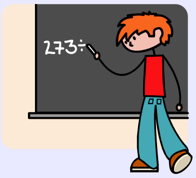
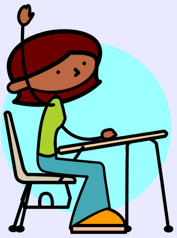
2001 National Survey of Children with Special Health Care Needs



INDICATOR AND OUTCOME MEASURES

SAS CODEBOOK



Version 1.0, January 2007

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

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Acknowledgements

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

Purpose of the 2001 NS-CSHCN SAS Codebook

This codebook contains SAS program statements that can be applied to the public use data files for the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN) to create the key children and youth with special health care needs (CSHCN) Indicators, Maternal and Child Health Bureau (MCHB) Outcomes, and variables used to stratify these items in the interactive data query feature of the National Data Resource Center for Child and Adolescent Health (DRC) located online at **www.childhealthdata.org.**

The codebook is designed to serve as a resource for researchers and analysts who are interested in replicating the indicator and outcome variables developed from the 2001 NS-CSHCN for the DRC. Its purpose is to expedite research by helping to standardize and improve the comparability of information derived from the 2001 NS-CSHCN.

The DRC maintains a complete 2001 NS-CSHCN indicator data set, available in either SAS or SPSS format. The data set includes all 15 Key Child Health Indicators and 5 MCHB Outcome variables, as well as demographic and individual question items. To request a copy, contact the Child and Adolescent Health Measurement Initiative (CAHMI) at **cahmi@ohsu.edu.**

The National Data Resource Center for Child and Adolescent Health

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

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

Overview of the 2001 NS-CSHCN

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

The 2001 NS-CSHCN sample was achieved by screening 372,174 children representing 196,888 households nationwide, using the CSHCN Screener. The CSHCN Screener (1) is a survey tool specifically developed and validated to identify children who meet the federal MCHB non-specific health-consequences-based special health care needs definition. The Screener asks parents about the presence of five different health consequences:

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

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

In depth interviews were completed for a total of 38,866 randomly selected children and youth who met the CSHCN Screener criteria — approximately 750 in each State and the District of Columbia. The survey data are weighted to reflect the population of non-institutionalized CSHCN ages 0–17 years in each State.

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

Data from the 2001 NS-CSHCN are publicly released in four files in SAS format: Household, Screener, Interview and Insurance. The public data sets and relevant background information and documentation are available online at: **www.cdc.gov/nchs/about/major/slaits/cshcn.htm.** Additional information and results from the NS-CSHCN are available in the DRC at: **www.childhealthdata.org.**

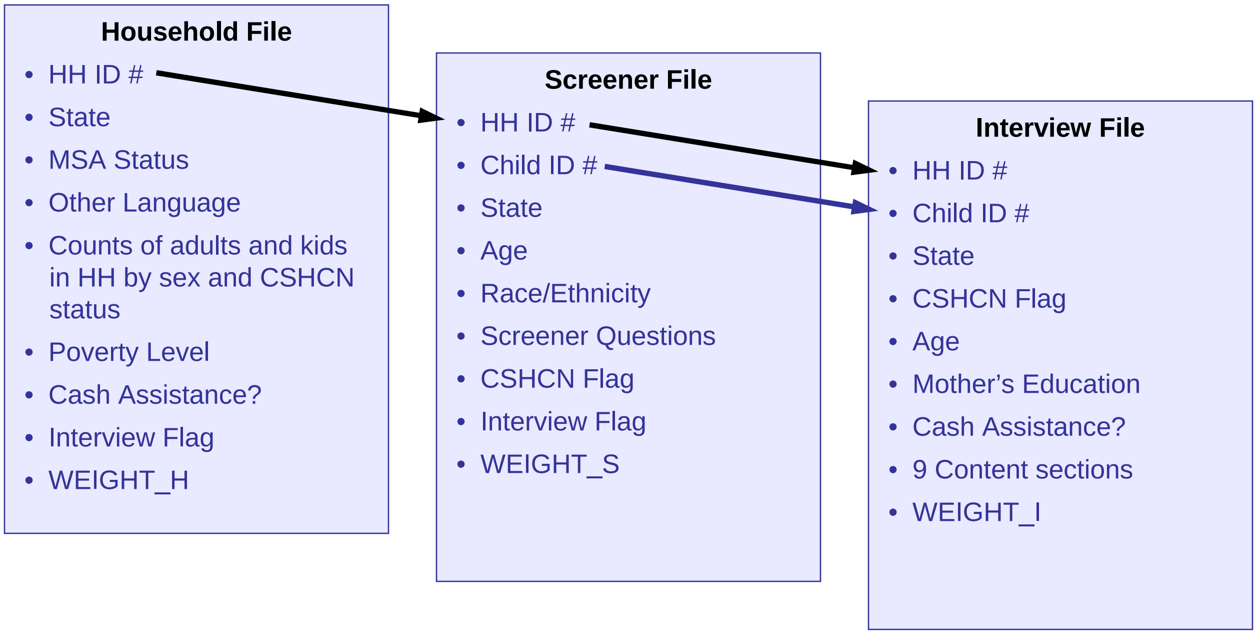
Linking the NS-CSHCN Data Files

Three of the four public use data files for the 2001 NS-CSHCN are used in this codebook as described in the following table:

NS-CSHCN Data Files	Number of Records (n)	Unique Identifier	Weighting Variable
Household file	196,888 randomly selected U.S. households with at least one child or youth ages 0–17	IDNUMR	WEIGHT_H
Screener file	372,174 children and youth ages 0–17 living in the randomly selected households with children	IDNUMXR	WEIGHT_S
Interview file	38,866 CSHCN ages 0–17 randomly selected from each household identified as has having one or more CSHCN during the initial screening process	IDNUMXR	WEIGHT_I

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

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



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

Important Information Regarding the 2001 NS-CSHCN

Weighting

The sampling weights provided in the publicly released data files are used to produce estimates representative of children or households with children at the State level and nationally. These sampling weights adjust the survey responses to reflect the underlying child population using the 2000 Census counts of children, stratified by sex, age, and race/ethnicity as the reference population. Additional adjustments are made to reflect telephone access and other non-response biases. The weighting variable WEIGHT_I, included in the Interview file, adjusts the survey responses to reflect the population of CSHCN ages 0–17 in each State and the District of Columbia.

Variance Estimation

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

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

The only substate geographic information included in the NS-CSHCN public use data set is a variable for Metropolitan Statistical Area (MSA) status, located in the Household file. MSA status information is available for the 35 States in which the population is at least 500,000 in both categories (MSA and non-MSA). Zip code data is collected with the NS-CSHCN but is not released in the public use data files due to confidentiality restrictions. The confidential zip code data can be made available to researchers for on site analysis at the Data Research Center of the National Center for Health Statistics (NCHS) in Hyattsville, MD. The process requires submitting a proposal to the NCHS. For more information, see: **www.cdc.gov/nchs/r&d/rdc.htm.**

Interpretation of Results

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

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

Verification

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

Additional Information on Survey Design and Methodology

The NCHS report, *Design and Operation of the National Survey of Children with Special Health Care Needs, 2001 (2)* is an excellent, comprehensive resource for anyone interested in using data from the NS-CSHCN. The report includes important information about questionnaire development, sample selection and weighting procedures, events that affected data collection, adjustments made to protect confidentiality, and more. View or download the methods report from the NCHS Web site at: **www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf.**

Appropriate Reference Citation

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

Child and Adolescent Health Measurement Initiative (CAHMI), "2001 NS-CSHCN Indicator and Outcome Variables SAS Codebook, Version 1, 2007," National Data Resource Center on Child and Adolescent Health, **www.childhealthdata.org**.

References

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

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

3. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. “The National Survey of Children with Special Health Care Needs Chartbook 2001.” Rockville, Maryland: U.S. Department of Health and Human Services, 2004.

4. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, Division of Health Interview Statistics, Special Population Surveys Branch. “Progress toward implementing community-based systems of services for children with special health care needs: Summary tables from the National Survey of Children with Special Health Care Needs, 2001.” April 2003.

INDICATOR #1	**Activity Limitations: Percent of CSHCN whose health conditions consistently and often greatly affect their daily activities**
Survey Items Used	C3Q02 and C3Q03
Numerator	Daily activities consistently affected, often a great deal
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose health conditions consistently and often greatly affect their daily lives.

Notes for Data-Users

This indicator combines the concepts of “how often” and “how much” CSHCN’s conditions affect their daily activities. For example, although a child may have asthma attacks only rarely, when such attacks do occur they may greatly affect the child’s abilities to do daily activities. CSHCN whose conditions “consistently, and often greatly, affect their daily activities” are those with responses of “Usually” or “Always” on C3Q02 and/or a response of “A great deal” on C3Q03.

SAS Code and Annotation

Format

```
value dailyact /*indic_1*/
  1 = “Daily activities never affected”
  2 = “Daily activities moderately affected some of time”
  3 = “Daily activities consistently affected, often a great deal”;
```

Code

```
indic_1 = .;
  if c3q02 = 1 then indic_1 = 1;
  if c3q02 = 2 then indic_1 = 2;
  if c3q02 = 3 then indic_1 = 3;
  if c3q02 = 4 then indic_1 = 3;
  if c3q03 = 1 then indic_1 = 3;
  label indic_1 = “INDICATOR #1: Percent of CSHCN whose health conditions consistently and often
  greatly affect their daily activities”;
```

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

Notes for Data-Users

This question was asked only for school-aged CSHCN.

SAS Code and Annotation

Format

```
value misssch /*indic_2*/
  1 = “0–3 days missed”
  2 = “4–6 days missed”
  3 = “7–10 days missed”
  4 = “11 or more days missed”;
```

Code

```
indic_2 = .;
  if c3q14r = 0 then indic_2 = 1;
  if c3q14r > = 1 and c3q14r < = 3 then indic_2 = 1;
  if c3q14r > = 4 and c3q14r < = 6 then indic_2 = 2;
  if c3q14r > = 7 and c3q14r < = 10 then indic_2 = 3;
  if c3q14r = 11 then indic_2 = 4;
  label indic_2 = “INDICATOR #2: Percent of CSHCN ages 5–17 with 11 or more days of school
  absences due to illness”;
```

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

Notes for Data-Users

Indicator #3 is based on the variable “UNINS_YR” which was derived by the NCHS from responses to the numerous questions about health insurance coverage in Section 7 of the NS-CSHCN. This variable is included in the publicly released Interview File from the survey. For more information on how insurance status was defined by the NCHS for purposes of the survey, go to http://www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf.

SAS Code and Annotation

Format

```
value insured /*indic_3*/
  1 = “NOT insured at some point during year”
  2 = “Insured entire year”;
```

Code

```
/*NOTE: Uses derived variable UNINS_YR (included in public release INTERVIEW file)*/
  indic_3 = unins_yr;
  if unins_yr in (6,7) then indic_3 = .;
  if indic_3 = 0 then indic_3 = 2; /*RECODED FROM (0,1) to (1,2)*/
  label indic_3 = “INDICATOR #3: Percent of CSHCN without insurance at some point during the past
  year”;
```

INDICATOR #4	Currently Uninsured: Percent of CSHCN uninsured at the time of the survey
Survey Items Used	UNINS
Numerator	Not currently insured
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 who were uninsured at the time of the survey.

Notes for Data-Users

Indicator #4 is based on the variable “UNINS” which was derived by the National Center for Health Statistics (NCHS) from responses to the numerous health insurance coverage questions in Section 7 of the NS-CSHCN. This variable is included in the publicly released Interview File from the survey. For more information on how insurance status was defined by the NCHS for purposes of the survey, go to http://www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf.

SAS Code and Annotation

Format

```
value currins /*indic_4*/
  1 = “Currently NOT insured”
  2 = “Currently insured”;
```

Code

```
/*NOTE: Uses derived variable UNINS (included in public release INTERVIEW file)*/
  indic_4 = unins;
  if indic_4 = 0 then indic_4 = 2; /*RECODED FROM (0,1) to (1,2)*/
  label indic_4 = “INDICATOR #4: Percent of CSHCN uninsured at the time of the survey”;
```

INDICATOR #5	**Adequacy of Current Insurance Coverage: Percent of currently insured CSHCN with coverage that is not adequate**
Survey Items Used	C8Q01_a, C8Q01_b, and C8Q01_c
Numerator	Current insurance is not adequate for CSHCN needs
Denominator	CSHCN ages 0–17 insured at the time of the survey
Description	Percent of currently insured CSHCN ages 0–17 whose insurance is not adequate for CSHCN needs.

Notes for Data-Users

“Adequate insurance” is defined as coverage which meets these three criteria:

- offers benefits or covers services that meet CSHCN’s needs AND
- has a reasonable level of uncovered costs AND
- allows CSHCN to see the health care providers they need.

Responses of “Usually or Always” to all 3 of the survey questions about adequacy of CSHCN’s current health insurance (C8Q01_a – C8Q01_c) are necessary to qualify as having adequate health insurance.

SAS Code and Annotation

Format

```
value adeqins /*indic_5*/
  1 = “Current insurance NOT adequate”
  2 = “Current insurance is adequate”;
```

Code

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

ins_unmetneeds = .;
  if c8q01_a = 1 or c8q01_a = 2 then ins_unmetneeds = 0;
  if c8q01_a = 3 or c8q01_a = 4 then ins_unmetneeds = 1;
  label ins_unmetneeds = “Health insurance benefits meet child needs”;

ins_reaschg = .;
  if c8q01_b = 1 or c8q01_b = 2 then ins_reaschg = 0;
  if c8q01_b = 3 or c8q01_b = 4 then ins_reaschg = 1;
  if c8q01_b = 6 then ins_reaschg = 2;
  label ins_reaschg = “Non-covered insurance charges reasonable”;

ins_providers = .;
  if c8q01_c = 1 or c8q01_c = 2 then ins_providers = 0;
  if c8q01_c = 3 or c8q01_c = 4 then ins_providers = 1;
  label ins_providers = “Insurance allows child to see needed providers”;


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

indic_5 = .;
```

```
if ins_unmetneeds = 1 and ins_reaschg = 1 and ins_providers = 1 then indic_5 = 0;
if ins_reaschg = 2 and ins_unmetneeds = 1 and ins_providers = 1 then indic_5 = 0;
if ins_reaschg = 2 and ins_unmetneeds = 0 or ins_providers = 0 then indic_5 = 1;
if ins_unmetneeds = 0 or ins_reaschg = 0 or ins_providers = 0 then indic_5 = 1;
if indic_5 = 0 then indic_5 = 2; /*RECODED FROM (0,1) to (1,2)*/
label indic_5 = “INDICATOR #5: Percent of currently insured CSHCN with coverage that is not
adequate”;
```

INDICATOR #6	**Unmet Needs for Care: Percent of CSHCN with one or more unmet needs for specific health care services**
Survey Items Used	C4Q05_01a – C4Q5_14a
Numerator	One or more unmet needs for specific health care services
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 with one or more unmet needs for specific health care services.

Notes for Data-Users

The survey asks if CSHCN needed any of 14 different health care services during the past 12 months. Respondents who indicate that the child needed a specific health care service are asked a follow up question about whether the child received all the care that he/she needed. Each response of “No” to any of the follow up questions about getting needed care is counted as an “unmet need” for Indicator #6.

SAS Code and Annotation

Format

```
value unmethcs /*indic_6*/
  1 = “1 or more unmet needs for specific health care services”
  2 = “No unmet needs for specific health care services”;
```

Code

```
/*STEP 1: Create interim count and summary variables for each of the 14 different health care services
  items.*/

unmet1 = .;
  if c4q5_1a = 0 then unmet1 = 1;
  if c4q5_2a = 0 then unmet2 = 1;
  if c4q5_3a = 0 then unmet3 = 1;
  if c4q5_4a = 0 then unmet4 = 1;
  if c4q5_5a = 0 then unmet5 = 1;
  if c4q5_6a = 0 then unmet6 = 1;
  if c4q5_7ar = 0 then unmet7 = 1;
  if c4q5_8a = 0 then unmet8 = 1;
  if c4q5_9a = 0 then unmet9 = 1;
  if c4q5_10a = 0 then unmet10 = 1;
  if c4q5_11ar = 0 then unmet11 = 1;
  if c4q5_12ar = 0 then unmet12 = 1;
  if c4q5_13a = 0 then unmet13 = 1;
  if c4q5_14a = 0 then unmet14 = 1;
  unmet_sum = SUM (unmet1, unmet2, unmet3, unmet4, unmet5, unmet6, unmet7, unmet8, unmet9,
  unmet10, unmet11, unmet12, unmet13, unmet14);
  label unmet_sum = “Number of unmet needs”;
```

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

indic_6 = .;
  if unmet_sum >0 then indic_6 = 1;
  if unmet_sum = . then indic_6 = 0;
  if indic_6 = 0 then indic_6 = 2; /*RECODED FROM (0,1) to (1,2)*/
  label indic_6 = “INDICATOR #6: Percent of CSHCN with one or more unmet needs for specific health
  care services”;
```

INDICATOR #7b	Unmet Needs for Family Support Services: Percent of CSHCN whose families needed but were not able to get all the respite care, genetic counseling and/or mental health services they needed
Survey Items Used	C4Q06_01a – C4Q06_3a
Numerator	One or more unmet needs for family support services
Denominator	CSHCN ages 0–17 whose families needed one or more of three specific family support services
Description	Percent of CSHCN ages 0–17 whose families needed but were not able to get all the respite care, genetic counseling, and/or mental health services they needed.

Notes for Data-Users

The survey asks if the child’s family members needed respite care, genetic counseling, or mental health care/counseling related to caring for a special needs child. Respondents who indicated that a family member needed a specific family support service during the past 12 months were asked a follow up question about whether the family member received all the care that he/she needed. Each response of “No” to any of the follow up questions about getting needed family support services is counted as an “unmet need” for Indicator #7b.

SAS Code and Annotation

Format

```
value unmetfss /*indic_7*/
  1 = “One or more unmet needs for family support services”
  2 = “No unmet needs for specific family support services”;
```

Code

```
/*NOTE: Version #7b of this indicator has the same numerator at the chartbook indicator BUT includes
  in the denominator ONLY CSHCN whose families needed one or more of the family support services.
  The chartbook version uses all CSHCN as the denominator, whether or not the families needed
  support services*/

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

respite_2 = .;
  if c4q06_01 = 0 then respite_2 = .;
  if c4q06_01 = 1 and c4q6_1a = 1 then respite_2 = 0;
  if c4q06_01 = 1 and c4q6_1a = 0 then respite_2 = 1;
  label respite_2 = “Families need for and receipt of respite care”;

gene_2 = .;
  if c4q06_02 = 0 then gene_2 = .;
  if c4q06_02 = 1 and c4q6_2a = 1 then gene_2 = 0;
```

```
  if c4q06_02 = 1 and c4q6_2a = 0 then gene_2 = 1;
  label gene_2 = “Families need for and receipt of genetic counseling”;

mhfam_2 = .;
  if c4q06_03 = 0 then mhfam_2 = .;
  if c4q06_03 = 1 and c4q6_3a = 1 then mhfam_2 = 0;
  if c4q06_03 = 1 and c4q6_3a = 0 then mhfam_2 = 1;
  label mhfam_2 = “Families need for and receipt of mental health care/counseling”;

fam_sum = SUM (respite_2, gene_2, mhfam_2);
  label fam_sum = “Number of unmet family support needs”;


/**STEP 2: Compute Indicator #7 from interim summary count variable (FAM_SUM)**/

indic_7 = .;
  if fam_sum > 0 then indic_7 = 1;
  if fam_sum = 0 then indic_7 = 0;
  if indic_7 = 0 then indic_7 = 2; /*RECODED FROM (0,1) to (1,2)*/
  label indic_7 = “INDICATOR #7b: Percent of CSHCN whose families needed but were not able to get
  all the respite care, genetic counseling and/or mental health services they needed”;
```

INDICATOR #8	**Problems Obtaining Referral: Percent of CSHCN needing specialty care who had problems getting a referral**
Survey Items Used	C4Q05_02 and C4Q07
Numerator	Problems getting referral for needed specialty care
Denominator	CSHCN ages 0–17 years who needed care from a specialty doctor during the past 12 months
Description	Among CSHCN ages 0–17 who needed specialty care during the past 12 months, percent who had problems getting a referral.

Notes for Data-Users

Only CSHCN who needed specialist care during the past 12 months are included in the denominator for Indicator #8 (C4Q05_02 = Yes). Nationally, about 51 percent of CSHCN needed care from a specialty doctor during the past 12 months. Responses of “A big problem” or “A small problem” to question C4Q07 are counted as having problems getting a referral for needed specialty care.

SAS Code and Annotation

Format

```
value diffref /*indic_8*/
  1 = “Problem getting referral for needed specialty care”;
  2 = “No problem getting referral for needed specialty care”;
```

Code

```
indic_8 = .;
  if c4q05_02 = 1 and c4q07 = 1 then indic_8 = 1;
  if c4q05_02 = 1 and c4q07 = 2 then indic_8 = 1;
  if c4q05_02 = 1 and c4q07 = 3 then indic_8 = 0;
  if indic_8 = 0 then indic_8 = 2; /*RECODED FROM (0,1) to (1,2)*/
  label indic_8 = “INDICATOR #8: Percent of CSHCN needing specialty care who had difficulties getting
  a referral”;
```

INDICATOR #9	**Usual Source for Sick Care: Percent of CSHCN without a usual source of care or who rely on the emergency room**
Survey Items Used	C4Q0a and C4Q0b
Numerator	No regular place or relies upon emergency room
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 who do not have a usual source of care, or who rely on the emergency room for medical care when ill.

Notes for Data-Users

“CSHCN without a usual source of care” are defined as those who either do not have a place they USUALLY go when they are sick or need advice about health (C4Q0a = “There is no place” OR C4Q0b = “Doesn’t go to one place most often”) or those who USUALLY rely upon the emergency room for this type of care (C4Q0b = “Hospital emergency room”).

SAS Code and Annotation

Format

```
value care /*indic_9*/
  1 = “Doctor’s office”
  2 = “Clinic, health center or other regular source”
  3 = “No regular place or relies on emergency room”;
```

Code

```
/*STEP #1: Compute interim “usual source of care” variable*/
  usualcare = .;
  if c4q0b = 1 then usualcare = 1;
  if c4q0b = 4 then usualcare = 2;
  if c4q0b = 3 then usualcare = 2;
  if c4q0b = 2 then usualcare = 4;
  if c4q0b = 5 or c4q0b = 6 or c4q0b = 8 then usualcare = 2;
  if c4q0b = 5 and c4q0b = 7 then usualcare = 3;
  if c4q0a = 2 then usualcare = 3;
  label usualcare = “Kind of place child usually goes for health care”;

/*STEP 2: Compute Indicator #9 from interim usual source of care variable (USUALCARE)*/
indic_9 = .;
  if c4q0b = 1 then indic_9 = 1;
  if c4q0b = 4 then indic_9 = 2;
  if c4q0b = 3 then indic_9 = 2;
  if c4q0b = 2 then indic_9 = 3;
  if c4q0b = 5 or c4q0b = 6 or c4q0b = 8 then indic_9 = 2;
  if c4q0b = 5 and c4q0b = 7 then indic_9 = 3;
```

```
if c4q0a = 2 then indic_9 = 3;
label indic_9 = “INDICATOR #9: Percent of CSHCN without a usual source of care or who rely on the
emergency room”;
```

INDICATOR #10	Personal Doctor or Nurse: Percent of CSHCN without a personal doctor or nurse (PDN)
Survey Items Used	C4Q02a
Numerator	Does not have a PDN
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 who do not have a PDN.

Notes for Data-Users

A personal doctor or nurse (PDN) is defined as a “health provider who knows the child best.” Question C4Q02a asks respondents if they have ONE person they think of as the child’s PDN.

SAS Code and Annotation

Format

```
value persdoc /*indic_10*/
  1 = “Yes, have a personal dr or nurse”
  2 = “Do not have a personal dr or nurse”;
```

Code

```
indic_10 = c4q02a;
  if c4q02a in (6,7) then indic_10 = .;
  if indic_10 = 0 then indic_10 = 2; /*RECODED FROM (0,1) to (1,2)*/
  label indic_10 = “INDICATOR #10: Percent of CSHCN without a PDN”;
```

INDICATOR #11	**Family Centered Care: Percent of CSHCN without family-centered care**
Survey Items Used	C6Q01 – C6Q06
Numerator	Does not have family-centered care
Denominator	CSHCN ages 0–17 with one or more doctor visits during the past 12 months
Description	Percent of CSHCN ages 0–17 whose medical care is not family-centered.

Notes for Data-Users

“Family-Centered Care” is defined as doctors or other health providers who USUALLY or ALWAYS do each of the following:

- spend enough time with child (C6Q02),
- listen carefully (C6Q03),
- are sensitive to the families’ values and customs (C6Q04),
- provide needed information about child’s health and health care to the family (C6Q05), and
- help family feel like a partner in child’s care (C6Q06).

Responses of “Usually” or “Always” must be achieved on each of the five questions in order for a CSHCN to meet the criteria for consistently receiving family-centered care.

CSHCN who did not visit a doctor during the past 12 months (C6Q01 = No) or CSHCN with one or more responses of “Don’t Know” or “Refused” on questions C6Q01 – C6Q06 are not included in the valid denominator for this indicator.

The version of Family Centered Care composite used on the DRC Web site is the same one that is used in construction of the Medical Home index reported in the NCHS/MCHB report: *“Progress Toward Implementing Community-Based Systems of Services for Children with Special Health Care Needs: Summary Tables from the National Survey of Children with Special Health Care Needs, 2001.”* It differs slightly from the version used in the HRSA chartbook because cases with responses of “Don’t Know” or “Refused” to number of doctor visits (C6Q01r) are excluded from the valid denominator.

SAS Code and Annotation

Format

```
value famcntcr /*indic_11*/
  1 = “CSHCN with family centered care”
  2 = “CSHCN without family centered care”;
```

Code

```
/*NOTE: The version of FCC composite used on the DRC website is the one used in construction of the
  Medical Home index reported in the NCHS/MCHB report: Progress Toward Implementing Community-
  Based Systems of Services for Children with Special Health Care Needs: Summary Tables from the
  National Survey of Children with Special Health Care Needs, 2001. It differs from the version used in
  the HRSA chartbook because cases with responses of DK or REF to # of doctor visits (C6Q01r) are
  excluded from the valid denominator.*/
```

```
/**STEP 1: Compute family centered care interim variables to collapse “never/sometimes” and set DK or
REF # of visits question (C6Q01r) to SYSMISS.**/
fcc_a = .;
  if c6q02 in (1,2) then fcc_a = 1;
  if c6q02 = 3 then fcc_a = 2;
  if c6q02 = 4 then fcc_a = 3;
  if c6q01r = 996 or c6q01r = 997 then fcc_a = .;
  label fcc_a = “How often drs spent enough time”;
fcc_b = .;
  if c6q03 in (1,2) then fcc_b = 1;
  if c6q03 = 3 then fcc_b = 2;
  if c6q03 = 4 then fcc_b = 3;
  if c6q01r = 996 or c6q01r = 997 then fcc_b = .;
  label fcc_b = “How often drs listened carefully”;
fcc_c = .;
  if c6q04 in (1,2) then fcc_c = 1;
  if c6q04 = 3 then fcc_c = 2;
  if c6q04 = 4 then fcc_c = 3;
  if c6q01r = 996 or c6q01r = 997 then fcc_c = .;
  label fcc_c = “How often drs sensitive to families values/customs”;
fcc_d = .;
  if c6q05 in (1,2) then fcc_d = 1;
  if c6q05 = 3 then fcc_d = 2;
  if c6q05 = 4 then fcc_d = 3;
  if c6q01r = 996 or c6q01r = 997 then fcc_d = .;
  label fcc_d = “How often got enough info from dr re: medical problems”;
fcc_e = .;
  if c6q06 in (1,2) then fcc_e = 1;
  if c6q06 = 3 then fcc_e = 2;
  if c6q06 = 4 then fcc_e = 3;
  if c6q01r = 996 or c6q01r = 997 then fcc_e = .;
  label fcc_e = “How drs helped parents feel like partners”;

/**STEP 2: Compute Indicator #11 using interim composite component variables.**/
indic_11 = .;
  if fcc_a eq 1 or fcc_b eq 1 or fcc_c eq 1 or fcc_d eq 1 or fcc_e eq 1 then indic_11 = 0;
  if fcc_a ge 2 and fcc_b ge 2 and fcc_c ge 2 and fcc_d ge 2 and fcc_e ge 2 then indic_11 = 1;
  if fcc_a eq . or fcc_b eq . or fcc_c eq . or fcc_d eq . or fcc_e eq . then indic_11 = .;
  if indic_11 eq 0 then indic_11 = 2; /*RECODED FROM (0,1) to (1,2)*/
  label indic_11 = “INDICATOR #11: Percent of CSHCN without family-centered care”;
```

INDICATOR #12	**Out-of-Pocket Expenses: Percent of CSHCN whose families pay more than $1000 per year out-of-pocket for child’s medical expenses**
Survey Items Used	C9Q01 and C9Q01a
Numerator	Family pays more than $1000 per year
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose families pay more than $1,000 per year in out-of-pocket expenses for child’s medical expenses.

Notes for Data-Users

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

SAS Code and Annotation

Format

```
value outofpck /*indic_12*/
  1 = “Less than $250”
  2 = “$250–$500”
  3 = “$501–$1000”
  4 = “More than $1000”;
```

Code

```
indic_12 = .;
  if c9q01 = 3 then indic_12 = 1;
  if c9q01 = 4 then indic_12 = 1;
  if c9q01 = 2 then indic_12 = 2;
  if c9q01_a = 3 then indic_12 = 3;
  if c9q01_a in (1,2) then indic_12 = 4;
  label indic_12 = “INDICATOR #12: Percent of CSHCN whose families pay more than $1000 per year
  out-of-pocket for child’s medical expenses”;
```

INDICATOR #13	**Family Financial Burden: Percent of CSHCN whose families experienced financial problems due to child’s health needs**
Survey Items Used	C9Q05
Numerator	Child’s family had financial problems due to child’s health needs
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose families experienced financial problems due to child’s health needs.

Notes for Data-Users

SAS Code and Annotation

Format

```
value finprob /*indic_13*/
  1 = “Yes, financial problems”
  2 = “No financial problems due to child’s health”;
```

Code

```
indic_13 = c9q05;
  if c9q05 in (6,7) then indic_13 = .;
  if indic_13 = 0 then indic_13 = 2; /*RECODED FROM (0,1) to (1,2)*/
  label indic_13 = “INDICATOR #13: Percent of CSHCN whose families experienced financial problems
  due to child’s health needs”;
```

INDICATOR #14	**Hours per Week Providing Care: Percent of CSHCN whose families spend 11 or more hours per week providing and/or coordinating health care for child**
Survey Items Used	C9Q02 – C9Q04
Numerator	11 or more hours per week
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose families spend 11 or more hours per week providing and/or coordinating health care for the child.

Notes for Data-Users

Indicator #14 is based on the summed total of the number of hours family members spend per week providing health care at home for CSHCN and the number hours family members spend per week arranging and coordinating health care for CSHCN. Question C9Q02 defines “home health care” as: changing bandages, care of feeding or breathing equipment, giving medication and therapies, and providing transportation to appointments. Question C9Q04 defines “arranging or coordinating health care” as: making appointments, making sure that care providers are exchanging information, and following up child’s care needs.

SAS Code and Annotation

Format

```
value hours /*indic_14*/
  1 = “Less than 1 hour“
  2 = “1–4 hours per week”
  3 = “5–10 hours per week”
  4 = “11 or more hours per week”;
```

Code

```
/*STEP 1: Create interim variables from number of hours spent items*/
if 0 < = c9q03r < = 12 then rc9q03r = c9q03r;
  if c9q03r in (.m,.l,.p) then rc9q03r = 0;
  if 0 < = c9q04r < = 12 then rc9q04r = c9q04r;
  if c9q04r in (.m,.l,.p) then rc9q04r = 0;
  hrs_sum = rc9q03r + rc9q04r;

/*STEP 2: Compute Indicator #14 from interim number of hours variables (RC9Q03r; RC9Q04r)*/
indic_14 = .;
  if hrs_sum = 0 then indic_14 = 1;
  if hrs_sum > = 1 and hrs_sum < = 4 then indic_14 = 2;
  if hrs_sum > = 5 and hrs_sum < = 10 then indic_14 = 3;
  if hrs_sum > = 11 then indic_14 = 4;
  label indic_14 = “INDICATOR #14: Percent of CSHCN whose families spend 11 or more hours per
  week providing and/or coordinating health care for child”;
```

INDICATOR #15	**Impact on Family Work Life: Percent of CSHCN whose family members cut back and/or stopped working because of child's health needs**
Survey Items Used	C9Q06 and C9Q10
Numerator	Family member(s) cut back and/or stopped working because of child's health needs
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose family members cut back and/or stopped working because of child's health needs.

Notes for Data-Users

Indicator #15 combines the concepts of family members "cutting down on hours worked" and/or "stopping work altogether" because of CSHCN's health conditions or health needs. The wording of questions C9Q06 and C9Q10 does not make it possible to distinguish which members of the family were affected and if the same or different family members cut back hours, stopped working, or both.

SAS Code and Annotation

Format

```
value chgwork /*indic_15*/
  1 = "Family member cut back hours or stopped working"
  2 = "Employment not affected";
```

Code

```
indic_15 = .;
  if c9q06 in (0,1) or c9q10 in (0,1) then indic_15 = 0;
  if c9q06 = 1 and c9q10 = 1 then indic_15 = 1;
  if c9q06 = 0 and c9q10 = 1 then indic_15 = 1;
  if c9q06 = 1 and c9q10 = 0 then indic_15 = 1;
  if indic_15 = 0 then indic_15 = 2; /*RECODED FROM (0,1) to (1,2)*/
  label indic_15 = "INDICATOR #15: Percent of CSHCN whose family members cut back and/or
  stopped working because of child's health needs";
```

OUTCOME #1	Families of CSHCN will be partners in decision-making and are satisfied with the services they receive
Survey Items Used	C6Q01, C6Q0C, C6Q06
Numerator	CSHCN for whom Outcome #1 was achieved
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN whose families who partner in decision-making and are satisfied with the services received.

Notes for Data-Users

Criteria for Outcome #1 are:

- Doctors usually or always make the family feel like a partner.
- Family is very satisfied with services received.

Question C6Q0C was added to survey more than halfway through the data collection cycle. As a result, there are 23,293 (60%) cases with missing data because the question was not asked.

Step 1 constructs an interim variable that identifies CSHCN with no doctor visits during past year and groups those with one or more doctor visits into those whose doctors never/sometimes vs. usually/always make family feel like partners in the child’s care. Step 2 creates the outcome variable.

SAS Code and Annotation

Format

```
value outcome /*format used for all outcome variables*/
  1 = “Outcome successfully achieved”
  2 = “Outcome not achieved”;

value partner /*interim variable*/
  0 = “No doctor visits during past 12 mos”
  1 = “Dr visits and family never-sometimes feels like partner”
  2 = “Dr visits and family usually-always feels like partner”;
```

Code

```
/*STEP 1: Construct interim variable that identifies CSHCN with no doctor visits during past year and
  groups those with 1 or more doctor visits into CSHCN whose doctors never/sometimes vs.
  usually/always make family feel like partners in child’s care. Variable FCC_E used in the construction
  of this interim variable is from the code used to derived the family centered care key Indicator #11.*/

partner1 = .;
  if c6q01r = 0 then partner1 = 0;
  if c6q06 in (1,2) then partner1 = 1;
  if c6q06 in (3,4) then partner1 = 2;
  label partner1 = “Interim variable for constructing Outcome #1”;


/*STEP 2: Create OUTCOME_1*/
```

```
outcome_1 = .;
  if partner1 = 0 and c6q0c = 1 then outcome_1 = 1;
  if partner1 = 0 and c6q0c >= 2 then outcome_1 = 0;
  if partner1 = 2 and c6q0c = 1 then outcome_1 = 1;
  if partner1 = 1 or c6q0c >= 2 then outcome_1 = 0;
  if partner1 = 1 or c6q0c >= 2 then outcome_1 = 0;
  if c6q01r in (996,997) then outcome_1 = .;
  if c6q0c in (6,7) then outcome_1 = .;
  if partner1 = . or c6q0c in (.M,.A,.) then outcome_1 = .;
  if outcome_1 = 0 then outcome_1 = 2; /*RECODES 0,1 to 1,2*/
  label outcome_1 = “OUTCOME #1: Families of CSHCN will be partners in decision making and are
  satisfied with the services they receive”;
```

OUTCOME #2	**CSHCN will receive coordinated, ongoing, comprehensive care within a medical home**
Survey Items Used	C4Q6X0aa, C4Q0a, C4Q0b, C4Q01, C4Q02, C4Q02a, C4Q05_02, C4Q06_0a, C4Q07, C5Q02, C5Q05, C5Q06, C6Q02, C6Q03, C6Q04, C6Q05, C6Q06
Numerator	CSHCN meeting the scoring criteria for having a medical home
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN who received coordinated ongoing comprehensive care within a medical home as defined by the American Academy of Pediatrics (AAP).

Notes for Data-Users

Criteria for Outcome #2 are:

- The child has usual source(s) for both sick care and preventive care.
    - AND
- The child has a personal doctor or nurse.
    - AND
- No problems obtaining referrals when needed.
- Effective care coordination is received when needed.
- Receives family-centered care from all child’s doctors and other health care providers.

The final medical home outcome score is derived from the five components constructed below.

SAS Code and Annotation

Format

```
value outcome /*format used for all outcome variables*/
1 = “Outcome successfully achieved”
2 = “Outcome not achieved”;
```

```
/*The following formats are for interim variables for Outcome #2*/
value coorrcv /*interim variable*/
  0 = “Needed, did not get all prof care coor”
  1 = “Needed & got all prof care coor”
  3 = “Did not need prof care coor”
  99 = “DK/Ref/Missing to one or both”;
value r_c5q05f /*interim variable*/
  1 = “Excellent/Very Good”
  2 = “Good/Fair/Poor”
  6 = “Communication not needed”
  999 = “DK/Ref”;
```

```
value doccomm /*interim variable*/
  1 = “Excellent/very good”
  2 = “Good/Fair/Poor”
  3 = “Legitimate skip”
  999 = “DK/Ref/Missing”;
value r_c5q06f /*interim variable*/
  1 = “Excellent/Very Good”
  2 = “Good/Fair/Poor”
  6 = “Communication not needed”
  999 = “DK/Ref”;
value othcom_1f /*interim variable*/
  1 = “Excellent/Very Good”
  2 = “Good/Fair/Poor”
  999 = “Communication not needed or DK/Ref”;
value othcom_2f /*interim variable*/
  1 = “Excellent/Very Good”
  2 = “Good/Fair/Poor”
  3 = “Professional care coordination NOT needed or needed/NEVER helped”
  999 = “DK/Ref”;
value othcomm /*interim variable*/
  1 = “Excellent/Very Good”
  2 = “Good/Fair/Poor”
  3 = “Legitimate skip”
  999 = “DK/Ref”;
value carecoor /*interim variable*/
  1 = “Yes”
  0 = “No”
  3 = “Legitimate skip—not needed or needed & never get help”;
value ny /*interim variable*/
  0 = “No”
  1 = “Yes”;
value usual /*interim variable*/
  0 = “Child does not have usual source of care”
  1 = “Child DOES have usual source of care”;
value r_c4q07f /*interim variable*/
  0 = “Big or small problem”
  1 = “No problems”
  4 = “Ch did NOT need to see a specialist”
  5 = “No need to get referrals”
  999 = “DK/Ref/Missing”;
value norefprb /*interim variable*/
  0 = “Needed referrals, problems getting”
```

```
  1 = “Needed referrals, no problems”
  3 = “Legitimate skip”;
value famcent /*interim variable*/
  0 = “Does NOT have fcc”
  1 = “Yes, has fcc”
  3 = “Legitimate skip”;
value pdn /*interim variable*/
  0 = “Do not have a personal dr or nurse”
  1 = “Yes, have a personal dr or nurse”;
```

Code

```
/****OUTCOME #2:****/
/*NOTE: The final medical home outcome score is derived from the five different components
  constructed below. The documentation used to validate the five medical home components is from
  Tables VI-a and VI-b in the report, Progress Toward Implementing Community-Based Services for
  Children with Special Health Care Needs prepared by the NCHS, April 2003.*/

/**STEP 1: Construct “Care Coordination” component of medical home score**/
coorrcv = 99;
  if c4q6x0aa = 1 then coorrcv = 1;
  if c4q6x0aa = 0 then coorrcv = 0;
  if c4q06_0a = 0 then coorrcv = 3;
  label coorrcv = “Received NEEDED professional care coordination”;
r_c5q05 = .;
  if c5q05 eq 6 then r_c5q05 = 6;
  if c5q05 eq 96 then r_c5q05 = 999;
  if c5q05 in (.M,.L,.A) then r_c5q05 = 999;
  if c5q05 in (1,2) then r_c5q05 = 1;
  if c5q05 in (3,4,5) then r_c5q05 = 2;
  doccomm = 999;
  if r_c5q05 = 1 then doccomm = 1;
  if r_c5q05 = 2 then doccomm = 2;
  if r_c5q05 = 6 then doccomm = 3;
  if c4q06_0a = 0 then doccomm = 3;
  if c5q02 = 1 then doccomm = 3;
  label doccomm = “Level of communication btw child’s doctors”;
r_c5q06 = 999;
  if c5q06 eq 6 then r_c5q06 = 6;
  if c5q06 eq 96 then r_c5q06 = 999;
  if c5q06 in (.M,.L,.A) then r_c5q06 = 999;
  if c5q06 in (1,2) then r_c5q06 = 1;
  if c5q06 in (3,4,5) then r_c5q06 = 2;
  label r_c5q06 = “Recoded level of dr communication with other services”;
```

```
othcom_1 = 999;
  if r_c5q06 = 1 then othcom_1 = 1;
  if r_c5q06 = 2 then othcom_1 = 2;
  othcom_2 = 999;
  if c4q06_0a = 0 then othcom_2 = 3;
  if c4q06_0a = 1 and othcom_1 = 1 then othcom_2 = 1;
  if c4q06_0a = 1 and othcom_1 = 2 then othcom_2 = 2;
  if c4q06_0a = 1 and c5q02 = 1 then othcom_2 = 3;
  if c4q06_0a = 1 and c5q02 >= 6 then othcom_2 = 999;
  othcomm = 999;
  if r_c5q06 = 1 and othcom_2 = 1 then othcomm = 1;
  if r_c5q06 = 1 and othcom_2 = 3 then othcomm = 3;
  if r_c5q06 = 2 and othcom_2 = 2 then othcomm = 2;
  if r_c5q06 = 2 and othcom_2 = 3 then othcomm = 3;
  if r_c5q06 = 6 and othcom_2 =3 then othcomm = 3;
  if r_c5q06 = 6 and othcom_2 =999 then othcomm = 3;
  if r_c5q06 = 999 and othcom_2 =3 then othcomm = 3;
  label othcomm = “Level of dr communication with other services”;
carecoor = 3;
  if coorrcv = 1 and (doccomm = 1 or doccomm = 3) and (othcomm = 1 or othcomm = 3) then carecoor =
  1;
  if coorrcv = 0 or doccomm = 2 or othcomm = 2 then carecoor = 0;
  if coorrcv = 99 or doccomm = 999 or othcomm = 999 then carecoor = .;
  label carecoor = “Effective care coordination received when needed”;

/**STEP 2: Construct “Usual Source of Care” component of medical home score**/
sick = .;
  if (c4q0a = 1 or c4q0a = 3) and (c4q0b = 1 or c4q0b = 3 or c4q0b = 4 or c4q0b = 5 or c4q0b = 6 or
  c4q0b = 8) then sick = 1;
  if (c4q0a = 2) or (c4q0b = 2 or c4q0b = 7) then sick = 0;
  label sick = “Child has usual place for sick care”;
well = .;
  if (c4q01 = 1) or (c4q02 = 2 or c4q02 = 4 or c4q02 = 5 or c4q02 = 6 or c4q02 = 7 or c4q02 = 9) then
  well = 1;
  if c4q02 = 1 or c4q02 = 3 or c4q02 = 8 or c4q02 = 10 then well = 0;
  if c4q02 = 96 or c4q02 = 97 then well = .;
  if c4q01 = 6 or c4q01 = 7 then well = .;
  if c4q01 = 1 and (c4q0b = 2 or c4q0b = 7) then well = 0;
  label well = “Child has usual place for well care”;
usual = .;
  if sick = 1 and well = 1 then usual = 1;
  if sick = 0 or well = 0 then usual = 0;
  if well = . or sick = . then usual = .;
  label usual = “Usual source of care component of Outcome #2”;
```

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

r_c4q07 = .;
  if c4q07 = 3 then r_c4q07 = 1;
  if c4q07 = 4 then r_c4q07 = 4;
  if c4q07 = 5 then r_c4q07 = 5;
  if c4q07 in (1,2) then r_c4q07 = 0;
  if c4q07 in (6,7) then r_c4q07 = 999;
  label r_c4q07 = “Problems getting referral to specialist”;

norefprb = .;
  if c4q05_02 = 1 and r_c4q07 = 0 then norefprb = 0;
  if c4q05_02 = 1 and r_c4q07 = 1 then norefprb = 1;
  if c4q05_02 = 0 or r_c4q07 = 4 or r_c4q07 = 5 then norefprb = 3;
  if c4q05_02 = 6 or c4q05_02 = 7 then norefprb = .;
  label norefprb = “Getting needed referrals component of Outcome #2”;

/**STEP 4: Construct “Family Centered Care” component of medical home score**/

/*NOTE: The following code uses variables that are created during the construction of Key State
Indicator #11. Please run the code for “Indicator #11: CSHCN without Family Centered Care” BEFORE
constructing Family Centered Care component of the medical home score*/

famcent = .;
  if indic_11 = 2 then famcent = 0;
  if indic_11 = 1 then famcent = 1;
  if fcc_a = . or fcc_b = . or fcc_c = . or fcc_d = . or fcc_e = . then famcent = .;
  if c6q01r = 0 then famcent = 3;
  label famcent = “Family centered care component of Outcome #2”;

/**STEP 5: Construct “Personal Doctor or Nurse” component of medical home score**/

pdn = c4q02a;
  if c4q02a in (6,7) then pdn = .;
  label pdn = “CSHCN without a personal doctor or nurse”;

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

outcome_2 = .;
  if (pdn = 1 and usual = 1) and (carecoor = 1 or carecoor = 3) and (norefprb = 1 or norefprb = 3) and
  (famcent = 1 or famcent = 3) then outcome_2 = 1;
  if (pdn = 0) or (usual = 0) or (carecoor = 0) or (norefprb = 0) or (famcent = 0) then outcome_2 = 0;
  if pdn = . or usual = . or famcent = . or norefprb = . or carecoor = . then outcome_2 = .;
  if outcome_2 = 0 then outcome_2 = 2;
  label outcome_2 = “OUTCOME #2: CSHCN will receive coordinated, ongoing, comprehensive care
  within a medical home”;
```

OUTCOME #3	**Families of CSHCN will have adequate private and public insurance to pay for the services they need**
Survey Items Used	UNINS, C8Q01_a, C8Q01_b, C8Q01_c
Numerator	CSHCN for whom Outcome #3 was achieved
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN who have adequate public and/or private insurance to pay for the services they need.

Notes for Data-Users

Criteria for Outcome #3 are:

- The child has public or private insurance at time of interview.
- The child has no gaps in coverage during the year prior to the interview.
- Insurance usually or always meets the child’s needs.
- Costs not covered by insurance are usually or always reasonable.
- Insurance usually or always permits child to see needed providers.

SAS Code and Annotation

Format

```
value outcome /*format used for all outcome variables*/
  1 = “Outcome successfully achieved”
  2 = “Outcome not achieved”;
value metneeds /*interim variable*/
  0 = “Never/sometimes”
  1 = “Usually/always”
  2 = “Uninsured”;
value reason /*interim variable*/
  0 = “Never/sometimes”
  1 = “Usually/always”
  2 = “Uninsured”;
value provide /*interim variable*/
  0 = “Never/sometimes”
  1 = “Usually/always”
  2 = “Uninsured”;
```

Code

```
/*STEP 1: Regroup responses to the three insurance adequacy items used to construct Outcome #3*/
metneeds = .;
  if c8q01_a = 1 or c8q01_a = 2 then metneeds = 0;
  if c8q01_a = 3 or c8q01_a = 4 then metneeds = 1;
  if unins = 1 then metneeds = 2;
  label metneeds = "Health insurance benefits meet child needs";
```

```
reason = .;
  if c8q01_b = 1 or c8q01_b = 2 then reason = 0;
  if c8q01_b = 3 or c8q01_b = 4 then reason = 1;
  if unins = 1 then reason = 2;
  label reason = "Non-covered insurance charges reasonable";
provide = .;
  if c8q01_c = 1 or c8q01_c = 2 then provide = 0;
  if c8q01_c = 3 or c8q01_c = 4 then provide = 1;
  if unins = 1 then provide = 2;
  label provide = "Insurance allows child to see needed providers";
/*STEP 2: Create Outcome #3*/
outcome_3 = .;
  if unins = 0 and unins_yr = 0 and metneeds = 1 and reason = 1 and provide = 1 then outcome_3 = 1;
  if unins = 1 or unins_yr = 1 or metneeds = 0 or reason = 0 or provide = 0 then outcome_3 = 0;
  if unins_yr in (.M,.) or metneeds = . or reason = . or provide = . then outcome_3 = .;
  if unins_yr in (6,7) then outcome_3 = .;
  if outcome_3 = 0 then outcome_3 = 2; /*RECODES 0,1 to 1,2*/
  label outcome_3 = "OUTCOME #3: Families of CSHCN will have adequate private and public
  insurance to pay for the services they need";
```

OUTCOME #5	**Community-based service systems will be organized so families can use them easily**
Survey Items Used	C6Q0d
Numerator	CSHCN for whom Outcome #5 was achieved
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN with community-based service systems that are organized so families can use them easily.

Notes for Data-Users

Criterion for Outcome #5 is:

- Services are usually or always organized for easy use.

Question C6Q0d was added to survey more than half way through the data collection cycle. As a result, there are 23,293 (60%) cases with missing data because the question was not asked.

SAS Code and Annotation

Format

```
value outcome /*format used for all outcome variables*/
  1 = “Outcome successfully achieved”
  2 = “Outcome not achieved”;
```

Code

```
outcome_5 = .;
  if c6q0d = 1 or c6q0d = 2 then outcome_5 = 0;
  if c6q0d = 3 or c6q0d = 4 then outcome_5 = 1;
  if c6q0d = 6 or c6q0d = 7 then outcome_5 = .;
  if c6q0d = . then outcome_5 = .;
  if outcome_5 = 0 then outcome_5 = 2; /*RECODES 0,1 to 1,2*/
  label outcome_5 = “OUTCOME #5: Community-based service systems will be organized so families
  can use them easily”;
```

OUTCOME #6	**Youth with special health care needs will receive services necessary to make a successful transition to adult life**
Survey Items Used	C6Q0a, C6Q0b
Numerator	CSHCN for whom Outcome #6 was achieved
Denominator	CSHCN ages 13–17 years
Description	Percent of youth with special health care needs who have received the services necessary to make transitions to adult life, including adult health care, work, and independence.

Notes for Data-Users

Criteria for Outcome # 6 are:

- The child receives guidance and support in the transition to adulthood, including: doctors have talked about changing needs, the child has a plan for addressing changing needs, and doctors discussed shift to adult provider.
- The child has received vocational or career training.

The questions used for the “transition to adulthood” outcome were added to survey more than halfway through the data collection cycle and these questions were asked only for CSHCN ages 13–17. As a result, there are only 5,351 cases (13.8% of total sample) with responses to these items.

SAS Code and Annotation

Format

```
value outcome /*format used for all outcome variables*/
  1 = “Outcome successfully achieved”
  2 = “Outcome not achieved”;

value adtrans /*interim variable*/
  0 = “No”
  1 = “Yes”;
```

Code

```
/*STEP 1: Recode response to the 4 items used for Outcome #6 and create interim variables used in
  construction of final outcome variable*/

needchg = c6q0ar;
  if c6q0ar in (6,7) then needchg = .;
  needplan = c6q0a_ar;
  if c6q0a_ar in (6,7) then needplan = .;
  adultdr = c6q0a_br;
  if c6q0a_br in (6,7) then adultdr = .;
  adtrain = c6q0br;
  if c6q0br in (6,7) then adtrain = .;
  step1 = 0;
  if needplan = 1 and adultdr = 1 then step1 = 1;
```

```
  if needplan = 0 or adultdr = 0 then step1 = 0;
  if needplan = . or adultdr = . then step1 = .;
  adtrans = .;
  if needchg = 0 and step1 = 0 then adtrans = 0;
  if needchg = 1 and step1 = 1 then adtrans = 1;
  if needchg = 1 and step1 = 0 then adtrans = 0;
  if needchg = . or step1= . then adtrans = .;
  label adtrans = “Dr discussed changing needs, helped plan, and talked about adult dr”;

/*STEP 2: Create Outcome #6*/
outcome_6 = .;
  if adtrans = 0 and adtrain = 0 then outcome_6 = 0;
  if adtrans = 1 and adtrain = 1 then outcome_6 = 1;
  if adtrans = 1 and adtrain = 0 then outcome_6 = 0;
  if adtrans = 0 and adtrain = 1 then outcome_6 = 0;
  if adtrans = . or adtrain = . then outcome_6 = .;
  if outcome_6 = 0 then outcome_6 = 2; /*RECODES 0,1 to 1,2*/
  label outcome_6 = “OUTCOME #6: Youth with special health care needs will receive services
  necessary to make a successful transition to adult life”;
```

Gender	How many males and females are in the CSHCN population?
Survey Items Used	C2Q03
Numerators	Male Female
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 who are male or female.

Notes for Data-Users

The variable for “child’s sex” is found in the publicly released 2001 NS_CSHCN Screener File. To add this variable to the 2001 NS_CSHCN Interview File, analysts will need to merge the variable SEX from the Screener File into the Interview File using the unique child identifier IDNUMXR as the linking variable.

SAS Code and Annotation

Format

```
value sex
  1 = “Male”
  2 = “Female”;
```

Code

```
if sex in (6,7) then sex = .;
  label sex = “How many males and females are in the CSHCN population?”;
```

Age Group (3)	**How many children of different ages are in the CSHCN population?**
Survey Items Used	Initial sampling questions
Numerators	• 0–5 years old • 6–11 years old • 12–17 years old
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN who are 0–5, 6–11, 12–17 years old.

Notes for Data-Users

The variable AGE is available in the publicly released 2001 NS-SHCN Interview File.

SAS Code and Annotation

Format

```
value agethree
  1 = “0–5 yrs old”
  2 = “6–11 yrs old”
  3 = “12–17 yrs old”;
```

Code

```
age_3 = .;
  if age ge 0 and age le 5 then age_3 = 1;
  if age ge 6 and age le 11 then age_3 = 2;
  if age ge 12 and age le 17 then age_3 = 3;
  label age_3 = “How many children of different ages are in the CSHCN population (Age - 3 groups)?”;
```

Race and Ethnicity	What is the race/ethnicity of the CSHCN population?
Survey Items Used	C11Q01_A – W9Q12a
Numerators	• Hispanic • White, non-Hispanic • Black, non-Hispanic • Multiracial, non-Hispanic • Other, non-Hispanic
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 who are Hispanic/Latino, or non-Hispanic and White, Black, Multiracial, or of another race.

Notes for Data-Users

Children/youth reporting Hispanic or Latino ethnicity (S11Q01 = Yes) are grouped as HISPANIC, regardless of race. Non-Hispanic children are grouped by race based on responses to S11Q02X01 – S11Q02X07. Non-Hispanic children reporting more than one race category are grouped as “MULTI-RACE.”

At the national level, non-Hispanic children reporting only one race category of Asian, American Indian, Alaska Native, Native Hawaiian, or Pacific Islander are combined into a single group called OTHER. This is done because only a handful of states meet the NCHS confidentiality standards for releasing data on these minority groups to the public. NCHS only includes individual-level data for these minority groups in the publicly available data files when a group comprises 5 percent or more of the total child population in a state. For more information see: **www.cdc.gov/nchs/data/slaits/NSCH_Methodology_Report.pdf**.

The variables used to construct “child race/ethnicity” are found in the publicly released 2001 NS_CSHCN Screener File. In order to construct a child race/ethnicity variable for the 2001 NS_CSHCN Interview File, analysts will first need to merge the variables HISPANIC and RACER from the Screener File into the Interview File using the unique child identifier IDNUMXR as the linking variable. Alternatively, the “child race/ethnicity” variable can be constructed in the Screener File and then merged into the Interview File, using IDNUMXR as the unique linking variable.

SAS Code and Annotation

Format

```
value race
  1 = “Hispanic”
  2 = “White, non-Hispanic”
  3 = “Black, non-Hispanic”
  4 = “Multiracial, non-Hispanic”
  5 = “Other, non-Hispanic”;
```

Code

```
race_5 = 0;
  if hispanic = 1 then race_5 = 1;
  if hispanic = 1 and racer = .M then race_5 = 1;
  if hispanic = 0 and racer = 1 then race_5 = 2;
  if hispanic = 0 and racer = 2 then race_5 = 3;
  if hispanic = 0 and racer = 3 then race_5 = 4;
  if hispanic = 0 and racer = 4 then race_5 = 5;
  if hispanic >= 6 and racer = 1 then race_5 = 2;
  if hispanic >= 6 and racer = 2 then race_5 = 3;
  if hispanic >= 6 and racer = 3 then race_5 = 4;
  if hispanic >= 6 and racer = 4 then race_5 = 5;
  if hispanic >= 6 and racer >= 96 then race_5 = 6;
  if hispanic = 0 and racer >= 96 then race_5 = 6;
  if racer = 1 and hispanic = .M then race_5 = 2;
  if racer = 2 and hispanic = .M then race_5 = 3;
  if racer = 3 and hispanic = .M then race_5 = 4;
  if racer = 4 and hispanic = .M then race_5 = 5;
  if hispanic = 0 and racer = .M then race_5 = 7;
  if racer >= 96 and hispanic = .M then race_5 = 7;
  if hispanic >= 6 and racer = .M then race_5 = 7;
  if hispanic = .M and racer = .M then race_5 = 7;
  if race_5 in (6,7) then race_5 = .;
  label race_5 = “What is the race/ethnicity of the CSHCN population?”;
```

Special Needs Type	**How many CSHCN qualified on specific types of special health needs criteria?**
Survey Items Used	FACCT1 – FACCT5_a
Numerators	• CSHCN qualifying on prescription medication criteria only • CSHCN qualifying on 1 or more of the service-use based criteria • CSHCN qualifying on prescription medication and meet one or more service-use criteria • CSHCN qualifying on functional limitations alone or with any other criteria
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN qualifying on prescription medication only, use of specialized services, both prescription medication and use of services, or functional limitations alone or with any other criteria.

Notes for Data-Users

These four mutually exclusive groupings of CSHCN by types of qualifying special needs are available under the data query subgroup option for comparing many of the child health and service system indicators, interview questions, and MCHB outcomes collected by the NS-CSHCN. For more information about the development, testing, and construction of the four mutually exclusive groupings of CSHCN based on the type and combination of their qualifying screening criteria, email CAHMI@ohsu.edu.

The variables used to construct this variable are found in the publicly released 2001 NS_CSHCN Screener File. In order to construct a "Special Needs Type" variable in the 2001 NS_CSHCN Interview File, analysts will first need to merge the following variables from the Screener File into the Interview File using the unique child identifier IDNUMXR as the linking variable:

FACCT1	FACCT1_a	FACCT1_b	FACCT2	FACCT2_a
FACCT2_b	FACCT3	FACCT3_a	FACCT3_b	FACCT4
FACCT4_a	FACCT4_b	FACCT5	FACCT5_a	

Alternatively, the "Special Needs Type" variable can be constructed in the Screener File and then merged into the Interview File, using IDNUMXR as the unique linking variable.

SAS Code and Annotation

Format

```
value ny /*used for screener items: rxmeds, serve, func, therapy, mhealth*/
  0 = "No"
  1 = "Yes";
```

Code

```
/**STEP 1: Create interim variables that identify children with qualifying responses on each of the five
different CSHCN Screener criteria. These five variables are also valuable analytic tools for further
studying the group of children identified by the CSHCN Screener**/
```

```
rxmeds = 0;
  if ((facct1 = 1) and (facct1_a = 1) and (facct1_b = 1)) then rxmeds = rxmeds + 1;
  label rxmeds = “Qualified on rx med use?”;
serve = 0;
  if ((facct2 = 1) and (facct2_a = 1) and (facct2_b = 1)) then serve = serve + 1;
  label serve = “Qualified on service use?”;
func = 0;
  if ((facct3 = 1) and (facct3_a = 1) and (facct3_b = 1)) then func = func + 1;
  label func = “Qualified on functional limits ?”;
therapy = 0;
  if ((facct4 = 1) and (facct4_a = 1) and (facct4_b = 1)) then therapy = therapy + 1;
  label therapy = “Qualified on use of special therapies?”;
mhealth = 0;
  if((facct5 = 1) and (facct5_a = 1)) then mhealth = mhealth + 1;
  label mhealth = “Qualified on use of mental health services?”;

/**STEP 2: Create mutually exclusive qualitative subgrouping of special health care need types – based
on type of qualifying screening criteria**/
def_4 = 0;
  if (func = 0) and ((rxmeds = 1)) and ((serve = 0) or (therapy = 0) or (mhealth = 0)) then def_4 = 1;
  if (func = 0) and ((rxmeds = 0)) and ((serve = 1) or (therapy = 1) or (mhealth = 1)) then def_4 = 2;
  if (func = 0) and ((rxmeds = 1)) and ((serve = 1) or (therapy = 1) or (mhealth = 1)) then def_4 = 3;
  if ((func = 1)) and ((serve = 1) or (therapy = 1) or (rxmeds = 1) or (mhealth = 1)) then def_4 = 4;
  if ((func = 1)) and ((serve = 0) or (therapy = 0) or (rxmeds = 0) or (mhealth = 0)) then def_4 = 4;
  if def_4 = 0 then def_4 = .;
  label def_4 = “CSHCN grouped according to type of qualifying criteria”;
```

Severity of Health Conditions	**How do parents rank the severity of their children’s health conditions?**
Survey Items Used	C3Q10
Numerators	CSHCN whose health conditions are ranked by parents on a scale of 0 (mildest) to 10 (most severe) as: • 0 - 2 • 3 - 6 • 7 - 8 • 9 - 10
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN who have mild, moderate, severe or most severe health conditions.

Notes for Data-Users

Parent rankings on a scale of 0–10 are grouped as follows: 0–2 = Mild; 3–6 = Moderate; 7–8 = Severe; 9–10 = Most severe. The variable C3Q10 is available in the publicly released 2001 NS_CSHCN Interview File.

SAS Code and Annotation

Format

```
value sevlev
  1 = “Mild (0–2)”
  2 = “Moderate (3–6)”
  3 = “Severe (7–8)”
  4 = “Most severe (9–10)”;
```

Code

```
sevlev_4 = .;
  if c3q10 in (0,1,2) then sevlev_4 = 1;
  if c3q10 in (3,4,5,6) then sevlev_4 = 2;
  if c3q10 in (7,8) then sevlev_4 = 3;
  if c3q10 in (9,10) then sevlev_4 = 4;
  if c3q10 in (96,97) then sevlev_4 = .;
  label sevlev_4 = “Parent-rated severity of CSHCN health problems”;
```

Household Income	**How many CSHCN live in households with incomes above/below the Federal poverty level (FPL)?**
Survey Items Used	C11Q01_A – W9Q12a
Numerators	• Household income less than 100 percent FPL • Household income 100–199 percent FPL • Household income 200–399 percent FPL • Household income 400 percent FPL or more
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 living in households with incomes 0–99 percent FPL, 100–199 percent FPL, 200–399 percent FPL, or 400 percent or more FPL.

Notes for Data-Users

Income level of household expressed as percent of FPL derived from total household income during prior year and number of people living in the household. Federal Poverty Guidelines released in 2002 and 2003 by the U.S. Department of Health and Human Services were used for the determination of household poverty status. The percent of unknown values for this variable is unusually high (10%). For more information see: **http://www.cdc.gov/nchs/data/slaits/NSCH_Methodology_Report.pdf**.

The variable used to construct “Household Income” is found in the publicly released 2001 NS_CSHCN Household File, which has household-level records only. In order to have a “Household Income” variable for the 2001 NS_CSHCN Interview File, analysts will first need to create a child-level household income variable by merging the variable POVLEVEL from the Household File into the Screener File using a many-to-one merge in order to assign each individual child record the household income status for his/her household. This new child-level household income variable is recoded into four categories and then merged into the Interview File using IDNUMXR as the unique linking variable. National level unweighted frequency tables for the income variables in the Household and Screener files are in Appendix B of this codebook.

SAS Code and Annotation

Format

```
value povlev
  1 = “HH income 0–99% FPL”
  2 = “HH income 100–199% FPL”
  3 = “HH income 200–399% FPL”
  4 = “HH income 400% FPL or more”;
```

Code

```
povlev_4 = .;
  if povlevel2 in (1,2) then povlev_4 = 1;
  if povlevel2 ge 3 and poverty_levelr le 6 then povlev_4 = 2;
  if povlevel2 ge 7 and poverty_levelr le 8 then povlev_4 = 3;
  if povlevel2 eq 9 then povlev_4 = 4;
```

```
if povlevel2 in (96,97) then povlev_4 = .;
label povlev_4 = “How many CSHCN live in households with incomes above/below Federal Poverty
Level (FPL)?”;
```

Insurance Type	**How many CSHCN have private or public insurance coverage?**
Survey Items Used	Derived from questions asked in Section 7
Numerators	• Private or employer-based insurance only • Medicaid, SCHIP, Title V, or other public insurance only • Combination of public & private insurance • Uninsured at time of the survey
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 whose health insurance coverage status at the time of the survey was private, public, combined private and public, or uninsured.

Notes for Data-Users

Private health insurance is defined as any type of health insurance (including HMO) other than public programs. Public health insurance is defined as Medicaid or the State Children’s Health Insurance Program (SCHIP).

This variable is derived from variables included in the publicly released 2001 NS_CSHCN Interview File. The code below replicates exactly the categories, prevalences and SEs reported in the National Chartbook and NCHS report #136: Estimated Prevalence of Uninsured Children in the NS-CSHCN, http://0-www.cdc.gov.mill1.sjlibrary.org/nchs/data/series/sr_02/sr02_136.pdf.

SAS Code and Annotation

Format

```
value pub_any
  0 = “No public ins”
  1 = “Any public insurance”
  2 = “Uninsured at time of survey”;
value priv_any
  0 = “No priv ins”
  1 = “Any private insurance”
  2 = “Uninsured at time of survey”;
value ins_type
  1 = “Private or employer-based ins only”
  2 = “Medicaid, SCHIP, Title V or other public ins only”
  3 = “Combination of public & private ins”
  4 = “Other comprehensive ins”
  5 = “Uninsured at time of the survey”;
```

Code

```
pub_any = 0;
  if medicaid = 1 or schip = 1 or titlev = 1 or otherpub = 1 then pub_any = 1;
```

```
  if unins = 1 then pub_any = 2;
  label pub_any = “Any public insurance”;

priv_any = 0;
  if private = 1 or military = 1 then priv_any = 1;
  if unins = 1 then priv_any = 2;
  label priv_any = “Any public insurance”;

ins_type = 99;
  if pub_any = 0 and priv_any = 1 then ins_type = 1;
  if pub_any = 1 and priv_any = 0 then ins_type = 2;
  if pub_any = 1 and priv_any = 1 then ins_type = 3;
  if pub_any = 0 and priv_any = 0 then ins_type = 4;
  if pub_any = 2 and priv_any = 2 then ins_type = 5;
  if ins_type = 4 then ins_type = .;
  label ins_type = “How many CSHCN have private or public insurance coverage?”;
```

Insurance Status	**Does (child's name) have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?**
Survey Items Used	UNINS
Numerators	• CSHCN insured at time of survey • CSHCN uninsured at time of survey
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN ages 0–17 with any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid at the time of the survey.

Notes for Data-Users

Refer to Indicator #4 on page 10.

SAS Code and Annotation

Format

value yn
  1 = "Yes"
  2 = "No";

Code

Refer to Indicator #4 on page 10.

Medical Home (Outcome #2)	**CSHCN will receive coordinated, ongoing, comprehensive care within a medical home**
Survey Items Used	C4Q6X0aa, C4Q0a, C4Q0b, C4Q01, C4Q02, C4Q02a, C4Q05, C4Q06_0a, C4Q07, C5Q02, C5Q05, C5Q06, C6Q01r, fcc_a, fcc_b, fcc_c, fcc_d, fcc_e
Numerator	• CSHCN whose medical care meets medical home criteria • CSHCN whose do not have medical care that meets medical home criteria
Denominator	CSHCN ages 0–17 years
Description	Percent of CSHCN who received coordinated ongoing comprehensive care within a medical home as defined by the American Academy of Pediatrics (AAP).
Notes for Data-Users	
Refer to Outcome #2 on page 29.	
SAS Code and Annotation	
Refer to Outcome #2 on page 29.	

Appendix A: Unweighted Frequency Tables

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

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

                              Frequency Missing = 216
```

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

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

                          Frequency Missing = 6043
```

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

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

                                  Frequency Missing = 85
```

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

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

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

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

                              Frequency Missing = 2257
```

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

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


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

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

                                   Frequency Missing = 30687


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

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

                             Frequency Missing = 18824


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

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

                                   Frequency Missing = 195


INDICATOR #10: Percent of CSHCN without a PDN

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

                                Frequency Missing = 155
```

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

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

                                Frequency Missing = 2848
```

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

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

                      Frequency Missing = 708
```

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

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

                                    Frequency Missing = 296
```

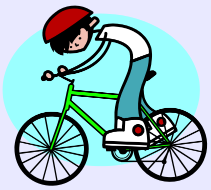
```
INDICATOR #14: Percent of CSHCN whose families spend 11 or more hours per week providing and/or
coordinating health care for child

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

                           Frequency Missing = 1437
```

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

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

                                    Frequency Missing = 118


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

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

                            Frequency Missing = 23612


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

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

                             Frequency Missing = 2156


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

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

                             Frequency Missing = 1478


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

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

                            Frequency Missing = 23556
```

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

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

                            Frequency Missing = 33515


How many males and females are in the CSHCN population?

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

                    Frequency Missing = 26


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

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

                        Frequency Missing = 27


What is the race/ethnicity of the CSHCN population?

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

                                    Frequency Missing = 136
```

```
CSHCN grouped according to type of qualifying criteria

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


Parent-rated severity of CSHCN health problems

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

                        Frequency Missing = 211


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

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

                            Frequency Missing = 3637


How many CSHCN have private or public insurance coverage?

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

                                   Frequency Missing = 146
```

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



coorrcv Received NEEDED professional care coordination

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

r_c5q05

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

doccomm Level of communication btw child's doctors

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

r_c5q06 Recoded level of dr communication with other services

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

othcom_1

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

othcom_2

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

othcomm Level of dr communication with other services

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

carecoor Effective care coordination received when needed

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

sick Ch. has usual place for sick care

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

well Ch. has usual place for well care

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

usual Usual source of care component of Outcome #2

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

r_c4q07 Problems getting referral to specialist

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

norefprb Getting needed referrals component of Outcome #2

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

fcc_a How often drs spent enough time

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

fcc_b How often drs listened carefully

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

fcc_c How often drs sensitive to families values/customs

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

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

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

fcc_e How drs helped parents feel like partners

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

fcc_all % of CSHCN without family-centered care

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

famcent Family centered care component of Outcome #2

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

pdn % of CYSHCN without a personal doctor or nurse

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

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

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

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

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

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

                        Frequency Missing = 29463
```

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

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

                        Frequency Missing = 54113
```

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

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

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

                           Frequency Missing = 3637
```