

2001 National Survey of Children with Special Health Care Needs

INDICATOR AND OUTCOME MEASURES
SPSS CODEBOOK

Version 1.0, January 2007

Child and Adolescent Health Measurement Initiative (CAHMI), *2001 National Survey of Children with Special Health Care Needs SPSS Codebook*, National Data Resource Center on Child and Adolescent Health, www.childhealthdata.org.



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Acknowledgements

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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.

Purpose of the 2001 NS-CSHCN SPSS Codebook



This codebook contains SPSS program statements that can be applied to the public use data files for the 2001 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 2001 NS-CSHCN for the DRC. Its purpose is to expedite research by helping to standardize and improve the comparability of information derived from the 2001 NS-CSHCN.

The DRC maintains a complete 2001 NS-CSHCN indicator data set, available 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 National Data Resource Center for Child and Adolescent Health

The National 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 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 2001 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 2001 NS-CSHCN sample was achieved by screening 372,174 children representing 196,888 households nationwide, using the CSHCN Screener. The CSHCN Screener (1) is a survey tool specifically developed and validated 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 to each of the two follow-up questions is considered to have special health care needs.

In-depth interviews were completed for a total of 38,866 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 CSHCN ages 0–17 years in each state.

The 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.

Data from the 2001 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 available online at: www.cdc.gov/nchs/about/major/slaits/cshcn.htm. Additional information and results from the NS-CSHCN are available in the DRC at: www.childhealthdata.org.

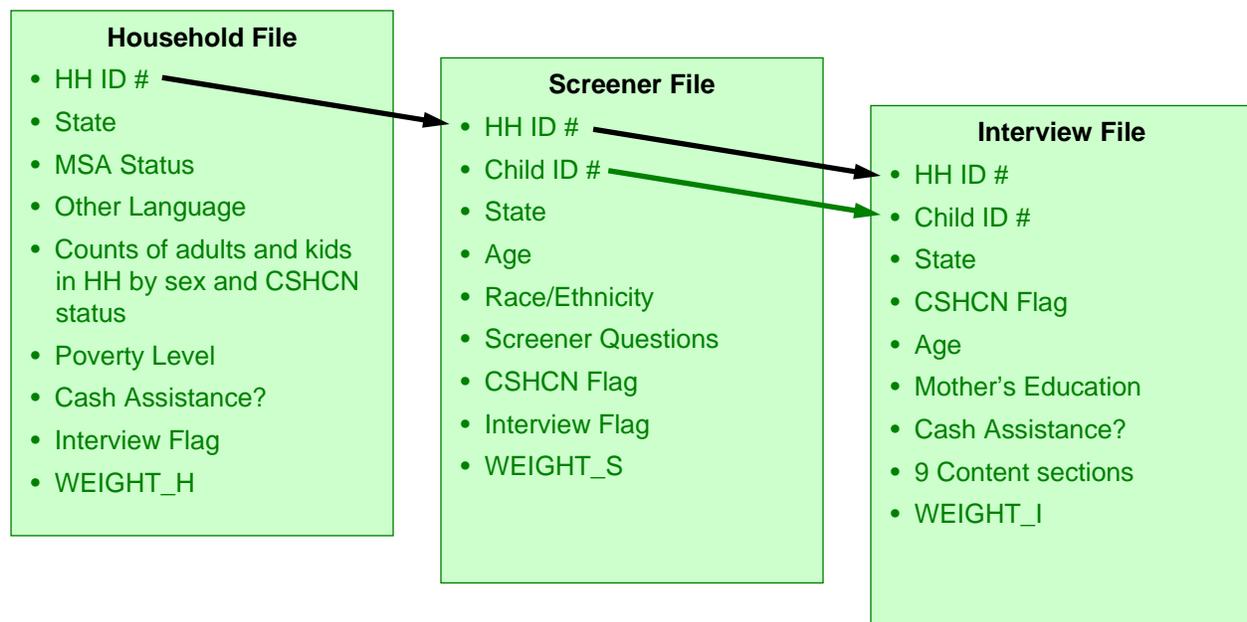
Linking the NS-CSHCN Data Files

Three of the four public use data files for the 2001 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	196,888 randomly selected U.S. households with at least one child or youth ages 0–17	IDNUMR	WEIGHT_H
Screener file	372,174 children and youth ages 0–17 living in the randomly selected households with children	IDNUMXR	WEIGHT_S
Interview file	38,866 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

The fourth file, Insurance, includes insurance data from a random sample of 215,162 randomly selected children without special health care needs. The four files reflect all data collected during the survey field period with the exception of variables or records suppressed to protect the confidentiality of the respondents.

The variables documented in this codebook are all based on the 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.



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 Regarding the 2001 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 2000 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 available. 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 NS-CSHCN public use data set is a variable for Metropolitan Statistical Area (MSA) status, located in the Household file. MSA status information is available for the 35 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 available 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: 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 all of 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, 2001 (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), "2001 NS-CSHCN Indicator and Outcome Variables SPSS Codebook, Version 1, 2007," National Data Resource Center on 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 Pediatrics*. 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.
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 2001." Rockville, Maryland: U.S. Department of Health and Human Services, 2004.
4. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, Division of Health Interview Statistics, Special Population 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, 2001." April 2003.

INDICATOR #1	
Activity Limitations: Percent of CSHCN whose health conditions consistently and often greatly affect their daily activities	
Survey Items Used	C3Q02 and C3Q03
Numerator	Daily activities consistently affected, often a great deal
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose health conditions consistently and often greatly affect their daily lives.
Notes for Data-Users	
<p>This indicator combines the concepts of “how often” and “how much” CSHCN’s conditions affect their daily activities. For example, although a child may have asthma attacks only rarely, when such attacks do 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.</p>	
SPSS Code and Annotation	
<pre> COMPUTE indic_1 = 99. IF (c3q02 = 1) indic_1 = 1. IF (c3q02 = 2) indic_1 = 2. IF (c3q02 = 3) indic_1 = 3. IF (c3q02 = 4) indic_1 = 3. IF (c3q03 = 1) indic_1 = 3. EXECUTE. VARIABLE LABEL indic_1 "INDICATOR #1: % of CSHCN whose health conditions consistently and often greatly affect their daily activities". VALUE LABEL indic_1 1 "Daily activities never affected" 2 "Daily activities moderately affected some of time" 3 "Daily activities consistently affected, often a great deal" 99 "DK, Ref or Missing to both items". MISSING VALUES indic_1 (99). FORMATS indic_1 (f2.0). </pre>	

INDICATOR #2		Missed School Days: Percent of CSHCN with 11 or more days of school absences due to illness
Survey Items Used	C3Q14	
Numerator	Missed 11 or more days of school due to illness	
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		
This question was asked only for school-aged CSHCN.		
SPSS Code and Annotation		
<pre> COMPUTE indic_2 = 99. IF (c3q14r = 0) indic_2 = 1. IF (c3q14r >= 1 and c3q14r <=3) indic_2 = 1. IF (c3q14r >=4 and c3q14r <= 6) indic_2 = 2. IF (c3q14r >= 7 and c3q14r <= 10) indic_2 = 3. IF (c3q14r = 11) indic_2 = 4. EXECUTE. VARIABLE LABEL indic_2 "INDICATOR #2: % of CSHCN ages 5-17 with 11 or more days of school absences due to illness". VALUE LABEL indic_2 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 indic_2 (99). FORMATS indic_2 (f2.0). </pre>		

INDICATOR #3	Inconsistently Insured: Percent of CSHCN without insurance at some point during the past year
Survey Items Used	UNINS_YR
Numerator	Not insured at some point during the 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	
<p>Indicator #3 is based on the variable “UNINS_YR” which was derived by the NCHS from responses to the numerous questions about health insurance coverage in Section 7 of the NS-CSHCN. This variable is included in the publicly released Interview File from the survey. For more information on how insurance status was defined by the NCHS for purposes of the survey, go to http://www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf.</p>	
SPSS Code and Annotation	
<p>**NOTE: Uses derived variable UNINS_YR (included in public release INTERVIEW file)</p> <p>COMPUTE indic_3 = unins_yr. EXECUTE.</p> <p>VARIABLE LABEL indic_3 “INDICATOR #3: % of CSHCN without insurance at some point during the past year”.</p> <p>VALUE LABELS indic_3 0 'Insured entire year' 1 'NOT insured at some point during year'.</p> <p>FORMATS indic_3 (f2.0).</p>	

INDICATOR #4	Currently Uninsured: Percent of CSHCN uninsured at the time of the survey
Survey Items Used	UNINS
Numerator	Not currently insured
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	
<p>Indicator #4 is based on the variable “UNINS” which was derived by the National Center for Health Statistics (NCHS) from responses to the numerous health insurance coverage questions in Section 7 of the NS-CSHCN. This variable is included in the publicly released Interview File from the survey. For more information on how insurance status was defined by the NCHS for purposes of the survey, go to http://www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf.</p>	
SPSS Code and Annotation	
<p>** NOTE: Uses derived variable UNINS (included in public release INTERVIEW file)</p> <p>COMPUTE indic_4 = unins. EXECUTE.</p> <p>VARIABLE LABEL indic_4 "INDICATOR #4: % of CSHCN uninsured at the time of the survey". VALUE LABEL indic_4 0 'Currently insured' 1 'Currently NOT insured'. FORMATS indic_4 (f2.0).</p>	

INDICATOR #5		Adequacy of Current Insurance Coverage: Percent of currently insured CSHCN with coverage that is not adequate
Survey Items Used	C8Q01_a, C8Q01_b, and C8Q01_c	
Numerator	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		
<p>“Adequate insurance” is defined as coverage which meets these three criteria:</p> <ul style="list-style-type: none"> • offers benefits or covers services that meet CSHCN’s needs AND • has a reasonable level of uncovered costs AND • allows CSHCN to see the health care providers they need. <p>Responses of “Usually or Always” to all 3 of the survey questions about adequacy of CSHCN’s current health insurance (C8Q01_a – C8Q01_c) are necessary to qualify as having adequate health insurance.</p>		
SPSS Code and Annotation		
<p>**STEP 1: Regroup responses to the three insurance adequacy items used to construct Indicator #5</p> <p>MISSING VALUES c8q01_b ().</p> <p>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.</p> <p>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'. MISSING VALUES ins_unmetneeds (99).</p> <p>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 = 6) ins_reaschg = 2. EXECUTE.</p> <p>VARIABLE LABEL ins_reaschg “Non-covered insurance charges reasonable” VALUE LABEL ins_reaschg 0 'Never/sometimes'</p>		

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1 'Usually/always'
2 'DK'
99 'Ref/Missing/Uninsured'.
MISSING VALUES ins_reaschg (99).

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'.
MISSING VALUES ins_providers (99).

** STEP 2: Construct Indicator #5 from regrouped item variables

COMPUTE indic_5 = 99.
IF (( ins_unmetneeds=1) and (ins_reaschg = 1) and (ins_providers = 1)) indic_5 = 0.
IF (ins_reaschg = 2) and ((ins_unmetneeds=1) and (ins_providers = 1)) indic_5 = 0.
IF (ins_reaschg = 2) and ((ins_unmetneeds=0) or (ins_providers = 0)) indic_5 = 1.
IF (( ins_unmetneeds=0) or (ins_reaschg = 0) or (ins_providers = 0)) indic_5 = 1.
EXECUTE.

VARIABLE LABEL indic_5 "INDICATOR #5: Currently insured CSHCN whose insurance is not
adequate".
VALUE LABEL indic_5
0 'Current insurance is adequate'
1 'Current insurance NOT adequate'
99 "DK or Ref to >1 item or Uninsured".
MISSING VALUES indic_5 (99).
FORMATS indic_5 (f2.0).

```

INDICATOR #6	Unmet Needs for Care: Percent of CSHCN with one or more unmet needs for specific health care services
Survey Items Used	C4Q05_01a – C4Q5_14a
Numerator	One or more unmet needs for specific health care services
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	
<p>The survey asks if CSHCN needed any of 14 different health care services during the past 12 months. Respondents who indicate that the child needed a specific health care service are asked a follow up question about whether the child received all the care that he/she needed. Each response of “No” to any of the follow up questions about getting needed care is counted as an “unmet need” for Indicator #6.</p>	
SPSS Code and Annotation	
<p>** STEP 1: Create interim count and summary variables for each of the 14 different health care services items.</p>	
<pre> COMPUTE unmet1 =99. IF (c4q5_1a = 0) unmet1 = 1. IF (c4q5_2a = 0) unmet2 = 1. IF (c4q5_3a = 0) unmet3 = 1. IF (c4q5_4a = 0) unmet4 = 1. IF (c4q5_5a = 0) unmet5 = 1. IF (c4q5_6a = 0) unmet6 = 1. IF (c4q5_7ar = 0) unmet7 = 1. IF (c4q5_8a = 0) unmet8 = 1. IF (c4q5_9a = 0) unmet9 = 1. IF (c4q5_10a = 0) unmet10 = 1. IF (c4q5_11a = 0) unmet11 = 1. IF (c4q5_12a = 0) unmet12 = 1. IF (c4q5_13a = 0) unmet13 = 1. IF (c4q5_14a = 0) unmet14 = 1. EXECUTE. MISSING VALUES unmet1 (99). </pre>	
<pre> COMPUTE unmet_sum = SUM (unmet1, unmet2, unmet3, unmet4, unmet5, unmet6, unmet7, unmet8, unmet9, unmet10, unmet11, unmet12, unmet13, unmet14). EXECUTE. </pre>	
<pre> VARIABLE LABEL unmet_sum 'Number of unmet needs'. </pre>	

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

COMPUTE indic_6=99.

IF (unmet_sum >0) indic_6 = 1.

IF (sysmis (unmet_sum)) indic_6 = 0.

EXECUTE.

VARIABLE LABEL indic_6 "INDICATOR #6: % of CSHCN with 1 or more unmet needs for specific health care services".

VALUE LABEL indic_6

0 'No unmet needs for specific health care services'

1 '1 or more unmet needs for specific health care services'.

FORMATS indic_6 (f2.0).

INDICATOR #7b	
Unmet Needs for Family Support Services: Percent of CSHCN whose families needed but were not able to get all the respite care, genetic counseling and/or mental health services they needed	
Survey Items Used	C4Q06_01a – C4Q06_3a
Numerator	One or more unmet needs for family support services
Denominator	CSHCN ages 0–17 whose families needed one or more of three specific family support services
Description	Percent of CSHCN ages 0–17 whose families needed but were not able to get all the respite care, genetic counseling, and/or mental health services they needed.
Notes for Data-Users	
<p>The survey asks if the child’s family members needed respite care, genetic counseling, or mental health care/counseling related to caring for a special needs child. Respondents who indicated that a family member needed a specific family support service during the past 12 months were asked a follow up question about whether the family member received all the care that he/she needed. Each response of “No” to any of the follow up questions about getting needed family support services is counted as an “unmet need” for Indicator #7b.</p>	
SPSS Code and Annotation	
<p>**NOTE: Version #7b of this indicator has the same numerator as the chartbook indicator BUT includes in the denominator ONLY CSHCN whose families needed one or more of the family support services -- the chartbook version uses all CSHCN as the denominator, whether or not the families needed support services.</p> <p>** STEP 1: Create interim count and summary variables for each of the 3 different family support services items.</p> <pre> COMPUTE respite_2 = 99. IF (c4q06_01 = 0) respite_2 = 99. IF (c4q06_01 = 1 and c4q6_1a = 1) respite_2 = 0. IF (c4q06_01 = 1 and c4q6_1a = 0) 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. </pre>	

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IF (c4q06_02 = 0) gene_2 = 99.
IF (c4q06_02 = 1 and c4q6_2a = 1) gene_2 = 0.
IF (c4q06_02 = 1 and c4q6_2a = 0) 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_03 = 0) mhfam_2 = 99.
IF (c4q06_03 = 1 and c4q6_3a = 1) mhfam_2 = 0.
IF (c4q06_03 = 1 and c4q6_3a = 0) 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 (respice_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)

COMPUTE indic_7 = 99.
IF (fam_sum > 0) indic_7 = 1.
IF (fam_sum = 0) indic_7 = 0.

VARIABLE LABEL indic_7 "INDICATOR #7: % of CSHCN whose families needed specific support
services and had one or more unmet needs".
VALUE LABEL indic_7
0 'No unmet needs for specific family support services'
1 'One or more unmet needs for family support services'
99 'DK/Ref/Not needed'.
MISSING VALUES indic_7 (99).
FORMATS indic_7 (f2.0).

```

INDICATOR #8		Problems Obtaining Referral: Percent of CSHCN needing specialty care who had problems getting a referral	
Survey Items Used	C4Q05_02 and C4Q07		
Numerator	Problems getting referral for needed specialty care		
Denominator	CSHCN ages 0–17 years who needed care from a specialty doctor during the past 12 months		
Description	Among CSHCN ages 0–17 who needed specialty care during the past 12 months, percent who had problems getting a referral		
Notes for Data-Users			
<p>Only CSHCN who needed specialist care during the past 12 months are included in the denominator for Indicator #8 (C4Q05_02 = Yes). Nationally, about 51 percent of CSHCN needed care from a specialty doctor during the past 12 months. Responses of “A big problem” or “A small problem” to question C4Q07 are counted as having problems getting a referral for needed specialty care.</p>			
SPSS Code and Annotation			
<pre> COMPUTE indic_8 = 99. IF (c4q05_02 = 1 and c4q07 = 1) indic_8 = 1. IF (c4q05_02 = 1 and c4q07 = 2) indic_8 = 1. IF (c4q05_02 = 1 and c4q07 = 3) indic_8 = 0. EXECUTE. VARIABLE LABELS indic_8 "INDICATOR #8: % of CSHCN needing specialty care who had difficulties getting a referral". VALUE LABELS indic_8 0 'No problem getting referral for needed specialty care' 1 'Problem getting referral for needed specialty care' 99 'DK/Ref/Not needed'. MISSING VALUES indic_8 (99). FORMATS indic_8 (f2.0). </pre>			

INDICATOR #9		Usual Source for Sick Care: Percent of CSHCN without a usual source of care or who rely on the emergency room
Survey Items Used	C4Q0a and C4Q0b	
Numerator	No regular place or relies upon emergency room	
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		
<p>“CSHCN without a usual source of care” are defined as those who either do not have a place they USUALLY go when they are sick or need advice about health (C4Q0a = “There is no place” OR C4Q0b = “Doesn’t go to one place most often”) or those who USUALLY rely upon the emergency room for this type of care (C4Q0b = “Hospital emergency room”).</p>		
SPSS Code and Annotation		
<p>**STEP #1: Compute interim "usual source of care" variable</p> <pre> COMPUTE usualcare = 99. IF (c4q0b = 1) usualcare = 1. IF (c4q0b = 4) usualcare = 2. IF (c4q0b = 3) usualcare = 2. IF (c4q0b = 2) usualcare = 4. IF (c4q0b = 5 or c4q0b = 6 or c4q0b = 8) usualcare = 2. IF (c4q0b = 5 and c4q0b = 7) usualcare = 3. IF (c4q0a = 2) usualcare = 3. EXECUTE. VARIABLE LABEL usualcare 'Kind of place child usually goes for health care'. VALUE LABEL usualcare 1 "Doctor's office" 2 'Clinic, health center or other usual source of care' 3 'No usual source of care' 4 'Hospital emergency room' 99 'DK/Ref to all' . MISSING VALUES usualcare (99). </pre> <p>**STEP 2: Compute Indicator #9 from interim usual source of care variable (USUALCARE)</p> <pre> COMPUTE indic_9 = 99. IF (c4q0b = 1) indic_9 = 1. IF (c4q0b = 4) indic_9 = 2. IF (c4q0b = 3) indic_9 = 2. </pre>		

Indicators

IF (c4q0b = 2) indic_9 = 3.
IF (c4q0b = 5 or c4q0b = 6 or c4q0b = 8) indic_9 = 2.
IF (c4q0b = 5 and c4q0b = 7) indic_9 = 3.
IF (c4q0a = 2) indic_9 = 3.
EXECUTE.

VARIABLE LABEL indic_9 "INDICATOR #9: % of CSHCN without a usual source of care or who rely on the emergency room".

VALUE LABEL indic_9

1 "Doctor's 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 indic_9 (99).

FORMATS indic_9 (f2.0).

INDICATOR #10	Personal Doctor or Nurse: Percent of CSHCN without a personal doctor or nurse (PDN)
Survey Items Used	C4Q02a
Numerator	Does not have a PDN
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 who do not have a PDN.
Notes for Data-Users	
A personal doctor or nurse (PDN) is defined as a “health provider who knows the child best.” Question C4Q02a asks respondents if they have ONE person they think of as the child’s PDN.	
SPSS Code and Annotation	
<pre> COMPUTE indic_10 = c4q02a. EXECUTE. VARIABLE LABEL indic_10 "INDICATOR #10: % of CSHCN without a personal doctor or nurse". VALUE LABEL indic_10 0 'Do not have a personal dr or nurse' 1 'Yes, have a personal dr or nurse'. FORMATS indic_10 (f2.0). </pre>	

INDICATOR #11	Family Centered Care: Percent of CSHCN without family-centered care
Survey Items Used	C6Q01 – C6Q06
Numerator	Does not 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	
<p>“Family-Centered Care” is defined as doctors or other health providers who USUALLY or ALWAYS do each of the following:</p> <ul style="list-style-type: none"> • spend enough time with child (C6Q02), • listen carefully (C6Q03), • are sensitive to the families’ values and customs (C6Q04), • provide needed information about child’s health and health care to the family (C6Q05), and • help family feel like a partner in child’s care (C6Q06). <p>Responses of “Usually” or “Always” must be achieved on each of the five questions in order for a CSHCN to meet the criteria for consistently receiving family-centered care.</p> <p>CSHCN who did not visit a doctor during the past 12 months (C6Q01 = No) or CSHCN with one or more responses of “Don’t Know” or “Refused” on questions C6Q01 – C6Q06 are not included in the valid denominator for this indicator.</p> <p>The version of Family Centered Care composite used on the DRC Web site is the same one that is used in construction of the Medical Home index reported in the NCHS/MCHB report: <i>“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, 2001.”</i> It differs slightly from the version used in the HRSA chartbook because cases with responses of “Don’t Know” or “Refused” to number of doctor visits (C6Q01r) are excluded from the valid denominator.</p>	
SPSS Code and Annotation	
<p>**STEP 1: Compute family centered care interim variables to collapse "never/sometimes" and set DK or REF # of visits question (C6Q01r) to MISSING.</p> <p>MISSING VALUES c6q01r ().</p> <p>*COMPUTE fcc_a. IF (c6q02 = 1 or c6q02 = 2) fcc_a = 1. IF (c6q02 = 3) fcc_a = 2. IF (c6q02 = 4) fcc_a = 3. IF (c6q01r = 996 or c6q01r = 997) fcc_a = 4. EXECUTE.</p> <p>VARIABLE LABEL fcc_a 'How often drs spent enough time'. VALUE LABELS fcc_a</p>	

1 'Sometimes or never'

2 'Usually'

3 'Always'.

MISSING VALUES fcc_a (4).

*COMPUTE fcc_b.

IF (c6q03 = 1 or c6q03 = 2) fcc_b = 1.

IF (c6q03 = 3) fcc_b = 2.

IF (c6q03 = 4) fcc_b = 3.

IF (c6q01r = 996 or c6q01r = 997) fcc_b = 4.

EXECUTE.

VARIABLE LABEL fcc_b 'How often drs listened carefully'.

VALUE LABELS fcc_b

1 'Sometimes or never'

2 'Usually'

3 'Always'.

MISSING VALUES fcc_b (4).

*COMPUTE fcc_c.

IF (c6q04 = 1 or c6q04 = 2) fcc_c = 1.

IF (c6q04 = 3) fcc_c = 2.

IF (c6q04 = 4) fcc_c = 3.

IF (c6q01r = 996 or c6q01r = 997) fcc_c = 4.

EXECUTE.

VARIABLE LABEL fcc_c 'How often drs sensitive to families values/customs'.

VALUE LABELS fcc_c

1 'Sometimes or never'

2 'Usually'

3 'Always'.

MISSING VALUES fcc_c (4).

*COMPUTE fcc_d.

IF (c6q05 = 1 or c6q05 = 2) fcc_d = 1.

IF (c6q05 = 3) fcc_d = 2.

IF (c6q05 = 4) fcc_d = 3.

IF (c6q01r = 996 or c6q01r = 997) fcc_d = 4.

EXECUTE.

VARIABLE LABEL fcc_d 'How often got enough info from dr re: medical problems'.

VALUE LABELS fcc_d

1 'Sometimes or never'

2 'Usually'

3 'Always'.

MISSING VALUES fcc_d (4).

*COMPUTE fcc_e.

IF (c6q06 = 1 or c6q06 = 2) fcc_e = 1.

IF (c6q06 = 3) fcc_e = 2.

IF (c6q06 = 4) fcc_e = 3.

IF (c6q01r = 996 or c6q01r = 997) fcc_e = 4.

EXECUTE.

VARIABLE LABEL fcc_e 'How drs helped parents feel like partners'.

VALUE LABELS fcc_e

1 'Sometimes or never'

2 'Usually'

3 'Always'.

MISSING VALUES fcc_e (4).

**STEP 2: Compute Indicator #11 using interim composite component variables.

COMPUTE indic_11 = 99.

IF (fcc_a = 1 or fcc_b = 1 or fcc_c = 1 or fcc_d = 1 or fcc_e = 1) indic_11 = 0.

IF (fcc_a >=2 and fcc_b >=2 and fcc_c >=2 and fcc_d >=2 and fcc_e >=2) indic_11 = 1.

IF (sysmis (fcc_a)) or (sysmis (fcc_b)) or (sysmis (fcc_c)) or (sysmis (fcc_d)) or (sysmis (fcc_e))

indic_11 = 99.

EXECUTE.

VARIABLE LABEL indic_11 "INDICATOR #11: % of CSHCN without family-centered care".

VALUE LABEL indic_11

0 'CSHCN without family centered care'

1 'CSHCN with family centered care'

99 'DK/Ref to any item or # of dr visits'.

MISSING VALUE indic_11 (99).

FORMATS indic_11 (f2.0).

INDICATOR #12		Out-of-Pocket Expenses: Percent of CSHCN whose families pay more than \$1000 per year out-of-pocket for child's medical expenses
Survey Items Used	C9Q01 and C9Q01a	
Numerator	Family pays more than \$1000 per year	
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		
<p>“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 are not included.</p>		
SPSS Code and Annotation		
<pre> COMPUTE indic_12 = 99. IF (c9q01 = 3) indic_12 = 1. IF (c9q01 = 4) indic_12 = 1. IF (c9q01 = 2) indic_12 = 2. IF (c9q01_a = 3) indic_12 = 3. IF (c9q01_a <=2) indic_12 = 4. EXECUTE. VARIABLE LABEL indic_12 "INDICATOR #12: % of CSHCN whose families pay more than \$1000 per year out-of-pocket for child's medical expenses". VALUE LABEL indic_12 1 'Less than \$250' 2 '\$250 - \$500' 3 '\$501 - \$1000' 4 'More than \$1000' 99 'DK/Ref'. MISSING VALUES indic_12 (99). FORMATS indic_12 (f2.0). </pre>		

INDICATOR #13		Family Financial Burden: Percent of CSHCN whose families experienced financial problems due to child's health needs
Survey Items Used	C9Q05	
Numerator	Child's family had financial problems due to child's health needs	
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		
SPSS Code and Annotation		
<p>COMPUTE indic_13 = c9q05. EXECUTE.</p> <p>VARIABLE LABEL indic_13 "INDICATOR #13: % of CSHCN whose families experienced financial problems due to child's health needs". VALUE LABEL indic_13 0 "No financial problems due to child's health" 1 "Yes, financial problems". FORMATS indic_13 (f2.0).</p>		

INDICATOR #14	
Hours per Week Providing Care: Percent of CSHCN whose families spend 11 or more hours per week providing and/or coordinating health care for child	
Survey Items Used	C9Q02 – C9Q04
Numerator	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	
<p>Indicator #14 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 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, and providing transportation to appointments. Question C9Q04 defines “arranging or coordinating health care” as: making appointments, making sure that care providers are exchanging information, and following up child’s care needs.</p>	
SPSS Code and Annotation	
<p>** STEP 1: Create interim variables from number of hours spent items</p> <pre> RECODE c9q03r c9q04r (SYSMIS=0) (997=SYSMIS) (0 thru 12=Copy) INTO rc9q03r rc9q04r . EXECUTE . COMPUTE hrs_sum = rc9q03r + rc9q04r. EXECUTE. </pre> <p>**STEP 2: Compute Indicator #14 from interim number of hours variables (RC9Q03r; RC9Q04r)</p> <pre> COMPUTE indic_14 = 99. IF (hrs_sum = 0) indic_14 = 1. IF (hrs_sum >= 1 and hrs_sum <= 4) indic_14 = 2. IF (hrs_sum >= 5 and hrs_sum <= 10) indic_14 = 3. IF (hrs_sum >= 11) indic_14 = 4. EXECUTE. VARIABLE LABELS indic_14 "INDICATOR #14: % of CSHCN whose families spend 11 or more hours per week providing and/or coordinating health care for child". VALUE LABELS indic_14 1 'Less than 1 hour ' 2 '1 - 4 hours per week' </pre>	

Indicators

3 '5 - 10 hours per week'

4 '11 or more hours per week'

99 'DK/Ref'.

MISSING VALUES indic_14 (99).

FORMATS indic_14 (f2.0).

INDICATOR #15		Impact on Family Work Life: Percent of CSHCN whose family members cut back and/or stopped working because of child's health needs
Survey Items Used	C9Q06 and C9Q10	
Numerator	Family member(s) cut back and/or stopped working because of child's health needs	
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		
<p>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. The wording of questions C9Q06 and C9Q10 does not make it possible to distinguish which members of the family were affected and if the same or different family members cut back hours, stopped working, or both.</p>		
SPSS Code and Annotation		
<pre> COMPUTE indic_15 = 99 . IF (c9q06 >= 0 or c9q10 >= 0) indic_15 = 0. IF (c9q06 = 1) and (c9q10 = 1) indic_15 = 1. IF (c9q06 = 0) and (c9q10 = 1) indic_15 = 1. IF (c9q06 = 1) and (c9q10 = 0) indic_15 = 1. EXECUTE. VARIABLE LABELS indic_15 "INDICATOR #15: % of CSHCN whose family members cut back and/or stopped working because of child's health needs". VALUE LABELS indic_15 0 'Employment not affected' 1 'Family member cut back hours or stopped working' 99 'DK/Ref'. MISSING VALUES indic_15 (99). FORMATS indic_15 (f2.0). </pre>		

OUTCOME #1	Families of CSHCN will be partners in decision-making and are satisfied with the services they receive
Survey Items Used	C6Q01, C6Q0C, C6Q06
Numerator	CSHCN for whom Outcome #1 was achieved
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	
<p>Criteria for Outcome #1 are:</p> <ul style="list-style-type: none"> • Doctors usually or always make the family feel like a partner. • Family is very satisfied with services received. <p>Question C6Q0C was added to survey more than halfway through the data collection cycle. As a result, there are 23,293 (60%) cases with missing data because the question was not asked.</p> <p>Step 1 constructs an interim variable that identifies CSHCN with no doctor visits during past year and groups those with one or more doctor visits into those whose doctors never/sometimes vs. usually/always make family feel like partners in the child's care. Step 2 creates the outcome variable.</p>	
SPSS Code and Annotation	
<p>**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. Variable FCC_E used in the construction of this interim variable is from the code used to derived the family centered care key Indicator #11.</p> <pre> COMPUTE partner1 = 99. IF (c6q01r = 0) partner1 = 0. IF (fcc_e = 1) partner1 = 1. IF (fcc_e = 2 or fcc_e = 3) partner1 = 2. EXECUTE. VAR LABEL partner1 'Interim variable for constructing Outcome 1'. VALUE LABEL partner1 0 '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' 99 'DK/Ref or missing to one or both questions'. RECODE partner1 (0=0) (1=1) (2=2) (99=SYSMIS). EXECUTE. **STEP 2: Create OUTCOME_1 </pre>	

Outcomes

MISSING VALUES c6q01r c6q0c ().

COMPUTE outcome_1 = 99.

IF (partner1 = 0) and (c6q0c = 1) outcome_1 = 1.

IF (partner1 = 0) and (c6q0c >= 2) outcome_1 = 0.

IF (partner1 = 2) and (c6q0c = 1) outcome_1 = 1.

IF (partner1 = 1) or (c6q0c >= 2) outcome_1 = 0.

IF (partner1 = 1) or (c6q0c >= 2) outcome_1 = 0.

IF (c6q01r = 996 or c6q01r = 997) outcome_1 = 2.

IF (c6q0c = 6 or c6q0c = 7) outcome_1 = 2.

IF (SYSMIS (c6q0c)) outcome_1 = 2.

IF (SYSMIS (partner1)) outcome_1 = 2.

EXECUTE.

MISSING VALUE outcome_1 (2).

VAR LABEL outcome_1 "OUTCOME #1: Families of CSHCN will be partners in decision making and are satisfied with the services they receive".

VAL LABEL outcome_1

0 'Outcome not achieved'

1 'Outcome successfully achieved'.

FORMATS outcome_1 (f2.0).

OUTCOME #2		CSHCN will receive coordinated, ongoing, comprehensive care within a medical home
Survey Items Used	C4Q6X0aa, C4Q0a, C4Q0b, C4Q01, C4Q02, C4Q02a, C4Q05_02, C4Q06_0a, C4Q07, C5Q02, C5Q05, C5Q06, C6Q02, C6Q03, C6Q04, C6Q05, C6Q06	
Numerator	CSHCN meeting the scoring criteria for having a medical home	
Denominator	CSHCN ages 0–17 years	
Description	Percent of CSHCN who received coordinated ongoing comprehensive care within a medical home as defined by the American Academy of Pediatrics (AAP).	
Notes for Data-Users		
<p>Criteria for Outcome #2 are:</p> <ul style="list-style-type: none"> The child has usual source(s) for both sick care and preventive care. <p style="text-align: center;">AND</p> <ul style="list-style-type: none"> The child has a personal doctor or nurse. <p style="text-align: center;">AND</p> <ul style="list-style-type: none"> No problems obtaining referrals when needed. Effective care coordination is received when needed. Receives family-centered care from all child's doctors and other health care providers. The final medical home outcome score is derived from the five components constructed below. 		
SPSS Code and Annotation		
<p>**OUTCOME #2**</p> <p>**STEP 1: Construct "Care Coordination" component of medical home score</p> <pre> COMPUTE coorrcv = 99. IF (c4q6x0aa = 1) coorrcv = 1. IF (c4q6x0aa = 0) coorrcv = 0. IF (c4q06_0a = 0) coorrcv = 3. EXECUTE. VARIABLE LABEL coorrcv 'Received NEEDED professional care coordination'. VALUE LABEL coorrcv 0 'Needed, did not get all prof care coor' 1 'Needed & got all prof care coor' 3 'Did not need prof care coor' 99 'DK/Ref/Missing to one or both'. </pre>		

```

RECODE
  c5q05
  (6=6) (96=999) (SYSMIS=999) (1 thru 2=1) (3 thru 5=2) INTO r_c5q05 .
EXECUTE .

COMPUTE doccomm = 999.
IF (r_c5q05 = 1) doccomm = 1.
IF (r_c5q05 = 2) doccomm = 2.
IF (r_c5q05 = 6) doccomm = 3.
IF (c4q06_0a = 0) doccomm = 3.
IF (c5q02 = 1) doccomm = 3.
EXECUTE.
VAR LABEL doccomm "Level of communication btw child's doctors".
VALUE LABEL doccomm
  1 'Excellent/very good'
  2 'Good/Fair/Poor'
  3 'Legitimate skip'
  999 'DK/Ref/Missing'.

RECODE
  c5q06
  (6=6) (96=999) (97=999) (SYSMIS=999) (1 thru 2=1) (3 thru 5=2) INTO r_c5q06 .
EXECUTE .
VAR LABEL r_c5q06 'Recoded level of dr communication with other services'.
VALUE LABEL r_c5q06
  1 'Excellent/Very Good'
  2 'Good/Fair/Poor'
  6 'Communication not needed'
  999 'DK/Ref'.

COMPUTE othcom_1 = 999.
IF (r_c5q06 = 1) othcom_1 = 1.
IF (r_c5q06 = 2) othcom_1 = 2.
EXECUTE.
VALUE LABEL othcom_1
  1 'Excellent/Very Good'
  2 'Good/Fair/Poor'
  999 'Communication not needed or DK/Ref'.

MISSING VALUES c5q02 ().
EXECUTE.

COMPUTE othcom_2 = 999.
IF (c4q06_0a = 0) othcom_2 = 3.

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IF (c4q06_0a = 1) and (othcom_1 = 1) othcom_2 = 1.
IF (c4q06_0a = 1) and (othcom_1 = 2) othcom_2 = 2.
IF (c4q06_0a = 1) and (c5q02 = 1) othcom_2 = 3.
IF (c4q06_0a = 1) and (c5q02 >= 6) othcom_2 = 999.
EXECUTE.
VALUE LABEL othcom_2
1 'Ex/VG'
2 'G/F/P'
3 'Prof care coor NOT needed or needed/NEVER helped'
999 'DK/Ref'.

COMPUTE othcomm = 999.
IF (r_c5q06 = 1) and (othcom_2 = 1) othcomm = 1.
IF (r_c5q06 = 1) and (othcom_2 = 3) othcomm = 3.
IF (r_c5q06 = 2) and (othcom_2 = 2) othcomm = 2.
IF (r_c5q06 = 2) and (othcom_2 = 3) othcomm = 3.
IF (r_c5q06 = 6) and (othcom_2 =3) othcomm = 3.
IF (r_c5q06 = 6) and (othcom_2 =999) othcomm = 3.
IF (r_c5q06 = 999) and (othcom_2 =3) othcomm = 3.
EXECUTE.
VAR LABEL othcomm 'Level of dr communication with other services'.
VALUE LABEL othcomm
1 'Ex/VG'
2 'G/F/P'
3 'Legitimate skip'
999 'DK/Ref'.

COMPUTE carecoor = 3.
IF (coorrcv = 1) and ((doccomm = 1) or (doccomm = 3)) and ((othcomm = 1) or (othcomm = 3)) carecoor
= 1.
IF (coorrcv = 0) or (doccomm = 2) or (othcomm = 2) carecoor = 0.
IF (coorrcv = 99) or (doccomm = 999) or (othcomm = 999) carecoor = 999.
EXECUTE.
VAR LABEL carecoor 'Effective care coordination received when needed'.
VALUE LABEL carecoor
1 'Yes'
0 'No'
3 'Legitimate skip -- not needed or needed & never get help'
999 'DK/Ref/Missing'.
RECODE
carecoor
(999=SYSMIS) .

**STEP 2: Construct "Usual Source of Care" component of medical home score

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COMPUTE sick = 99.
IF ((c4q0a = 1) or (c4q0a = 3)) and ((c4q0b = 1 or c4q0b = 3 or c4q0b = 4 or c4q0b = 5 or c4q0b = 6 or
c4q0b = 8)) sick = 1.
IF (c4q0a = 2) or ((c4q0b = 2 or c4q0b = 7)) sick = 0.
EXECUTE.
RECODE
sick (1=1) (0=0) (ELSE=SYSMIS).
VARIABLE LABEL sick 'Ch. has usual place for sick care'.
VALUE LABEL sick
0 'No'
1 'Yes'.

COMPUTE well = 99.
IF (c4q01 = 1) or ((c4q02 = 2 or c4q02 = 4 or c4q02 = 5 or c4q02 = 6 or c4q02 = 7 or c4q02 = 9)) well =
1.
IF (c4q02 = 1 or c4q02 = 3 or c4q02 = 8 or c4q02 = 10) well = 0.
IF (c4q02 = 96 or c4q02 = 97) well = 4.
IF (c4q01 = 6 or c4q01 = 7) well = 4.
IF ((c4q01 = 1) and (c4q0b = 2 or c4q0b = 7)) well = 0.
EXECUTE.
MISSING VALUES well (4).
RECODE
well (1=1) (0=0) (ELSE=SYSMIS) .
EXECUTE .
VARIABLE LABEL well 'Ch. has usual place for well care'.
VALUE LABEL well
0 'No'
1 'Yes'.

COMPUTE usual = 99.
IF (sick = 1) and (well = 1) usual = 1.
IF (sick = 0) or (well = 0) usual = 0.
IF (SYSMIS (well)) or (SYSMIS (sick)) usual = 4.
EXECUTE.
MISSING VALUES usual (4).
RECODE
usual (1=1) (0=0) (ELSE=SYSMIS) .
EXECUTE .
VARIABLE LABEL usual 'Usual source of care component of Outcome #2'.
VALUE LABEL usual
0 'Ch. does not have usual source of care'
1 'Ch. DOES have usual source of care'.

```

**STEP 3: Construct No Problems Getting Needed Referrals component of medical home score

MISSING VALUES c4q07 c4q05_02 ().
EXECUTE.

RECODE

c4q07

(3=1) (4=4) (5=5) (1 thru 2=0) (6 thru 7=999) INTO r_c4q07 .

EXECUTE .

VAR LABEL r_c4q07 'Problems getting referral to specialist'.

VALUE LABEL r_c4q07

0 'Big or small problem'

1 'No problems'

4 'Ch did NOT need to see a specialist'

5 'No need to get referrals'

999 'DK/Ref/Missing'.

COMPUTE norefprb = 999.

IF (c4q05_02 = 1) and (r_c4q07 = 0) norefprb = 0.

IF (c4q05_02 = 1) and (r_c4q07 = 1) norefprb = 1.

IF (c4q05_02 = 0) or (r_c4q07 = 4) or (r_c4q07 = 5) norefprb = 3.

IF (c4q05_02 = 6 or c4q05_02 = 7) norefprb = 999.

EXECUTE.

VARIABLE LABELS norefprb 'Getting needed referrals component of Outcome #2'.

VALUE LABELS norefprb

0 'Needed referrals, problems getting'

1 'Needed referrals, no problems'

3 'Legitimate skip'

999 'DK/Ref/Missing'.

RECODE norefprb

(999=SYSMIS).

****STEP 4: Construct "Family Centered Care" component of medical home score**

****NOTE: The following code uses variables that are created during the construction of Key State Indicator #11**

MISSING VALUES c6q01r ().

EXECUTE.

*COMPUTE fcc_a.

IF (c6q02 = 1 or c6q02 = 2) fcc_a = 1.

IF (c6q02 = 3) fcc_a = 2.

IF (c6q02 = 4) fcc_a = 3.

IF (c6q01r = 996 or c6q01r = 997) fcc_a = 4.

EXECUTE.

```
VARIABLE LABEL fcc_a 'How often drs spent enough time'.
```

```
VALUE LABELS fcc_a
```

```
1 'Sometimes or never'
```

```
2 'Usually'
```

```
3 'Always'.
```

```
MISSING VALUES fcc_a (4).
```

```
*COMPUTE fcc_b.
```

```
IF (c6q03 = 1 or c6q03 = 2) fcc_b = 1.
```

```
IF (c6q03 = 3) fcc_b = 2.
```

```
IF (c6q03 = 4) fcc_b = 3.
```

```
IF (c6q01r = 996 or c6q01r = 997) fcc_b = 4.
```

```
EXECUTE.
```

```
VARIABLE LABEL fcc_b 'How often drs listened carefully'.
```

```
VALUE LABELS fcc_b
```

```
1 'Sometimes or never'
```

```
2 'Usually'
```

```
3 'Always'.
```

```
MISSING VALUES fcc_b (4).
```

```
*COMPUTE fcc_c.
```

```
IF (c6q04 = 1 or c6q04 = 2) fcc_c = 1.
```

```
IF (c6q04 = 3) fcc_c = 2.
```

```
IF (c6q04 = 4) fcc_c = 3.
```

```
IF (c6q01r = 996 or c6q01r = 997) fcc_c = 4.
```

```
EXECUTE.
```

```
VARIABLE LABEL fcc_c 'How often drs sensitive to families values/customs'.
```

```
VALUE LABELS fcc_c
```

```
1 'Sometimes or never'
```

```
2 'Usually'
```

```
3 'Always'.
```

```
MISSING VALUES fcc_c (4).
```

```
*COMPUTE fcc_d.
```

```
IF (c6q05 = 1 or c6q05 = 2) fcc_d = 1.
```

```
IF (c6q05 = 3) fcc_d = 2.
```

```
IF (c6q05 = 4) fcc_d = 3.
```

```
IF (c6q01r = 996 or c6q01r = 997) fcc_d = 4.
```

```
EXECUTE.
```

```
VARIABLE LABEL fcc_d 'How often got enough info from dr re: medical problems'.
```

```
VALUE LABELS fcc_d
```

1 'Sometimes or never'

2 'Usually'

3 'Always'.

MISSING VALUES fcc_d (4).

*COMPUTE fcc_e.

IF (c6q06 = 1 or c6q06 = 2) fcc_e = 1.

IF (c6q06 = 3) fcc_e = 2.

IF (c6q06 = 4) fcc_e = 3.

IF (c6q01r = 996 or c6q01r = 997) fcc_e = 4.

EXECUTE.

VARIABLE LABEL fcc_e 'How drs helped parents feel like partners'.

VALUE LABELS fcc_e

1 'Sometimes or never'

2 'Usually'

3 'Always'.

MISSING VALUES fcc_e (4).

COMPUTE fcc_all = 99.

IF (fcc_a = 1 or fcc_b = 1 or fcc_c = 1 or fcc_d = 1 or fcc_e = 1) fcc_all = 0.

IF (fcc_a >=2 and fcc_b >=2 and fcc_c >=2 and fcc_d >=2 and fcc_e >=2) fcc_all = 1.

IF (sysmis (fcc_a)) or (sysmis (fcc_b)) or (sysmis (fcc_c)) or (sysmis (fcc_d)) or (sysmis (fcc_e)) fcc_all = 99.

EXECUTE.

VARIABLE LABEL fcc_all '% of CSHCN without family-centered care'.

VALUE LABEL fcc_all

0 'CSHCN without family centered care'

1 'CSHCN with family centered care'

99 'DK/REF to any item or # of dr visits'.

MISSING VALUE fcc_all (99).

COMPUTE famcent = 99.

IF (fcc_all = 1) famcent = 1.

IF (fcc_all = 0) famcent = 0.

IF ((SYSMIS (fcc_a)) or (SYSMIS (fcc_b)) or (SYSMIS (fcc_c)) or (SYSMIS (fcc_d)) or (SYSMIS (fcc_e))) famcent = 4.

IF (c6q01r = 0) famcent = 3.

EXECUTE.

MISSING VALUES famcent (4).

RECODE

famcent (1=1) (0=0) (3=3) (ELSE=SYSMIS) .

EXECUTE .

VARIABLE LABEL famcent 'Family centered care component of Outcome #2'.

VALUE LABEL famcent

0 'Does NOT have fcc'

1 'Yes, has fcc'

3 'Legitimate skip'.

****STEP 5: Construct "Personal Doctor or Nurse" component of medical home score**

COMPUTE pdn = c4q02a.

EXECUTE.

VARIABLE LABEL pdn ' % of CYSHCN without a personal doctor or nurse'.

VALUE LABEL pdn

0 'Do not have a personal dr or nurse'

1 'Yes, have a personal dr or nurse'.

****STEP 6: Create Medical Home summary score using the various components constructed above**

COMPUTE outcome_2 = 99.

IF ((pdn = 1) and (usual = 1)) and ((carecoor = 1) or (carecoor = 3)) and ((norefprb = 1) or (norefprb = 3)) and ((famcent = 1) or (famcent = 3)) outcome_2 = 1.

IF (pdn = 0) or (usual = 0) or (carecoor = 0) or (norefprb = 0) or (famcent = 0) outcome_2 = 0.

IF (SYSMIS (pdn)) or (SYSMIS (usual)) or (SYSMIS (famcent)) or (SYSMIS (norefprb)) or (SYSMIS (carecoor)) outcome_2 = 99.

EXECUTE.

MISSING VALUES outcome_2 (99).

VARIABLE LABEL outcome_2 "OUTCOME #2: CYSHCN will receive coordinated, ongoing, comprehensive care within a medical home".

VALUE LABEL outcome_2

0 'Outcome not achieved'

1 'Outcome successfully achieved'.

FORMATS outcome_2 (f2.0).

OUTCOME #3 Families of CSHCN will have adequate private and public insurance to pay for the services they need	
Survey Items Used	UNINS, C8Q01_a, C8Q01_b, C8Q01_c
Numerator	CSHCN for whom Outcome #3 was achieved
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	
<p>Criteria for Outcome #3 are:</p> <ul style="list-style-type: none"> • The child has public or private insurance at time of interview. • The child has no gaps in coverage during the year prior to the interview. • Insurance usually or always meets the child’s needs. • Costs not covered by insurance are usually or always reasonable. • Insurance usually or always permits child to see needed providers. 	
SPSS Code and Annotation	
<p>**STEP 1: Regroup responses to the three insurance adequacy items used to construct Outcome #3</p> <pre> COMPUTE metneeds = 99. IF (c8q01_a = 1) or (c8q01_a = 2) metneeds = 0. IF (c8q01_a = 3) or (c8q01_a = 4) metneeds = 1. IF (unins = 1) metneeds = 2. EXECUTE. VARIABLE LABEL metneeds 'Health insurance benefits meet child needs'. VALUE LABEL metneeds 0 'Never/sometimes' 1 'Usually/always' 2 'Uninsured' 99 'DK/Ref/Missing.' COMPUTE reason = 99. IF (c8q01_b = 1) or (c8q01_b = 2) reason = 0. IF (c8q01_b = 3) or (c8q01_b = 4) reason = 1. IF (unins = 1) reason = 2. EXECUTE. VARIABLE LABEL reason 'Non-covered insurance charges reasonable'. VALUE LABEL reason 0 'Never/sometimes' 1 'Usually/always' 2 'Uninsured' 99 'DK/Ref/Missing.' COMPUTE provide = 99. IF (c8q01_c = 1) or (c8q01_c = 2) provide = 0. IF (c8q01_c = 3) or (c8q01_c = 4) provide = 1. IF (unins = 1) provide = 2. EXECUTE. </pre>	

Outcomes

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

RECODE
  metneeds reason provide (2=2) (1=1) (0=0) (99=SYSMIS).
EXECUTE .

**STEP 2: Create Outcome #3

MISSING VALUES unins_yr (.).

COMPUTE outcome_3 = 9.
IF ((unins = 0) and (unins_yr = 0) and (metneeds = 1) and (reason = 1) and (provide = 1)) outcome_3 =
1.
IF ((unins = 1) or (unins_yr = 1) or (metneeds = 0) or (reason = 0) or (provide = 0)) outcome_3 = 0.
IF (SYSMIS (unins_yr)) or (SYSMIS (metneeds)) or (SYSMIS (reason)) or (SYSMIS (provide))
outcome_3 = 9.
IF (unins_yr = 6) or (unins_yr = 7) outcome_3 = 9.
EXECUTE.
VAR LABEL outcome_3 "OUTCOME #3: Families of CSHCN will have adequate private and public
insurance to pay for the services they need".
VALUE LABEL outcome_3
0 'Outcome not achieved'
1 'Outcome successfully achieved'
9 'DK/Ref/Missing to 1 or more questions'.
MISSING VALUEs outcome_3 (9).
FORMATS outcome_3 (f2.0).
```

OUTCOME #5	Community-based service systems will be organized so families can use them easily
Survey Items Used	C6Q0d
Numerator	CSHCN for whom Outcome #5 was achieved
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	
<p>Criterion for Outcome #5 is:</p> <ul style="list-style-type: none"> Services are usually or always organized for easy use. <p>Question C6Q0d was added to survey more than half way through the data collection cycle. As a result, there are 23,293 (60%) cases with missing data because the question was not asked.</p>	
SPSS Code and Annotation	
<pre> COMPUTE outcome_5 =99. IF (c6q0d = 1 or c6q0d = 2) outcome_5 = 0. IF (c6q0d = 3 or c6q0d = 4) outcome_5 = 1. IF (c6q0d = 6 or c6q0d = 7) outcome_5 = 99. IF (SYSMIS (c6q0d)) outcome_5 = 99. EXECUTE. MISSING VALUES outcome_5 (4). EXECUTE . VARIABLE LABEL outcome_5 "OUTCOME #5: Community-based service systems will be organized so families can use them easily". VALUE LABEL outcome_5 0 'Outcome not achieved' 1 'Outcome successfully achieved'. FORMATS outcome_5 (f2.0). </pre>	

OUTCOME #6 Youth with special health care needs will receive services necessary to make a successful transition to adult life	
Survey Items Used	C6Q0a, C6Q0b
Numerator	CSHCN for whom Outcome #6 was achieved
Denominator	CSHCN ages 13–17 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	
<p>Criteria for Outcome # 6 are:</p> <ul style="list-style-type: none"> The child receives guidance and support in the transition to adulthood, including: doctors have talked about changing needs, the child has a plan for addressing changing needs, and doctors discussed shift to adult provider. The child has received vocational or career training. <p>The questions used for the “transition to adulthood” outcome were added to survey more than halfway through the data collection cycle and these questions were asked only for CSHCN ages 13–17. As a result, there are only 5,351 cases (13.8% of total sample) with responses to these items.</p>	
SPSS Code and Annotation	
<p>**STEP 1: Recode response to the 4 items used for Outcome #6 and create interim variables used in construction of final outcome variable</p> <pre> RECODE c6q0ar c6q0a_ar c6q0a_br c6q0br (1=1) (0=0) (6= 99) (7=99) INTO needchg needplan adultdr adtrain . EXECUTE . COMPUTE step1 = 0. IF (needplan = 1) and (adultdr = 1) step1 = 1. IF (needplan = 0) or (adultdr = 0) step1 = 0. IF (needplan = 99) or (adultdr = 99) step1 = 99. EXECUTE. COMPUTE adtrans = 999. IF (needchg = 0) and (step1 = 0) adtrans = 0. IF (needchg = 1) and (step1 = 1) adtrans = 1. IF (needchg = 1) and (step1 = 0) adtrans = 0. IF (needchg = 99) or (step1= 99) adtrans = 99. EXECUTE. VAR LABEL adtrans 'Dr discussed changing needs, helped plan, and talked about adult dr'. VALUE LABEL adtrans </pre>	

```
0 'No'
1 'Yes'
999 'DK/Ref to 1 or more items'
99 'Not asked or under 13 yrs'.

**STEP 2: Create Outcome #6

COMPUTE outcome_6 = 999.
IF (adtrans = 0) and (adtrain = 0) outcome_6 = 0.
IF (adtrans = 1) and (adtrain = 1) outcome_6 = 1.
IF (adtrans = 1) and (adtrain = 0) outcome_6 = 0.
IF (adtrans = 0) and (adtrain = 1) outcome_6 = 0.
IF (adtrans = 99) or (adtrain = 99) outcome_6 = 99.
EXECUTE.
VAR LABEL outcome_6 "OUTCOME #6: Youth with special health care needs will receive services
necessary to make a successful transition to adult life".
VALUE LABEL outcome_6
0 'Outcome not achieved'
1 'Outcome successfully achieved'
99 'DK/Ref to 1 or more components'
999 'Under 13 yrs old OR surveyed before questions added'.
MISSING VALUES outcome_6 (99, 999).
FORMATS outcome_6 (f4.0).
```

Gender		How many males and females are in the CSHCN population?
Survey Items Used	C2Q03	
Numerators	<ul style="list-style-type: none"> • Male • Female 	
Denominator	CSHCN ages 0–17 years	
Description	Percent of CSHCN ages 0–17 who are male or female.	
Notes for Data-Users		
<p>The variable for “child’s sex” is found in the publicly released 2001 NS_CSHCN Screener File. To add this variable to the 2001 NS_CSHCN Interview File, analysts will need to merge the variable SEX from the Screener File into the Interview File using the unique child identifier IDNUMXR as the linking variable.</p>		
SPSS Code and Annotation		
<p>VARIABLE LABEL sex ‘Sex of child’. VALUE LABEL sex 1 ‘Male’ 2 ‘Female’. MISSING VALUES sex (6,7). FORMATS sex (f2.0).</p>		

Age Group (3)		How many children of different ages are in the CSHCN population?
Survey Items Used	Initial sampling questions	
Numerators	<ul style="list-style-type: none"> • 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 available in the publicly released 2001 NS_CSHCN Interview File.		
SPSS Code and Annotation		
<pre> RECODE age (0 thru 5=1) (6 thru 11=2) (12 thru 17=3) INTO age_3. EXECUTE. VARIABLE LABEL age_3 'Children's 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). </pre>		

Race and Ethnicity What is the race/ethnicity of the CSHCN population?	
Survey Items Used	C11Q01_A – W9Q12a
Numerators	<ul style="list-style-type: none"> • Hispanic • White, non-Hispanic • Black, non-Hispanic • Multiracial, non-Hispanic • Other, non-Hispanic
Denominator	CSHCN ages 0–17 years
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	
<p>Children/youth reporting Hispanic or Latino ethnicity (S11Q01 = Yes) are grouped as HISPANIC, regardless of race. Non-Hispanic children are grouped by race based on responses to S11Q02X01 – S11Q02X07. Non-Hispanic children reporting more than one race category are grouped as “MULTI-RACE.”</p> <p>At the national level, non-Hispanic children reporting only one race category of Asian, American Indian, Alaska Native, Native Hawaiian, or Pacific Islander are combined into a single group called OTHER. This is done because only a handful of states meet the NCHS confidentiality standards for releasing data on these minority groups to the public. NCHS only includes individual-level data for these minority groups in the publicly available data files when a group comprises 5 percent or more of the total child population in a state. For more information see: www.cdc.gov/nchs/data/slaits/NSCH_Methodology_Report.pdf.</p> <p>The variables used to construct “child race/ethnicity” are found in the publicly released 2001 NS_CSHCN Screener File. In order to construct a child race/ethnicity variable for the 2001 NS_CSHCN Interview File, analysts will first need to merge the variables HISPANIC and RACER from the Screener File into the Interview File using the unique child identifier IDNUMXR as the linking variable. Alternatively, the “child race/ethnicity” variable can be constructed in the Screener File and then merged into the Interview File, using IDNUMXR as the unique linking variable.</p>	
SPSS Code and Annotation	
<p>**** 2001 NS_CSHCN stratifier: Race categories for mutually exclusive groupings of Hispanic ethnicity versus non-Hispanic races</p> <p>**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.</p> <p>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.</p>	

```

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'

7 'System missing'.

MISSING VALUES race_5 (6,7).

FORMAST race_5 (f2.0).

Special Needs Type	How many CSHCN qualified on specific types of special health needs criteria?															
Survey Items Used	FACCT1 – FACCT5_a															
Numerators	<ul style="list-style-type: none"> • CSHCN qualifying on prescription medication criteria only • CSHCN qualifying on 1 or more of the service-use based criteria • CSHCN qualifying on prescription medication and meet one or more service-use criteria • CSHCN qualifying on functional limitations alone or with any other criteria 															
Denominator	CSHCN ages 0–17 years															
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																
<p>These four mutually exclusive groupings of CSHCN by types of qualifying special needs are available 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 NS-CSHCN. For more information about the development, testing, and construction of the four mutually exclusive groupings of CSHCN based on the type and combination of qualifying screening criteria, email CAHMI@ohsu.edu.</p>																
<p>The variables used to construct this variable are found in the publicly released 2001 NS_CSHCN Screener File. In order to construct a “Special Needs Type” variable in the 2001 NS_CSHCN Interview File, analysts will first need to merge the following variables from the Screener File into the Interview File using the unique child identifier IDNUMXR as the linking variable:</p>																
<table border="0"> <tr> <td>FACCT1</td> <td>FACCT1_a</td> <td>FACCT1_b</td> <td>FACCT2</td> <td>FACCT2_a</td> </tr> <tr> <td>FACCT2_b</td> <td>FACCT3</td> <td>FACCT3_a</td> <td>FACCT3_b</td> <td>FACCT4</td> </tr> <tr> <td>FACCT4_a</td> <td>FACCT4_b</td> <td>FACCT5</td> <td>FACCT5_a</td> <td></td> </tr> </table>		FACCT1	FACCT1_a	FACCT1_b	FACCT2	FACCT2_a	FACCT2_b	FACCT3	FACCT3_a	FACCT3_b	FACCT4	FACCT4_a	FACCT4_b	FACCT5	FACCT5_a	
FACCT1	FACCT1_a	FACCT1_b	FACCT2	FACCT2_a												
FACCT2_b	FACCT3	FACCT3_a	FACCT3_b	FACCT4												
FACCT4_a	FACCT4_b	FACCT5	FACCT5_a													
<p>Alternatively, the “Special Needs Type” variable can be constructed in the Screener File and then merged into the Interview File, using IDNUMXR as the unique linking variable.</p>																
SPSS Code and Annotation																
<p>**STEP 1: Identifying children who qualify on the each of five different CSHCN screening criteria</p> <pre> COMPUTE rxmeds = 0. IF ((facct1 = 1) and (facct1_a = 1) and (facct1_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. </pre>																

```

If ((facct2 = 1) and (facct2_a = 1) and (facct2_b = 1)) serve = serve + 1.
EXECUTE.
VARIABLE LABEL serve 'Qualified on service use?'.
VALUE LABEL serve 0 'No' 1 'Yes'.

```

```

COMPUTE func = 0.
IF ((facct3 = 1) and (facct3_a = 1) and (facct3_b = 1)) func = func + 1.
EXECUTE.
VARIABLE LABEL func 'Qualified on functional limits?'.
VALUE LABEL func 0 'No' 1 'Yes'.

```

```

COMPUTE therapy = 0.
IF ((facct4 = 1) and (facct4_a = 1) and (facct4_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 ((facct5 = 1) and (facct5_a = 1)) mhealth = mhealth + 1.
EXECUTE.
VARIABLE LABEL mhealth 'Qualified on use of mental health services?'.
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.
MISSING VALUES def_4 ("0.").
VARIABLE LABELS def_4 "Def_4 re-grouped screener qualifying categories".
VALUE LABELS def_4
0 "Non-SHCN"
1 "Func (only or w/ any other)"
2 "Rx meds ONLY"
3 "Service use ONLY"
4 "Rx meds AND service use".
FORMATS def_4 (f2.0).

```

Severity of Health Conditions		How do parents rank the severity of their children's health conditions?
Survey Items Used	C3Q10	
Numerators	CSHCN whose health conditions are ranked by parents on a scale of 0 (mildest) to 10 (most severe) as: <ul style="list-style-type: none"> • 0 - 2 • 3 - 6 • 7 - 8 • 9 - 10 	
Denominator	CSHCN ages 0–17 years	
Description	Percent of CSHCN who have mild, moderate, severe or most severe health conditions.	
Notes for Data-Users		
Parent rankings on a scale of 0–10 are grouped as follows: 0–2 = Mild; 3–6 = Moderate; 7–8 = Severe; 9–10 = Most severe. The variable C3Q10 is available in the publicly released 2001 NS_CSHCN Interview File.		
SPSS Code and Annotation		
<p>**NOTE: The variable C3Q10 is available in the publicly released 2001 NS_CSHCN Interview file.</p> <pre> RECODE c3q10 (0 thru 2=1) (3 thru 6=2) (7 thru 8=3) (9 thru 10=4) (96 = 99) (97 = 99) INTO sevlev_4. EXECUTE . VARIABLE LABEL sevlev_4 "Parent-rated severity of ch. health problems". VALUE LABEL sevlev_4 1 "Mild (0-2)" 2 "Moderate (3-6)" 3 "Severe (7-8)" 4 "Most Severe (9-10)" 99 "DK/REF". MISSING VALUES sevlev_4 (99). FORMATS sevlev_4 (f2.0).</pre>		

Household Income	
How many CSHCN live in households with incomes above/below the Federal poverty level (FPL)?	
Survey Items Used	C11Q01_A – W9Q12a
Numerators	<ul style="list-style-type: none"> Household income less than 100 percent FPL Household income 100–199 percent FPL Household income 200–399 percent FPL Household income 400 percent FPL or more
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 living in households with incomes 0–99 percent FPL, 100–199 percent FPL, 200–399 percent FPL, or 400 percent or more FPL.
Notes for Data-Users	
<p>Income level of household expressed as percent of FPL derived from total household income during prior year and number of people living in the household. Federal Poverty Guidelines released in 2002 and 2003 by the U.S. Department of Health and Human Services were used for the determination of household poverty status. The percent of unknown values for this variable is unusually high (10%). For more information see: http://www.cdc.gov/nchs/data/slait/NSCH_Methodology_Report.pdf.</p> <p>The variable used to construct “Household Income” is found in the publicly released 2001 NS_CSHCN Household File, which has household-level records only. In order to have a “Household Income” variable for the 2001 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 Screener File using a many-to-one merge in order to assign each individual child record the household income status for his/her household. This new child-level household income variable is recoded into four categories and then merged into the Interview File using IDNUMXR as the unique linking variable. National level unweighted frequency tables for the income variables in the Household and Screener files are in Appendix B of this codebook.</p>	
SPSS Code and Annotation	
<pre> RECODE POVLEVEL2 (9=4) (1 thru 2=1) (3 thru 6=2) (7 thru 8=3) INTO povlev_4 . EXECUTE. VAR LABEL povlev_4 "Poverty level of HH which individual child resides -- 4 categories". VALUE LABEL povlev_4 1 "0% - 99% FPL" 2 "100% - 199% FPL" 3 "200% - 399% FPL" 4 "400% FPL or greater". FORMATS povlev_4 (f4.0). </pre>	

Insurance Type	How many CSHCN have private or public insurance coverage?
Survey Items Used	Derived from questions asked in Section 7
Numerators	<ul style="list-style-type: none"> • Private or employer-based insurance only • Medicaid, SCHIP, Title V, or other public insurance only • Combination of public & private insurance • Uninsured at time of the survey
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose health insurance coverage status at the time of the survey was private, public, combined private and public, or uninsured.
Notes for Data-Users	
<p>Private health insurance is defined as any type of health insurance (including HMO) other than public programs. Public health insurance is defined as Medicaid or the State Children’s Health Insurance Program (SCHIP).</p> <p>This variable is derived from variables included in the publicly released 2001 NS_CSHCN Interview File. The code below replicates exactly the categories, prevalences and SEs reported in the National Chartbook and NCHS report #136: Estimated Prevalence of Uninsured Children in the NS-CSHCN, http://0-www.cdc.gov.mill1.sjlibrary.org/nchs/data/series/sr_02/sr02_136.pdf.</p>	
SPSS Code and Annotation	
<p>**NOTE: This variable is derived from variable included in the publicly released 2001 NS_CSHCN Interview file.</p> <pre> COMPUTE pub_any = 0. IF (medicaid = 1) or (schip = 1) or (titlev = 1) or (otherpub = 1) pub_any = 1. IF (unins = 1) pub_any = 2. EXECUTE. VARIABLE LABEL pub_any 'Any public insurance'. VALUE LABEL pub_any 0 'No public ins' 1 'Any public insurance' 2 'Uninsured at time of survey'. COMPUTE priv_any = 0. IF (private = 1) or (military = 1) priv_any = 1. IF (unins = 1) priv_any = 2. EXECUTE. VARIABLE LABEL priv_any 'Any public insurance'. VALUE LABEL priv_any </pre>	

```
0 'No priv ins'  
1 'Any private insurance'  
2 'Uninsured at time of survey'.  
  
COMPUTE ins_type =99.  
IF (pub_any = 0) and (priv_any = 1) ins_type = 1.  
IF (pub_any = 1) and (priv_any = 0) ins_type = 2.  
IF (pub_any = 1) and (priv_any = 1) ins_type = 3.  
IF (pub_any = 0) and (priv_any = 0) ins_type = 4.  
IF (pub_any = 2) and (priv_any = 2) ins_type = 5.  
EXECUTE.  
VARIABLE LABEL ins_type 'Insurance coverage type for CSHCN'.  
VALUE LABEL ins_type  
1 "Private or employer-based ins only"  
2 "Medicaid, SCHIP, TitleV or other public ins only"  
3 "Combination of public & private ins"  
4 "Other comprehensive ins"  
5 "Uninsured at time of the survey".  
MISSING VALUES ins_type (4).  
FORMATS ins_type (f2.0).
```

Insurance Status	Does (child's name) have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?
Survey Items Used	UNINS
Numerators	<ul style="list-style-type: none"> • CSHCN insured at time of survey • CSHCN uninsured at time of survey
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 with 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	
Refer to Indicator #4 on page 10.	
SPSS Code and Annotation	
NOTE: Use the NCHS derived insurance status variable UNINS that is included in the publicly released 2001 NS_CSHCN Interview file.	

Medical Home (Outcome #2)	CSHCN will receive coordinated, ongoing, comprehensive care within a medical home
Survey Items Used	C4Q6X0aa, C4Q0a, C4Q0b, C4Q01, C4Q02, C4Q02a, C4Q05, C4Q06_0a, C4Q07, C5Q02, C5Q05, C5Q06, C6Q01r, fcc_a, fcc_b, fcc_c, fcc_d, fcc_e
Numerator	<ul style="list-style-type: none"> • CSHCN whose medical care meets medical home criteria • CSHCN whose do not have medical care that meets medical home criteria
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN who received coordinated ongoing comprehensive care within a medical home as defined by the American Academy of Pediatrics (AAP).
Notes for Data-Users	
Refer to Outcome #2 on page 31.	
SPSS Code and Annotation	
Refer to Outcome #2 on page 31.	

Appendix A: Unweighted Frequency Tables



Appendix A: Unweighted Frequency Tables

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

indic_1	Freq	Percent	Cumulative Frequency	Cumulative Percent
Daily activities never affected	15685	40.58	15685	40.58
Daily activities moderately affected some of time	14642	37.88	30327	78.47
Daily activities consistently affected, often a great deal	8323	21.53	38650	100.00

Frequency Missing = 216

INDICATOR #2: Percent of CSHCN ages 5-17 with 11 or more days of school absences due to illness

indic_2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0 - 3 days missed	17251	52.56	17251	52.56
4 - 6 days missed	6668	20.32	23919	72.87
7 - 10 days missed	4111	12.52	28030	85.40
11 or more days missed	4793	14.60	32823	100.00

Frequency Missing = 6043

INDICATOR #3: Percent of CSHCN without insurance at some point during the past year

indic_3	Frequency	Percent	Cumulative Frequency	Cumulative Percent
NOT insured at some point during year	4115	10.61	4115	10.61
Insured entire year	34666	89.39	38781	100.00

Frequency Missing = 85

INDICATOR #4: Percent of CSHCN uninsured at the time of the survey

indic_4	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Currently NOT insured	1937	4.98	1937	4.98
Currently insured	36929	95.02	38866	100.00

INDICATOR #5: Percent of currently insured CSHCN with coverage that is not adequate

indic_5	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Current insurance NOT adequate	11862	32.40	11862	32.40
Current insurance is adequate	24747	67.60	36609	100.00

Frequency Missing = 2257

Appendix A: Unweighted Frequency Tables

INDICATOR #6: Percent of CSHCN with one or more unmet needs for specific health care services

indic_6	Freq	Percent	Cumulative Freq	Cumulative Percent
1 or more unmet needs for specific health care services	6107	15.71	6107	15.71
No unmet needs for specific health care services	32759	84.29	38866	100.00

INDICATOR #7b: Percent of CSHCN whose families needed but were not able to get all the respite care, genetic counseling and/or mental health services they needed

indic_7	Frequency	Percent	Cumulative Frequency	Cumulative Percent
One or more unmet needs for family support services	1874	22.91	1874	22.91
No unmet needs for specific family support services	6305	77.09	8179	100.00

Frequency Missing = 30687

INDICATOR #8: Percent of CSHCN needing specialty care who had difficulties getting a referral

indic_8	Freq	Percent	Cumulative Freq	Cumulative Percent
Problem getting referral for needed specialty care	4026	20.09	4026	20.09
No problem getting referral for needed specialty care	16016	79.91	20042	100.00

Frequency Missing = 18824

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

indic_9	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Doctor's office	27849	72.02	27849	72.02
Clinic, health center or other regular source	7236	18.71	35085	90.73
No regular place or relies on emergency room	3586	9.27	38671	100.00

Frequency Missing = 195

INDICATOR #10: Percent of CSHCN without a PDN

indic_10	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Yes, have a personal dr or nurse	34784	89.86	34784	89.86
Do not have a personal dr or nurse	3927	10.14	38711	100.00

Frequency Missing = 155

Appendix A: Unweighted Frequency Tables

INDICATOR #11: Percent of CSHCN without family-centered care

indic_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
CSHCN with family centered care	24987	69.37	24987	69.37
CSHCN without family centered care	11031	30.63	36018	100.00

Frequency Missing = 2848

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

indic_12	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Less than \$250	18419	48.27	18419	48.27
\$250 - \$500	9893	25.93	28312	74.20
\$501 - \$1000	5209	13.65	33521	87.85
More than \$1000	4637	12.15	38158	100.00

Frequency Missing = 708

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

indic_13	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Yes, financial problems	7876	20.42	7876	20.42
No financial problems due to child's health	30694	79.58	38570	100.00

Frequency Missing = 296

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

indic_14	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Less than 1 hour	16932	45.24	16932	45.24
1 - 4 hours per week	12526	33.47	29458	78.70
5 - 10 hours per week	3391	9.06	32849	87.76
11 or more hours per week	4580	12.24	37429	100.00

Frequency Missing = 1437

Appendix A: Unweighted Frequency Tables

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

indic_15	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Family member cut back hours or stopped working	10879	28.08	10879	28.08
Employment not affected	27869	71.92	38748	100.00

Frequency Missing = 118

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

outcome_1	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Outcome successfully achieved	9052	59.34	9052	59.34
Outcome not achieved	6202	40.66	15254	100.00

Frequency Missing = 23612

OUTCOME #2: CSHCN will receive coordinated, ongoing, comprehensive care within a medical home

outcome_2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Outcome successfully achieved	20019	54.53	20019	54.53
Outcome not achieved	16691	45.47	36710	100.00

Frequency Missing = 2156

OUTCOME #3: Families of CSHCN will have adequate private and public insurance to pay for the services they need

outcome_3	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Outcome successfully achieved	22897	61.24	22897	61.24
Outcome not achieved	14491	38.76	37388	100.00

Frequency Missing = 1478

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

outcome_5	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Outcome successfully achieved	11607	75.81	11607	75.81
Outcome not achieved	3703	24.19	15310	100.00

Frequency Missing = 23556

Appendix A: Unweighted Frequency Tables

OUTCOME #6: Youth with special health care needs will receive services necessary to make a successful transition to adult life

outcome_6	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Outcome successfully achieved	270	5.05	270	5.05
Outcome not achieved	5081	94.95	5351	100.00

Frequency Missing = 33515

How many males and females are in the CSHCN population?

SEX	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Male	23320	60.04	23320	60.04
Female	15520	39.96	38840	100.00

Frequency Missing = 26

How many children of different ages are in the CSHCN population (Age - 3 groups)?

age_3	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0 - 5 yrs old	6964	17.93	6964	17.93
6 - 11 yrs old	15054	38.76	22018	56.69
12 - 17 yrs old	16821	43.31	38839	100.00

Frequency Missing = 27

What is the race/ethnicity of the CSHCN population?

race_5	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Hispanic	3424	8.84	3424	8.84
White, non-Hispanic	28967	74.79	32391	83.63
Black, non-Hispanic	3833	9.90	36224	93.53
Multiracial, non-Hispanic	1231	3.18	37455	96.71
Other (including Asian), non-Hispanic	1275	3.29	38730	100.00

Frequency Missing = 136

Appendix A: Unweighted Frequency Tables

CSHCN grouped according to type of qualifying criteria

def_4	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Rx meds ONLY	14757	37.97	14757	37.97
Service use ONLY	6396	16.46	21153	54.43
Rx meds AND service use	9389	24.16	30542	78.58
Func (only or w/ any other)	8324	21.42	38866	100.00

Parent-rated severity of CSHCN health problems

sevlev_4	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Mild (0-2)	12455	32.22	12455	32.22
Moderate (3-6)	18318	47.39	30773	79.61
Severe (7-8)	5991	15.50	36764	95.11
Most severe (9-10)	1891	4.89	38655	100.00

Frequency Missing = 211

How many CSHCN live in households with incomes above/below Federal Poverty Level (FPL)?

povlev_4	Frequency	Percent	Cumulative Frequency	Cumulative Percent
HH income 0 - 99% FPL	5205	14.77	5205	14.77
HH income 100 - 199% FPL	8145	23.12	13350	37.89
HH income 200 - 399% FPL	12569	35.68	25919	73.57
HH income 400% FPL or more	9310	26.43	35229	100.00

Frequency Missing = 3637

How many CSHCN have private or public insurance coverage?

ins_type	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Private or employer-based ins only	25531	65.94	25531	65.94
Medicaid, SCHIP, TitleV or other public ins only	7990	20.64	33521	86.57
Combination of public & private ins	3262	8.42	36783	95.00
Uninsured at time of the survey	1937	5.00	38720	100.00

Frequency Missing = 146

Appendix B: Medical Home Component and Subcomponent Variable Unweighted Frequency Tables



coorrcv Received NEEDED professional care coordination

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 Needed, did not get all prof care coor	779	2.0	2.0	2.0
	1.00 Needed & got all prof care coor	3748	9.6	9.6	11.6
	3.00 Did not need prof care coor	34160	87.9	87.9	99.5
	99.00 DK/Ref/Missing to one or both	179	.5	.5	100.0
	Total	38866	100.0	100.0	

r_c5q05

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	1970	5.1	5.1	5.1
	2.00	1740	4.5	4.5	9.5
	6.00	66	.2	.2	9.7
	999.00	35090	90.3	90.3	100.0
	Total	38866	100.0	100.0	

doccomm Level of communication btw child's doctors

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Excellent/very good	1970	5.1	5.1	5.1
	2.00 Good/Fair/Poor	1740	4.5	4.5	9.5
	3.00 Legitimate skip	34919	89.8	89.8	99.4
	999.00 DK/Ref/Missing	237	.6	.6	100.0
	Total	38866	100.0	100.0	

r_c5q06 Recoded level of dr communication with other services

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Excellent/Very Good	15706	40.4	40.4	40.4
	2.00 Good/Fair/Poor	13763	35.4	35.4	75.8
	6.00 Communication not needed	8427	21.7	21.7	97.5
	999.00 DK/Ref	970	2.5	2.5	100.0
	Total	38866	100.0	100.0	

othcom_1

			Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	Excellent/Very Good	15706	40.4	40.4	40.4
	2.00	Good/Fair/Poor	13763	35.4	35.4	75.8
	999.00	Communication not needed or DK/Ref	9397	24.2	24.2	100.0
		Total	38866	100.0	100.0	

othcom_2

			Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	Ex/VG	1203	3.1	3.1	3.1
	2.00	G/F/P	1993	5.1	5.1	8.2
	3.00	Prof care coor NOT needed or needed/NEVER helped	34852	89.7	89.7	97.9
	999.00	DK/Ref	818	2.1	2.1	100.0
		Total	38866	100.0	100.0	

othcomm Level of dr communication with other services

			Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	Ex/VG	1203	3.1	3.1	3.1
	2.00	G/F/P	1993	5.1	5.1	8.2
	3.00	Legitimate skip	35409	91.1	91.1	99.3
	999.00	DK/Ref	261	.7	.7	100.0
		Total	38866	100.0	100.0	

carecoor Effective care coordination received when needed

			Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	No	2665	6.9	6.9	6.9
	1.00	Yes	1691	4.4	4.4	11.3
	3.00	Legitimate skip -- not needed or needed & never get help	34160	87.9	88.7	100.0
		Total	38516	99.1	100.0	
Missing		System	350	.9		
Total			38866	100.0		

sick Ch. has usual place for sick care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 No	3661	9.4	9.4	9.4
	1.00 Yes	35083	90.3	90.6	100.0
	Total	38744	99.7	100.0	
Missing	System	122	.3		
Total		38866	100.0		

well Ch. has usual place for well care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 No	369	.9	1.0	1.0
	1.00 Yes	38368	98.7	99.0	100.0
	Total	38737	99.7	100.0	
Missing	System	129	.3		
Total		38866	100.0		

usual Usual source of care component of Outcome #2

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 Ch. does not have usual source of care	3664	9.4	9.5	9.5
	1.00 Ch. DOES have usual source of care	34964	90.0	90.5	100.0
	Total	38628	99.4	100.0	
Missing	System	238	.6		
Total		38866	100.0		

r_c4q07 Problems getting referral to specialist

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 Big or small problem	5676	14.6	14.6	14.6
	1.00 No problems	29787	76.6	76.6	91.2
	4.00 Ch did NOT need to see a specialist	2210	5.7	5.7	96.9
	5.00 No need to get referrals	1098	2.8	2.8	99.8
	999.00 DK/Ref/Missing	95	.2	.2	100.0
	Total	38866	100.0	100.0	

norefprb Getting needed referrals component of Outcome #2

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 Needed referrals, problems getting	4026	10.4	10.4	10.4
	1.00 Needed referrals, no problems	16016	41.2	41.4	51.8
	3.00 Legitimate skip	18670	48.0	48.2	100.0
	Total	38712	99.6	100.0	
Missing	System	154	.4		
Total		38866	100.0		

fcc_a How often drs spent enough time

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Sometimes or never	5391	13.9	14.6	14.6
	2.00 Usually	9255	23.8	25.2	39.8
	3.00 Always	22153	57.0	60.2	100.0
	Total	36799	94.7	100.0	
Missing	4.00	503	1.3		
	System	1564	4.0		
	Total	2067	5.3		
Total		38866	100.0		

fcc_b How often drs listened carefully

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Sometimes or never	4015	10.3	10.9	10.9
	2.00 Usually	9005	23.2	24.4	35.3
	3.00 Always	23852	61.4	64.7	100.0
	Total	36872	94.9	100.0	
Missing	4.00	503	1.3		
	System	1491	3.8		
	Total	1994	5.1		
Total		38866	100.0		

fcc_c How often drs sensitive to families values/customs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Sometimes or never	4258	11.0	11.7	11.7
	2.00 Usually	9176	23.6	25.2	36.9
	3.00 Always	22991	59.2	63.1	100.0
	Total	36425	93.7	100.0	
Missing	4.00	503	1.3		
	System	1938	5.0		
	Total	2441	6.3		
Total		38866	100.0		

fcc_d How often got enough info from dr re: medical problems

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Sometimes or never	6497	16.7	17.7	17.7
	2.00 Usually	10100	26.0	27.5	45.2
	3.00 Always	20137	51.8	54.8	100.0
	Total	36734	94.5	100.0	
Missing	4.00	503	1.3		
	System	1629	4.2		
	Total	2132	5.5		
Total		38866	100.0		

fcc_e How drs helped parents feel like partners

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Sometimes or never	4633	11.9	12.6	12.6
	2.00 Usually	8130	20.9	22.1	34.6
	3.00 Always	24074	61.9	65.4	100.0
	Total	36837	94.8	100.0	
Missing	4.00	503	1.3		
	System	1526	3.9		
	Total	2029	5.2		
Total		38866	100.0		

fcc_all % of CSHCN without family-centered care

			Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	CSHCN without family centered care	11031	28.4	30.6	30.6
	1.00	CSHCN with family centered care	24987	64.3	69.4	100.0
		Total	36018	92.7	100.0	
Missing	99.00	DK/REF to any item or # of dr visits	2848	7.3		
Total			38866	100.0		

famcent Family centered care component of Outcome #2

			Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	Does NOT have fcc	11031	28.4	29.5	29.5
	1.00	Yes, has fcc	24987	64.3	66.8	96.2
	3.00	Legitimate skip	1404	3.6	3.8	100.0
		Total	37422	96.3	100.0	
Missing		System	1444	3.7		
Total			38866	100.0		

pdn % of CYSHCN without a personal doctor or nurse

			Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	Do not have a personal dr or nurse	3927	10.1	10.1	10.1
	1.00	Yes, have a personal dr or nurse	34784	89.5	89.9	100.0
		Total	38711	99.6	100.0	
Missing		System	155	.4		
Total			38866	100.0		

outcome_2 OUTCOME #2: CYSHCN will receive coordinated, ongoing, comprehensive care within a medical home

			Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	Outcome not achieved	16691	42.9	45.5	45.5
	1	Outcome successfully achieved	20019	51.5	54.5	100.0
		Total	36710	94.5	100.0	
Missing	99		2156	5.5		
Total			38866	100.0		

Appendix C: Income Variable Frequency Tables in Household and Screener Files



POVLEVEL, a household income variable from the HOUSEHOLD file (N=196,888):

POVLEVEL	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Below 50% FPL	7349	4.39	7349	4.39
Below 100% FPL	14269	8.52	21618	12.91
Below 133% FPL	11306	6.75	32924	19.66
Below 150% FPL	6691	4.00	39615	23.66
Below 185% FPL	13250	7.91	52865	31.58
Below 200% FPL	5393	3.22	58258	34.80
Below 300% FPL	34473	20.59	92731	55.39
Below 400% FPL	27650	16.51	120381	71.90
At or above 400% FPL	47044	28.10	167425	100.00

Frequency Missing = 29463

POVLEVEL2, a child-level household income variable created by merging the variable POVLEVEL from the HOUSEHOLD File into the SCREENER File (N=372,174) linking on the unique household identifier IDNUMR using a many-to-one merge in order to assign each individual child record the household income status for his/her household:

povlevel2	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Below 50% FPL	16823	5.29	16823	5.29
Below 100% FPL	31240	9.82	48063	15.11
Below 133% FPL	24193	7.61	72256	22.72
Below 150% FPL	14183	4.46	86439	27.18
Below 185% FPL	26933	8.47	113372	35.64
Below 200% FPL	10999	3.46	124371	39.10
Below 300% FPL	66395	20.87	190766	59.98
Below 400% FPL	49922	15.70	240688	75.67
At or above 400% FPL	77373	24.33	318061	100.00

Frequency Missing = 54113

POVLEV_4, a grouped child-level income variable created after merging POVLEVEL2 into the Interview file (N= 38,866), linking on the unique child identifier IDNUMXR:

Poverty level of HH which individual child resides -- 4 categories

povlev_4	Frequency	Percent	Cumulative Frequency	Cumulative Percent
HH income 0 - 99% FPL	5205	14.77	5205	14.77
HH income 100 - 199% FPL	8145	23.12	13350	37.89
HH income 200 - 399% FPL	12569	35.68	25919	73.57
HH income 400% FPL or more	9310	26.43	35229	100.00

Frequency Missing = 3637

Frequency Missing = 146