

2009-2010 National Survey of Children with Special Health Care Needs

SPSS CODE FOR DATA USERS:

CHILD HEALTH OUTCOME MEASURES,
INDICATORS AND SUBGROUPS

Version 1.0: May 2012



Recommended 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:

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CONTENTS

Purpose of the 2009-2010 NS-CSHCN SPSS Codebook	1
The CAHMI Data Resource Center for Child and Adolescent Health	1
Overview of the 2009-2010 NS-CSHCN	2
Linking the NS-CSHCN Data Files	4
Important Information Regarding the 2009-2010 NS-CSHCN	5

CSHCN Prevalence and Demographics

Prevalence of CSHCN among All Children	8
Prevalence of Households with Children that Have One or More CSHCN	9

National Chartbook Indicators

Indicator #1: Activity Limitations	10
Indicator #2: Missed School Days	11
Indicator #3: Inconsistently Insured	12
Indicator #4: Currently Uninsured	13
Indicator #5: Adequacy of Current Insurance Coverage	14
Indicator #6: Unmet Needs for Care	16
Indicator #7: Unmet Needs for Family Support Services	22
Indicator #8: Problems Obtaining Referral	25
Indicator #9: Usual Source for Sick Care	26
Indicator #10: Personal Doctor or Nurse	27
Indicator #11: Family-Centered Care	28
Indicator #12: Out-of-Pocket Expenses	31
Indicator #13: Family Financial Burden	32
Indicator #14: Hours per Week Providing Care	33
Indicator #15: Impact on Family Work Life	35

MCHB Core Outcomes & System of Care

Outcome #1: Shared decision-making for child's optimal health	36
Outcome #2: Coordinated, ongoing, comprehensive care within a medical home	38
Outcome #3: Adequate private and/or public insurance	46
Outcome #4: Early and continuous screening for special health care needs	49
Outcome #5: Community-based service systems organized for ease of use	51
Outcome #6: Transition to adulthood	54
System of Care #1: System of Care criteria met for CSHCN ages 0-11	57
System of Care #2: System of Care criteria met for CSHCN ages 12-17	59
System of Care #3: System of Care criteria met for all CSHCN, all ages	61

Conditions & Functional Difficulties

Conditions: Number of current health conditions reported from list of 20 different conditions	63
Difficulties: Number of functional difficulties reported from list of 14 different difficulties	65
Emotional: CSHCN ages 1½ to 17 reporting emotional or behavioral difficulties.....	67
Activity: CSHCN ages 0 to 17 reporting difficulties involving activities or participation	69
Body: CSHCN ages 0 to 17 reporting difficulties involving bodily functions	71

Stratifiers

Gender	73
Age	74
Race & Ethnicity	75
Special Health Care Needs Type.....	77
Emotional Behavioral or Developmental Issues	80
Number of CSHCN Screener Qualifying Criteria Met	81
Household Income Version 1	82
Household Income Version 2	84
Insurance Type	86
Family Structure	87
Household Language	88
Highest Parental Education Level.....	90

Appendix A: Unweighted Frequency Tables for Codebook Variables.....	A-1
Appendix B: Medical Home Components and Interim Variables	B-1
Appendix C: Methods Notes on Imputation of Income Level.....	C-1
Appendix D: Comparison of 2001, 2005/06 & 2009-2010 NS-CSHCN Indicators & Outcome Measures	D-1



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We further recognize the National Center for Health Statistics (NCHS) SLAITS team who led the data collection and development of the initial code for many DRC indicators. The indicators outlined here represent the intellectual leadership of many DRC advisors and experts nationally and in states.

We also thank the many researchers who continue to seek assistance from CAHMI in understanding and replicating DRC indicators for their own analyses. Their experiences and observations have been very helpful to us in formulating indicator development methods and supplemental content of this codebook.

Purpose of the 2009-2010 NS-CSHCN SPSS Codebook



This codebook contains SPSS program statements that can be applied to the public use data files for the 2009-2010 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 understanding the construction of indicator and outcome variables developed from the 2009/10 NS-CSHCN for the DRC. Its purpose is to expedite research by helping to standardize and improve the comparability of information derived from the 2009-2010 NS-CSHCN.

The DRC maintains a complete 2009-2010 NS-CSHCN indicator data set, available in either SAS or SPSS format. The data set includes all 15 Key Child Health Indicators and 6 MCHB Outcome variables, as well as demographic and individual question items. To request a copy, contact the Child and Adolescent Health Measurement Initiative (CAHMI) at: cahmi@ohsu.edu.

The CAHMI Data Resource Center for Child and Adolescent Health

The Data Resource Center for Child and Adolescent Health (DRC) is an easy-to-use public Web site that eliminates barriers and reduces time and resources needed to obtain key findings on the health and health care of children, youth and 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 200 standardized indicators from five national- and state-based surveys on the health and health care of children and youth: the 2001, 2005-2006 and 2009-2010 *National Survey of Children with Special Health Care Needs* (NS-CSHCN), and the 2003 and 2007 *National Survey of Children's Health* (NSCH). Data search results can be stratified by 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 2009-2010 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, Health Resources Services Administration, Maternal and Child Health Bureau (MCHB), and conducted by the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention, using State and Local Area Integrated Telephone Survey (SLAITS) technology for sampling and administration. The survey was first conducted in 2001 and repeated in 2005/06.

The 2009/10 NS-CSHCN interview sample was achieved by screening 372,698 children 0-17 years old living in 196,159 households nationwide, using the CSHCN Screener. The CSHCN Screener (1) is a survey tool developed and validated specifically to identify children who meet the federal MCHB health-consequences-based special health care needs definition. The Screener asks parents about the presence of five different health consequences:

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

Parents of children 0-17 years old who experience one or more of the health consequences are then asked whether the specific health consequences are attributable to a medical, behavioral, or other health condition and whether this condition has lasted or is expected to last for at least 12 months. Any child with an affirmative response to one or more of the five consequences and its follow-up questions is considered to have special health care needs.

Of the 372,698 children screened with the CSHCN Screener, 59,941 were identified with special health care needs. For households with more than one child with a special health care need, one child was randomly chosen to be the subject of the final interview. In-depth interviews were then completed for a total of 40,242 CSHCN— approximately 750 in each state and the District of Columbia, ranging from 751 in the District of Columbia to 878 in Texas. The survey data are weighted to reflect the population of non-institutionalized children ages 0–17 years in each state and the District of Columbia.

The 2009/10 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

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.

services, and care coordination. Additional Fast Facts about the survey can be found on the DRC website at www.childhealthdata.org.

Data from the 2009/10 NS-CSHCN are publicly released in five files in SAS format: (1) Household, (2) Screener, (3) Interview, (4) an additional Household file containing imputed data and (5) an additional Screener file containing imputed data. The public data sets and relevant background information and documentation are available online at:

http://www.cdc.gov/nchs/slait/imp_data.htm. Additional information and results from the 2009/10 NS-CSHCN are available in the DRC at: www.childhealthdata.org.

For the 2009/10 National Survey of Children with Special Health Care Needs, the sample of landline telephone numbers was supplemented with an independent random-digit-dial sample of cell phone numbers. Households contacted by cell phone were eligible if the respondent indicated that they did not have a landline or they were unlikely to be reached through their landline. The cell phone sample was new for this administration of the survey. The variable SAMPLE contains information on whether a survey respondent was interviewed via a cell phone or a landline. Cell phone and landline cases together make up the complete sample for the 2009/10 NS-CSHCN; stratification by the SAMPLE variable is not recommended as the variable SAMPLE does NOT imply that a cell phone sample respondent does not have a landline. The SAMPLE variable is an important component of the survey design and must be used in statistical software packages to account for the complex design of the survey.

A slight change was made in the scoring of the National Chartbook Indicators and MCHB Core Outcomes for the 2009/10 NS-CSHCN. Cases were only included in the valid denominator for each Indicator if they had valid responses on every item used in the scoring of the measure. Cases with “don’t know” “refused” or “missing” values on any of the items used in the scoring of the measure were set to “missing” for the composite measure. This varies slightly from previous versions of the survey and the construction and design of key indicators. This does not represent a change in the scoring of the 6 core outcomes.

Linking the NS-CSHCN Data Files

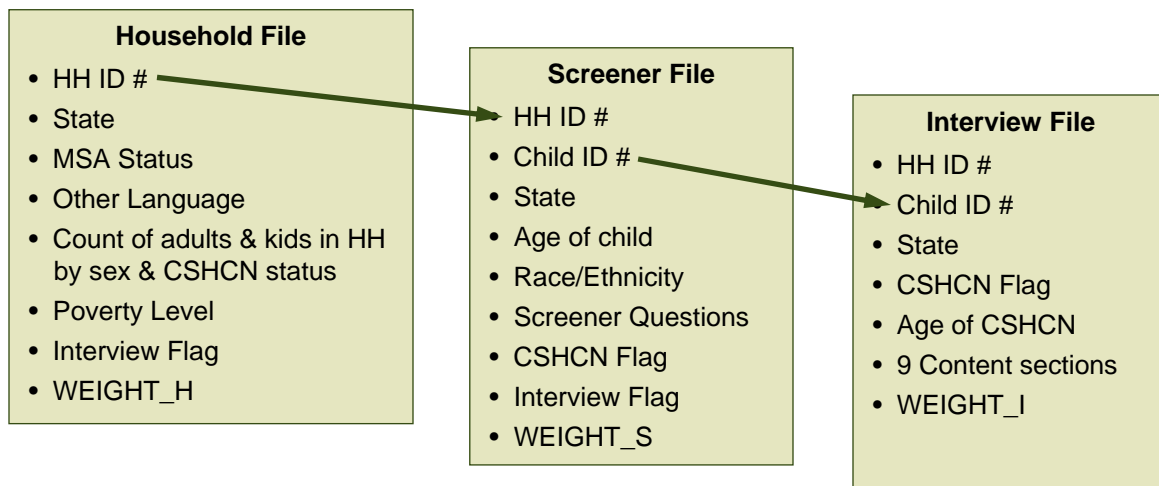
Three of the five public use data files for the 2009/10 NS-CSHCN are used in this codebook as described in the following table:

NS-CSHCN Data Files	Number of Records (n)	Unique Identifier	Weighting Variable
Household file	196,159 randomly selected U.S. households with at least one child or youth ages 0–17	IDNUMR	WEIGHT_H
Screener file	371,617 children and youth ages 0–17 living in the randomly selected households with children (1,081 children were removed from the screener file to protect confidentiality by the CDC-NCHS)	IDNUMXR	WEIGHT_S
Interview file	40,242 CSHCN age 0-17 years randomly selected from each household identified as has having a CSHCN during the initial screening process	IDNUMXR	WEIGHT_I

Two additional files contain imputed data that should be merged into the final interview file. The National Center for Health Statistics decides to impute data when there are sufficient missing cases to hinder the analytic capabilities of the data sets. This threshold is approximately 10% missing cases. Once the imputed variables are used in the interview file they will have zero missing cases. Please see **Appendix D** in this document for additional details on imputed values. The following variables were imputed in the two additional files:

- Household file: Household language, household income, highest parental education in household, total number of adults in the household
- Screener file: Race and ethnicity

The variables in this codebook are all based on the 2009/10 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.



2009/2010 NS-CSHCN Indicators & Outcomes: SPSS Codebook for Data Users -- Version 1.0

Important Information About the 2009-2010 NS-CSHCN

Weighting

The sampling weights provided in the publicly released data files are used to produce estimates representative of CSHCN or households with CSHCN at the state and national levels. These sampling weights adjust the survey responses to reflect the underlying child population using the U.S. Census counts of children, stratified by sex, age, and race/ethnicity as the reference population. Initial weights are calculated 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 age 0-17 years in each state and the District of Columbia. This weight variable should be applied to all work using the Interview File.

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, 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. **A 1-stage sampling plan should be set up using STATE and SAMPLE variables as strata, IDNUMR as the cluster and WEIGHT_I as the weight.**

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 subsetting 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 2009-2010 NS-CSHCN public use dataset is a variable for Metropolitan Statistical Area (MSA) status, located in the Household file. MSA status information is available for the 16 states in which the population is at least 500,000 in both categories (MSA and non-MSA). Zip code data is collected with the NS-CSHCN but is not released in the public use data files due to confidentiality restrictions. The confidential zip code data can be made available to researchers for on-site analysis at the Research Data Center of the National Center for Health Statistics (NCHS) in Hyattsville, MD. The process requires submitting a proposal to the NCHS. For more information, see:

<http://www.cdc.gov/nchs/r&d/rdc.htm>.

Interpretation of Results

The respondents to the CSHCN in depth interview are parents/guardians; 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 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.

Comparing Across Survey Years

With this third implementation of the NS-CSHCN, there is a natural desire to want to compare results across the three survey years. This may be done but with some caution. There are a variety of reasons why something should not be compared across survey years. For example, the items may have changed, they may have changed location in the survey, they may be asked of different ages than previous years or the response options to the items may have changed. All of these are taken into consideration by the DRC and summarized in a document on our website at <http://www.childhealthdata.org/learn/methods#AcrossYears>.

However, in addition to these normal changes which happen when surveys are revised and re-fielded, there was an additional change to the 2009/10 NS-CSHCN. This was the first year that a separate cell phone sample was included in the sampling frame. As cell phones become more commonplace, there is a need to understand their effect on a survey which is conducted by phone. Though cell phones were in wide use in 2005/06 during the previous administration of the survey, they were not sampled separately. Therefore results about the effects of including cell phones in the 2009/10 NS-CSHCN cannot be made and the data between the two surveys should be compared with caution. Please see **Appendix E** for more detailed information.

Verification

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

Additional Information on Survey Design and Methodology

The NCHS is currently developing a final *Design and Operation of the National Survey of Children with Special Health Care Needs, 2009/10*. In the meantime, they have produced a Frequently Asked Questions guide to provide practical assistance with understanding how the NS-CSHCN was conducted. View or download these frequently asked questions from the NCHS Web site at: <http://www.cdc.gov/nchs/data/slait/NSCSHCNfaqs2009.pdf>



National Chartbook Indicators

PREVALENCE OF CSHCN	Prevalence of CSHCN among All Children (screener file)
Survey Items Used	CSHCN_1 through CSHCN_5A
Numerator	Children and youth who have been identified as having special health care needs based on the CSHCN Screener
Denominator	Children age 0-17 years
Description	Prevalence of children with special health care needs among all children (screener file)
Notes for Data-Users	
<p>The screener is administered for all children in the sample household. 372,698 children were screened for special health care needs; however, some of these cases were removed from the Screener file to maintain confidentiality. Of the 371,617 children included in the final Screener file, 59,941 were identified as having special health care needs. The prevalence of children with special health care needs in the nation and in all states is based on the 2009/10 NS-CSHCN Screener file. This file includes all children screened in every household that was sampled. The Screener file is the sole source of determining children who are identified with special health care needs (CSHCN) and those who do not have special needs.</p>	
Revisions in 2009/10	
No changes; these items are the same as 2001 and 2005/06.	
SPSS Code and Annotation	
<p>recode needtype (1=0) (2=1) into CSHCN_09.</p> <p>VARIABLE LABELS CSHCN_09 "How many children have special health care needs? Screener file, all children".</p> <p>VALUE LABELS CSHCN_09 0 "Non-CSHCN" 1 "CSHCN".</p> <p>formats CSHCN_09 (F4.0).</p>	

CSHCN Prevalence and Demographics

HOUSEHOLDS WITH CSHCN	Households with one or more CSHCN (household file)
Survey Items Used	NM_SPR
Numerator	Households with 1 or more CSHCN age 0-17 years
Denominator	Households with 1 or more children age 0-17 years
Description	Prevalence of households with one or more CSHCN age 0-17 years among households with children age 0-17 years (household file)
Notes for Data-Users	
N/A	
Revisions in 2009/10	
No changes; this item is the same as 2005/06.	
SPSS Code and Annotation	
<p>recode NM_SPR (0=0) (1 thru 6=1) into CSHCNhh_09.</p> <p>VARIABLE LABELS CSHCNhh_09 "How many households have 1 or more CSHCN?".</p> <p>VALUE LABELS CSHCNhh_09</p> <p>0 "No CSHCN living in HH"</p> <p>1 "1 or more CSHCN living in HH".</p> <p>formats CSHCNhh_09 (F4.0).</p>	

National Chartbook Indicators

INDICATOR #1	Activity Limitations: CSHCN whose health conditions consistently affect daily activities
Survey Items Used	C3Q02 C3Q03
Numerator	Daily activities consistently affected, often a great deal; Daily activities moderately affected some of the time; Daily activities never affected
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years 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" conditions affect daily activities of CSHCN. For example, a child may have asthma attacks only rarely, however, when such attacks occur they may greatly affect the child's abilities to do daily activities. CSHCN whose conditions "consistently, and often greatly, affect their daily activities" are those with responses of "Usually or Always" on C3Q02 AND/OR a response of "A great deal" on C3Q03. Valid responses on both items are required. If either is don't know or refused, child is set to missing.</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2001 and 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<pre> COMPUTE indic1_09 = 99. IF (c3q02 = 1) indic1_09 = 1. IF (c3q02 = 2) indic1_09 = 2. IF (c3q02 = 3) indic1_09 = 3. IF (c3q02 = 4) indic1_09 = 3. IF (c3q03 = 1) indic1_09 = 3. IF (c3q03 = 6 or C3Q03=7) indic1_09 = 99. EXECUTE. VARIABLE LABELS indic1_09 "Activity Limitations: CSHCN whose health conditions consistently affect daily activities". VALUE LABELS indic1_09 1 "Daily activities never affected" 2 "Daily activities moderately affected some of the time" 3 "Daily activities consistently affected, often a great deal" 99 "DK, Ref or Missing to both items". MISSING VALUES indic1_09 (99). FORMATS indic1_09 (f2.0). </pre>	

National Chartbook Indicators

INDICATOR #2	Missed School Days: CSHCN ages 5-17 with 11 or more school absences due to illness
Survey Items Used	C3Q14
Numerator	0-3 days missed; 4-6 days missed; 7-10 days missed; 11 or more days missed
Denominator	CSHCN ages 5–17 years
Description	Percent of CSHCN ages 5–17 who had 11 or more days of school absences due to illness during the past 12 months.
Notes for Data-Users	
Parents answering “don’t know” or “refused” to ANY of the items used for the measure are not included in the scoring of outcomes or indicators (they are set to missing).	
Revisions in 2009/10	
These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.	
SPSS Code and Annotation	
<p>RECODE C3Q14R (0 thru 3=1) (4 thru 6=2) (7 thru 10=3) (11 thru 13=4) (994 thru 997=99) into indic2_09. EXECUTE.</p> <p>VARIABLE LABELS indic2_09 "Missed School Days: CSHCN ages 5-17 with 11 or more school absences due to illness". VALUE LABELS indic2_09 1 '0 - 3 days missed' 2 '4 - 6 days missed' 3 '7 - 10 days missed' 4 '11 or more days missed' 99 "DK, Ref, or ch <5 yrs old". MISSING VALUES indic2_09 (99). FORMATS indic2_09 (f2.0).</p>	

National Chartbook Indicators

INDICATOR #3	Inconsistently Insured: CSHCN without insurance at some point during the past year
Survey Items Used	UNINS_YR
Numerator	Insured entire year; Not insured at some point during past year
Denominator	CSHCN age 0–17 years
Description	Percent of CSHCN age 0-17 years who were without insurance at some point during the past 12 months.
Notes for Data-Users	
<p>This indicator is based on the variable "UNINS_YR" which is derived by the National Center for Health Statistics from responses to the numerous questions about health insurance coverage in Section 7 of the National Survey of CSHCN. This variable is included in the public use Interview file for the survey. For more information on how insurance status was defined by the National Center for Health Statistics for purposes of the survey, go to: http://www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2001 and 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<p>** NOTE: Uses derived variable UNINS_YR included in public release INTERVIEW file.</p> <p>COMPUTE indic3_09 = unins_yr. EXECUTE. VARIABLE LABELS indic3_09 "Inconsistently Insured: CSHCN without insurance at some point during the past year". VALUE LABELS indic3_09 0 'Insured entire year' 1 'NOT insured at some point during year' 6 'DK' 7 'Refused'. MISSING VALUES indic3_09 (6, 7). FORMATS indic3_09 (f2.0).</p>	

National Chartbook Indicators

INDICATOR #4	Currently Uninsured: CSHCN without insurance at time of the survey
Survey Items Used	UNINS
Numerator	CSHCN with no health insurance at the time of the survey; CSHCN with health insurance at the time of the survey
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years who were uninsured at the time of the survey.
Notes for Data-Users	
<p>This indicator is based on the variable "UNINS" which is derived by the National Center for Health Statistics from responses to the numerous health insurance coverage questions in Section 7 of the National Survey of CSHCN. This variable is included in the public use Interview data file of the survey. For more information on how insurance status was defined by the National Center for Health Statistics for purposes of the survey, go to: http://www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2001 and 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<p>** NOTE: Uses derived variable UNINS included in public release INTERVIEW file</p> <pre> COMPUTE indic4_09 = unins. EXECUTE. VARIABLE LABELS indic4_09 "Currently Uninsured: CSHCN without insurance at time of the survey". VALUE LABELS indic4_09 0 'Currently insured' 1 'Currently NOT insured'. MISSING VALUES indic4_09 (6,7). FORMATS indic4_09 (f2.0). </pre>	

National Chartbook Indicators

INDICATOR #5	Adequacy of Current Insurance Coverage: Currently insured CSHCN whose insurance coverage is not adequate
Survey Items Used	C8Q01_A C8Q01_B C8Q01_C
Numerator	Current insurance is adequate for CSHCN needs; Current insurance is not adequate for CSHCN needs
Denominator	CSHCN age 0–17 years insured at the time of the survey
Description	Percent of currently insured CSHCN age 0–17 years whose insurance is not adequate for CSHCN needs.
Notes for Data-Users	
<p>To be scored as having inadequate insurance children have responses of never or sometimes to each item. That is their current insurance coverage never/sometimes covers services and/or never/sometimes has reasonable out of pocket expenses and/or never/sometimes allows CSHCN to see needed health providers. Valid responses on all three items are required. If any item is don't know or refused, then child is set to missing.</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<p>**STEP 1: Regroup responses to the three insurance adequacy items used to construct Indicator #5.</p> <pre> COMPUTE ins_unmetneeds = 99. IF (c8q01_a = 1) or (c8q01_a = 2) ins_unmetneeds = 0. IF (c8q01_a = 3) or (c8q01_a = 4) ins_unmetneeds = 1. EXECUTE. VARIABLE LABELS ins_unmetneeds 'Health insurance benefits meet child needs'. VALUE LABELS ins_unmetneeds 0 'Never/sometimes' 1 'Usually/always' 99 'DK/Ref/Missing/Uninsured'. COMPUTE ins_reaschg = 99. IF (c8q01_b = 1) or (c8q01_b = 2) ins_reaschg = 0. IF (c8q01_b = 3) or (c8q01_b = 4) ins_reaschg = 1. IF (c8q01_b = 5) ins_reaschg = 1. EXECUTE. VARIABLE LABELS ins_reaschg 'Non-covered insurance charges reasonable'. VALUE LABELS ins_reaschg 0 'Never/sometimes'</pre>	

National Chartbook Indicators

```
1 'Usually/always or no out of pocket costs'
99 'Ref/Missing/Uninsured'.
COMPUTE ins_providers = 99.
IF (c8q01_c = 1) or (c8q01_c = 2) ins_providers = 0.
IF (c8q01_c = 3) or (c8q01_c = 4) ins_providers = 1.
EXECUTE.
VARIABLE LABELS ins_providers 'Insurance allows child to see needed providers'.
VALUE LABELS ins_providers
0 'Never/sometimes'
1 'Usually/always'
99 'DK/Ref/Missing/Uninsured'.

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

COMPUTE indic5_09 = 99.
IF ( ins_unmetneeds=1) and (ins_reaschg = 1) and (ins_providers = 1) indic5_09 = 0.
IF ((ins_reaschg = 0) or (ins_unmetneeds=0) or (ins_providers = 0)) indic5_09 = 1.
IF ((ins_unmetneeds=99) or (ins_reaschg = 99) or (ins_providers = 99)) indic5_09 = 99.
EXECUTE.
VARIABLE LABELS indic5_09 'Currently insured CSHCN whose insurance is not adequate'.
VALUE LABELS indic5_09
0 'Current insurance is adequate'
1 'Current insurance NOT adequate'
99 'DK or Ref to all items or Uninsured'.
MISSING VALUES indic5_09 (99).
FORMATS indic5_09 (f2.0).

**STEP 3: Must have valid responses to all items. So set don't know or refused responses to missing.

MISSING VALUES metneeds_09 reasonable_09 providers_09 (.).
COMPUTE indic5_09=99.
IF (indic4_09=1) indic5_09=999.
IF (metneeds_09=1) and (reasonable_09=1) and (providers_09=1) indic5_09=1.
IF (metneeds_09=0) or (reasonable_09=0) or (providers_09=0) indic5_09=0.
IF (metneeds_09>2) or (reasonable_09>2) or (providers_09>2) indic5_09=99.
EXECUTE.
VARIABLE LABELS indic5_09 "Adequacy of Current Insurance Coverage: Currently insured CSHCN
whose insurance coverage is not adequate".
VALUE LABELS indic5_09
0 'Current insurance is NOT adequate'
1 'Current insurance IS adequate'
99 'DK or Ref to any item'
999 "Uninsured".
MISSING VALUES indic5_09 (99,999).
FORMATS indic5_09 (f2.0).
```

National Chartbook Indicators

INDICATOR #6	Unmet Needs for Care: CSHCN with any unmet need for any of 14 specific health care services or equipment, past 12 months
Survey Items Used	C4Q05_1 & 1A; C4Q05_2 & 2A; C4Q05_31 & 31A; C4Q05_32 & 32A; C4Q05_4 & 4A; C4Q05_5 & 5A; C4Q05_6 & 6A; C4Q05_7 & 7A; C4Q05_8 & 8A; C4Q05_9 & 9A; C4Q05_10 & 10A; C4Q05_11 & 11A; C4Q05_12 & 12A; C4Q05_14 & 14A
Numerator	No unmet needs; 1 unmet need; 2 or more unmet needs from the list of 14 services and products asked about in the survey
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years with one or more unmet needs for specific health care services.
Notes for Data-Users	
<p>Respondents are asked whether CSHCN needed each of 14 different health care services or equipment during the past 12 months. Respondents giving an affirmative answer to the need for a specific health care service or equipment, are asked a follow up question to determine if child got all the care in that he/she needed in that area. These responses are summed to create an overall count of unmet needs for care. The 14 different services/equipment needs asked about in the survey include: routine preventive care; specialist care; preventive dental care; other dental care; prescription medicines; OT, PT or speech therapy; mental health care or counseling; substance abuse treatment or counseling; home health care; vision care or eyeglasses; hearing aids or hearing care; mobility aids or devices; communication aids or devices; disposable medical supplies; durable medical equipment. Items are simple yes/no answers. Any child with an answer of "yes" on at least one item will be in the numerator as "1 or or more unmet needs." Valid responses on all items are required. If any item is don't know or refused, then the child is set to missing.</p>	
Revisions in 2009/10	
<p>In 2009/10, the assessment of unmet need for preventive medical care and preventive dental care changed. K4Q20 and K4Q21 were added and while they are not used for this measure, their addition did change the skip pattern and scoring of C4Q05_1 & 1A and C4Q05_31 & 31A. Additionally, the questions assessing need and unmet need for disposable medical supplies were not asked in 2009/10, which changed this into any unmet need for 14 (as opposed to 15) services. Indicator 6 cannot be compared across survey years.</p>	
SPSS Code and Annotation	
<p>*Indicator 6 - Unmet Needs for Care: CSHCN with any unmet need for any of 14 specific health care services or equipment, past 12 months. *Preventive Care. (Used to be 15 items, but disposable medical equipment was dropped from 2009/10 survey</p>	

National Chartbook Indicators

**11-30-11 RESCORED to account for complex skip pattern for K4Q20R and K4Q21R

**RESCORED to throw out any case with missing data for any item

**STEP 1: Compute variable for each of 14 healthcare items.

*Preventive medical care.

COMPUTE prevmed_unmet_09=0.

IF (C4Q05_1A=0) prevmed_unmet_09=1.

if (C4Q05_1=1) prevmed_unmet_09=1.

if (C4Q05_1=6 or C4Q05_1=7) or (C4Q05_1A=6 or C4Q05_1A=7) prevmed_unmet_09=99.

EXECUTE.

VARIABLE LABELS prevmed_unmet_09 'Unmet needs for preventive care'.

VALUE LABELS prevmed_unmet_09

0 "no unmet preventive med needs"

1 "Unmet preventive med needs"

99 "DK/REF on any of the three items".

formats prevmed_unmet_09 (F4.0).

MISSING VALUES prevmed_unmet_09 ().

*Specialist Care.

COMPUTE specialist_unmet_09=0.

IF (C4Q05_2A=0) specialist_unmet_09=1.

IF (C4Q05_2=1) and (SYSMIS(C4Q05_2a)) specialist_unmet_09=99.

if (C4Q05_2=6 or C4Q05_2=7) or (C4Q05_2A=6 or C4Q05_2A=7) specialist_unmet_09=99.

EXECUTE.

VARIABLE LABELS specialist_unmet_09 'Unmet needs for specialist care'.

value labels specialist_unmet_09

0 "no unmet specialist needs"

1 "Unmet specialist needs"

99 "DK/REF on either".

formats specialist_unmet_09 (F4.0).

MISSING VALUES specialist_unmet_09 ().

*Preventive Dental Care.

COMPUTE prevden_unmet_09=0.

IF (C4Q05_31A=0) prevden_unmet_09=1.

if (C4Q05_31=1) prevden_unmet_09=1.

if (C4Q05_31=6 or C4Q05_31=7) or (C4Q05_31A=6 or C4Q05_31A=7) prevden_unmet_09=99.

EXECUTE.

VARIABLE LABELS prevden_unmet_09 'Unmet needs for preventive dental care'.

VALUE LABELS prevden_unmet_09

0 "no unmet preventive dental needs"

1 "Unmet preventive dental needs"

99 "DK/REF on any of the three items".

formats prevden_unmet_09 (F4.0).

MISSING VALUES prevden_unmet_09 ().

*Other Dental Care.

COMPUTE odental_unmet_09=0.

IF (C4Q05_32A=0) odental_unmet_09=1.

if (C4Q05_32=6 or C4Q05_32=7) or (C4Q05_32A=6 or C4Q05_32A=7) odental_unmet_09=99.

EXECUTE.

VARIABLE LABELS odental_unmet_09 'Unmet needs for other dental care'.

value labels odental_unmet_09

National Chartbook Indicators

0 "no unmet other dental needs"

1 "Unmet other dental needs"

99 "DK/REF on either".

formats odental_unmet_09 (F4.0).

MISSING VALUES odental_unmet_09 ().

*Prescriptions.

COMPUTE rxmedsl_unmet_09=0.

IF (C4Q05_4A=0) rxmedsl_unmet_09=1.

if (C4Q05_4=6 or C4Q05_4=7) or (C4Q05_4A=6 or C4Q05_4A=7) rxmedsl_unmet_09=99.

EXECUTE.

VARIABLE LABELS rxmedsl_unmet_09 'Unmet needs for prescription medicine'.

value labels rxmedsl_unmet_09

0 "no unmet meds needs"

1 "Unmet meds needs"

99 "DK/REF on either".

formats rxmedsl_unmet_09 (F4.0).

MISSING VALUES rxmedsl_unmet_09 ().

*Physical/Occupational/Speech Therapy.

COMPUTE therapy_unmet_09=0.

IF (C4Q05_5A=0) therapy_unmet_09=1.

IF (C4Q05_5=1) AND (SYSMIS(C4Q05_5A)) therapy_unmet_09=99.

if (C4Q05_5=6 or C4Q05_5=7) or (C4Q05_5A=6 or C4Q05_5A=7) therapy_unmet_09=99.

EXECUTE.

VARIABLE LABELS therapy_unmet_09 'Unmet needs for OT, PT or speech therapy'.

value labels therapy_unmet_09

0 "no unmet therapy needs"

1 "Unmet therapy needs"

99 "DK/REF on either".

formats therapy_unmet_09 (F4.0).

MISSING VALUES therapy_unmet_09 ().

*Mental Health.

COMPUTE mhealth_unmet_09=0.

IF (C4Q05_6A=0) mhealth_unmet_09=1.

if (C4Q05_6=6 or C4Q05_6=7) or (C4Q05_6A=6 or C4Q05_6A=7) mhealth_unmet_09=99.

EXECUTE.

VARIABLE LABELS mhealth_unmet_09 'Unmet needs for mental health care'.

value labels mhealth_unmet_09

0 "no unmet mental health needs"

1 "Unmet mental health needs"

99 "DK/REF on either".

formats mhealth_unmet_09 (F4.0).

MISSING VALUES mhealth_unmet_09 ().

*Substance Abuse. 8-17 years ONLY. First have to identify the 5 children who missing in error but in proper age range.

COMPUTE subabuse_unmet_09=0.

IF (C4Q05_7A=0) subabuse_unmet_09=1.

if (C4Q05_7=6 or C4Q05_7=7 or C4Q05_7=99) or (C4Q05_7A=6 or C4Q05_7A=7)

subabuse_unmet_09=99.

if (age<8) subabuse_unmet_09=98.

if (age>=8) and (sysmis(C4Q05_7)) subabuse_unmet_09=99.

National Chartbook Indicators

EXECUTE.

VARIABLE LABELS subabuse_unmet_09 'Unmet needs for substance abuse tx'.

value labels subabuse_unmet_09

0 "no unmet sub abuse tx needs"

1 "Unmet sub abuse tx needs"

98 "0-8 year old"

99 "DK/REF/missing on either".

formats subabuse_unmet_09 (F4.0).

MISSING VALUES subabuse_unmet_09 ().

*Home Health.

COMPUTE homehlth_unmet_09=0.

IF (C4Q05_8A=0) homehlth_unmet_09=1.

if (C4Q05_8=6 or C4Q05_8=7) or (C4Q05_8A=6 or C4Q05_8A=7) homehlth_unmet_09=99.

EXECUTE.

VARIABLE LABELS homehlth_unmet_09 'Unmet needs for home health care'.

value labels homehlth_unmet_09

0 "no unmet home health needs"

1 "Unmet home health needs"

99 "DK/REF on either".

formats homehlth_unmet_09 (F4.0).

MISSING VALUES homehlth_unmet_09 ().

*Eyeglasses/Needed Vision Care.

COMPUTE vision_unmet_09=0.

IF (C4Q05_9A=0) vision_unmet_09=1.

if (C4Q05_9=6 or C4Q05_9=7) or (C4Q05_9A=6 or C4Q05_9A=7) vision_unmet_09=99.

EXECUTE.

VARIABLE LABELS vision_unmet_09 'Unmet needs for eyeglasses or vision care'.

value labels vision_unmet_09

0 "no unmet vision needs"

1 "Unmet vision needs"

99 "DK/REF on either".

formats vision_unmet_09 (F4.0).

MISSING VALUES vision_unmet_09 ().

*Hearing Aids/Care.

COMPUTE hearing_unmet_09=0.

IF (C4Q05_10A=0) hearing_unmet_09=1.

IF (C4Q05_10=1) and (SYSMIS(C4Q05_10A)) hearing_unmet_09=99.

if (C4Q05_10=6 or C4Q05_10=7) or (C4Q05_10A=6 or C4Q05_10A=7) hearing_unmet_09=99.

EXECUTE.

VARIABLE LABELS hearing_unmet_09 'Unmet needs for hearing aids/hearing care'.

value labels hearing_unmet_09

0 "no unmet hearing needs"

1 "Unmet hearing needs"

99 "DK/REF on either".

formats hearing_unmet_09 (F4.0).

MISSING VALUES hearing_unmet_09 ().

*Mobility Aids or Devices. Age 3-17 ONLY. First need to identify the 9 children of proper age range who are missing in error.

COMPUTE mobility_unmet_09=0.

IF (C4Q05_11A=0) mobility_unmet_09=1.

if (C4Q05_11=6 or C4Q05_11=7) or (C4Q05_11A=6 or C4Q05_11A=7) mobility_unmet_09=99.

National Chartbook Indicators

```
if (age<3) mobility_unmet_09=98.
if (age>=3) and (sysmis(C4Q05_11)) mobility_unmet_09=99.
EXECUTE.
VARIABLE LABELS mobility_unmet_09 'Unmet needs for mobility aids or devices'.
value labels mobility_unmet_09
0 "no unmet mobility needs"
1 "Unmet mobility needs"
99 "DK/REF on either".
formats mobility_unmet_09 (F4.0).
MISSING VALUES mobility_unmet_09 (.).

*Communication Aids or Devices. Age 3-17 ONLY. First need to identify the 9 children of proper age
range who are missing in error.
COMPUTE commun_unmet_09=0.
IF (C4Q05_12A=0) commun_unmet_09=1.
if (C4Q05_12=6 or C4Q05_12=7) or (C4Q05_12A=6 or C4Q05_12A=7) commun_unmet_09=99.
if (age<3) commun_unmet_09=98.
if (age>=3) and (sysmis(C4Q05_12)) commun_unmet_09=99.
EXECUTE.
VARIABLE LABELS commun_unmet_09 'Unmet needs for communication aids or devices'.
value labels commun_unmet_09
0 "no unmet comm device needs"
1 "Unmet comm device needs"
98 "0-2 years old"
99 "DK/REF on either".
formats commun_unmet_09 (F4.0).
MISSING VALUES commun_unmet_09 (.).

*Durable Medical Equipment.
COMPUTE durable_unmet_09=0.
IF (C4Q05_14A=0) durable_unmet_09=1.
IF (C4Q05_14=1) and (SYSMIS(C4Q05_14A)) durable_unmet_09=99.
if (C4Q05_14=6 or C4Q05_14=7) or (C4Q05_14A=6 or C4Q05_14A=7) durable_unmet_09=99.
EXECUTE.
VARIABLE LABELS durable_unmet_09 'Unmet needs for durable medical equip'.
value labels durable_unmet_09
0 "no unmet durable equip needs"
1 "Unmet durable equip needs"
99 "DK/REF on either".
formats durable_unmet_09 (F4.0).
MISSING VALUES durable_unmet_09 (.).

COUNT unmet_sum = prevmed_unmet_09, specialist_unmet_09, prevden_unmet_09,
odontal_unmet_09, rxmedsl_unmet_09, therapy_unmet_09,
mhealth_unmet_09, subabuse_unmet_09, homehlth_unmet_09, vision_unmet_09, hearing_unmet_09,
mobility_unmet_09, commun_unmet_09, durable_unmet_09 (1).
if (prevmed_unmet_09=99) or (specialist_unmet_09=99) or (prevden_unmet_09=99) or
(odental_unmet_09=99) or (rxmedsl_unmet_09=99) or
(therapy_unmet_09=99) or (mhealth_unmet_09=99) or (subabuse_unmet_09=99) or
(homehlth_unmet_09=99) or (vision_unmet_09=99) or (hearing_unmet_09=99) or
(mobility_unmet_09=99) or (commun_unmet_09=99) or (durable_unmet_09=99) unmet_sum=99.
EXECUTE.
VARIABLE LABELS unmet_sum 'Number of unmet needs out of 14 total'.
VALUE LABELS unmet_sum
0 "No unmet needs"
```

National Chartbook Indicators

14 "all 14 unmet needs"
99 "DK/REF to any of the 14".
formats unmet_sum (F4.0).

**STEP 2: Compute Indicator #6 from interim summary count variable (UNMET_SUM). Sets one child identified above as SYSMIS on all 14 items as 98 and then sets to missing.

RECODE unmet_sum
(2 thru 14=2) (else=copy) INTO indic6_09.

VARIABLE LABELS indic6_09 "Unmet Needs for Care: CSHCN with any unmet need for any of 14 specific health care services or equipment, past 12 months".

VALUE LABELS indic6_09

0 'No unmet needs for 14 specific health care services'

1 '1 unmet need for services/equip'

2 '2 or more unmet needs for services/equip'

99 'DK/REF to any'.

missing values indic6_09 (99).

FORMATS indic6_09 (f2.0).

RECODE unmet_sum (1 thru 12=1) (else=copy) into indic6a_09.

VARIABLE LABELS indic6a_09 "Percent of CSHCN with 1 or more unmet needs for 14 specific health care services".

VALUE LABELS indic6a_09

0 'No unmet needs for 14 specific health care services'

1 '1 or more unmet need for services/equip'

99 'DK/REF to any'.

missing values indic6a_09 (99).

FORMATS indic6a_09 (f2.0).

***TEST count variable to test how many cases are 99 on all items

COUNT unmetsum_test = prevmed_unmet_09, specialist_unmet_09, prevden_unmet_09,
odontal_unmet_09, rxmedsl_unmet_09,
therapy_unmet_09, mhealth_unmet_09, subabuse_unmet_09, homehlth_unmet_09, vision_unmet_09,
hearing_unmet_09, mobility_unmet_09, commun_unmet_09, durable_unmet_09 (99).

National Chartbook Indicators

INDICATOR #7	Unmet Needs for Family Support Services: CSHCN with any unmet needs for family support services
Survey Items Used	C4Q06_1, C4Q06_1A, C4Q06_2, C4Q06_2A, C4Q06_3, C4Q06_3A
Numerator	CSHCN with no unmet needs for family support services; CSHCN with one or more unmet needs for family support services from the three asked about in the survey
Denominator	CSHCN age 0–17 years
Description	Percent of CSHCN with any unmet needs for family support services
Notes for Data-Users	
<p>The need for three specific family support services are asked about in the 2009/10 NS-CSHCN: a) respite care; b) family genetic counseling; and c) family mental health care or counseling. These are services that family members specifically need because of child's medical, behavioral or other health conditions. Items are simple yes/no responses. Yes on any item is used to score numerator of "1 or more unmet needs for family support services." Valid responses on all items are required. If an item is don't know or refused, then the child is set to missing.</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<p>*Indicator 7 - Unmet Needs for Family Support Services: CSHCN with any unmet needs for family 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_09 = 99. IF (C4Q06_1 = 0) respite_09 = 2. IF (c4q06_1a = 1 and c4q06_1 = 1) respite_09 = 0. IF (c4q06_1a = 0 and c4q06_1 = 1) respite_09 = 1. EXECUTE. </pre> <p>VARIABLE LABELS respite_09 'Families need for and receipt of respite care'. VALUE LABELS respite_09 0 'Needed and got all respite care' 1 'Needed, did not get all respite care' 2 "Legit skip, did not need" 99 'DK/REF/SYSMIS'.</p>	

National Chartbook Indicators

MISSING VALUES respite_09 ().

```
COMPUTE gene_09 = 99.  
IF (c4q06_2 = 0) gene_09 = 2.  
IF (c4q06_2a = 1 and c4q06_2 = 1) gene_09 = 0.  
IF (c4q06_2a = 0 and c4q06_2 = 1) gene_09 = 1.  
EXECUTE.
```

```
VARIABLE LABELS gene_09 'Families need for and receipt of genetic counseling'.  
VALUE LABELS gene_09  
0 'Needed and got all genetic counseling'  
1 'Needed, did not get all genetic counseling'  
2 "Legit skip, did not need"  
99 'DK/REF/SYSMIS'.  
MISSING VALUES gene_09 ().
```

```
COMPUTE mhfam_09 = 99.  
IF (c4q06_3 = 0) mhfam_09 = 2.  
IF (c4q06_3a = 1 and c4q06_3 = 1) mhfam_09 = 0.  
IF (c4q06_3a = 0 and c4q06_3 = 1) mhfam_09 = 1.  
EXECUTE.
```

```
VARIABLE LABELS mhfam_09 'Families need for and receipt of mental health care/counseling'.  
VALUE LABELS mhfam_09  
0 'Needed and got all fam MH care'  
1 'Needed, did not get all fam MH'  
2 "Legit skip, did not need"  
99 'DK/REF/SYSMIS'.  
MISSING VALUES mhfam_09 ().
```

```
count famsum_09=respite_09, gene_09, mhfam_09 (1).  
VARIABLE LABELS famsum_09 'Number of unmet family support needs'.
```

****STEP 2: Compute Indicator #7 from interim summary count variable (famsum_09). This is the version using all CSHCN - whether or not services were needed -- as the denominator**

```
COMPUTE indic7_09 = 999.  
IF (famsum_09 > 0) indic7_09 = 1.  
IF ((respite_09=0 or respite_09=2 or respite_09=99) AND (gene_09=0 or gene_09=2 or gene_09=99)  
AND (mhfam_09=0 or mhfam_09=2 or mhfam_09=99)) indic7_09=0.  
if (respite_09=99) or (gene_09=99) or (mhfam_09=99) indic7_09 = 99.  
EXECUTE.  
VARIABLE LABELS indic7_09 "Unmet Needs for Family Support Services: CSHCN with any unmet  
needs for family support services".  
VALUE LABELS indic7_09  
0 'No unmet needs for specific family support services or did not need'  
1 'One or more unmet needs for family support services'  
99 'DK/REF'.  
MISSING VALUES indic7_09 (99).  
FORMATS indic7_09 (f2.0).
```

*****NEED TO RECODE TO ONLY AMONG THOSE WHO NEEDED FAMILY SUPPORT SERVICES***JR 11-22-2011*****

National Chartbook Indicators

```
COMPUTE indic7b_09 = 999.  
IF (famsum_09 > 0) indic7b_09 = 1.  
IF ((respite_09=0 or respite_09=2 ) AND (gene_09=0 or gene_09=2 ) AND (mhfam_09=0 or  
mhfam_09=2)) indic7b_09=0.  
IF (respite_09=2 ) AND (gene_09=2 ) AND (mhfam_09=2) indic7b_09 = 2.  
IF (respite_09=99) or (gene_09=99) or (mhfam_09=99) indic7b_09 = 99.  
EXECUTE.  
  
VARIABLE LABELS indic7b_09 '% of CSHCN who needed and have one or more unmet needs for  
family services'.  
VALUE LABELS indic7b_09  
0 'No unmet needs for specific family support services'  
1 'One or more unmet needs for family support services'  
2 'Did not need family support services'  
99 'DK/REF'.  
MISSING VALUES indic7b_09 (2,99).  
FORMATS indic7b_09 (f2.0).
```

National Chartbook Indicators

INDICATOR #8	Problems Obtaining Referral: CSHCN needing specialty care who had problems getting a referral
Survey Items Used	C4Q07 C5Q11
Numerator	Needed referral(s) and had no problems getting; Needed referral(s) and did have big or small problems getting
Denominator	CSHCN age 0-17 years yrs who needed referrals for specialty care or services during past 12 months
Description	Percent of CSHCN age 0-17 years who needed referrals for specialty care or services in the past 12 months and who had problems getting them.
Notes for Data-Users	
<p>The denominator for this indicator includes <u>only</u> those CSHCN who needed a referral for care or services during the past 12 months (C5Q11 = Yes). In the 2009/10 NS-CSHCN, approximately 34% of CSHCN nationally needed to obtain a referral during the past 12 months. Children who did NOT need a referral are set to missing. CSHCN who experienced big or small problems obtaining referrals (C4Q07) are scored as not meeting the indicator, e.g. they had problems getting needed referrals..</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<pre> COMPUTE indic8_09 = 99. IF (C4Q07 = 1) or (c4q07 = 2) indic8_09 = 1. IF (C4Q07 = 3) indic8_09 = 0. EXECUTE. VARIABLE LABELS indic8_09 "Problems Obtaining Referral: CSHCN needing specialty care who had problems getting a referral". VALUE LABELS indic8_09 0 'Needed referral, no problems getting it' 1 'Needed referral, YES problems getting it' 99 'DK/REF or did not need a referral'. MISSING VALUES indic8_09 (99). FORMATS indic8_09 (f2.0). </pre>	

National Chartbook Indicators

INDICATOR #9	Usual Source for Sick Care: CSHCN without a usual source of care or who rely on the emergency room
Survey Items Used	C4Q0A C4Q0B
Numerator	Usual source for sick care is doctor's office; Usual source for sick care is clinic, health center, or other; No regular place for sick care / ER only
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years 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	
Valid responses on both items are required. If either item is don't know or refused, then child is set to missing.	
Revisions in 2009/10	
These items are the same as in the 2001 and 2005/06 NS-CSHCN. These measures may be compared across surveys.	
SPSS Code and Annotation	
<p>COMPUTE indic9_09 = 99. IF (C4Q0BR = 1) indic9_09 = 1. IF ((C4Q0BR = 3 or C4Q0BR = 4 or C4Q0BR = 5 or C4Q0BR = 6 or C4Q0BR = 8 or C4Q0BR =10 or C4Q0BR =11 or C4Q0BR =12)) indic9_09 = 2. IF (C4Q0A = 2) or ((C4Q0BR = 2 or C4Q0BR = 7 or C4Q0BR = 9)) indic9_09 = 3. IF (C4Q0A = 6) or (C4Q0A = 7) indic9_09=99. EXECUTE.</p> <p>VARIABLE LABELS indic9_09 "Usual Source for Sick Care: CSHCN without a usual source of care or who rely on the emergency room". VALUE LABELS indic9_09 1 'Docs office is usual source for sick care' 2 'Clinic, health center or other regular source for sick care' 3 'No usual source for sick care-- or ER,Mexico or no one place most often' 99 'DK/REF/MISSING'. FORMATS indic9_09 (F4.0). missing values indic9_09 (99).</p>	

National Chartbook Indicators

INDICATOR #10	Personal Doctor or Nurse: CSHCN without a personal doctor or nurse (PDN)
Survey Items Used	C4Q02A
Numerator	CSHCN does not have personal doctor or nurse (PDN); CSHCN has 1 or more personal doctors or nurses
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years who do not have a PDN.
Notes for Data-Users	
Valid responses on this item are required. If the item is don't know or refused, then child is set to missing.	
Revisions in 2009/10	
These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.	
SPSS Code and Annotation	
RECODE C4Q02A (1 thru 2=1) (3=0) (6 thru 7=99) into indic10_09. VARIABLE LABELS indic10_09 'Indicator #10: Personal Doctor or Nurse: CSHCN without a personal doctor or nurse (PDN)'. VALUE LABELS indic10_09 0 "No, does not have a PDN" 1 "Yes, has one or more PDNs" 99 "DK/REF/MISSING". MISSING VALUES indic10_09 (99). FORMATS indic10_09 (f2.0).	

National Chartbook Indicators

INDICATOR #11	Family Centered Care: CSHCN without family-centered care
Survey Items Used	C6Q02; C6Q03; C6Q04; C6Q05; C6Q06
Numerator	CSHCN who receive family centered care; CSHCN who did not receive family centered care
Denominator	CSHCN age 0-17 years with one or more doctor visits during the past 12 months
Description	Percent of CSHCN age 0-17 years whose medical care is not family-centered.
Notes for Data-Users	
<p>CSHCN receive family centered care if they have responses of Usually or Always to all five family-centered care questions (C6Q02 thru C6Q06). Children must have valid responses to all five items to receive a score. CSHCN with responses of “don’t know” or “refused” on any of the five items are set to missing for this measure.</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<pre> COMPUTE time_09 = 99. IF (c6q02 = 1 or c6q02 = 2) time_09 = 0. IF (c6q02 = 3 or c6q02 = 4) time_09 = 1. IF (sysmis (c6q02)) and (C6Q01=0 or C6Q01=6) time_09 = 2. EXECUTE. VARIABLE LABELS time_09 'Drs/other health providers spend enough time (c6q02 recoded)'. VALUE LABELS time_09 0 'Never/sometimes' 1 'Usually/always' 2 'No dr visits past 12 mos' 99 'DK/Ref/SYSMIS'. FORMATS time_09 (F4.0). COMPUTE listen_09 = 99. IF (c6q03 = 1 or c6q03 = 2) listen_09 = 0. IF (c6q03 = 3 or c6q03 = 4) listen_09 = 1. IF (sysmis (c6q03)) and (C6Q01=0 or C6Q01=6) listen_09 = 2. EXECUTE. VARIABLE LABELS listen_09 'Drs/other health providers listen well (c6q03 recoded)'. VALUE LABELS listen_09 </pre>	

National Chartbook Indicators

0 'Never/sometimes'

1 'Usually/always'

2 'No dr visits past 12 mos'

99 'DK/Ref/SYSMIS'.

COMPUTE sensitive_09 = 99.

IF (c6q04 = 1 or c6q04 = 2) sensitive_09 = 0.

IF (c6q04 = 3 or c6q04 = 4) sensitive_09 = 1.

IF (sysmis (c6q04)) and (C6Q01=0 or C6Q01=6) sensitive_09 = 2.

EXECUTE.

VARIABLE LABELS sensitive_09 'Drs/other health providers sensitive to family values/customs (c6q04 recoded)'.

VALUE LABELS sensitive_09

0 'Never/sometimes'

1 'Usually/always'

2 'No dr visits past 12 mos'

99 'DK/Ref/SYSMIS'.

FORMATS sensitive_09 (F4.0).

COMPUTE infofcc_09 = 99.

IF (c6q05 = 1 or c6q05 = 2) infofcc_09 = 0.

IF (c6q05 = 3 or c6q05 = 4) infofcc_09 = 1.

IF (sysmis (c6q05)) and (C6Q01=0 or C6Q01=6) infofcc_09 = 2.

EXECUTE.

VARIABLE LABELS infofcc_09 'Drs/other health providers provide needed information (c6q05 recoded)'.

VALUE LABELS infofcc_09

0 'Never/sometimes'

1 'Usually/always'

2 'No dr visits past 12 mos'

99 'DK/Ref/SYSMIS'.

FORMATS infofcc_09 (F4.0).

COMPUTE partner_09 = 99.

IF (c6q06 = 1 or c6q06 = 2) partner_09 = 0.

IF (c6q06 = 3 or c6q06 = 4) partner_09 = 1.

IF (sysmis (c6q06)) and (C6Q01=0 or C6Q01=6) partner_09 = 2.

EXECUTE.

VARIABLE LABELS partner_09 'Drs/other health providers make family feel like a partner (c6q06 recoded)'.

VALUE LABELS partner_09

0 'Never/sometimes'

1 'Usually/always'

2 'No dr visits past 12 mos'

99 'DK/Ref/SYSMIS'.

FORMATS partner_09 (F4.0).

***** Step 2: Construct "Family-Centered Care" Indicator 11

COMPUTE indic11_09 = 99.

IF (time_09 = 0) or (listen_09 = 0) or (sensitive_09 = 0) or (infofcc_09 = 0) or (partner_09 = 0)
indic11_09 = 0.

IF (time_09 = 1) and (listen_09 = 1) and (sensitive_09 = 1) and (infofcc_09 = 1) and (partner_09 = 1)
indic11_09 = 1.

National Chartbook Indicators

IF (time_09 = 99) or (listen_09 = 99) or (sensitive_09 = 99) or (infofcc_09 = 99) or (partner_09 = 99)
indic11_09 = 99.

IF (C6Q01 = 0) or (C6Q01=6) indic11_09 = 2.

EXECUTE.

VARIABLE LABELS indic11_09 'Indicator #11: Family Centered Care: CSHCN without family-centered care'.

VALUE LABELS indic11_09

0 'Does NOT have family centered care'

1 'Yes, has family centered care'

2 'Legitimate skip - no dr visit past 12 mos'

99 'DK/Ref to all or SYSMIS'.

FORMATS indic11_09 (F4.0).

MISSING VALUES indic11_09 (2,99).

National Chartbook Indicators

INDICATOR #12	Out-of-Pocket Expenses: CSHCN whose families pay more than \$1000 per year out-of-pocket for child's medical expenses
Survey Items Used	C9Q01 C9Q01_A
Numerator	Less than \$250; \$250-\$500; \$501-\$999; \$1000 or more
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years whose families pay more than \$1,000 per year in out-of-pocket expenses for child's medical expenses, past 12 months.
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, vision or dental care, special foods, adaptive clothing, durable equipment, home modifications, and any kind of therapy. Health insurance premiums or costs that were reimbursed by insurance or other sources not included. Valid responses on both items are required. If either item is don't know or refused, then child is set to missing.</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<pre> COMPUTE indic12_09 = 99. IF (C9Q01 = 3) or (C9Q01=4) indic12_09 = 1. IF (C9Q01 = 2) indic12_09 = 2. IF (C9Q01_A = 3) indic12_09 = 3. IF (C9Q01_A <=2) indic12_09 = 4. EXECUTE. VARIABLE LABELS indic12_09 "INDICATOR #12: Out-of-Pocket Expenses: CSHCN whose families pay more than \$1000 per year out-of-pocket for child's medical expenses". VALUE LABELS indic12_09 1 'Less than \$250' 2 '\$250 - \$500' 3 '\$501 - \$1000' 4 'More than \$1000' 99 'DK/REF'. MISSING VALUES indic12_09 (99). FORMATS indic12_09 (f2.0). </pre>	

National Chartbook Indicators

INDICATOR #13	Family Financial Burden: CSHCN whose families experienced financial problems due to child's health needs
Survey Items Used	C9Q05
Numerator	No financial problems due to child's health conditions; Yes, financial problems due to child's health conditions
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years whose families experienced financial problems due to child's health needs.
Notes for Data-Users	
"Don't know" or "refused" answers to this item are set to missing.	
Revisions in 2009/10	
These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.	
SPSS Code and Annotation	
RECODE C9Q05 (0=0) (1=1) (6 thru 7=99) into indic13_09. EXECUTE. VARIABLE LABELS indic13_09 "INDICATOR #13: Family Financial Burden: CSHCN whose families experienced financial problems due to child's health needs". VALUE LABELS indic13_09 0 "No financial problems due to child's health" 1 "Yes, financial problems" 99 "DK/REF or MISSING". MISSING VALUES indic13_09 (99). FORMATS indic13_09 (f2.0).	

National Chartbook Indicators

INDICATOR #14	Hours per Week Providing Care: CSHCN whose families spend 11 or more hours per week providing and/or coordinating health care for child
Survey Items Used	C9Q02 C9Q03 C9Q04
Numerator	Less than 1 hour; 1-4 hours per week; 5-10 hours per week; 11 or more hours per week
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years whose families spend 11 or more hours per week providing and/or coordinating health care for the child.
Notes for Data-Users	
<p>This indicator is based on the summed total of the number of hours family members spend per week providing health care at home for CSHCN and the number of hours family members spend per week arranging and coordinating health care for CSHCN. Question C9Q02 defines "home health care" as: changing bandages, care of feeding or breathing equipment, giving medication and therapies, etc. Question C9Q04 defines "arranging or coordinating health care" as: making appointments, making sure that care providers are exchanging information, and following up on child's care needs. To be scored on this indicator, valid responses to both items must be given. If either item is don't know or refused, then the child is set to missing.</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<p>** STEP 1: Create interim variables from number of hours spent items.</p> <pre> RECODE C9Q02 (SYSMIS=999) (ELSE=Copy) INTO C9Q02R. EXECUTE . DO IF (C9Q02R = 0). COMPUTE RC9Q03 = 0. ELSE. COMPUTE RC9Q03 = C9Q03R. END IF. MISSING VALUES RC9Q03 (996, 997). MISSING VALUES C9Q04R (996, 997). COMPUTE hrs_sum = SUM (RC9Q03, C9Q04R). </pre>	

National Chartbook Indicators

EXECUTE.

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

RECODE RC9Q03 C9Q04R
(SYSMIS=999).

MISSING VALUES C9Q02R RC9Q03 C9Q04R ().

COMPUTE indic14_09 = 99.

IF (hrs_sum = 0) indic14_09 = 1.

IF (hrs_sum >= 1 and hrs_sum <= 4) indic14_09 = 2.

IF (hrs_sum >= 5 and hrs_sum <= 10) indic14_09 = 3.

IF (hrs_sum >= 11) indic14_09 = 4.

IF (RC9Q03>=0) and (C9Q04R>98) indic14_09=99.

IF (RC9Q03>98) and (C9Q04R>=0) indic14_09=99.

IF (C9Q02R>1) or (RC9Q03>98) or (C9Q04R>98) indic14_09=99.

EXECUTE.

VARIABLE LABELS indic14_09 "INDICATOR #14: Hours per Week Providing Care: CSHCN whose families spend 11 or more hours per week providing and/or coordinating health care for child".

VALUE LABELS indic14_09

1 'Less than 1 hour '

2 '1 - 4 hours per week'

3 '5 - 10 hours per week'

4 '11 or more hours per week'

99 'DK/REF'.

MISSING VALUES indic14_09 (99).

FORMATS indic14_09 (f2.0).

National Chartbook Indicators

INDICATOR #15	Impact on Family Work Life: CSHCN whose family members cut back and/or stopped working because of child's health needs
Survey Items Used	C9Q06 C9Q10
Numerator	Family members did not cut back/stop working; Family members cut back and/or stopped working
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years whose family members cut back and/or stopped working because of child's health needs.
Notes for Data-Users	
<p>This indicator combines the concepts of family members "cutting down on hours worked" and/or "stopping work" altogether because of CSHCN's health conditions. To be scored in the numerator for "cut back or stopped working" child may have yes response to either C9Q06 (stopped working) or C9Q10 (cut back on hours) or both. Valid responses on both items are required. If either is "don't know" or "refused", the child is set to missing.</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<pre> RECODE C9q10 c9q06 (SYSMIS=999). EXECUTE. COMPUTE indic15_09 =99. IF (C9Q10 = 1) and (c9q06 = 1) indic15_09 = 1. IF (c9q10 = 1) and (c9q06=0) indic15_09=1. IF (c9q10 = 0) and (c9q06 =1) indic15_09=1. IF (c9q10 = 0) and (c9q06 = 0) indic15_09 = 0. IF (c9q10>1) or (c9q06 >1) indic15_09 = 99. EXECUTE. VARIABLE LABELS indic15_09 "INDICATOR #15: Impact on Family Work Life: CSHCN whose family members cut back and/or stopped working because of child's health needs". VALUE LABELS indic15_09 0 'Employment not affected' 1 'Family member cut back hours or stopped working or both'. MISSING VALUES indic15_09 (99). FORMATS indic15_09 (f2.0). </pre>	

MCHB Core Outcomes & System of Care

OUTCOME #1	CSHCN whose families are partners in decision-making for child's optimal health
Survey Items Used	C6Q21, C6Q22, C6Q23, C6Q24
Numerator	CSHCN whose families usually or always feel that they are partners in decision making around issues important to their child's health; Outcome not successfully achieved
Denominator	CSHCN age 0–17 years
Description	CSHCN age 0-17 years whose families are partners in decision-making for child's optimal health
Notes for Data-Users	
<p>A parent had to answer “usually” or “always” to items C6Q21, C6Q22, C6Q23 and C6Q24 for their child to meet the criteria for this outcome. Parents answering “don’t know” or “refused” to any of the items used for the measure are not included in the scoring of outcomes or indicators (they are set to missing).</p>	
Revisions in 2009/10	
<p>The items used to develop this measure were revised substantially between 2005/06 and 2009/10. This measure is now based on whether CSHCN have families who usually or always feel that they: 1) discuss with providers a range of options to consider for their child's treatment; 2) are encouraged to ask questions or raise concerns; 3) it is easy to ask questions or raise concerns; and 4) their health care providers consider and respect what treatment choices the parent feels would be best for child.</p> <p>This outcome should not be compared with the results from Outcome #1 from the 2005/06 NS-CSHCN.</p>	
SPSS Code and Annotation	
<p>*STEP 1: Recode variables C6Q21-C6Q24 to combine usually with always and never with sometimes.</p> <p>RECODE C6Q21 (1 thru 2 =0) (3 thru 5=1) (6 thru 7 =99) into range_09.</p> <p>RECODE C6Q22 (1 thru 2 =0) (3 thru 4=1) (6 thru 7 =99) into raise_09.</p> <p>RECODE C6Q23 (1 thru 2 =0) (3 thru 4=1) (6 thru 7 =99) into easytoask_09.</p> <p>RECODE C6Q24</p>	

MCHB Core Outcomes & System of Care

(1 thru 2 =0) (3 thru 4=1) (6 thru 7 =99)
into choices_09.

VARIABLE LABELS range_09 "How often did Drs discuss range of treatment options?".
VARIABLE LABELS raise_09 "How often did Drs encourage you to raise concerns?".
VARIABLE LABELS easytoask_09 "How often did Drs make it easy to ask questions?".
VARIABLE LABELS choices_09 "How often did Drs consider and respect your thoughts treatment choices?".

VALUE LABELS range_09 raise_09 easytoask_09 choices_09
0 "Never/Sometimes"
1 "Usually/Always or N/A"
99 "Missing".

*STEP 2: Create Outcome #1.

COMPUTE outcome1_09=0.
if (range_09=0) or (raise_09=0) or (easytoask_09=0) or (choices_09=0) outcome1_09=0.
if (range_09=1) and (raise_09=1) and (easytoask_09=1) and (choices_09=1) outcome1_09=1.
if (range_09=99) or (raise_09=99) or (easytoask_09=99) or (choices_09=99) outcome1_09=99.
if (SYSMIS(range_09)) or (SYSMIS(raise_09)) or (SYSMIS(easytoask_09)) or (SYSMIS(choices_09))
outcome1_09=99.
EXECUTE.

VARIABLE LABELS outcome1_09 " CSHCN whose families are partners in decision-making for child's optimal health".
VALUE LABELS outcome1_09
0 "Did not meet Outcome #1"
1 "Met Outcome #1"
99 "DK/REF on all".
FORMATS outcome1_09 (F4.0).
MISSING VALUES outcome1_09 (99).

MCHB Core Outcomes & System of Care

OUTCOME #2	Children with special health care needs (CSHCN) receiving ongoing, coordinated and comprehensive care within a medical home
Survey Items Used	C4Q02A, C4Q0BR, C4Q0A, C4Q0D, C4Q01, C4Q02R, C6Q02 – C6Q06, C4Q07, C5Q11, C5Q17, C5Q09, C5Q12, C4Q05_2, C4Q05_2A, C4Q05_2C, C4Q05_5, C4Q05_5A, C4Q05_5C, C4Q05_6, C4Q05_6A, C4Q05_6C, C4Q05_7, C4Q05_7A, C4Q05_7C, C4Q05_8, C4Q05_8A, C4Q05_8C, C5Q10, C5Q05, C5Q06
Numerator	CSHCN receiving adequate care on all needed components of medical home assessed by the survey
Denominator	CSHCN age 0-17 years
Description	CSHCN age 0-17 years receiving ongoing, coordinated and comprehensive care within a medical home
Notes for Data-Users	
<p>The medical home composite measure and its sub-components are designed to operationalize the American Academy of Pediatrics (AAP) definition of “medical home”. According to this definition, children ideally should have access to “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care within a medical home.”</p> <p>The presence of a medical home for CSHCN is one of the six performance measures or outcomes that states submit as part of the Title V Block Grant reporting requirements. The final medical home composite score used to measure this outcome is derived from the five sub-components constructed below. Parents answering “don’t know” or “refused” to any of the items used for the measure are not included in the scoring of outcomes or indicators (they are set to missing).</p> <p>See the CAHMI produced Medical Home Manual for full details on the construction of this indicator: http://www.childhealthdata.org/docs/medical-home/mhmanual-_body_sept2009-cb-edit-1-pdf.pdf</p>	
Revisions in 2009/10	
Need for interpreter—an item within family centered care—was dropped in 2009/10. Please take this change into consideration when comparing with 2005/06.	
SPSS Code and Annotation	
<p>**Outcome #2: Children with special health care needs (CSHCN) receiving ongoing, coordinated and comprehensive care within a medical home.</p> <p>*SUBCOMPONENT 1: PERSONAL DOCTOR OR NURSE (PDN)*</p> <p>*STEP 1: Create personal doctor or nurse sub-component of the medical home composite measure.</p>	

MCHB Core Outcomes & System of Care

RECODE C4Q02A
(1 thru 2=1) (3=0) (6 thru 7=99)
into
pdn_09.

VARIABLE LABELS pdn_09 'Personal Doctor or Nurse sub-component of MEDICAL HOME composite measure'.

VALUE LABELS pdn_09
0 'Do not have a personal dr or nurse'
1 'Yes, have a personal dr or nurse'
99 'DK/REF/MISSING'.
FORMATS pdn_09 (F4.0).

RECODE pdn_09 (99=SYSMIS).

SUBCOMPONENT 2: USUAL SOURCES FOR SICK AND WELL CARE

***STEP 1: Set up the interim variables used to derive the overall score for "Usual Sources for Sick and Well Care" sub-component of the medical home composite measure.**

COMPUTE sick_09 = 99.
IF ((C4Q0BR = 1 or C4Q0BR = 3 or C4Q0BR = 4 or C4Q0BR = 5 or C4Q0BR = 6 or C4Q0BR = 8 or C4Q0BR = 10 or C4Q0BR = 11 or C4Q0BR = 12)) sick_09 = 1.
IF (C4Q0A = 2) or ((C4Q0BR = 2 or C4Q0BR = 7 or C4Q0BR = 9)) sick_09 = 0.
IF (C4Q0A = 6) or (C4Q0A = 7) sick_09=99.
EXECUTE.

VARIABLE LABELS sick_09 'Child has 1 or more usual place for sick care'.
VALUE LABELS sick_09
0 'No usual source for sick care-- or ER,Mexico or no one place most often'
1 'Yes has a usual source for sick care'
99 'DK/REF/MISSING'.
FORMATS sick_09 (F4.0).

COMPUTE well_09= 99.
IF ((C4Q0D= 1) or (C4Q0D = 3)) and ((sick_09 = 1) and (C4Q01 = 1)) or (C4Q02R = 1 or C4Q02R = 3 or C4Q02R = 4 or C4Q02R = 5 or C4Q02R= 6 or C4Q02R = 8 or C4Q02R = 11 or C4Q02R = 12) well_09 = 1.
IF (sick_09 = 0) and (C4Q01 = 1) well_09 = 0.
IF (C4Q0D = 2) or (C4Q02R = 2 or C4Q02R = 7 or C4Q02R = 9) well_09 = 0.
IF ((C4Q0D= 1) or (C4Q0D = 3)) and ((sick_09 = 99) and (C4Q01 = 1)) well_09= 99.
IF ((C4Q0D= 1) or (C4Q0D = 3)) and (C4Q01 = 6 or C4Q01 = 7) well_09 = 99.
IF (C4Q0D= 6 or C4Q0D = 7) or (C4Q02R = 96 or C4Q02R = 97) well_09 = 99.
EXECUTE.

VARIABLE LABELS well_09 'Child has 1 or more usual places for well care'.
VALUE LABELS well_09
0 'No usual source for well care--or ER, Mexico or no one place most often'
1 'Yes has a usual source for well care'
99 'DK/REF/MISSING'.
FORMATS well_09 (F4.0).

***STEP 2: Construct "Usual Sources for Sick and Well Care " sub-component**

COMPUTE usual_09 = 99.

MCHB Core Outcomes & System of Care

```
IF (sick_09 = 1 or sick_09 = 99) and (well_09 = 1 or well_09 = 99) usual_09= 1.  
IF (sick_09 = 0) or (well_09 = 0 ) usual_09 = 0.  
IF (well_09= 99) or (sick_09 = 99) usual_09= 99.  
EXECUTE.
```

```
VARIABLE LABELS usual_09 'Usual Sources for Sick and Well Care sub-component of MEDICAL  
HOME composite measure'.  
VALUE LABELS usual_09  
0 'Child does not have usual sources for sick and well care'  
1 'Child DOES have usual sources for sick and well care'  
99 'DK/REF/MISSING to all'.  
FORMATS usual_09 (F4.0).
```

```
RECODE usual_09 (99=SYSMIS).
```

SUBCOMPONENT 3: FAMILY-CENTERED CARE

***STEP 1: Set up the interim variables used to derive the overall score for "Family-Centered Care" sub-component of medical home composite measure.**

```
COMPUTE time_09 = 99.  
IF (C6Q02 = 1 or C6Q02 = 2) time_09 = 0.  
IF (C6Q02 = 3 or C6Q02 = 4) time_09 = 1.  
IF (sysmis (C6Q02)) and (C6Q01=0 or C6Q01=6) time_09 = 2.  
EXECUTE.  
VARIABLE LABELS time_09 'Drs/other health providers spend enough time (C6Q02 recoded)'.  
VALUE LABELS time_09  
0 'Never/sometimes'  
1 'Usually/always'  
2 'No dr visits past 12 mos'  
99 'DK/Ref/SYSMIS'.  
FORMATS time_09 (F4.0).
```

```
COMPUTE listen_09 = 99.  
IF (C6Q03 = 1 or C6Q03 = 2) listen_09 = 0.  
IF (C6Q03 = 3 or C6Q03 = 4) listen_09 = 1.  
IF (sysmis (C6Q03)) and (C6Q01=0 or C6Q01=6) listen_09 = 2.  
EXECUTE.
```

```
VARIABLE LABELS listen_09 'Drs/other health providers listen well (C6Q03 recoded)'.  
VALUE LABELS listen_09  
0 'Never/sometimes'  
1 'Usually/always'  
2 'No dr visits past 12 mos'  
99 'DK/Ref/SYSMIS'.
```

```
COMPUTE sensitive_09 = 99.  
IF (C6Q04 = 1 or C6Q04 = 2) sensitive_09 = 0.  
IF (C6Q04 = 3 or C6Q04 = 4) sensitive_09 = 1.  
IF (sysmis (C6Q04)) and (C6Q01=0 or C6Q01=6) sensitive_09 = 2.  
EXECUTE.
```

```
VARIABLE LABELS sensitive_09 'Drs/other health providers sensitive to family values/customs (C6Q04  
recoded)'.  
VALUE LABELS sensitive_09
```

MCHB Core Outcomes & System of Care

0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref/SYSMIS'.
FORMATS sensitive_09 (F4.0).

COMPUTE infofcc_09 = 99.
IF (C6Q05 = 1 or C6Q05 = 2) infofcc_09 = 0.
IF (C6Q05 = 3 or C6Q05 = 4) infofcc_09 = 1.
IF (sysmis (C6Q05)) and (C6Q01=0 or C6Q01=6) infofcc_09 = 2.
EXECUTE.
VARIABLE LABELS infofcc_09 'Drs/other health providers provide needed information (C6Q05 recoded)'.
VALUE LABELS infofcc_09
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref/SYSMIS'.
FORMATS infofcc_09 (F4.0).

COMPUTE partner_09 = 99.
IF (C6Q06 = 1 or C6Q06 = 2) partner_09 = 0.
IF (C6Q06 = 3 or C6Q06 = 4) partner_09 = 1.
IF (sysmis (C6Q06)) and (C6Q01=0 or C6Q01=6) partner_09 = 2.
EXECUTE.
VARIABLE LABELS partner_09 'Drs/other health providers make family feel like a partner (C6Q06 recoded)'.
VALUE LABELS partner_09
0 'Never/sometimes'
1 'Usually/always'
2 'No dr visits past 12 mos'
99 'DK/Ref/SYSMIS'.
FORMATS partner_09 (F4.0).

*STEP 2: Construct "Family-Centered Care" sub-component of medical home composite measure

COMPUTE famcent_09 = 99.
IF (time_09 = 0) or (listen_09 = 0) or (sensitive_09 = 0) or (infofcc_09 = 0) or (partner_09 = 0)
famcent_09 = 0.
IF (time_09 = 1) and (listen_09 = 1) and (sensitive_09 = 1) and (infofcc_09 = 1) and (partner_09 = 1)
famcent_09 = 1.
IF (time_09 = 99 or listen_09 = 99 or sensitive_09 = 99 or infofcc_09 = 99 or partner_09 = 99)
famcent_09 = 99.
IF (C6Q01 = 0) or (C6Q01=6) famcent_09 = 2.
EXECUTE.

VARIABLE LABELS famcent_09 'Family-Centered Care sub-component of MEDICAL HOME composite measure'.
VALUE LABELS famcent_09
0 'Does NOT have family centered care'
1 'Yes, has family centered care'
2 'Legitimate skip - no dr visit past 12 mos'
99 'DK/Ref to any or SYSMIS'.
FORMATS famcent_09 (F4.0).

MCHB Core Outcomes & System of Care

RECODE famcent_09 (99=SYSMIS).

SUBCOMPONENT 4: NO PROBLEMS GETTING NEEDED REFERRALS

*STEP 1: Construct "no problems getting needed referrals" sub-component of the medical home composite measure

```
COMPUTE norefprb_09= 99.
IF (C4Q07 = 1) or (C4Q07 = 2) norefprb_09= 0.
IF (C4Q07 = 3) norefprb_09= 1.
IF (C5Q11 = 0) norefprb_09= 2.
VARIABLE LABELS norefprb_09 'Getting Needed Referrals sub-component of MEDICAL HOME composite measure'.
VALUE LABELS norefprb_09
0 'Big or small problem getting referral, when needed'
1 'No problems getting referral, when needed'
2 'Legitimate skip b/c referrals are not needed'
99 'DK/REF/MISSING'.
```

RECODE norefprb_09 (99=SYSMIS).

SUBCOMPONENT 5: EFFECTIVE CARE COORDINATION

*STEP 1: Set up the interim variables used to derive the overall score for "Effective Care Coordination" sub-component of medical home composite measure

MISSING VALUES C5Q17 C5Q09 C5Q12 ().

RECODE

C5Q17 C5Q09 C5Q12 (MISSING=999).

EXECUTE.

VALUE LABELS c5q09

```
1 'Never'
2 'Sometimes'
3 'Usually'
6 'DK'
7 'Refused'
999 'SYSMIS'.
VALUE LABELS c5q17 c5q12
0 'No'
1 'Yes'
6 'DK'
7 'Refused'
999 'SYSMIS'.
```

COMPUTE carehelp_09 = 99.

IF (C5Q12 = 1) and (C5Q17 = 0) carehelp_09 = 1.

IF (C5Q09 = 3) carehelp_09 = 1.

IF (C5Q09 = 1) or (C5Q09 = 2) carehelp_09 = 0.

IF (C5Q12 = 0) and (C5q17 = 0) carehelp_09 = 2.

IF (C5Q12 = 999) carehelp_09 = 2.

IF (C5Q09 = 6) or (C5Q09 = 7) carehelp_09 = 99.

IF (C5Q12 = 6 or C5Q12 = 7) and (C5Q17 = 0) carehelp_09 = 99.

IF (C5Q09 = 6) or (C5Q17 = 6 or C5Q17 = 7) carehelp_09 = 99.

EXECUTE.

MCHB Core Outcomes & System of Care

VARIABLE LABELS carehelp_09 'Got some type of help with care coordination'.

VALUE LABELS carehelp_09

0 'Needed extra help/did not get it'

1 'Gets help with care coor'

2 'Legit skip -- <2 services or did not need extra help'

99 'DK/Ref to any or MISSING'.

FORMATS carehelp_09 (F4.0).

**Children identified as missing for item C4Q05_7 must be identified in order to determine if they are missing in error or legitimate skip. There ar 5 cases in error.

recode C4Q05_7

(SYSMIS=99).

COMPUTE needcomm_09 = 99.

IF (C4q05_2a = 1 or C4q05_2c = 1) or (C4q05_5a = 1 or C4q05_5c = 1) or (C4q05_6a = 1 or C4q05_6c = 1) or (C4q05_7a = 1 or C4q05_7c = 1) or (C4q05_8a = 1 or C4q05_8c = 1) needcomm_09 = 1.

IF (C4q05_2 = 0 or C4q05_2c = 0) and (C4q05_5 = 0 or C4q05_5c = 0) and (C4q05_6 = 0 or C4q05_6c = 0) and (C4q05_7 = 0 or C4q05_7c = 0 or (AGE<8 and C4Q05_7=99)) and (C4q05_8 = 0 or C4q05_8c = 0) needcomm_09 = 0.

EXECUTE.

VARIABLE LABELS needcomm_09 'Used some or all specialist care, MH, PT/OT/Speech, sub abuse, or home hlth care'.

VALUE LABELS needcomm_09

1 'Used 1 or more services for dr comm denominator'

0 'Did not use services for dr comm denominator'

99 'DK/Ref'.

FORMATS needcomm_09 (f4.0).

MISSING VALUES C5q10 ().

RECODE

C5q10 (SYSMIS = 999).

EXECUTE.

VALUE LABELS c5q10

1 'Very satisfied'

2 'Somewhat satisfied'

3 'Somewhat dissatisfied'

4 'Very dissatisfied'

5 'No communication needed or wanted'

6 'DK'

7 'Refused'

999 'SYSMISS'.

COMPUTE drcomm_09 = 99.

IF (C5q10 = 1) and (needcomm_09 = 1) drcomm_09 = 1.

IF (C5q10 = 2 or C5q10 = 3 or C5q10 = 4) and (needcomm_09 = 1) drcomm_09 = 0.

IF (C5q10 = 5) and (needcomm_09 = 1) drcomm_09 = 2.

IF (C5q10 = 6 or C5q10 = 7) and (needcomm_09 = 1) drcomm_09 = 99.

IF (C5q10 = 999) drcomm_09 = 2.

IF (needcomm_09 = 0) drcomm_09 = 2.

IF (needcomm_09 = 99) drcomm_09 = 99.

EXECUTE.

MCHB Core Outcomes & System of Care

VARIABLE LABELS drcomm_09 'Level of satisfaction with dr to dr communication among those who needed it'.

VALUE LABELS drcomm_09

0 'Less than very satisfied'

1 'Very satisfied, when needed'

2 'Legit skip -- no comm needed or did not use required services'

99 'DK/Ref to any'.

FORMATS drcomm_09 (F4.0).

MISSING VALUES c5q05 c5q06 ().

RECODE

C5q06 C5q05 (SYSMIS = 999).

EXECUTE.

VALUE LABELS c5q06

1 'Very satisfied'

2 'Somewhat satisfied'

3 'Somewhat dissatisfied'

4 'Very dissatisfied'

5 'No communication needed or wanted'

6 'DK'

7 'Refused'

999 'SYSMISS'.

VALUE LABEL c5q05

0 'No'

1 'Yes'

6 'DK'

7 'Refused'

999 'SYSMISS'.

COMPUTE othercomm_09 = 99.

IF (C5q05 = 0) othercomm_09 = 2.

IF (C5q05 = 6 or C5Q05 = 7) othercomm_09 = 99.

IF (C5q05 = 999) othercomm_09 = 2.

IF (C5q06 = 1) othercomm_09 = 1.

IF (C5q06 = 2 or C5q06 = 3 or C5q06 = 4) othercomm_09= 0.

IF (C5q06 = 6 or C5q06 = 7) othercomm_09 = 99.

EXECUTE.

VAR LABEL othercomm_09 'If needed, level of satisfaction w/ dr comm to other providers or programs'.

VALUE LABEL othercomm_09

0 'Less than very satisfied'

1 'Very satisfied'

2 'Legit skip -- used >2 services'

99 'DK/Ref to any'.

FORMATS othercomm_09 (F4.0).

*STEP 2: Construct "effective care coordination" sub-component of medical composite measure

COMPUTE carecoor_09 = 99.

IF ((carehelp_09 = 1) or (carehelp_09 = 2)) and ((drcomm_09 = 1) or (drcomm_09 = 2)) and ((othercomm_09 = 1) or (othercomm_09 = 2)) carecoor_09= 1.

IF (carehelp_09 = 0) or (drcomm_09 = 0) or (othercomm_09 = 0) carecoor_09 = 0.

IF (carehelp_09 = 2) and (drcomm_09 = 2) and (othercomm_09 = 2) carecoor_09 = 2.

IF (carehelp_09 = 99) or (drcomm_09 = 99) or (othercomm_09 = 99) carecoor_09 = 99.

EXECUTE.

MCHB Core Outcomes & System of Care

VARIABLE LABELS carecoor_09 'Effective Care Coordination sub-component of MEDICAL HOME composite measure'.

VALUE LABELS carecoor_09

0 'Did not meet 1 or more needed elements of care coordination'

1 'Met all needed components of care coordination or legitimate skip'

2 'Legit skip -- no one helps with care coor or >2 services used past 12 mos on all items'

99 'DK/REF/MISSING to any'.

FORMATS carecoor_09 (F4.0).

RECODE carecoor_09 (99=SYSMIS).

MEDICAL HOME COMPOSITE MEASURE

***STEP 1: Use the five sub-components created above to derive the MEDICAL HOME composite measure using the ON EVERY scoring approach**

COMPUTE outcome2_09= 999.

IF (pdn_09 = 1) and (usual_09 = 1) and (carecoor_09 = 1 or carecoor_09 = 2) and (norefprb_09 = 1 or norefprb_09 = 2)

and (famcent_09 = 1 or famcent_09 = 2) outcome2_09 = 1.

IF (pdn_09 = 0) or (usual_09 = 0) or (carecoor_09 = 0) or (norefprb_09 = 0) or (famcent_09 = 0) outcome2_09 = 0.

IF ((SYSMIS (pdn_09)) or (SYSMIS (usual_09)) or (SYSMIS (famcent_09)) or (SYSMIS (norefprb_09)) or (SYSMIS (carecoor_09))) outcome2_09 =99.

EXECUTE.

VARIABLE LABELS outcome2_09 "Children with special health care needs (CSHCN) receiving ongoing, coordinated and comprehensive care within a medical home".

VALUE LABELS outcome2_09

0 'Care DOES NOT meet medical home criteria'

1 'Care MEETS medical home criteria'

99 'DK/Ref to any'.

MISSING VALUES outcome2_09 (99).

FORMATS outcome2_09 (F4.0).

MCHB Core Outcomes & System of Care

OUTCOME #3	CSHCN whose families have adequate private and/or public insurance to pay for the services they need
Survey Items Used	C8Q01_A C8Q01_B C8Q01_C UNINS UNINS_YR
Numerator	CSHCN whose private and/or public insurance coverage is continuous and adequate to meet the child's health needs
Denominator	CSHCN age 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>The variables UNINS and UNINS_YR used in the construction of this outcome are included in the 2009-2010 NS-CSHCN public use file. These summary variables are derived by the National Center for Health Statistics from responses to the extensive set of questions on health insurance coverage asked in Section 7 of the survey. Parents answering "don't know" or "refused" to any of the items used for the measure are not included in the scoring of outcomes or indicators (they are set to missing).</p>	
Revisions in 2009/10	
No changes; measure may be compared with 2001 and 2005/06 results.	
SPSS Code and Annotation	
<p>*Outcome 3: CSHCN whose families have adequate private and/or public insurance to pay for the services they need</p> <p>*STEP 1: Create interim variables for constructing outcome.</p> <pre> COMPUTE hasins_09 = 99. IF (unins = 0) hasins_09 = 0. IF (unins = 1) hasins_09 = 1. EXECUTE. VARIABLE LABELS hasins_09 'Insurance status at time of survey'. VALUE LABELS hasins_09 0 'Currently insured' 1 'Not insured' 99 'DK/Ref'. COMPUTE nogaps_09 = 999. IF (unins_yr = 0) nogaps_09 = 0. IF (unins_yr = 1) nogaps_09 = 1. IF (unins_yr = 6 or unins_yr = 7) nogaps_09 = 99. EXECUTE. </pre>	

MCHB Core Outcomes & System of Care

```
VARIABLE LABELS nogaps_09 'One or more gaps in insurance, past year'.
VALUE LABELS nogaps_09
0 'Insured continuously all year'
1 'One or more periods of no insurance'
999 'SYSMISS'
99 'DK/Ref'.

COMPUTE metneeds_09 = 99.
IF (SYSMIS (c8q01_a)) metneeds_09 = 3.
IF (hasins_09 = 1) metneeds_09 = 2.
IF (c8q01_a = 1) or (c8q01_a = 2) metneeds_09 = 0.
IF (c8q01_a = 3) or (c8q01_a = 4) metneeds_09 = 1.
EXECUTE.
VARIABLE LABELS metneeds_09 'Health insurance benefits meet child needs'.
VALUE LABELS metneeds_09
0 'Never/sometimes'
1 'Usually/always'
2 'Legit skip b/c uninsured'
3 'Sys missing'
99 'DK/Ref'.

COMPUTE reasonable_09 = 99.
IF (SYSMIS (c8q01_b)) reasonable_09 = 3.
IF (hasins_09 = 1) reasonable_09 = 2.
IF (c8q01_b = 1) or (c8q01_b = 2) reasonable_09 = 0.
IF (c8q01_b = 3) or (c8q01_b = 4) reasonable_09 = 1.
IF (c8q01_b = 5) reasonable_09 = 1.
EXECUTE.
VARIABLE LABELS reasonable_09 'Non-covered insurance charges reasonable'.
VALUE LABELS reasonable_09
0 'Never/sometimes'
1 'Usually/always'
2 'Legit skip b/c uninsured'
3 'Sys missing'
99 'DK/Ref'.

COMPUTE providers_09 = 99.
IF (SYSMIS (c8q01_c)) providers_09 = 3.
IF (hasins_09 = 1) providers_09 = 2.
IF (c8q01_c = 1) or (c8q01_c = 2) providers_09 = 0.
IF (c8q01_c = 3) or (c8q01_c = 4) providers_09 = 1.
EXECUTE.
VARIABLE LABELS providers_09 'Insurance allows child to see needed providers'.
VALUE LABELS providers_09
0 'Never/sometimes'
1 'Usually/always'
2 'Legit skip b/c uninsured'
3 'Sys missing'
99 'DK/Ref'.

*STEP 2: Construct Outcome 3.

compute outcome3_09=1.
if (nogaps_09=1) outcome3_09=0.
if (metneeds_09 = 0 ) or (reasonable_09 = 0) or (providers_09 = 0) outcome3_09=0.
```

MCHB Core Outcomes & System of Care

if (nogaps_09>98) or (metneeds_09 >2) or (reasonable_09 >2) or (providers_09 >2) outcome3_09=99.
EXE.

VARIABLE LABELS outcome3_09 'CSHCN whose families have adequate private and/or public insurance to pay for the services they need'.

VALUE LABELS outcome3_09

0 'Did not meet outcome'

1 'Met outcome'

99 'DK/REF/MISSING on any'.

MISSING VALUES outcome3_09 (99).

FORMATS outcome3_09 (f2.0).

MCHB Core Outcomes & System of Care

OUTCOME #4	CSHCN who are screened early and continuously for special health care needs
Survey Items Used	K4Q20R; K4Q21R
Numerator	CSHCN who had at least 1 preventive medical visit and at least 1 preventive dental visit in the past 12 months
Denominator	CSHCN age 0 -17 years
Description	Percent of CSHCN who receive both preventive medical and dental care during the past 12 months.
Notes for Data-Users	
CSHCN meet outcome #4 if they received at least 1 preventive medical visit (K4Q20R) and 1 preventive dental visit (K4Q21R) in the past 12 months. Parents answering “don’t know” or “refused” to either of the items used for the measure are not included in the scoring of outcomes or indicators (they are set to missing).	
Revisions in 2009/10	
The items used to construct this measure were substantially altered from the way the measure was constructed in the 2005/06 NS-CSHCN. Items K4Q20R and K4Q21R measuring the number of preventive medical and dental visits (respectively) were used. These items align with the measurement of similar services in the 2007 National Survey of Children's Health. This measure should not be compared with 2005/06; this outcome was not calculated in 2001.	
SPSS Code and Annotation	
<p>*Outcome 4: CSHCN who are screened early and continuously for special health care needs.</p> <p>*STEP 1: Construct interim variables for outcome 4, preventive medical care and preventive dental care in the prior 12 months.</p> <p>*Step 1a: preventive medical care.</p> <p>RECODE K4Q20R (0=0) (1 thru 12=1) (96 thru 97=99) (SYSMIS=99) into prevmed_09. variable labels prevmed_09 "Number of preventive medical visits recoded into dichotomous variable". value labels prevmed_09 0 "No preventive visits in past 12 months" 1 "At least 1 preventive visit in past 12 months" 99 "DK/REF/SYSMIS". FORMATS prevmed_09 (F4.0).</p>	

MCHB Core Outcomes & System of Care

*Step 1b: preventive dental care.

RECODE K4Q21R

(0=0) (1 thru 10=1) (96 thru 97=99) (SYSMIS=99)

into

prevdent_09.

variable labels prevdent_09 "Number of preventive dental visits recoded into dichotomous variable".

value labels prevdent_09

0 "No preventive dental visits in past 12 months"

1 "At least 1 preventive visit in past 12 months"

99 "DK/REF/SYSMIS".

FORMATS prevdent_09 (F4.0).

COMPUTE prevdental_09=999.

if (age>0) and (prevdent_09=0) prevdental_09=0.

if (age>0) and (prevdent_09=1) prevdental_09=1.

if (prevdent_09=99) prevdental_09=99.

if (age=0) prevdental_09=999.

variable labels prevdental_09 "Preventive dental visits 1-17 years in dichotomous variable".

value labels prevdental_09

0 "No preventive dental visits in past 12 months"

1 "At least 1 preventive visit in past 12 months"

99 "DK/REF/SYSMIS"

999 "Less than 1 year old".

FORMATS prevdental_09 (F4.0).

*STEP 2: Construct outcome 4.

COMPUTE outcome4_09=99.

if (prevmed_09=1) and ((prevdental_09=1) or (prevdental_09=999)) outcome4_09=1.

if (prevmed_09=0) or (prevdental_09=0) outcome4_09=0.

if (prevmed_09=99) or (prevdental_09=99) outcome4_09=99.

EXECUTE.

VARIABLE LABELS outcome4_09 "CSHCN who are screened early and continuously for special health care needs".

VALUE LABELS outcome4_09

0 "Did not meet outcome criteria"

1 "Met outcome 4 criteria"

99 "DK/REF/SYSMISS on either".

MISSING VALUES outcome4_09 (99).

FORMATS outcome4_09 (F4.0).

MCHB Core Outcomes & System of Care

OUTCOME #5	CSHCN who can easily access community-based services
Survey Items Used	C4Q03_A, C4Q03_B, C4Q03_C, C4Q03_D, C4Q03_E, C4Q03_F, C4Q04
Numerator	CSHCN whose families report no difficulties or frustration accessing services needed for their child in the past 12 months
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN whose families report no difficulties or frustration accessing services needed for their child in the past 12 months.
Notes for Data-Users	
<p>Though the concept about ease of access to services remains the same, this measure was completely revised in 2009/10. This measure is now comprised of six difficulties with accessing care: 1) not eligible for services; 2) services not available in your area; 3) waiting lists or other problems getting appointments; 4) issues related to cost; 5) trouble getting the information you needed; 6) any other difficulties not mentioned AND an assessment of how often parents were frustrated in their efforts to get services. Those CSHCN in the numerator answered YES to one of the six difficulties and usually or always to the frustration item. Parents answering “don’t know” or “refused” to any of the items used for the measure are not included in the scoring of outcomes or indicators (they are set to missing).</p>	
Revisions in 2009/10	
<p>Measurement of this outcome was completely revised in 2009/10. This measure is not comparable to outcome #5 from the 2005/06 NS-CSHCN survey.</p>	
SPSS Code and Annotation	
<p>***NEW outcome #5 scoring, ease of access to service use based on new items for 2009/10. This is different and not comparable with the 2005/06 measure**</p> <p>*STEP 1: Recode C4Q03_A through C4Q03_E to set DK/REF and SYSMIS values to 99**</p> <p>RECODE C4Q03_A (6 thru 7=99) (else=copy) into ineligible_09. RECODE C4Q03_B (6 thru 7=99) (else=copy) into unavailable_09. RECODE C4Q03_C (6 thru 7=99) (else=copy) into backlogs_09. RECODE C4Q03_D (6 thru 7=99) (SYSMIS=99) (else=copy) into costs_09. RECODE C4Q03_E (6 thru 7=99) (SYSMIS=99) (else=copy) into information_09.</p> <p>VARIABLE LABELS ineligible_09 "In past 12 months, any difficulties or delays because child was not eligible for services?". VARIABLE LABELS unavailable_09 "In past 12 months, any difficulties or delays because services not available in your area?". VARIABLE LABELS backlogs_09 "In past 12 months, any difficulties or delays because there were</p>	

MCHB Core Outcomes & System of Care

waitlists, backlogs or problems getting an appointment?".

VARIABLE LABELS costs_09 "In past 12 months, any difficulties or delays because because of issues related to costs?".

VARIABLE LABELS information_09 "In past 12 months, any difficulties or delays because of trouble getting info you needed?".

value labels ineligible_09 unavailable_09 backlogs_09 costs_09 information_09

0 "Did not experience this difficulty"

1 "Experienced this difficulty"

99 "DK/REF/SYSMIS".

*STEP 2: C4Q03F (which asks about any other difficulties) legitimately skips cases who have already given a positive response on one of the other five difficulties. First recode C4Q03_F to set SYSMIS to 99. Then create count variable to assess which of the SYSMIS cases are due to previous positive answers (12,055) this leaves one SYSMIS case to be set to 99 in final variable otherdelay_09.

RECODE C4Q03_F (SYSMIS=99) (else=copy) into odelay_09.

VARIABLE LABELS odelay_09 "In past 12 months, any difficulties or delays because of other reasons--interim step variable?".

value labels odelay_09

0 "Did not experience this difficulty"

1 "Experienced OTHER difficulty"

6 "DK"

99 "SYSMIS-legit skip".

FORMATS ineligible_09 unavailable_09 backlogs_09 costs_09 information_09 odelay_09 otherdelay_09 (F4.0).

count delaytest_09=C4Q03_A C4Q03_B C4Q03_C C4Q03_D C4Q03_E (1).

variable labels delaytest_09 "Count of delays experienced in C4Q03_A thru C4Q03_E to assess those with legit skip on C4Q03_F".

value labels delaytest_09

0 "No delays or legit skip"

5 "All 5 delays or difficulties".

COMPUTE otherdelay_09=99.

if (odelay_09=1) otherdelay_09=1.

if (odelay_09=6) otherdelay_09=99.

if (delaytest_09>0) and (odelay_09=99) otherdelay_09=1.

if (delaytest_09=0) and (odelay_09=0) otherdelay_09=0.

if (delaytest_09=0) and (odelay_09=99) otherdelay_09=99.

value labels otherdelay_09

0 "Did not experience this difficulty"

1 "Experienced OTHER or one of the previous 5 difficulties"

99 "DK/REF".

VARIABLE LABELS otherdelay_09 "In past 12 months, any difficulties or delays because of other reasons (legit skip children set to 1 since they already experienced one of the other delays)?".

*STEP 3: recode C4Q04 (frustration) variable.

recode C4Q04

(1 thru 2=0) (3 thru 4=1) (6 thru 7=99) (SYSMIS=99)

MCHB Core Outcomes & System of Care

into
frustrated_09.

variable labels frustrated_09 "How often were you frustrated in efforts to get services for child?".

value labels frustrated_09

0 "Never/sometimes"

1 "Usually/always frustrated"

99 "DK/REF/SYSMIS".

formats frustrated_09 (F4.0).

*STEP 4: Create outcome 5.

COMPUTE outcome5_09=0.

if (ineligible_09=0) and (unavailable_09=0) and (backlogs_09=0) and (costs_09=0) and
(information_09=0) and (otherdelay_09=0) and (frustrated_09=0) outcome5_09=1.

if (ineligible_09=1) or (unavailable_09=1) or (backlogs_09=1) or (costs_09=1) or (information_09=1) or
(otherdelay_09=1) or (frustrated_09=1) outcome5_09=0.

if (ineligible_09=99) or (unavailable_09=99) or (backlogs_09=99) or (costs_09=99) or
(information_09=99) or (otherdelay_09=99) or (frustrated_09=99) outcome5_09=99.

VARIABLE LABELS outcome5_09 "CSHCN who can easily access community-based services".

VALUE LABELS outcome5_09

0 "Did not meet outcome #5"

1 "Met outcome #5"

99 "DK/REF/SYSMIS on any".

FORMATS outcome5_09 (F4.0).

MISSING VALUES outcome5_09 (99).

MCHB Core Outcomes & System of Care

OUTCOME #6	Youth with special health care needs who receive the necessary services for transition to adulthood
Survey Items Used	C6Q07 C6Q0A_B C6Q0A_C C6Q0A, C6Q0A_D C6Q0A_E C6Q0A_F C6Q08
Numerator	CSHCN ages 12-17 whose doctors usually/always encourage increasing responsibility for self-care AND (when needed) have discussed transitioning to adult health care, changing health care needs, and how to maintain insurance coverage.
Denominator	CSHCN age 12–17 years
Description	Percent of youth with special health care needs who received the necessary services to transition to adulthood
Notes for Data-Users	
<p>Youth with special health care needs meet if their doctor or other healthcare providers provided anticipatory guidance for the transition to adult care and if they usually or always encourage the child to take age-appropriate responsibility for his or her own health needs. Anticipatory guidance is assessed with three components (all must be met for the child to meet the outcome): (1) discussing the shift to adult health care, if needed, (2) discussing changing needs as youth becomes an adult, if needed and (3) discussing health insurance as youth becomes an adult, if needed. Parents answering “don’t know” or “refused” to any of the items used for the measure are not included in the scoring of outcomes or indicators (they are set to missing).</p>	
Revisions in 2009/10	
This measure is comparable with 2005/06 results.	
SPSS Code and Annotation	
<p>*Outcome 6: Youth with special health care needs who receive the necessary services for transition to adulthood.</p> <p>*STEP 1: Compute interim variables to express if drs discussed shift to adult provider (mettrans1), changing needs as becomes adult (mettrans2), and/or insurance coverage during transition to adulthood (mettrans3)</p> <pre> COMPUTE mettrans1_09 = 99. IF (C6Q07 = 1) and (C6Q0A_B = 1) mettrans1_09 = 1. IF (C6Q07 = 1) and ((C6Q0A_B = 0) and (C6Q0A_C = 1)) mettrans1_09 = 0. IF (C6Q07 = 1) and ((C6Q0A_B = 0) and (C6Q0A_C = 0)) mettrans1_09 = 2. IF (C6Q07 = 0) mettrans1_09 = 2. IF (age <12) mettrans1_09 = 98. EXECUTE. VARIABLE LABELS mettrans1_09 "Drs discussed shift to adult provider, if helpful". </pre>	

MCHB Core Outcomes & System of Care

VALUE LABELS mettrans1_09

0 'No'

1 'Yes'

2 'Legit skip b/c discussion not needed or sees provider who can transition'

98 "Child 0-11 years of age"

99 'DK/REF to any'.

formats mettrans1_09 (F4.0).

COMPUTE mettrans2_09 = 99.

IF (C6Q0A = 1) mettrans2_09 = 1.

IF (C6Q0A_D = 0) mettrans2_09 = 2.

IF (C6Q0A_D = 1) mettrans2_09 = 0.

IF (age <12) mettrans2_09 = 98.

EXECUTE.

VARIABLE LABELS mettrans2_09 "Drs talked about changing needs as becomes adult, if helpful".

VALUE LABELS mettrans2_09

0 'No'

1 'Yes'

2 'Legit skip b/c discussion not needed'

98 "Child is 0-11 years of age"

99 'DK/REF to any'.

Formats mettrans2_09 (F4.0).

COMPUTE mettrans3_09= 99.

IF (C6Q0A_E = 1) mettrans3_09 = 1.

IF (C6Q0A_F = 0) mettrans3_09 = 2.

IF (C6Q0A_F = 1) mettrans3_09 = 0.

IF (age <12) mettrans3_09 = 98.

EXECUTE.

VARIABLE LABELS mettrans3_09 "Drs talked about insurance coverage as becomes adult, if needed".

VALUE LABELS mettrans3_09

0 'No'

1 'Yes'

2 'Legit skip b/c discussion not needed'

98 "Child is 0-11 years of age"

99 'DK/REF to any'.

Formats mettrans3_09 (F4.0).

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

COMPUTE adtrans_09 = 99.

IF (mettrans1_09 = 1 or mettrans1_09 = 2) and (mettrans2_09 = 1 or mettrans2_09 = 2) and (mettrans3_09 = 1 or mettrans3_09 = 2) adtrans_09 = 1.

IF (mettrans1_09 = 0) or (mettrans2_09 = 0) or (mettrans3_09 = 0) adtrans_09 = 0.

IF (mettrans1_09 = 2) and (mettrans2_09 = 2) and (mettrans3_09 = 2) adtrans_09 = 2.

IF (mettrans1_09 = 99) or (mettrans2_09 = 99) or (mettrans3_09 = 99) adtrans_09 = 99.

IF (age <12) adtrans_09 = 98.

EXECUTE.

VARIABLE LABELS adtrans_09 "Met criteria for getting all 3 adult transition components".

VALUE LABELS adtrans_09

0 'No'

1 'Yes'

99 'DK/REF to any'

98 "Child is 0-11 years of age"

MCHB Core Outcomes & System of Care

2 'Legit skip b/c all 3 components were not needed'.
FORMATS adtrans_09 (F4.0).

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

COMPUTE mettrans4_09 = 99.

IF (age >= 12) and (C6Q08 = 1 or C6Q08 = 2) mettrans4_09= 0.

IF (age >= 12) and (C6Q08 = 3 or C6Q08 = 4) mettrans4_09= 1.

IF (age <12) mettrans4_09 = 98.

EXECUTE.

VARIABLE LABELS mettrans4_09 "Drs encourage ch to engage in age appropriate self care -- ages 12-17 only".

VALUE LABELS mettrans4_09

0 'Never/Sometimes'

1 'Usually/Always'

99 'DK/REF/MISSING to any'

98 'Legitimate skip b/c <12 yrs old'.

FORMATS mettrans4_09 (F4.0).

*STEP 3: Construct outcome 6.

COMPUTE outcome6_09 = 99.

IF (adtrans_09 = 0) or (mettrans4_09 = 0) outcome6_09 = 0.

IF (adtrans_09 = 1 or adtrans_09=2) and (mettrans4_09 = 1) outcome6_09 = 1.

IF (adtrans_09 = 99) or (mettrans4_09 = 99) outcome6_09 = 99.

IF (mettrans4_09 = 98) and (adtrans_09 = 98) outcome6_09 = 98.

EXECUTE.

VARIABLE LABELS outcome6_09 "Youth with special health care needs who receive the necessary services for transition to adulthood".

VALUE LABELS outcome6_09

0 'Did not meet outcome'

1 'Met outcome'

99 'DK/REF/MISSING on both'

98 'Legitimate skip b/c <12 yrs old'.

MISSING VALUES outcome6_09 (98, 99).

FORMATS outcome6_09 (f2.0).

MCHB Core Outcomes & System of Care

SYSTEM OF CARE #1	CSHCN age 0-11 years who are served by systems of care meeting all age-relevant core outcomes
Survey Items Used	Over 50 different survey questions are used to construct the 5 derived variables counted for purposes of this indicator; items are specified under each of the MCHB Core Outcomes #1-5.
Numerator	0-2 outcomes achieved; 3-4 outcomes achieved; All 5 outcomes achieved
Denominator	CSHCN age 0-11 years
Description	CSHCN age 0-11 years who are served by systems of care meeting all five age-relevant core outcomes
Notes for Data-Users	
CSHCN ages 0-11 years were considered to be served by a "service system" as described in the Healthy People objective, if their care met the criteria on each of the age-relevant outcomes. Five of the six MCHB core outcomes for CSHCN apply to children birth through age 11 years.	
Revisions in 2009/10	
Substantial revisions in core outcomes 1, 4 and 5 took place between 2005/06 and 2009/10 implementations of the NS-CSHCN. These composite measures are not comparable across survey years.	
SPSS Code and Annotation	
<p>*System of Care indicator for CSHCN age 0-11 years</p> <p>*NOTE: Make sure that user missing values (99) are NOT set to MISSING in the MCHB outcome variables before running this code</p> <p>MISSING VALUES outcome1_09 outcome2_09 outcome3_09 outcome4_09 outcome5_09 ().</p> <p>count syst1_ct = outcome1_09 outcome2_09 outcome3_09 outcome4_09 outcome5_09 (1).</p> <p>if (outcome1_09 = 99) or (outcome2_09 = 99) or (outcome3_09 = 99) or (outcome4_09 = 99) or (outcome5_09 = 99) syst1_ct = 99.</p> <p>if (AGE >=12) syst1_ct = 999.</p> <p>VARIABLE LABELS syst1_ct 'CSHCN ages 0-11 meeting one or more of five criteria for system of care'.</p> <p>VALUE LABELS syst1_ct</p> <p>0 '0 outcomes achieved'</p> <p>1 '1 outcome achieved'</p> <p>2 '2 outcomes achieved'</p> <p>3 '3 outcomes achieved'</p> <p>4 '4 outcomes achieved'</p> <p>5 'All 5 outcomes achieved'</p>	

MCHB Core Outcomes & System of Care

```
99 'DK/Ref to any'  
999 'CSHCN ages 12 -17'.  
MISSING VALUES syst1_ct (99, 999).  
  
RECODE syst1_ct (0 thru 2 = 1) (3 thru 4 = 2) (5 = 3) (else=copy) into systcare_09.  
EXECUTE.  
VARIABLE LABELS systcare_09 "CSHCN age 0-11 years who are served by systems of care meeting  
all age-relevant core outcomes".  
VALUE LABELS systcare_09  
1 '0-2 outcomes achieved'  
2 '3-4 outcomes achieved'  
3 'All 5 outcomes achieved'  
99 'DK/Ref to any'  
999 'CSHCN ages 12 -17'.  
MISSING VALUES systcare_09 (99,999).  
FORMATS systcare_09 (f2.0).
```


MCHB Core Outcomes & System of Care

SYSTEM OF CARE #2	CSHCN age 12-17 years who are served by systems of care meeting all 6 MCHB core outcomes
Survey Items Used	Over 50 different survey questions are used to construct the 6 derived variables counted for purposes of this indicator; items are specified under each of the MCHB Core Outcomes #1-6.
Numerator	Achieved 0-2 outcomes; Achieved 3-4 outcomes; Achieved 5 outcomes; Achieved all 6 outcomes
Denominator	CSHCN age 12 -17 years
Description	CSHCN age 12-17 years who are served by systems of care meeting all 6 core outcomes
Notes for Data-Users	
CSHCN ages 12-17 years were considered to be served by a "service system" as described in the Healthy People objective, if their care met the criteria on each of the age-relevant outcomes. Five of the six MCHB core outcomes for CSHCN apply to children birth through age 11 years. The sixth outcome, transition to adulthood, only pertains to youth ages 12 years and over.	
Revisions in 2009/10	
Substantial revisions in core outcomes 1, 4 and 5 took place between 2005/06 and 2009/10 implementations of the NS-CSHCN. These composite measures are not comparable across survey years.	
SPSS Code and Annotation	
<p>*CSHCN age 12-17 years who are served by systems of care meeting all 6 core outcomes</p> <p>*NOTE: Make sure that user missing values (99) are not set to MISSING in the MCHB outcome variables before running this code.</p> <p>MISSING VALUES outcome1_09 outcome2_09 outcome3_09 outcome4_09 outcome5_09 outcome6_09 ().</p> <p>count syst2_ct = outcome1_09 outcome2_09 outcome3_09 outcome4_09 outcome5_09 outcome6_09 (1).</p> <p>if (outcome1_09 = 99) or (outcome2_09 = 99) or (outcome3_09 = 99) or (outcome4_09 = 99) or (outcome5_09 = 99) or (outcome6_09 = 99) syst2_ct = 99.</p> <p>if (AGE <12) syst2_ct = 999.</p> <p>VARIABLE LABELS syst2_ct 'CSHCN ages 12-17 meeting one or more of six criteria for system of care'.</p> <p>VALUE LABELS syst2_ct</p> <p>0 '0 outcomes achieved'</p>	

MCHB Core Outcomes & System of Care

1 '1 outcome achieved'
2 '2 outcomes achieved'
3 '3 outcomes achieved'
4 '4 outcomes achieved'
5 '5 outcomes achieved'
6 'All 6 outcomes achieved'
99 'DK/Ref to any'
999 'CSHCN ages 0-11'.
MISSING VALUES syst2_ct (99,999).

RECODE syst2_ct (0 thru 2 = 1) (3 thru 4 = 2) (5 = 3) (6=4) into systcare2_09.
EXECUTE.

variable labels systcare2_09 "CSHCN age 12-17 years who are served by systems of care meeting all 6 MCHB core outcomes".

VALUE LABELS systcare2_09

1 '0-2 outcomes achieved'
2 '3-4 outcomes achieved'
3 '5 outcomes achieved'
4 'Outcomes achieved in all 6 areas'
99 'DK/Ref to any'
999 'CSHCN ages 0-11'.
MISSING VALUES systcare2_09 (999).
FORMATS systcare2_09 (f2.0).

MCHB Core Outcomes & System of Care

SYSTEM OF CARE #3	CSHCN age 0-17 years who are served by systems of care meeting all age-relevant MCHB core outcomes
Survey Items Used	Over 50 different survey questions are used to construct the 6 derived variables counted for purposes of this indicator; items are specified under each of the MCHB Core Outcomes #1-6.
Numerators	CSHCN served by care systems that fail to meet at least two age-relevant core outcomes; CSHCN served by care systems that meet all but one age-relevant core outcomes; CSHCN served by care systems that meet all age-relevant core outcomes
Denominator	CSHCN age 0-17 years
Description	CSHCN age 0-17 years who are served by systems of care meeting all age-relevant core outcomes
Notes for Data-Users	
CSHCN ages 12-17 years were considered to be served by a "service system" as described in the Healthy People objective, if their care met the criteria on each of the 6 age-relevant outcomes. Five of the six MCHB core outcomes for CSHCN apply to children birth through age 11 years. The sixth outcome, transition to adulthood, only pertains to youth ages 12 years and over.	
Revisions in 2009/10	
Substantial revisions in core outcomes 1, 4 and 5 took place between 2005/06 and 2009/10 implementations of the NS-CSHCN. These composite measures are not comparable across survey years.	
SPSS Code and Annotation	
<p>*NOTE: Make sure to run the syntax above to create syst1_ct and syst2_count before running the syntax below.</p> <p>Missing values syst1_ct syst2_ct ().</p> <pre> compute systcare_all_09 = 999. if age<12 and syst1_ct=5 systcare_all_09= 2. if age<12 and syst1_ct=4 systcare_all_09=1. if age<12 and syst1_ct<4 systcare_all_09= 0. if age>11 and syst2_ct=6 systcare_all_09= 2. if age>11 and syst2_ct=5 systcare_all_09= 1. if age>11 and syst2_ct<5 systcare_all_09 = 0. if syst2_ct=99 or syst1_ct=99 systcare_all_09=99. variable labels systcare_all_09 "CSHCN age 0-17 years who are served by systems of care meeting all age-relevant MCHB core outcomes". value labels systcare_all_09 2 "All age-relevant core outcomes achieved" 1 "1 age-relevant core outcome NOT achieved" 0 "2 or more age-relevant core outcomes NOT achieved" 99 "missing". formats systcare_all_09 (f3.0). </pre>	

MCHB Core Outcomes & System of Care

missing values systcare_all_09 (99).

Conditions & Functional Difficulties

NUMBER OF CONDITIONS	Number of current health conditions reported from list of 20 different conditions asked in the survey
Survey Items Used	K2Q31A/B; K2Q32A/B; K2Q33A/B; K2Q34A/B; K2Q35A/B; K2Q36A/B; K2Q37A/B; K2Q38A/B; K2Q39A/B; K2Q40A/B; K2Q41A/B; K2Q42A/B; K2Q43A/B; K2Q44A/B; K2Q45A/B; K2Q46A/B; K2Q47A/B; K2Q48A/B; K2Q49A/B; K2Q50A/B; K2Q51A/B; K2Q52A/B
Numerator	No conditions on list; 1 condition on list; 2 conditions on list; 3 conditions on list; 4 or more conditions on list.
Denominator	CSHCN age 0-17 years
Description	Number of current health conditions reported from list of 20 different conditions asked in the survey
Notes for Data-Users	
<p>After each assessment of whether the child was ever told they had a condition, a follow up item was asked to see if the child currently has the condition. The items assessing ever told are labeled "A" in the interview guide. The questions assessing whether the condition is current are labeled "B" in the interview guide. This measure of how many children currently have conditions is based on the list of 20 conditions asked about in the survey and whether or not the child's condition is CURRENT. Therefore, those who were ever told they had a condition but do not currently have that condition are not included in this measure.</p>	
Revisions in 2009/10	
<p>In 2009/10, significant changes were made to the wording of the introduction respondents heard prior to answering questions K2Q31A through K2Q52A. In 2005/06, parents were asked if "to the best of your knowledge, does [child] currently have...". In 2009/10, the introduction was changed to "For each condition, please tell me if a doctor or other health care provider ever told you that [CHILD] had the condition, even if (he/she) does not have the condition now." Take these changes into consideration when comparing results across survey years.</p>	
SPSS Code and Annotation	
<p>COUNT condcount_09 = K2Q31B K2Q32B K2Q33B K2Q34B K2Q35B K2Q36B K2Q37B K2Q40B K2Q41B K2Q42B K2Q43B K2Q44B K2Q45B K2Q46B K2Q47B K2Q48B K2Q49B K2Q50B K2Q51B K2Q52B (1). IF (K2Q31A>3 AND K2Q32A>3 AND K2Q33A>3 AND K2Q34A>3 AND K2Q35A>3 AND K2Q36A>3 AND K2Q37A>3 AND K2Q40A>3 AND K2Q41A>3 AND K2Q42A>3 AND K2Q43A>3 AND K2Q44A>3 AND K2Q45A>3 AND K2Q46A>3 AND K2Q47A>3 AND K2Q48A>3 AND K2Q49A>3 AND K2Q50A>3 AND K2Q51A>3 AND K2Q52A>3) condcount_09=99.</p>	

Conditions & Functional Difficulties

VARIABLE LABELS condcount_09 'Number of CURRENT health conditions reported from a list of 20'.
RECODE condcount_09 (0=0) (1=1) (2=2) (3=3) (4 thru 20=4) (99=99) INTO conditions20_09 .

VARIABLE LABELS conditions20_09 "Number of current health conditions reported from list of 20 different conditions asked in the survey".

VALUE LABELS conditions20_09

0 'No conditions reported'

1 '1 cond reported'

2 '2 conds reported'

3 '3 conds reported'

4 '4 or more conds reported'

99 'DK/REF to all conds'.

FORMATS conditions20_09 (f2.0).

MISSING VALUES conditions20_09 (99).

Conditions & Functional Difficulties

NUMBER OF DIFFICULTIES	Number of functional difficulties reported from list of 14 different difficulties asked in the survey
Survey Items Used	C3Q21 through C3Q34
Numerator	Number of functional difficulties (either a little or a lot of difficulty) reported from list of 14 different difficulties asked in the survey
Denominator	CSHCN age 0-17 years
Description	Number of functional difficulties reported from list of 14 different difficulties asked in the survey
Notes for Data-Users	
This measure is scored as the count of CSHCN who experience either a little or a lot of each of the 14 difficulties asked about.	
Revisions in 2009/10	
In 2009/10 changes were made to the response options for questions C3Q21 - C3Q34. They changed from "yes/no" in 2005/06 to "a lot of difficulty/a little difficulty/no difficulty" in 2009/10. There were also minor changes to the questions themselves to accommodate the change in response options. The questions assessing vision and hearing difficulties were also changed. Each series of three questions from 2005/06 (for example, "Without glasses or contact lenses, would you say (he/she) experiences any difficulty seeing?"/"Does (S.C.) wear glasses or contact lenses?"/"Does (S.C.) have any difficulty seeing even when wearing glasses or contact lenses?") was changed to just one question in 2009/10 (for example, "Would you say [he/she] experiences a lot, a little, or no difficulty seeing even when wearing glasses or contact lenses?"). Take these changes into consideration when comparing results across survey years.	
SPSS Code and Annotation	
<p>COUNT funcdif_09=C3Q23 C3Q24 C3Q25 C3Q26 C3Q21 C3Q22 C3Q27 C3Q28 C3Q29 C3Q30 C3Q31 C3Q32 C3Q33 C3Q34 (1,2).</p> <p>VARIABLE LABELS funcdif_09 "Count of 14 functional difficulties items, how many children experience a lot or a little difficulty".</p> <p>formats funcdif_09 (F4.0).</p> <p>RECODE funcdif_09 (0=0) (1=1) (2=2) (3=3) (4 thru highest=4) into funcdif5_09.</p> <p>VARIABLE LABELS funcdif5_09 "Number of functional difficulties reported from list of 14 different difficulties asked in the survey".</p>	

Conditions & Functional Difficulties

```
value labels funcdif5_09
0 "NO difficulties reported from list"
1 "1 difficulty reported from list"
2 "2 difficulties reported from list"
3 "3 difficulties reported from list"
4 "4 or more difficulties reported from list".
formats funcdif5_09 (F4.0).
```


Conditions & Functional Difficulties

EMOTIONAL DIFFICULTIES	CSHCN age 18 months - 17 years who have a little or a lot of difficulty with one or more emotional or behavioral factors
Survey Items Used	C3Q32-C3Q34
Numerators	CSHCN who have a little or a lot of difficulty with one or more emotional or behavioral factors; CSHCN with no emotional or behavioral difficulties
Denominator	CSHCN age 18 months - 17 years
Description	CSHCN who have a little or a lot of difficulty with 1 or more of the following: feeling anxious or depressed, acting-out, fighting, bullying or arguing, making and keeping friends, age 18 months-17 years
Notes for Data-Users	
All information from the 2009-2010 survey about children's current functional difficulties is based on parent report.	
Revisions in 2009/10	
In 2009/10 changes were made to the response options for this question. They were changed from "yes" or "no" in 2005/06 to "a lot of difficulty" "a little difficulty" or "no difficulty" in 2009/10. There were also minor changes to the wording of the question to accommodate the new response options. Take these changes into consideration when comparing across survey years.	
SPSS Code and Annotation	
missing values C3Q32 C3Q33 C3Q34 ().	
*STEP 1: Recode needed variables into new variables with no system missing cases.	
recode C3Q32 (sysmis=999) (else=copy) into C3Q32R. recode C3Q33 (sysmis=999) (else=copy) into C3Q33R. recode C3Q34 (sysmis=999) (else=copy) into C3Q34R.	
*STEP 2: Compute emotional or behavioral difficulties variable.	
COMPUTE emot_ICF_09 =0. IF (C3Q32R<3) or (C3Q33R<3) or (C3Q34R<3) emot_ICF_09=1. IF ((C3Q32R>3) and (C3Q33R>3) and (C3Q34R>3)) emot_ICF_09=99. VARIABLE LABELS emot_ICF_09 'CSHCN age 18 months - 17 years who have a little or a lot of difficulty with one or more emotional or behavioral factors (C3Q32-C3Q34)'. VALUE LABELS emot_ICF_09 0 'No emotional or behavioral difficulties' 1 'A little or a lot of difficulty with one or more emotional or behavioral factors' 99 "DK/RF or not in age range for all".	

Conditions & Functional Difficulties

FORMATS emot_ICF_09 (f3.0).
missing values emot_ICF_09 (99).

Conditions & Functional Difficulties

ACTIVITY DIFFICULTIES	CSHCN age 0 - 17 years who have a little or a lot of difficulty with one or more activities or participation
Survey Items Used	C3Q27-C3Q31
Numerators	CSHCN who have a little or a lot of difficulty with one or more activities; CSHCN with no difficulties involving activities
Denominator	CSHCN age 0-17 years
Description	CSHCN who have a little or a lot of difficulty with 1 or more of the following: self care, coordination or moving around, using hands, learning, understanding or paying attention, speaking, communicating or being understood
Notes for Data-Users	
All information from the 2009-2010 survey about children's current functional difficulties is based on parent report. Some questions used for this measure are not asked of all ages. For children under 12 months old, this measure is based on questions C3Q28-C3Q29 only and for children 12-35 months old, this measure is based on questions C3Q28-C3Q31 only.	
Revisions in 2009/10	
In 2009/10 changes were made to the response options for this question. They were changed from "yes" or "no" in 2005/06 to "a lot of difficulty" "a little difficulty" or "no difficulty" in 2009/10. There were also minor changes to the wording of the question to accommodate the new response options. Take these changes into consideration when comparing across survey years.	
SPSS Code and Annotation	
missing values C3Q27 C3Q28 C3Q29 C3Q30 C3Q31 ().	
*STEP 1: Recode variables with age skips into new variables with no system missing cases.	
recode C3Q31 (sysmis=999) (else=copy) into C3Q31R. recode C3Q30 (sysmis=999) (else=copy) into C3Q30R. recode C3Q27 (sysmis=999) (else=copy) into C3Q27R.	
*STEP 2: Compute activity difficulties variable.	
COMPUTE activity_ICF_09 =0. IF (C3Q27R<3) or (C3Q28<3) or (C3Q29<3) or (C3Q30R<3) or (C3Q31R<3) activity_ICF_09 = 1. IF ((C3Q27R>3) and (C3Q28>3) and (C3Q29>3) and (C3Q30R>3) and (C3Q31R>3)) activity_ICF_09=99. VARIABLE LABELS activity_ICF_09 'CSHCN age 0 - 17 years who have a little or a lot of difficulty with one or more activities or participation (C3Q27-C3Q31)'. VALUE LABELS activity_ICF_09	

Conditions & Functional Difficulties

0 'No difficulties with activities'
1 'A little or a lot of difficulty with one or more activities'
99 "DK/RF or not in age range for all".
FORMATS activity_ICF_09 (f3.0).
missing values activity_ICF_09 (99).

Conditions & Functional Difficulties

BODY DIFFICULTIES	CSHCN age 0-17 years who have a little or a lot of difficulty with one or more body functions
Survey Items Used	C3Q23 C3Q24 C3Q25 C3Q26 C3Q21 C3Q22
Numerator	CSHCN who have a little or a lot of difficulty with one or more bodily functions; CSHCN with no difficulties involving bodily functions
Denominator	CSHCN age 0-17 years
Description	CSHCN who have a little or a lot of difficulty with 1 or more of the following: breathing or respiration, swallowing or digestion, blood circulation, chronic physical pain including headaches, seeing even when wearing glasses or contacts, hearing even when using a hearing aid
Notes for Data-Users	
All information from the 2009-2010 survey about children's current functional difficulties is based on parent report.	
Revisions in 2009/10	
In 2009/10 changes were made to the response options for this question. They were changed from "yes" or "no" in 2005/06 to "a lot of difficulty" "a little difficulty" or "no difficulty" in 2009/10. There were also minor changes to the wording of the question to accommodate the new response options. The questions assessing vision and hearing difficulties were also changed. Each series of three questions from 2005/06 (for example, "Without glasses or contact lenses, would you say (he/she) experiences any difficulty seeing?"/"Does (S.C.) wear glasses or contact lenses?"/"Does (S.C.) have any difficulty seeing even when wearing glasses or contact lenses?") was changed to just one question in 2009/10 (for example, "Would you say [he/she] experiences a lot, a little, or no difficulty seeing even when wearing glasses or contact lenses?"). Take these changes into consideration when comparing results across survey years. Take these changes into consideration when comparing across survey years.	
SPSS Code and Annotation	
missing values C3Q23 C3Q24 C3Q25 C3Q26 C3Q21 C3Q22 (). COMPUTE body_ICF_09 =0. IF (C3Q23<3) or (C3Q24<3) or (C3Q25<3) or (C3Q26<3) or (C3Q21<3) or (C3Q22<3) body_ICF_09 = 1. IF (C3Q23>3) and (C3Q24>3) and (C3Q25>3) and (C3Q26>3) and (C3Q21>3) and (C3Q22>3) body_ICF_09=99. VARIABLE LABELS body_ICF_09 'CSHCN age 0-17 years who have a little or a lot of difficulty with one or more body functions (C3Q21-C3Q26)'. VALUE LABELS body_ICF_09 0 'No difficulties involving bodily functions' 1 'A little or a lot of difficulty with one or more bodily functions' 99 "DK/RF to all".	

Conditions & Functional Difficulties

FORMATS body_ICF_09 (f3.0).
missing values body_ICF_09 (99).

Stratifiers

SEX	How many males and females are in the CSHCN population?
Survey Items Used	C2Q03
Numerators	Male; Female
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years who are male or female
Notes for Data-Users	
None	
Revisions in 2009/10	
No changes; same as 2005/06 and 2001	
SPSS Code and Annotation	
RECODE SEX (6 thru 7=99) (else=copy) into SEX_09. VARIABLE LABELS SEX_09 'Sex of child'. VALUE LABELS SEX_09 1 "Male" 2 "Female" 99 "DK/RF". MISSING VALUES SEX_09 (99). FORMATS SEX_09 (f2.0).	

Stratifiers

AGE GROUP	How many children of different ages are in the CSHCN population?
Survey Items Used	Initial sampling question
Numerators	0–5 years old; 6–11 years old; 12–17 years old
Denominator	CSHCN age 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 2009-2010 NS_CSHCN Interview File.	
Revisions in 2009/10	
No changes; same as 2005/06 and 2001	
SPSS Code and Annotation	
<p>***How many children of different ages are in the CSHCN population?***</p> <pre> RECODE AGE (0 thru 5=1) (6 thru 11=2) (12 thru 17=3) INTO age3_09. EXECUTE. VARIABLE LABELS age3_09 'How many children of different ages are in the CSHCN population?'. VALUE LABELS age3_09 1 '0-5 yrs old' 2 '6-11 yrs old' 3 '12-17 yrs old'. FORMATS age3_09 (f2.0). </pre>	

Stratifiers

RACE/ETHNICITY	What is the race/ethnicity of the CSHCN population?
Survey Items Used	HISPANIC_IMP, RACER_IMP
Numerators	Hispanic ethnicity (any race); White (non-Hispanic); Black (non-Hispanic); Other (non-Hispanic)
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years who are Hispanic/Latino, or non-Hispanic and White, Black, or of another race.
Notes for Data-Users	
<p>This variable is constructed from variables in the publicly released 2009-2010 NS_CSHCN Screener file. It was constructed in the 2009-2010 NS_CSHCN Interview file after merging the needed variables from the Screener file into the interview file using the unique household identifier IDNUMR and the unique child identifier IDNUMXR as the linking variables. Unweighted frequency tables for this variable in the Screener and Interview files are included in Appendix B. Additional variables with imputed race and ethnicity for missing cases were merged from the Screener Imputation File.</p> <p>Children reporting Hispanic or Latino origin (HISPANIC_IMP = Yes) are counted as Hispanic regardless of reported race. Non-Hispanic children are grouped by race based on responses to RACER_IMP (CW10Q02 in the questionnaire); those reporting a single race category of either White or Black are grouped respectively; those reporting more than one race category or those reporting only one race category of Asian, American Indian, Alaska Native, Native Hawaiian, or Pacific Islander are all counted as "Other" except in a handful of states where the population meets the minimum 5% threshold for making the data public without breaching confidentiality.</p> <p>This version of race/ethnicity uses the 3rd imputed version of HISPANIC and RACER that was included in the Screener Imputation File. In the interview file, 1.6% of cases were imputed for race and 1.2% of cases were imputed for Hispanic ethnicity. Though this does not change prevalence rates significantly, this is a departure from the previous two versions of the survey where race variables were not imputed and those not reporting a race or ethnicity were set to missing.</p> <p>Additional information regarding race and ethnicity classification and imputation will be included in a forthcoming Design and Operations Manual released by NCHS.</p>	
Revisions in 2009/10	
<p>This construction of this variable varies slightly from the 2001 and 2005/06 NS-CSHCN. First, NCHS publicly release the variable RACER with one fewer category than previous years. In 2009/10 the categories of "multiracial" and "other" were combined into one group for confidentiality reasons. Second, based on a higher than expected number of missing race cases in the Screener File, NCHS created imputed race variables. Though this only affects approximately 650 cases in the Interview File, it does mean that there are zero missing cases in 2009 which is not true of previous years. Please take these issues into consideration when comparing across years.</p>	

Stratifiers

SPSS Code and Annotation

****NOTE:** Multiracial, 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. Race ethnicity variable is calculated with all HISPANIC cases left in the final variable. However, a case is categorized as one of the other non-Hispanic races only if they had a valid "no" answer for the HISPANIC ethnicity variable.

```
COMPUTE race4_09 = 99.  
IF (HISPANIC_IMP = 1) race4_09 = 1.  
IF (HISPANIC_IMP = 0 and RACER_IMP = 1) race4_09 = 2.  
IF (HISPANIC_IMP = 0 and RACER_IMP = 2) race4_09 = 3.  
IF (HISPANIC_IMP = 0 and RACER_IMP = 3) race4_09 = 4.  
VARIABLE LABELS race4_09 "Race/ethnicity categories - 4 categories based on imputed screener file  
data".  
VALUE LABELS race4_09  
1 'Hispanic'  
2 'White, non-Hisp'  
3 'Black, non-Hisp'  
4 'Other, non-Hisp'.  
FORMATS race4_09 (f3.0).
```

Stratifiers

SPECIAL HEALTH CARE NEEDS TYPE	How many CSHCN qualified on specific types of special health needs criteria?
Survey Items Used	CSHCN_1 THROUGH CSHCN_5A
Numerators	Functional limitation (alone or with any other qualifying need); Prescription medication ONLY; Services needs ONLY; Prescription medication AND service needs
Denominator	CSHCN age 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>This variable is constructed from CSHCN Screener variables in the publicly released 2009-2010 NS_CSHCN Screener file. To construct this variable in the 2009-2010 NS_CSHCN Interview file, analysts will need to merge the variables CSHCN1 through CSHCN5_A, from the Screener file using the unique child identifier IDNUMXR as the linking variable. Unweighted frequency tables for these variables in the Screener and Interview files are included in Appendix B.</p> <p>This variable stratifies CSHCN according to four mutually exclusive categories, each representing specific combinations of CSHCN Screener health consequences. This measure is based on the CSHCN Screener, developed by the Child and Adolescent Health Measurement Initiative (CAHMI). The four CSHCN types are defined as follows: Rx meds only - CSHCN identified by current need for or use of prescription medication to manage an ongoing medical, behavioral, or other chronic health condition, and who qualified on no other CSHCN Screener criterion; Service use only - CSHCN who did not qualify on Rx medications or functional limitation but did qualify on one or more of three service-related screener criteria: elevated need or use of medical, mental health or educational services; need or use of specialized therapies; need for treatment or counseling for chronic emotional, behavioral, or developmental condition Rx meds AND service use - CSHCN who did not qualify on functional limitation, but did qualify based on both prescription medication use AND elevated service use (described above) Functional limitation - CSHCN qualifying on functional limitation criteria (limited ability to do things most other children the same age can do, due to the presence of an on-going medical, behavioral or other health condition) alone or in combination with any other screening criteria A detailed analysis of CSCHN subtypes has been published: Bramlett, M.D., Read, D., Bethell, C. and Blumberg, S.J. Differentiating subgroups of children with special health care needs by health status and complexity of health care needs. <i>Maternal and Child Health Journal</i>. 2009; 13:151-163.</p> <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 National Survey of CSHCN.</p>	
Revisions in 2009/10	
No changes; same as 2005/06 and 2001	

Stratifiers

SPSS Code and Annotation

How many CSHCN qualified on specific types of special health needs criteria?

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

*STEP 1: Identify children who qualify on the each of five different CSHCN screening criteria

```
COMPUTE rxmeds_09 = 0.  
IF ((cshcn1 = 1) and (cshcn1_a = 1) and (cshcn1_b = 1)) rxmeds_09 = 1.  
EXECUTE .  
VARIABLE LABELS rxmeds_09 "Qualified on rx'd med use?".  
VALUE LABELS rxmeds_09  
0 "No"  
1 "Yes".  
FORMATS rxmeds_09 (F4.0).
```

```
COMPUTE service_09 = 0.  
IF ((cshcn2 = 1) and (cshcn2_a = 1) and (cshcn2_b = 1)) service_09 = 1.  
EXECUTE.  
VARIABLE LABELS service_09 'Qualified on elevated service use or needs?'.  
VALUE LABELS service_09  
0 'No' 1 'Yes'.  
FORMATS service_09 (F4.0).
```

```
COMPUTE limits_09 = 0.  
IF ((cshcn3 = 1) and (cshcn3_a = 1) and (cshcn3_b = 1)) limits_09 = 1.  
EXECUTE.  
VARIABLE LABELS limits_09 'Qualified on functional limits?'.  
VALUE LABELS limits_09  
0 'No' 1 'Yes'.  
FORMATS limits_09 (F4.0).
```

```
COMPUTE therapies_09 = 0.  
IF ((cshcn4 = 1) and (cshcn4_a = 1) and (cshcn4_b = 1)) therapies_09 = 1.  
EXECUTE.  
VARIABLE LABELS therapies_09 'Qualified on use of special therapies?'.  
VALUE LABELS therapies_09  
0 'No' 1 'Yes'.  
FORMATS therapies_09 (F4.0).
```

```
COMPUTE mhealth_09 = 0.  
IF ((cshcn5 = 1) and (cshcn5_a = 1)) mhealth_09 = 1.  
EXECUTE.  
VARIABLE LABELS mhealth_09 'Qualified on ongoing emotional, developmental or behavioral  
conditions?'.  
VALUE LABELS mhealth_09  
0 'No' 1 'Yes'.  
FORMATS mhealth_09 (F4.0).
```

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

Stratifiers

```
COMPUTE def4_09 = 0.  
IF (limits_09=1) def4_09=1.  
IF (limits_09=0) and ((rxmeds_09=1)) and ((service_09=0) or (therapies_09=0) or (mhealth_09=0))  
def4_09=2.  
IF (limits_09=0) and ((rxmeds_09=0)) and ((service_09=1) or (therapies_09=1) or (mhealth_09=1))  
def4_09=3.  
IF (limits_09 = 0) and ((rxmeds_09 = 1)) and ((service_09 = 1) or (therapies_09 = 1) or (mhealth_09 = 1))  
def4_09 = 4.  
EXECUTE.  
VARIABLE LABELS def4_09 "How many CSHCN qualified on specific types of special health needs  
criteria?".  
VALUE LABELS def4_09  
1 "CSHCN qualifying on Func Limits (only or w/ any other)"  
2 "CSHCN qualifying on Rx meds ONLY"  
3 "CSHCN qualifying on Service use ONLY"  
4 "CSHCN qualifying on Rx meds AND service use".  
FORMATS def4_09 (f2.0).
```

Stratifiers

EBD ISSUES	CSHCN with emotional, behavioral or developmental issues
Survey Items Used	CSHCN_5 CSHCN_5A
Numerator	CSHCN with one or more qualifying EBD conditions
Denominator	CSHCN age 0-17 years
Description	CSHCN who qualified on the CSHCN Screener with emotional, behavioral or developmental issues
Notes for Data-Users	
N/A	
Revisions in 2009/10	
No changes; this measure can be compared to 2005/06 and 2001	
SPSS Code and Annotation	
<pre> COMPUTE mhealth_09 = 0. IF ((cshcn5 = 1) and (cshcn5_a = 1)) mhealth_09 = 1. EXECUTE. VARIABLE LABELS mhealth_09 'Qualified on ongoing emotional, developmental or behavioral conditions?'. VALUE LABELS mhealth_09 0 'No' 1 'Yes'. FORMATS mhealth_09 (F4.0). </pre>	

Stratifiers

# OF SCREENER CRITERIA MET	Number of CSHCN Screener criteria on which CSHCN qualified
Survey Items Used	CSHCN_1 THROUGH CSHCN_5A
Numerator	Qualified on 1 Screener criterion; qualified on 2 Screener criteria; qualified on 3 Screener criteria; qualified on 4-5 Screener criteria
Denominator	CSHCN age 0-17 years
Description	Number of CSHCN Screener criteria on which CSHCN qualified
Notes for Data-Users	
N/A	
Revisions in 2009/10	
No changes; this measure can be compared to 2005/06 and 2001	
SPSS Code and Annotation	
<p>*note: run syntax for type of special health care needs before running the syntax below.</p> <p>count qualnum_09=rxmeds_09 therapies_09 service_09 limits_09 mhealth_09 (1).</p> <p>recode qualnum_09 (5=4) (else=copy).</p> <p>VARIABLE LABELS qualnum_09 "How many of the screener criteria were met by CSHCN?". VALUE LABELS qualnum_09 1 "Qualified on 1 screener criterion" 2 "Qualified on 2 screener criteria" 3 "Qualified on 3 screener criteria" 4 "CSHCN who qualified on 4 or all 5 Screener criteria". FORMATS qualnum_09 (F4.0).</p>	

Stratifiers

HOUSEHOLD INCOME VERSION 1	How many CHSCN live in households at specified levels of income according to Federal Poverty Level (FPL) guidelines?
Survey Items Used	POVLEVEL_IMP
Numerators	0-99% FPL; 100-199% FPL; 200-399% FPL; 400% FPL or more
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years living in households with income below 100%, 100–199%, 200–399%, or 400% or more of Federal Poverty Level (FPL) for family size
Notes for Data-Users	
<p>This variable is constructed from a variable in the publicly released 2009-2010 NS_CSHCN Household file. This variable was constructed in the 2009-2010 NS_CSHCN Interview file after merging the variable POVLEVEL from the Household Imputation File using the unique household identifier IDNUMR as the linking variable. Unweighted frequency tables for this variable in the Household and Interview files are included in Appendix B.</p> <p>For 18.8% of participating households, income was not determined due to participants refusing to answer or not knowing the answer to the income questions. An additional 11.7% of households only provided an income range. Therefore, income was imputed for 30.5% of households, which is equivalent to 19.9% of cases in the interview file. The SPSS code below is based upon the imputed version; the non-imputed income variable is also available in the DRC indicator dataset.</p> <p>Income is expressed in categories according to percentage of Federal Poverty Level (FPL), according to guidelines released by the U.S. Department of Health and Human Services. Details will be included in a forthcoming Design and Operations Manual from the National Center for Health Statistics.</p> <p>IMPORTANT NOTE: Results for this question are weighted to represent the number of <i>children</i> ages 0-17 in the United States. The accurate way to report results is, "X% of CSHCN age 0-17 years living in households with incomes 0-99% of the FPL." It is <u>not</u> accurate to report results as "X% of households have incomes that are 0-99% of the FPL."</p>	
Revisions in 2009/10	
<p>This variable is the same as 2005/06 and 2001 except that in prior years households reporting an income range were not imputed, they were assigned the median value of the range. This resulted in additional cases of income being imputed in the 2009/10 NS-CSHCN. Please take this into consideration when comparing across years.</p>	
SPSS Code and Annotation	
<pre>RECODE POVLEVEL_IMP (1 thru 2=1) (3 thru 6=2) (7 thru 8=3) (9=4) INTO povlev4_09. EXECUTE.</pre>	

Stratifiers

VARIABLE LABELS povlev4_09 "Version 1: How many CHSCN live in households at specified levels of income according to Federal Poverty Level (FPL) guidelines?".

VALUE LABELS povlev4_09

1 '0% - 99% FPL'

2 '100% - 199% FPL'

3 '200% - 399% FPL'

4 '400% FPL or greater'.

FORMATS povlev4_09 (f2.0).

Stratifiers

HOUSEHOLD INCOME VERSION 2	How many CHSCN live in households at specified SCHIP-relevant levels of income according to Federal Poverty Level (FPL) guidelines?
Survey Items Used	POVLEVEL_IMP
Numerator	0-199% FPL; 200-299% FPL; 300-399% FPL; 400% FPL or more
Denominator	CSHCN age 0-17 years
Description	Percent of CSHCN age 0-17 years living in households with income below 200%, 200–299%, 300–399%, or 400% or more of Federal Poverty Level (FPL) for family size
Notes for Data-Users	
<p>This variable is constructed from a variable in the publicly released 2009-2010 NS_CSHCN Household file. This variable was constructed in the 2009-2010 NS_CSHCN Interview file after merging the variable POVLEVEL from the Household Imputation File using the unique household identifier IDNUMR as the linking variable. Unweighted frequency tables for this variable in the Household and Interview files are included in Appendix B.</p> <p>For 18.8% of participating households, income was not determined due to participants refusing to answer or not knowing the answer to the income questions. An additional 11.7% of households only provided an income range. Therefore, income was imputed for 30.5% of households, which is equivalent to 19.9% of cases in the interview file. The SPSS code below is based upon the imputed version; the non-imputed income variable is also available in the DRC indicator dataset.</p> <p>Income is expressed in categories according to percentage of Federal Poverty Level (FPL), according to guidelines released by the U.S. Department of Health and Human Services. Details will be included in a forthcoming Design and Operations Manual from the National Center for Health Statistics.</p> <p>IMPORTANT NOTE: Results for this question are weighted to represent the number of <i>children</i> ages 0-17 in the United States. The accurate way to report results is, "X% of CSHCN age 0-17 years living in households with incomes 0-99% of the FPL." It is <u>not</u> accurate to report results as "X% of households have incomes that are 0-99% of the FPL."</p>	
Revisions in 2009/10	
<p>This variable is the same as 2005/06 and 2001 except that in prior years households reporting an income range were not imputed, they were assigned the median value of the range. This resulted in additional cases of income being imputed in the 2009/10 NS-CSHCN. Please take this into consideration when comparing across years.</p>	
SPSS Code and Annotation	
<p>** NOTE: This is a second version of child-level household income using SCHIP policy relevant grouping of 200 - 299% FPL.</p>	

Stratifiers

```
RECODE POVLEVEL_IMP  
(1 thru 6=1) (7=2) (8=3) (9=4) INTO povSCHIP_09.  
EXECUTE.  
VARIABLE LABELS povschip_09 "Version 2: How many CHSCN live in households at specified SCHIP-  
relevant levels of income according to Federal Poverty Level (FPL) guidelines?".  
VALUE LABELS povschip_09  
1 '0% - 199% FPL'  
2 '200% - 299% FPL'  
3 '300% - 399% FPL'  
4 '400% FPL or greater'.  
FORMATS povschip_09 (f2.0).
```

Stratifiers

INSURANCE TYPE	How many CSHCN have private or public insurance coverage?
Survey Items Used	TYPEINS
Numerators	CSHCN with private insurance only; CSHCN with public insurance only; CSHCN with both public and private insurance; Uninsured CSHCN
Denominator	CSHCN age 0-17 years with either private and/or public insurance or no insurance coverage at the time of the survey.
Description	Percent of CSHCN age 0-17 years whose health insurance coverage at the time of the survey was private, public, combined private and public, or uninsured
Notes for Data-Users	
<p>Nationally, approximately 3.6% of CSHCN interviewed had coverage classified as "other comprehensive insurance" at the time of the survey. Due to its small size, this group is not included in the results summarized in the data query tables or charts for this indicator.</p> <p>The variable TYPEINS in the 2009-2010 NS-CSHCN Interview File was derived by the National Center for Health Statistics from responses to the numerous health insurance coverage questions in Section 7 of the survey. Information on how the insurance variables in the public use file were defined will be found in a forthcoming Design and Operations report from NCHS.</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<pre> RECODE TYPEINS (SYSMIS=99) (4=99) (5=4) (else=copy) INTO instype_09. VARIABLE LABELS instype_09 "Type of Insurance Coverage". VALUE LABELS instype_09 1 'Private only' 2 'Public only' 3 'Both Public and Private' 4 'Uninsured' 99 "Missing or comprehensive other insurance". MISSING VALUES instype_09 (99). FORMATS instype_09 (f2.0). EXECUTE. </pre>	

Stratifiers

FAMILY STRUCTURE	Family structure of the CSHCN population
Survey Items Used	FAMSTRUCT
Numerator	Two parent biological or adoptive family; Two parent family, at least one step-parent; Mother only (no father present); Other family structure
Denominator	CSHCN age 0-17 years
Description	CSHCN living in two parent biological or adoptive families, two parent families with at least one step-parent, mother only families with no father present or other family structures
Notes for Data-Users	
<p>The summary variable FAMSTRUCT was derived from responses to questions in Section 10 and is the only information about family structure included in the public use files for the 2009-2010 NS-CSHCN. Responses for individual questions C11Q01_A thru C10Q05 in Section 10 were suppressed in order to protect the confidentiality of respondents. Information on how “family structure” in the public use file was defined will be found in a forthcoming Design and Operations report from NCHS.</p>	
Revisions in 2009/10	
<p>These items are the same as in the 2005/06 NS-CSHCN. These measures may be compared across surveys.</p>	
SPSS Code and Annotation	
<p>*NOTE: Uses the NCHS derived variable FAMSTRUCT in the publicly released 2009-2010 NS_CSHCN Interview file.</p> <p>COMPUTE famstruct_09=FAMSTRUCT.</p> <p>VARIABLE LABELS famstruct_09 "Family structure of the CSHCN population". VALUE LABELS famstruct_09 1 "CSHCN in parent household biological or adopted" 2 "CSHCN in 2 parent stepfamily household" 3 "CSHCN in mother only household" 4 "CSHCN in other family structure household". FORMATS famstruct_09 (f2.0).</p>	

Stratifiers

HOUSEHOLD LANGUAGE	How many Hispanic CSHCN live in households in which Spanish is the primary language?
Survey Items Used	PLANGUAGE_IMP
Numerator	Spanish speaking household; English speaking household; Non-Hispanic CSHCN
Denominator	CSHCN age 0-17 years
Description	% of CSHCN who are Hispanic and living in primarily Spanish language households
Notes for Data-Users	
<p>For the purposes of this indicator, Spanish is assumed to be the household language for Hispanic children living in non-English primary language households.</p> <p>This item is constructed using race4_09, which is derived from HISPANIC_IMP (Hispanic or Latino ethnicity) and RACER_IMP in the publicly released 2009-2010 NS_CSHCN Screener File and PLANGUAGE_IMP (the imputed version of the primary language spoken in the household) from the publicly released 2009-2010 NS_CSHCN Household File. The non-imputed versions of both variables are also provided in the DRC indicator dataset. Unweighted frequency tables for these variables in the Screener, Household and Interview files are included in Appendix B.</p>	
Revisions in 2009/10	
<p>The question about primary household language was not asked in 2001. In addition, the race and language variables used to construct this in the 2005/06 NS-CSHCN were not imputed; they therefore had missing cases. Now that both variables used to derive this measure contain imputed data, use caution when comparing across years.</p>	
SPSS Code and Annotation	
<p>*Note: construct race4_09 before running the syntax below.</p> <pre> COMPUTE PLANGUAGER=PLANGUAGE_IMP. VARIABLE LABELS PLANGUAGER "Does child live in primary English or non-English household?". VALUE LABELS PLANGUAGER 1 "English language HH" 2 "Non-English HH". FORMATS PLANGUAGER (F4.0). COMPUTE hhlang_09 = 99. IF (race4_09 = 1) and (PLANGUAGER= 1) hhlang_09 = 2. IF (race4_09 = 1) and (PLANGUAGER= 2) hhlang_09 = 1. </pre>	

Stratifiers

```
IF (race4_09 > 1) hhlang_09 = 3.  
EXECUTE.
```

```
VARIABLE LABELS hhlang_09 'Hispanic ethnicity parsed by child's PRIMARY HOUSEHOLD  
language'.
```

```
VALUE LABELS hhlang_09
```

```
1 'Hisp child / primary HH lang is NOT English lang'
```

```
2 'Hisp child / primary HH lang is ENGLISH'
```

```
3 'Non-Hispanic children'.
```

```
FORMATS hhlang_09 (f2.0).
```

Stratifiers

HOUSEHOLD EDUCATION	Highest education level of parents in household
Survey Items Used	EDUCR_IMP
Numerator	Less than high school; high school graduate; more than high school
Denominator	CSHCN age 0-17 years
Description	Highest education level of parents in household
Notes for Data-Users	
<p>For the purposes of this indicator, Spanish is assumed to be the household language for Hispanic children living in non-English primary language households.</p> <p>This item is constructed using race4_09, which is derived from HISPANIC_IMP (Hispanic or Latino ethnicity) and RACER_IMP in the publicly released 2009-2010 NS_CSHCN Screener File and PLANGUAGE_IMP (the imputed version of the primary language spoken in the household) from the publicly released 2009-2010 NS_CSHCN Household File. The non-imputed versions of both variables are also provided in the DRC indicator dataset. Unweighted frequency tables for these variables in the Screener, Household and Interview files are included in Appendix B.</p>	
Revisions in 2009/10	
<p>The education question changed in 2009/10. In 2005/06, it asked about the highest level of school that anyone in the household had completed and in 2009/10, they survey only asks about the highest grade or year of school completed by the child's parents, individually, which is similar to how the question was asked in 2001. In addition, missing values for this variable were not imputed in 2005/06 or 2001, whereas they were in 2009/10 – this variable should not be compared across years.</p>	
SPSS Code and Annotation	
<p>COMPUTE educ_09 = EDUCR_IMP.</p> <p>VARIABLE LABELS educ_09 "What is the highest education level attained by any parent in the household?".</p> <p>VALUE LABELS educ_09 1 "Less than high school" 2 "High school grad" 3 "More than high school".</p> <p>formats educ_09 (F4.0). missing values educ_09 (99).</p>	

Appendix A: Unweighted Frequency Tables for Codebook Variables



NATIONAL CHARTBOOK INDICATORS

indic1_09 Activity Limitations: CSHCN whose health conditions consistently affect daily activities

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Daily activities never affected	14795	36.8	36.9	36.9
	2 Daily activities moderately affected some of the time	15611	38.8	38.9	75.8
	3 Daily activities consistently affected, often a great deal	9730	24.2	24.2	100.0
	Total	40136	99.7	100.0	
Missing	99 DK, Ref or Missing to both items	106	.3		
Total		40242	100.0		

indic2_09 Missed School Days: CSHCN ages 5-17 with 11 or more school absences due to illness

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0 - 3 days missed	17196	42.7	50.3	50.3
	2 4 - 6 days missed	7452	18.5	21.8	72.1
	3 7 - 10 days missed	4710	11.7	13.8	85.9
	4 11 or more days missed	4815	12.0	14.1	100.0
	Total	34173	84.9	100.0	
Missing	99 DK, Ref, or ch <5 yrs old	715	1.8		
	System	5354	13.3		
	Total	6069	15.1		
Total		40242	100.0		

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

indic3_09 "Inconsistently Insured: CSHCN without insurance at some point during the past year"

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Insured entire year	37043	92.1	92.4	92.4
	1 NOT insured at some point during year	3065	7.6	7.6	100.0
	Total	40108	99.7	100.0	
Missing	6 DK	68	.2		
	7 Refused	5	.0		
	System	61	.2		
	Total	134	.3		
Total		40242	100.0		

indic4_09 "Currently Uninsured: CSHCN without insurance at time of the survey"

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Currently insured	39035	97.0	97.1	97.1
	1 Currently NOT insured	1149	2.9	2.9	100.0
	Total	40184	99.9	100.0	
Missing	6	53	.1		
	7	5	.0		
	Total	58	.1		
Total		40242	100.0		

indic5_09 "Adequacy of Current Insurance Coverage: Currently insured CSHCN whose insurance coverage is not

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Current insurance is NOT adequate	12776	31.7	33.1	33.1
	1 Current insurance IS adequate	25854	64.2	66.9	100.0
	Total	38630	96.0	100.0	
Missing	99 DK or Ref to any item	463	1.2		
	999 Uninsured	1149	2.9		
	Total	1612	4.0		
Total		40242	100.0		

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

indic6_09 Unmet Needs for Care: CSHCN with any unmet need for any of 14 specific health care services or equipment, past 12 months

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No unmet needs for 14 specific health care services	31424	78.1	79.6	79.6
	1 1 unmet need for services/equip	5283	13.1	13.4	92.9
	2 2 or more unmet needs for services/equip	2791	6.9	7.1	100.0
	Total	39498	98.2	100.0	
Missing	99 DK/REF to any	744	1.8		
Total		40242	100.0		

indic7_09 “Unmet Needs for Family Support Services: CSHCN with any unmet needs for family support services”

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No unmet needs for specific family support services or did not need	37577	93.4	93.6	93.6
	1 One or more unmet needs for family support services	2568	6.4	6.4	100.0
	Total	40145	99.8	100.0	
Missing	99 DK/REF	97	.2		
Total		40242	100.0		

indic8_09 Problems Obtaining Referral: CSHCN needing specialty care who had problems getting a referral

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Needed referral, no problems getting it	10649	26.5	80.2	80.2
	1 Needed referral, YES problems getting it	2625	6.5	19.8	100.0
	Total	13274	33.0	100.0	
Missing	99 DK/REF or did not need a referral	26968	67.0		
Total		40242	100.0		

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

indic9_09 "Usual Source for Sick Care: CSHCN without a usual source of care or who rely on the emergency room"

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Docs office is usual source for sick care	30174	75.0	75.1	75.1
	2 Clinic, health center or other regular source for sick care	6737	16.7	16.8	91.9
	3 No usual source for sick care-- or ER,Mexico or no one place most often	3253	8.1	8.1	100.0
	Total	40164	99.8	100.0	
Missing	99 DK/REF/MISSING	78	.2		
Total		40242	100.0		

indic10_09 Indicator #10: Personal Doctor or Nurse: CSHCN without a personal doctor or nurse (PDN)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No, does not have a PDN	2451	6.1	6.1	6.1
	1 Yes, has one or more PDNs	37735	93.8	93.9	100.0
	Total	40186	99.9	100.0	
Missing	99 DK/REF/MISSING	56	.1		
Total		40242	100.0		

indic11_09 Indicator #11: Family Centered Care: CSHCN without family-centered care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Does NOT have family centered care	12579	31.3	31.7	31.7
	1 Yes, has family centered care	27106	67.4	68.3	100.0
	Total	39685	98.6	100.0	
Missing	2 Legitimate skip - no dr visit past 12 mos	84	.2		
	99 DK/Ref to all or SYSMIS	473	1.2		
	Total	557	1.4		
Total		40242	100.0		

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

**indic12_09 INDICATOR #12: Out-of-Pocket Expenses: CSHCN whose families pay
more than \$1000 per year out-of-pocket for child's medical expenses**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Less than \$250	15400	38.3	38.8	38.8
	2 \$250 - \$500	8859	22.0	22.3	61.2
	3 \$501 - \$1000	5238	13.0	13.2	74.4
	4 More than \$1000	10144	25.2	25.6	100.0
	Total	39641	98.5	100.0	
Missing	99 DK/REF	601	1.5		
Total		40242	100.0		

**indic13_09 INDICATOR #13: Family Financial Burden: CSHCN whose families experienced financial
problems due to child's health needs**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No financial problems due to child's health	31847	79.1	79.7	79.7
	1 Yes, financial problems	8087	20.1	20.3	100.0
	Total	39934	99.2	100.0	
Missing	99 DK/REF or MISSING	70	.2		
	System	238	.6		
	Total	308	.8		
Total		40242	100.0		

**indic14_09 INDICATOR #14: Hours per Week Providing Care: CSHCN whose families spend 11
or more hours per week providing and/or coordinating health care for child**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Less than 1 hour	16722	41.6	43.2	43.2
	2 1 - 4 hours per week	14147	35.2	36.6	79.8
	3 5 - 10 hours per week	3564	8.9	9.2	89.0
	4 11 or more hours per week	4271	10.6	11.0	100.0
	Total	38704	96.2	100.0	
Missing	99 DK/REF	1538	3.8		
Total		40242	100.0		

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

**indic15_09 INDICATOR #15: Impact on Family Work Life: CSHCN whose family members cut back
and/or stopped working because of child's health needs**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Employment not affected	30935	76.9	77.4	77.4
	1 Family member cut back hours or stopped working or both	9010	22.4	22.6	100.0
	Total	39945	99.3	100.0	
Missing	99	297	.7		
Total		40242	100.0		

MCHB CORE OUTCOMES

outcome1_09 CSHCN whose families are partners in decision-making for child's optimal health

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Did not meet Outcome #1	10442	25.9	26.2	26.2
	1 Met Outcome #1	29434	73.1	73.8	100.0
	Total	39876	99.1	100.0	
Missing	99 DK/REF on all	366	.9		
Total		40242	100.0		

**outcome2_09 Children with special health care needs (CSHCN) receiving ongoing, coordinated and
comprehensive care within a medical home**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Care DOES NOT meet medical home criteria	20671	51.4	53.1	53.1
	1 Care MEETS medical home criteria	18279	45.4	46.9	100.0
	Total	38950	96.8	100.0	
Missing	99 DK/Ref to any	1292	3.2		
Total		40242	100.0		

**outcome3_09 CSHCN whose families have adequate private and/or public insurance to pay for
the services they need**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Did not meet outcome	14880	37.0	37.5	37.5
	1 Met outcome	24840	61.7	62.5	100.0
	Total	39720	98.7	100.0	
Missing	99 DK/REF/MISSING on any	522	1.3		
Total		40242	100.0		

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

outcome4_09 CSHCN who are screened early and continuously for special health care needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Did not meet outcome criteria	8071	20.1	20.2	20.2
	1 Met outcome 4 criteria	31806	79.0	79.8	100.0
	Total	39877	99.1	100.0	
Missing	99 DK/REF/SYSMISS on either	365	.9		
Total		40242	100.0		

outcome5_09 CSHCN who can easily access community-based services

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Did not meet outcome #5	12993	32.3	32.5	32.5
	1 Met outcome #5	26997	67.1	67.5	100.0
	Total	39990	99.4	100.0	
Missing	99 DK/REF/SYSMIS on any	252	.6		
Total		40242	100.0		

outcome6_09 Youth with special health care needs who receive the necessary services for transition to adulthood

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Did not meet outcome	9027	22.4	55.6	55.6
	1 Met outcome	7195	17.9	44.4	100.0
	Total	16222	40.3	100.0	
Missing	98 Legitimate skip b/c <12 yrs old	23128	57.5		
	99 DK/REF/MISSING on both	892	2.2		
	Total	24020	59.7		
Total		40242	100.0		

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

MCHB SYSTEM OF CARE SUMMARY VARIABLES

syscare_09 CSHCN age 0-11 years who are served by systems of care meeting all age-relevant core outcomes

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0-2 outcomes achieved	6201	15.4	28.4	28.4
	2 3-4 outcomes achieved	10753	26.7	49.2	77.6
	3 'All 5 outcomes achieved'	4894	12.2	22.4	100.0
	Total	21848	54.3	100.0	
Missing	99 DK/Ref to any	1280	3.2		
	999 CSHCN ages 12 -17	17114	42.5		
	Total	18394	45.7		
Total		40242	100.0		

syscare2_09 "CSHCN age 12-17 years who are served by systems of care meeting all 6 MCHB core outcomes"

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0-2 outcomes achieved	3379	8.4	22.0	22.0
	2 3-4 outcomes achieved	5861	14.6	38.2	60.3
	3 5 outcomes achieved	3614	9.0	23.6	83.8
	4 Outcomes achieved in all 6 areas	2479	6.2	16.2	100.0
	Total	15333	38.1	100.0	
Missing	System	24909	61.9		
Total		40242	100.0		

syscare_all_09 CSHCN age 0-17 years who are served by systems of care meeting all age-relevant MCHB core outcomes

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 2 or more age-relevant core outcomes NOT achieved	20232	50.3	54.4	54.4
	1 1 age-relevant core outcome NOT achieved	9576	23.8	25.8	80.2
	2 All age-relevant core outcomes achieved	7373	18.3	19.8	100.0
	Total	37181	92.4	100.0	
Missing	99 missing	3061	7.6		
Total		40242	100.0		

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

CONDITIONS & FUNCTIONAL DIFFICULTIES

conditions20_09 "Number of current health conditions reported from list of 20 different conditions asked in the

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No conditions reported	4988	12.4	12.4	12.4
	1 1 cond reported	12883	32.0	32.0	44.4
	2 2 conds reported	11561	28.7	28.7	73.1
	3 3 conds reported	4907	12.2	12.2	85.3
	4 4 or more conds reported	5900	14.7	14.7	100.0
	Total	40239	100.0	100.0	
Missing	99 DK/REF to all conds	3	.0		
Total		40242	100.0		

funcdif5_09 Number of functional difficulties reported from list of 14 different difficulties asked in the survey

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 NO difficulties reported from list	3890	9.7	9.7	9.7
	1 1 difficulty reported from list	8429	20.9	20.9	30.6
	2 2 difficulties reported from list	6029	15.0	15.0	45.6
	3 3 difficulties reported from list	4906	12.2	12.2	57.8
	4 4 or more difficulties reported from list	16988	42.2	42.2	100.0
	Total	40242	100.0	100.0	

emot_ICF_09 CSHCN age 18 months - 17 years who have a little or a lot of difficulty with one or more emotional or behavioral factors (C3Q32-C3Q34)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No emotional or behavioral difficulties	17217	42.8	43.8	43.8
	1 A little or a lot of difficulty with one or more emotional or behavioral factors	22103	54.9	56.2	100.0
	Total	39320	97.7	100.0	
Missing	99 DK/RF or not in age range for all	922	2.3		
Total		40242	100.0		

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

activity_ICF_09 CSHCN age 0 - 17 years who have a little or a lot of difficulty with one or more activities or participation (C3Q27-C3Q31)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No difficulties with activities	16878	41.9	41.9	41.9
	1 A little or a lot of difficulty with one or more activities	23363	58.1	58.1	100.0
	Total	40241	100.0	100.0	
Missing	99 DK/RF or not in age range for all	1	.0		
Total		40242	100.0		

body_ICF_09 CSHCN age 0-17 years who have a little or a lot of difficulty with one or more body functions (C3Q21-C3Q26)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No difficulties involving bodily functions	13406	33.3	33.3	33.3
	1 A little or a lot of difficulty with one or more bodily functions	26835	66.7	66.7	100.0
	Total	40241	100.0	100.0	
Missing	99 DK/RF to all	1	.0		
Total		40242	100.0		

STRATIFICATION VARIABLES

age3_09 'How many children of different ages are in the CSHCN population?'

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0-5 yrs old	7294	18.1	18.1	18.1
	2 6-11 yrs old	15834	39.3	39.3	57.5
	3 12-17 yrs old	17114	42.5	42.5	100.0
	Total	40242	100.0	100.0	

SEX_09 'Sex of child'

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Male	24139	60.0	60.1	60.1
	2 Female	16033	39.8	39.9	100.0
	Total	40172	99.8	100.0	
Missing	99 DK/RF	70	.2		
Total		40242	100.0		

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

race4_09 Race/ethnicity categories - 4 categories based on imputed screener file data

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Hispanic	4479	11.1	11.1	11.1
	2 White, non-Hisp	27989	69.6	69.6	80.7
	3 Black, non-Hisp	4010	10.0	10.0	90.6
	4 Other, non-Hisp	3764	9.4	9.4	100.0
	Total	40242	100.0	100.0	

hhlang_09 Hispanic ethnicity parsed by child's PRIMARY HOUSEHOLD language

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Hisp child / primary HH lang is NOT English lang	1159	2.9	2.9	2.9
	2 Hisp child / primary HH lang is ENGLISH	3320	8.3	8.3	11.1
	3 Non-Hispanic children	35763	88.9	88.9	100.0
	Total	40242	100.0	100.0	

def4_09 How many CSHCN qualified on specific types of special health needs criteria?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 CSHCN qualifying on Func Limits (only or w/ any other)	9022	22.4	22.4	22.4
	2 CSHCN qualifying on Rx meds ONLY	16570	41.2	41.2	63.6
	3 CSHCN qualifying on Service use ONLY	5881	14.6	14.6	78.2
	4 CSHCN qualifying on Rx meds AND service use	8769	21.8	21.8	100.0
	Total	40242	100.0	100.0	

mhealth_09 Qualified on ongoing emotional, developmental or behavioral conditions?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 No	27850	69.2	69.2	69.2
	1 Yes	12392	30.8	30.8	100.0
	Total	40242	100.0	100.0	

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

qualnum_09 How many of the screener criteria were met by CSHCN?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Qualified on 1 screener criterion	21059	52.3	52.3	52.3
	2 Qualified on 2 screener criteria	8252	20.5	20.5	72.8
	3 Qualified on 3 screener criteria	5550	13.8	13.8	86.6
	4 CSHCN who qualified on 4 or all 5 Screener criteria	5381	13.4	13.4	100.0
	Total	40242	100.0	100.0	

**povlev4_09 Version 1: How many CHSCN live in households at specified levels of income
according to Federal Poverty Level (FPL) guidelines?**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0% - 99% FPL	6899	17.1	17.1	17.1
	2 100% - 199% FPL	7722	19.2	19.2	36.3
	3 200% - 399% FPL	12572	31.2	31.2	67.6
	4 400% FPL or greater	13049	32.4	32.4	100.0
	Total	40242	100.0	100.0	

**povSCHIP_09 Version 2: How many CHSCN live in households at specified SCHIP-
relevant levels of income according to Federal Poverty Level (FPL) guidelines?**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0% - 199% FPL	14621	36.3	36.3	36.3
	2 200% - 299% FPL	6763	16.8	16.8	53.1
	3 300% - 399% FPL	5809	14.4	14.4	67.6
	4 400% FPL or greater	13049	32.4	32.4	100.0
	Total	40242	100.0	100.0	

**APPENDIX A:
Unweighted Frequency Tables for Codebook Variables**

famstruct_09 Family structure of the CSHCN population

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 "CSHCN in parent household biological or adopted"	25098	62.4	63.3	63.3
	2 "CSHCN in 2 parent stepfamily household"	3622	9.0	9.1	72.4
	3 "CSHCN in mother only household"	7803	19.4	19.7	92.1
	4 "CSHCN in other family structure household"	3137	7.8	7.9	100.0
	Total	39660	98.6	100.0	
Missing	System	582	1.4		
Total		40242	100.0		

instype_09 Type of Insurance Coverage

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Private only	23315	57.9	60.2	60.2
	2 Public only	11362	28.2	29.3	89.5
	3 Both Public and Private	2910	7.2	7.5	97.0
	4 Uninsured	1149	2.9	3.0	100.0
	Total	38736	96.3	100.0	
Missing	99 Missing or comprehensive other insurance	1506	3.7		
Total		40242	100.0		

educ_09 What is the highest education level attained by any parent in the household?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Less than high school	2145	5.3	5.3	5.3
	2 High school grad	6007	14.9	14.9	20.3
	3 More than high school	32090	79.7	79.7	100.0
	Total	40242	100.0	100.0	

Appendix B: Medical Home Components and Interim Variables



Measuring Medical Home using Data Elements from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN)

SPSS scoring program variable names for the five sub-component scores and associated interim variables used to derive the Medical Home composite measure

2009-2010 NS-CSHCN		
	SPSS Variable names	Survey items or interim variables used to construct:
Meet overall criteria for having a Medical Home:	OUTCOME #2	[pdn_09; famcent_09; norefprb_09; usual_09; carecoor_09]
ESTABLISHED RELATIONSHIP WITH A SPECIFIC PROVIDER		
1) <u>Child has at least one “personal doctor or nurse”</u>	pdn_09	C4Q02A
ACCESSIBLE	<i>Not assessed by the survey</i>	
FAMILY CENTERED		
2) <u>Child’s doctors and other health providers do each of the following:</u>	famcent_09	[time_09;listen_09; sensitive_09; infofcc_09; partner_09]
a) <u>Usually or always</u> spend enough time with child and parent	time_09	C6Q02
b) <u>Usually or always</u> listen carefully to child and parent	listen_09	C6Q03
c) <u>Usually or always</u> sensitive to family’s values and customs	sensitive_09	C6Q04
d) <u>Usually or always</u> provide needed information	infofcc_09	C6Q05
e) <u>Usually or always</u> make family feel like a partner in child’s care	partner_09	C6Q06
CONTINUOUS	--	--
COMPREHENSIVE		
3) <u>IF needed, no problems obtaining referrals</u>	norefprb_09	C5Q11, C4Q07
4) <u>Usual source(s) of care</u>	usual_09	C4Q0A; C4Q0BR; C4Q0D;C4Q01; C4Q02R
COORDINATED		
5) <u>Gets effective care coordination when needed</u>	carecoor_09	[carehelp_09; drcomm_09; othercomm_09]
a) <u>Needed and usually got</u> extra help with care coordination	carehelp_09	C5Q09;C5Q12;C5Q17
b) <u>IF needed, very satisfied</u> with communication btw doctors	needcomm_09	C4Q05_2A; C4Q05_2C; C4Q05_5A; C4Q05_5C; C4Q05_6A; C4Q05_6C; C4Q05_7A; C4Q05_7C; C4Q05_8A; C4Q05_8C C4Q05_2;C4Q05_5;C4Q05_6; C4Q05_7;C4Q05_8;
c) <u>IF needed, very satisfied</u> with how doctors communicate with school or other programs the child attends	drcomm_09 othercomm_09	C5Q10; needcomm_09 C5Q05; C5Q06
COMPASSIONATE	<i>Assessed under the Family Centered Care component</i>	
CULTURALLY EFFECTIVE	<i>Assessed under the Family Centered Care component</i>	

**APPENDIX B:
Medical Home Components and Interim Variables**

Unweighted Frequency Tables for Medical Home Variables

PERSONAL DOCTOR OR NURSE

pdn_09 Personal Doctor or Nurse sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Do not have a personal dr or nurse	2451	6.1	6.1	6.1
	1 Yes, have a personal dr or nurse	37735	93.8	93.9	100.0
	Total	40186	99.9	100.0	
Missing	System	56	.1		
Total		40242	100.0		

FAMILY CENTERED CARE

time_09 Drs/other health providers spend enough time (c6q02 recoded)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never/sometimes	7692	19.1	19.1	19.1
	1 Usually/always	32340	80.4	80.4	99.5
	2 No dr visits past 12 mos	84	.2	.2	99.7
	99 DK/Ref/SYSMIS	126	.3	.3	100.0
	Total	40242	100.0	100.0	

listen_09 Drs/other health providers listen well (c6q03 recoded)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 Never/sometimes	4141	10.3	10.3	10.3
	1.00 Usually/always	35932	89.3	89.3	99.6
	2.00 No dr visits past 12 mos	84	.2	.2	99.8
	99.00 DK/Ref/SYSMIS	85	.2	.2	100.0
	Total	40242	100.0	100.0	

sensitive_09 Drs/other health providers sensitive to family values/customs (c6q04 recoded)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never/sometimes	3604	9.0	9.0	9.0
	1 Usually/always	36341	90.3	90.3	99.3
	2 No dr visits past 12 mos	84	.2	.2	99.5
	99 DK/Ref/SYSMIS	213	.5	.5	100.0
	Total	40242	100.0	100.0	

**APPENDIX B:
Medical Home Components and Interim Variables**

infofcc_09 Drs/other health providers provide needed information (c6q05 recoded)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never/sometimes	6356	15.8	15.8	15.8
	1 Usually/always	33702	83.7	83.7	99.5
	2 No dr visits past 12 mos	84	.2	.2	99.8
	99 DK/Ref/SYSMIS	100	.2	.2	100.0
	Total	40242	100.0	100.0	

partner_09 Drs/other health providers make family feel like a partner (c6q06 recoded)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Never/sometimes	4485	11.1	11.1	11.1
	1 Usually/always	35596	88.5	88.5	99.6
	2 No dr visits past 12 mos	84	.2	.2	99.8
	99 DK/Ref/SYSMIS	77	.2	.2	100.0
	Total	40242	100.0	100.0	

famcent_09 Family-Centered Care sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Does NOT have family centered care	12579	31.3	31.6	31.6
	1 Yes, has family centered care	27106	67.4	68.2	99.8
	2 Legitimate skip - no dr visit past 12 mos	84	.2	.2	100.0
	Total	39769	98.8	100.0	
Missing	System	473	1.2		
Total		40242	100.0		

**APPENDIX B:
Medical Home Components and Interim Variables**

NO REFERRAL PROBLEMS

norefprb_09 Getting Needed Referrals sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 Big or small problem getting referral, when needed	2625	6.5	6.6	6.6
	1.00 No problems getting referral, when needed	10649	26.5	26.6	33.1
	2.00 Legitimate skip b/c referrals are not needed	26774	66.5	66.9	100.0
	Total	40048	99.5	100.0	
Missing	System	194	.5		
Total		40242	100.0		

USUAL SOURCES OF CARE

usual_09 Usual Sources for Sick and Well Care sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Child does not have usual sources for sick and well care	3693	9.2	9.2	9.2
	1 Child DOES have usual sources for sick and well care	36407	90.5	90.8	100.0
	Total	40100	99.6	100.0	
Missing	System	142	.4		
Total		40242	100.0		

EFFECTIVE CARE COORDINATION

carehelp_09 Got some type of help with care coordination

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Needed extra help/did not get it	4953	12.3	12.3	12.3
	1 Gets help with care coor	7945	19.7	19.7	32.1
	2 Legit skip -- <2 services or did not need extra help	27260	67.7	67.7	99.8
	99 DK/Ref to any or MISSING	84	.2	.2	100.0
	Total	40242	100.0	100.0	

**APPENDIX B:
Medical Home Components and Interim Variables**

needcomm_09 Used some or all specialist care, MH, PT/OT/Speech, sub abuse, or home hlth care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Did not use services for dr comm denominator	13442	33.4	33.4	33.4
	1 Used 1 or more services for dr comm denominator	26675	66.3	66.3	99.7
	99 DK/Ref	125	.3	.3	100.0
	Total	40242	100.0	100.0	

drcomm_09 Level of satisfaction with dr to dr communication among those who needed it

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Less than very satisfied	9562	23.8	23.8	23.8
	1 Very satisfied, when needed	16853	41.9	41.9	65.6
	2 Legit skip -- no comm needed or did not use required services	13636	33.9	33.9	99.5
	99 DK/Ref to any	191	.5	.5	100.0
	Total	40242	100.0	100.0	

othercomm_09 If needed, level of satisfaction w/ dr comm to other providers or programs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Less than very satisfied	5344	13.3	13.3	13.3
	1 Very satisfied	6179	15.4	15.4	28.6
	2 Legit skip -- used >2 services	28382	70.5	70.5	99.2
	99 DK/Ref to any	337	.8	.8	100.0
	Total	40242	100.0	100.0	

**APPENDIX B:
Medical Home Components and Interim Variables**

carecoor_09 Effective Care Coordination sub-component of MEDICAL HOME composite measure

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Did not meet 1 or more needed elements of care coordination	12455	31.0	31.4	31.4
	1 Met all needed components of care coordination or legitimate skip	17390	43.2	43.8	75.3
	2 Legit skip -- no one helps with care coor or >2 services used past 12 mos on all items	9815	24.4	24.7	100.0
	Total	39660	98.6	100.0	
Missing	System	582	1.4		
Total		40242	100.0		

**MEDICAL HOME
Composite Measure**

outcome2_09 Children with special health care needs (CSHCN) receiving ongoing, coordinated and comprehensive care within a medical home

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Care DOES NOT meet medical home criteria	20671	51.4	51.4	51.4
	1 Care MEETS medical home criteria	18279	45.4	45.4	96.8
	99 DK/Ref to any	1292	3.2	3.2	100.0
	Total	40242	100.0	100.0	

Appendix C: Methods Notes on Imputation of Missing Values



The 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) provides a rich source of data for studying the relationships between income and health and for monitoring health and health care for various subgroups of CSHCN. However, as is common for most household interview surveys, nonresponse rates can occasionally be higher for certain demographic questions. For the 2009/10 NS-CSHCN, the following variables were imputed: household income, race/ethnicity, highest education level of any parent in the household, household language and total number of adults in the household.

Imputation is one commonly used method for handling nonresponse data in a survey – especially when the proportion of missing, refused, or “don’t know” responses exceed 5% or more of the total. Imputation accomplishes three things. First, it adjusts for observed differences between non-respondents and respondents to an item. Second, imputed response values permit bivariate and multivariate statistical analysis without the need to exclude cases that are missing a value for the imputed variable yet have valid responses on other items. Finally, imputation offers a standardized approach to resolving non-response issues and contributes to improved consistency and comparability of analyses conducted by many researchers. The National Center for Health Statistics website offers a downloadable file with multiple imputed income values for the 2009/10 NS-CSHCN. Interested users can access this file and accompanying instructions free of charge at: http://www.cdc.gov/nchs/slait/imputed_data.htm. The datasets provided by the National Center for Health Statistics contain five sets of imputed values for each imputed variable in the 2009/10 NS-CSHCN. These files are appropriate for use with software able to accommodate multiple imputation analyses and are available free of charge. All imputed variables in the DRC 2009/10 NS-CSHCN Indicator Dataset were generated using a single imputation value from the imputed data file. Analyses based upon single imputation procedures tend to underestimate standard error because they do not fully account for the inherent uncertainty resulting from lack of knowledge about the true values. The DRC Indicator Dataset also contains the non-imputed versions of each imputed variable in addition to the imputation flag for each variable indicating which cases were imputed and which were not.

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

Income: An index of income relative to the Department of Health and Human Services Federal Poverty Guidelines (FPL) is constructed based on reported household income and the reported number of people (adults and children) living in the household. To determine household income level, the survey contains a question about the total combined household income for the previous calendar year (C11Q01). If the survey respondent answers “don’t know” or “refused” to C11Q01, they are then asked a series of ‘cascade’ questions, assessing if their combined household income falls within certain ranges (C11Q01_DON'TKNOW or C11Q01_REFUSED and W9Q03-W9Q12A). If the respondent did not provide any income information either from the original question or the cascade series following it, they were assigned an imputed income

APPENDIX C

Methods notes on Imputation

value. If the respondent did not answer C11Q01 but provided a household income range based upon the cascade questions, they were also assigned an income value using an imputation procedure that anchored their imputed income value to the range they provided. The income variables are at the household level. In the household file, 18.8% of 196,159 households were missing on income altogether and 11.7% of households had income ranges from the cascade questions, which resulted in imputed income for 30.5% of households. For the interview file, this translates to 9.7% of 40,242 cases that were missing on income altogether and 10.2% of cases reported an income range from the cascade questions, resulting in 19.9% total imputed cases for income. Please note that the process used to impute income for the 2009/10 NS-CSHCN differs slightly from prior survey years. Previously, income was only imputed for cases that provided no income information at all and cases that provided an income range based on the cascade questions were assigned an income value equivalent to the median of the range they provided. Also note that for the 2009/10 NS-CSHCN, the total number of adults in the household (which is also needed to determine household income relative to the FPL) was imputed for 7,971 (4.1%) of 196,159 households in the household file, which is equivalent to 294 (0.7%) of the 40,242 cases in the interview file.

Other Imputed Variables: For the first time in 2009/10, variables other than income were imputed. Below lists each imputed variable and the number of cases in the interview file that were missing and therefore imputed for that variable. RACER (child's race): 653 imputed cases; HISPANIC (Hispanic ethnicity of child): 495 imputed cases; PLANGUAGE (primary household language): 454 imputed cases; EDUCR (highest education level of any parent in the household): 606 imputed cases; TOTADULTR (total number of adults living in the household): 294 imputed cases.

The National Center for Health Statistics generates their imputed variables using complex, simultaneous imputation methods. Therefore, for each of the five imputations, income, race, family composition etc. are all simultaneously and are meant to form a coherent portrait of the children whose data is being imputed. For this reason, using any single imputation should result in using that imputation cycle for ALL imputed variables.

The Data Resource Center chose to use imputation 3 for all of the imputed variables from the Household and Screener Files. This choice was randomly made.

Appendix D: Comparison of 2009-2010, 2005/06 & 2001 Indicator & Outcome Measures



The release of the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN) provides the opportunity to conduct trend analyses for selected indicators measured in previous survey years. However, the addition of a cell-phone sample in 2009/10 challenged MCHB and NCHS to think critically about the comparability of the most recent data with those from previous years. Preliminary analyses by NCHS indicate that observed changes (or lack of changes) since 2005/06 in comparably-measured Core Outcomes and Key Indicators may be due to both real changes over time **and/or** the inclusion of cell-phone interviews. The primary issue is coverage bias in 2005/06 due to the inability to adjust for undercoverage of CSHCN living in cell-only households (about 8% over the course of that survey). Because significant differences exist between the cell- and landline-samples with respect to the proportion of CSHCN who met selected indicators (cell users generally fared worse), not being able to account for these differences in 2005/06 limits the ability to draw conclusions about changes over the latter half of the decade. This was not an issue in 2001 as most households did not yet have cell-phones. Given these challenges, analytic processes may be needed to address possible coverage bias when conducting trend analyses with various NS-CSHCN survey years. Detailed information will be available in the forthcoming Design and Operations Manual from the National Center for Health Statistics. In the interim, NCHS recommends the following guidelines:

- Analyses should be conducted in a single concatenated file, with variables for survey year and sample type (landline vs cell phone)
 - Significance testing between 2005/06 and 2009/10 should be adjusted for sample type (landline vs cell phone)
 - Regression analyses using Complex Samples Module are required for SPSS users to evaluate statistical differences between 2005/06 and 2009/10. The sampling plan should include the state and sample type as strata, as well as a combined weight variable from 2005/06 and 2009/10, with weights from the year-specific files. Finally, the “survey year” variable will be included in the Regression Factors to determine whether there is a statistical difference across years.
 - Significance testing between 2001 and 2009/10 should not be adjusted for sample type (landline vs cell phone) because coverage bias is not an issue between these two survey years.
 - Significance testing between 2001 and 2005/06 should be conducted with extreme caution because sampling adjustment cannot be conducted because sample type was not collected in 2005/06.
- Where possible, comparisons between 2001 and 2009/10 are preferred as they avoid the potential bias associated with under-coverage in 2005/06.

Browse Data Trends

The Data Resource Center provides information on the comparability of specific survey items in the 2001, 2005/06 and 2009/10 NS-CSHCN, which can be accessed at www.childhealthdata.org/browse/trends. In order to compare data across multiple years, the question and response options must be identical. Changes in the overall content of the question, the specific wording of the question or response options can result in changes in overall prevalence and interpretation of the survey item.

- [Comparing MCHB Core Outcomes and Indicators Across All Three Years](#)
- [Overview of MCHB Core Outcome Trending for 2005/06 and 2009/10](#)
- [Overview of Key Indicators Trending for 2001 and 2005/06 to 2009/10](#)