

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

SAS 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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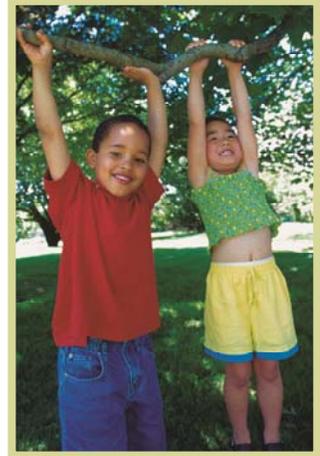
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Acknowledgments

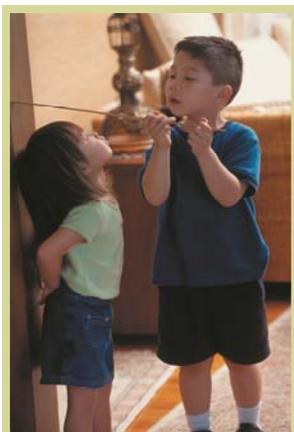
This publication is prepared and updated (when needed) by the Child and Adolescent Health Measurement Initiative (CAHMI).

The CAHMI team extends heartfelt thanks to the Federal Maternal and Child Health Bureau for assuring the availability of high-quality national and state-level survey data on children's health that makes it possible to create the measures included in this document, and for support of the Data Resource Center for Children and Adolescent Health (DRC).

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 SAS Codebook



This codebook contains SAS 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 on the DRC website 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

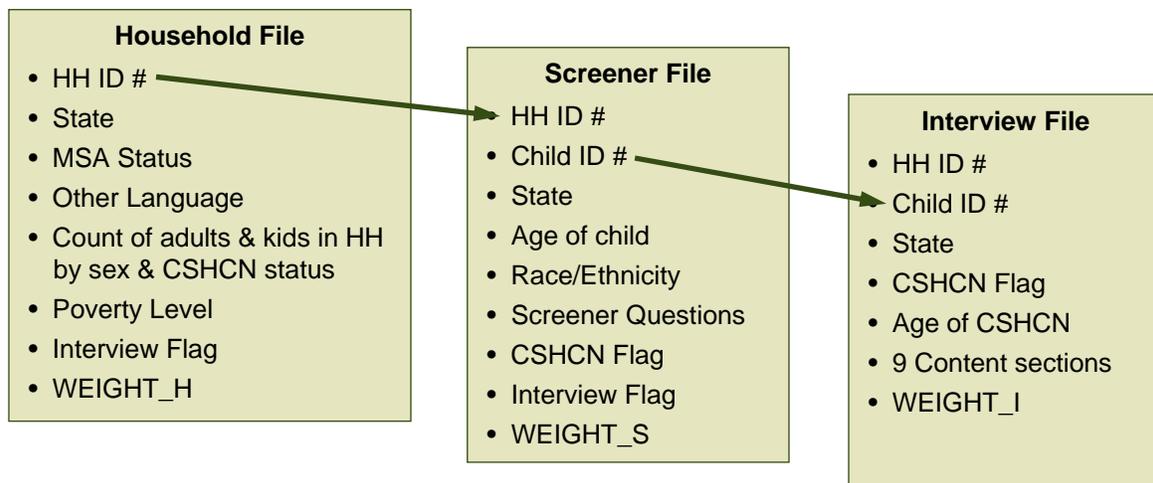
Three of the five public use data files for the 2009/10 NS-CSHCN are used in this codebook as described in the following table:

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.



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 D** 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.

Note for SAS users – Codes for missing values in public use data files

The 2009/10 NS-CSHCN public use data files provided by the National Center for Health Statistics includes special codes to differentiate several types of missing values. Since these values are referred to in code for some of the indicator variables, their definitions are shown in the accompanying table.

Code	Category	Description
.N	NOT IN QUESTION UNIVERSE	Respondents skipped the questions based on eligibility criteria. For the 2009/10 NS-CSHCN, some specific questions were asked only for children who live in California.
.L	LEGITIMATE SKIP	Variable is missing due to valid questionnaire paths based on a previous answer to a root question.
.P	PARTIAL INTERVIEW	Variable is missing because the respondent ended the interview before completing the full interview.
.M	MISSING IN ERROR	Variable is missing due to interviewer or system errors. In cases of interviewer error, the interviewer may have deleted the data by accident or simply may not have entered the response. In cases of system error, the data may not have been collected or saved properly after it was entered by the interviewer in the CATI system.
.A	ADDED QUESTION	Variable is missing because this question was added after the start of data collection and the interview was conducted before the question was added.

NOTE: It is important to note that derived variables (i.e., variables whose response was not directly provided by the respondent) do not include the detailed coding of missing data. All missing values for derived variables received a “.M” code regardless of the reason for the missing data. Similarly, “.M” was used when derived variables were suppressed to protect the confidentiality of the survey participants.

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>



CSHCN Prevalence and Demographics

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.	
SAS Code and Annotation	
<pre> CSHCN_09 = needtype; If needtype = 1 then CSHCN_09 = 0; If needtype = 2 then CSHCN_09 = 1; label CSHCN_09 = 'How many children have special health care needs? Screener file, all children'; value CSHCN_09 0 = 'Non-CSHCN' 1 = 'CSHCN'; </pre>	

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.	
SAS Code and Annotation	
<pre> CSHCNhh_09 = .; if NM_SPR = 0 then CSHCNhh_09 = 0; if NM_SPR ge 1 then CSHCNhh_09 = 1; label CSHCNhh_09 = 'How many households have 1 or more CSHCN?'; value CSHCNhh_09 0 = 'No CSHCN living in HH' 1 = '1 or more CSHCN living in HH'; </pre>	

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>	
SAS Code and Annotation	
<pre> indicl_09 = .; if C3Q02 = 1 then indicl_09 = 1; if C3Q02 = 2 then indicl_09 = 2; if C3Q02 = 3 then indicl_09 = 3; if C3Q02 = 4 then indicl_09 = 3; if C3Q03 = 1 then indicl_09 = 3; if C3Q02 >= 6 then indicl_09 = .M; if C3Q03 >= 6 then indicl_09 = .M; label indicl_09 = 'INDICATOR 1: Activity Limitations: CSHCN whose health conditions consistently affect daily activities'; value dailyact /*indicl_09*/ 1 = 'Daily activities never affected' 2 = 'Daily activities moderately affected some of time' 3 = 'Daily activities consistently affected, often a great deal' .M = 'DK, Ref or Missing to both items'; </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.	
SAS Code and Annotation	
<pre> indic2_09 = .; if C3Q14R >= 0 and C3Q14R <=3 then indic2_09 = 1; if C3Q14R >=4 and C3Q14R <= 6 then indic2_09 = 2; if C3Q14R >= 7 and C3Q14R <= 10 then indic2_09 = 3; if C3Q14R >= 11 and C3Q14R <= 13 then indic2_09 = 4; if C3Q14R >= 994 then indic2_09 = .M; if C3Q14R = .M then indic2_09 = .M; if C3Q14R = .L then indic2_09 = .L; label indic2_09 = 'INDICATOR 2: Missed School Days: CSHCN ages 5-17 with 11 or more school absences due to illness'; value misssch /*indic2_09*/ 1 = '0 - 3 days missed' 2 = '4 - 6 days missed' 3 = '7 - 10 days missed' 4 = '11 or more days missed' .M = 'DK, Ref, Did not go to school or Home schooled' .L = '<5 years old'; </pre>	

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>	
SAS Code and Annotation	
<p>** NOTE: Uses derived variable UNINS_YR included in public release INTERVIEW file.</p> <pre> indic3_09 = .; if UNINS_YR = 1 then indic3_09 = 1; if UNINS_YR = 0 then indic3_09 = 0; if UNINS_YR in (6,7,.M) then indic3_09 = .M; label indic3_09 = 'INDICATOR 3: Inconsistently Insured: CSHCN without insurance at some point during the past year'; value insured /*indic3_09*/ 0 = 'Insured entire year' 1 = 'NOT insured at some point during year' .M = 'DK, Ref or Missing/Not ascertained'; </pre>	

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>	
SAS Code and Annotation	
<p>** NOTE: Uses derived variable UNINS included in public release INTERVIEW file</p> <pre> indic4_09 = .; if UNINS = 1 then indic4_09 = 1; if UNINS = 0 then indic4_09 = 0; if UNINS in (6,7) then indic4_09 = .M; label indic4_09 = 'INDICATOR 4: Currently Uninsured: CSHCN without insurance at time of the survey'; value currins /*indic4_09*/ 0 = 'Currently insured' 1 = 'Currently NOT insured' .M = 'DK or Ref'; </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>	
SAS Code and Annotation	
<p>**STEP 1: Regroup responses to the three insurance adequacy items used to construct Indicator #5.</p> <pre> metneeds_09 = .; if UNINS = 1 then metneeds_09 = 2; else if UNINS in (6,7) then metneeds_09 = .M; else if C8Q01_A in (1,2) then metneeds_09 = 0; else if C8Q01_A in (3,4) then metneeds_09 = 1; else if C8Q01_A = .L then metneeds_09 = 2; else if C8Q01_A in (6,7,.M) then metneeds_09 = .M; else if C8Q01_A = .P then metneeds_09 = .P; label metneeds_09 = 'Health insurance benefits meet child needs'; reasonable_09 = .; if UNINS = 1 then reasonable_09 = 2; else if UNINS in (6,7) then reasonable_09 = .M; else if C8Q01_B in (1,2) then reasonable_09 = 0; else if C8Q01_B in (3,4,5) then reasonable_09 = 1; else if C8Q01_B = .L then reasonable_09 = 2; else if C8Q01_B in (6,7,.M) then reasonable_09 = .M; </pre>	

National Chartbook Indicators

```
else if C8Q01_B = .P then reasonable_09 = .P;
label reasonable_09 = 'Non-covered insurance charges reasonable';

providers_09 = .;
if UNINS = 1 then providers_09 = 2;
else if UNINS in (6,7) then providers_09 = .M;
else if C8Q01_C in (1,2) then providers_09 = 0;
else if C8Q01_C in (3,4) then providers_09 = 1;
else if C8Q01_C = .L then providers_09 = 2;
else if C8Q01_C in (6,7,.M) then providers_09 = .M;
else if C8Q01_C = .P then providers_09 = .P;
label providers_09 = 'Insurance allows child to see needed providers';

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

indic5_09 = .;
if metneeds_09 = 1 and reasonable_09 = 1 and providers_09 = 1 then indic5_09
= 1;
if metneeds_09 = 0 or reasonable_09 = 0 or providers_09 = 0 then indic5_09 =
0;
if metneeds_09 in (.M,.P) or reasonable_09 in (.M,.P) or providers_09 in
(.M,.P) then indic5_09 = .M;
if metneeds_09 = 2 then indic5_09 = .L;
label indic5_09 = 'INDICATOR 5: "Adequacy of Current Insurance Coverage:
Currently insured CSHCN whose insurance coverage is not adequate';

value adeqins /*metneeds_09 reasonable_09 providers_09*/
0 = 'Never/sometimes'
1 = 'Usually/always'
2 = 'Legit skip b/c uninsured';

value insadeq /*indic_5*/
0 = 'Current insurance is NOT adequate'
1 = 'Current insurance IS adequate'
.M = 'DK or Ref to any item'
.L = 'Uninsured';
```

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 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>	
SAS 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.

**Routine preventive care;*

prevmed_need_09 = 0;

if K4Q20R > 0 or C4Q05_1 = 1 then prevmed_need_09 = 1;

if K4Q20R in (96,97) or C4Q05_1 = 6 then prevmed_need_09 = .M;

label prevmed_need_09 = 'Need for preventive medical care';

prevmed_unmet_09 = .;

if prevmed_need_09 = 0 then prevmed_unmet_09 = 0;

if C4Q05_1A = 1 then prevmed_unmet_09 = 1;

if C4Q05_1A = 0 or C4Q05_1 = 1 then prevmed_unmet_09 = 2;

label prevmed_unmet_09 = 'Unmet needs for preventive care';

**Specialist Care;*

specialist_unmet_09 = .;

if C4Q05_2 = 0 then specialist_unmet_09 = 0;

if C4Q05_2A = 1 then specialist_unmet_09 = 1;

if C4Q05_2A = 0 then specialist_unmet_09 = 2;

label specialist_unmet_09 = 'Unmet needs for specialist care';

**Preventive Dental Care;*

prevden_need_09 = 0;

if K4Q21R > 0 or C4Q05_31 = 1 then prevden_need_09=1;

if K4Q21R in (96,97) or C4Q05_31 in (6,7) then prevden_need_09 = .M;

label prevden_need_09 = 'Need for preventive dental care';

prevden_unmet_09 = .;

if prevden_need_09 = 0 then prevden_unmet_09 = 0;

if C4Q05_31A = 1 then prevden_unmet_09 = 1;

if C4Q05_31A = 0 or C4Q05_31=1 then prevden_unmet_09 = 2;

label prevden_unmet_09= 'Unmet needs for preventive dental care';

**Other Dental Care;*

odental_unmet_09 = .;

if C4Q05_32 = 0 then odental_unmet_09 = 0;

if C4Q05_32A = 1 then odental_unmet_09 = 1;

if C4Q05_32A = 0 then odental_unmet_09 = 2;

label odental_unmet_09= 'Unmet needs for other dental care';

**Prescriptions;*

rxmedsl_unmet_09 = .;

if C4Q05_4 = 0 then rxmedsl_unmet_09 = 0;

if C4Q05_4A = 1 then rxmedsl_unmet_09 = 1;

if C4Q05_4A = 0 then rxmedsl_unmet_09 = 2;

label rxmedsl_unmet_09 = 'Unmet needs for prescription medicine';

**Physical/Occupational/Speech therapy;*

therapy_unmet_09 = .;

if C4Q05_5 = 0 then therapy_unmet_09 = 0;

if C4Q05_5A = 1 then therapy_unmet_09 = 1;

National Chartbook Indicators

```
if C4Q05_5A = 0 then therapy_unmet_09 = 2;
label therapy_unmet_09 = 'Unmet needs for OT, PT or speech therapy';

*Mental Health;
mhealth_unmet_09 = .;
if C4Q05_6 = 0 then mhealth_unmet_09 = 0;
if C4Q05_6A = 1 then mhealth_unmet_09 = 1;
if C4Q05_6A = 0 then mhealth_unmet_09 = 2;
label mhealth_unmet_09 = 'Unmet needs for mental health care';

*Substance Abuse;
*Skipped for CSHCN < 8 YO;
subabuse_unmet_09 = .;
if C4Q05_7 = 0 then subabuse_unmet_09 = 0;
if C4Q05_7A = 1 then subabuse_unmet_09 = 1;
if C4Q05_7A = 0 then subabuse_unmet_09 = 2;
if 8 > AGE >= 0 then subabuse_unmet_09 = .L;
label subabuse_unmet_09 = 'Unmet needs for substance abuse tx, 8-17 years';

*Home Health;
homehlth_unmet_09 = .;
if C4Q05_8 = 0 then homehlth_unmet_09 = 0;
if C4Q05_8A = 1 then homehlth_unmet_09 = 1;
if C4Q05_8A = 0 then homehlth_unmet_09 = 2;
label homehlth_unmet_09 = 'Unmet needs for home health care';

*Eyeglasses/ Needed Vision Care;
vision_unmet_09 = .;
if C4Q05_9 = 0 then vision_unmet_09 = 0;
if C4Q05_9A = 1 then vision_unmet_09 = 1;
if C4Q05_9A = 0 then vision_unmet_09 = 2;
label vision_unmet_09 = 'Unmet needs for eyeglasses or vision care';

*Hearing Aids/ Care;
hearing_unmet_09 = .;
if C4Q05_10 = 0 then hearing_unmet_09 = 0;
if C4Q05_10A = 1 then hearing_unmet_09 = 1;
if C4Q05_10A = 0 then hearing_unmet_09 = 2;
label hearing_unmet_09= 'Unmet needs for hearing aids/hearing care';

*Mobility Aids or Devices;
*Skipped for CSHCN < 3 YO;
mobility_unmet_09 = .;
if C4Q05_11 = 0 then mobility_unmet_09 = 0;
if C4Q05_11A = 1 then mobility_unmet_09 = 1;
if C4Q05_11A = 0 then mobility_unmet_09 = 2;
if 3 > AGE >= 0 then mobility_unmet_09 = .L;
label mobility_unmet_09= 'Unmet needs for mobility aids or devices, 3-17
years';

*Communication Aids or Devices;
*Skipped for CSHCN < 3 YO;
commun_unmet_09 = .;
if C4Q05_12 = 0 then commun_unmet_09 = 0;
if C4Q05_12A = 1 then commun_unmet_09 = 1;
```

National Chartbook Indicators

```
if C4Q05_12A = 0 then commun_unmet_09 = 2;
if 3 > AGE >= 0 then commun_unmet_09 = .L;
label commun_unmet_09= 'Unmet needs for communication aids or devices, 3-17
years';

*Durable Medical Equipment;
durable_unmet_09 = .;
if C4Q05_14 = 0 then durable_unmet_09 = 0;
if C4Q05_14A = 1 then durable_unmet_09 = 1;
if C4Q05_14A = 0 then durable_unmet_09 = 2;
label durable_unmet_09= 'Unmet needs for durable medical equipment';

unmet_sum = 0;
if prevmed_unmet_09 = 2 then unmet_sum + 1;
if specialist_unmet_09 = 2 then unmet_sum + 1;
if prevden_unmet_09 = 2 then unmet_sum + 1;
if odontal_unmet_09 = 2 then unmet_sum + 1;
if rxmedsl_unmet_09 = 2 then unmet_sum + 1;
if therapy_unmet_09 = 2 then unmet_sum + 1;
if mhealth_unmet_09 = 2 then unmet_sum + 1;
if subabuse_unmet_09 = 2 then unmet_sum + 1;
if homehlth_unmet_09 = 2 then unmet_sum + 1;
if vision_unmet_09 = 2 then unmet_sum + 1;
if hearing_unmet_09 = 2 then unmet_sum + 1;
if mobility_unmet_09 = 2 then unmet_sum + 1;
if commun_unmet_09 = 2 then unmet_sum + 1;
if durable_unmet_09 = 2 then unmet_sum + 1;
if prevmed_unmet_09=. or specialist_unmet_09=. or prevden_unmet_09=. or
odontal_unmet_09=. or rxmedsl_unmet_09=. or therapy_unmet_09=.
or mhealth_unmet_09=. or subabuse_unmet_09=. or homehlth_unmet_09=. or
vision_unmet_09=. or hearing_unmet_09=. or mobility_unmet_09=.
or commun_unmet_09=. or durable_unmet_09=. then unmet_sum = .;
label unmet_sum = 'Number of unmet needs - all 14 services';

**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.

indic6_09 = .;
if unmet_sum > 1 then indic6_09 = 2;
if unmet_sum = 1 then indic6_09 = 1;
if unmet_sum = 0 then indic6_09 = 0;
if prevmed_unmet_09=. or specialist_unmet_09=. or prevden_unmet_09=. or
odontal_unmet_09=. or rxmedsl_unmet_09=. or therapy_unmet_09=.
or mhealth_unmet_09=. or subabuse_unmet_09=. or homehlth_unmet_09=. or
vision_unmet_09=. or hearing_unmet_09=. or mobility_unmet_09=.
or commun_unmet_09=. or durable_unmet_09=. then indic6_09 = .M;
label indic6_09 = 'INDICATOR 6: Unmet Needs for Care: CSHCN with any unmet
need for any of 14 specific health care services or equipment, past 12
months';

value prevmed /*prevmed_need_09*/
0 = 'Did not need preventive medical care'
1 = 'Needed preventive medical care';
```

National Chartbook Indicators

```
value prevden /*prevden_need_09*/
0 = 'Did not need preventive dental care'
1 = 'Needed preventive dental care';

value medunmet /*prevmed_unmet_09*/
0 = 'Did not need preventive med care'
1 = 'Got all needed preventive med care'
2 = 'Unmet preventive care needs';

value spunmet /*specialist_unmet_09*/
0 = 'Did not need specialist care'
1 = 'Got all needed specialist care'
2 = 'Unmet specialist care needs';

value denunmet /*prevden_unmet_09*/
0 = 'Did not need prev dental care'
1 = 'Got all needed prev dental care'
2 = 'Unmet prev dental care needs';

value odenunmet /*odental_unmet_09*/
0 = 'Did not need other dental care'
1 = 'Got all needed other dental care'
2 = 'Unmet other dental care needs';

value rxunmet /*rxmedsl_unmet_09*/
0 = 'Did not need prescription medicine'
1 = 'Got all needed prescription medicine'
2 = 'Unmet prescription medicine needs';

value therunmet /*therapy_unmet_09*/
0 = 'Did not need therapy'
1 = 'Got all needed therapy'
2 = 'Unmet therapy needs';

value mhlthunmet /*mhealth_unmet_09*/
0 = 'Did not need mental health care'
1 = 'Got all needed mental health care'
2 = 'Unmet mental health care needs';

value subunmet /*subabuse_unmet_09*/
0 = 'Did not need sub abuse tx'
1 = 'Got all needed sub abuse tx'
2 = 'Unmet sub abuse tx needs';

value homeunmet /*homehlth_unmet_09*/
0 = 'Did not need home health care'
1 = 'Got all needed home health care'
2 = 'Unmet home care needs';

value visunmet /*vision_unmet_09*/
0 = 'Did not need vision care'
1 = 'Got all needed vision care'
2 = 'Unmet vision care needs';
```

National Chartbook Indicators

```
value hearunmet /*hearing_unmet_09*/
0 = 'Did not need hearing care'
1 = 'Got all needed hearing care'
2 = 'Unmet hearing care needs';

value mobunmet /*mobility_unmet_09*/
0 = 'Did not need mobility device'
1 = 'Got all needed mobility devices'
2 = 'Unmet mobility device needs';

value comunmet /*commun_unmet_09*/
0 = 'Did not need comm device'
1 = 'Got all needed comm devices'
2 = 'Unmet comm device needs';

value durunmet /*durable_unmet_09*/
0 = 'Did not need durable equip'
1 = 'Got all needed durable equip'
2 = 'Unmet durable equip needs';

value unmet /*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'
.M = 'DK or Ref to any';
```

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>	
SAS 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> *Respite care; respite_09 = .; if C4Q06_1 = 0 then respite_09 = 2; if C4Q06_1A = 1 then respite_09 = 0; if C4Q06_1A = 0 then respite_09 = 1; label respite_09 = 'Families need for and receipt of respite care'; *Genetic Counseling; gene_09 = .; if C4Q06_2 = 0 then gene_09 = 2; if C4Q06_2A = 1 then gene_09 = 0; if C4Q06_2A = 0 then gene_09 = 1; </pre>	

National Chartbook Indicators

```
label gene_09 = 'Families need for and receipt of genetic counseling';

*Mental Health Care;
mhfam_09 = .;
if C4Q06_3 = 0 then mhfam_09 = 2;
if C4Q06_3A = 1 then mhfam_09 = 0;
if C4Q06_3A = 0 then mhfam_09 = 1;
label mhfam_09 = 'Families need for and receipt of mental health
care/counseling';

famsum_09 = 0;
if respite_09 = 1 then famsum_09 + 1;
if gene_09 = 1 then famsum_09 + 1;
if mhfam_09 =1 then famsum_09 + 1;
label 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

indic7_09 = 0;
if famsum_09 >0 then indic7_09 = 1;
if respite_09 in (0,2,.) and gene_09 in (0,2,.) and mhfam_09 in (0,2,.) then
indic7_09 = 0;
if respite_09 =. or gene_09 =. or mhfam_09 =. then indic7_09 = .M;
label indic7_09 = 'INDICATOR 7: Unmet Needs for Family Support Services:
CSHCN with any unmet needs for family support services';

*** Among CSHCN who needed family support services

indic7b_09 = 0;
if famsum_09 >0 then indic7b_09 = 1;
if respite_09 in (0,2) and gene_09 in (0,2) and mhfam_09 in (0,2) then
indic7b_09 = 0;
if respite_09 = 2 and gene_09 = 2 and mhfam_09 = 2 then indic7b_09 = .L;
if respite_09 =. or gene_09 =. or mhfam_09 =. then indic7b_09 = .;
label indic7b_09 = 'INDICATOR 7: % of CSHCN with one or more unmet needs for
family services';

value respite /*respite_09*/
0 = 'Needed and got all respite care'
1 = 'Needed, did not get all respite care'
2 = 'Legit skip, did not need';

value gene /*gene_09*/
0 = 'Needed and got all genetic counseling'
1 = 'Needed, did not get all genetic counseling'
2 = 'Legit skip, did not need';

value mhfam /*mhfam_09*/
0 = 'Needed and got all fam MH care'
1 = 'Needed, did not get all fam MH'
2 = 'Legit skip, did not need';
```

National Chartbook Indicators

```
value unmetfss /*indic_7_09*/
0 = 'No unmet needs for specific family support services or did not need'
1 = 'One or more unmet needs for family support services'
.M = 'DK or Ref';

value unmetlfss /*indic_7b_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';
```

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>	
SAS Code and Annotation	
<pre> indic8_09 = .; if C4Q07 = 1 then indic8_09 = 1; if C4Q07 = 2 then indic8_09 = 1; if C4Q07 = 3 then indic8_09 = 0; if C4Q07 = .L then indic8_09 = .L; if C4Q07 in (6,.M) then indic8_09 = .M; label indic8_09 = 'INDICATOR 8: Problems Obtaining Referral: CSHCN needing specialty care who had problems getting a referral'; value diffref /*indic8_09*/ 0 = 'Needed referral, no problems getting it' 1 = 'Needed referral, YES problems getting it' .M = 'DK or Missing' .L = 'Did not need referral'; </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.	
SAS Code and Annotation	
<pre> indic9_09 = .M; if C4Q0BR = 1 then indic9_09 = 1; if C4Q0BR in (3,4,5,6,8,10,11,12) then indic9_09 = 2; if C4Q0A = 2 or C4Q0BR in (2,7,9) then indic9_09 = 3; label indic9_09 = 'INDICATOR 9: Usual Source for Sick Care: CSHCN without a usual source of care or who rely on the emergency room'; value ussick /*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' .M = 'DK or Ref'; </pre>	

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.	
SAS Code and Annotation	
<pre> indic10_09 = .; if C4Q02A = 1 then indic10_09 = 1; if C4Q02A = 2 then indic10_09 = 1; if C4Q02A = 3 then indic10_09 = 0; if C4Q02A in (6,7) then indic10_09 = .M; label indic10_09 = 'INDICATOR 10: Personal Doctor or Nurse: CSHCN without a personal doctor or nurse (PDN)'; value persdn /*indic10_09 */ 0 = 'No, does not have a PDN' 1 = 'Yes, has one or more PDNs' .M = 'DK or Ref'; </pre>	

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>	
SAS Code and Annotation	
<pre> /*Family Centered Care (FCC): Dr. spends enough time*/ time_09=.; if C6Q02 in (6,7) then time_09 = .M; else if C6Q02 = .L then time_09 = 2; else if C6Q02 = 1 or C6Q02 = 2 then time_09 = 0; else if C6Q02 = 3 or C6Q02 = 4 then time_09 = 1; label time_09 = 'Drs/other health providers spend enough time'; /*FCC:Doctors usually or always listen carefully*/ listen_09=.; if C6Q03 in (6,7) then listen_09 = .M; else if C6Q03 = .L then listen_09 = 2; else if C6Q03 = 1 or C6Q03 = 2 then listen_09 = 0; else if C6Q03 = 3 or C6Q03 = 4 then listen_09 = 1; label listen_09 = 'FCC: Drs/other health providers usually or always listen carefully'; </pre>	

National Chartbook Indicators

```
/*FCC: Doctors are usually or always sensitive to values and customs*/
sensitive_09=.;
if C6Q04 in (6,7) then sensitive_09 = .M;
else if C6Q04 = .L then sensitive_09 = 2;
else if C6Q04 = 1 or C6Q04 = 2 then sensitive_09 = 0;
else if C6Q04 = 3 or C6Q04 = 4 then sensitive_09 = 1;
label sensitive_09 = 'Drs/other health providers sensitive to family
values/customs';

/*FCC: Doctors usually or always provide needed information*/

infofcc_09=.;
if C6Q05 in (6,7) then infofcc_09 = .M;
else if C6Q05 = .L then infofcc_09 = 2;
else if C6Q05 = 1 or C6Q05 = 2 then infofcc_09 = 0;
else if C6Q05 = 3 or C6Q05 = 4 then infofcc_09 = 1;
label infofcc_09 = 'Drs/other health providers provide needed information';

/*FCC: Doctors usually or always make the family feel like a partner*/

partner_09=.;
if C6Q06 in (6,7) then partner_09 = .M;
else if C6Q06 = .L then partner_09 = 2;
else if C6Q06 = 1 or C6Q06 = 2 then partner_09 = 0;
else if C6Q06 = 3 or C6Q06 = 4 then partner_09 = 1;
label partner_09 = 'Drs/other health providers make family feel like a
partner';

/*Receives family-centered care (1+ visits in past year)*/

indic11_09 = .;
if time_09 = 0 or listen_09 = 0 or sensitive_09 = 0 or infofcc_09 = 0 or
partner_09 = 0 then indic11_09 = 0;
if time_09 = 1 and listen_09 = 1 and sensitive_09 = 1 and infofcc_09 = 1 and
partner_09 = 1 then indic11_09 = 1;
if time_09 = .M or listen_09 = .M or sensitive_09 = .M or infofcc_09 = .M or
partner_09 = .M then indic11_09 = .M;
if C6Q01 = 0 or C6Q01 = 6 then indic11_09 = .L;
label indic11_09 = 'INDICATOR 11: Family Centered Care: CSHCN without
family-centered care';

value indfcc /*indic11_09*/
0 = 'Does NOT have family centered care'
1 = 'Yes, has family centered care'
.M = 'DK/Ref to all or SYSMIS'
.L = ' Legitimate skip - no dr visit past 12 mos';
```

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>	
SAS Code and Annotation	
<pre> indic12_09 = .; if C9Q01 in (3,4) then indic12_09 = 1; if C9Q01 = 2 then indic12_09 = 2; if C9Q01_A = 3 then indic12_09 = 3; if C9Q01_A in (1,2) then indic12_09 = 4; if C9Q01 in (6,7,.P) or C9Q01_A in (6,7,.P) then indic12_09 = .M; label 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 outofpck /*indic12_09*/ 1 = 'Less than \$250' 2 = '\$250 - \$500' 3 = '\$501 - \$1000' 4 = 'More than \$1000' .M = 'DK or Ref'; </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.	
SAS Code and Annotation	
<pre> indic13_09 = C9Q05; if C9Q05 in (6,7,.P) then indic13_09 = .M; label indic13_09 = 'INDICATOR 13: Family Financial Burden: CSHCN whose families experienced financial problems due to child's health needs'; value finprob /*indic13_09 */ 0 = "No financial problems due to child's health" 1 = 'Yes, financial problems' .M = 'DK, Ref or Missing'; </pre>	

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>	
SAS Code and Annotation	
<p>** STEP 1: Create interim variables from number of hours spent items.</p> <pre> c9q02r = C9Q02; if C9Q02 in (6,7,.P) then c9q02r = .M; label c9q02r = 'Do you or other family members provide health care at home for [S.C.]?'; rc9q03r = C9Q03R; if C9Q03R in (996,997,.P) or c9q02r = .M then rc9q03r = .M; else if c9q02r = 0 then rc9q03r = 0; else if C9Q03R = .L then rc9q03r = 0; label rc9q03r = 'How many hours per week do you or other family members spend providing health care at home?'; </pre>	

National Chartbook Indicators

```
rc9q04r = C9Q04R;
if C9Q04R in (996,997,.P) then rc9q04r = .M;
label rc9q04r = "How many hours per week do you or other family members
spend arranging or coordinating child's care?";

hrs_sum = .;
hrs_sum = sum (rc9q03r,rc9q04r);
if rc9q03r = .M and rc9q04r = .M then hrs_sum = .M;

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

indic14_09 = .;
if hrs_sum = 0 then indic14_09 = 1;
if hrs_sum >= 1 and hrs_sum <= 4 then indic14_09 = 2;
if hrs_sum >= 5 and hrs_sum <= 10 then indic14_09 = 3;
if hrs_sum >= 11 then indic14_09 = 4;
if hrs_sum = .M then indic14_09 = .M;
IF C9Q02 in (6,7,.P) or C9Q03R in (.P,996,997) or C9Q04R in (.P, 996,997)
then indic14_09 = .M;
label 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 hours /*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'
.M = 'DK or Ref';
```

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>	
SAS Code and Annotation	
<pre> indic15_09=.; if C9Q10 = 1 or C9Q06 = 1 then indic15_09 = 1; if C9Q10 = 0 and C9Q06 = 0 then indic15_09 = 0; if C9Q10 in (.P,6,7) or C9Q06 in (.P,6,7) then indic15_09 = .M; label 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 chgwork /*indic15_09*/ 0 = 'Employment not affected' 1 = 'Family member cut back hours or stopped working or both' .M = 'DK or Ref'; </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

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).

Revisions in 2009/10

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.

This outcome should not be compared with the results from Outcome #1 from the 2005/06 NS-CSHCN.

SAS Code and Annotation

*STEP 1: Recode variables C6Q21-C6Q24 to combine usually with always and never with sometimes. This measure was revised and cannot be compared with Outcome #1 from 2005/06.**

```

/*Doctors usually/always discussed range of options*/
range_09 = .;
if C6Q21 in (3,4,5) then range_09 = 1;
else if C6Q21 in (1,2) then range_09 = 0;
else if C6Q21 in (6,7) then range_09 = .M;
else if C6Q21 = .L then range_09 = .L;
label range_09 = 'How often did Drs discuss range of treatment options?';

/*Doctors usually/always encourage parent to ask questions*/
raise_09 = .;
if C6Q22 in (3,4) then raise_09 = 1;
else if C6Q22 in (1,2) then raise_09 = 0;
else if C6Q22 in (6,7) then raise_09 = .M;

```

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```
else if C6Q22 = .L then raise_09 = .L;
label raise_09 = 'How often did Drs encourage you to raise concerns?';

/*Doctors usually/always make it easy to ask questions*/
easytoask_09 = .;
if C6Q23 in (3,4) then easytoask_09 = 1;
else if C6Q23 in (1,2) then easytoask_09 = 0;
else if C6Q23 in (6,7) then easytoask_09 = .M;
else if C6Q23 = .L then easytoask_09 = .L;
label easytoask_09 = 'How often did Drs make it easy to ask questions?';

/*Doctors usually/always consider and respect parent choices*/
choices_09 = .;
if C6Q24 in (3,4) then choices_09 = 1;
else if C6Q24 in (1,2) then choices_09 = 0;
else if C6Q24 in (6,7) then choices_09 = .M;
else if C6Q24 = .L then choices_09 = .L;
label choices_09 = 'How often did Drs consider and respect your thoughts
treatment choices?';

*STEP 2: Create Outcome #1.

outcome1_09 = .;
if range_09 = .M or raise_09 = .M or easytoask_09 = .M or choices_09 = .M
then outcome1_09 = .M;
else if range_09 = .L and raise_09 = .L and easytoask_09 = .L and choices_09
= .L then outcome1_09 = .L;
else if range_09 = 1 and raise_09 = 1 and easytoask_09 = 1 and choices_09 = 1
then outcome1_09 = 1;
else if range_09 = 0 or raise_09 = 0 or easytoask_09 = 0 or choices_09 = 0
then outcome1_09 = 0;
else outcome1_09 = .M;
label outcome1_09 = 'OUTCOME #1: How many children met Outcome #1 on shared
decision making, usually/always on all questions';

value decmake /*range_09 raise_09 easytoask_09 choices_09*/
0 = 'Never/Sometimes'
1 = 'Usually/Always or N/A';

value outlcome /*outcome1_09*/
0 = 'Did not meet Outcome #1'
1 = 'Met Outcome #1'
.M = 'DK or Ref on all'
.L = 'Legit skip';
```

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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.	
SAS Code and Annotation	
SUBCOMPONENT 1: PERSONAL DOCTOR OR NURSE (PDN)	
*STEP 1: Create personal doctor or nurse sub-component of the medical home composite measure.	
<pre> pdn_09=. ; if C4Q02A in (1,2) then pdn_09 = 1; else if C4Q02A = 3 then pdn_09 = 0; else if C4Q02A in (6,7,.M) then pdn_09 = .M; </pre>	

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```
label pdn_09 = 'Personal Doctor or Nurse sub-component of MEDICAL HOME composite measure';
```

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.

```
/*Has a usual source for sick care*/
sick_09 = .;
if C4Q0A in (1,3) and C4Q0BR in (1,3,4,5,6,8,10,11,12) then sick_09 = 1;
else if C4Q0A = 2 or C4Q0BR in (2,7,9) then sick_09 = 0;
else if C4Q0A in (6,7) or C4Q0BR in (.M,96,97) then sick_09 = .M;
label sick_09 = 'Child has 1 or more usual place for sick care';

/*Has a usual source for preventive care*/
well_09 = .;
if C4Q0D in (1,3) and (sick_09 = .M and C4Q01 = 1) then well_09 = .M;
else if C4Q0D in (1,3) and C4Q01 in (6,7) then well_09 = .M;
else if C4Q0D in (1,3) and ((sick_09 = 1 and C4Q01 = 1) or (C4Q02R in (1,3,4,5,6,8,10,11,12))) then well_09 = 1;
else if C4Q0D in (1,3) and (sick_09 = 0 and C4Q01 = 1) then well_09 = 0;
else if C4Q0D = 2 or C4Q02R in (2,7,9) then well_09 = 0;
else if C4Q0D in (6,7) or C4Q02R in (96,97) then well_09 = .M;
label well_09 = 'Child has 1 or more usual places for well care';
```

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

```
usual_09 = .;
if sick_09 = .M or well_09 = .M then usual_09 = .M;
else if sick_09 = 1 and well_09 = 1 then usual_09 = 1;
else if sick_09 = 0 or well_09 = 0 then usual_09 = 0;
label usual_09 = 'Usual Sources for Sick and Well Care sub-component of MEDICAL HOME composite measure';
```

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.

```
/*Family Centered Care (FCC): Doctors usually or always spend enough time*/
time_09=.;
if C6Q02 in (6,7) then time_09 = .M;
else if C6Q02 = .L then time_09 = 2;
else if C6Q02 = 1 or C6Q02 = 2 then time_09 = 0;
else if C6Q02 = 3 or C6Q02 = 4 then time_09 = 1;
label time_09 = 'Drs/other health providers spend enough time(C6Q02 recoded)';

/*FCC:Doctors usually or always listen carefully*/
listen_09=.;
if C6Q03 in (6,7) then listen_09 = .M;
else if C6Q03 = .L then listen_09 = 2;
else if C6Q03 = 1 or C6Q03 = 2 then listen_09 = 0;
else if C6Q03 = 3 or C6Q03 = 4 then listen_09 = 1;
```

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```
label listen_09 = 'Drs/other health providers listen carefully (C6Q03
recoded)';

/*FCC: Doctors are usually or always sensitive to values and customs*/
sensitive_09=.;
if C6Q04 in (6,7) then sensitive_09 = .M;
else if C6Q04 = .L then sensitive_09 = 2;
else if C6Q04 = 1 or C6Q04 = 2 then sensitive_09 = 0;
else if C6Q04 = 3 or C6Q04 = 4 then sensitive_09 = 1;
label sensitive_09 = 'Drs/other health providers sensitive to family
values/customs (C6Q04 recoded)';

/*FCC: Doctors usually or always provide needed information*/
infofcc_09=.;
if C6Q05 in (6,7) then infofcc_09 = .M;
else if C6Q05 = .L then infofcc_09 = 2;
else if C6Q05 = 1 or C6Q05 = 2 then infofcc_09 = 0;
else if C6Q05 = 3 or C6Q05 = 4 then infofcc_09 = 1;
label infofcc_09 = 'Drs/other health providers provide needed information
(C6Q05 recoded)';

/*FCC: Doctors usually or always make the family feel like a partner*/
partner_09=.;
if C6Q06 in (6,7) then partner_09 = .M;
else if C6Q06 = .L then partner_09 = 2;
else if C6Q06 = 1 or C6Q06 = 2 then partner_09 = 0;
else if C6Q06 = 3 or C6Q06 = 4 then partner_09 = 1;
label partner_09 = 'Drs/other health providers make family feel like a
partner (C6Q06 recoded)';
```

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

```
famcent_09 = .;
if time_09 = 0 or listen_09 = 0 or sensitive_09 = 0 or infofcc_09 = 0 or
partner_09 = 0 then famcent_09 = 0;
if time_09 = 1 and listen_09 = 1 and sensitive_09 = 1 and infofcc_09 = 1 and
partner_09 = 1 then famcent_09 = 1;
if time_09 = .M or listen_09 = .M or sensitive_09 = .M or infofcc_09 = .M or
partner_09 = .M then famcent_09 = .M;
if C6Q01 = 0 or C6Q01 = 6 then famcent_09 = 2;
label famcent_09 = 'Family-Centered Care sub-component of MEDICAL HOME
composite measure';
```

SUBCOMPONENT 4: NO PROBLEMS GETTING NEEDED REFERRALS

```
norefprb_09 = .;
if C5Q11 in (0,.L) then norefprb_09 = 2;
else if C5Q11 in (6,7) then norefprb_09 = .M;
else if C4Q07 in (1,2) then norefprb_09 = 0;
else if C4Q07 = 3 then norefprb_09 = 1;
else if C4Q07 in (6,7,.M) then norefprb_09 = .M;
label norefprb_09 = 'Getting Needed Referrals sub-component of MEDICAL HOME
composite measure';
```

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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

```
/*Family usually or always gets sufficient help coordinating care if needed*/
carehelp_09 = .;
if C5Q12 = .L then carehelp_09 = 2;
else if C5Q12 = .M then carehelp_09 = .M;
else if C5Q12 = 0 and C5Q17 = 0 then carehelp_09 = 2;
else if C5Q12 in (6,7) and C5Q17 = 0 then carehelp_09 = .M;
else if C5Q17 in (6,7) then carehelp_09 = .M;
else if C5Q09 in (6,7) then carehelp_09 = .M;
else if C5Q12 = 1 and C5Q17 = 0 then carehelp_09 = 1;
else if C5Q09 = 3 then carehelp_09 = 1;
else if C5Q09 in (1,2) then carehelp_09 = 0;
label carehelp_09 = 'Got some type of help with care coordination';

/*Doctor communication needed if specialist, MH, PT/OT/ST, sub abuse, or home
hlth care used*/
needcomm_09 = .;
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) then needcomm_09 = 1;
else 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 = .L or
C4Q05_7C = 0)
    and (C4Q05_8 = 0 or C4Q05_8C = 0) then needcomm_09 = 0;
else needcomm_09 = .M;
label needcomm_09 = 'Used some or all specialist care, MH, PT/OT/Speech, sub
abuse, or home hlth care';

/*Family is very satisfied with doctors communication with each other*/
drcomm_09 = .;
if needcomm_09 = 0 then drcomm_09 = 2;
else if needcomm_09 = .M then drcomm_09 = .M;
else if C5Q10 = 1 then drcomm_09 = 1;
else if C5Q10 in (2,3,4) then drcomm_09 = 0;
else if C5Q10 = 5 then drcomm_09 = 2;
else if C5Q10 in (6,7,.M) then drcomm_09 = .M;
else if C5Q10 = .L then drcomm_09 = 2;
label drcomm_09 = 'Level of satisfaction with dr to dr communication among
those who needed it';

/*Family is very satisfied with doctors communication with other programs*/
othercomm_09 = .;
if C5Q05 = 0 then othercomm_09 = 2;
else if C5Q05 in (6,7) then othercomm_09 = .M;
else if C5Q06 = 1 then othercomm_09 = 1;
else if C5Q06 in (2,3,4) then othercomm_09 = 0;
else if C5Q06 in (6,7,.M) then othercomm_09 = .M;
else if C5Q06 = .L then othercomm_09 = 2;
label othercomm_09 = 'Level of satisfaction with dr communication to other
providers or programs among those who needed it';
```

MCHB Core Outcomes & System of Care

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

```
carecoor_09 = .;
if carehelp_09 = .M or drcomm_09 = .M or othercomm_09 = .M then carecoor_09 =
.M;
else if carehelp_09 = 2 and drcomm_09 = 2 and othercomm_09 = 2 then
carecoor_09 = 2;
else if carehelp_09 in (1,2) and drcomm_09 in (1,2) and othercomm_09 in (1,2)
then carecoor_09= 1;
else if carehelp_09 = 0 or drcomm_09 = 0 or othercomm_09 = 0 then carecoor_09
= 0;
label carecoor_09 = 'Effective Care Coordination sub-component of MEDICAL
HOME composite measure';
```

MEDICAL HOME COMPOSITE MEASURE

*Use the five sub-components created above to derive the MEDICAL HOME composite measure using the "must meet all needed criteria" scoring approach

```
outcome2_09 = .;
if pdn_09 = .M or usual_09 = .M or famcent_09 = .M or norefprb_09 = .M or
carecoor_09 = .M then outcome2_09 = .M;
else if pdn_09 = 2 and usual_09 = 2 and famcent_09 = 2 and norefprb_09 = 2
and carecoor_09 = 2 then outcome2_09 = .L;
else if pdn_09 = 1 and usual_09 = 1 and norefprb_09 in (1,2) and famcent_09
in (1,2) and carecoor_09 in (1,2) then outcome2_09 = 1;
else if pdn_09 = 0 or usual_09 = 0 or norefprb_09 = 0 or famcent_09 = 0 or
carecoor_09 = 0 then outcome2_09 = 0;
label outcome2_09 = 'OUTCOME #2: CSHCN receiving coordinated, ongoing,
comprehensive care within a medical home';
```

```
value pdn /*pdn_09*/
0 = 'Do not have a personal dr or nurse'
1 = 'Yes, have a personal dr or nurse';
```

```
value sick /*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';
```

```
value well /*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';
```

```
value usual /*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';
```

```
value fccint /*time_09 listen_09 sensitive_09 infofcc_09 partner_09*/
0 = 'Never/sometimes'
1 = 'Usually/always'
2 = 'No dr visits past 12 mos';
```

```
value famcent /*famcent_09*/
0 = 'Does NOT have family centered care'
1 = 'Yes, has family centered care'
2 = 'Legitimate skip - no dr visit past 12 mos';
```

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```
value norefprob /*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';

value carehelp /*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';

value needcom /*needcomm_09*/
1 = 'Used 1 or more services for dr comm denominator'
0 = 'Did not use services for dr comm denominator';

value drcom /*drcomm_09*/
0 = 'Less than very satisfied'
1 = 'Very satisfied, when needed'
2 = 'Legit skip -- no comm needed or did not use required services';

value othcom /*othercomm_09*/
0 = 'Less than very satisfied'
1 = 'Very satisfied'
2 = 'Legit skip -- used >2 services';

value carecoor /*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';

value out2come /*outcome2_09*/
0 = 'Care DOES NOT meet medical home criteria'
1 = 'Care MEETS medical home criteria'
.M = 'DK or Ref to any';
```

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.	
SAS Code and Annotation	
<p>*STEP 1: Create interim variables for constructing outcome.</p> <pre> /*Had public or private insurance at time of interview*/ hasins_09 = .; if UNINS = 0 then hasins_09 = 0; else if UNINS = 1 then hasins_09 = 1; else hasins_09 = .M; label hasins_09 = 'Insurance status at time of survey'; /*Had no gaps in coverage during the year before the interview*/ nogaps_09 = .M; if UNINS_YR = 0 then nogaps_09 = 0; else if UNINS_YR = 1 then nogaps_09 = 1; else if UNINS_YR in (6,7) then nogaps_09 = .M; label nogaps_09 = 'One or more gaps in insurance, past year'; </pre>	

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```
/*Insurance usually or always meets the childs needs (insured at time of
survey)*/
metneeds_09 = .;
if UNINS = 1 then metneeds_09 = 2;
else if UNINS in (6,7) then metneeds_09 = .M;
else if C8Q01_A in (1,2) then metneeds_09 = 0;
else if C8Q01_A in (3,4) then metneeds_09 = 1;
else if C8Q01_A = .L then metneeds_09 = 2;
else if C8Q01_A in (6,7,.M) then metneeds_09 = .M;
else if C8Q01_A = .P then metneeds_09 = .P;
label metneeds_09 = 'Health insurance benefits meet child needs';

/*Costs not covered by insurance are usually or always reasonable (insured at
time of survey)*/
reasonable_09 = .;
if UNINS = 1 then reasonable_09 = 2;
else if UNINS in (6,7) then reasonable_09 = .M;
else if C8Q01_B in (1,2) then reasonable_09 = 0;
else if C8Q01_B in (3,4,5) then reasonable_09 = 1;
else if C8Q01_B = .L then reasonable_09 = 2;
else if C8Q01_B in (6,7,.M) then reasonable_09 = .M;
else if C8Q01_B = .P then reasonable_09 = .P;
label reasonable_09 = 'Non-covered insurance charges reasonable';

/*Insurance usually or always permits child to see needed providers (insured
at time of survey)*/
providers_09 = .;
if UNINS = 1 then providers_09 = 2;
else if UNINS in (6,7) then providers_09 = .M;
else if C8Q01_C in (1,2) then providers_09 = 0;
else if C8Q01_C in (3,4) then providers_09 = 1;
else if C8Q01_C = .L then providers_09 = 2;
else if C8Q01_C in (6,7,.M) then providers_09 = .M;
else if C8Q01_C = .P then providers_09 = .P;
label providers_09 = 'Insurance allows child to see needed providers';

*STEP 2: Construct Outcome 3.

outcome3_09 = .;
if metneeds_09 = .P or reasonable_09 = .P or providers_09 = .P then
outcome3_09 = .M;
else if hasins_09 = .M or nogaps_09 = .M or metneeds_09 = .M or reasonable_09
= .M or providers_09 = .M then outcome3_09 = .M;
else if hasins_09 = 0 and nogaps_09 in (0,2) and metneeds_09 in (1,2) and
reasonable_09 in (1,2) and providers_09 in (1,2) then outcome3_09 = 1;
else if hasins_09 = 1 or nogaps_09 = 1 or metneeds_09 = 0 or reasonable_09 =
0 or providers_09 = 0 then outcome3_09 = 0;
label outcome3_09 = 'OUTCOME #3: Families of CSHCN have adequate insurance to
pay for the services they need';

value hasins /*hasins_09*/
0 = 'Currently insured'
1 = 'Not insured';
```

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```
value nogaps /*nogaps_09*/  
0 = 'Insured continuously all year'  
1 = 'One or more periods of no insurance';  
  
value adeqins /*metneeds_09 reasonable_09 providers_09*/  
0 = 'Never/sometimes'  
1 = 'Usually/always'  
2 = 'Legit skip b/c uninsured';  
  
value out3come /*outcome3_09*/  
0 = 'Did not meet outcome #3'  
1 = 'Met outcome #3'  
.M = 'DK, Ref or Missing to any';
```

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	
<p>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).</p>	
Revisions in 2009/10	
<p>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.</p>	
SAS Code and Annotation	
<p>*STEP 1: Construct interim variables for outcome 4, preventive medical care and preventive dental care in the prior 12 months.</p> <pre> /*Has received routine preventive medical care in past year*/ prevmed_09=.; if K4Q20R = 0 then prevmed_09 = 0; else if K4Q20R in (96,97) then prevmed_09 = .M; else if K4Q20R >= 1 and K4Q20R <= 12 then prevmed_09 = 1; label prevmed_09 = 'Number of preventive medical visits recoded into dichotomous variable'; /*Has received routine preventive dental care in past year*/ prevdent_09=.; if K4Q21R = 0 then prevdent_09 = 0; else if K4Q21R in (96,97) then prevdent_09 = .M; else if K4Q21R >= 1 and K4Q21R <= 10 then prevdent_09 = 1; label prevdent_09 = 'Number of preventive dental visits recoded into dichotomous variable'; </pre>	

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```
prevdental_09=.;
if K4Q21R = 0 then prevdental_09 = 0;
else if K4Q21R in (96,97) then prevdental_09 = .M;
else if K4Q21R >= 1 and K4Q21R <= 10 then prevdental_09 = 1;
if AGE = 0 then prevdental_09 = .L;
label prevdental_09 = 'Preventive dental visits 1-17 years in dichotomous
variable';

*STEP 2: Construct outcome 4.

outcome4_09 = .;
if prevmed_09 = .M or prevdental_09 = .M then outcome4_09 = .M;
else if prevmed_09 = .L and prevdental_09 = .L then outcome4_09 = .L;
else if prevmed_09 in (1,.L) and prevdental_09 in (1,.L) then outcome4_09 =
1;
else if prevmed_09 = 0 or prevdental_09 = 0 then outcome4_09 = 0;
label outcome4_09 = 'OUTCOME #4: Number of CSHCN with both preventive
medical AND dental visits in the past 12 months';

value prevmed /*prevmed_09*/
0 = 'No preventive visits in past 12 months'
1 = 'At least 1 preventive visit in past 12 months';

value prevdent /*prevdent_09 prevdental_09*/
0 = 'No preventive dental visits in past 12 months'
1 = 'At least 1 preventive visit in past 12 months';

value out4come /*outcome4_09*/
0 = 'Did not meet outcome #4 criteria'
1 = 'Met outcome #4 criteria'
.M = 'DK, Ref or Missing on either';
```

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

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).

Revisions in 2009/10

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.

SAS Code and Annotation

***New outcome #5 scoring, ease of access to service use based on new items for 2009/10. This is not comparable with the 2005/06 measure**

*STEP 1: Recode C4Q03_A through C4Q03_E to set DK/REF and SYSMIS values to .M**

```

/*Difficulties or delays due to lack of eligibility*/
ineligible_09 = C4Q03_A;
if C4Q03_A in (6,7) then ineligible_09 = .M;
label ineligible_09 = 'In past 12 months, any difficutlies or delays because
child was not eligible for services?';

/*Difficulties or delays due to lack of availability*/
unavailable_09 = C4Q03_B;
if C4Q03_B in (6,7) then unavailable_09 = .M;
label unavailable_09 = 'In past 12 months, any difficutlies or delays because
services not available in your area?';

```

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```
/*Difficulties or delays due to problems with appointments*/
backlogs_09 = C4Q03_C;
if C4Q03_C in (6,7) then backlogs_09 = .M;
label backlogs_09 = 'In past 12 months, any difficutlies or delays because
there were waitlists, backlogs or problems getting an appointment?';

/*Difficulties or delays due to costs of care*/
costs_09 = C4Q03_D;
if C4Q03_D in (6,7,.M) then costs_09 = .M;
label costs_09 = 'In past 12 months, any difficutlies or delays because of
issues related to costs?';

/*Difficulties or delays due to trouble getting information*/
information_09 = C4Q03_E;
if C4Q03_E in (6,7,.M) then information_09 = .M;
label information_09 = 'In past 12 months, any difficutlies or delays because
of trouble getting info you needed?';

/*Difficulties or delays due to other reasons*/
odelay_09 = C4Q03_F;
if C4Q03_F = 6 then odelay_09 = .M;
else if C4Q03_F = .L then odelay_09 = .L;
label odelay_09 = 'In past 12 months, any difficutlies or delays because of
other reasons--interim step variable?';

/*Difficulties or delays*/
delay_09 = 0;
if odelay_09 = .M then delay_09 = .M;
else if ineligible_09 = 1 or unavailable_09 = 1 or backlogs_09 = 1 or
costs_09 = 1 or information_09 = 1 then delay_09 = 1;
else if odelay_09 in (1,.L) then delay_09 = 1;
label delay_09 = 'In past 12 months, any difficutlies or delays because of
other reasons, (legit skip children set to 1 since they already experienced
one of the other delays)';

/*Family is never or only sometimes frustrated when trying to get services*/
frustrated_09=. ;
if C4Q04 in (6,7) then frustrated_09 = .M;
else if C4Q04 in (1,2) then frustrated_09 = 0;
else if C4Q04 in (3,4) then frustrated_09 = 1;
label frustrated_09 = 'How often were you frustrated in efforts to get
services for child?';

*STEP 2: Create outcome 5.

outcome5_09 = 0;
if ineligible_09 = 0 and unavailable_09 = 0 and backlogs_09 = 0 and costs_09
= 0 and information_09 = 0 and odelay_09 = 0 and frustrated_09 = 0 then
outcome5_09 = 1;
if ineligible_09 = 1 or unavailable_09 = 1 or backlogs_09 = 1 or costs_09 = 1
or information_09 = 1 or odelay_09 = 1 or frustrated_09 = 1 then outcome5_09
= 0;
if ineligible_09 = .M or unavailable_09 = .M or backlogs_09 = .M or costs_09
= .M or information_09 = .M or odelay_09 = .M or frustrated_09 = .M then
outcome5_09 = .M;
label outcome5_09 = 'OUTCOME #5: How many children met outcome #5, ease of
```

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```
access to service use/experienced no barriers or difficulties in accessing
care?';

value delay /*ineligible_09 unavailable_09 backlogs_09 costs_09
information_09*/
0 = 'Did not experience this difficulty'
1 = 'Experienced this difficulty';

value odelay /*odelay_09*/
0 = 'Did not experience this difficulty'
1 = 'Experienced OTHER difficulty';

value delayn /*delay_09*/
0 = 'Did not experience this difficulty'
1 = 'Experienced OTHER or one of the previous 5 difficulties';

value frust /*frustrated_09*/
0 = 'Never/sometimes'
1 = 'Usually/always frustrated';

value out5come /*outcome5_09*/
0 = 'Did not meet outcome #5'
1 = 'Met outcome #5'
.M = 'DK, Ref or Missing to any';
```

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.	
SAS Code and Annotation	
<p>*STEP 1: Compute interim variables to express if doctors discussed shift to adult provider (mettrans1_09), changing needs as becomes adult (mettrans2_09), and/or insurance coverage during transition to adulthood (mettrans3_09)</p> <pre> /*Doctors have discussed shift to adult provider, if necessary*/ mettrans1_09 = .; if C6Q07 = 1 and C6Q0A_B = 1 then mettrans1_09 = 1; else if C6Q07 = 1 and C6Q0A_B = 0 and C6Q0A_C = 1 then mettrans1_09 = 0; else if C6Q07 = 1 and C6Q0A_B = 0 and C6Q0A_C = 0 then mettrans1_09 = .L; else if C6Q07 = 0 then mettrans1_09 = .L; else if C6Q07 in (6,7,.M) or C6Q0A_B in (6,7,.M) or C6Q0A_C in (6,7,.M) then mettrans1_09 = .M; if AGE < 12 then mettrans1_09 = .L; label mettrans1_09 = 'Drs discussed shift to adult provider, if helpful'; </pre>	

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```
/*Doctors have discussed future health care needs, if necessary*/
mettrans2_09 = .;
if C6Q0A = 1 then mettrans2_09 = 1;
else if C6Q0A_D = 1 then mettrans2_09 = 0;
else if C6Q0A_D = 0 then mettrans2_09 = .L;
else if C6Q0A in (6,7,.M) or C6Q0A_D in (6,7,.M) then mettrans2_09 = .M;
if AGE < 12 then mettrans2_09 = .L;
label mettrans2_09 = 'Drs talked about changing needs as becomes adult, if helpful';
```

```
/*Doctors have discussed future insurance needs, if necessary*/
mettrans3_09 = .;
if C6Q0A_E = 1 then mettrans3_09 = 1;
else if C6Q0A_F = 1 then mettrans3_09 = 0;
else if C6Q0A_F = 0 then mettrans3_09 = .L;
else if C6Q0A_E in (6,7,.M) or C6Q0A_F in (6,7,.M) then mettrans3_09 = .M;
if AGE < 12 then mettrans3_09 = .L;
label mettrans3_09 = "Drs talked about insurance coverage as becomes adult, if needed";
```

STEP 2: Construct variable (ADTRANS) summarizing results across mettrans1_09, mettrans2_09, and mettrans3_09

```
adtrans_09 = .;
if mettrans1_09 = .M or mettrans2_09 = .M or mettrans3_09 = .M then
adtrans_09 = .M;
else if mettrans1_09 = .L and mettrans2_09 = .L and mettrans3_09 = .L then
adtrans_09 = .L;
else if mettrans1_09 in (1,.L) and mettrans2_09 in (1,.L) and mettrans3_09 in
(1,.L) then adtrans_09 = 1;
else if mettrans1_09 = 0 or mettrans2_09 = 0 or mettrans3_09 = 0 then
adtrans_09 = 0;
label adtrans_09 = "Met criteria for getting all 3 adult transition
components";
```

*STEP 3: Compute interim variable to express if doctors encourage children 12-17 years to engage in age-appropriate self-care

```
mettrans4_09 = .;
if C6Q08 in (6,7,.M) then mettrans4_09 = .M;
else if C6Q08 = .L then mettrans4_09 = .L;
else if C6Q08 in (1,2) then mettrans4_09 = 0;
else if C6Q08 in (3,4) then mettrans4_09 = 1;
if AGE < 12 then mettrans4_09 = .L;
label mettrans4_09 = "Drs encourage ch to engage in age appropriate self-care
- ages 12-17 only";
```

*STEP 4: Construct outcome 6.

```
outcome6_09 = .;
if adtrans_09 = .M or mettrans4_09 = .M then outcome6_09 = .M;
else if adtrans_09 = .L and mettrans4_09 = .L then outcome6_09 = .L;
else if adtrans_09 in (1,.L) and mettrans4_09 in (1,.L) then outcome6_09 = 1;
else if adtrans_09 = 0 or mettrans4_09 = 0 then outcome6_09 = 0;
label outcome6_09 = "OUTCOME #6: Transition to adulthood - ages 12 -17 only";
```

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```
value trans /*mettrans1_09 mettrans2_09 mettrans3_09 adtrans_09*/
0 = 'No'
1 = 'Yes'
.L = 'Legit skip b/c discussion not needed or sees provider who can
transition OR child 0-11 years of age'
.M = 'DK/REF to any';

value encrge /*mettrans4_09*/
0 = 'Never/Sometimes'
1 = 'Usually/Always'
.M = 'DK/REF/MISSING to any'
.L = 'Legitimate skip b/c <12 yrs old';

value out6come /*outcome6_09*/
0 = 'Did not meet outcome #6'
1 = 'Met outcome #6'
.M = 'DK/REF/MISSING on both'
.L = 'Legitimate skip b/c <12 yrs old';
```

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.	
SAS Code and Annotation	
<p>*System of Care indicator for CSHCN age 0-11 years</p> <pre> syst1_ct = 0; if outcome1_09 = 1 then syst1_ct + 1; if outcome2_09 = 1 then syst1_ct + 1; if outcome3_09 = 1 then syst1_ct + 1; if outcome4_09 = 1 then syst1_ct + 1; if outcome5_09 = 1 then syst1_ct + 1; if outcome1_09 in (.M,.L) or outcome2_09 in (.M,.L) or outcome3_09 in (.M,.L,.P) or outcome4_09 in (.M,.L) or outcome5_09 = .M then syst1_ct = .M; if AGE > 11 then syst1_ct = .L; label syst1_ct = 'CSHCN ages 0-11 meeting one or more of five criteria for system of care'; systcare_09 = .; if syst1_ct in (0,1,2) then systcare_09 = 1; if syst1_ct in (3,4) then systcare_09 = 2; if syst1_ct = 5 then systcare_09 = 3; if syst1_ct = .M then systcare_09 = .M; </pre>	

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```
if AGE > 11 then systcare_09 = .L;
label systcare_09 = 'CSHCN ages 0-11 meeting criteria for system of care --
3 groups';

value systcare /*systcare_09*/
1 = '0-2 outcomes achieved'
2 = '3-4 outcomes achieved'
3 = 'Outcomes achieved in all 5 areas'
.M = 'DK or Ref to any'
.L = 'CSHCN ages 12 -17';
```

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.	
SAS Code and Annotation	
*CSHCN age 12-17 years who are served by systems of care meeting all 6 core outcomes	
<pre> syst2_ct = 0; if outcome1_09 = 1 then syst2_ct + 1; if outcome2_09 = 1 then syst2_ct + 1; if outcome3_09 = 1 then syst2_ct + 1; if outcome4_09 = 1 then syst2_ct + 1; if outcome5_09 = 1 then syst2_ct + 1; if outcome6_09 = 1 then syst2_ct + 1; if outcome1_09 in (.M,.L) or outcome2_09 in (.M,.L) or outcome3_09 in (.M,.L,.P) or outcome4_09 in (.M,.L) or outcome5_09 = .M or outcome6_09 in (.M,.L) then syst2_ct = .M; if AGE < 12 then syst2_ct = .L; label syst2_ct = 'CSHCN ages 12-17 meeting one or more of six criteria for system of care'; </pre>	

MCHB Core Outcomes & System of Care

```
systcare2_09 = .;
if syst2_ct in (0,1,2) then systcare2_09 = 1;
if syst2_ct in (3,4) then systcare2_09 = 2;
if syst2_ct = 5 then systcare2_09 = 3;
if syst2_ct = 6 then systcare2_09 = 4;
if syst2_ct = .M then systcare2_09 = .M;
if AGE < 12 then systcare2_09 = .L;
label systcare2_09 = 'CSHCN ages 12-17 meeting criteria for system of care -
- 4 groups';

value sys2care /*systcare2_09*/
1 = '0-2 outcomes achieved'
2 = '3-4 outcomes achieved'
3 = '5 outcomes achieved'
4 = 'Outcomes achieved in all 6 areas'
.M = 'DK or Ref to any'
.L = 'CSHCN ages 0-11';
```

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.	
SAS Code and Annotation	
<pre> systcare_all_09 = .; if AGE < 12 and syst1_ct = 5 then systcare_all_09 = 2; if AGE < 12 and syst1_ct = 4 then systcare_all_09 = 1; if AGE < 12 and syst1_ct < 4 then systcare_all_09 = 0; if AGE > 11 and syst2_ct = 6 then systcare_all_09 = 2; if AGE > 11 and syst2_ct = 5 then systcare_all_09 = 1; if AGE > 11 and syst2_ct < 5 then systcare_all_09 = 0; if syst2_ct = .M or syst1_ct = .M then systcare_all_09 = .M; label systcare_all_09 = 'System of care for all CSHCN -- met all age- relevant outcomes'; value systcareall /*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' .M = 'Missing'; </pre>	

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>	
SAS Code and Annotation	
<pre>condcount_09 = 0; if K2Q31B = 1 then condcount_09 + 1; if K2Q32B = 1 then condcount_09 + 1; if K2Q33B = 1 then condcount_09 + 1; if K2Q34B = 1 then condcount_09 + 1; if K2Q35B = 1 then condcount_09 + 1; if K2Q36B = 1 then condcount_09 + 1; if K2Q37B = 1 then condcount_09 + 1; if K2Q40B = 1 then condcount_09 + 1; if K2Q41B = 1 then condcount_09 + 1;</pre>	

Conditions & Functional Difficulties

```
if K2Q42B = 1 then condcount_09 + 1;
if K2Q43B = 1 then condcount_09 + 1;
if K2Q44B = 1 then condcount_09 + 1;
if K2Q45B = 1 then condcount_09 + 1;
if K2Q46B = 1 then condcount_09 + 1;
if K2Q47B = 1 then condcount_09 + 1;
if K2Q48B = 1 then condcount_09 + 1;
if K2Q49B = 1 then condcount_09 + 1;
if K2Q50B = 1 then condcount_09 + 1;
if K2Q51B = 1 then condcount_09 + 1;
if K2Q52B = 1 then condcount_09 + 1;
if K2Q31A in (6,7,.M) and K2Q32A in (6,7,.M) and K2Q33A in (6,7,.M) and
K2Q34A in (6,7,.M) and K2Q35A in (6,7,.M) and K2Q36A in (6,7,.M) and K2Q37A
in (6,7,.M)
and K2Q40A >2 and K2Q41A >2 and K2Q42A >2 and K2Q43A >2 and K2Q44A >2 and
K2Q45A >2 and K2Q46A in (6,7,.M) and K2Q47A >2 and K2Q48A > 2 and K2Q49A >2
and K2Q50A >2 and K2Q51A >2 and K2Q52A >2 then condcount_09 = .M;
label condcount_09 = 'Number of CURRENT health conditions reported from a
list of 20';

conditions20_09 = 0;
if condcount_09 = 1 then conditions20_09 = 1;
if condcount_09 = 2 then conditions20_09 = 2;
if condcount_09 = 3 then conditions20_09 = 3;
if condcount_09 > 3 then conditions20_09 = 4;
if K2Q31A in (6,7,.M) and K2Q32A in (6,7,.M) and K2Q33A in (6,7,.M) and
K2Q34A in (6,7,.M) and K2Q35A in (6,7,.M) and K2Q36A in (6,7,.M) and K2Q37A
in (6,7,.M)
and K2Q40A >2 and K2Q41A >2 and K2Q42A >2 and K2Q43A >2 and K2Q44A >2 and
K2Q45A >2 and K2Q46A in (6,7,.M) and K2Q47A >2 and K2Q48A > 2 and K2Q49A >2
and K2Q50A >2 and K2Q51A >2 and K2Q52A >2 then conditions20_09 = .M;
label conditions20_09 = 'Number of current health conditions reported from
list of 20 different conditions asked in the survey';

value cond /*conditions20_09*/
0 = 'No conditions reported'
1 = '1 cond reported'
2 = '2 conds reported'
3 = '3 conds reported'
4 = '4 or more conds reported'
.M = 'DK or Ref to all conds';
```

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.	
SAS Code and Annotation	
<pre> diff_cnt = 0; if C3Q21 in (1,2) then diff_cnt + 1; if C3Q22 in (1,2) then diff_cnt + 1; if C3Q23 in (1,2) then diff_cnt + 1; if C3Q24 in (1,2) then diff_cnt + 1; if C3Q25 in (1,2) then diff_cnt + 1; if C3Q26 in (1,2) then diff_cnt + 1; if C3Q27 in (1,2) then diff_cnt + 1; if C3Q28 in (1,2) then diff_cnt + 1; if C3Q29 in (1,2) then diff_cnt + 1; if C3Q30 in (1,2) then diff_cnt + 1; if C3Q31 in (1,2) then diff_cnt + 1; if C3Q32 in (1,2) then diff_cnt + 1; </pre>	

Conditions & Functional Difficulties

```
if C3Q33 in (1,2) then diff_cnt + 1;
if C3Q34 in (1,2) then diff_cnt + 1;
label diff_cnt = 'Number of functional difficulties reported (4 categories)
-- using most restrictive criteria for Vision or Hearing';

diff5_09 = .;
if diff_cnt = 0 then diff5_09 = 0;
if diff_cnt = 1 then diff5_09 = 1;
if diff_cnt = 2 then diff5_09 = 2;
if diff_cnt = 3 then diff5_09 = 3;
if diff_cnt > 3 then diff5_09 = 4;
if C3Q21 in (6,7) and C3Q22 in (6,7) and C3Q23 in (6,7) and C3Q24 in (6,7)
and C3Q25 in (6,7) and C3Q26 in (6,7)
and C3Q27 in (6,7,.M) and C3Q28 in (6,7) and C3Q29 in (6,7) and C3Q30 in
(6,7,.M) and C3Q31 in (6,7,.M) and
C3Q32 in (6,7,.M) and C3Q33 in (6,7,.M) and C3Q34 in (6,7,.M) then diff5_09
= .M;
label diff5_09 = 'Number of functional difficulties reported from list of 14
different difficulties asked in the survey';

value diff /*diff5_09*/
0 = 'No difficulties reported'
1 = '1 difficulty reported'
2 = '2 difficulties reported'
3 = '3 difficulties reported'
4 = '4 or more difficulties reported';
```

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.	
SAS Code and Annotation	
<pre> emot_ICF_09 = 0; if C3Q32 in (1,2) or C3Q33 in (1,2) or C3Q34 in (1,2) then emot_ICF_09 = 1; if C3Q32 in (6,7,.M,.L) and C3Q33 in (6,7,.M,.L) and C3Q34 in (6,7,.M,.L) then emot_ICF_09 = .M; label 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 emotICF /*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' .M = 'DK/RF or not in age range for all'; </pre>	

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	
<p>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.</p>	
Revisions in 2009/10	
<p>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.</p>	
SAS Code and Annotation	
<pre> activity_ICF_09 = 0; if C3Q27 in (1,2) or C3Q28 in (1,2) or C3Q29 in (1,2) or C3Q30 in (1,2) or C3Q31 in (1,2) then activity_ICF_09 = 1; if C3Q27 in (6,7,.M,.L) and C3Q28 in (6,7) and C3Q29 in (6,7) and C3Q30 in (6,7,.M,.L) and C3Q31 in (6,7,.M,.L) then activity_ICF_09 = .M; label 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 activityICF /*activity_ICF_09*/ 0 = 'No difficulties with activities' 1 = 'A little or a lot of difficulty with one or more activities' .M = 'DK or Ref'; </pre>	

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	
<p>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.</p>	
SAS Code and Annotation	
<pre>body_ICF_09 = 0; if C3Q21 in (1,2) or C3Q22 in (1,2) or C3Q23 in (1,2) or C3Q24 in (1,2) or C3Q25 in (1,2) or C3Q26 in (1,2) then body_ICF_09 = 1; if C3Q21 in (6,7) and C3Q22 in (6,7) and C3Q23 in (6,7) and C3Q24 in (6,7) and C3Q25 in (6,7) and C3Q26 in (6,7) then body_ICF_09 = .M; label 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 bodyICF /*body_ICF_09*/ 0 = 'No difficulties involving bodily functions' 1 = 'A little or a lot of difficulty with one or more bodily functions' .M = 'DK or Ref';</pre>	

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	
SAS Code and Annotation	
<pre>sex_09 = SEX; if SEX in (6,7) then sex_09 = .M; label sex_09 = 'Sex of child'; value sex /*sex_09*/ 1 = 'Male' 2 = 'Female' .M = 'DK or Ref';</pre>	

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	
SAS Code and Annotation	
<pre> age3_09 = .; if AGE >= 0 and AGE <= 5 then age3_09 = 1; if AGE >= 6 and AGE <= 11 then age3_09 = 2; if AGE >= 12 then age3_09 = 3; label age3_09 = 'Ages of CSHCN in 3 categories'; value agethree /*age3_09*/ 1 = '0-5 yrs old' 2 = '6-11 yrs old' 3 = '12-17 yrs old'; </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

SAS 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.

```
race4_09 = .;
if HISPANIC_IMP = 1 then race4_09 = 1;
if HISPANIC_IMP = 0 and RACER_IMP = 1 then race4_09 = 2;
if HISPANIC_IMP = 0 and RACER_IMP = 2 then race4_09 = 3;
if HISPANIC_IMP = 0 and RACER_IMP = 3 then race4_09 = 4;
label race4_09 = 'Race/ethnicity categories - 4 categories based on imputed
screener file data';

value race /* race4_09*/
1 = 'Hispanic'
2 = 'White, non-Hisp'
3 = 'Black, non-Hisp'
4 = 'Other, non-Hisp';
```

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. Maternal and Child Health Journal. 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

SAS 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

```
rxmeds_09 = 0;
if ((CSHCN1 = 1) and (CSHCN1_A = 1) and (CSHCN1_B = 1)) then rxmeds_09 =
rxmeds_09 + 1;
label rxmeds_09 = "Qualified on rx med use?";

service_09 = 0;
if ((CSHCN2 = 1) and (CSHCN2_A = 1) and (CSHCN2_B = 1)) then service_09 =
service_09 + 1;
label service_09 = "Qualified on elevated service use or needs?";

limits_09 = 0;
if ((CSHCN3 = 1) and (CSHCN3_A = 1) and (CSHCN3_B = 1)) then limits_09 =
limits_09 + 1;
label limits_09 = "Qualified on functional limits ?";

therapies_09 = 0;
if ((CSHCN4 = 1) and (CSHCN4_A = 1) and (CSHCN4_B = 1)) then therapies_09 =
therapies_09 + 1;
label therapies_09 = "Qualified on use of special therapies?";

mhealth_09 = 0;
if((CSHCN5 = 1) and (CSHCN5_A = 1)) then mhealth_09 = mhealth_09 + 1;
label mhealth_09 = "Qualified on ongoing emotional, developmental or
behavioral conditions?";
```

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

```
def4_09 = 0;
if ((limits_09 = 1)) and ((service_09 = 1) or (therapies_09 = 1) or
(rxmeds_09 = 1) or (mhealth_09 = 1)) then def4_09 = 1;
if ((limits_09 = 1)) and ((service_09 = 0) or (therapies_09 = 0) or
(rxmeds_09 = 0) or (mhealth_09 = 0)) then def4_09 = 1;
if (limits_09 = 0) and ((rxmeds_09 = 1)) and ((service_09 = 0) or
(therapies_09 = 0) or (mhealth_09 = 0)) then def4_09 = 2;
if (limits_09 = 0) and ((rxmeds_09 = 0)) and ((service_09 = 1) or
(therapies_09 = 1) or (mhealth_09 = 1)) then def4_09 = 3;
if (limits_09 = 0) and ((rxmeds_09 = 1)) and ((service_09 = 1) or
(therapies_09 = 1) or (mhealth_09 = 1)) then def4_09 = 4;
if def4_09 = 0 then def4_09 = .;
label def4_09 = "How many CSHCN qualified on specific types of special health
needs criteria?";

value cshcnr /*rxmeds_09 service_09 limits_09 therapies_09 mhealth_09*/
0 = 'No'
1 = 'Yes';
```

Stratifiers

```
value screener /*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';
```

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	
SAS Code and Annotation	
<pre> mhealth_09 = 0; if((CSHCN5 = 1) and (CSHCN5_A = 1)) then mhealth_09 = mhealth_09 + 1; label mhealth_09 = "Qualified on ongoing emotional, developmental or behavioral conditions?"; value cshcnr /*mhealth_09*/ 0 = 'No' 1 = 'Yes'; </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	
SAS Code and Annotation	
<p>*Note: run syntax for "type of special health care needs" (see above) before running the syntax below.</p> <pre> qualnum = sum (limits_09, service_09, therapies_09, rxmeds_09, mhealth_09); qualnum_09 = 0; if qualnum = 1 then qualnum_09 = 1; if qualnum = 2 then qualnum_09 = 2; if qualnum = 3 then qualnum_09 = 3; if qualnum in (4,5) then qualnum_09 = 4; label qualnum_09 = 'How many of the screener criteria were met by CSHCN?'; value qualnum /*qualnum_09*/ 1 = 'Qualified on 1 screener criteria' 2 = 'Qualified on 2 screener criteria' 3 = 'Qualified on 3 screener criteria' 4 = 'CSHCN who qualified on 4 or all 5 Screener criteria'; </pre>	

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 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 SAS 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>	
SAS Code and Annotation	
<pre>povlev4_09 = .; if POVLEVEL_IMP in (1,2) then povlev4_09 = 1; if POVLEVEL_IMP in (3,4,5,6) then povlev4_09 = 2; if POVLEVEL_IMP in (7,8) then povlev4_09 = 3;</pre>	

Stratifiers

```
if POVLEVEL_IMP = 9 then povlev4_09 = 4;
label povlev4_09 = 'Version 1: How many CHSCN live in households at specified
levels of income according to Federal Poverty Level (FPL) guidelines?';

value povlev /*povlev4_09*/
1 = '0% - 99% FPL'
2 = '100% - 199% FPL'
3 = '200% - 399% FPL'
4 = '400% FPL or greater';
```

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 SAS 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>	
SAS 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

```
povschip_09 = .;
if POVLEVEL_IMP in (1,2,3,4,5,6) then povschip_09 = 1;
if POVLEVEL_IMP = 7 then povschip_09 = 2;
if POVLEVEL_IMP = 8 then povschip_09 = 3;
if POVLEVEL_IMP = 9 then povschip_09 = 4;
label 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 povschip /*povschip_09*/
1 = '0% - 199% FPL'
2 = '200% - 299% FPL'
3 = '300% - 399% FPL'
4 = '400% FPL or greater';
```

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>	
SAS Code and Annotation	
<pre> instype_09 = TYPEINS; if TYPEINS in (4,.M) then instype_09 = .M; if TYPEINS = 5 then instype_09 = 4; label instype_09 = 'Type of Insurance Coverage'; value typeins /*instype_09*/ 1 = 'Private only' 2 = 'Public only' 3 = 'Both Public and Private' 4 = 'Uninsured' .M = 'Missing or comprehensive other insurance'; </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>	
SAS Code and Annotation	
<p>*NOTE: Uses the NCHS derived variable FAMSTRUCT in the publicly released 2009-2010 NS_CSHCN Interview file.</p> <pre> famstuct_09 = FAMSTRUCT; label famstuct_09 = 'Family structure of the CSHCN population'; value famstruc /*famstuct_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' .M = 'Missing'; </pre>	

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. In 2009/10 NS_CSHCN both variables used to derive this measure contain imputed data, so use caution when comparing across years.</p>	
SAS Code and Annotation	
<p>*Note: construct race4_09 before running the syntax below.</p> <pre> hhlang_09 = .; if race4_09 = 1 and PLANGUAGE_IMP = 2 then hhlang_09 = 2; if race4_09 = 1 and PLANGUAGE_IMP = 1 then hhlang_09 = 1; if race4_09 > 1 then hhlang_09 = 3; label hhlang_09 = 'Hispanic ethnicity parsed by child's PRIMARY HOUSEHOLD language'; value phhl /*hhlang_09*/ 1 = 'Hisp child / primary HH lang is ENGLISH' 2 = 'Hisp child / primary HH lang is NOT English lang' 3 = 'Non-Hispanic children'; </pre>	

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, the 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. Use caution when comparing across years.</p>	
SAS Code and Annotation	
<pre>educ_09 = EDUCR_IMP; if EDUCR_IMP in (6,7) then educ_09 = .M; label educ_09 = 'What is the highest education level attained of any adult in the family?'; value educ /*educ_09*/ 1 = 'Less than high school' 2 = 'High school grad' 3 = 'More than high school';</pre>	

Appendix A: Unweighted Frequency Tables for Codebook Variables



NATIONAL CHARTBOOK INDICATORS

INDICATOR 1: Activity Limitations: CSHCN whose health conditions consistently affect daily activities				
indic1_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK, Ref or Missing to both items	106	0.26	106	0.26
Daily activities never affected	14795	36.77	14901	37.03
<i>Daily activities moderately affected some of time</i>	15611	38.79	30512	75.82
Daily activities consistently affected, often a great deal	9730	24.18	40242	100.00

INDICATOR 2: Missed School Days: CSHCN ages 5-17 with 11 or more school absences due to illness				
indic2_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
<5 years old	5349	13.29	5349	13.29
DK, Ref, Did not go to school or Home schooled	720	1.79	6069	15.08
0 - 3 days missed	17196	42.73	23265	57.81
4 - 6 days missed	7452	18.52	30717	76.33
7 - 10 days missed	4710	11.70	35427	88.03
11 or more days missed	4815	11.97	40242	100.00

INDICATOR 3: Inconsistently Insured: CSHCN without insurance at some point during the past year				
indic3_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK, Ref or Missing/Not ascertained	134	0.33	134	0.33
Insured entire year	37043	92.05	37177	92.38
NOT insured at some point during year	3065	7.62	40242	100.00

INDICATOR 4: Currently Uninsured: CSHCN without insurance at time of the survey				
indic4_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	58	0.14	58	0.14
Currently insured	39035	97.00	39093	97.14
Currently NOT insured	1149	2.86	40242	100.00

INDICATOR 5: "Adequacy of Current Insurance Coverage: Currently insured CSHCN whose insurance coverage is not adequate				
indic5_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref to any item	463	1.15	463	1.15
Uninsured	1149	2.86	1612	4.01
Current insurance is NOT adequate	12776	31.75	14388	35.75
Current insurance IS adequate	25854	64.25	40242	100.00

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

INDICATOR 6: Unmet Needs for Care: CSHCN with any unmet need for any of 14 specific health care services or equipment, past 12 months				
indic6_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref to any	744	1.85	744	1.85
No unmet needs for 14 specific health care services	31424	78.09	32168	79.94
1 unmet need for services/equip	5283	13.13	37451	93.06
2 or more unmet needs for services/equip	2791	6.94	40242	100.00

INDICATOR 7: Unmet Needs for Family Support Services: CSHCN with any unmet needs for family support services				
indic7_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	97	0.24	97	0.24
No unmet needs for specific family support services or did not need	37577	93.38	37674	93.62
One or more unmet needs for family support services	2568	6.38	40242	100.00

INDICATOR 8: Problems Obtaining Referral: CSHCN needing specialty care who had problems getting a referral				
indic8_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Missing	22	0.05	22	0.05
Did not need referral	26946	66.96	26968	67.01
Needed referral, no problems getting it	10649	26.46	37617	93.48
Needed referral, YES problems getting it	2625	6.52	40242	100.00

INDICATOR 9: Usual Source for Sick Care: CSHCN without a usual source of care or who rely on the emergency room				
indic9_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	78	0.19	78	0.19
Docs office is usual source for sick care	30174	74.98	30252	75.18
Clinic, health center or other regular source for sick care	6737	16.74	36989	91.92
No usual source for sick care-- or ER, Mexico or no one place most often	3253	8.08	40242	100.00

INDICATOR 10: Personal Doctor or Nurse: CSHCN without a personal doctor or nurse (PDN)				
indic10_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	56	0.14	56	0.14
No, does not have a PDN	2451	6.09	2507	6.23
Yes, has one or more PDNs	37735	93.77	40242	100.00

INDICATOR 11: Family Centered Care: CSHCN without family-centered care				
indic11_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Legitimate skip - no dr visit past 12 mos	84	0.21	84	0.21
DK/Ref to all or SYSMIS	473	1.18	557	1.38
Does NOT have family centered care	12579	31.26	13136	32.64
Yes, has family centered care	27106	67.36	40242	100.00

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

INDICATOR 12: Out-of-Pocket Expenses: CSHCN whose families pay more than \$1000 per year out-of-pocket for child's medical expenses				
indic12_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	601	1.49	601	1.49
Less than \$250	15400	38.27	16001	39.76
\$250 - \$500	8859	22.01	24860	61.78
\$501 - \$1000	5238	13.02	30098	74.79
More than \$1000	10144	25.21	40242	100.00

INDICATOR 13: Family Financial Burden: CSHCN whose families experienced financial problems due to child's health needs				
indic13_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK, Ref or Missing	308	0.77	308	0.77
No financial problems due to child's health	31847	79.14	32155	79.90
Yes, financial problems	8087	20.10	40242	100.00

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				
indic14_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	1538	3.82	1538	3.82
Less than 1 hour	16722	41.55	18260	45.38
1 - 4 hours per week	14147	35.15	32407	80.53
5 - 10 hours per week	3564	8.86	35971	89.39
11 or more hours per week	4271	10.61	40242	100.00

INDICATOR 15: Impact on Family Work Life: CSHCN whose family members cut back and/or stopped working because of child's health needs				
indic15_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	297	0.74	297	0.74
Employment not affected	30935	76.87	31232	77.61
Family member cut back hours or stopped working or both	9010	22.39	40242	100.00

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

MCHB CORE OUTCOMES

OUTCOME #1: How many children met Outcome #1 on shared decision making, usually/always on all questions				
outcome1_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref on all	282	0.70	282	0.70
Legit. skip	84	0.21	366	0.91
Did not meet Outcome #1	10442	25.95	10808	26.86
Met Outcome #1	29434	73.14	40242	100.00

OUTCOME #2: CSHCN receiving coordinated, ongoing, comprehensive care within a medical home				
outcome2_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref to any	1292	3.21	1292	3.21
Care DOES NOT meet medical home criteria	20671	51.37	21963	54.58
Care MEETS medical home criteria	18279	45.42	40242	100.00

OUTCOME #3: Families of CSHCN have adequate insurance to pay for the services they need				
outcome3_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK, Ref or Missing to any	522	1.30	522	1.30
Did not meet outcome #3	14880	36.98	15402	38.27
Met outcome #3	24840	61.73	40242	100.00

OUTCOME #4: Number of CSHCN with both preventive medical AND dental visits in the past 12 months				
outcome4_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK, Ref or Missing on either	365	0.91	365	0.91
Did not meet outcome #4 criteria	8071	20.06	8436	20.96
Met outcome #4 criteria	31806	79.04	40242	100.00

OUTCOME #5: How many children met outcome #5, ease of access to service use/experienced no barriers or difficulties in accessing care?				
outcome5_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK, Ref or Missing to any	252	0.63	252	0.63
Did not meet outcome #5	12993	32.29	13245	32.91
Met outcome #5	26997	67.09	40242	100.00

1

OUTCOME #6: Transition to adulthood -- ages 12 -17 only				
outcome6_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK/REF/MISSING on both	892	2.22	892	2.22
Legitimate skip b/c <12 yrs old	23128	57.47	24020	59.69
Did not meet outcome #6	9027	22.43	33047	82.12
Met outcome #6	7195	17.88	40242	100.00

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

MCHB SYSTEM OF CARE SUMMARY VARIABLES

CSHCN ages 0-11 meeting criteria for system of care -- 3 groups				
systcare_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
CSHCN ages 12 -17	17114	42.53	17114	42.53
DK or Ref to any	1280	3.18	18394	45.71
0-2 outcomes achieved	6201	15.41	24595	61.12
3-4 outcomes achieved	10753	26.72	35348	87.84
Outcomes achieved in all 5 areas	4894	12.16	40242	100.00

CSHCN ages 12-17 meeting criteria for system of care -- 4 groups				
systcare2_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
CSHCN ages 0-11	23128	57.47	23128	57.47
DK or Ref to any	1781	4.43	24909	61.90
0-2 outcomes achieved	3379	8.40	28288	70.29
3-4 outcomes achieved	5861	14.56	34149	84.86
5 outcomes achieved	3614	8.98	37763	93.84
Outcomes achieved in all 6 areas	2479	6.16	40242	100.00

System of care for all CSHCN -- met all age-relevant outcomes				
systcare_all_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Missing	3061	7.61	3061	7.61
2 or more age-relevant core outcomes NOT achieved	20232	50.28	23293	57.88
1 age-relevant core outcome NOT achieved	9576	23.80	32869	81.68
All age-relevant core outcomes achieved	7373	18.32	40242	100.00

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

CONDITIONS & FUNCTIONAL DIFFICULTIES

Number of current health conditions reported from list of 20 different conditions asked in the survey				
conditions20_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref to all conds	3	0.01	3	0.01
No conditions reported	4988	12.40	4991	12.40
1 cond reported	12883	32.01	17874	44.42
2 conds reported	11561	28.73	29435	73.14
3 conds reported	4907	12.19	34342	85.34
4 or more conds reported	5900	14.66	40242	100.00

Number of functional difficulties reported from list of 14 different difficulties asked in the survey				
diff5_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No difficulties reported	3890	9.67	3890	9.67
1 difficulty reported	8429	20.95	12319	30.61
2 difficulties reported	6029	14.98	18348	45.59
3 difficulties reported	4906	12.19	23254	57.79
4 or more difficulties reported	16988	42.21	40242	100.00

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)				
emot_ICF_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK/RF or not in age range for all	922	2.29	922	2.29
No emotional or behavioral difficulties	17217	42.78	18139	45.07
A little or a lot of difficulty with one or more emotional or behavioral factors	22103	54.93	40242	100.00

CSHCN age 0 - 17 years who have a little or a lot of difficulty with one or more activities or participation (C3Q27-C3Q31)				
activity_ICF_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	1	0.00	1	0.00
No difficulties with activities	16878	41.94	16879	41.94
A little or a lot of difficulty with one or more activities	23363	58.06	40242	100.00

CSHCN age 0-17 years who have a little or a lot of difficulty with one or more body functions (C3Q21-C3Q26)				
body_ICF_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	1	0.00	1	0.00
No difficulties involving bodily functions	13406	33.31	13407	33.32
A little or a lot of difficulty with one or more bodily functions	26835	66.68	40242	100.00

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

STRATIFICATION VARIABLES

Ages of CSHCN in 3 categories				
age3_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0-5 yrs old	7294	18.13	7294	18.13
6-11 yrs old	15834	39.35	23128	57.47
12-17 yrs old	17114	42.53	40242	100.00

Sex of child				
sex_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	70	0.17	70	0.17
Male	24139	59.98	24209	60.16
Female	16033	39.84	40242	100.00

Race/ethnicity categories - 4 categories based on imputed screener file data				
race4_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Hispanic	4479	11.13	4479	11.13
White, non-Hisp	27989	69.55	32468	80.68
Black, non-Hisp	4010	9.96	36478	90.65
Other, non-Hisp	3764	9.35	40242	100.00

Hispanic ethnicity parsed by child's PRIMARY HOUSEHOLD language				
hhlng_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Hisp child / primary HH lang is ENGLISH	3320	8.25	3320	8.25
Hisp child / primary HH lang is NOT English lang	1159	2.88	4479	11.13
Non-Hispanic children	35763	88.87	40242	100.00

"How many CSHCN qualified on specific types of special health needs criteria?"				
def4_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
CSHCN qualifying on Func Limits (only or w/ any other)	9022	22.42	9022	22.42
CSHCN qualifying on Rx meds ONLY	16570	41.18	25592	63.60
CSHCN qualifying on Service use ONLY	5881	14.61	31473	78.21
CSHCN qualifying on Rx meds AND service use	8769	21.79	40242	100.00

"Qualified on ongoing emotional, developmental or behavioral conditions?"				
mhealth_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No	27850	69.21	27850	69.21
Yes	12392	30.79	40242	100.00

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

How many of the screener criteria were met by CSHCN?				
qualnum_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Qualified on 1 screener criteria	21059	52.33	21059	52.33
Qualified on 2 screener criteria	8252	20.51	29311	72.84
Qualified on 3 screener criteria	5550	13.79	34861	86.63
CSHCN who qualified on 4 or all 5 Screener criteria	5381	13.37	40242	100.00

Version 1: How many CHSCN live in households at specified levels of income according to Federal Poverty Level (FPL) guidelines?				
povlev4_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0% - 99% FPL	6899	17.14	6899	17.14
100% - 199% FPL	7722	19.19	14621	36.33
200% - 399% FPL	12572	31.24	27193	67.57
400% FPL or greater	13049	32.43	40242	100.00

Version 2: How many CHSCN live in households at specified SCHIP-relevant levels of income according to Federal Poverty Level (FPL) guidelines?				
povschip_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0% - 199% FPL	14621	36.33	14621	36.33
200% - 299% FPL	6763	16.81	21384	53.14
300% - 399% FPL	5809	14.44	27193	67.57
400% FPL or greater	13049	32.43	40242	100.00

Family structure of the CSHCN population				
famstuct_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Missing	582	1.45	582	1.45
CSHCN in parent household biological or adopted	25098	62.37	25680	63.81
CSHCN in 2 parent stepfamily household	3622	9.00	29302	72.81
CSHCN in mother only household	7803	19.39	37105	92.20
CSHCN in other family structure household	3137	7.80	40242	100.00

Type of Insurance Coverage				
instype_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Missing or comprehensive other insurance	1506	3.74	1506	3.74
Private only	23315	57.94	24821	61.68
Public only	11362	28.23	36183	89.91
Both Public and Private	2910	7.23	39093	97.14
Uninsured	1149	2.86	40242	100.00

What is the highest education level attained of any adult in the family?				
educ_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Less than high school	2145	5.33	2145	5.33
High school grad	6007	14.93	8152	20.26
More than high school	32090	79.74	40242	100.00

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)

SAS 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		
	SAS 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

Personal Doctor or Nurse sub-component of MEDICAL HOME composite measure				
pdn_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	56	0.14	56	0.14
Do not have a personal dr or nurse	2451	6.09	2507	6.23
Yes, have a personal dr or nurse	37735	93.77	40242	100.00

FAMILY CENTERED CARE

Drs/other health providers spend enough time				
time_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	126	0.31	126	0.31
Never/sometimes	7692	19.11	7818	19.43
Usually/always	32340	80.36	40158	99.79
No dr visits past 12 mos	84	0.21	40242	100.00

FCC: Drs/other health providers usually or always listen carefully				
listen_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	85	0.21	85	0.21
Never/sometimes	4141	10.29	4226	10.50
Usually/always	35932	89.29	40158	99.79
No dr visits past 12 mos	84	0.21	40242	100.00

Drs/other health providers sensitive to family values/customs				
sensitive_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	213	0.53	213	0.53
Never/sometimes	3604	8.96	3817	9.49
Usually/always	36341	90.31	40158	99.79
No dr visits past 12 mos	84	0.21	40242	100.00

Drs/other health providers provide needed information				
infoccc_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	100	0.25	100	0.25
Never/sometimes	6356	15.79	6456	16.04
Usually/always	33702	83.75	40158	99.79
No dr visits past 12 mos	84	0.21	40242	100.00

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

Drs/other health providers make family feel like a partner				
partner_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	77	0.19	77	0.19
Never/sometimes	4485	11.15	4562	11.34
Usually/always	35596	88.45	40158	99.79
No dr visits past 12 mos	84	0.21	40242	100.00

Family-Centered Care sub-component of MEDICAL HOME composite measure				
famcent_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref to any	473	1.18	473	1.18
Does NOT have family centered care	12579	31.26	13052	32.43
Yes, has family centered care	27106	67.36	40158	99.79
Legitimate skip - no dr visit past 12 mos	84	0.21	40242	100.00

NO REFERRAL PROBLEMS

Getting Needed Referrals sub-component of MEDICAL HOME composite measure					
norefprb_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent	
DK, Ref or Missing	194	0.48	194	0.48	
Big or small problem getting referral, when needed	2625	6.52	2819	7.01	
No problems getting referral, when needed	10649	26.46	13468	33.47	
Legitimate skip b/c referrals are not needed	26774	66.53	40242	100.00	

USUAL SOURCES OF CARE

Usual Sources for Sick and Well Care sub-component of MEDICAL HOME composite measure					
usual_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent	
DK or Ref	142	0.35	142	0.35	
Child does not have usual sources for sick and well care	3693	9.18	3835	9.53	
Child DOES have usual sources for sick and well care	36407	90.47	40242	100.00	

EFFECTIVE CARE COORDINATION

Got some type of help with care coordination					
carehelp_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent	
DK or Ref to any or Missing	84	0.21	84	0.21	
Needed extra help/did not get it	4953	12.31	5037	12.52	
Gets help with care coor	7945	19.74	12982	32.26	
Legit skip -- <2 services or did not need extra help	27260	67.74	40242	100.00	

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

Used some or all specialist care, MH, PT/OT/Speech, sub abuse, or home hlth care				
needcomm_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref	125	0.31	125	0.31
Did not use services for dr comm denominator	13442	33.40	13567	33.71
Used 1 or more services for dr comm denominator	26675	66.29	40242	100.00

Level of satisfaction with dr to dr communication among those who needed it				
drcomm_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK, Ref or Missing	191	0.47	191	0.47
Less than very satisfied	9562	23.76	9753	24.24
Very satisfied, when needed	16853	41.88	26606	66.12
Legit skip -- no comm needed or did not use required services	13636	33.88	40242	100.00

Level of satisfaction with dr communication to other providers or programs among those who needed it				
othercomm_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK, Ref or Missing	337	0.84	337	0.84
Less than very satisfied	5344	13.28	5681	14.12
Very satisfied	6179	15.35	11860	29.47
Legit skip -- used >2 services	28382	70.53	40242	100.00

Effective Care Coordination sub-component of MEDICAL HOME composite measure				
carecoor_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK, Ref or Missing to any	582	1.45	582	1.45
Did not meet 1 or more needed elements of care coordination	12455	30.95	13037	32.40
Met all needed components of care coordination or legitimate skip	17390	43.21	30427	75.61
Legit skip -- no one helps with care coor or >2 services used past 12 mos on all items	9815	24.39	40242	100.00

**MEDICAL HOME
Composite Measure**

OUTCOME #2: CSHCN receiving coordinated, ongoing, comprehensive care within a medical home				
outcome2_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
DK or Ref to any	1292	3.21	1292	3.21
Care DOES NOT meet medical home criteria	20671	51.37	21963	54.58
Care MEETS medical home criteria	18279	45.42	40242	100.00

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 SAS 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](#)