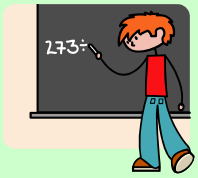
2005-2006 National Survey of Children with Special Health Care Needs

INDICATOR AND OUTCOME MEASURES

SPSS CODE & DOCUMENTATION



VERSION 1.0, MAY 2008

Child and Adolescent Health Measurement Initiative (CAHMI), *2005/2006 National Survey of Children with Special Health Care Needs SPSS Codebook,* Data Resource Center for Child and Adolescent Health, www.childhealthdata.org.

Table of Contents

Purpose of the 2005-2006 NS-CSHCN SPSS Codebook 4
The CAHMI Data Resource Center for Child and Adolescent Health 4
Overview of the 2005-2006 NS-CSHCN 5
Linking the NS-CSHCN Data Files 6
Important Information Regarding the 2005-2006 NS-CSHCN 7
Appropriate Reference Citation 8
References 9

National Chartbook Indicators 10
Indicator #1: Activity Limitations 10
Indicator #2: Missed School Days 11
Indicator #3: Inconsistently Insured 12
Indicator #4: Currently Uninsured 13
Indicator #5: Adequacy of Current Insurance Coverage 14
Indicator #6: Unmet Needs for Care 16
Indicator #7: Unmet Needs for Family Support Services 19
Indicator #8: Problems Obtaining Referral 21
Indicator #9: Usual Source for Sick Care 22
Indicator #10: Personal Doctor or Nurse 24
Indicator #11: Family-Centered Care 25
Indicator #12: Out-of-Pocket Expenses 28
Indicator #13: Family Financial Burden 29
Indicator #14: Hours per Week Providing Care 30
Indicator #15: Impact on Family Work Life 32

MCHB Core Outcomes & System of Care 34
Outcome #1: Families partner in decision-making and are satisfied with services 34
Outcome #2: Coordinated, ongoing, comprehensive care within a medical home 36
Outcome #3: Adequate private and/or public insurance 44
Outcome #4: Early and continuous screening for special health care needs 47
Outcome #5: Community-based service systems organized for ease of use 49
Outcome #6: Transition to adulthood 50
System of Care #1: System of Care criteria met for CSHCN ages 0-11 53
System of Care #2: System of Care criteria met for CSHCN ages 12-17 55

Table of Contents (continued)

Conditions & Functional Difficulties ***57***
Conditions: Number of current health conditions reported from list of 16 different conditions 57
Difficulties: Number of functional difficulties reported from list of 15 different difficulties 58
Emotional: CSHCN ages 1½ to 17 reporting emotional or behavioral difficulties..... 59
Activity: CSHCN ages 0 to 17 reporting difficulties involving activities or participation 60
Body: CSHCN ages 0 to17 reporting difficulties involving bodily functions 61

Stratifiers ***62***
Gender 62
Age 63
Race & Ethnicity 64
Special Needs Type 66
Household Income Version 1 68
Household Income Version 2 70
Insurance Status 72
Consistency of Insurance 73
Insurance Type 74
Family Structure 75
Hispanic Household Language 76

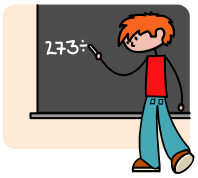
Appendix A: Unweighted Frequency Tables: Codebook Variables in Interview File A-1
Appendix B: Unweighted Frequency Tables: Stratification Variables in Household & Screener Files B-1
Appendix C: Methods Notes on Imputation of Income Level C-1
Appendix D: Comparison of 2001 & 2005-2006 NS-CSHCN Indicators & Outcome Measures D-1

Acknowledgements

The Data Resource Center for Child and Adolescent Health is a project of the Child and Adolescent Health Measurement Initiative (CAHMI), supported by a Cooperative Agreement from the Maternal and Child Health Bureau Health Resources and Services Administration, U.S. Department of Health and Human Services.

The indicators specified in this codebook were developed under the leadership of the Maternal and Child Health Bureau with input from Data Resource Center Advisory Committee members. Special thanks to our many collaborators and colleagues in for their support, expertise and advice.

Finally, we would like to acknowledge our intern Tim Main, for his excellent work pulling together and testing the SPSS syntax, assembling background information and data for the Appendices, and formatting the codebook pages.


273÷

Purpose of the 2005-2006 NS-CSHCN SPSS Codebook

This codebook contains SPSS program statements that can be applied to the public use data files for the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) to create the key children and youth with special health care needs (CSHCN) Indicators, Maternal and Child Health Bureau (MCHB) Outcomes, and variables used to stratify these items in the interactive data query feature of the National Data Resource Center for Child and Adolescent Health (DRC) located online at **www.childhealthdata.org.**

The codebook is designed to serve as a resource for researchers and analysts who are interested in replicating the indicator and outcome variables developed from the 2005 NS-CSHCN for the DRC. Its purpose is to expedite research by helping to standardize and improve the comparability of information derived from the 2005 NS-CSHCN.

The DRC maintains a complete 2005 NS-CSHCN indicator data set, avaiLABEL in either SAS or SPSS format. The data set includes all 15 Key Child Health Indicators and 5 MCHB Outcome variables, as well as demographic and individual question items. To request a copy, contact the Child and Adolescent Health Measurement Initiative (CAHMI) at: **cahmi@ohsu.edu.**

The CAHMI Data Resource Center for Child and Adolescent Health

The Data Resource Center for Child and Adolescent Health (DRC) is an easy-to-use public Web site that eliminates barriers and reduces time and resources needed to obtain key findings on the health and health care of children and youth families in the United States. The DRC is sponsored by the Maternal and Child Health Bureau and is led by the Child and Adolescent Health Measurement Initiative (CAHMI) based at the Oregon Health and Science University in Portland, Oregon. It is located online at **www.childhealthdata.org.**

The main feature of the DRC is an interactive data search tool that includes over 100 standardized indicators from the two extensive national- and state-based surveys on the health and health care of children and youth: the 2001 and 2005-2006 *National Survey of Children with Special Health Care Needs* (NS-CSHCN), and the *2003 National Survey of Children's Health* (NSCH). Data search results can be stratified by the age, race/ethnicity, income and other pertinent characteristics of children and youth nationally or for individual states. Links to the survey instruments, sampling diagrams, methods reports and other survey specific resources are included on the DRC Web site.

Overview of the 2005-2006 NS-CSHCN

The National Survey of Children with Special Health Care Needs (NS-CSHCN) is a nationwide telephone survey sponsored by the U.S. Department of Health and Human Services Administration Maternal and Child Health Bureau (MCHB), and conducted by the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention, using State and Local Area Integrated Telephone Survey (SLAITS) technology for sampling and administration. The survey was conducted first in 2001 and repeated in 2005-2006.

The 2005-2006 NS-CSHCN interview sample was achieved by screening 364,841 children representing 192,083 households nationwide, using the CSHCN Screener. The CSHCN Screener (1) is a survey tool developed and validated specifically to identify children who meet the federal MCHB health-consequences-based special health care needs definition. The Screener asks parents about the presence of five different health consequences:

- need for or use of prescription medications;
- elevated need for or use of medical, mental health, or educational services;
- functional limitations;
- need for or use of special therapies; or
- emotional, developmental or behavioral conditions that require treatment.

Parents of children who experience one or more of the health consequences are then asked whether the specific health consequences are attributable to a medical, behavioral, or other health condition and whether this condition has lasted or is expected to last for at least 12 months. Any child with an affirmative response to one or more of the five consequences and its follow-up questions is considered to have special health care needs.

In-depth interviews were completed for a total of 40,840 randomly selected children and youth who met the CSHCN Screener criteria — approximately 750 in each state and the District of Columbia. The survey data are weighted to reflect the population of non-institutionalized children ages 0–17 years in each state and the District of Columbia.

The 2005-2006 NS-CSHCN provides detailed state- and national-level parent-reported information on the health status and health care system experiences of children and youth with special health care needs (CSHCN) and their families. Topics covered by the survey include health and functional status, insurance coverage and adequacy of coverage, access to health care services, medical home, impact of children's special needs on their families, family-centeredness of services, and care coordination. A section on selected conditions and functional difficulties was added to the 2005/2006 survey.

Data from the 2005-2006 NS-CSHCN are publicly released in four files in SAS format: Household, Screener, Interview and Insurance. The public data sets and relevant background

information and documentation are avaiLABEL online at: **http://www.cdc.gov/nchs/about/major/slaits/nscshcn_05_06.htm.** Additional information and results from the 2005-2006 NS-CSHCN are avaiLABEL in the DRC at: **www.childhealthdata.org.**

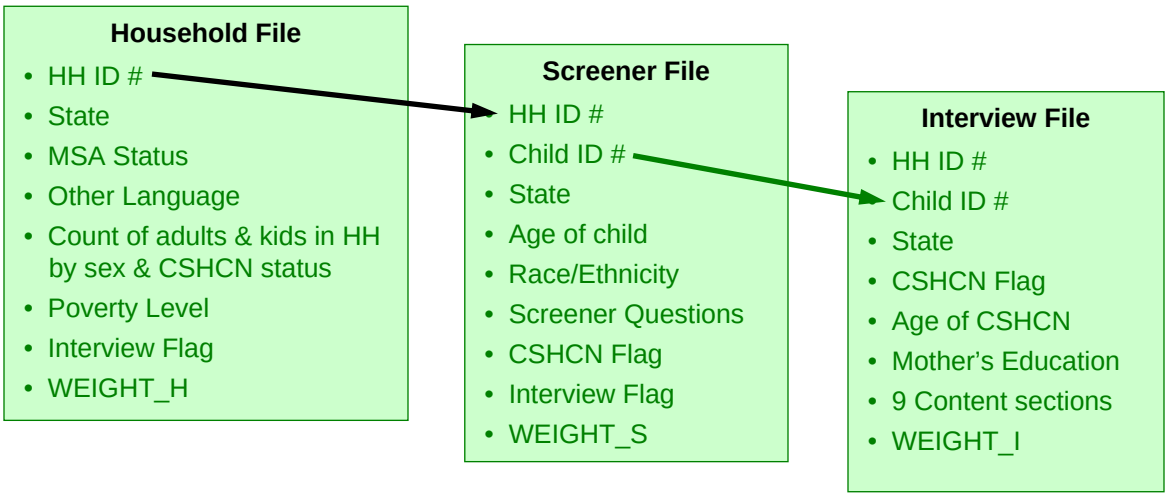
Linking the NS-CSHCN Data Files

Three of the four public use data files for the 2005 NS-CSHCN are used in this codebook as described in the following table:

NS-CSHCN Data Files	Number of Records (n)	Unique Identifier	Weighting Variable
Household file	191,640 randomly selected U.S. households with at least one child or youth ages 0–17	IDNUMR	WEIGHT_H
Screener file	363,183 children and youth ages 0–17 living in the randomly selected households with children	IDNUMXR	WEIGHT_S
Interview file	40,723 CSHCN ages 0–17 randomly selected from each household identified as has having one or more CSHCN during the initial screening process	IDNUMXR	WEIGHT_I

A fourth file contains a national referent sample of 4945 children without special health care needs who were randomly selected so that characteristics of CSHCN and children without special health care needs may be compared.

The variables in this codebook are all based on the 2005-2006 NS-CSHCN Interview file. However, some are derived from data fields that must be merged into the Interview file from the Household or Screener files. The source file for these variables is identified in the text and annotated in the code. The diagram below illustrates the location of key variables in each of the three main data files.



Source: Sharp, V. "Analyzing State Data from the National Survey of CSHCN," 2003 presentation, Center for Children with Special Needs, Children's Hospital, Seattle WA

Important Information About the 2005-2006 NS-CSHCN

Weighting

The sampling weights provided in the publicly released data files are used to produce estimates representative of children or households with children at the state and national levels. These sampling weights adjust the survey responses to reflect the underlying child population using the U.S. Census counts of children, stratified by sex, age, and race/ethnicity as the reference population. Additional adjustments are made to reflect telephone access and other non-response biases. The weighting variable WEIGHT_I, included in the Interview file, adjusts the survey responses to reflect the population of CSHCN ages 0–17 in each state and the District of Columbia.

Variance Estimation

Use of statistical software with the capacity to take into account the complex sampling design of the survey is necessary to appropriately calculate the variances and associated standard errors and confidence intervals required for accurate statistical hypothesis testing. Computer programs capable of variance estimation for complex sample designs include SUDAAN, SAS V 9.0+, STATA, WesVar, and SPSS Complex Samples.

The NS-CSHCN is designed to provide independent data sets for each of the 50 states and the District of Columbia. Subsetting the survey data to a particular state does not compromise the design structure of the survey. However, subsetting further to a specific population subgroup (age group, race/ethnicity, or poverty level, for example), within or across states, will lead to incorrect standard error estimation. Most software packages that analyze complex sample data will incorrectly compute variances for subsetted data when the sample design is compromised because complete design information is not avaiLABEL. To avoid this issue, use a subpopulation procedure, such as SUDAAN's SUBPOPN option, that allows for the targeting of specific subpopulations for analysis while retaining the full sample design information.

The only substate geographic information included in the 2005-2006 NS-CSHCN public use data set is a variable for Metropolitan Statistical Area (MSA) status, located in the Household file. MSA status information is avaiLABEL for the 16 states in which the population is at least 500,000 in both categories (MSA and non-MSA). Zip code data is collected with the NS-CSHCN but is not released in the public use data files due to confidentiality restrictions. The confidential zip code data can be made avaiLABEL to researchers for on-site analysis at the Data Research Center of the National Center for Health Statistics (NCHS) in Hyattsville, MD. The process requires submitting a proposal to the NCHS. For more information, see:
http://www.cdc.gov/nchs/r&d/rdc.htm.

Interpretation of Results

The respondents to the CSHCN in depth interview are parents; however, the results are weighted to reflect the population of CSHCN ages 0–17, not parents or families. Thus, results are always reported in terms of CSHCN, even if the question refers to the parents or family. For example, "…CSHCN whose family members spend 11 or more hours a week providing or coordinating child's health care," rather than: "…families with CSHCN who spend 11 or more…."

Pay careful attention to the valid denominator of responders to specific questions when interpreting results for this survey. Although most questions were asked for all CSHCN, in several parts of the survey follow-up questions were asked only if parents gave a specific response to a previous filter question or only for specific groups, such as school-age CSHCN.

Verification

Unweighted frequency distributions for the variables in this codebook are located in Appendix A, as a resource for cross checking results. Results may also be compared with results from the interactive data query in the DRC.

Additional Information on Survey Design and Methodology

The NCHS report, *Design and Operation of the National Survey of Children with Special Health Care Needs, 2005/06 (2)* is an excellent, comprehensive resource for anyone interested in using data from the NS-CSHCN. The report includes important information about questionnaire development, sample selection and weighting procedures, events that affected data collection, adjustments made to protect confidentiality, and more. View or download the methods report from the NCHS Web site at: **www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf.**

Appropriate Reference Citation

Appropriate citation must accompany publication or presentation of any analysis involving variables constructed using code from this document in any form. The following format is recommended:

> Child and Adolescent Health Measurement Initiative (CAHMI), "2005-2006 NS-CSHCN Indicator and Outcome Variables SPSS Codebook, Version 1," 2008, Data Resource Center for Child and Adolescent Health, **www.childhealthdata.org**.

References

1. Bethell CD, Read D, Stein REK, Blumberg SJ, Wells N, Newacheck PW. “Identifying children with special health care needs: development and evaluation of a short screening instrument.” *Ambulatory Pediatric*s. 2002; 2:38-47.

2. Blumberg SJ, Olson L, Frankel M, et al. “Design and operation of the National Survey of Children with Special Health Care Needs, 2001.” National Center for Health Statistics. Vital Health Stat 1(41). 2003, www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf.

2. Blumberg SJ, Welch EM, Chowdhury SR, Upchurch HL, Parker EK, Skalland BJ. “Design and operation of the National Survey of Children with Special Health Care Needs, 2005-06.” National Center for Health Statistics. Vital Health Stat 1. Forthcoming. Advance Access Online Version (November 28, 2007) http://www.cdc.gov/nchs/data/slaits/NSCSHCN_0506_DO_112807.pdf

3. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2005–2006*. Rockville, Maryland: U.S. Department of Health and Human Services, 2007. http://mchb.hrsa.gov/cshcn05/MI/NSCSHCN.pdf

4. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, Division of Health Interview Statistics, Survey Planning and Special Surveys Branch. “Progress toward implementing community-based systems of services for children with special health care needs: Summary tables from the National Survey of Children with Special Health Care Needs, 2005-2006.” December, 2007. http://www.cdc.gov/nchs/data/slaits/Summary_tables_NSCSHCN_0506.pdf

INDICATOR #1	Activity Limitations: CSHCN whose health conditions consistently affect daily activities
Survey Items Used	C3Q02 C3Q03
Numerator	Daily activities consistently affected, often a great deal; Daily activities moderately affected some of the time; Daily activities never affected
Denominator	CSHCN ages 0-17
Description	Percent of CSHCN ages 0–17 whose health conditions consistently and often greatly affect their daily lives.

Notes for Data-Users

This indicator combines the concepts of "how often" and "how much" CSHCN's conditions affect their daily activities. FOR EXAMPLE: A child may have asthma attacks only rarely, however, when such attacks occur they may greatly affect the child's abilities to do daily activities. CSHCN whose conditions "consistently, and often greatly, affect their daily activities" are those with responses of "Usually or Always" on C3Q02 AND/OR a response of "A great deal" on C3Q03.

Revisions in 2005

In 2005-2006, significant changes were made to the wording of the introduction respondents heard prior to answering questions C3Q02 and C3Q03. Different wording was used in 2005-2006 to describe type of health condition for the subset of CSHCN with emotional, developmental or behavioral health issues only. Take these changes into consideration when comparing results across years.

SPSS Code and Annotation

```
COMPUTE indic1_05 = 99.
IF (c3q02 = 1) indic1_05 = 1.
IF (c3q02 = 2) indic1_05 = 2.
IF (c3q02 = 3) indic1_05 = 3.
IF (c3q02 = 4) indic1_05 = 3.
IF (c3q03 = 1) indic1_05 = 3.
EXECUTE.

VARIABLE LABEL indic1_05  'INDICATOR #1: % of CSHCN whose health conditions consistently and often greatly affect their daily activities'.
VALUE LABEL indic1_05
1 "Daily activities never affected"
2 "Daily activities moderately affected some of the time"
3 "Daily activities consistently affected, often a great deal"
99 "DK, Ref or Missing to both items".
MISSING VALUES  indic1_05 (99).
FORMATS indic1_05 (f2.0).
```

INDICATOR #2	Missed School Days: CSHCN ages 5-17 with 11 or more school absences due to illness
Survey Items Used	C3Q14
Numerator	0-3 days missed; 4-6 days missed; 7-10 days missed; 11 or more days missed
Denominator	CSHCN ages 5–17 years
Description	Percent of CSHCN ages 5–17 who had 11 or more days of school absences due to illness during the past 12 months.

Notes for Data-Users

n/a

Revisions in 2005

Same question wording in 2001 and 2005-2006; placement of question changed significantly in 2005-2006 survey. Take these changes into consideration when comparing results across survey years.

SPSS Code and Annotation

```
RECODE
  C3Q14r  (997=996)  .
EXECUTE .
MISSING VALUES c3q14r (994, 995, 996).

COMPUTE indic2_05 = 99.
IF (c3q14r = 0)  indic2_05 = 1.
IF (c3q14r >= 1 and c3q14r  <=3)  indic2_05 = 1.
IF (c3q14r >=4 and c3q14r <= 6)  indic2_05 = 2.
IF (c3q14r >= 7 and c3q14r <= 10)  indic2_05 = 3.
IF (c3q14r > 10)  indic2_05 = 4.
EXECUTE.

VARIABLE LABEL indic2_05  'INDICATOR #2: % of CSHCN ages 5-17 with 11 or more days of school absences due to illness'.
VALUE LABEL indic2_05
1  '0 - 3 days missed'
2  '4 - 6 days missed'
3  '7 - 10 days missed'
4  '11 or more days missed'
99 "DK, Ref, or ch <5 yrs old".
MISSING VALUES indic2_05 (99).
FORMATS indic2_05 (f2.0).
```

INDICATOR #3	Inconsistently Insured: CSHCN without insurance at some point during the past year
Survey Items Used	UNINS_YR
Numerator	Insured entire year; Not insured at some point during past year
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 who were without insurance at some point during the past 12 months.

Notes for Data-Users

This indicator is based on the variable "UNINS_YR" which is derived by the National Center for Health Statistics from responses to the numerous questions about health insurance coverage in Section 7 of the National Survey of CSHCN. This variable is included in the public use Interview file for the survey. For more information on how insurance status was defined by the National Center for Health Statistics for purposes of the survey, go to: http://www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf

Revisions in 2005

No changes; same as 2001

SPSS Code and Annotation

```
** NOTE:  Uses derived variable UNINS_YR  included in Ipublic release INTERVIEW file

COMPUTE indic3_05 = unins_yr.
EXECUTE.

VARIABLE LABEL indic3_05 'INDICATOR #3: % of CSHCN without insurance at some point during the
past year'.
VALUE LABEL indic3_05
0 'Insured entire year'
1 'NOT insured at some point during year'
6 'DK'
7 'Refused'.
MISSING VALUES indic3_05 (6, 7).
FORMATS indic3_05 (f2.0).
```

INDICATOR #4	Currently Uninsured: CSHCN without insurance at time of the survey
Survey Items Used	UNINS
Numerator	Insured, Not insured at time of survey
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 who were uninsured at the time of the survey.

Notes for Data-Users

This indicator is based on the variable "UNINS" which is derived by the National Center for Health Statistics from responses to the numerous health insurance coverage questions in Section 7 of the National Survey of CSHCN. This variable is included in the public use Interview data file of the survey. For more information on how insurance status was defined by the National Center for Health Statistics for purposes of the survey, go to: http://www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf

Revisions in 2005

No changes; same as 2001

SPSS Code and Annotation

```
** NOTE:  Uses derived variable UNINS included in public release INTERVIEW file

COMPUTE indic4_05 = unins.
EXECUTE.

VARIABLE LABEL indic4_05  'INDICATOR #4: % of CSHCN uninsured at the time of the survey'.
VALUE LABEL indic4_05
0 'Currently insured'
1 'Currently NOT insured'.
FORMATS indic4_05 (f2.0).
```

INDICATOR #5	Adequacy of Current Insurance Coverage: Currently insured CSHCN whose insurance coverage is not adequate
Survey Items Used	C8Q01_A C8Q01_B C8Q01_C
Numerator	Current insurance is adequate for CSHCN needs; Current insurance is not adequate for CSHCN needs
Denominator	CSHCN ages 0–17 insured at the time of the survey
Description	Percent of currently insured CSHCN ages 0–17 whose insurance is not adequate for CSHCN needs.

Notes for Data-Users

In 2005/06, about 97% of CSHCN nationally were currently insured at time of the survey. "Adequate insurance" is defined as coverage which offers benefits or covers services that meet CSHCN's needs AND have a reasonable level of uncovered costs AND allow CSHCN to see the health care providers that they need. Responses of "Usually or Always" to all 3 of the survey questions about adequacy of CSHCN's current health insurance (questions C8Q01_a thru C8Q01_c) are necessary to qualify as having adequate health insurance.

Revisions in 2005

Minor change to response options for out-of-pocket costs question (C8Q01_B); all other questions same as 2001.

SPSS Code and Annotation

```
**STEP 1:  Regroup responses to the three insurance adequacy items used to construct Indicator #5

COMPUTE ins_unmetneeds = 99.
IF (c8q01_a = 1) or (c8q01_a = 2)  ins_unmetneeds = 0.
IF (c8q01_a = 3) or (c8q01_a = 4)  ins_unmetneeds = 1.
EXECUTE.

VARIABLE LABEL ins_unmetneeds  'Health insurance benefits meet child needs'.
VALUE LABEL ins_unmetneeds
0 'Never/sometimes'
1 'Usually/always'
99 'DK/Ref/Missing/Uninsured'.

COMPUTE ins_reaschg = 99.
IF (c8q01_b = 1) or (c8q01_b = 2)  ins_reaschg = 0.
IF (c8q01_b = 3) or (c8q01_b = 4)  ins_reaschg = 1.
IF (c8q01_b = 5) ins_reaschg = 1.
EXECUTE.
```

```
VARIABLE LABEL ins_reaschg  'Non-covered insurance charges reasonable'.
VALUE LABEL ins_reaschg
0 'Never/sometimes'
1 'Usually/always or no out of pocket costs'
99 'Ref/Missing/Uninsured'.


COMPUTE ins_providers = 99.
IF (c8q01_c = 1) or (c8q01_c = 2)   ins_providers = 0.
IF (c8q01_c = 3) or (c8q01_c = 4)   ins_providers = 1.
EXECUTE.

VARIABLE LABEL  ins_providers 'Insurance allows child to see needed providers'.
VALUE LABEL  ins_providers
0 'Never/sometimes'
1 'Usually/always'
99 'DK/Ref/Missing/Uninsured'.

** STEP 2:  Construct Indicator #5 from interim variables above

COMPUTE indic5_05 = 99.
IF (( ins_unmetneeds=1or ins_unmetneeds=99) and (ins_reaschg = 1or ins_reaschg = 99) and
(ins_providers = 1or ins_providers = 99)) indic5_05 = 0.
IF ((ins_reaschg = 0) or (ins_unmetneeds=0) or (ins_providers = 0))  indic5_05 = 1.
IF (( ins_unmetneeds=99) and  (ins_reaschg = 99) and  (ins_providers = 99)) indic5_05 = 99.
EXECUTE.

VARIABLE LABEL  indic5_05 'Currently insured CSHCN whose insurance is not adequate'.
VALUE LABEL  indic5_05
0 'Current insurance is adequate'
1 'Current insurance NOT adequate'
99 'DK or Ref to all items or Uninsured'.
MISSING VALUES  indic5_05 (99).
FORMATS indic5_05 (f2.0).
```

INDICATOR #6	Unmet Needs for Care: CSHCN with any unmet need for any of 15 specific health care services or equipment, past 12 months
Survey Items Used	C4Q05_01A thru C4Q05_14A
Numerator	No unmet needs; 1 unmet need; 2 or more unmet needs
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 with one or more unmet needs for specific health care services.

Notes for Data-Users

Respondents are asked whether CSHCN needed each of 15 different health care services or equipment during the past 12 months. Respondents giving an affirmative answer to the need for a specific health care service or equipment, are asked a follow up question to determine if child got all the care in that he/she needed in that area. These responses are summed to create an overall count of unmet needs for care. The 15 different services/equipment needs asked about in the survey include: routine preventive care; specialist care; preventive dental care; other dental care; prescription medicines; OT, PT or speech therapy; mental health care or counseling; substance abuse treatment or counseling; home health care; vision care or eyeglasses; hearing aids or hearing care; mobility aids or devices; communication aids or devices; disposable medical supplies; durable medical equipment.

Revisions in 2005

In 2005-2006, the single question on unmet needs for dental care from the 2001 survey was split into 2 new questions (C4Q05_X031a and C4Q05_X032a) that distinguish preventive dental care from other types of dental care. No other changes were made to the wording or ordering to the other services needs/unmet needs questions; same as 2001. Take these changes into consideration when comparing results across survey years.

SPSS Code and Annotation

```
*Preventive Care.
COMPUTE unmet1=99.
IF (C4Q05X01A=0) unmet1=1.
EXECUTE.
VAR LABEL unmet1 'Unmet needs for preventive care'.
MISSING VALUES unmet1 (99).

*Specialist Care.
COMPUTE unmet2=99.
IF (C4Q05X02A=0)  unmet2=1.
EXECUTE.
VAR LABEL unmet2 'Unmet needs for specialist care'.
MISSING VALUES unmet2 (99).
```

```
*Preventive Dental Care.
COMPUTE unmet3=99.
IF (C4Q05X031A=0) unmet3=1.
EXECUTE.
VAR LABEL unmet3 'Unmet needs for preventive dental care'.
MISSING VALUES unmet3 (99).

*Other Dental Care.
COMPUTE unmet4=99.
IF (C4Q05X032A=0) unmet4=1.
EXECUTE.
VAR LABEL unmet4 'Unmet needs for other dental care'.
MISSING VALUES unmet4 (99).

*Prescriptions.
COMPUTE unmet5=99.
IF (C4Q05X04A=0) unmet5=1.
EXECUTE.
VAR LABEL unmet5 'Unmet needs for prescription medicine'.
MISSING VALUES unmet5 (99).

*Physical/Occupational/Speech Therapy.
COMPUTE unmet6=99.
IF (C4Q05X05A=0) unmet6=1.
EXECUTE.
VAR LABEL unmet6 'Unmet needs for OT, PT or speech therapy'.
MISSING VALUES unmet6 (99).

*Mental Health.
COMPUTE unmet7=99.
IF (C4Q05X06A=0) unmet7=1.
EXECUTE.
VAR LABEL unmet7 'Unmet needs for mental health care'.
MISSING VALUES unmet7 (99).

*Substance Abuse.
COMPUTE unmet8=99.
IF (C4Q05X07A=0) unmet8=1.
EXECUTE.
VAR LABEL unmet8 'Unmet needs for substance abuse tx'.
MISSING VALUES unmet8 (99).

*Home Health.
COMPUTE unmet9=99.
IF (C4Q05X08A=0) unmet9=1.
EXECUTE.
VAR LABEL unmet9 'Unmet needs for home health care'.
MISSING VALUES unmet9 (99).

*Eyeglasses/Needed Vision Care.
COMPUTE unmet10=99.
IF (C4Q05X09A=0) unmet10=1.
EXECUTE.
VAR LABEL unmet10 'Unmet needs for eyeglasses or vision care'.
```

```
MISSING VALUES unmet10 (99).

*Hearing Aids/Care
COMPUTE unmet11=99.
IF (C4Q05X10A=0) unmet11=1.
EXECUTE.
VAR LABEL unmet11 'Unmet needs for hearing aids/hearing care'.
MISSING VALUES unmet11 (99).

*Mobility Aids or Devices.
COMPUTE unmet12=99.
IF (C4Q05X11A=0) unmet12=1.
EXECUTE.
VAR LABEL unmet12 'Unmet needs for mobility aids or devices'.
MISSING VALUES unmet12 (99).

*Communication Aids or Devices.
COMPUTE unmet13=99.
IF (C4Q05X12A=0) unmet13=1.
EXECUTE.
VAR LABEL unmet13 'Unmet needs for communication aids or devices'.
MISSING VALUES unmet13 (99).

*Medical Supplies.
COMPUTE unmet14=99.
IF (C4Q05X13A=0) unmet14=1.
EXECUTE.
VAR LABEL unmet14 'Unmet needs for disposable medical supplies'.
MISSING VALUES unmet14 (99).

*Durable Medical Equipment.
COMPUTE unmet15=99.
IF (C4Q05X14A=0) unmet15=1.
EXECUTE.
VAR LABEL unmet15 'Unmet needs for durable medical equip'.
MISSING VALUES unmet15 (99).

COMPUTE unmet_sum = SUM (unmet1, unmet2, unmet3, unmet4, unmet5, unmet6, unmet7, unmet8,
unmet9, unmet10, unmet11, unmet12, unmet13, unmet14, unmet15).
EXECUTE.
VARIABLE LABEL unmet_sum 'Number of unmet needs out of 15 total'.

**STEP 2:  Compute Indicator #6 from interim summary count variable (UNMET_SUM)

RECODE  unmet_sum  (SYSMIS = 2) (0=0) (1 thru highest =1)  INTO  indic6_05 .
EXECUTE .
VARIABLE LABEL indic6_05 '% of CSHCN with 1 or more unmet needs for 15 specific health care
services'.
VALUE LABEL indic6_05
0 'No unmet needs for 15 specific health care services'
1 '1 or more unmet need for services/equip'
2 'No unmet needs for services/equip'.
FORMATS indic6_05 (f2.0).
```

INDICATOR #7	Unmet Needs for Family Support Services: CSHCN with any unmet needs for family support services
Survey Items Used	C4Q06X01A C4Q06X02A C4Q06X03A
Numerator	None; 1 or more unmet needs for family support services
Denominator	CSHCN ages 0–17
Description	Percent of CSHCN with any unmet needs for family support services

Notes for Data-Users

Unmet needs for three specific family support services are asked about in the 2005/06 NS-CSHCN: a) respite care; b) family genetic counseling; and c) family mental health care or counseling. All services are those needed due to child's medical, behavioral or other health conditions.

Revisions in 2005

Wording changes in 2005/06 to the question about needs for family respite care. Descriptive text defining respite care ("for example, having someone care for (ch's name) so you or other family members could do other things") was removed from the wording of question C4Q06_X01. No changes to the questions about genetic counseling or family mental health care; same as 2001. Take these changes into consideration when comparing results across survey

SPSS Code and Annotation

```
** STEP 1:  Create interim count and summary variables for each of the 3 different family support services items.

COMPUTE respite_2 = 99.
IF (c4q06_x01 = 0) respite_2 = 99.
IF (c4q06x01a = 1 and c4q06_x01 = 1) respite_2 = 0.
IF (c4q06x01a = 0 and c4q06_x01 = 1) respite_2 = 1.
EXECUTE.

VARIABLE LABEL respite_2  'Families need for and receipt of respite care'.
VALUE LABEL respite_2
0 'Needed and got all respite care'
1 'Needed, did not get all respite care'
99 'DK/REF/NOT NEEDED'.
MISSING VALUES respite_2 (99).

COMPUTE gene_2 = 99.
IF (c4q06_x02 = 0) gene_2 = 99.
IF (c4q06x02a = 1 and c4q06_x02 = 1) gene_2 = 0.
```

```
IF (c4q06x02a = 0 and c4q06_x02 = 1) gene_2 = 1.
EXECUTE.

VARIABLE LABEL gene_2  'Families need for and receipt of genetic counseling'.
VALUE LABEL gene_2
0 'Needed and got all genetic counseling'
1 'Needed, did not get all genetic counseling'
99 'DK/REF/NOT NEEDED'.
MISSING VALUES gene_2 (99).

COMPUTE mhfam_2 = 99.
IF (c4q06_x03 = 0) mhfam_2 = 99.
IF (c4q06x03a = 1 and c4q06_x03 = 1)  mhfam_2 = 0.
IF (c4q06x03a = 0 and c4q06_x03 = 1)  mhfam_2 = 1.
EXECUTE.

VARIABLE LABEL  mhfam_2 'Families need for and receipt of mental health care/counseling'.
VALUE LABEL  mhfam_2
0  'Needed and got all fam MH care'
1 'Needed, did not get all fam MH'
99 'DK/REF/NOT NEEDED'.
MISSING VALUES mhfam_2 (99).

COMPUTE fam_sum = SUM (respite_2, gene_2, mhfam_2).
EXECUTE.

VARIABLE LABEL fam_sum 'Number of unmet family support needs'.

**STEP 2:  Compute Indicator #7 from interim summary count variable (FAM_SUM). This is the version
using all CSHCN - whether or not services were needed -- as the denominator

COMPUTE indic7_05 = 99.
IF (fam_sum > 0) indic7_05 = 1.
IF (fam_sum = 0) or (SYSMIS (fam_sum)) indic7_05 = 0.
IF (SYSMIS (respite_2)) and (SYSMIS (gene_2)) and (SYSMIS (mhfam_2)) indic7_05 = 99.
EXECUTE.

VARIABLE LABEL  indic7_05  '% of CSHCN with one or more unmet needs for family services'.
VALUE LABEL  indic7_05
0 'No unmet needs for specific family support services or did not need'
1 'One or more unmet needs for family support services'
99 'DK/REF'.
MISSING VALUES indic7_05 (99).
FORMATS indic7_05 (f2.0).
```

INDICATOR #8	Problems Obtaining Referral: CSHCN needing specialty care who had problems getting a referral
Survey Items Used	C4Q07 C5Q11
Numerator	NO problems getting needed referral; YES had problems getting needed referral
Denominator	CSHCN ages 0-17 yrs who needed referrals for specialty care or services during past 12 months
Description	Percent of CSHCN ages 0-17 who needed referrals for specialty care or services in the past 12 months and who had problems getting them.

Notes for Data-Users

The denominator for this indicator includes ONLY those CSHCN who needed a referral for care or services during the past 12 months (C5Q11 = Yes). In the 2005-2006 NS-CSHCN, approximately 33% of CSHCN nationally needed to obtain a referral during the past 12 months.

Revisions in 2005

Significant changes were made in the 2005-2006 survey to the wording, ordering and placement of the questions used to construct this indicator. The most important difference is the addition of a new question (C5Q11) asking whether CSHCN needed a referral to see other doctors or receive services during the past 12 months. Only respondents with affirmative response to this new question are asked question C4Q07 about problems with referrals. This is a significant change from the methods used in 2001 version of the survey. Take these changes into consideration when comparing results across survey years.

SPSS Code and Annotation

```
COMPUTE indic8_05 = 99.
IF (c4q07 = 1)  indic8_05  = 1.
IF (c4q07 = 2)  indic8_05  = 1.
IF (c4q07 = 3)  indic8_05  = 0.
EXECUTE.

VARIABLE LABELS indic8_05  '% of CSHCN needing referrals who had problems with getting them'.
VALUE LABELS indic8_05
0 'Needed referral, no problems getting it'
1 'Needed referral, YES problems getting it'
99 'DK/REF or did not need a referral'.
MISSING VALUES indic8_05  (99).
FORMATS indic8_05 (f2.0).
```

INDICATOR #9	Usual Source for Sick Care: CSHCN without a usual source of care or who rely on the emergency room
Survey Items Used	C4Q0A C4Q0B
Numerator	Doctor's office; Clinic, health center, or other; No regular place / ER
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 who do not have a usual source of care, or who rely on the emergency room for medical care when ill.

Notes for Data-Users

n/a

Revisions in 2005

No changes; same as 2001

SPSS Code and Annotation

```
**STEP #1: Compute interim "usual source of care" variable

COMPUTE usualcare = 99.
IF (C4Q0Br = 1) usualcare = 1.
IF (C4Q0Br = 2) usualcare = 3.
IF (C4Q0Br = 3) usualcare = 4.
IF (C4Q0Br = 4) usualcare = 2.
IF (C4Q0Br = 5) usualcare = 4.
IF (C4Q0Br = 6) usualcare = 4.
IF (C4Q0Br = 7) usualcare = 4.
IF (C4Q0Br = 8) usualcare = 4.
IF (C4Q0Br = 10) usualcare = 4.
IF (C4Q0Br = 9) usualcare = 5.
IF (C4Q0A = 2) usualcare =  5.
EXECUTE.

VARIABLE LABEL usualcare 'Kind of place child usually goes for health care'.
VALUE LABEL usualcare
1 'Doctors office'
2 'Clinic or health center'
3 'Hospital emergency room'
4 'Other source'
5 'No place / no place most often'
99 'DK/REF to all' .
MISSING VALUES usualcare (99).
```

```
**STEP 2:  Compute Indicator #9 from interim usual source of care variable  (USUALCARE)

COMPUTE indic9_05  = 99.
IF (usualcare = 1) indic9_05  =  1.
IF (usualcare = 2 or usualcare = 4) indic9_05  =  2.
IF (usualcare = 3) indic9_05  =  3.
IF (usualcare = 5) indic9_05  =  3.
EXECUTE.

VARIABLE LABEL  indic9_05  'INDICATOR #9: % of CSHCN without a usual source of care or who rely
on the emergency room'.
VALUE LABEL indic9_05
1 'Doctors office'
2 'Clinic, health center or other regular source'
3 'No regular place or relies on emergency room'
99 'DK/REF to all'.
MISSING VALUES indic9_05 (99).
FORMATS indic9_05 (f2.0).
```

INDICATOR #10	Personal Doctor or Nurse: CSHCN without a personal doctor or nurse (PDN)
Survey Items Used	C4Q02A
Numerator	No, does not have personal doctor or nurse (PDN); Yes, has 1 or more personal doctors or nurses
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 who do not have a PDN.
Notes for Data-Users	
n/a	
Revisions in 2005	
In 2005-2006, the wording of question C4Q02A was revised to ask if there are "one or more persons" that the parent-respondent considers to be the child's personal doctor or nurse. This is a change from the 2001 version of the same question which asked if there was one person who fulfilled the role of personal doctor or nurse for the child. Take these changes into consideration when comparing results across survey years.	
SPSS Code and Annotation	

```
RECODE C4Q02a
(1=1) (2=1) (3=0) (6=99) (7=99) INTO indic10_05.
EXECUTE.

VARIABLE LABELS indic10_05 'Indicator #10: Percent of CSHCN without a personal doctor or nurse'.
VALUE LABEL indic10_05
0 "No, does not have a PDN"
1 "Yes, has one or more PDNs"
99 "DK/REF/MISSING".
MISSING VALUES indic10_05 (99).
FORMATS indic10_05 (f2.0).
```

INDICATOR #11	Family Centered Care: CSHCN without family-centered care
Survey Items Used	C6Q02 thru C6Q06 S5Q13a
Numerator	No, does not have family centered care; Does have family centered care
Denominator	CSHCN ages 0–17 with one or more doctor visits during the past 12 months
Description	Percent of CSHCN ages 0–17 whose medical care is not family-centered.

Notes for Data-Users

CSHCN with responses of Usually or Always to all five family-centered care questions (C6Q02 thru C6Q06); and, if needed, Usually or Always response to availability of language services question (S5Q13a).

Revisions in 2005

The newly added question about availability of language interpretation services during child's health care visits (Question S5Q13a) is only asked for children with primary household languages other than English. Nationally, about 1.0% of CSHCN needed language interpretation services during health care visits.

No changes to wording or ordering of the family centered care questions C6Q02 thru C6Q06; same as 2001. However, placement of these questions within the survey is substantially different in the 2005/06 version of the NS-CSHCN. The content and type of questions that immediately preceded the five family centered questions also changed significantly in the 2005/06 survey. These types of revisions may affect how respondents understand and answer questions. Take all of these changes into consideration when comparing results across survey years.

SPSS Code and Annotation

```
**STEP 1: Compute family centered care interim variables to collapse "never/sometimes"

COMPUTE time = 99.
IF (c6q02 = 1 or c6q02 = 2) time = 0.
IF (c6q02 = 3 or c6q02 = 4) time = 1.
IF (sysmis (c6q02)) time = 2.
EXECUTE.

VAR LABEL time 'Drs/other health providers spend enough time (c6q02 recoded)'.
VALUE LABEL time
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref'.
```

```
COMPUTE listen = 99.
IF (c6q03 = 1 or c6q03 = 2) listen = 0.
IF (c6q03 = 3 or c6q03 = 4) listen = 1.
IF (sysmis (c6q03)) listen = 2.
EXECUTE.

VAR LABEL listen 'Drs/other health providers listen well (c6q03 recoded)'.
VALUE LABEL listen
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref'.

COMPUTE sensitiv = 99.
IF (c6q04 = 1 or c6q04 = 2) sensitiv = 0.
IF (c6q04 = 3 or c6q04 = 4) sensitiv = 1.
IF (sysmis (c6q04)) sensitiv = 2.
EXECUTE.

VAR LABEL sensitiv 'Drs/other health providers sensitive to family values/customs (c6q04 recoded)'.
VALUE LABEL sensitiv
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref'.

COMPUTE info = 99.
IF (c6q05 = 1 or c6q05 = 2) info = 0.
IF (c6q05 = 3 or c6q05 = 4) info = 1.
IF (sysmis (c6q05)) info = 2.
EXECUTE.

VAR LABEL info 'Drs/other health providers provide needed information (c6q05 recoded)'.
VALUE LABEL info
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref'.

COMPUTE partner = 99.
IF (c6q06 = 1 or c6q06 = 2) partner = 0.
IF (c6q06 = 3 or c6q06  = 4) partner = 1.
IF (sysmis (c6q06)) partner = 2.
EXECUTE.

VAR LABEL partner 'Drs/other health providers make family feel like a partner (c6q06 recoded)'.
VALUE LABEL partner
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref'.

RECODE
S5q13A  (SYSMIS = 999).
EXECUTE .
```

```
COMPUTE interpret = 99.
IF (S5q13A = 1 or S5q13A  = 2) interpret = 0.
IF (S5q13A  = 3 or s5q13A = 4) interpret = 1.
IF (S5q13A  = 999) interpret = 2.
EXECUTE.

VAR LABEL interpret "Able to get interpreter if needed during ch's dr visits (S5q13A recoded)".
VALUE LABEL interpret
0 'Never/sometimes'
1 'Usually/always'
2 'Does not need interpreter'
99 'DK/Ref'.


**STEP 2: Compute Indicator 11_05 using interim variables from above

COMPUTE indic11_05  = 99.
IF (time = 0) or (listen = 0) or (sensitiv = 0) or (info = 0) or (partner = 0) or (interpret = 0) indic11_05  = 0.
IF (time =1 or time = 99) and (listen =1 or listen =99) and (sensitiv =1 or sensitiv = 99) and (info =1 or
info = 99) and (partner =1 or partner =99) and ((interpret =1) or (interpret >=2)) indic11_05  = 1.
IF (time = 99 and listen = 99 and sensitiv = 99 and info = 99 and partner = 99) indic11_05 = 99.
IF (c6q01r = 0) indic11_05 = 2.
EXECUTE.

MISSING VALUES indic11_05 (99, 2).
VARIABLE LABEL indic11_05 'INDICATOR #11: % of CSHCN without family-centered care'.
VALUE LABEL indic11_05
0 'Does NOT have fcc'
1 'Yes, has fcc'
2 'Legitimate skip - no dr visit past 12 mos'
99 'DK/Ref to all'.
MISSING VALUES indic11_05 (2, 99).
FORMATS indic11_05 (f2.0).
```

INDICATOR #12	Out-of-Pocket Expenses: CSHCN whose families pay more than $1000 per year out-of-pocket for child's medical expenses
Survey Items Used	C9Q01 C9Q01_A
Numerator	Less than $250; $250-$500; $501-$999; $1000 or more
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose families pay more than $1,000 per year in out-of-pocket expenses for child's medical expenses.

Notes for Data-Users

"Out of pocket" expenses for CSHCN health care includes payments for all types of health-related needs such as medications, special foods, adaptive clothing, durable equipment, home modifications, and any kind of therapy. Health insurance premiums or costs that were reimbursed by insurance or other sources not included.

Revisions in 2005

Ordering of questions same in 2001 and 2005-2006. In the 2005-2006 survey, "co-payments, dental or vision care" were newly added to the list of out-of-pocket payments that respondents are asked to consider when answering question C9Q01. Take these changes into consideration when comparing results across survey years.

SPSS Code and Annotation

```
COMPUTE indic12_05 = 99.
IF (c9q01 = 3 )  indic12_05  = 1.
IF (c9q01 = 4 )  indic12_05  = 1.
IF (c9q01 = 2 )  indic12_05  = 2.
IF (c9q01_a = 3 )  indic12_05  = 3.
IF (c9q01_a <=2 )  indic12_05  = 4.
EXECUTE.

VARIABLE LABEL indic12_05  "INDICATOR #12: % of CSHCN whose families pay more than $1000
per year out-of-pocket for child's medical expenses".
VALUE LABEL indic12_05
1 'Less than $250'
2 '$250 - $500'
3 '$501 - $1000'
4 'More than $1000'
99 'DK/REF'.
MISSING VALUES indic12_05 (99).
FORMATS indic12_05 (f2.0).
```

INDICATOR #13	Family Financial Burden: CSHCN whose families experienced financial problems due to child's health needs
Survey Items Used	C9Q05
Numerator	No financial problems due to child's health conditions; Yes, financial problems due to child's health conditions
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose families experienced financial problems due to child's health needs.
Notes for Data-Users	
n/a	
Revisions in 2005	
No changes, same as 2001	
SPSS Code and Annotation	

```
COMPUTE indic13_05= 99.
IF (c9q05 = 0) indic13_05 = 0.
IF (c9q05 = 1) indic13_05  = 1.
IF (c9q05 >1) indic13_05 =  99.
EXECUTE.

VARIABLE LABEL indic13_05  "INDICATOR #13: % of CSHCN whose families experienced financial
problems due to child's health needs".
VALUE LABEL indic13_05
0 "No financial problems due to child's health"
1 "Yes, financial problems"
99 "DK/REF or MISSING".
MISSING VALUES indic13_05 (99).
FORMATS indic13_05 (f2.0).
```

INDICATOR #14	Hours per Week Providing Care: CSHCN whose families spend 11 or more hours per week providing and/or coordinating health care for child
Survey Items Used	C9Q02 C9Q03 C9Q04
Numerator	Less than 1 hour; 1-4 hours per week; 5-10 hours per week; 11 or more hours per week
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose families spend 11 or more hours per week providing and/or coordinating health care for the child.

Notes for Data-Users

This indicator is based on the summed total of the number of hours family members spend per week providing health care at home for CSHCN and the number of hours family members spend per week arranging and coordinating health care for CSHCN. Question C9Q02 defines "home health care" as: changing bandages, care of feeding or breathing equipment, giving medication and therapies, etc. Question C9Q04 defines "arranging or coordinating health care" as: making appointments, making sure that care providers are exchanging information, and following up on child's care needs.

Revisions in 2005

Minor wording changes to C9Q02 in 2005-2006; ordering and placement same as 2001. Take these changes into consideration when comparing results across survey years.

SPSS Code and Annotation

```
** STEP 1:  Create interim variables from number of hours spent items

RECODE
  C9Q02
  (SYSMIS=999)  (ELSE=Copy)  INTO  rC9q02 .
EXECUTE .

DO IF (rc9q02 = 0).
COMPUTE rc9q03 = 0.
ELSE.
COMPUTE rc9q03 = c9q03r.
END IF.
MISSING VALUES rc9q03 (996, 997).

RECODE c9q04r
(555 = 0) (ELSE=Copy)  INTO rc9q04r.
EXECUTE .
```

```
MISSING VALUES rc9q04r (996, 997).

COMPUTE hrs_sum  = SUM (rc9q03, rc9q04r).
EXECUTE.

**STEP 2: Compute Indicator #14 from interim number of hours variables (RC9Q03r; RC9Q04r)

COMPUTE indic14_05 = 99.
IF (hrs_sum = 0)  indic14_05 = 1.
IF (hrs_sum >= 1 and hrs_sum <= 4)  indic14_05 = 2.
IF (hrs_sum >= 5 and hrs_sum  <= 10)  indic14_05 = 3.
IF (hrs_sum >= 11)  indic14_05 = 4.
EXECUTE.

VARIABLE LABELS indic14_05 "INDICATOR #14: % of CSHCN whose families spend 11 or more
hours per week providing and/or coordinating health care for child".
VALUE LABELS indic14_05
1 'Less than 1 hour '
2 '1 - 4 hours per week'
3  '5 - 10 hours per week'
4 '11 or more hours per week'
99 'DK/REF'.
MISSING VALUES indic14_05 (99).
FORMATS indic14_05 (f2.0).
```

INDICATOR #15	Impact on Family Work Life: CSHCN whose family members cut back and/or stopped working because of child's health needs
Survey Items Used	C9Q06 C9Q10
Numerator	Family members did not cut back/stop working; Family members cut back or stopped working
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose family members cut back and/or stopped working because of child's health needs.

Notes for Data-Users

Indicator #15 combines the concepts of family members "cutting down on hours worked" and/or "stopping work altogether" because of CSHCN's health conditions or health needs.

Revisions in 2005

Significant changes to the wording and ordering of questions C9Q06 and C9Q10 in the 2005-2006 survey now make it possible to distinguish whether the same or different family members cut back hours, stopped working, or both. Such a distinction was not possible with the 2001 version of the questions. Take these changes into consideration when comparing results across survey years.

SPSS Code and Annotation

```
RECODE
c9q10 c9q06 (SYSMIS=999).
EXECUTE.

COMPUTE indic15_05 =99.
IF (c9q10 = 1 and c9q06 = 1) indic15_05 = 1.
IF (c9q10 = 1) and (c9q06=0) indic15_05=1.
IF (c9q10 = 1) and (c9q06 >1) indic15_05=1.
IF (c9q06 = 1) and (c9q10 = 0) indic15_05 = 1.
IF (c9q06 = 1) and (c9q10 >1) indic15_05 = 1.
IF (c9q10 = 0) and (c9q06 = 0)  indic15_05 = 0.
IF (c9q10 = 0) and  (c9q06 >1) indic15_05 = 0.
IF (c9q06 = 0) and  (c9q10 >1) indic15_05 = 0.
IF (c9q10 = 0) and  (c9q06 = 999) indic15_05 = 99.
IF (c9q10 = 1) and  (c9q06 = 999) indic15_05 = 99.
EXECUTE.

VAR LABEL indic15_05 "INDICATOR #15: % of CSHCN whose family members cut back and/or
stopped working because of child's health needs".
VALUE LABEL indic15_05
```

```
0 'Employment not affected'
1 'Family member cut back hours or stopped working or both'.
MISSING VALUES indic15_05 (99).
FORMATS indic15_05 (f2.0).
```

Outcome #1	**CSHCN whose families are partners in decision-making at all levels and are satisfied with the services they receive**
Survey Items Used	C6Q06 C6Q0C
Numerator	CSHCN whose families usually or always feel included as a partner in child's care (C6Q06 = 3 or 4) AND are very satisfied with all health services that child receives (C6Q0C = 1).
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN whose families who partner in decision-making and are satisfied with the services received.

Notes for Data-Users

n/a

Revisions in 2005

Same question wording used in 2001 and 2005-2006. Significant changes in the ordering and placement of question C6Q0C in the 2005-2006 survey may affect how respondents understand and answer the question. Take these changes into consideration when comparing results across survey years.

SPSS Code and Annotation

```
**STEP 1:  Construct interim variable that identifies CSHCN with no doctor visits during past year and groups those with 1 or more doctor visits into CSHCN whose doctors never/sometimes vs. usually/always make family feel like partners in child's care.

COMPUTE partner1 = 999.
IF (c6q01r = 0) partner1 = 0.
IF (c6q06 = 1 or c6q06 = 2) partner1 = 1.
IF (c6q06 = 3 or c6q06 = 4) partner1 = 2.
EXECUTE.

VAR LABEL partner1 'Interim variable for constructing Outcome 1'.
VALUE LABEL partner1
0 'Legit skip -- No doctor visits during past 12 mos'
1 'Dr visits and family never-sometimes feels like partner'
2 'Dr visits and family usually-always feels like partner'
999 'DK/REF/MISSING to question'.

RECODE partner1 (0=0) (1=1) (2=2) (999=999).
EXECUTE.

COMPUTE satisfd = 99.
```

```
IF (C6q0c = 1)  satisfd = 1.
IF (C6q0c = 2) or (C6q0c = 3) or (C6q0c = 4) satisfd = 2.
IF (C6q0c = 6) or (C6q0c = 7) satisfd = 999.
EXECUTE.

VARIABLE LABEL satisfd 'Level of satisfaction with services received'.
VALUE LABEL satisfd
1 'Very satisfied'
2 'Less than very satisfied'
999 'DK/Ref '.

**STEP 2:  Create OUTCOME_1

COMPUTE outcome1_05 = 99.
IF (partner1 = 0) and (satisfd = 1) outcome1_05  = 1.
IF (partner1 = 2) and (satisfd = 1) outcome1_05  = 1.
IF (partner1 = 1) and (satisfd = 1) outcome1_05  = 0.
IF (partner1 = 1) or (satisfd = 2) outcome1_05  = 0.
IF (partner1 = 999) or  (satisfd = 999) outcome1_05  = 99.
EXECUTE.

VARIABLE LABEL outcome1_05 ‘OUTCOME #1: Families of CSHCN will be partners in decision making
and are satisfied with the services they receive'.
VALUE LABEL outcome1_05
0 'Outcome not achieved'
1 'Outcome successfully achieved'
99 'DK/REF to 1 or both'.
MISSING VALUES outcome1_05 (99).
FORMATS outcome1_05 (f2.0).
```

Outcome #2: MEDICAL HOME Composite measure	**Children with special health care needs (CSHCN) receiving ongoing, coordinated and comprehensive care within a medical home**
Survey Items Used	C4Q02a, C6Q02 – C6Q06, S5Q13, S5Q13a, C5Q11, C4Q07, C4Q0a, C4Q0b, C4Q0d, C4Q01, C4Q02, C5Q12, C5Q17, C5Q09, C5Q10, C5Q05, C5Q06
Numerator	Children with special health care needs (CSHCN) meeting scoring criteria for having a Medical Home
Denominator	Children with special health care needs (CSHCN) ages 0–17 years

Description

Notes for Data-Users

The medical home composite measure and its sub-components are designed to operationalize the American Academy of Pediatrics (AAP) definition of "medical home". According to this definition, children ideally should have access to "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care within a medical home."

The presence of medical home for CSHCN is one of the six performance measures or outcomes that states submit as part of the Title V Block Grant reporting requirements. The final medical home composite score used to measure this outcome is derived from the five sub-components constructed below.

SPSS Code and Annotation

```
**************************Personal doctor or nurse (PDN) Component ***************************

***PERSONAL DOCTOR or NURSE  sub-component of MEDICAL HOME composite measure

COMPUTE pdn = 99.
IF (c4q02a = 1) pdn = 1.
IF (c4q02a = 2) pdn = 1.
IF (c4q02a = 3) pdn = 0.
EXECUTE.
VARIABLE LABEL pdn 'Personal Doctor or Nurse sub-component of MEDICAL HOME composite
measure'.
VALUE LABEL pdn
0 'Do not have a personal dr or nurse'
1 'Yes, have a personal dr or nurse'
99 'DK/REF/MISSING'.
RECODE pdn (99=SYSMIS).
```

```
************************** Family Centered Care Component *********************************

*** FAMILY-CENTERED CARE sub-component of MEDICAL HOME composite measure

****** Step 1:  The following syntax sets up the interim variables used to derive the overall score
for "Family-Centered Care" sub-component of MEDICAL HOME composite measure

MISSING VALUES c6q01r ().
EXECUTE.

COMPUTE time = 99.
IF (c6q02 = 1 or c6q02 = 2) time = 0.
IF (c6q02 = 3 or c6q02 = 4) time = 1.
IF (sysmis (c6q02)) time = 2.
EXECUTE.
VAR LABEL time 'Drs/other health providers spend enough time (c6q02 recoded)'.
VALUE LABEL time
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref'.

COMPUTE listen = 99.
IF (c6q03 = 1 or c6q03 = 2) listen = 0.
IF (c6q03 = 3 or c6q03 = 4) listen = 1.
IF (sysmis (c6q03)) listen = 2.
EXECUTE.
VAR LABEL listen 'Drs/other health providers listen well (c6q03 recoded)'.
VALUE LABEL listen
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref'.

COMPUTE sensitiv = 99.
IF (c6q04 = 1 or c6q04 = 2) sensitiv = 0.
IF (c6q04 = 3 or c6q04 = 4) sensitiv = 1.
IF (sysmis (c6q04)) sensitiv = 2.
EXECUTE.
VAR LABEL sensitiv 'Drs/other health providers sensitive to family values/customs (c6q04 recoded)'.
VALUE LABEL sensitiv
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref'.

COMPUTE info = 99.
IF (c6q05 = 1 or c6q05 = 2) info = 0.
IF (c6q05 = 3 or c6q05 = 4) info = 1.
IF (sysmis (c6q05)) info = 2.
EXECUTE.
VAR LABEL info 'Drs/other health providers provide needed information (c6q05 recoded)'.
```

```
VALUE LABEL info
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref'.

COMPUTE partner = 99.
IF (c6q06 = 1 or c6q06 = 2) partner = 0.
IF (c6q06 = 3 or c6q06  = 4) partner = 1.
IF (sysmis (c6q06)) partner = 2.
EXECUTE.
VAR LABEL partner 'Drs/other health providers make family feel like a partner (c6q06 recoded)'.
VALUE LABEL partner
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref'.

RECODE
S5q13A  (SYSMIS = 999).
EXECUTE .

COMPUTE interpret = 99.
IF (S5q13A = 1 or S5q13A  = 2) interpret = 0.
IF (S5q13A  = 3 or s5q13A = 4) interpret = 1.
IF (S5q13A  = 999) interpret = 2.
EXECUTE.
VAR LABEL interpret "Able to get interpreter if needed during ch's dr visits".
VALUE LABEL  interpret
0 'Never/sometimes'
1 'Usually/always'
2 'Does not need interpreter'
99 'DK/Ref'.

****** Step 2:  Construct "Family-Centered Care" sub-component of MEDICAL HOME composite
measure

COMPUTE famcent  = 99.
IF (time = 0) or (listen = 0) or (sensitiv = 0) or (info = 0) or (partner = 0) or (interpret = 0) famcent  = 0.
IF (time =1 or time = 2) and (listen =1 or listen = 2) and (sensitiv =1 or sensitiv = 2) and (info =1 or info =
2)
and (partner =1 or partner =2) and ((interpret =1) or (interpret = 1 or interpret = 2)) famcent  = 1.
IF (time = 99 or listen = 99 or sensitiv = 99 or info = 99 or partner = 99 or interpret = 99) famcent = 99.
IF (c6q01r = 0) famcent = 2.
EXECUTE.
VARIABLE LABEL famcent  'Family-Centered Care sub-component of MEDICAL HOME composite
measure'.
VALUE LABEL famcent
0 'Does NOT have fcc'
1 'Yes, has fcc'
2 'Legitimate skip - no dr visit past 12 mos'
99 'DK/Ref to any'.
RECODE famcent (99=SYSMIS).
```

```
************************************Comprehensive Care Component **********************************

*** GETTING NEEDED REFERRALS sub-component of MEDICAL HOME composite measure

****** Construct "No Problems Getting Needed Referrals " sub-component of MEDICAL HOME
composite measure

RECODE C4Q07 (SYSMIS=999).
EXECUTE .

COMPUTE norefprb= 99.
IF (c4q07 = 1) or (c4q07 = 2)norefprb= 0.
IF (c4q07 = 3) norefprb= 1.
IF (c5q11 = 0) norefprb= 2.
VAR LABEL norefprb 'Getting Needed Referrals sub-component of MEDICAL HOME composite
measure'.
VALUE LABEL norefprb
0 'Big or small problem getting referral, when needed'
1 'No problems getting referral, when needed'
99 'DK/REF/MISSING'.
2 'Legitimate skip b/c referrals are not needed'.
RECODE norefprb (99=SYSMIS).


***USUAL SOURCES FOR SICK AND WELL CARE sub-component of MEDICAL HOME composite
measure

****** Step 1:  The following syntax sets up the interim variables used to derive the overall score for
"Usual Sources for Sick and Well Care" sub-component of MEDICAL HOME composite measure

COMPUTE sick = 99.
IF ((C4q0br = 1 or C4q0br = 3 or C4q0br = 4 or C4q0br = 5 or C4q0br = 6 or C4q0br = 8 or C4q0br =10))
sick = 1.
IF (c4q0a = 2) or ((c4q0br = 2 or c4q0br = 7 or c4q0br = 9)) sick = 0.
IF ((c4q0a = 6) or (c4q0a = 7)) or ((c4q0br = 96) or (c4q0br = 97)) sick = 99.
EXECUTE.
VARIABLE LABEL sick 'Ch. has usual place for sick care'.
VALUE LABEL sick
0 'No or ER or Mexico or no one place most often'
1 'Yes'
99 'DK/REF/MISSING'.

COMPUTE well = 99.
IF ((c4q0d= 1) or (c4q0d = 3)) and ((sick = 1) and (c4q01 = 1)) or (c4q02r = 1 or c4q02r = 3 or c4q02r = 4
or c4q02r = 5 or c4q02r= 6 or c4q02r = 8) well = 1.
IF (sick = 0) and (c4q01 = 1) well = 0.
IF (c4q0d = 2) or (c4q02r = 2 or c4q02r = 7 or c4q02r = 9) well = 0.
IF ((c4q0d= 1) or (c4q0d = 3)) and ((sick = 99) and (c4q01 = 1)) well = 99.
IF ((c4q0d= 1) or (c4q0d = 3)) and (c4q01 = 6 or c4q01 = 7) well = 99.
IF (c4q0d = 6 or c4q0d = 7) or (c4q02r = 96 or c4q02r = 97) well = 99.
EXECUTE.
VARIABLE LABEL well  'Ch. has usual place for well care'.
VALUE LABEL well
```

```
0 'No or ER or Mexico or no one place most often'
1 'Yes'
99 'DK/REF/MISSING'.

****** Step 2:  Construct "Usual Sources for Sick and Well Care " sub-component of MEDICAL HOME
composite measure

COMPUTE usual = 99.
IF (sick = 1 or sick = 99) and (well  = 1 or well = 99) usual = 1.
IF (sick = 0)  or (well = 0 ) usual = 0.
IF (well  = 99) or (sick = 99) usual = 99.
EXECUTE.
EXECUTE .
VARIABLE LABEL usual ' Usual Sources for Sick and Well Care sub-component of MEDICAL HOME
composite measure'.
VALUE LABEL usual
0 'Ch. does not have usual sources for sick and well care'
1 'Ch. DOES have usual sources for sick and well care'
99 'DK/REF/MISSING to all'.
RECODE usual (99=SYSMIS).


**********Coordinated Care Component **********

***EFFECTIVE CARE COORDINATION sub-component of MEDICAL HOME composite measure

****** Step 1:  The following syntax sets up the interim variables used to derive the overall score
for "Effective Care Coordination" sub-component of MEDICAL HOME composite measure

MISSING VALUES C5Q17 C5Q09 C5Q12 ().

RECODE
  C5Q17 C5Q09 C5Q12 (MISSING=999).
EXECUTE.
VALUE LABELS c5q09
1 'Never'
2 'Sometimes'
3 'Usually'
4 'Always'
6 'DK'
7 'Refused'
999 'SYSMIS'.
VALUE LABELS c5q17 c5q12
0 'No'
1 'Yes'
6 'DK'
7 'Refused'
999 'SYSMIS'.
```

** The variable TEST09 in the code below refers to a "patch" variable created to accommodate update changes made by NCHS to the missing cases status for C5Q09 prior to releasing the public use file for the 2005/06 NS-CSHCN. SPSS users will need this patch variable in order to successfully replicate the Effective Care Coordination sub-component. Contact cahmi@ohsu.edu to obtain a copy of the patch variable.

```
COMPUTE c5q09r = 99.
IF (C5Q09 = 1) c5q09r = 1.
IF (C5Q09 = 2) c5q09r = 2.
IF (C5Q09 = 3) c5q09r = 3.
IF (C5Q09 = 4) c5q09r = 4.
IF (C5Q09 = 6) c5q09r = 6.
IF (C5Q09 = 999) and (test09 = 0) c5q09r = 999.
IF (C5Q09 = 999) and (test09 = 1) c5q09r = 99.
EXECUTE.

COMPUTE carehlp = 99.
IF (C5Q12 = 1)  and ( C5Q17 = 0) carehlp = 1.
IF (C5Q09r = 3 or C5Q09r = 4) carehlp = 1.
IF (C5Q09r = 1 or C5Q09r = 2) carehlp = 0.
IF (C5q12 = 0) and (C5q17 = 0) carehlp = 2.
IF (c5q12 = 999) carehlp = 2.
IF (C5Q09r = 6 or C5Q09r = 7) carehlp = 99.
IF (c5q12 = 6 or C5q12 = 7) and (C5q17 = 0) carehlp = 99.
IF (c5q09r = 6) or (C5q17 = 6 or c5q17 = 7) carehlp = 99.
IF (c5q09r = 99) carehlp = 99.
EXECUTE.
VAR LABEL carehlp 'Got some type of help with care coor'.
VALUE LABEL carehlp
0 'Needed extra help/did not get it'
1 'Gets help with care coor'
2 'Legit skip -- <2 services or did not need extra help'
99 'DK/Ref to any or MISSING'.

COMPUTE need_drcomm = 99.
IF (C4q05x02a = 1 or C4q05x02c = 1) or (C4q05x05a = 1 or C4q05x05c = 1) or (C4q05x06a = 1 or
C4q05x06c = 1)
or (C4q05x07a = 1 or C4q05x07c = 1) or (C4q05x08a = 1 or C4q05x08c = 1) need_drcomm = 1.
IF (C4q05_x02 = 0 or C4q05x02c = 0) and (C4q05_x05 = 0 or C4q05x05c = 0) and (C4q05_x06 = 0 or
C4q05x06c = 0)
and (C4q05_x07 = 0 or C4q05x07c = 0 or (SYSMISS (C4q05_x07))) and (C4q05_x08 = 0 or C4q05x08c
= 0) need_drcomm = 0.
EXECUTE.
VAR LABEL  need_drcomm 'Used some or all specialist care, MH, PT/OT/Speech, sub abuse, or home
hlth care'.
VALUE LABEL  need_drcomm
1 'Used 1 or more services for dr comm denominator'
0  'Did not use services for dr comm denominator'
99 'DK/Ref'.

MISSING VALUES C5q10 ().

RECODE
C5q10 (SYSMIS = 999).
EXECUTE.
```

```
VALUE LABEL c5q10
1 'Very satisfied'
2 'Somewhat satisfied'
3 'Somewhat dissatisfied'
4 'Very dissatisfied'
5 'No communication needed or wanted'
6 'DK'
7 'Refused'
999 'SYSMISS'.


COMPUTE drcomm = 99.
IF (C5q10 = 1) and (need_drcomm = 1) drcomm = 1.
IF (C5q10 = 2 or C5q10 = 3 or C5q10 = 4) and (need_drcomm = 1) drcomm = 0.
IF (C5q10 = 5) and (need_drcomm = 1)  drcomm = 2.
IF (C5q10 = 6 or C5q10 = 7) and (need_drcomm = 1)  drcomm = 99.
IF (C5q10 = 999) drcomm = 2.
IF (test09 = 1 or test10 = 1) drcomm = 99.
IF (need_drcomm = 0) drcomm = 2.


IF (need_drcomm = 99) drcomm = 99.
EXECUTE.
VAR LABEL  drcomm 'Level of satisfaction with dr to dr communication'.
VALUE LABEL  drcomm
0 'Less than very satisfied'
1 'Very satisfied'
2 'Legit skip -- no comm needed or did not use required services'
99 'DK/Ref to any'.

MISSING VALUES c5q05 c5q06 ().

RECODE
C5q06 C5q05 (SYSMIS = 999).
EXECUTE.
VALUE LABEL c5q06
1 'Very satisfied'
2 'Somewhat satisfied'
3 'Somewhat dissatisfied'
4 'Very dissatisfied'
5 'No communication needed or wanted'
6 'DK'
7 'Refused'
999 'SYSMISS'.
VALUE LABEL c5q05
0 'No'
1 'Yes'
6 'DK'
7 'Refused'
999 'SYSMISS'.

COMPUTE othercomm = 99.
IF (C5q05 = 0) othercomm = 2.
IF (C5q05 = 6 or C5Q05 = 7) othercomm = 99.
```

```
IF (C5q05 = 999) othercomm = 2.
IF  (test09 = 1) or (test10 = 1) othercomm = 99.
IF (C5q06 = 1) othercomm = 1.
IF (C5q06 = 2 or C5q06 = 3 or C5q06 = 4) othercomm = 0.
IF (C5q06 = 6 or C5q06 = 7) othercomm = 99.
EXECUTE.
VAR LABEL othercomm 'If needed, level of satisfaction w/ dr comm to other providers or programs'.
VALUE LABEL othercomm
0 'Less than very satisfied'
1 'Very satisfied'
2 'Legit skip -- used >2 services'
99 'DK/Ref to any'.

****** Step 2:  Construct "EFFECTIVE CARE COORDINATION " sub-component of MEDICAL HOME
composite measure

COMPUTE carecoor = 99.
IF ((carehlp = 1) or (carehlp = 2)) and ((drcomm = 1) or (drcomm = 2)) and ((othercomm = 1) or
(othercomm = 2)) carecoor = 1.
IF (carehlp = 0) or (drcomm = 0) or (othercomm = 0) carecoor = 0.
IF (carehlp = 2) and (drcomm = 2) and (othercomm = 2) carecoor = 2.
IF (carehlp = 99) or (drcomm = 99) or (othercomm = 99) carecoor = 99.
EXECUTE.
VAR LABEL carecoor  'Effective Care Coordination sub-component of MEDICAL HOME composite
measure'.
VALUE LABEL  carecoor
0 'Did not meet 1 or more needed elements of care coor'
1'Met all needed components of care coor or legitimate skip'
2 'Legit skip -- no one helps with care coor or >2 services used past 12 mos'
99 'DK/REF/MISSING to any'.
RECODE carecoor  (99=SYSMIS).


********** MEDICAL HOME COMPOSITE MEASURE**********

***The following code uses the five sub-components created above to derive the MEDICAL HOME
composite measure using the ON EVERY scoring approach

COMPUTE mh_comp= 999.
IF (pdn = 1) and (usual = 1) and (carecoor = 1 or carecoor = 2) and (noreferpblm = 1 or noreferpblm = 2)
and (famcent = 1 or famcent = 2) mh_comp = 1.
IF (pdn = 0) or (usual = 0) or (carecoor = 0) or (noreferpblm = 0) or (famcent = 0) mh_comp = 0.
IF ((SYSMIS (pdn)) or (SYSMIS (usual)) or (SYSMIS (famcent)) or (SYSMIS (noreferpblm)) or (SYSMIS
(carecoor))) mh_comp =99.
EXECUTE.

VAR LABEL mh_comp '% CSHCN receiving coordinated, ongoing, comprehensive care within a medical
home' .
VALUE LABEL mh_comp
0 'Care DOES NOT meet medical home criteria'
1 'Care MEETS medical home criteria'
99 'DK/Ref to any'.
MISSING VALUES mh_comp (99).
FORMATS mh_comp(f2.0
```

OUTCOME #3	CSHCN whose families have adequate private and/or public insurance to pay for the services they need
Survey Items Used	C8Q01_A C8Q01_B C8Q01_C UNINS UNINS_YR
Numerator	Currently insured CSHCN who had no gaps in coverage during past year AND insurance benefits that usually or always cover needed services, have reasonable out of pocket costs, and allow child to see needed providers.
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN who have adequate public and/or private insurance to pay for the services they need.

Notes for Data-Users

The variables UNINS and UNINS_YR used in the construction of this outcome are included in the 2005-2006 NS-CSHCN public use file. These summary variables are derived by the National Center for Health Statistics from responses to the extensive set of questions on health insurance coverage asked in Section 7 of the survey.

Revisions in 2005

No changes; same as 2001

SPSS Code and Annotation

```
******Create interim variables for constructing outcome

COMPUTE hasins = 99.
IF (unins = 0) hasins = 0.
IF (unins = 1) hasins = 1.
EXECUTE.

VAR LABEL hasins 'Insurance status at time of survey'.
VALUE LABEL hasins
0 'Currently insured'
1 'Not insured'
99 'DK/Ref'.

COMPUTE nogaps = 999.
IF (unins_yr = 0) nogaps = 0.
IF (unins_yr = 1) nogaps = 1.
IF (unins_yr = 6 or unins_yr = 7) nogaps = 99.
EXECUTE.

VAR LABEL nogaps 'One or more gaps in insurance, past year'.
```

```
VALUE LABEL nogaps
0 'Insured continously all year'
1 'One or more periods of no insurance'
999 'SYSMISS'
99 'DK/Ref'.

COMPUTE metneeds = 99.
IF (SYSMIS (c8q01_a)) metneeds = 3.
IF (hasins = 1) metneeds = 2.
IF (c8q01_a = 1) or (c8q01_a = 2)  metneeds = 0.
IF (c8q01_a = 3) or (c8q01_a = 4)  metneeds = 1.
EXECUTE.

VARIABLE LABEL metneeds  'Health insurance benefits meet child needs'.
VALUE LABEL metneeds
0 'Never/sometimes'
1 'Usually/always'
2 'Legit skip b/c uninsured'
3 'Sys missing'
99 'DK/Ref'.

COMPUTE reaschg = 99.
IF (SYSMIS (c8q01_b)) reaschg = 3.
IF (hasins = 1) reaschg = 2.
IF (c8q01_b = 1) or (c8q01_b = 2)  reaschg = 0.
IF (c8q01_b = 3) or (c8q01_b = 4)  reaschg = 1.
IF (c8q01_b = 5) reaschg = 1.
EXECUTE.

VARIABLE LABEL reaschg  'Non-covered insurance charges reasonable'.
VALUE LABEL reaschg
0 'Never/sometimes'
1 'Usually/always'
2 'Legit skip b/c uninsured'
3 'Sys missing'
99 'DK/Ref'.

COMPUTE providers = 99.
IF (SYSMIS (c8q01_c)) providers = 3.
IF (hasins = 1) providers = 2.
IF (c8q01_c = 1) or (c8q01_c = 2)   providers = 0.
IF (c8q01_c = 3) or (c8q01_c = 4)   providers = 1.
EXECUTE.

VARIABLE LABEL  providers 'Insurance allows child to see needed providers'.
VALUE LABEL  providers
0 'Never/sometimes'
1 'Usually/always'
2 'Legit skip b/c uninsured'
3 'Sys missing'
99 'DK/Ref'.


**** Compute OUTCOME #3:  CSHCN will have adequate private or public insurance
```

```
COMPUTE outcome3_05 = 99.
IF (nogaps = 1) or (hasins = 1) or (metneeds = 0 ) or (reaschg = 0) or (providers = 0) outcome3_05 = 0.
IF (nogaps= 0) and (hasins = 0) and (metneeds = 1) and (reaschg = 1) and (providers = 1) outcome3_05
= 1.
IF (hasins = 1) and ((metneeds = 1) or (reaschg = 1) or (providers = 1)) outcome3_05 = 99.
IF (hasins = 0) and ((metneeds = 3) or (reaschg = 3) or (providers = 3)) outcome3_05 = 99.
IF (nogaps = 99) or (metneeds = 99) or (reaschg = 99) or (providers = 99) outcome3_05 = 99.
IF (nogaps = 999) and (metneeds = 3) and (reaschg = 3) and (providers = 3) outcome3_05 = 99.
EXECUTE.

VAR LABEL outcome3_05 'OUTCOME #3: CSHCN will have adequate private and public insurance'.
VALUE LABEL outcome3_05
0 'Did not meet outcome'
1 'Met outcome'
99 'DK/REF/MISSING on any'.
MISSING VALUES outcome3_05 (99).
FORMATS outcome3_05 (f2.0).
```

OUTCOME #4	CSHCN who are screened early and continuously for special health care needs
Survey Items Used	C4Q05_X01 C4Q05X01A C4Q05X01C C4Q05_X031 C4Q05X031A, C4Q05X031C
Numerator	CSHCN receiving both preventive medical and dental care during the past 12 months
Denominator	CSHCN ages 0 -17
Description	Percent of CSHCN who receive both preventative medical and dental care during the past 12 months.

Notes for Data-Users

The NS-CSHCN measures Goal #4 for CSHCN only -- not the population of all children ages 0-17.

Revisions in 2005

The questions about preventive dental care (C4Q05_X031, C4Q05X031a, C4Q05X031c) were newly added to the NS-CSHCN in 2005-2006. The 2005-2006 survey is the first time that Goal #4 has been measured using data from the NS-CSHCN

SPSS Code and Annotation

```
***NOTE:  This outcome was not calculated in 2001.  When this version is constructed using the interview file data, only CSHCN are included in the denominator -- not all children.  When constructed using the referent sample file, the denominator is all children -- not CSHCN only.

*STEP 1:  Compute interim variables to express if ch received some or all needed preventive medical and dental care

COMPUTE prevmed = 99.
IF (c4q05_x01 = 0) prevmed = 0.
IF (c4q05x01a = 1) prevmed = 1.
IF (c4q05x01a = 0) and (c4q05x01c = 1) prevmed = 1.
IF (c4q05x01a = 0) and (c4q05x01c = 0) prevmed = 0.
EXECUTE.

VAR LABEL prevmed 'Received some or all needed routine preventive medical care'.
VALUE LABEL prevmed
0 'Did not received any preventive medical care'
1 'Received some or all needed preventive medical care'
99 'DK/REF/MISSING to all'.

COMPUTE prevden = 99.
```

```
IF (c4q05_x031 = 0) prevden = 0.
IF (c4q05x031a = 1) prevden = 1.
IF (c4q05x031a = 0) and (c4q05x031c = 1) prevden = 1.
IF (c4q05x031a = 0) and (c4q05x031c = 0) prevden = 0.
IF (age = 0) prevden = 2.
EXECUTE.

VAR LABEL prevden 'Received some or all needed routine preventive dental care'.
VALUE LABEL prevden
0 'Did not received any preventive dental care'
1 'Received some or all needed preventive dental care'
2 'Legit skip -- less than 1 yr old'
99 'DK/REF to all'.

*STEP 2:  Construct outcome #4 from interim variables re: ch received some or all needed preventive
medical and dental care

COMPUTE outcome4_05 = 99.
IF (prevmed = 1) and (prevden = 1) outcome4_05 = 1.
IF (prevmed = 1) and (prevden = 2) outcome4_05 = 1.
IF (prevmed = 0) or (prevden = 0) outcome4_05 = 0.
IF (prevmed = 99) or (prevden = 99) outcome4_05 = 99.
EXECUTE.

VAR LABEL outcome4_05 'OUTCOME #4: Children are screened early and continously for special
health needs'.
VALUE LABEL outcome4_05
0 'Outcome not achieved'
1 'Outcome successfully achieved'
99 'DK/REF/MISSING to one or both'.
MISSING VALUES outcome4_05 (99).
FORMATS outcome4_05 (f2.0).
```

OUTCOME #5	CSHCN whose services are organized in ways that families can use them easily
Survey Items Used	C6Q0D
Numerator	CSHCN whose families report no difficulties using any of the health related services needed by child during the past 12 months
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN with community-based service systems that are organized so families can use them easily.

Notes for Data-Users

When answering, respondents are asked to "think about child's health needs and all the services he/she needs" -- including early intervention programs, childcare facilities, vocational education and rehabilitation programs, and other community programs."

Revisions in 2005

Significant changes in the wording, ordering and placement of question C6Q0D in the 2005-2006 survey may affect how respondents understand and answer the question. Take these changes into consideration when comparing results across survey years.

SPSS Code and Annotation

```
** NOTE:  In the 2005 survey, the placement, skip patterns, and wording of question c6q0d are all significantly different than the 2001 version of the same question.

COMPUTE outcome5_05 =99.
IF (c6q0d = 0) outcome5_05 = 1.
IF (c6q0d = 1) outcome5_05 = 0.
IF (c6q0d = 6 or c6q0d = 7) outcome5_05  = 99.
IF (SYSMIS (c6q0d)) outcome5_05 = 99.
EXECUTE.

MISSING VALUES outcome5_05 (99).
VARIABLE LABEL outcome5_05  'OUTCOME #5: Community-based service systems will be organized so families can use them easily'.
VALUE LABEL outcome5_05
0 'Outcome not achieved'
1 'Outcome successfully achieved'
99 'DK/REF'.
FORMATS outcome5_05 (f2.0).
```

OUTCOME #6	Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work and independence
Survey Items Used	C6Q07 C6Q0A_B C6Q0A_C C6Q0A, C6Q0A_D C6Q0A_E C6Q0A_F C6Q08
Numerator	CSHCN ages 12-17 whose doctors usually/always encourage increasing responsibility for self-care AND (when needed) have discussed transitioning to adult health care, changing health care needs, and how to maintain insurance coverage.
Denominator	CSHCN ages 12–17 years
Description	Percent of youth with special health care needs who have received the services necessary to make transitions to adult life, including adult health care, work, and independence.

Notes for Data-Users

Technical expert panel review of the 2001 NS-CSHCN methods for assessing transition to adulthood led to significant revisions and additions to the 2005-2006 version of these questions. In particular, filter questions were added to identify CSHCN who needed the services being assessed and a new question was added to assess whether health care providers help CSHCN to take increasing responsibility for self-care.

Revisions in 2005

In the 2005-2006 version of the NS-CSHCN, significant wording changes and new additions were made to the set of questions used to assess Transition to Adulthood. The result is an improved and more robust assessment of this important concept. The 2001 version of the outcome is based on CSHCN ages 13-17; the 2005/06 outcome is calculated for CSHCN ages 12-17. Take these changes into consideration when comparing results across survey years. See Additional Notes section below for more details.

SPSS Code and Annotation

```
**NOTE:  The questions used to construct this indicator in 2005 differ dramatically in content and skip patterns from those in the 2001 version of the survey

*STEP 1:  Compute interim variables to express if drs discussed shift to adult provider (mettrans1), changing needs as becomes adult (mettrans2),
and/or insurance coverage during transition to adulthood (mettrans3)

COMPUTE mettrans1 = 99.
IF (C6Q07 = 1) and (C6Q0A_B = 1) mettrans1 = 1.
IF (C6Q07 = 1) and ((C6Q0A_B = 0) and (C6Q0A_C = 1)) mettrans1 = 0.
IF (C6Q07 = 1) and ((C6Q0A_B = 0) and (C6Q0A_C = 0)) mettrans1 = 2.
```

```
IF (C6Q07 = 0) mettrans1 = 2.
IF (age <12) mettrans1 = 2.
EXECUTE.

VAR LABEL mettrans1 "Drs discussed shift to adult provider, if helpful".
VALUE LABEL mettrans1
0 'No'
1 'Yes'
2 'Legit skip b/c discussion not needed or <12 yrs old'
99 'DK/REF to any'.

COMPUTE mettrans2 = 99.
IF (C6Q0A = 1) mettrans2  = 1.
IF (C6Q0A_D = 0) mettrans2 = 2.
IF (C6Q0A_D = 1) mettrans2 = 0.
IF (age <12) mettrans2 = 2.
EXECUTE.

VAR LABEL mettrans2 "Drs talked about changing needs as becomes adult, if helpful".
VALUE LABEL mettrans2
0 'No'
1 'Yes'
2 'Legit skip b/c discussion not needed or <12 yrs old'
99 'DK/REF to any'.

COMPUTE mettrans3= 99.
IF (C6Q0A_E = 1) mettrans3  = 1.
IF (C6Q0A_F = 0) mettrans3 = 2.
IF (C6Q0A_F = 1) mettrans3 = 0.
IF (age <12) mettrans3 = 2.
EXECUTE.

VAR LABEL mettrans3 "Drs talked about insurance coverage as becomes adult, if needed".
VALUE LABEL mettrans3
0 'No'
1 'Yes'
2 'Legit skip b/c discussion not needed or <12 yrs old'
99 'DK/REF to any'.

*****Construct variable (ADTRANS) summarizing results across mettrans1, mettrans2, and mettrans3

COMPUTE  adtrans = 99.
IF (mettrans1 = 1 or mettrans1 = 2) and (mettrans2 = 1 or mettrans2 = 2) and (mettrans3 = 1 or
mettrans3 = 2) adtrans = 1.
IF (mettrans1 = 0) or (mettrans2 = 0) or (mettrans3 = 0) adtrans = 0.
IF (mettrans1 = 2) and (mettrans2 = 2) and (mettrans3 = 2) adtrans = 2.
IF (mettrans1 = 99) or (mettrans2 = 99) or (mettrans3 = 99) adtrans = 99.
EXECUTE.

VAR LABEL adtrans "Met criteria for getting all 3 adult transition components".
VALUE LABEL adtrans
0 'No'
1 'Yes'
99 'DK/REF to any'
2 'Legit skip b/c not needed or <12 yrs old'.
```

```
*STEP 2:  Compute interim variable to express if drs encourage chs 12-17 to engage in age-appropriate self care

COMPUTE mettrans4 = 99.
IF (age >= 12) and (C6Q08 = 1 or C6Q08 = 2) mettrans4= 0.
IF (age >= 12) and (C6Q08 = 3 or C6Q08 = 4) mettrans4= 1.
IF (age <12) mettrans4 = 2.
EXECUTE.

VAR LABEL mettrans4 "Drs encourage ch to engage in age appropriate self care -- ages 12-17 only".
VALUE LABEL mettrans4
0 'Never/Sometimes'
1 'Usually/Always'
99 'DK/REF/MISSING to any'
2 'Legitimate skip b/c <12 yrs old'.

**** This version of Outcome #6 updated to use children ages 12-17 as the denominator

COMPUTE outcome6_05 = 99.
IF (adtrans = 0) or (mettrans4 = 0)  outcome6_05 = 0.
IF (adtrans = 1 or adtrans = 2) and (mettrans4 = 1 or mettrans4 = 2) outcome6_05 = 1.
IF (adtrans = 99) or (mettrans4 = 99)  outcome6_05 = 99.
IF (mettrans4 = 2) and (adtrans = 2) outcome6_05 = 2.
EXECUTE.

VAR LABEL outcome6_05 "Met Outcome #6: Transition to adulthood -- ages 12 -17 only".
VALUE LABEL outcome6_05
0 'Did not meet outcome'
1 'Met outcome'
99 'DK/REF/MISSING on both'
2 'Legitimate skip b/c <12 yrs old'.
MISSING VALUES outcome6_05 (99, 2).
FORMATS outcome6_05 (f2.0).
```

System of Care #1	CSHCN ages 0-11 whose care meets System of Care criteria for MCHB Core Outcomes
Survey Items Used	Over 50 different survey questions are used to construct the 5 derived variables counted for purposes of this indicator; items are specified under each of the MCHB Core Outcomes #1-5.
Numerator	0-2 outcomes achieved; 3-4 outcomes achieved; All 5 outcomes achieved
Denominator	CSHCN ages 0-11
Description	CSHCN ages 0-11 meeting criteria for system of care.

Notes for Data-Users

CSHCN ages 0-11 years were considered to be served by a "service system" as described in the Healthy People objective, if their care met the criteria on each of the age-relevant outcomes. Five of the six MCHC core outcomes for CSHCN apply to children birth through age 11 years. The sixth outcome, transition to adulthood, only pertains to youth ages 12 years and over. For more information on calculating each of the core outcome measures derived from the survey, email: readd@ohsu.edu

Revisions in 2005

n/a

SPSS Code and Annotation

```
*****System of Care indicator for CSHCN ages 0-12 (updated using new age denominator per MCHB)
*Count of outcomes achieved version for CSHCN ages 0-11
*NOTE:  Make sure that '99' is NOT set to USER MISSING in the MCHB outcome variables when
running this code.....

MISSING VALUES outcome1_05 outcome2_05 outcome3_05 outcome4_05 outcome5_05
outcome6_05  ().

DO IF (AGE <12).
COMPUTE syst1_ct = 0.
IF (outcome1_05 = 1)  syst1_ct = syst1_ct +1.
IF (outcome2_05 = 1)  syst1_ct = syst1_ct +1.
IF (outcome3_05 = 1)  syst1_ct = syst1_ct +1.
IF (outcome4_05 = 1)  syst1_ct = syst1_ct +1.
IF (outcome5_05 = 1)  syst1_ct = syst1_ct +1.
IF (outcome1_05 = 99) or (outcome2_05 = 99) or (outcome3_05 = 99) or (outcome4_05 = 99) or
(outcome5_05 = 99) syst1_ct = 99.
ELSE IF (AGE >=12).
COMPUTE syst1_ct = 999.
END IF.
```

```
VAR LABEL syst1_ct 'CSHCN ages 0-11 meeting one or more of five criteria for system of care'.
VALUE LABEL syst1_ct
0 '0 outcomes achieved'
1 '1 outcome achieved'
2 '2 outcomes achieved'
3 '3 outcomes achieved'
4 '4 outcomes achieved'
5 'All 5 outcomes achieved'
99 'DK/Ref to any'
999 'CSHCN ages 12 -17'.
MISSING VALUES syst1_ct (99, 999).

RECODE syst1_ct (0 thru 2 = 1) (3 thru 4 = 2) (5 = 3) into syst1_3.
EXECUTE.

VAR LABEL syst1_3 'CSHCN ages 0-11 meeting criteria for system of care -- 3 groups'.
VALUE LABEL syst1_3
1 ' 0-2 outcomes acheived'
2 ' 3-4 outcomes acheived'
3 'Outcomes achieved in all 5 areas'
99 'DK/Ref to any'
999 'CSHCN ages 12 -17'.
MISSING VALUES syst1_3 (999).
FORMATS syst1_3 (f2.0).
```

System of Care #2	CSHCN ages 12-17 whose care meets System of Care Criteria for MCHB Core Outcomes
Survey Items Used	Over 50 different survey questions are used to construct the 6 derived variables counted for purposes of this indicator; items are specified under each of the MCHB Core Outcomes #1-6.
Numerator	Achieved 0-2 outcomes; Achieved 3-4 outcomes; Achieved 5 outcomes; Achieved all 6 outcomes
Denominator	CSHCN ages 12 -17
Description	CSHCN ages 12-17 meeting criteria for system of care.

Notes for Data-Users

CSHCN ages 12-17 years were considered to be served by a "service system" as described in the Healthy People objective, if their care met the criteria on each of the age-relevant outcomes. Five of the six MCHC core outcomes for CSHCN apply to children birth through age 11 years. The sixth outcome, transition to adulthood, only pertains to youth ages 12 years and over. For more information on calculating each of the core outcome measures derived from the survey, email: readd@ohsu.edu.

Revisions in 2005

N/A

SPSS Code and Annotation

```
*NOTE:  Make sure that '99' is NOT set to USER MISSING in the MCHB outcome variables when running this code.....

MISSING VALUES outcome1_05 outcome2_05 outcome3_05 outcome4_05 outcome5_05 outcome6_05  ().

DO IF (AGE >=12).
COMPUTE syst2_ct = 0.
IF (outcome1_05 = 1)  syst2_ct = syst2_ct +1.
IF (outcome2_05 = 1)  syst2_ct = syst2_ct +1.
IF (outcome3_05 = 1)  syst2_ct = syst2_ct +1.
IF (outcome4_05 = 1)  syst2_ct = syst2_ct +1.
IF (outcome5_05 = 1)  syst2_ct = syst2_ct +1.
IF (outcome6_05 = 1)  syst2_ct = syst2_ct +1.
IF (outcome1_05 = 99) or (outcome2_05 = 99) or (outcome3_05 = 99) or (outcome4_05 = 99) or (outcome5_05 = 99) or (outcome6_05 = 99) syst2_ct = 99.
ELSE IF (AGE <12).
COMPUTE syst2_ct = 999.
END IF.
```

```
VAR LABEL syst2_ct 'CSHCN ages 12-17 meeting one or more of six criteria for system of care'.
VALUE LABEL syst2_ct
0 '0 outcomes achieved'
1 '1 outcome achieved'
2 '2 outcomes achieved'
3 '3 outcomes achieved'
4 '4 outcomes achieved'
5 '5 outcomes achieved'
6 'All 6 outcomes achieved'
99 'DK/Ref to any'
999 'CSHCN ages 0-11'.
MISSING VALUES syst2_ct (99,999).

RECODE syst2_ct (0 thru 2 = 1) (3 thru 4 = 2) (5 = 3) (6=4) into syst2_4.
EXECUTE.

VAR LABEL syst2_4 'CSHCN ages 12-17 meeting criteria for system of care -- 3 groups'.
VALUE LABEL syst2_4
1 ' 0-2 outcomes achieved'
2 ' 3-4 outcomes achieved'
3' 5 outcomes achieved'
4 'Outcomes achieved in all 6 areas'
99 'DK/Ref to any'
999 'CSHCN ages 0-11'.
MISSING VALUES syst2_4 (999).
FORMATS syst2_4 (f2.0).
```

Conditions	Number of current health conditions reported from list of 16 different conditions asked in the survey
Survey Items Used	S3Q16 thru S3Q31_A
Numerator	None reported; 1 reported; 2 reported; 3 reported; 4 or more reported
Denominator	CSHCN ages 0-17
Description	Number of current health conditions reported from list of 16 different conditions asked in the survey
Notes for Data-Users	
All information from the 2005-2006 survey about children's current diagnoses is based on parent report.	
Revisions in 2005	
The questions about CSHCN's current health conditions were newly added in 2005-2006; not asked in 2001 survey.	
SPSS Code and Annotation	

```
COUNT
cond_cnt = S3Q16 S3Q17 S3Q18 S3Q19 S3Q20 S3Q21 S3Q22 S3Q23 S3Q25 S3Q26 S3Q27 S3Q28
S3Q29 S3Q30 S3Q32 S3Q31 (1).
EXECUTE.
VAR LABEL cond_cnt 'Number of hlth conditions reported'.

RECODE
  cond_cnt (0=0)  (1=1)  (2=2)  (3=3)  (4 thru Highest=4)  INTO cond_5 .
EXECUTE .
VAR LABEL cond_5 'Number of health conditions reported (4 categories)'.
VALUE LABEL cond_5
0 'No conditions reported'
1 '1 cond reported'
2 '2 conds reported'
3 '3 conds reported'
4 '4 or more conds reported'.
FORMATS cond_5 (f2.0).
```

Stratifiers

Difficulties	Number of functional difficulties reported from list of 15 different difficulties asked in the survey
Survey Items Used	S3Q01B thru S3Q14
Numerator	None reported; 1 reported; 2 reported; 3 reported; 4 or more reported
Denominator	CSHCN ages 0-17
Description	Number of functional difficulties reported from list of 15 different difficulties asked in the survey
Notes for Data-Users	
All information from the 2005-2006 survey about children's current functional difficulties is based on parent report.	
Revisions in 2005	
The questions about CSHCN's functional difficulties were newly added in 2005-2006; not asked in 2001 survey.	
SPSS Code and Annotation	

```
COUNT
diff_cnt = S3Q01B S3Q02A S3Q02B S3Q03 S3Q04 S3Q05 S3Q06 S3Q07 S3Q08 S3Q09 S3Q10
S3Q11 S3Q12 S3Q13 S3Q14 (1).
EXECUTE.

VAR LABEL diff_cnt 'Number of functional difficulties reported using most restrictive criteria for Vision or
Hearing'.

RECODE
  diff_cnt (0=0)  (1=1)  (2=2)  (3=3)  (4 thru Highest=4)  INTO diff_5 .
EXECUTE .

VAR LABEL diff_5 'Number of functional difficulties reported (4 categories) -- using most restrictive
criteria for Vision or Hearing'.
VALUE LABEL diff_5
0 'No difficulties reported'
1 '1 difficulty reported'
2 '2 difficulties reported'
3 '3 difficulties reported'
4 '4 or more difficulties reported'.
FORMATS diff_5 (f2.0).
```

Emotional	**CSHCN ages 18 months - 17 yrs reporting none or one or more emotional or behavioral difficulties**
Survey Items Used	S3Q12 S3Q13 S3Q14
Numerator	None of listed emotional/behavioral difficulties; 1 or more of listed emotional/behavioral difficulties reported
Denominator	CSHCN ages 18 mos - 17 yrs
Description	% of CSHCN ages 18 mos -17 yrs reporting none or one or more emotional or behavioral difficulties.
Notes for Data-Users	
All information from the 2005-2006 survey about children's current functional difficulties is based on parent report.	
Revisions in 2005	
The questions about CSHCN's functional difficulties were newly added in 2005-2006; not asked in 2001 survey.	
SPSS Code and Annotation	

```
COMPUTE emot_ICF =99.
IF (s3q12 = 0) or (s3q13 = 0) or (s3q14 = 0) emot_ICF = 0.
IF (s3q12 = 1) or (s3q13 = 1) or (s3q14 = 1) emot_ICF = 1.
EXECUTE.

VAR LABEL emot_ICF 'Any other emotional or behavioral difficulty (S3q07 - S3q11)'.
VALUE LABEL emot_ICF
0 'No emotional or behavioral difficulties'
1 'One or more emotional or behavioral difficulties'
99 'Less than 18 mos old/not asked'.
MISSING VALUES emot_ICF (99).
FORMATS Emot_ICF (f2.0).
```

Stratifiers

Activity	CSHCN ages 0 - 17 yrs reporting none or one or more difficulties involving activities or participation
Survey Items Used	S3Q07 S3Q08 S3Q09 S3Q10 S3Q11
Numerator	None of listed activity/participation difficulties; 1 or more of listed activity/participation difficulties reported
Denominator	CSHCN ages 0-17 yrs
Description	% of CSHCN ages 0 -17 yrs reporting none or one or more difficulties involving activities or participation
Notes for Data-Users	
All information from the 2005-2006 survey about children's current functional difficulties is based on parent report.	
Revisions in 2005	
The questions about CSHCN's functional difficulties were newly added in 2005-2006; not asked in 2001 survey.	
SPSS Code and Annotation	

```
COMPUTE activity_ICF =0.
IF (s3q07 = 1) or (s3q08 = 1) or (s3q09 = 1) or (s3q10 = 1) or (s3q11 = 1) activity_ICF = 1.
EXECUTE.

VAR LABEL activity_ICF 'Any activity or participation difficulty (S3q07 - S3q11)'.
VALUE LABEL activity_ICF
0 'No activity or participation difficulties'
1 'One or more activity/participation difficulties'.
FORMATS activity_ICF (f2.0).
```

Body	CSHCN ages 0 -17 yrs reporting none or one or more difficulties involving bodily functions
Survey Items Used	S3Q01B S3Q02B S3Q03 S3Q04 S3Q05 S3Q06
Numerator	None of listed body difficulties; 1 or more of listed body difficulties reported
Denominator	CSHCN ages 0-17
Description	% of CSHCN ages 0 -17 yrs reporting none or one or more difficulties involving bodily functions

Notes for Data-Users

All information from the 2005-2006 survey about children's current functional difficulties is based on parent report.

Revisions in 2005

The questions about CSHCN's functional difficulties were newly added in 2005-2006; not asked in 2001 survey.

SPSS Code and Annotation

```
COMPUTE body_ICF =0.
IF (s3q01b = 1) or (s3q02b = 1) or (s3q03 = 1) or (s3q04 = 1) or (s3q05 = 1) or (s3q06 = 1) body_ICF =
1.
EXECUTE.

VAR LABEL body_ICF 'Any bodily difficulty (S3q01b - S3q06)'.
VALUE LABEL body_ICF
0 'No bodily function difficulties'
1 'One or more bodily func difficulties'.
FORMATS body_ICF (f2.0).
```

Stratifiers

Gender	How many males and females are in the CSHCN population?
Survey Items Used	C2Q03
Numerators	Male; Female
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 who are male or female
Notes for Data-Users	
The variable for “child’s sex” is found in the publicly released 2005-2006 NS_CSHCN Screener file. To add this variable to the 2005-2006 NS_CSHCN Interview file, analysts will need to merge the variable SEX from the Screener file, using the unique child identifier IDNUMXR as the linking variable. Unweighted frequency tables for this variable in the Screener and Interview files are included in Appendix B.	
Revisions in 2005	
No changes; same as 2001	
SPSS Code and Annotation	
VARIABLE LABEL SEX ‘Sex of child’. VALUE LABEL SEX 1 ‘Male’ 2 ‘Female’. MISSING VALUES SEX (6,7). FORMATS SEX (f2.0).	

Age Group (3)	**How many children of different ages are in the CSHCN population?**
Survey Items Used	Initial sampling questions
Numerators	0–5 years old; 6–11 years old; 12–17 years old
Denominator	CSHCN ages 0–17 years
Description	Percent of CSCHN who are 0–5, 6–11, 12–17 years old
Notes for Data-Users	
The variable AGE is avaiLABEL in the publicly released 2005-2006 NS_CSHCN Interview File.	
Revisions in 2005	
No changes; same as 2001	
SPSS Code and Annotation	

```
RECODE
  AGE
  (0 thru 5=1)  (6 thru 11=2)  (12 thru 17=3)  INTO  age_3.
EXECUTE.

VARIABLE LABEL age_3 ‘Childrens age in 3 categories’.
VALUE LABEL  age_3
1 '0-5 yrs old'
2 '6-11 yrs old'
3 '12-17 yrs old'.
FORMATS age_3 (f2.0).
```

Race and Ethnicity	What is the race/ethnicity of the CSHCN population?
Survey Items Used	CW10Q01 CW10Q02
Numerators	Hispanic ethnicity (any race); White (non-Hispanic); Black (non-Hispanic); Multi-racial (non-Hispanic); Other (non-Hispanic)
Denominator	CSHCN ages 0-17
Description	Percent of CSHCN ages 0–17 who are Hispanic/Latino, or non-Hispanic and White, Black, Multiracial, or of another race.

Notes for Data-Users

This variable is constructed from two variables from the publicly released 2005-2006 NS_CSHCN Screener File. To construct this variable in the 2005-2006 NS_CSHCN Interview File, analysts will need to merge the variables HISPANIC and RACER from the Screener file using the unique child identifier IDNUMXR as the linking variable. Unweighted frequency tables for these variables in the Screener and Interview files are included in Appendix B.

Children reporting Hispanic or Latino origin (CW10Q01 = Yes) are counted as Hispanic regardless of race. Non-Hispanic children are grouped by race based on responses to CW10Q02; those reporting a single race category of either White or Black are grouped respectively; those reporting more than one race category are counted as "Multi-racial"; and those reporting only one race category of Asian, American Indian, Alaska Native, Native Hawaiian, or Pacific Islander are counted as "Other".

Additional information regarding race and ethnicity classification in included in the methods report for this survey: http://www.cdc.gov/nchs/data/slaits/NSCSHCN_0506_DO_112807.pdf.

Revisions in 2005

No changes; same as 2001

SPSS Code and Annotation

```
**NOTE:  Asian, Hawaiian, Pacific Islander, Native American, and Native Alaskan children are combined into the group OTHER because state level data for these groups are only released by NCHS for states where these minorities comprise 5% or more of the age 0-17 population.

COMPUTE race_5 = 0.
IF (HISPANIC = 1) race_5 = 1.
IF ((HISPANIC = 1) and (sysmis(RACER))) race_5 = 1.
IF (HISPANIC = 0) and (RACER = 1) race_5 = 2.
IF (HISPANIC = 0) and (RACER = 2) race_5 = 3.
IF (HISPANIC = 0) and (RACER = 3) race_5 = 4.
IF (HISPANIC = 0) and (RACER = 4) race_5 = 5.
IF (HISPANIC >=6) and (RACER = 1) race_5 = 2.
IF (HISPANIC >=6) and (RACER = 2) race_5 = 3.
```

```
IF (HISPANIC >=6) and (RACER = 3) race_5 = 4.
IF (HISPANIC >=6) and (RACER = 4) race_5 = 5.
IF (HISPANIC >=6) and (RACER >=96) race_5 = 6.
IF (HISPANIC = 0) and (RACER >=96) race_5 = 6.
IF (RACER = 1) and (sysmis (HISPANIC)) race_5 = 2.
IF (RACER = 2) and (sysmis (HISPANIC)) race_5 = 3.
IF (RACER = 3) and (sysmis (HISPANIC)) race_5 = 4.
IF (RACER = 4) and (sysmis (HISPANIC)) race_5 = 5.
IF ((hispanic = 0)  and (sysmis (RACER))) race_5 = 7.
IF ((RACER >=96)  and (sysmis (HISPANIC))) race_5 = 7.
IF ((hispanic >=6)  and (sysmis (RACER))) race_5 = 7.
IF ((sysmis(HISPANIC)) and (sysmis (RACER))) race_5 = 7.
EXECUTE.

VARIABLE LABEL race_5 'Mutually exclusive race & Hisp ethnicity for screened children'.
VALUE LABEL  race_5
1 'Hispanic'
2 'White, non-Hisp'
3 'Black, non-Hisp'
4 'Multi racial, non-Hisp'
5 'Other (including Asian), non-Hisp'
6 'DK / Ref to both hisp & race or race only'
7 'System missing'.
MISSING VALUES race_5 (6,7).
FORMATS race_5 (f2.0).
```

Stratifiers

Special Needs Type	How many CSHCN qualified on specific types of special health needs criteria?
Survey Items Used	CSHCN1 CSHCN1_A CSHCN1_B CSHCN2 CSHCN2_A CSHCN2_B CSHCN3 CSHCN3_A CSHCN3_B CSHCN4 CSHCN4_A CSHCN4_B CSHCN5 CSHCN5_A
Numerators	Use of prescription medication only; use of specialized services only; use of BOTH prescription medication and specialized services; functional limitations with or without other qualifying criteria
Denominator	CSHCN ages 0-17
Description	Percent of CSHCN qualifying on prescription medication only, use of specialized services, both prescription medication and use of services, or functional limitations alone or with any other criteria

Notes for Data-Users

This variable is constructed from CSHCN Screener variables in the publicly released 2005-2006 NS_CSHCN Screener file. To construct this variable in the 2005-2006 NS_CSHCN Interview file, analysts will need to merge the variables CSHCN1 through CSHCN5_A, from the Screener file using the unique child identifier IDNUMXR as the linking variable. Unweighted frequency tables for these variables in the Screener and Interview files are included in Appendix B.

These four mutually exclusive groupings of CSHCN by types of qualifying special needs are avaiLABEL under the data query subgroup option for comparing many of the child health and service system indicators, interview questions, and MCHB outcomes collected by the National Survey of CSHCN. Information about the development, testing, and construction of the four mutually exclusive groupings of CSHCN based on the type and combination of their qualifying screening criteria, may be obtained from the Child and Adolescent Health Measurement Initiative at CAHMI@ohsu.edu.

Revisions in 2005

No changes; same as 2001

SPSS Code and Annotation

```
**NOTE: Before constructing this variable, merge CSHCN Screener variables from the 2005-2006 NS-CSHCN Screener public use file, linking on IDNUMXR.

**STEP 1:  Identifying children who qualify on the each of five different CSHCN screening criteria, number of qualifying criteria and overall number of ch identified

COMPUTE rxmeds = 0.
IF ((cshcn1 = 1) and (cshcn1_a = 1) and (cshcn1_b = 1)) rxmeds = rxmeds +1.
EXECUTE .
```

```
VARIABLE LABEL  rxmeds "Qualified on rx'd med use?".
VALUE LABEL rxmeds 0 'No'  1 'Yes'.

COMPUTE serve = 0.
If ((cshcn2 = 1) and (cshcn2_a =1) and (cshcn2_b = 1)) serve = serve + 1.
EXECUTE.
VARIABLE LABEL serve 'Qualified on elevated service use or needs?'.
VALUE LABEL serve 0 'No'  1 'Yes'.

COMPUTE func = 0.
IF ((cshcn3 = 1) and (cshcn3_a = 1) and (cshcn3_b = 1)) func = func + 1.
EXECUTE.
VARIABLE LABEL func 'Qualified on functional limits?'.
VALUE LABEL func  0 'No'  1 'Yes'.

COMPUTE therapy = 0.
IF ((cshcn4 = 1) and (cshcn4_a = 1) and (cshcn4_b = 1)) therapy = therapy + 1.
EXECUTE.
VARIABLE LABEL therapy 'Qualified on use of special therapies?'.
VALUE LABEL therapy  0 'No'  1 'Yes'.

COMPUTE mhealth = 0.
IF ((cshcn5 = 1) and (cshcn5_a = 1)) mhealth = mhealth + 1.
EXECUTE.
VARIABLE LABEL mhealth 'Qualified on ongoing emotional, developmental or behavioral conditions?'.
VALUE LABEL mhealth 0 'No'  1 'Yes'.


** STEP 2:  Compute .mutually exclusive sub groupings of special health care need types -- based on
type of qualifying screening criteria (qualitative approach)

COMPUTE def_4 = 0.
IF ((func = 1)) and ((serve = 1) or (therapy = 1) or (rxmeds = 1) or (mhealth = 1)) def_4 = 1.
IF ((func = 1)) and ((serve = 0) or (therapy = 0) or (rxmeds = 0) or (mhealth = 0)) def_4 = 1.
IF (func = 0) and ((rxmeds = 1)) and ((serve = 0) or (therapy = 0) or (mhealth = 0)) def_4 = 2.
IF (func = 0) and ((rxmeds = 0)) and ((serve = 1) or (therapy = 1) or (mhealth = 1)) def_4 = 3.
IF (func = 0) and ((rxmeds = 1)) and ((serve = 1) or (therapy = 1) or (mhealth = 1)) def_4 = 4.
EXECUTE.

VARIABLE LABELS def_4 "Def_4 re-grouped screener qualifying categories".
VALUE LABELS def_4
1 "CSHCN qualifying on Func (only or w/ any other)"
2 "CSHCN qualifying on Rx meds ONLY"
3 "CSHCN qualifying on Service use ONLY"
4 "CSHCN qualifying on Rx meds AND service use".
FORMATS def_4 (f2.0).
```

Stratifiers

Household Income Version 1	How many CHSCN live in households at specified levels of income according to Federal Poverty guidelines (FPL)
Survey Items Used	C11Q01 through W9Q12A
Numerators	0-99% FPL; 100-199% FPL; 200-399% FPL; 400% or more; Not reported
Denominator	CSHCN ages 0-17
Description	Percent of CSHCN ages 0–17 living in households with income below 100%, 100–199%, 200–399%, or 400% or more of Federal Poverty Level (FPL) for family size; or income level not determined from responses to survey questions.

Notes for Data-Users

This variable is constructed from variables in the publicly released 2005-2006 NS_CSHCN Household file. To construct this variable in the 2005-2006 NS_CSHCN Interview file, analysts will need to merge the variable POVLEVEL, from the Household file using the unique household identifier IDNUMR as the linking variable. Unweighted frequency tables for this variable in the Household and Interview files are included in Appendix B.

Income level was not determined for 18% of participating households, because of missing responses to questions about income. The SPSS code below includes a category for CSHCN living in households for which income was not determined. Imputation of missing income data is beyond the scope of this document; see Appendix C for further details.

Income is expressed in categories according to percentage of Federal Poverty Level (FPL), according to guidelines released by the U.S. Department of Health and Human Services. Details are included in Appendix VII of the methods report for this survey:
http://www.cdc.gov/nchs/data/slaits/NSCSHCN_0506_DO_112807.pdf

IMPORTANT NOTE: Results for this question are weighted to represent the number of children ages 0-17 in the United States. Percent of CSHCN ages 0-17 living in households with incomes 0-99% of the FPL" is the accurate way to report results -- do not report as "Percent of households with incomes 0-99%.

Revisions in 2005

No changes; same as 2001

SPSS Code and Annotation

**IMPORTANT: The variable used to construct child-level CSHCN's NON-IMPUTED household poverty level is found in the publicly released 2005-2006 NS_CSHCN Household File, which has household-level records only. In order to construct categorical "child's household poverty level status" variables for the 2005-2006 NS_CSHCN Interview file, analysts will first need to create a child-level household income variable by merging the variable POVLEVEL from the Household File into the 2005-2006 Interview.

RECODE POVLEVEL

```
   (1 thru 2=1) (3 thru 6=2) (7 thru 8=3) (9=4) (SYSMIS=999) INTO povlev_4 .
EXECUTE.

VAR LABEL povlev_4 "Version 1: Income level of CSHCN's household (% of Federal Poverty Level)".
VALUE LABEL povlev_4
1 '0% - 99% FPL'
2 '100% - 199% FPL'
3 '200% - 399% FPL'
4 '400% FPL or greater'
999 'Income not reported'.
MISSING VALUES povlev_4 (999).
FORMATS povlev_4 (f2.0).
```

Household Income Version 2	How many CHSCN live in households at specified SCHIP-relevant levels of income according to Federal Poverty guidelines (FPL)
Survey Items Used	C11Q01 - W9Q12A
Numerator	0-199% FPL; 200-299% FPL; 300-399% FPL; 400% or more; Not reported
Denominator	CSHCN ages 0-17
Description	Percent of CSHCN ages 0–17 living in households with income below 200%, 200–299%, 300–399%, or 400% or more of Federal Poverty Level (FPL) for family size; or income level not determined from responses to survey questions.

Notes for Data-Users

This variable is constructed from variables in the publicly released 2005-2006 NS_CSHCN Household file. To construct this variable in the 2005-2006 NS_CSHCN Interview file, analysts will need to merge the variable POVLEVEL, from the Household file using the unique household identifier IDNUMR as the linking variable. Unweighted frequency tables for this variable in the Household and Interview files are included in Appendix B.

Income level was not determined for 18% of participating households, because of missing responses to questions about income. The SPSS code below includes a category for CSHCN living in households for which income was not determined. Imputation of missing income data is beyond the scope of this document; see Appendix C for further details.

Income is expressed in categories according to percentage of Federal Poverty Level (FPL), according to guidelines released by the U.S. Department of Health and Human Services. Details are included in Appendix VII of the methods report for this survey:
http://www.cdc.gov/nchs/data/slaits/NSCSHCN_0506_DO_112807.pdf

IMPORTANT NOTE: Results for this question are weighted to represent the number of children ages 0-17 in the United States. Percent of CSHCN ages 0-17 living in households with incomes 0-199% of the FPL" is the accurate way to report results -- do not report as "Percent of households with incomes 0-199%.

Revisions in 2005

No changes; same as 2001

SPSS Code and Annotation

** NOTE: This is a second version of child-level household income using SCHIP policy relevant grouping of 200 - 299% FPL. The variable used to construct child-level CSHCN's NON-IMPUTED household poverty level is found in the publicly released 2005-2006 NS_CSHCN Household File, which has household-level records only. In order to construct categorical "child's household poverty level status" variables for the 2005-2006 NS_CSHCN Interview file, analysts will first need to create a child-level household income variable by merging the variable POVLEVEL from the Household File into the 2005-

Stratifiers

2006 Interview.

```
RECODE POVLEVEL_IMP
(1 thru 6=1) (7=2) (8=3) (9=4) (SYSMIS=999) INTO pov_schip.
EXECUTE.

VAR LABEL pov_schip "Version 2: SCHIP relevant income level of CSHCN's household (% of Federal
Poverty Level)".
VALUE LABEL pov_schip
1 '0% - 199% FPL'
2 '200% - 299% FPL'
3 '300% - 399% FPL'
4 '400% FPL or greater'
999 'Income not reported'.
MISSING VALUES pov_schip (999).
FORMATS pov_schip (f2.0).
```

Stratifiers

Insurance Status	How many CSHCN currently have any kind of health care coverage?
Survey Items Used	UNINS
Numerators	Currently insured; Not currently insured
Denominator	CSHCN ages 0-17
Description	Percent of CSHCN ages 0–17 without any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid at the time of the survey

Notes for Data-Users

The variable UNINS in the 2005-2006 NS-CSHCN Interview File was derived by the National Center for Health Statistics from responses to the numerous health insurance coverage questions in Section 7 of the survey.

Information on how the insurance variables in the public use file were defined may be found in the NCHS methods report for this survey: http://www.cdc.gov/nchs/data/slaits/NSCSHCN_0506_DO_112807.pdf

Revisions in 2005

No changes; same as 2001

SPSS Code and Annotation

```
***NOTE: Use the NCHS derived variable UNINS in the publicly released 2005-2006 NS_CSHCN
Interview file.

VAR LABEL UNINS "Current insurance status of CSHCN".
VALUE LABEL UNINS
0 ‘Insured at time of survey’
1 ‘Not insured at time of survey’.
FORMATS UNINS (f2.0).
```

Stratifiers

Consistently Insured	CSHCN without insurance at some point during the past year
Survey Items Used	UNINS_YR
Numerator	Insured entire year; Not insured at some point during past year
Denominator	CSHCN ages 0-17
Description	% of CSHCN without insurance at some point during the past year

Notes for Data-Users

The variable UNINS_YR in the 2005-2006 NS-CSHCN Interview File was derived by the National Center for Health Statistics from responses to the numerous health insurance coverage questions in Section 7 of the survey. Information on how the insurance variables in the public use file were defined may be found in the NCHS methods report for this survey:
http://www.cdc.gov/nchs/data/slaits/NSCSHCN_0506_DO_112807.pdf

Revisions in 2005

No changes; same as 2001

SPSS Code and Annotation

***NOTE: Use the NCHS derived variable UNINS in the publicly released 2005-2006 NS_CSHCN Interview file.

```
VAR LABEL UNINS_YR "CSHCN ever not insured during past 12 months".
VALUE LABEL UNINS_YR
0 'Insured entire year'
1 'NOT insured at some point during year'
6 'DK'
7 'Refused'.
MISSING VALUES UNINS_YR (6,7).
FORMATS UNINS_YR (f2.0).
```

Stratifiers

Insurance Type	How many CSHCN have private or public insurance coverage?
Survey Items Used	TYPEINS
Numerators	Private only; Public only; BOTH public and private; Uninsured
Denominator	CSHCN ages 0-17 with either private and/or public insurance or no insurance coverage at the time of the survey.
Description	Percent of CSHCN ages 0–17 whose health insurance coverage at the time of the survey was private, public, combined private and public, or uninsured

Notes for Data-Users

Nationally, approximately 2% of CSHCN had coverage classified as "other comprehensive insurance" at the time of the survey. Due to its small size, this group is not included in the results summarized in the data query tables or charts for this indicator.

The variable TYPEINS in the 2005-2006 NS-CSHCN Interview File was derived by the National Center for Health Statistics from responses to the numerous health insurance coverage questions in Section 7 of the survey. Information on how the insurance variables in the public use file were defined may be found in the NCHS methods report for this survey:
http://www.cdc.gov/nchs/data/slaits/NSCSHCN_0506_DO_112807.pdf

Revisions in 2005

Minor changes in 2005/06 to ask about employer/union insurance separately from private insurance purchased directly; no other changes.

SPSS Code and Annotation

```
RECODE TYPEINS
(1=1) (2=2) (3=3) (4=4) (5=5) INTO ins_type.
EXE.

VAR LABEL ins_type "Type of Insurance Coverage".
VALUE LABEL ins_type
1 'Private only'
2 'Public only'
3 'Both Public and Private'
4 'Other comprehensive ins'
5 'Uninsured'.
MISSING VALUE ins_type (4).
FORMATS ins_type (f2.0).
```

Stratifiers

Family Structure	How many CSHCN were living in two parent, step/blended, mother only, or other types of family households at the time of the survey?
Survey Items Used	C11Q01_A thru C10Q05
Numerator	2-parent (biological/adoptive); 2-parent step/blended; Mother only; All other family structure types; Not reported
Denominator	CSHCN ages 0-17 yrs
Description	% of CSHCN living in 2-parent households, biological/adoptive or step/blended, households headed by a single mother, or households with any other family structure, at the time of the survey.

Notes for Data-Users

The summary variable FAMSTRUCT was derived from responses to questions in Section 10 and is the only information about family structure included in the public use files for the 2005-2006 NS-CSHCN. Responses for individual questions C11Q01_A thru C10Q05 in Section 10 were suppressed in order to protect the confidentiality of respondents. For more information, see the NSCH methods report for the survey at: http://www.cdc.gov/nchs/data/slaits/NSCSHCN_0506_DO_112807.pdf

Revisions in 2005

Questions C11Q01_A thru C10Q05 were added to the NS-CSHCN in 2005-2006; not asked in 2001.

SPSS Code and Annotation

***NOTE: Use the NCHS derived variable FAMSTRUCT in the publicly released 2005-2006 NS_CSHCN Interview file.

```
VAR LABEL FAMSTRUCT "CSHCN's household according to family type".
VALUE LABEL FAMSTRUCT
1  "CSHCN in 2 biological and/or adopted parent household"
2  "CSHCN in 2 parent stepfamily household"
3  "CSHCN in mother only (no father figure) household"
4  "CSHCN in other family structure household (grandparents, single father, foster, etc.)"
FORMATS FAMSTRUCT (f2.0).
```

Hispanic HH Language	How many Hispanic CSHCN live in households in which Spanish is the primary language?
Survey Items Used	CW10Q01 CW10Q02 C2Q05
Numerator	Spanish speaking household; English speaking household; Non-Hispanic CSHCN
Denominator	CSHCN ages 0-17 years
Description	% CSHCN who are Hispanic and living in primarily Spanish language households

Notes for Data-Users

In 2005-2006, 57% of Hispanic children ages 0-17 yrs in the U.S lived in households where the primary language was not English. Hispanic children living in non-English language households represent 11% of the U.S. child population overall. About 2% of the U.S. child population are non-Hispanic and live in households where English in not the primary language. For the purposes of this indicator, Spanish is assumed to be the household language for Hispanic children living in non-English primary language households.

This item is constructed using race_5, which is derived from HISPANIC (Hispanic or Latino ethnicity) and RACER in the publicly released 2005-2006 NS_CSHCN Screener File (see page 64-65), and C2Q05R (primary language spoken in the household) from the publicly released 2005-2006 NS_CSHCN Household File. To create the variable in the 2005-2006 NS_CSHCN Interview File, analysts will need to merge these variables into the Interview file using their respective unique child and household identifiers as the linking variables. Unweighted frequency tables for these variables in the Screener, Household and Interview files are included in Appendix B.

Additional information regarding race and ethnicity classification in included in the methods report for this survey: http://www.cdc.gov/nchs/data/slaits/NSCSHCN_0506_DO_112807.pdf.

Revisions in 2005

The question about primary household language was added in 2005-2006; not asked in 2001.

SPSS Code and Annotation

```
**NOTE: Skip STEP 1 if race_5 has already been constructed.

**STEP 1: Construct race_5, using variabls HISPANIC (Hispanic or Latino ethnicity) and RACER in the screener file (see page 64-65).

COMPUTE race_5 = 0.
IF (HISPANIC = 1) race_5 = 1.
IF ((HISPANIC = 1) and (sysmis(RACER))) race_5 = 1.
IF (HISPANIC = 0) and (RACER = 1) race_5 = 2.
```

```
IF (HISPANIC = 0) and (RACER = 2) race_5 = 3.
IF (HISPANIC = 0) and (RACER = 3) race_5 = 4.
IF (HISPANIC = 0) and (RACER = 4) race_5 = 5.
IF (HISPANIC >=6) and (RACER = 1) race_5 = 2.
IF (HISPANIC >=6) and (RACER = 2) race_5 = 3.
IF (HISPANIC >=6) and (RACER = 3) race_5 = 4.
IF (HISPANIC >=6) and (RACER = 4) race_5 = 5.
IF (HISPANIC >=6) and (RACER >=96) race_5 = 6.
IF (HISPANIC = 0) and (RACER >=96) race_5 = 6.
IF (RACER = 1) and (sysmis (HISPANIC)) race_5 = 2.
IF (RACER = 2) and (sysmis (HISPANIC)) race_5 = 3.
IF (RACER = 3) and (sysmis (HISPANIC)) race_5 = 4.
IF (RACER = 4) and (sysmis (HISPANIC)) race_5 = 5.
IF ((hispanic = 0)  and (sysmis (RACER))) race_5 = 7.
IF ((RACER >=96)  and (sysmis (HISPANIC))) race_5 = 7.
IF ((hispanic >=6)  and (sysmis (RACER))) race_5 = 7.
IF ((sysmis(HISPANIC)) and (sysmis (RACER))) race_5 = 7.
EXECUTE.

VARIABLE LABEL race_5 'Mutually exclusive race & Hisp ethnicity for screened children'.
VALUE LABEL  race_5
1 'Hispanic'
2 'White, non-Hisp'
3 'Black, non-Hisp'
4 'Multi racial, non-Hisp'
5 'Other (including Asian), non-Hisp'
6 'DK / Ref to both hisp & race or race only'
7 'System missing'.
MISSING VALUES race_5 (6,7).
FORMATS race_5 (f2.0).



**STEP 2: Construct hisp_3 using race_5 and C2Q05R (merged from Household file).

COMPUTE  hisp_3 = 99.
IF ((race_5 = 1) and  (c2q05r = 1)) hisp_3 = 2.
IF ((race_5 = 1) and (c2q05r = 2)) hisp_3 = 1.
IF (race_5 > 1) hisp_3 = 3.
EXE.

VAR LABEL hisp_3 'Hispanic ethnicity parsed by childs PRIMARY HOUSEHOLD lang'.
VALUE LABEL hisp_3
1 'Hisp child / primary HH lang is SPANISH lang'
2 'Hisp child / primary HH lang is ENGLISH'
3 'Non-Hispanic children'
99 'DK/REF/Missing'.
MISSING VALUE hisp_3 (99).
FORMATS hisp_3 (f2.0).
```

Appendix A: Unweighted Frequency Tables

APPENDIX A

Unweighted Frequency Tables: Codebook Variables in Interview File

NATIONAL CHARTBOOK INDICATORS

indic1_05 INDICATOR #1: % of CSHCN whose health conditions consistently and often greatly affect their daily activities

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Daily activities never affected	15755	38.7	38.8	38.8
	2 Daily activities moderately affected some of the time	15646	38.4	38.5	77.3
	3 Daily activities consistently affected, often a great deal	9205	22.6	22.7	100.0
	Total	40606	99.7	100.0	
Missing	99 DK, Ref or Missing to both items	117	.3		
Total		40723	100.0		

ıdic2_05 INDICATOR #2: % of CSHCN ages 5-17 with 11 or more days of school absence due to illness

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0 - 3 days missed	17901	44.0	51.9	51.9
	2 4 - 6 days missed	7372	18.1	21.4	73.3
	3 7 - 10 days missed	4343	10.7	12.6	85.9
	4 11 or more days missed	4859	11.9	14.1	100.0
	Total	34475	84.7	100.0	
Missing	99 DK, Ref, or ch <5 yrs old	6248	15.3		
Total		40723	100.0		

ıdic3_05 INDICATOR #3: % of CSHCN without insurance at some point during the past yea

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Insured entire year	37168	91.3	91.6	91.6
	1 NOT insured at some point during year	3395	8.3	8.4	100.0
	Total	40563	99.6	100.0	
Missing	System	160	.4		
Total		40723	100.0		

APPENDIX A

Unweighted Frequency Tables: Codebook Variables in Interview File

indic4_05 INDICATOR #4: % of CSHCN uninsured at the time of the survey

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 Currently insured	39197	96.3	96.5	96.5
	1.00 Currently NOT insured	1437	3.5	3.5	100.0
	Total	40634	99.8	100.0	
Missing	System	89	.2		
Total		40723	100.0		

indic5_05 Currently insured CSHCN whose insurance is not adequate

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Current insurance is adequate	26582	65.3	67.9	67.9
	1 Current insurance NOT adequate	12576	30.9	32.1	100.0
	Total	39158	96.2	100.0	
Missing	99 DK or Ref to all items or Uninsured	1565	3.8		
Total		40723	100.0		

indic6_05 % of CSHCN with 1 or more unmet needs for 15 specific health care services

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 1 or more unmet need for services/equip	6225	15.3	15.3	15.3
	2 No unmet needs for services/equip	34498	84.7	84.7	100.0
	Total	40723	100.0	100.0	

indic7_05 % of CSHCN with one or more unmet needs for family services

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No unmet needs for specific family support services or did not need	38808	95.3	95.3	95.3
	1 One or more unmet needs for family support services	1915	4.7	4.7	100.0
	Total	40723	100.0	100.0	

APPENDIX A

Unweighted Frequency Tables: Codebook Variables in Interview File

indic8_05 % of CSHCN needing referrals who had problems with getting them

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Needed referral, no problems getting it	10675	26.2	79.9	79.9
	1 Needed referral, YES problems getting it	2683	6.6	20.1	100.0
	Total	13358	32.8	100.0	
Missing	99 DK/REF or did not need a referral	27365	67.2		
Total		40723	100.0		

indic9_05 INDICATOR #9: % of CSHCN without a usual source of care or who rely on the emergency room

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Doctors office	30714	75.4	75.6	75.6
	2 Clinic, health center or other regular source	7792	19.1	19.2	94.8
	3 No regular place or relies on emergency room	2108	5.2	5.2	100.0
	Total	40614	99.7	100.0	
Missing	99 DK/REF to all	109	.3		
Total		40723	100.0		

indic10_05 Indicator #10: Percent of CSHCN without a personal doctor or nurse

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No, does not have a PDN	2300	5.6	5.7	5.7
	1 Yes, has one or more PDNs	38358	94.2	94.3	100.0
	Total	40658	99.8	100.0	
Missing	99 DK/REF/MISSING	65	.2		
Total		40723	100.0		

APPENDIX A

Unweighted Frequency Tables: Codebook Variables in Interview File

indic11_05 INDICATOR #11: % of CSHCN without family-centered care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Does NOT have fcc	12614	31.0	32.4	32.4
	1 Yes, has fcc	26288	64.6	67.6	100.0
	Total	38902	95.5	100.0	
Missing	2 Legitimate skip - no dr visit past 12 mos	1808	4.4		
	99 DK/Ref to all	13	.0		
	Total	1821	4.5		
Total		40723	100.0		

indic12_05 INDICATOR #12: % of CSHCN whose families pay more than $1000 per year out-of-pocket for child's medical expenses

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Less than $250	15579	38.3	39.0	39.0
	2 $250 - $500	9988	24.5	25.0	64.0
	3 $501 - $1000	5468	13.4	13.7	77.7
	4 More than $1000	8932	21.9	22.3	100.0
	Total	39967	98.1	100.0	
Missing	99 DK/REF	756	1.9		
Total		40723	100.0		

indic13_05 INDICATOR #13: % of CSHCN whose families experienced financial problems due to child's health needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No financial problems due to child's health	32907	80.8	81.5	81.5
	1 Yes, financial problems	7457	18.3	18.5	100.0
	Total	40364	99.1	100.0	
Missing	99 DK/REF or MISSING	359	.9		
Total		40723	100.0		

indic14_05 INDICATOR #14: % of CSHCN whose families spend 11 or more hours per week providing and/or coordinating health care for child

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Less than 1 hour	19997	49.1	49.6	49.6
	2 1 - 4 hours per week	13477	33.1	33.4	83.0
	3 5 - 10 hours per week	3258	8.0	8.1	91.0
	4 11 or more hours per week	3618	8.9	9.0	100.0
	Total	40350	99.1	100.0	
Missing	99 DK/REF	373	.9		
Total		40723	100.0		

ndic15_05 INDICATOR #15: % of CSHCN whose family members cut back and/or stopped working because of child's health needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Employment not affected	31290	76.8	77.3	77.3
	1 Family member cut back hours or stopped working or both	9167	22.5	22.7	100.0
	Total	40457	99.3	100.0	
Missing	99	266	.7		
Total		40723	100.0		

MCHB CORE OUTCOMES

outcome1_05 'OUTCOME #1: Families of CSHCN will be partners in decision making and are satisfied with the services they receive'

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Outcome not achieved	16485	40.5	40.5	40.5
	1 Outcome successfully achieved	23179	56.9	56.9	97.4
	99 DK/REF to 1 or both	1059	2.6	2.6	100.0
	Total	40723	100.0	100.0	

APPENDIX A

Unweighted Frequency Tables: Codebook Variables in Interview File

outcome2_05 OUTCOME 2 version 2 using Oct 1 code updates from NCHS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Outcome not achieved	19909	48.9	51.2	51.2
	1 Outcome successfully achieved	18977	46.6	48.8	100.0
	Total	38886	95.5	100.0	
Missing	99 DK/Ref to any	1837	4.5		
Total		40723	100.0		

outcome3_05 OUTCOME #3: CSHCN will have adequate private and public insurance

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Did not meet outcome	14849	36.5	36.5	36.5
	1 Met outcome	25212	61.9	61.9	98.4
	99 DK/REF/MISSING on any	662	1.6	1.6	100.0
	Total	40723	100.0	100.0	

outcome4_05 OUTCOME #4: Children are screened early and continously for special health needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Outcome not achieved	13985	34.3	34.3	34.3
	1 Outcome successfully achieved	26506	65.1	65.1	99.4
	99 DK/REF/MISSING to one or both	232	.6	.6	100.0
	Total	40723	100.0	100.0	

outcome5_05 OUTCOME #5: Community-based service systems will be organized so families can use them easily

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Outcome not achieved	4418	10.8	10.8	10.8
	1 Outcome successfully achieved	35926	88.2	88.2	99.1
	99 DK/REF	379	.9	.9	100.0
	Total	40723	100.0	100.0	

outcome6_05 Met Outcome #6: Transition to adulthood -- ages 12 -17 only

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Did not meet outcome	9413	23.1	23.1	23.1
	1 Met outcome	7476	18.4	18.4	41.5
	2 Legitimate skip b/c <12 yrs old	22525	55.3	55.3	96.8
	99 DK/REF/MISSING on both	1309	3.2	3.2	100.0
	Total	40723	100.0	100.0	

MCHB SYSTEM OF CARE SUMMARY VARIABLES

syst1_3 CSHCN ages 0-11 meeting criteria for system of care -- 3 groups

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0-2 outcomes acheived	2384	5.9	68.8	68.8
	2 3-4 outcomes acheived	1026	2.5	29.6	98.5
	3 Outcomes achieved in all 5 areas	53	.1	1.5	100.0
	Total	3463	8.5	100.0	
Missing	System	37260	91.5		
Total		40723	100.0		

syst2_4 CSHCN ages 12-17 meeting criteria for system of care -- 3 groups

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0-2 outcomes achieved	1728	4.2	64.2	64.2
	2 3-4 outcomes achieved	861	2.1	32.0	96.2
	3 5 outcomes achieved	85	.2	3.2	99.4
	4 Outcomes achieved in all 6 areas	16	.0	.6	100.0
	Total	2690	6.6	100.0	
Missing	System	38033	93.4		
Total		40723	100.0		

APPENDIX A

Unweighted Frequency Tables: Codebook Variables in Interview File

CONDITIONS & FUNCTIONAL DIFFICULTIES

cond_5 Number of health conditions reported (4 categories)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No conditions reported	3746	9.2	9.2	9.2
	1 1 cond reported	14264	35.0	35.0	44.2
	2 2 conds reported	13187	32.4	32.4	76.6
	3 3 conds reported	5389	13.2	13.2	89.8
	4 4 or more conds reported	4137	10.2	10.2	100.0
	Total	40723	100.0	100.0	

diff_5 Number of functional difficulties reported (4 categories) -- using most restrictive criteria for Vision or Hearing

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No difficulties reported	6687	16.4	16.4	16.4
	1 1 difficulty reported	12615	31.0	31.0	47.4
	2 2 difficulties reported	6280	15.4	15.4	62.8
	3 3 difficulties reported	4348	10.7	10.7	73.5
	4 4 or more difficulties reported	10793	26.5	26.5	100.0
	Total	40723	100.0	100.0	

emot_ICF Any other emotional or behavioral difficulty (S3q07 - S3q11)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No emotional or behavioral difficulties	23498	57.7	59.1	59.1
	1 One or more emotional or behavioral difficulties	16295	40.0	40.9	100.0
	Total	39793	97.7	100.0	
Missing	99 Less than 18 mos old/not asked	930	2.3		
Total		40723	100.0		

APPENDIX A

Unweighted Frequency Tables: Codebook Variables in Interview File

activity_ICF Any activity or participation difficulty (S3q07 - S3q11)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No activity or participation difficulties	21084	51.8	51.8	51.8
	1 One or more activity/participation difficulties	19639	48.2	48.2	100.0
	Total	40723	100.0	100.0	

body_ICF Any bodily difficulty (S3q01b - S3q06)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No bodily function difficulties	18113	44.5	44.5	44.5
	1 One or more bodily func difficulties	22610	55.5	55.5	100.0
	Total	40723	100.0	100.0	

STRATIFICATION VARIABLES

SEX Sex of child

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Male	24150	59.3	59.4	59.4
	2 Female	16498	40.5	40.6	100.0
	Total	40648	99.8	100.0	
Missing	6	4	.0		
	7	68	.2		
	System	3	.0		
	Total	75	.2		
Total		40723	100.0		

age_3 Children

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0-5 yrs old	7416	18.2	18.2	18.2
	2 6-11 yrs old	15109	37.1	37.1	55.3
	3 12-17 yrs old	18198	44.7	44.7	100.0
	Total	40723	100.0	100.0	

APPENDIX A

Unweighted Frequency Tables: Codebook Variables in Interview File

race_5 Mutually exclusive race & Hisp ethnicity for screened children

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Hispanic	4016	9.9	9.9	9.9
	2 White, non-Hisp	29119	71.5	71.8	81.8
	3 Black, non-Hisp	4204	10.3	10.4	92.1
	4 Multi racial, non-Hisp	1652	4.1	4.1	96.2
	5 Other (including Asian), non-Hisp	1541	3.8	3.8	100.0
	Total	40532	99.5	100.0	
Missing	6 DK / Ref to both hisp & race or race only	188	.5		
	7 System missing	3	.0		
	Total	191	.5		
Total		40723	100.0		

def_4 Def_4 re-grouped screener qualifying categories

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 CSHCN qualifying on Func (only or w/ any other)	8719	21.4	21.4	21.4
	2 CSHCN qualifying on Rx meds ONLY	17730	43.5	43.5	64.9
	3 CSHCN qualifying on Service use ONLY	5589	13.7	13.7	78.7
	4 CSHCN qualifying on Rx meds AND service use	8685	21.3	21.3	100.0
	Total	40723	100.0	100.0	

povlev_4 Version 1: Child-level income status of child's HH -- 4 categories

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 0% - 99% FPL	5577	13.7	15.1	15.1
	2.00 100% - 199% FPL	7771	19.1	21.0	36.0
	3.00 200% - 399% FPL	12507	30.7	33.8	69.8
	4.00 400% FPL or greater	11177	27.4	30.2	100.0
	Total	37032	90.9	100.0	
Missing	999.00 Income not reported	3691	9.1		
Total		40723	100.0		

Note: DRC results and DRC Indicator dataset variable “povlev_4” use imputed values. See Appendix C for more information.

APPENDIX A

Unweighted Frequency Tables: Codebook Variables in Interview File

pov_schip Version 2: SCHIP relevant child level income status of child's HH -- 4 categories

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 0% - 199% FPL	13348	32.8	36.0	36.0
	2.00 200% - 299% FPL	6670	16.4	18.0	54.1
	3.00 300% - 399% FPL	5837	14.3	15.8	69.8
	4.00 400% FPL or greater	11177	27.4	30.2	100.0
	Total	37032	90.9	100.0	
Missing	999.00 Income not reported	3691	9.1		
Total		40723	100.0		

Note: DRC results and DRC Indicator dataset variable "pov_schip" use imputed values. See Appendix C for more information.

UNINS INSURANCE STATUS AT TIME OF SURVEY -- with 89 cases set to SYSMISS based on NCHS NOV 8 revisions

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Insured at time of survey	39197	96.3	96.5	96.5
	1 Not insured at time of survey	1437	3.5	3.5	100.0
	Total	40634	99.8	100.0	
Missing	System	89	.2		
Total		40723	100.0		

UNINS_YR PAST 12 MONTHS, CHILD EVER NOT INSURED. DERIVED

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Insured entire year	37168	91.3	91.6	91.6
	1 NOT insured at some point during year	3395	8.3	8.4	100.0
	Total	40563	99.6	100.0	
Missing	6 DK	70	.2		
	7 Refused	1	.0		
	System	89	.2		
	Total	160	.4		
Total		40723	100.0		

APPENDIX A

Unweighted Frequency Tables: Codebook Variables in Interview File

ins_type Type of Insurance Coverage

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Private only	25519	62.7	64.3	64.3
	2 Public only	9779	24.0	24.7	89.0
	3 Both Public and Private	2932	7.2	7.4	96.4
	5 Uninsured	1437	3.5	3.6	100.0
	Total	39667	97.4	100.0	
Missing	4 Other comprehensive ins	967	2.4		
	System	89	.2		
	Total	1056	2.6		
Total		40723	100.0		

FAMSTRUCT FAMILY STRUCTURE TYPE -- for CSHCN

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 CSHCN w/ 2 biological or adopted parents in HH	22512	55.3	57.6	57.6
	2 CSHCN w/ 2 parent stepfamilies	4151	10.2	10.6	68.2
	3 CSHCN w/ mother only family/no father figure in HH	10258	25.2	26.3	94.5
	4 Other family structure -- including grandparents, foster, etc.	2154	5.3	5.5	100.0
	Total	39075	96.0	100.0	
Missing	System	1648	4.0		
Total		40723	100.0		

hisp_3 Hispanic ethnicity parsed by child

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Hisp child / primary HH lang is SPANISH lang	1057	2.6	2.6	2.6
	2 Hisp child / primary HH lang is ENGLISH	2943	7.2	7.3	9.9
	3 Non-Hispanic children	36516	89.7	90.1	100.0
	Total	40516	99.5	100.0	
Missing	99 DK/REF/Missing	207	.5		
Total		40723	100.0		

Appendix B: Unweighted Frequency Tables for Income Variables in the Household & Screener Files

Screener File Frequencies for Demographic Variables (CSHCN only)

age_3 Children's age in 3 categories

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0-5 yrs old	10138	18.2	18.2	18.2
	2 6-11 yrs old	21176	38.0	38.0	56.2
	3 12-17 yrs old	24453	43.8	43.8	100.0
	Total	55767	100.0	100.0	

SEX SEX OF TARGET CHILD

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 MALE	32826	58.9	59.0	59.0
	2 FEMALE	22823	40.9	41.0	100.0
	Total	55649	99.8	100.0	
Missing	6 DON'T KNOW	7	.0		
	7 REFUSED	102	.2		
	System	9	.0		
	Total	118	.2		
Total		55767	100.0		

HISPANIC CHILD IS OF HISPANIC ORGIN / ETHNICITY

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	47623	85.4	89.8	89.8
	1 YES	5402	9.7	10.2	100.0
	Total	53025	95.1	100.0	
Missing	6 DON'T KNOW	139	.2		
	7 REFUSED	138	.2		
	System	2465	4.4		
	Total	2742	4.9		
Total		55767	100.0		

RACER RACE re-coded to collapse OTHER categories

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 White only	39763	71.3	75.0	75.0
	2 Black only	6133	11.0	11.6	86.5
	3 Multi race only	2405	4.3	4.5	91.1
	4 Other only	4362	7.8	8.2	99.3
	96 DK	137	.2	.3	99.6
	97 Refused	233	.4	.4	100.0
	Total	53033	95.1	100.0	
Missing	System	2734	4.9		
Total		55767	100.0		

Screener File Frequencies for Special Needs Type (def_4) (CSHCN only)

CSHCN1 CHILD CURRENTLY NEEDS PRESCRIPTION MEDS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	10747	19.3	19.3	19.3
	1 YES	44990	80.7	80.7	99.9
	6 DON'T KNOW	11	.0	.0	100.0
	7 REFUSED	19	.0	.0	100.0
	Total	55767	100.0	100.0	

CSHCN1_A PRESC MEDS NEEDED DUE TO MED/BEHAV/OTH HLTH

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	588	1.1	1.3	1.3
	1 YES	44353	79.5	98.6	99.9
	6 DON'T KNOW	38	.1	.1	100.0
	7 REFUSED	11	.0	.0	100.0
	Total	44990	80.7	100.0	
Missing	System	10777	19.3		
Total		55767	100.0		

CSHCN1_B CONDITION HAS LASTED/IS EXPECTED TO LAST 12 MOS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	314	.6	.7	.7
	1 YES	43812	78.6	98.8	99.5
	6 DON'T KNOW	226	.4	.5	100.0
	7 REFUSED	1	.0	.0	100.0
	Total	44353	79.5	100.0	
Missing	System	11414	20.5		
Total		55767	100.0		

CSHCN2 CHILD NEEDS MORE MED CARE/MENTAL HLTH/EDUC THAN PEERS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	30714	55.1	55.1	55.1
	1 YES	24105	43.2	43.2	98.3
	6 DON'T KNOW	927	1.7	1.7	100.0
	7 REFUSED	21	.0	.0	100.0
	Total	55767	100.0	100.0	

APPENDIX B

Unweighted Frequency Tables: Income Variables in Household & Screener Files

CSHCN2_A MORE CARE NEEDED DUE TO MED/BEHAV/OTH HLTH

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	1862	3.3	7.7	7.7
	1 YES	21973	39.4	91.2	98.9
	6 DON'T KNOW	265	.5	1.1	100.0
	7 REFUSED	5	.0	.0	100.0
	Total	24105	43.2	100.0	
Missing	System	31662	56.8		
Total		55767	100.0		

CSHCN2_B CONDITION HAS LASTED/IS EXPECTED TO LAST 12 MOS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	163	.3	.7	.7
	1 YES	21635	38.8	98.5	99.2
	6 DON'T KNOW	173	.3	.8	100.0
	7 REFUSED	2	.0	.0	100.0
	Total	21973	39.4	100.0	
Missing	System	33794	60.6		
Total		55767	100.0		

CSHCN3 CHILD LIMITED IN ABILITY TO DO THINGS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	42848	76.8	76.8	76.8
	1 YES	12725	22.8	22.8	99.7
	6 DON'T KNOW	178	.3	.3	100.0
	7 REFUSED	16	.0	.0	100.0
	Total	55767	100.0	100.0	

CSHCN3_A LIMITED ABILITY DUE TO MED/BEHAV/OTH HLTH COND

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	750	1.3	5.9	5.9
	1 YES	11822	21.2	92.9	98.8
	6 DON'T KNOW	151	.3	1.2	100.0
	7 REFUSED	2	.0	.0	100.0
	Total	12725	22.8	100.0	
Missing	System	43042	77.2		
Total		55767	100.0		

CSHCN3_B CONDITION HAS LASTED/IS EXPECTED TO LAST 12 MOS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	62	.1	.5	.5
	1 YES	11708	21.0	99.0	99.6
	6 DON'T KNOW	52	.1	.4	100.0
	Total	11822	21.2	100.0	
Missing	System	43945	78.8		
Total		55767	100.0		

CSHCN4 CHILD NEEDS PHYSICAL/OCCUPATIONAL/SPEECH THERAPY

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	43937	78.8	78.8	78.8
	1 YES	11768	21.1	21.1	99.9
	6 DON'T KNOW	54	.1	.1	100.0
	7 REFUSED	8	.0	.0	100.0
	Total	55767	100.0	100.0	

CSHCN4_A THERAPY NEEDED DUE TO MED/BEHAV/OTH HLTH COND

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	1529	2.7	13.0	13.0
	1 YES	9994	17.9	84.9	97.9
	6 DON'T KNOW	242	.4	2.1	100.0
	7 REFUSED	3	.0	.0	100.0
	Total	11768	21.1	100.0	
Missing	System	43999	78.9		
Total		55767	100.0		

CSHCN4_B CONDITION HAS LASTED/IS EXPECTED TO LAST 12 MOS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	192	.3	1.9	1.9
	1 YES	9703	17.4	97.1	99.0
	6 DON'T KNOW	97	.2	1.0	100.0
	7 REFUSED	2	.0	.0	100.0
	Total	9994	17.9	100.0	
Missing	System	45773	82.1		
Total		55767	100.0		

CSHCN5 CHILD HAS EMOTIONAL/DEVELOPMENTAL/BEHAVIORAL PROBLEM

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	38440	68.9	68.9	68.9
	1 YES	17072	30.6	30.6	99.5
	6 DON'T KNOW	197	.4	.4	99.9
	7 REFUSED	58	.1	.1	100.0
	Total	55767	100.0	100.0	

CSHCN5_A EMOTIONAL/DEVELOPMENTAL/BEHAVIORAL LASTED >12 MOS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO	435	.8	2.5	2.5
	1 YES	16351	29.3	95.8	98.3
	6 DON'T KNOW	283	.5	1.7	100.0
	7 REFUSED	3	.0	.0	100.0
	Total	17072	30.6	100.0	
Missing	System	38695	69.4		
Total		55767	100.0		

Screener File Frequencies for Income Level (CSHCN only)

povlev_4 Version 1: Child-level income status of child's HH -- 4 categories

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0% - 99% FPL	9422	16.9	16.9	16.9
	2 100% - 199% FPL	12277	22.0	22.0	38.9
	3 200% - 399% FPL	17932	32.2	32.2	71.1
	4 400% FPL or greater	16136	28.9	28.9	100.0
	Total	55767	100.0	100.0	

pov_schip Version 2: SCHIP relevant child level income status of child's HH -- 4 categories

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0% - 199% FPL	21699	38.9	38.9	38.9
	2 200% - 299% FPL	9861	17.7	17.7	56.6
	3 300% - 399% FPL	8071	14.5	14.5	71.1
	4 400% FPL or greater	16136	28.9	28.9	100.0
	Total	55767	100.0	100.0	

Household File Frequencies for Income Level (CSHCN households only)

OVLEVEL Non-Imputed POVERTY LEVEL OF HOUSEHOLD BASED ON DHHS GUIDELINES

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 BELOW 50% POVERTY LEVEL (AA)	1958	4.4	5.3	5.3
	2 BELOW 100% POVERTY LEVEL (A)	3619	8.1	9.8	15.1
	3 BELOW 133% POVERTY LEVEL (B)	2582	5.8	7.0	22.0
	4 BELOW 150% POVERTY LEVEL (C)	1284	2.9	3.5	25.5
	5 BELOW 185% POVERTY LEVEL (D)	2648	5.9	7.2	32.7
	6 BELOW 200% POVERTY LEVEL (E)	1257	2.8	3.4	36.0
	7 BELOW 300% POVERTY LEVEL (F)	6670	14.9	18.0	54.1
	8 BELOW 400% POVERTY LEVEL (G)	5837	13.0	15.8	69.8
	9 AT OR ABOVE 400% POVERTY LEVEL	11177	25.0	30.2	100.0
	Total	37032	82.7	100.0	
Missing	System	7763	17.3		
Total		44795	100.0		

Household File Frequencies for Hispanic Spanish Language HH (CSHCN households only)

C2Q05R PRIMARY LANGUAGE SPOKEN IN HOUSEHOLD RECODED

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 English	40996	91.5	96.5	96.5
	2 Any other language	1439	3.2	3.4	99.9
	6 DK	19	.0	.0	100.0
	7 Refused	15	.0	.0	100.0
	Total	42469	94.8	100.0	
Missing	System	2326	5.2		
Total		44795	100.0		

Appendix C: Methods Notes on Imputation of Income Level

APPENDIX C

Methods notes on Imputation of Income Level

METHODS NOTES: Single imputation household income variables (POVLEV4_IMP; SCHIP_IMP)

The 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN) provides a rich source of data for studying the relationships between income and health and for monitoring health and health care for CSHCN at different income levels. However, as is common for most household interview surveys, nonresponse rates tend to be high for the question on total combined household income for the previous calendar year. Answers to this question, along with answers to a question about the number of people living in the household, are used to create an index of income relative to the Department of Health and Human Services Federal Poverty Guidelines (FPL). If data for either of these two components were missing, refused, or had a "don't know" response, the household poverty status indicator was assigned a missing value code in the publicly released datasets.

As is common for most household interview surveys, the 2005/2006 NS-CSHCN nonresponse rates tend to be high for the question on total combined household income for the previous calendar year. Answers to this question, along with answers to a question about the number of people living in the household, are used to create an index of income relative to the Department of Health and Human Services Federal Poverty Guidelines (FPL). If data for either of these two components were missing, refused, or had a "don't know" response, the household poverty status indicator was assigned a missing value code in the publicly released datasets. In 2005-2006 NS-CSHCN Interview file, about 9% of the CSHCN sample had missing values for Household Income variable (POVLEVEL).

Imputation is one commonly used method for handling nonresponse data in a survey – especially when the proportion of missing, refused, or "don't know" responses exceed 5% or more of the total. Imputation accomplishes three things: 1) it adjusts for observed differences between item nonrespondents and item respondents; 2) imputation provides in a completed data set, so that the data can be analyzed using standard software packages without discarding any observed values; and 3) imputation using a standardized approach addresses the nonresponse problem in the same way so that analyses will be consistent across users.

The National Center for Health Statistics website offers a downloadable file with multiple imputed income values for the 2005/2006 NS-CSHCN. Interested users can access this file and accompanying instructions free of charge at: http://www.cdc.gov/nchs/about/major/slaits/imputed_data.htm

The multiple imputed income file contains each of the five imputations drawn from a valid distribution based on a regression model. Analysts with access to software able to accommodate multiple imputation analyses will want to use the complete file. Another option is to use only a single imputation from the multiple imputation files. This is the method that was used to generate the POVLEV4_IMP and SCHIP_IMP variables included in the 2005/2006 NS-CSHCN Indicator Dataset. Using single imputation income tends to underestimate standard errors because it doesn't take into account the inherent uncertainty resulting from lack of knowledge about the true (unobserved) value as happens when multiple imputed values are used. At the same time, using a single imputed income is superior to excluding the cases with missing income data from analyses.

For more information about downloadable multiple imputation income files and a detailed report describing the options for using these data, go to: http://www.cdc.gov/nchs/about/major/slaits/imputed_data.htm

Appendix D: Comparison of 2001 & 2005-2006 Indicators & Outcome Measures