (2) NO [SKIP TO C5Q17] (6) DON'T KNOW [SKIP TO C5Q17] (7) REFUSED [SKIP TO C5Q17] | |
| If Yes: C4q06x0aa Did you or your family receive all the professional care coordination that was needed? (1) YES (2) NO (6) DON'T KNOW (7) REFUSED | | C5Q17 During the past 12 months, have you felt that you could have used extra help arranging or coordinating (S.C.)'s care among these different health care providers or services? (1) YES (2) NO [SKIP TO C5Q10] (6) DON'T KNOW [SKIP TO C5Q10] (7) REFUSED [SKIP TO C5Q10] | |
| C5q02] Earlier you told me that you or other family members needed professional assistance coordinating ("S" CHILD)'s care. How often does a professional help you coordinate ("S" CHILD)'s care among (his/her) different providers and services? (1) Never [SKIP TO C5q06] (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW [SKIP TO C5q06] (7) REFUSED [SKIP TO C5q06] | | If Yes: C5Q09 During the past 12 months, how often did you get as much help as you wanted with arranging or coordinating (S.C.)'s care? (1) NEVER (2) SOMETIMES (3) USUALLY (6) DON'T KNOW (7) REFUSED | |

| 2001 NS-CSHCN | 2005/2006 NS-CSHCN |
|---|--|
| <p>C5q06 How well do you think ("S" CHILD) 's doctors and other health care providers communicate with (his/her) school, early intervention program, child care providers, or vocational rehabilitation program?</p> <p>(01) Excellent (02) Very Good (03) Good (04) Fair or (05) Poor (06) COMMUNICATION NOT NEEDED (96) DON'T KNOW (97) REFUSED</p> | <p>C5Q05 Do (S.C.)'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?</p> <p>(1) YES (2) NO (6) DON'T KNOW (7) REFUSED</p> <p>[SKIP TO C6Q02] [SKIP TO C6Q02] [SKIP TO C6Q02]</p> |
| <p>C5q05 How well do you think ("S" CHILD) 's doctors and other health care providers communicate with each other about ("S" CHILD)'s care?</p> <p>(01) Excellent (02) Very Good (03) Good (04) Fair or (05) Poor (06) COMMUNICATION NOT NEEDED (96) DON'T KNOW (97) REFUSED</p> | <p>C5Q06 Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with that communication?</p> <p>(1) VERY SATISFIED (2) SOMEWHAT SATISFIED (3) SOMEWHAT DISSATISFIED (4) VERY DISSATISFIED (6) DON'T KNOW (7) REFUSED</p> <p>C5q10 Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among (S.C.)'s doctors and other health care providers?</p> <p>(1) VERY SATISFIED (2) SOMEWHAT SATISFIED (3) SOMEWHAT DISSATISFIED (4) VERY DISSATISFIED (5) NO COMMUNICATION NEEDED OR WANTED (6) DON'T KNOW (7) REFUSED</p> |

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| <p>Outcome #3: CSHCN whose families have adequate private and/or public insurance to pay for the services they need</p> | <p>59.6% 95% CI: 58.7-60.5</p> | <p>62.0% 95% CI: 61.2-62.8</p> |  | <p>Insured at time of survey: UNINS</p> <p>Insured entire year: UNINS_YR</p> <p>Adequacy of insurance benefits: C8Q01_A C8Q01_B C8Q01_C</p> | <p>In 2005/06, the response option of “no out of pocket costs” was added to question C8Q01_B.</p> <p>No changes to any other questions; same as 2001.</p> <p>To meet threshold criteria for OUTCOME #3, a child must have responses of USUALLY or ALWAYS to each of the three adequacy of insurance questions (C8Q01_A thru C8Q01_C) AND be currently insured AND have no gaps in coverage during the past 12 months. Same scoring criteria used in 2001 and 2005/06.</p> |

| 2001 NS-CSHCN | 2005/2006 NS-CSHCN |
|---|---|
| <p>Section 7. HEALTH INSURANCE</p> <p>UNINS CHILD INSURED BY NCHS DEFINITION – DERIVED* <i>(variable released with public use file)</i> (0) Insured at time of survey (1) Not insured at time of survey</p> <p>UNINS_YR ONE OR MORE PERIODS WITHOUT INSURANCE, PAST YEAR – DERIVED* <i>(variable released with public use file)</i> (0) Insured entire year (1) One or more periods without insurance</p> <p><i>*Derived variable included in public use data file – based on responses to questions in Section 7</i></p> | <p>Section 7. HEALTH INSURANCE</p> <p>UNINS CHILD INSURED BY NCHS DEFINITION – DERIVED* <i>(variable released with public use file)</i> (0) Insured at time of survey (1) Not insured at time of survey</p> <p>UNINS_YR ONE OR MORE PERIODS WITHOUT INSURANCE, PAST YEAR – DERIVED* <i>(variable released with public use file)</i> (0) Insured at time of survey (1) Not insured at time of survey</p> <p><i>*Derived variable included in public use data file – based on responses to questions in Section 7</i></p> |
| <p>Section 8. ADEQUACY OF HEALTH CARE COVERAGE</p> <p>C8Q01_A The next questions are about (S.C.)'s health insurance or health care plans. Does (S.C.)'s health insurance offer benefits or cover services that meet (his/her) needs? Would you say: (1) Never (2) Sometimes (3) Usually (4) Always</p> <p>C8Q01_B Are the costs not covered by (S.C.)'s health insurance reasonable? Would you say: (1) Never (2) Sometimes (3) Usually (4) Always</p> <p>C8Q01_C Does (S.C.)'s health insurance allow (him/her) to see the health care providers (he/she) needs? Would you say: (1) Never (2) Sometimes (3) Usually (4) Always</p> | <p>Section 8. ADEQUACY OF HEALTH CARE COVERAGE</p> <p>C8Q01_A The next questions are about (S.C.)'s health insurance or health care plans. Does (S.C.)'s health insurance offer benefits or cover services that meet (his/her) needs? Would you say: (1) Never (2) Sometimes (3) Usually (4) Always</p> <p>C8Q01_B Are the costs not covered by (S.C.)'s health insurance reasonable? Would you say: (1) Never (2) Sometimes (3) Usually (4) Always</p> <p>C8Q01_C Does (S.C.)'s health insurance allow (him/her) to see the health care providers (he/she) needs? Would you say: (1) Never (2) Sometimes (3) Usually (4) Always</p> |

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|---|------------------------------------|--|---|---|---|
| <p>Outcome #4: CSHCN who are screened early and continuously for special health care needs</p> | <p>Not assessed in 2001 survey</p> | <p align="center">63.8% 95% CI: 63.0-64.6</p> |  | <p>Routine preventive medical care: C4Q05_X01 C4Q05X01A C4Q05X01C</p> <p>Preventive dental care: C4Q05_X031 C4Q05X031A C4Q05X031C</p> | <p>Outcome #4 was assessed using data from the NS-CSHCN for the first time in 2005/06.</p> <p>The preventive dental care questions (C4Q05_X031 - C4Q05X031C) are newly added in 2005/06; not asked in 2001. A question assessing whether any routine preventive medical care (C4Q05X01C) was received by children with unmet preventive care needs was also added in 2005/06.</p> <p>To meet threshold criteria for OUTCOME #4, a child must have responses indicating that during the past 12 months he/she received both routine preventive medical care (C4Q05_X01 thru C4Q05X01C) AND preventive dental care (C4Q05_X031 thru C4Q05X031C). Receipt of both types of care is necessary to meet the scoring criteria for the outcome.</p> |

| 2001 NS-CSHCN | 2005/2006 NS-CSHCN |
|------------------------------------|---|
| <i>Not assessed in 2001 survey</i> | Section 4. ACCESS TO CARE: UTILIZATION and UNMET NEEDS |
| | C4Q05_X01 During the past 12 months, was there any time when (S.C.) needed routine preventive care such as a physical examination or well child check-up? (1) Yes (2) No [SKIP TO C4Q05_X02] |
| | C4Q05X01A Did (S.C.) receive all the routine preventive care that [he/she] needed? (1) Yes [SKIP TO C4Q05_X02] (2) No |
| | C4Q05X01C Did (S.C.) get any routine preventive care during the past 12 months? (1) Yes (2) No |
| | C4Q05_X031 During the past 12 months, was there any time when (S.C.) needed preventive care such as a physical dental care such as check ups or dental cleanings? (1) Yes (2) No [SKIP TO C4Q05_X032] |
| | C4Q05X031A Did (S.C.) receive all the preventive dental care that [he/she] needed? (1) Yes [SKIP TO C4Q05_X032] (2) No |
| | C4Q05X031C Did (S.C.) get any preventive dental care during the past 12 months? (1) Yes (2) No |

**National Survey of Children with Special Health Care Needs (NS-CSHCN)
MCHB Core Outcomes**

Summary of key differences in measurement: 2001 to 2005-2006



 = Outcome comparable across survey years
 = Outcome not comparable across survey years


| MCHB Core Outcome | 2001 NS-CSHCN | 2005/06 NS-CSHCN | | Survey items used | Key differences to consider when comparing results across survey years |
|---|--|--|---|---|--|
| <p>Outcome #5: CSHCN whose community-based services are organized in ways that so families can use them easily</p> | <p style="text-align: center;">74.3% 95% CI: 72.9-75.7</p> | <p style="text-align: center;">89.1% 95% CI: 88.6-89.6</p> |  | <p>Ease of services use: C6Q0D</p> | <p><u>In 2005/06, significant revisions were made to question C6Q0D:</u></p> <p>In 2001, respondents were asked how often services were organized for easy use. For 2005/06, question C6Q0D was modified to ask if respondents had any difficulties trying to use services</p> <p>The response options for question C6Q0D changed to YES/NO in 2005/06 and a lengthy new introduction was added.</p> <p>In 2001, question C6Q0D was added to survey Section 6 about half way through the data collection cycle. Consequently, 2001 estimates for Outcome #5 are based on only part of the sample.</p> <p><u>To meet threshold criteria</u> for OUTCOME #5, a child must have a YES response to question C6Q0D – indicating no difficulties were experienced by child’s family when trying to use any of the health related services that child needed during the past 12 months.</p> |

| 2001 NS-CSHCN | 2005/2006 NS-CSHCN |
|--|--|
| <p>Section 6. SATISFACTION WITH CARE</p> <p>C6Q0D Thinking about the services (S.C.) needs, are those services organized in a way that makes them easy to use? Would you say this is true never, sometimes, usually or always?</p> <p>(1) Never (2) Sometimes (3) Usually (4) Always</p> | <p>Section 6. SATISFACTION WITH CARE</p> <p>We have been talking primarily about medical services provided by your child's doctors. There are other types of services children may need or use because of their health. These services may be provided by (IF AGE < 36 MONTHS, SHOW: early intervention programs; ELSE SHOW: schools), child care facilities, vocational education and rehabilitation programs, and other community programs.</p> <p>C6Q0D Thinking about (S.C.)'s health needs and all the services that (he/she) needs, have you had any difficulties trying to use these services (IF AGE = 12 MONTHS OR GREATER, SHOW: during the past 12 months; ELSE SHOW: since (his/her) birth)?</p> <p>(1) YES (2) NO [SKIP TO C6Q0C]</p> <p>IF THE PARENT SAYS THAT THE CHILD DID NOT NEED ANY SERVICES, READ: This question asks about difficulty using ANY services that your child needed because of his/her health. Did you have ANY difficulty using ANY services during the past 12 months?</p> |

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Summary of key differences in measurement: 2001 to 2005-2006

 = Outcome comparable across survey years
 = Outcome not comparable across survey years

| MCHB Core Outcome | 2001 NS-CSHCN | 2005/06 NS-CSHCN | | Survey items used | Key differences to consider when comparing results across survey years |
|--|---------------------------------|------------------------------------|---|---|---|
| <p>Outcome #6: Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence (CSHCN ages 12-17 only)</p> | <p>5.8% 95% CI: 4.6-7.0</p> | <p>41.2% 95% CI: 40.0-42.5</p> |  | <p><u>2005/06:</u> C6Q07 C6Q0A_B C6Q0A_C C6Q0A C6Q0A_D C6Q0A_E C6Q0A_F C6Q08</p> <p><u>2001:</u> C6Q0A C6Q0A_A C6Q0A_B C6AQ0B</p> | <p><u>In 2005/06, age range for Outcome #6 was changed to 12-17 yrs and several new questions were added:</u></p> <p>In 2001, the transition to adulthood question sequence was added to survey Section 6 about half way through the data collection cycle. Consequently, 2001 estimates for Outcome #5 are based on only part of the sample and included only CSHCN ages 13-17 yrs. In 2005/06, Outcome #5 was assessed for the full survey sample.</p> <p>To meet threshold criteria for OUTCOME #6, a youth must have responses indicating that his/her doctors have EITHER discussed transitioning to doctors who treat adults, changing health needs as youth becomes adult, and/or how to maintain health insurance coverage upon reaching adulthood OR that such discussions were not needed (C6Q07 thru C6Q0A_F) AND responses indicating that his/her doctors USUALLY or ALWAYS encourage the youth to take age-appropriate responsibility for managing own health care needs (C6Q08).</p> |

| 2001 NS-CSHCN | 2005/2006 NS-CSHCN |
|--|---|
| Section 6. <u>SATISFACTION WITH CARE</u> | Section 6B. <u>TRANSITION ISSUES</u> |
| <p>C6Q0A Have (S.C.) doctors or other health providers talked with you or (S.C.) about how his/her health care needs might change when he/she becomes an adult? (1) YES (2) NO [SKIP TO C6Q0B]</p> | <p>C6Q07 [IF CHILD IS LESS THAN 5 YEARS OF AGE, SKIP TO C6Q0D. IF CHILD IS 5-11 YEARS OF AGE, SKIP TO C6Q08] The next questions are about preparing for (S.C.)'s health care needs as (he/she) becomes an adult. Do any of (S.C.)'s doctors or other health care providers treat only children? (1) YES (2) NO [SKIP TO C6Q0A]</p> |
| <p>C6Q0A_A Has a plan for addressing these changing needs been developed with (S.C.)'s doctor or other health care providers? (1) YES (2) NO</p> | <p>C6Q0A_B Have they talked with you about having (S.C.) eventually see doctors or other health care providers who treat adults? (1) YES [SKIP TO C6Q0A] (2) NO</p> |
| <p>C6Q0A_B Have (S.C.)'s doctors or other health care providers discussed having (S.C.) eventually see a doctor who treats adults? (1) YES (2) NO</p> | <p>C6Q0A_C Would a discussion about doctors who treat adults have been helpful to you? (1) YES (2) NO</p> |
| <p>C6Q0B Has (S.C.) received any vocational or career training to help him/her prepare for a job when he/she becomes an adult? (1) YES (2) NO</p> | <p>C6Q0A Have (S.C.)'s doctors or other health care providers talked with you or (S.C.) about (his/her) health care needs as (he/she) becomes an adult? (1) YES [SKIP TO C6Q0A_E] (2) NO</p> |
| | <p>C6Q0A_D Would a discussion about (S.C.)'s health care needs have been helpful? (1) YES (2) NO</p> |
| | <p>C6Q0A_E 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 (S.C.) becomes an adult? (1) YES [SKIP TO C6Q08] (2) NO</p> |
| | <p>C6Q0A_F Would a discussion about health insurance have been helpful to you? (1) YES (2) NO</p> |
| | <p>C6Q08 How often do (S.C.)'s doctors or other health care providers encourage [him/her] to take responsibility for [his/her] health care needs, such as: [IF CHILD IS 5-11 YEARS OF AGE, THEN READ: "learning about [his/her] conditions or helping with treatments and medications?"] [IF CHILD IS 12+ YEARS OF AGE, THEN READ : "taking medication, understanding [his/her] diagnosis, or following medical advice?"] Would you say never, sometimes, usually, or always? (1) Never (2) Sometimes (3) Usually (4) Always</p> |