2011 Survey of Pathways to Diagnosis and Services (Pathways)

SPSS CODE FOR DATA USERS:

OUTCOME MEASURES AND SUBGROUPS

Version 1.0: July 2015

Recommended Citation

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

Child and Adolescent Health Measurement Initiative (CAHMI), "2011 Pathways Outcome Measures SPSS Codebook, Version 1," 2015, Data Resource Center for Child and Adolescent Health, **www.childhealthdata.org**.

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Purpose of the 2011 Pathways SPSS Codebook

This codebook contains documentation and SPSS program statements for the 2011 Survey of Pathways to Diagnosis and Services (Pathways) to understand how the DRC created key outcome measures and variables. The variables included are those used to stratify these items for children and youth with special health care needs (CSHCN) who ever had autism spectrum disorder (ASD), intellectual disability, and/or developmental delay. The codebook is designed to serve as a resource for researchers and analysts who are interested in understanding the construction of outcome variables developed from the 2011 Pathways survey for the interactive data query feature of the National Data Resource Center for Child and Adolescent Health (DRC) located online at **www.childhealthdata.org**. Its purpose is to expedite research by helping to standardize and improve the comparability of information derived from the 2011 Pathways survey.

The DRC maintains a complete 2011 Pathways variable data set, available in either SAS or SPSS format. The data set includes over 100 key child health outcome measures, as well as demographic and individual question items. To request a copy, contact the Child and Adolescent Health Measurement Initiative (CAHMI) at: **info@cahmi.org**.

The CAHMI Data Resource Center for Child and Adolescent Health

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

The main feature of the DRC is an interactive data search tool that includes over 200 standardized indicators from six national- and state-based surveys on the health and health care of children and youth: the 2001, 2005-2006 and 2009-2010 *National Survey of Children with Special Health Care Needs* (NS-CSHCN), and the *2003, 2007, and 2011-2012 National Survey of Children's Health* (NSCH). The data query also includes child indicators from the National Health Interview Survey and its Complementary and Alternative Medicine Supplements and the Survey of Pathways to Diagnosis and Services. Data search results can be stratified by age, race/ethnicity, income and other pertinent characteristics of children and youth nationally or for individual states or regions. Links to the survey instruments, sampling diagrams, methods reports and other survey specific resources are included on the DRC Web site.

Overview of the 2011 Pathways Survey

The 2011 Pathways survey is a follow-up survey of CSHCN who ever had autism spectrum disorder, intellectual disability and/or developmental delay from the 2009/10 NS-CSHCN. The NS-CSHCN was a nationwide telephone survey sponsored by the U.S. Department of Health and Human Services, Health Resources Services Administration, Maternal and Child Health Bureau (MCHB), and conducted by the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention, using State and Local Area Integrated Telephone Survey (SLAITS) technology for sampling and administration. Children were screened for having a special health care need using the CSHCN Screener (1) a survey tool developed and validated specifically to identify children who meet the federal MCHB health-consequences-based special health care needs definition. The Screener asks parents about the use of prescriptive mediations, treatments or services, and special therapies; and the presence of emotional, developmental or behavioral conditions that require treatment, and/or functional limitations.

The Pathways survey was sponsored by the National Institute of Mental Health with funds available from the American Recovery and Reinvestment Act of 2009 (ARRA) (Public Law 111-5), and was also conducted by NCHS using the SLAITS sampling and administrative mechanism. The 2011 Pathways survey includes a telephone interview component and self-administered mail questionnaire (SAQ). The telephone sample was achieved by re-contacting the same respondents for children who were 6-16 years old reported to ever have ASD, intellectual disability or developmental delay from the 2009/10 NS-CSHCN. Respondents of re-contacted children were asked to confirm the child's diagnosis. The telephone interview was administered to CSHCN who met the following eligibility criteria:

- The same respondent who completed the 2009/10 NS-CSHCN was re-contacted and able to complete the Pathways interview.
- The Pathways-eligible child with special health care needs was 6 to 17 years old at the time of the Pathways interview.
- The Pathways-eligible child still lived in the same household as the respondent.
- The respondent confirmed that the Pathways-eligible child with special health care needs ever had ASD, intellectual disability, and developmental delay.

Of the 6,090 CSHCN sampled for the Pathways survey, 4,032 completed in-depth telephone interviews. The SAQ was mailed to those who completed the telephone interview and agreed to have the SAQ mailed to them, and 2,988 completed SAQs were returned. The survey data are weighted to reflect the population of non-institutionalized CSHCN ages 6–17 years who ever had ASD, intellectual disability, and/or developmental delay in the United States. **As such, every indicator from the 2011 Pathways survey should be understood to represent a child with special health care needs who was ever told that they had ASD, DD or ID.**

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.*

The 2011 Pathways survey provides detailed national- and regional-level parent-reported information. Topics covered by the telephone interview in the Pathways survey include: parental first concerns about the child's development, the diagnostic experience, health and educational services, unmet needs and inadequate insurance, parental views of services and the child's condition, and wandering concerns. The Pathways survey also includes two validated instruments in the SAQ: the Strength and Difficulties Questionnaire (Goodman, 1997), and the Children's Social Behavioral Questionnaire (Hartman et al, 2006). A modified, five-question Strength and Difficulties Questionnaire is included in the Pathways telephone interview. Additional Fast Facts about the survey can be found on the DRC website at **www.childhealthdata.org**.

Data from the 2011 Pathways survey are publicly released in two files in SAS format: (1) Interview file, and (2) an additional file containing imputed data. The public data sets and relevant background information and documentation are available online at: **http://www.cdc.gov/nchs/slaits/imputed_data.htm.** Additional information and results from the 2011 Pathways survey are available on the DRC website at: **www.childhealthdata.org.**

As a follow-up survey of the 2009/10 NS-CSHCN, the 2011 Pathways survey does include both a landline telephone and cell phone sample. The 2009/10 NS-CSHCN sample of landline telephone numbers was supplemented with an independent random-digit-dial sample of cell phone numbers of household respondents that indicated they did not have a landline or were unlikely to be reached through their landline. The variable SAMPLE contains information on whether a survey respondent was interviewed via a cell phone or a landline. Stratification by the SAMPLE variable is not recommended as the variable SAMPLE does **not** imply that a cell phone sample respondent does not have a landline. The SAMPLE variable is an important component of the survey design and must be used in statistical software packages to account for the complex design of the survey.

Linking the Pathways and NS-CSHCN Data Files

Both the interview and imputed public use data files for the 2011 Pathways survey are used in this codebook. Both files include 4,032 CSHCN ages 6-17 years old who ever had ASD, ID, and/or DD and were randomly selected for the 2009/10 NS-CSHCN.

The variables in this codebook are all based on the 2011 Pathways Interview file. The DRC provides an enhanced Pathways dataset that has been merged with the NS-CSHCN interview file and a single imputation file. The National Center for Health Statistics imputes data when there are approximately 10% missing cases. The imputed variables used in the merged dataset will have zero missing cases. The unique identifier used to link these files is IDNUMXR. The Pathways dataset provided by the DRC, which also includes the core outcome and indicator variables from the NS-CSHCN, can be requested at no charge in SAS/SPSS/STATA/CVS format through the DRC. When using the DRC linked Pathways dataset, do note that estimates and confidence intervals based on single imputation may differ slightly from those obtained using multiple imputation methods. Please see **Appendix C** in this document for details on imputed values. To access all imputation files, please visit the [NCHS website](#).

Important Information about the 2011 Pathways Survey

Weighting

The sampling weights provided in the publicly released data files are used to produce estimates representative of CSHCN 6-17 years old who ever had ASD, DD, and/or ID at the Census region and national levels. The data are weighted to be representative at the state level; however, sample size at the state level is very small. State level estimates are not reliable or precise and state information may pose a disclosure risk for Pathways participants. Therefore the variable STATE is not included in the public use files. These sampling weights adjust the survey responses to reflect the underlying non-institutionalized child with special health care needs population using the U.S. Census counts of children, stratified by sex, age, and race/ethnicity as the reference population. Initial weights are calculated to reflect telephone access and other non-response biases. The weighting variable WEIGHT_CATI, included in the Interview file, adjusts the survey responses to reflect the population of CSHCN age 6-17 years old who ever had ASD, DD, and/or ID. This weight variable should be applied to all analytic work using the Pathways survey.

Variance Estimation

Use of statistical software with the capacity to take into account the complex sampling design of the survey is necessary to appropriately calculate the variances, associated standard errors and confidence intervals required for accurate statistical hypothesis testing. Computer programs capable of variance estimation for complex sample designs include SUDAAN, SAS V 9.0+, STATA, WesVar, and SPSS Complex Samples. The stratum variable, PSTRAT, was created to account for the complex survey design to properly calculate variance estimates. **A 1-stage**

sampling plan should be set up using PSTRAT and SAMPLE variables as strata, IDNUMR as the cluster and WEIGHT_CATI as the weight.

Keeping only selected records or deleting records from your dataset is called subsetting the data. Subsetting to a specific population subgroup (diagnostic group, age group, race/ethnicity, or poverty level, for example), within or across regions, 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 sub-state geographic information included in the 2011 Pathways public use dataset is a variable for Metropolitan Statistical Area (MSA) status, located in the Household file. MSA status information was only available for 16 states in which the population is at least 500,000 in both categories (MSA and non-MSA), similar to what was done for the 2009/10 NS-CSHCN. State and Zip code data are collected with the Pathways survey but are not released in the public use data files due to confidentiality restrictions. The confidential state and zip code data can be made available to researchers for on-site analysis at the Research Data Center of the National Center for Health Statistics (NCHS) in Hyattsville, MD. The process requires submitting a proposal to the NCHS. For more information, see: **http://www.cdc.gov/nchs/r&d/rdc.htm**.

Interpretation of Results

The respondents to the CSHCN in depth Pathways interview are parents/guardians; however, the results are weighted to reflect the population of CSHCN ages 6–17 who ever had ASD, intellectual disability, and/or developmental delay, 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, "Among CSHCN whose parent was first concerned that…", rather than: "Among parents who were first concerned that…".

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 interviewed for the Pathways survey, 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 condition groups, such as CSHCN with ASD.

Comparing Across Surveys

This is the first generation of the Survey of Pathways to Diagnosis and Services, therefore one cannot compare between Pathways surveys. However, some questions in the Pathways survey may be similar to questions included in other survey, and there is a natural desire to want to compare these results. This should be done with extreme caution. The main reasons why Pathways measures should not be compared with other surveys is the difference in sampling

design. Furthermore, the items may have changed or use different denominator groups so that the questions are tailored for the purposes of the Pathways survey. All of these are taken into consideration by the DRC and summarized in a document on our website and will be available soon.

Verification

Unweighted frequency distributions for the variables in this codebook are located in **Appendix A**, as a resource for cross checking results for CSHCN ages 6-17 years who EVER had ASD, DD and/or ID (the entire Pathways sample). Results are not directly comparable with results from the interactive data query in the DRC. The denominator of the estimates in the DRC data query are CSHCN ages 6-17 years who CURRENTLY have ASD, DD and/or ID. To replicate the estimates displayed in the data query, stratify the data with the 'Dx_curr_11' variable provided in the dataset. To generate estimates for children with ASD, stratify the data with the 'Dx_aut_11' variable in the dataset.

Additional Information on Survey Design and Methodology

The NCHS is currently developing a final *Design and Operation of the Survey of Pathways to Diagnosis and Services, 2011.* In the meantime, they have produced a Frequently Asked Questions guide to provide practical assistance with understanding how the Pathways survey was conducted. View or download these frequently asked questions from the NCHS Web site at: **http://www.cdc.gov/nchs/data/slaits/PathwaysFAQ.pdf**.

Developmental Concerns

Pathways Sample	Children with ASD, Intellectual Disability, or Developmental Delay (exclusively)
Description	CSHCN who currently have ASD, intellectual disability, or developmental delay (exclusively)
Survey Items Used	DE_AUT11; DE_DEV11; DE_INT11
Denominator	CSHCN age 6-17 years who ever have ASD, intellectual disability, and/or developmental delay
Numerator	CSHCN who currently have ASD, Intellectual Disability, or Developmental Delay (exclusively)

Notes for Data-Users
The denominator of the estimates in the DRC data query are CSHCN ages 6-17 years who CURRENTLY have ASD, DD and/or ID. To replicate the estimates displayed in the data query, stratify the data with the 'Dx_curr_11' variable provided in the dataset. To generate estimates for children with ASD, stratify the data with the 'Dx_ASD_11' variable in the dataset.

SPSS Code and Annotation

```
RECODE DE_AUT11
(0=2) (1=1) (SYSMIS=2) (6=99) into dx_aut_11.
VARIABLE LABELS dx_aut_11 "CSHCN who currently have Autism/ASD".
VALUE LABELS dx_aut_11
1 "CSHCN currently has autism/AS"
2 "CSHCN does not currently have autism/ASD"
99 "DK".
FORMATS dx_aut_11(f2.0).
*MISSING VALUES dx_aut_11(90,99).

RECODE  DE_DEV11
(0=2) (1=1) (SYSMIS=2) (6=99) into dx_dev_11.
VARIABLE LABELS dx_dev_11 "CSHCN who currently have developmental delay".
VALUE LABELS dx_dev_11
1 "CSHCN currently has DD"
2 "CSHCN does not currently have DD"
99 "DK".
FORMATS dx_dev_11(f2.0).
*MISSING VALUES dx_dev_11(90,99).

RECODE DE_INT11
(0=2) (1=1) (SYSMIS=2) (6=99) into dx_int_11.
VARIABLE LABELS dx_int_11 "CSHCN who currently have intellectual disability".
VALUE LABELS dx_int_11
1 "CSHCN currently has ID"
2 "CSHCN does not currently have ID"
99 "DK".
FORMATS dx_int_11(f2.0).
*MISSING VALUES dx_int_11(90,99).

COMPUTE Dx_curr_11=999.
IF (DE_AUT11=0 or (SYSMIS(DE_AUT11))) or (DE_DEV11=0 or (SYSMIS(DE_DEV11))) or
(DE_INT11=6 or (SYSMIS(DE_INT11))) Dx_curr_11=2.
IF DE_AUT11=1 or DE_DEV11=1 or DE_INT11=1  Dx_curr_11=1.
```

Developmental Concerns

```
IF DE_AUT11=6 and DE_DEV11=6 and DE_INT11=6 Dx_curr_11=99.
VARIABLE LABELS Dx_curr_11 "CSHCN currently have ASD, ID and or DD".
VALUE LABELS Dx_curr_11
1 "CSHCN currently has ASD, ID and/or ID"
2 "CSHCN does not currently have any of the 3 conditions"
99 "DK to all".
FORMATS Dx_curr_11(f2.0).
MISSING VALUES Dx_curr_11(99).
EXECUTE.
```

Developmental Concerns

Age of child when parent first concerned	
Description	How old was child when you first noticed something was not quite right with child's development?
Survey Items Used	PC1; PC1A
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability whose parent(s) ever had a developmental concern or condition was present at birth
Numerator	Age at which parents were first concerned that something was different with child: At or before birth; 1-23 months; 24-47 months; 4 or more years

Notes for Data-Users

Not included in the denominator are CSHCN whose parents reported that the developmental concern was present before the child or parent entered the family, or the parent was never concerned.

SPSS Syntax and Annotation

```
COMPUTE pc_age_all_11 = 999.
IF (PC1_A = 2) pc_age_all_11 = PC1.
IF (PC1_A = 1) pc_age_all_11 = PC1/12.
IF (PC1 = 94) pc_age_all_11 = 0.
IF (PC1 = 93 or PC1 = 95) pc_age_all_11 = 90.
IF (PC1 = 96 or PC1 = 96) pc_age_all_11 = 99.
VALUE LABELS  pc_age_all_11
90 "Skip"
99 "Missing".
EXECUTE.

COMPUTE pc_age_11 = pc_age_all_11.
IF (pc_age_all_11 >= 0 and Pc_age_all_11 < .08) pc_age_11 = 1.
IF (pc_age_all_11 >= .08 and PC_AGE_all_11< 2) pc_age_11 = 2.
IF (pc_age_all_11 >= 2 and Pc_age_all_11 <4) pc_age_11 = 3.
IF (pc_age_all_11 >= 4 and Pc_age_all_11 < 18) pc_age_11 = 4.
VARIABLE LABELS pc_age_11 "Age when parents were first concerned about their child's development ".
VALUE LABELS  pc_age_11
1 "Condition/concern at or before birth"
2 "1 - 23 months"
3 "24 - 47 months"
4 "48+ months"
90 "Skip"
99 "Missing".
EXECUTE.
```

Developmental Concerns

Number of developmental concerns out of 7 types	
Description	How many parents had one or more concerns about their child's development, out of 7 types of developmental domains?
Survey Items Used	PC_VRBL_11; PC_BEH_11; PC_MOTOR_11; PC_NONVR_11; PC_LEARN_11; PC_GEST_11; PC_MED_11
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	CSHCN whose parents had 0-1 concerns; 2-3 concerns; 4 or more concerns in any of the developmental domains.

Notes for Data-Users

N/A

SPSS Syntax and Annotation

***Parent concerned that child had problems talking later, not talking at all, or losing speech skills

```
COMPUTE pc_vrbl_11 = 999.
RECODE PC2_G (0=2).
COMPUTE PC2_GR = PC2_G.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 < .75) PC2_GR = 90.
IF (PC2_G = 6 or PC2_G = 7) PC2_GR = 99.
RECODE PC2_H (0=2).
COMPUTE PC2_HR = PC2_H.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 <= .75) PC2_HR = 90.
IF (PC2_H = 6 or PC2_H = 7) PC2_HR = 99.
RECODE PC2_I (0=2).
COMPUTE PC2_IR = PC2_I.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 <= .75) PC2_IR = 90.
IF (PC2_I= 6 or PC2_I = 7) PC2_IR = 99.
RECODE PC2_J (0=2).
COMPUTE PC2_JR = PC2_J.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 <= .75) PC2_JR = 90.
IF (PC2_J = 6 or PC2_J = 7) PC2_JR = 99.
FORMATS PC2_GR PC2_HR  PC2_IR PC2_JR (f4.0).
EXECUTE.


IF (PC2_GR = 1) or (PC2_HR = 1) or (PC2_IR = 1) or (PC2_JR = 1) pc_vrbl_11 = 1.
```

IF (PC2_GR = 2) and (PC2_HR = 2 or PC2_HR = 90) and (PC2_IR = 2 or PC2_IR = 90) and (PC2_JR = 2 or PC2_JR = 90) pc_vrbl_11 = 2.

IF (PC2_GR = 90) pc_vrbl_11 = 90.

IF (PC2_GR = 99) and (PC2_HR = 99 or PC2_IR = 99 or PC2_JR = 99) pc_vrbl_11 = 99.

VARIABLE LABELS pc_vrbl_11 "Parent was concerned that child had problems talking later, not talking at all, or loosing speech skills".

VALUE LABELS pc_vrbl_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

***Parent concerned that child had difficulties playing with others, difficulties with change, or any other behavior difficulties (sleeping/eating, hyper, wandering, tantrums, aggressive/destructive)

COMPUTE pc_beh_11 = 999.

RECODE PC2_E (0=2).

COMPUTE PC2_ER = PC2_E.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 = 0) PC2_ER = 90.

IF (PC2_E = 6 or PC2_E = 7) PC2_ER = 99.

RECODE PC2_M (0=2).

COMPUTE PC2_MR = PC2_M.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 <= 1) PC2_MR = 90.

IF (PC2_M = 6 or PC2_M = 7) PC2_MR = 99.

RECODE PC2_N (0=2).

COMPUTE PC2_NR = PC2_N.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 <= 1) PC2_NR = 90.

IF (PC2_N = 6 or PC2_N = 7) PC2_NR = 99.

FORMATS PC2_ER PC2_MR PC2_NR (f4.0).

EXECUTE.

IF (PC2_ER = 99 or PC2_MR = 99 or PC2_NR = 99) pc_beh_11 = 99.

IF (PC2_ER = 1) or (PC2_MR = 1) or (PC2_NR = 1) pc_beh_11 = 1.

IF (PC2_ER = 2) and (PC2_MR = 2 or PC2_MR = 90) and (PC2_NR = 2 or PC2_NR = 90) pc_beh_11 = 2.

IF (PC2_ER = 90) pc_beh_11 = 90.

VARIABLE LABELS pc_beh_11 "Parent was concerned that child had difficulties playing with others, difficulties with change, or any other behavior difficulties (sleeping/eating, hyper, wandering, tantrums, aggressive/destructive)".

VALUE LABELS pc_beh_11

1 "Yes"

2 "No"

99 "Missing"
90 "Skip".
EXECUTE.

***Parent concerned that child had problems with coordination/gross motor skills, or fine motor skills

COMPUTE pc_motor_11 = 999.
RECODE PC2_F (0=2).
COMPUTE PC2_FR = PC2_F.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 = 0) PC2_FR = 90.
IF (PC2_F = 6 or PC2_F = 7) PC2_FR = 99.
RECODE PC2_L (0=2).
COMPUTE PC2_LR = PC2_L.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 <= 1) PC2_LR = 90.
IF (PC2_L = 6 or PC2_L = 7) PC2_LR = 99.
FORMATS PC2_FR PC2_LR (f4.0).
EXECUTE.

IF (PC2_LR = 99) or (PC2_FR =99) pc_motor_11 = 99.
IF (PC2_FR = 1) or (PC2_LR = 1) pc_motor_11 = 1.
IF (PC2_FR = 2) and (PC2_LR = 2 or PC2_LR = 90) pc_motor_11 = 2.
IF (PC2_FR = 90) pc_motor_11 = 90.
VARIABLE LABELS pc_motor_11 "Parent was concerned that child had problems with coordination/gross motor skills, or fine motor skills".
VALUE LABELS pc_motor_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".
EXECUTE.

***Parent concerned that child had problems making eye contact, responding when called/to sounds, or with other forms of non-verbal communication (tone of voice, facial expressions, body language)

COMPUTE pc_nonvr_11 = 999.
RECODE PC2_B (0=2).
COMPUTE PC2_BR = PC2_B.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 = 0) PC2_BR = 90.
IF (PC2_B = 6 or PC2_B = 7) PC2_BR = 99.
RECODE PC2_C (0=2).
COMPUTE PC2_CR = PC2_C.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 = 0) PC2_CR = 90.

IF (PC2_C = 6 or PC2_C = 7) PC2_CR = 99.

RECODE PC2_D (0=2).

COMPUTE PC2_DR = PC2_D.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 = 0) PC2_DR = 90.

IF (PC2_D = 6 or PC2_D = 7) PC2_DR = 99.

FORMATS PC2_BR PC2_CR PC2_DR (f4.0).

EXECUTE.

IF (PC2_BR = 99) or (PC2_CR = 99) or (PC2_DR = 99) pc_nonvr_11 = 99.

IF (PC2_BR = 1) or (PC2_CR = 1) or (PC2_DR = 1) pc_nonvr_11 = 1.

IF (PC2_BR = 2) and (PC2_CR = 2) and (PC2_DR = 2) pc_nonvr_11 = 2.

IF (PC2_BR = 90) and (PC2_CR = 90) and (PC2_DR = 90) pc_nonvr_11 = 90.

VARIABLE LABELS pc_nonvr_11 "Parent was concerned that child had problems making eye contact, responding when called/to sounds, or with other forms of non-verbal communication (tone of voice, facial expressions, body language)".

VALUE LABELS pc_nonvr_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

***Parent concerned that child had problems understanding what others say or difficulty learning new things or skills

COMPUTE pc_learn_11 = 999.

RECODE PC2_K (0=2).

COMPUTE PC2_KR = PC2_K.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 <= .75) PC2_KR = 90.

IF (PC2_K = 6 or PC2_K = 7) PC2_KR = 99.

RECODE PC2_O (0=2).

COMPUTE PC2_OR = PC2_O.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 <= 1) PC2_OR = 90.

IF (PC2_O = 6 or PC2_O = 7) PC2_OR = 99.

RECODE PC2_P (0=2).

COMPUTE PC2_PR = PC2_P.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 <= 1) PC2_PR = 90.

IF (PC2_P = 6 or PC2_P = 7) PC2_PR = 99.

FORMATS PC2_LR PC2_OR PC2_PR (f4.0).

```
EXECUTE.

IF (PC2_KR = 99) or (PC2_OR = 99) or (PC2_PR = 99) pc_learn_11 = 99.
IF (PC2_KR = 1) or (PC2_OR = 1) or (PC2_PR = 1) pc_learn_11 = 1.
IF (PC2_KR = 2) and (PC2_OR = 2 or PC2_OR = 90) and (PC2_PR = 2 or PC2_PR = 90) pc_learn_11 =
2.
IF (PC2_KR = 90) pc_learn_11 = 90.
VARIABLE LABELS pc_learn_11 "Parent was concerned that child had problems understanding what
others say or difficulty learning new things or skills".
VALUE LABELS  pc_learn_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".
EXECUTE.
```

***Parent concerned that child had unusual gestures or movements such as hand-flapping, toe-walking, or self-spinning?

```
COMPUTE pc_gest_11 = 999.
RECODE PC2_Q (0=2).
COMPUTE PC2_QR = PC2_Q.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 <= 1) PC2_QR
= 90.
IF (PC2_Q = 6 or PC2_Q = 7) PC2_QR = 99.
FORMATS PC2_QR (f4.0).
EXECUTE.

IF (PC2_QR = 99) pc_gest_11 = 99.
IF (PC2_QR = 1) pc_gest_11 = 1.
IF (PC2_QR = 2) pc_gest_11 = 2.
IF (PC2_QR = 90) pc_gest_11 = 90.
VARIABLE LABELS pc_gest_11 "Parent was concerned that child had unusual gestures or movements
such as hand flapping, toe walking, or self-spinning".
VALUE LABELS pc_gest_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".
EXECUTE.
```

***Parent concerned that child had medical problems such as seizures, lack of physical growth, or stomach problems

```
COMPUTE pc_med_11 = 999.
```

RECODE PC2_A (0=2).

COMPUTE PC2_AR = PC2_A.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (PC_AGE_all_11 = 0) PC2_AR = 90.

IF (PC2_A = 6 or PC2_A = 7) PC2_AR = 99.

FORMATS PC2_AR (f4.0).

EXECUTE.

IF (PC2_AR = 99) pc_med_11 = 99.

IF (PC2_AR = 1) pc_med_11 = 1.

IF (PC2_AR = 2) pc_med_11 = 2.

IF (PC2_AR = 90) pc_med_11 = 90.

VARIABLE LABELS pc_med_11 "Parent was concerned that child had medical problems such as seizures, lack of physical growth, or stomach problems".

VALUE LABELS pc_med_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

***Parents who had 0-1, 2-3, or 4+ of the 7 types of developmental concerns

COMPUTE count_any7 = 999.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 96) or (PC1 = 97) count_any7 = 90.

COUNT count_any7=pc_vrbl_11 pc_med_11 pc_learn_11 pc_gest_11 pc_motor_11 pc_nonvr_11 pc_beh_11 (1).

COMPUTE count_noany7a = 999.

COUNT count_noany7a =pc_vrbl_11 pc_med_11 pc_learn_11 pc_gest_11 pc_motor_11 pc_nonvr_11 pc_beh_11 (2).

COMPUTE count_noany7b = 999.

COUNT count_noany7b = pc_vrbl_11 pc_med_11 pc_learn_11 pc_gest_11 pc_motor_11 pc_nonvr_11 pc_beh_11 (90).

COMPUTE pc_count_11 = 999.

IF (count_noany7a + count_noany7b GE 7) pc_count_11 = 1.

IF (count_any7 = 1 or count_any7 = 0) pc_count_11 = 1.

IF (count_any7 = 2 or count_any7 = 3) pc_count_11 = 2.

IF (count_any7 GE 4 and count_any7 < 80) pc_count_11 = 3.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 96) or (PC1 = 97) pc_count_11 = 90.

IF (pc_vrbl_11 = 90 & pc_med_11 = 90 & pc_learn_11 = 90 & pc_gest_11 = 90 & pc_motor_11 = 90 & pc_nonvr_11 = 90 & pc_beh_11 = 90) pc_count_11 = 90.

IF (PC1 = 95) pc_count_11 = 1.

Developmental Concerns

```
VARIABLE LABELS pc_count_11 "Parents who had 0-1, 2-3, or 4+ of the 7 types of developmental
concerns".
VALUE LABELS  pc_count_11
0 "None"
1 "0-1"
2 "2-3"
3 "4+"
90 "Skip"
99 "Missing".
EXECUTE.
```

Developmental Concerns

Parent concerned that child had problems talking or communicating

Description	Among CSHCN whose parents had a developmental concern, was parent concerned that child had problems talking, communicating, or loosing speech skills?
Survey Items Used	PC_2G; PC_2H; PC_2I; PC_2J
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability and/or developmental delay whose parent(s) ever had a developmental concern when child was 9 months of age or older
Numerator	Yes, parent concerned that child had speech/communication problems; No, parent did not have this concern

Notes for Data-Users

Questions about the child's verbal development (problems talking or loosing speech skills) are age specific. Therefore, parents who had a developmental concern before the child was 9 months old were not asked questions about verbal developmental concerns. CSHCN whose parents reported that the developmental concern was present before the child or parent entered the family, or the parent was never concerned are also not included in the denominator.

SPSS Syntax and Annotation

```
COMPUTE pc_vrbl_11 = 999.
RECODE PC2_G (0=2).
COMPUTE PC2_GR = PC2_G.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (pc_age_all_11 < .75) PC2_GR
= 90.
IF (PC2_G = 6 or PC2_G = 7) PC2_GR = 99.
RECODE PC2_H (0=2).
COMPUTE PC2_HR = PC2_H.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (pc_age_all_11 <= .75) PC2_HR
= 90.
IF (PC2_H = 6 or PC2_H = 7) PC2_HR = 99.
RECODE PC2_I (0=2).
COMPUTE PC2_IR = PC2_I.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (pc_age_all_11 <= .75) PC2_IR
= 90.
IF (PC2_I= 6 or PC2_I = 7) PC2_IR = 99.
RECODE PC2_J (0=2).
COMPUTE PC2_JR = PC2_J.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (pc_age_all_11 <= .75) PC2_JR
= 90.
IF (PC2_J = 6 or PC2_J = 7) PC2_JR = 99.
FORMATS PC2_GR PC2_HR PC2_IR PC2_JR (f4.0).
EXECUTE.


IF (PC2_GR = 1) or (PC2_HR = 1) or (PC2_IR = 1) or (PC2_JR = 1) pc_vrbl_11 = 1.
```

Developmental Concerns

IF (PC2_GR = 2) and (PC2_HR = 2 or PC2_HR = 90) and (PC2_IR = 2 or PC2_IR = 90) and (PC2_JR = 2 or PC2_JR = 90) pc_vrbl_11 = 2.

IF (PC2_GR = 90) pc_vrbl_11 = 90.

IF (PC2_GR = 99) and (PC2_HR = 99 or PC2_IR = 99 or PC2_JR = 99) pc_vrbl_11 = 99.

VARIABLE LABELS pc_vrbl_11 "Parent concerned that child had problems talking later, not talking at all, or loosing speech skills".

VALUE LABELS pc_vrbl_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

Developmental Concerns

Parent concerned that child had behavioral problems	
Description	Was parent concerned that the child had difficulties playing with others, difficulties with change, or any other difficulties (sleeping/eating, hyper, wandering, tantrums, aggressive/ destructive)?
Survey Items Used	PC2_E; PC2_M; PC2_N
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability whose parent(s) ever had a developmental concern after child was born
Numerator	Yes, parent concerned that child had behavioral difficulties; No, parent did not have this concern

Notes for Data-Users

Questions about the child's behavioral development (difficulties with change, playing and other behaviors) are age specific. Therefore, parents who had a developmental concern before the child was born or at the time the child was born were not asked questions about behavioral developmental concerns. CSHCN whose parents reported that the developmental concern was present before the child or parent entered the family, or the parent was never concerned are also not included in the denominator.

SPSS Syntax and Annotation

COMPUTE pc_beh_11 = 999.

RECODE PC2_E (0=2).

COMPUTE PC2_ER = PC2_E.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (Pc_age_all_11 = 0) PC2_ER = 90.

IF (PC2_E = 6 or PC2_E = 7) PC2_ER = 99.

RECODE PC2_M (0=2).

COMPUTE PC2_MR = PC2_M.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (Pc_age_all_11 <= 1) PC2_MR = 90.

IF (PC2_M = 6 or PC2_M = 7) PC2_MR = 99.

RECODE PC2_N (0=2).

COMPUTE PC2_NR = PC2_N.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (Pc_age_all_11 <= 1) PC2_NR = 90.

IF (PC2_N = 6 or PC2_N = 7) PC2_NR = 99.

FORMATS PC2_ER PC2_MR PC2_NR (f4.0).

EXECUTE.

IF (PC2_ER = 99 or PC2_MR = 99 or PC2_NR = 99) pc_beh_11 = 99.

IF (PC2_ER = 1) or (PC2_MR = 1) or (PC2_NR = 1) pc_beh_11 = 1.

IF (PC2_ER = 2) and (PC2_MR = 2 or PC2_MR = 90) and (PC2_NR = 2 or PC2_NR = 90) pc_beh_11 = 2.

IF (PC2_ER = 90) pc_beh_11 = 90.

VARIABLE LABELS pc_beh_11 "Parent was concerned that child had difficulties playing with others, difficulties with change, or any other behavior difficulties (sleeping/eating, hyper, wandering, tantrums, aggressive/destructive)".

VALUE LABELS pc_beh_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

Developmental Concerns

	Parent concerned that child had problems with motor skills
Description	Among CSHCN whose parents had a developmental concern, was parent concerned that child had problems with coordination, gross motor skills, or fine motor skills?
Survey Items Used	PC2_F, PC2_L
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability whose parent(s) ever had a developmental concern after child was born
Numerator	Yes, parent concerned that child had problems with coordination, gross motor skills, or fine motor skills; No, parent did not have this concern

Notes for Data-Users

Questions about the child's motor skill development (difficulties with coordination, gross/fine motor skills) are age specific. Therefore, parents who had a developmental concern before the child was born or at the time the child was born were not asked questions about motor skill developmental concerns. CSHCN whose parents reported that the developmental concern was present before the child or parent entered the family, or the parent was never concerned are also not included in the denominator.

SPSS Syntax and Annotation

```
COMPUTE pc_motor_11 = 999.
RECODE PC2_F (0=2).
COMPUTE PC2_FR = PC2_F.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (pc_age_all_11 = 0) PC2_FR =
90.
IF (PC2_F = 6 or PC2_F = 7) PC2_FR = 99.
RECODE PC2_L (0=2).
COMPUTE PC2_LR = PC2_L.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (pc_age_all_11 <= 1) PC2_LR =
90.
IF (PC2_L = 6 or PC2_L = 7) PC2_LR = 99.
FORMATS PC2_FR PC2_LR (f4.0).
EXECUTE.


IF (PC2_LR = 99) or (PC2_FR =99) pc_motor_11 = 99.
IF (PC2_FR = 1) or (PC2_LR = 1) pc_motor_11 = 1.
IF (PC2_FR = 2) and (PC2_LR = 2 or PC2_LR = 90) pc_motor_11 = 2.
IF (PC2_FR = 90) pc_motor_11 = 90.
VARIABLE LABELS pc_motor_11 "Parent was concerned that child had problems with coordination/gross
motor skills, or fine motor skills".
VALUE LABELS  pc_motor_11
1 "Yes"
2 "No"
99 "Missing"
```

```
90 "Skip".
EXECUTE.
```

Developmental Concerns

Parent concerned that child had problems with non-verbal communication	
Description	Among CSHCN whose parents had a developmental concern, was parent concerned that child had problems making eye contact, responding when called/to sounds, or with other forms of non-verbal communication?
Survey Items Used	PC2_B; PC2_C; PC2_D
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability whose parent(s) ever had a developmental concern after child was born
Numerator	Yes, parent concerned that child had problems with non-verbal communication; No, parent did not have this concern

Notes for Data-Users

Questions about the child's non-verbal development (problems making eye contact, responding, and other communication forms) are age specific. Therefore, parents who had a developmental concern before the child was born or at the time the child was born were not asked questions about non-verbal developmental concerns. CSHCN whose parents reported that the developmental concern was present before the child or parent entered the family, or the parent was never concerned are also not included in the denominator.

SPSS Syntax and Annotation

```
COMPUTE pc_nonvr_11 = 999.
RECODE PC2_B (0=2).
COMPUTE PC2_BR = PC2_B.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (Pc_age_all_11 = 0) PC2_BR = 90.
IF (PC2_B = 6 or PC2_B = 7) PC2_BR = 99.
RECODE PC2_C (0=2).
COMPUTE PC2_CR = PC2_C.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (Pc_age_all_11 = 0) PC2_CR = 90.
IF (PC2_C = 6 or PC2_C = 7) PC2_CR = 99.
RECODE PC2_D (0=2).
COMPUTE PC2_DR = PC2_D.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (Pc_age_all_11 = 0) PC2_DR = 90.
IF (PC2_D = 6 or PC2_D = 7) PC2_DR = 99.
FORMATS PC2_BR PC2_CR PC2_DR (f4.0).
EXECUTE.


IF (PC2_BR = 99) or (PC2_CR = 99) or (PC2_DR = 99) pc_nonvr_11 = 99.
IF (PC2_BR = 1) or (PC2_CR = 1) or (PC2_DR = 1) pc_nonvr_11 = 1.
```

IF (PC2_BR = 2) and (PC2_CR = 2) and (PC2_DR = 2) pc_nonvr_11 = 2.

IF (PC2_BR = 90) and (PC2_CR = 90) and (PC2_DR = 90) pc_nonvr_11 = 90.

VARIABLE LABELS pc_nonvr_11 "Parent was concerned that child had problems making eye contact, responding when called/to sounds, or with other forms of non-verbal communication (tone of voice, facial expressions, body language)".

VALUE LABELS pc_nonvr_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

Developmental Concerns

Parent concerned that child had problems with learning or understanding	

Description	Among CSHCN whose parents had a developmental concern, was parent concerned that child had problems understanding what others say or difficulty learning new things or skills?
Survey Items Used	PC2_K,; PC2_O; PC2_P
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability and/or developmental delay whose parent(s) ever had a developmental concern when child was 9 months of age or older.
Numerator	Yes, parent was concerned that child had problems understanding what others say or difficulty learning new things or skills; No, parent did not have this concern.

Notes for Data-Users
Questions about the child's learning (problems understanding what others say or difficulties learning new things/skills) are age specific. Therefore, parents who had a developmental concern before the child was 9 months old were not asked questions about learning developmental concerns. CSHCN whose parents reported that the developmental concern was present before the child or parent entered the family, or the parent was never concerned are also not included in the denominator.

SPSS Syntax and Annotation

COMPUTE pc_learn_11 = 999.

RECODE PC2_K (0=2).

COMPUTE PC2_KR = PC2_K.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (Pc_age_all_11 <= .75) PC2_KR = 90.

IF (PC2_K = 6 or PC2_K = 7) PC2_KR = 99.

RECODE PC2_O (0=2).

COMPUTE PC2_OR = PC2_O.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (Pc_age_all_11 <= 1) PC2_OR = 90.

IF (PC2_O = 6 or PC2_O = 7) PC2_OR = 99.

RECODE PC2_P (0=2).

COMPUTE PC2_PR = PC2_P.

IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (Pc_age_all_11 <= 1) PC2_PR = 90.

IF (PC2_P = 6 or PC2_P = 7) PC2_PR = 99.

FORMATS PC2_LR PC2_OR PC2_PR (f4.0).

EXECUTE.

IF (PC2_KR = 99) or (PC2_OR = 99) or (PC2_PR = 99) pc_learn_11 = 99.

IF (PC2_KR = 1) or (PC2_OR = 1) or (PC2_PR = 1) pc_learn_11 = 1.

IF (PC2_KR = 2) and (PC2_OR = 2 or PC2_OR = 90) and (PC2_PR = 2 or PC2_PR = 90) pc_learn_11 = 2.

IF (PC2_KR = 90) pc_learn_11 = 90.

VARIABLE LABELS pc_learn_11 "Parent was concerned that child had problems understanding what others say or difficulty learning new things or skills".

VALUE LABELS pc_learn_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

Developmental Concerns

	Parent concerned that child had unusual gestures or movements
Description	Among CSHCN whose parents had a developmental concern, was parent concerned that child had unusual gestures or movements such as hand-flapping, toe-walking, or self-spinning?
Survey Items Used	PC2_Q
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability and/or developmental delay whose parent(s) ever had a developmental concern when child was 12 months of age or older.
Numerator	Yes, parent was concerned that child had unusual gestures or movements; No, parent did not have this concern

Notes for Data-Users

Questions about the child's gestures (unusual gestures or movements) are age specific. Therefore, parents who had a developmental concern before the child was 12 months old were not asked questions about unusual gesture/movement concerns. CSHCN whose parents reported that the developmental concern was present before the child or parent entered the family, or the parent was never concerned are also not included in the denominator.

SPSS Syntax and Annotation

```
COMPUTE pc_gest_11 = 999.
RECODE PC2_Q (0=2).
COMPUTE PC2_QR = PC2_Q.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (Pc_age_all_11 <= 1) PC2_QR = 90.
IF (PC2_Q = 6 or PC2_Q = 7) PC2_QR = 99.
FORMATS PC2_QR (f4.0).
EXECUTE.


IF (PC2_QR = 99) pc_gest_11 = 99.
IF (PC2_QR = 1) pc_gest_11 = 1.
IF (PC2_QR = 2) pc_gest_11 = 2.
IF (PC2_QR = 90) pc_gest_11 = 90.
VARIABLE LABELS pc_gest_11 "Parent was concerned that child had unusual gestures or movements such as hand flapping, toe walking, or self-spinning".
VALUE LABELS pc_gest_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".
EXECUTE.
```

Developmental Concerns

<table>
<tr><td colspan="2" align="center">Parent concerned that child had medical problems</td></tr>
<tr><td>Description</td><td>Among CSHCN whose parents had a developmental concern, was parent concerned that child had medical problems such as seizures, lack of physical growth, or stomach problems?</td></tr>
<tr><td>Survey Items Used</td><td>PC2_A</td></tr>
<tr><td>Denominator</td><td>CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability or developmental delay whose parent(s) ever had a developmental concern after child was born.</td></tr>
<tr><td>Numerator</td><td>Yes, parent concerned that child had medical problems; No, parent did not have this concern</td></tr>
</table>

Notes for Data-Users

Questions about the child's medical (problems making eye contact, responding, and other communication forms) are age specific. Therefore, parents who had a developmental concern before the child was born or at the time the child was born were not asked questions about non-verbal developmental concerns. CSHCN whose parents reported that the developmental concern was present before the child or parent entered the family, or the parent was never concerned are also not included in the denominator.

Revisions

N/A

SPSS Syntax and Annotation

```
COMPUTE pc_med_11 = 999.
RECODE PC2_A (0=2).
COMPUTE PC2_AR = PC2_A.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (PC1 = 96) or (PC1 = 97) or (pc_age_all_11 = 0) PC2_AR =
90.
IF (PC2_A = 6 or PC2_A = 7) PC2_AR = 99.
FORMATS PC2_AR (f4.0).
EXECUTE.

IF (PC2_AR = 99) pc_med_11 = 99.
IF (PC2_AR = 1) pc_med_11 = 1.
IF (PC2_AR = 2) pc_med_11 = 2.
IF (PC2_AR = 90) pc_med_11 = 90.
VARIABLE LABELS pc_med_11 "Parent was concerned that child had medical problems such as seizures,
lack of physical growth, or stomach problems".
VALUE LABELS pc_med_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".
EXECUTE.
```

Developmental Concerns

	Person first concerned with child's development
Description	Who first had concerns that something was not right with child's development?
Survey Items Used	PC3, PC4
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability whose parents had a developmental concern
Numerator	Person who first had concern that something was not right with child's development: Parent; Health Care Professional; Teacher, Counselor, or Nurse at School; Other

Notes for Data-Users
N/A

SPSS Syntax and Annotation

COMPUTE PC3m = 999.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (Pc_age_all_11 = 0) PC3m = 90.
IF (PC3 = 6 or PC3 = 7) PC3m = 99.
IF (PC3 = 1) PC3m = 1.
IF (PC3 = 0) PC3m = 2.
EXECUTE.

COMPUTE PC4m = 999.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (Pc_age_all_11 = 0) or (PC3m = 90) PC4m = 90.
IF (PC3m = 1) PC4m = 90.
IF (PC4R = 96 or PC4R = 97) PC4m = 99.
IF (PC4R = 1) PC4m = 1.
IF (PC4R = 2) PC4m = 2.
IF (PC4R = 3) PC4m = 3.
IF (PC4R = 4) PC4m = 4.
IF (PC4R = 5) PC4m = 5.
IF (PC4R = 6) PC4m = 6.
IF (PC4R = 7) PC4m = 7.
IF (PC4R = 8) PC4m = 8.

COMPUTE talk_1st_11 = 999.
IF (PC1 = 93) or (PC1 = 94) or (PC1 = 95) or (Pc_age_all_11 = 0) talk_1st_11 = 90.
IF (PC3 = 6 or PC3 = 7) talk_1st_11 = 90.
EXECUTE.
IF (PC3 = 1) and (RELATIONR = 1 or RELATIONR = 2) talk_1st_11 = 1.
IF (PC4R = 1 or PC4R = 2) talk_1st_11 = 1.
IF (PC4R = 4) talk_1st_11 = 2.
IF (PC4R = 5 or PC4R = 6) talk_1st_11 = 3.
IF (PC3 = 1) and (RELATIONR = 3) talk_1st_11 = 4.

Developmental Concerns

IF (PC4R = 3 or PC4R = 7 or PC4R = 8) talk_1st_11 = 4.

IF (PC4R = 96 or PC4R = 97) talk_1st_11 = 99.

IF (PC3m = 99 or PC4m = 99) talk_1st_11 = 99.

VARIABLE LABELS talk_1st_11 "Among parents with any developmental concern, person who first had concern that something was not right with child's development ".

VALUE LABELS talk_1st_11

1 "Parent"

2 "Health Care Professional"

3 "Teacher, School Counselor, or Nurse"

4 "Other"

99 "Missing"

90 "Skip".

EXECUTE.

Developmental Concerns

	Age first talked to doctor
Description	What was child's age when parent first talked to a doctor or health care provider about their concerns?
Survey Items Used	PC6; PC6A
Denominator	CSHCN ages 6-17 years with current autism spectrum disorder, developmental delay, and/or intellectual disability whose parents had a developmental concern
Numerator	Child's age when parent talked to a doctor or health care provider about their concern: Before birth - 11 months; 12-23 months; 24-47 months; 48+ months

Notes for Data-Users
N/A

SPSS Syntax and Annotation

```
COMPUTE TALK_YR = 999.
IF (PC6_A = 2) TALK_YR = PC6.
IF (PC6_A = 1) TALK_YR = PC6/12.
IF (PC1 = 95) TALK_YR = 90.
IF (PC5 = 0) or (PC5 = 6) or (PC5 = 7) TALK_YR = 90.
IF (PC6 = 96) TALK_YR = 99.
EXECUTE.
VALUE LABELS TALK_YR
90 "Skip"
99 "Missing".
EXECUTE.


COMPUTE talk_age_11 = 999.
IF (TALK_YR >= 0 and TALK_YR < 1) talk_age_11 = 1.
IF (TALK_YR >= 1 and TALK_YR < 2) talk_age_11 = 2.
IF (TALK_YR >= 2 and TALK_YR <4) talk_age_11 = 3.
IF (TALK_YR >= 4 and TALK_YR < 18) talk_age_11 = 4.
IF (TALK_YR = 90) talk_age_11 = 90.
IF (TALK_YR = 99) talk_age_11 = 99.
EXECUTE.
VARIABLE LABELS talk_age_11 "Child's age when parent first talked to doctor or health care provider about his/her concerns ".
VALUE LABELS  talk_age_11
1 "Before birth - <1 yr"
2 "1 - < 2yrs old"
3 "2 - <4yrs old"
4 "4+ yrs old"
99 "Missing"
```

```
90 "Skip".
EXECUTE.
```

Developmental Concerns

Child's parent talked to a doctor about their concerns

Description	Did parent talk to a doctor or health care provider about their concerns?
Survey Items Used	PC5
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, or intellectual disability whose parents had a developmental concern
Numerator	Yes, parent talked to doctor about concern; Parent did not talk to doctor about concern

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE talk_dr_11 = 999.
IF (PC1 = 95) talk_dr_11 = 90.
IF (PC5 = 1) talk_dr_11 = 1.
IF (PC5 = 0) talk_dr_11 = 2.
IF (PC5 = 6 or PC5 = 7) talk_dr_11 = 99.
VARIABLE LABELS talk_dr_11 "Parent talked to a doctor or health care provider about their concern".
VALUE LABELS talk_dr_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".
EXECUTE.

Developmental Concerns

Doctor or health care provider conducted a developmental test	
Description	After parent expressed concerns, did the doctor or health care provider conduct a developmental test?
Survey Items Used	PC7_AR01
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability and/or developmental delay whose parents expressed developmental concerns to the doctor or health care provider.
Numerator	Yes, doctor conducted developmental test; No, developmental test was not conducted

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE PC7_AR01R = PC7_AR01.

IF (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) PC7_AR01R = 90.

IF (PC7_AR01 = 6 or PC7_AR01 = 7) PC7_AR01R = 99.

IF (SYSMIS(PC7_AR01R)) PC7_AR01R = 99.

EXECUTE.

COMPUTE dr_test_11 = 999.

IF (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) dr_test_11 = 90.

IF (PC7_AR01R = 0) dr_test_11 = 2.

IF (PC7_AR01R = 1) dr_test_11 =1.

IF (PC7_AR01R = 99) dr_test_11=99.

VARIABLE LABELS dr_test_11 "Doctor or health care provider conducted a developmental test when parent had a developmental concern".

VALUE LABELS dr_test_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

Developmental Concerns

Doctor or health care provider referred child to a specialist	
Description	After parent expressed concerns, did doctor or health care provider refer the child to a specialist?
Survey Items Used	PC7_AR02
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability or developmental delay whose parents expressed developmental concerns to the doctor or health care provider.
Numerator	Yes, doctor referred child to a specialist; No referral made

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE PC7_AR02R = PC7_AR02.

IF (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) PC7_AR02R = 90.

IF (PC7_AR02 = 6 or PC7_AR02 = 7) PC7_AR02R = 99.

IF (SYSMIS(PC7_AR02R)) PC7_AR02R = 99.

EXECUTE.

COMPUTE dr_refer_11 = 999.

IF (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) dr_refer_11 = 90.

IF (PC7_AR02R = 0) dr_refer_11= 2.

IF (PC7_AR02R = 1) dr_refer_11=1.

IF (PC7_AR02R = 99) dr_refer_11=99.

VARIABLE LABELS dr_refer_11 "Doctor or healthcare provider made a referral to a special when parent had a developmental concern".

VALUE LABELS dr_refer_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

Developmental Concerns

Doctor or health care provider suggested parents talk with child's school

Description	After parent expressed concerns, did the doctor or health care provider suggest that parent talk with the child's school?
Survey Items Used	PC7_AR03
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability or developmental delay whose parents expressed developmental concerns to the doctor or health care provider.
Numerator	Yes, doctor suggested parents talk to child's school; No, suggestion was not made

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE PC7_AR03R = PC7_AR03.

IF (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) PC7_AR03R = 90.

IF (PC7_AR03 = 6 or PC7_AR03 = 7) PC7_AR03R = 99.

IF (SYSMIS(PC7_AR03R)) PC7_AR03R = 99.

EXECUTE.

COMPUTE dr_sch_11 = 999.

IF (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) dr_sch_11 = 90.

IF (PC7_AR03R = 0) dr_sch_11= 2.

IF (PC7_AR03R = 1) dr_sch_11=1.

IF (PC7_AR03R = 99) dr_sch_11=99.

VARIABLE LABELS dr_sch_11 "Doctor or healthcare provider suggested that parent talk with the school when parent had a developmental concern".

VALUE LABELS dr_sch_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

Developmental Concerns

Doctor or health care provider told parents nothing was wrong

Description	After parent expressed concerns, did the doctor or health care provider say that nothing was wrong or behavior was normal?
Survey Items Used	PC7_AR04
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability or developmental delay whose parents expressed developmental concerns to the doctor or health care provider.
Numerator	Yes, doctor told parents that nothing wrong or behavior was normal; No, doctor did not tell parents that nothing wrong or behavior was normal

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE PC7_AR04R = PC7_AR04.

IF (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) PC7_AR04R = 90.

IF (PC7_AR04 = 6 or PC7_AR04 = 7) PC7_AR04R = 99.

IF (SYSMIS(PC7_AR04R)) PC7_AR04R = 99.

EXECUTE.

COMPUTE dr_norm_11 = 999.

IF (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) dr_norm_11 = 90.

IF (PC7_AR04R = 0) dr_norm_11= 2.

IF (PC7_AR04R = 1) dr_norm_11=1.

IF (PC7_AR04R = 99) dr_norm_11=99.

VARIABLE LABELS dr_norm_11 "Doctor or healthcare provider said nothing was wrong or behavior was normal when parent had a developmental concern".

VALUE LABELS dr_norm_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

Doctor or health care provider told parents it was too early to tell

Description	After parent expressed concerns, did the doctor or health care provider tell you that it was too early to tell if this was a developmental concern?
Survey Items Used	PC7_AR05
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability and/or developmental delay whose parents expressed developmental concerns to the doctor or health care provider.
Numerator	Yes, doctor told parents it's too early to tell; No, doctor did not tell parents that it's too early to tell.

Notes for Data-Users
N/A

SPSS Syntax and Annotation

COMPUTE PC7_AR05R = PC7_AR05.

IF (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) PC7_AR05R = 90.

IF (PC7_AR05 = 6 or PC7_AR05 = 7) PC7_AR05R = 99.

IF (SYSMIS(PC7_AR05R)) PC7_AR05R = 99.

EXECUTE.

COMPUTE dr_early_11 = 999.

IF (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) dr_early_11 = 90.

IF (PC7_AR05R = 0) dr_early_11= 2.

IF (PC7_AR05R = 1) dr_early_11=1.

IF (PC7_AR05R = 99) dr_early_11=99.

VARIABLE LABELS dr_early_11 "Doctor or healthcare provider said 'it's too early to tell' when parent had a developmental concern".

VALUE LABELS dr_early_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

Developmental Concerns

	Doctor or health care provider said child might grow out of it
Description	After parent expressed concerns, did the doctor or health care provider tell you that the child might grow out of it?
Survey Items Used	PC7_AR06
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability or developmental delay whose parents expressed developmental concerns to the doctor or health care provider.
Numerator	Yes, doctor said child might grow out of it; No, doctor did not say child might grow out of it

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE PC7_AR06R = PC7_AR06.

If (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) PC7_AR06R = 90.

If (PC7_AR06 = 6 or PC7_AR06 = 7) PC7_AR06R = 99.

If (SYSMIS(PC7_AR06R)) PC7_AR06R = 99.

EXECUTE.

COMPUTE dr_grow_11 = 999.

If (PC1 = 95 or PC5 = 0 or PC5 = 6 or PC5 = 7) dr_grow_11 = 90.

If (PC7_AR06R = 0) dr_grow_11= 2.

If (PC7_AR06R = 1) dr_grow_11=1.

If (PC7_AR06R = 99) dr_grow_11=99.

VARIABLE LABELS dr_grow_11 "Doctor or healthcare provider said child might 'grow out of it' when parent had a developmental concern".

VALUE LABELS dr_grow_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

Developmental Concerns

	Child's parent talked to school about their concerns
Description	Did parent talk to teacher, school nurse, school counselor, or other school professional about their concern?
Survey Items Used	PC8
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability and/or developmental delay whose parents had a developmental concern
Numerator	Yes, parent talked to teacher, school nurse, school counselor, or other school professional about their concern; No, parent did not talk to teacher, school nurse, school counselor, or other school professional about their concern

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE talk_sch_11 = 999.

IF (PC1 = 95) talk_sch_11 = 90.

IF (PC8 = 1) talk_sch_11 = 1.

IF (PC8 = 0) talk_sch_11 = 2.

IF (PC8 = 6 or PC8 = 7) talk_sch_11 = 99.

VARIABLE LABELS talk_sch_11 "Parent talked to teacher, school nurse, school counselor, or other school professional about their concern".

VALUE LABELS talk_sch_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

Developmental Concerns

Developmental screening	
Description	Was a developmental screening or assessment completed by the parent, doctor, or health care provider?
Survey Items Used	PC7_B; PC7_C; PC7_D; PC7_E; PC7_F; PC7_G; PC7_H
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability or developmental delay whose parent(s) had developmental concern before the child was 6 years old.
Numerator	Developmental screening or assessment completed by parent/health provider: Had screening; No screening; Did not talk to doctor or provider

Notes for Data-Users
N/A

SPSS Syntax and Annotation

** Parent completed screener/assessment
COMPUTE PC7_BR = 999.
IF (PC1 = 95 or TALK_YR >= 6) PC7_BR = 90.
IF (PC7_B = 1) PC7_BR = 1.
IF (PC7_B = 0) PC7_BR = 2.
IF (PC7_B = 6) PC7_BR = 99.
IF (PC7_B = 7) PC7_BR = 99.

COMPUTE PC7_CR = 999.
IF (PC1 = 95 or TALK_YR >= 6 or PC7_B = 0 or PC7_B = 6 or PC7_B = 7 or TALK_YR >= 2) PC7_CR = 90.
IF (PC7_C = 1) PC7_CR = 1.
IF (PC7_C = 0) PC7_CR = 2.
IF (PC7_C = 6) PC7_CR = 99.
IF (PC7_C = 7) PC7_CR = 99.

COMPUTE PC7_DR = 999.
IF (PC1 = 95 or TALK_YR >= 6 or PC7_B = 0 or PC7_B = 6 or PC7_B = 7 or TALK_YR >= 2) PC7_DR = 90.
IF (PC7_D = 1) PC7_DR = 1.
IF (PC7_D = 0) PC7_DR = 2.
IF (PC7_D = 6) PC7_DR = 99.
IF (PC7_D = 7) PC7_DR = 99.

COMPUTE PC7_ER = 999.
IF (PC1 = 95 or TALK_YR >= 6 or PC7_B = 0 or PC7_B = 6 or PC7_B = 7 or TALK_YR < 2) PC7_ER = 90.

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IF (PC7_E = 1) PC7_ER = 1.
IF (PC7_E = 0) PC7_ER = 2.
IF (PC7_E = 6) PC7_ER = 99.
IF (PC7_E = 7) PC7_ER = 99.


COMPUTE PC7_FR = 999.
IF (PC1 = 95 or TALK_YR >= 6 or PC7_B = 0 or PC7_B = 6 or PC7_B = 7 or TALK_YR < 2) PC7_FR = 90.
IF (PC7_F = 1) PC7_FR = 1.
IF (PC7_F = 0) PC7_FR = 2.
IF (PC7_F = 6) PC7_FR = 99.
IF (PC7_F = 7) PC7_FR = 99.


COMPUTE scr_p_11 = 999.
IF (PC1 = 95 or TALK_YR >= 6) scr_p_11 = 90.
IF (PC7_BR = 90 and PC7_CR = 90 and PC7_ER = 90 and PC7_ER = 90 and PC7_FR = 90) scr_p_11 =
90.
IF (PC7_BR = 99 or PC7_CR = 99 or PC7_DR = 99 or PC7_ER = 99 or PC7_FR = 99) scr_p_11 = 99.
IF (PC7_BR = 1) and (PC7_C = 6 or PC7_D = 6 or PC7_E = 6 or PC7_F = 6) SCR_P_11 = 99.
IF (PC7_BR = 1) and (PC7_C = 7 or PC7_D = 7 or PC7_E = 7 or PC7_F = 7) SCR_P_11 = 99.
IF (PC7_BR = 1) and (PC7_CR = 1 or PC7_ER = 1) and (PC7_DR = 1 or PC7_FR = 1) scr_p_11 = 1.
IF (PC7_BR = 2) or (PC7_CR = 2 or PC7_ER = 2) or (PC7_DR = 2 or PC7_FR = 2) scr_p_11 = 2.
VARIABLE LABELS scr_p_11 "Parent completed screener/assessment".
VALUE LABELS  scr_p_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".
EXECUTE.


** Physician completed screener/assessment


COMPUTE PC7_GR = 999.
IF (PC1 = 95 or TALK_YR >= 6) PC7_GR = 90.
IF (PC7_G = 1) PC7_GR = 1.
IF (PC7_G = 0) PC7_GR = 2.
IF (PC7_G = 6) PC7_GR = 99.
IF (PC7_G = 7) PC7_GR = 99.


COMPUTE PC7_HR = 999.
IF (PC1 = 95) or (TALK_YR >= 6) or (TALK_YR < 1) PC7_HR = 90.
IF (PC7_H = 1) PC7_HR = 1.
IF (PC7_H = 0) PC7_HR = 2.
```

IF (PC7_H = 6) PC7_HR = 99.

IF (PC7_H = 7) PC7_HR = 99.

COMPUTE scr_dr_11 = 999.

IF (PC1 = 95 or TALK_YR >= 6) scr_dr_11 = 90.

IF (PC7_GR = 99 or PC7_HR = 99) scr_dr_11 = 99.

IF (PC7_G = 0) or (PC7_H = 0) scr_dr_11 = 2.

IF (PC7_G = 1) or (PC7_H = 1) scr_dr_11 = 1.

IF (PC7_GR = 90 and PC7_HR = 90) scr_dr_11 = 90.

VARIABLE LABELS scr_dr_11 "Physician completed screener/assessment".

VALUE LABELS scr_dr_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

*** Developmental screening or assessment completed by parent/health provider

COMPUTE PC_SCR_11 = 999.

IF (PC1 = 95 or TALK_YR >= 6) PC_SCR_11 = 90.

IF (scr_p_11 = 2 or scr_dr_11 = 2) PC_SCR_11 = 2.

IF (scr_p_11 = 1 or scr_dr_11 = 1) PC_SCR_11 = 1.

IF (scr_p_11 = 99 and scr_dr_11 = 99) PC_SCR_11 = 99.

IF (scr_p_11 = 90 and scr_dr_11 = 90) PC_SCR_11 = 90.

IF (PC7_BR = 90) PC_SCR_11 = 3.

VARIABLE LABELS PC_SCR_11 "Developmental screening or assessment completed by parent/health provider".

 VALUE LABELS PC_SCR_11

1 "Completed screening"

2 "No screening"

3 "Didn't talk to provider"

99 "Missing"

90 "Skip".

Developmental Concerns

Physician completed a developmental screener	
Description	Did doctor or health care provider complete a developmental screening or assessment of child?
Survey Items Used	PC7_G; PC7_H
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability whose parent(s) had a developmental concern before the child was 6 years old
Numerator	Yes, physician completed screener; No, physician did not complete screener

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE PC7_GR = 999.
IF (PC1 = 95 or TALK_YR >= 6) PC7_GR = 90.
IF (PC7_G = 1) PC7_GR = 1.
IF (PC7_G = 0) PC7_GR = 2.
IF (PC7_G = 6) PC7_GR = 99.
IF (PC7_G = 7) PC7_GR = 99.

COMPUTE PC7_HR = 999.
IF (PC1 = 95) or (TALK_YR >= 6) or (TALK_YR < 1) PC7_HR = 90.
IF (PC7_H = 1) PC7_HR = 1.
IF (PC7_H = 0) PC7_HR = 2.
IF (PC7_H = 6) PC7_HR = 99.
IF (PC7_H = 7) PC7_HR = 99.

COMPUTE scr_dr_11 = 999.
IF (PC1 = 95 or TALK_YR >= 6) scr_dr_11 = 90.
IF (PC7_GR = 99 or PC7_HR = 99) scr_dr_11 = 99.
IF (PC7_G = 0) or (PC7_H = 0) scr_dr_11 = 2.
IF (PC7_G = 1) or (PC7_H = 1) scr_dr_11 = 1.
IF (PC7_GR = 90 and PC7_HR = 90) scr_dr_11 = 90.
VARIABLE LABELS scr_dr_11 "Physician completed screener/assessment".
VALUE LABELS scr_dr_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".

Developmental Concerns

Parent completed a developmental screener	
Description	Did parent complete a developmental screening or assessment of child?
Survey Items Used	PC7_B; PC7_C; PC7_D; PC7_E; PC7_F
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability and/or developmental delay whose parent(s) ever talked to a health care provider about their developmental concern before the child was 6 years old
Numerator	Yes, parent completed screener; No parent did not complete screener

Notes for Data-Users
N/A

SPSS Syntax and Annotation

COMPUTE PC7_BR = 999.
IF (PC1 = 95 or TALK_YR >= 6) PC7_BR = 90.
IF (PC7_B = 1) PC7_BR = 1.
IF (PC7_B = 0) PC7_BR = 2.
IF (PC7_B = 6) PC7_BR = 99.
IF (PC7_B = 7) PC7_BR = 99.

COMPUTE PC7_CR = 999.
IF (PC1 = 95 or TALK_YR >= 6 or PC7_B = 0 or PC7_B = 6 or PC7_B = 7 or TALK_YR >= 2) PC7_CR = 90.
IF (PC7_C = 1) PC7_CR = 1.
IF (PC7_C = 0) PC7_CR = 2.
IF (PC7_C = 6) PC7_CR = 99.
IF (PC7_C = 7) PC7_CR = 99.

COMPUTE PC7_DR = 999.
IF (PC1 = 95 or TALK_YR >= 6 or PC7_B = 0 or PC7_B = 6 or PC7_B = 7 or TALK_YR >= 2) PC7_DR = 90.
IF (PC7_D = 1) PC7_DR = 1.
IF (PC7_D = 0) PC7_DR = 2.
IF (PC7_D = 6) PC7_DR = 99.
IF (PC7_D = 7) PC7_DR = 99.

COMPUTE PC7_ER = 999.
IF (PC1 = 95 or TALK_YR >= 6 or PC7_B = 0 or PC7_B = 6 or PC7_B = 7 or TALK_YR < 2) PC7_ER = 90.
IF (PC7_E = 1) PC7_ER = 1.
IF (PC7_E = 0) PC7_ER = 2.

```
IF (PC7_E = 6) PC7_ER = 99.
IF (PC7_E = 7) PC7_ER = 99.


COMPUTE PC7_FR = 999.
IF (PC1 = 95 or TALK_YR >= 6 or PC7_B = 0 or PC7_B = 6 or PC7_B = 7 or TALK_YR < 2) PC7_FR = 90.
IF (PC7_F = 1) PC7_FR = 1.
IF (PC7_F = 0) PC7_FR = 2.
IF (PC7_F = 6) PC7_FR = 99.
IF (PC7_F = 7) PC7_FR = 99.


COMPUTE scr_p_11 = 999.
IF (PC1 = 95 or TALK_YR >= 6) scr_p_11 = 90.
IF (PC7_BR = 90 and PC7_CR = 90 and PC7_ER = 90 and PC7_ER = 90 and PC7_FR = 90) scr_p_11 =
90.
IF (PC7_BR = 99 or PC7_CR = 99 or PC7_DR = 99 or PC7_ER = 99 or PC7_FR = 99) scr_p_11 = 99.
IF (PC7_BR = 1) and (PC7_C = 6 or PC7_D = 6 or PC7_E = 6 or PC7_F = 6) SCR_P_11 = 99.
IF (PC7_BR = 1) and (PC7_C = 7 or PC7_D = 7 or PC7_E = 7 or PC7_F = 7) SCR_P_11 = 99.
IF (PC7_BR = 1) and (PC7_CR = 1 or PC7_ER = 1) and (PC7_DR = 1 or PC7_FR = 1) scr_p_11 = 1.
IF (PC7_BR = 2) or (PC7_CR = 2 or PC7_ER = 2) or (PC7_DR = 2 or PC7_FR = 2) scr_p_11 = 2.
VARIABLE LABELS scr_p_11 "Parent completed screener/assessment".
VALUE LABELS  scr_p_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".
EXECUTE.
```

Child's age when parent first told that child had one of three developmental conditions

Description	Age at which child was first told they had any of 3 developmental conditions
Survey Items Used	How old was child when you were first told he/she had any of 3 conditions: autism spectrum disorder, developmental delay and/or intellectual disability?
Survey Items Used	DE_AUT2; DE_AUT2A; DE_DEV2; DE_DEV2A; DE_INT2; DE_INT2A
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Child's age when parent first told: 0-2 years old; 3-5 years old; 6-17 years old

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE aut_age_all=999.
IF DE_AUT2A=2 aut_age_all=DE_AUT2*1.
IF DE_AUT2A=1 aut_age_all=DE_AUT2/12.

RECODE aut_age_all
(0 thru 2.99=1) (3.0 thru 5.9=2) (6.0 thru 17=3) (else=copy) into aut_age_11.
IF DE_AUT2=96 aut_age_11=99.
IF DE_AUT2=95 aut_age_11=95.
IF (SYSMIS(DE_AUT2)) aut_age_11=90.
VARIABLE LABELS aut_age_11 "Age when parent was first told by Dr that child had ASD (ever and current diagnosis)".
VALUE LABELS aut_age_11
1 "0-2 years"
2 "3-5 years"
3 "6-17 years"
90 "System missing"
95 "No one ever told child has ASD"
99 "DK".
FORMATS aut_age_11 (F4.0).
MISSING VALUES aut_age_11(90,95,99).
EXECUTE.

COMPUTE dev_age_all=999.
IF DE_DEV2A=2 dev_age_all=DE_DEV2*1.
IF DE_DEV2A=1 dev_age_all=DE_DEV2/12.

RECODE dev_age_all

(0 thru 2.99=1) (3.0 thru 5.9=2) (6.0 thru 17=3) (else=copy) into dev_age_11.

IF DE_DEV2=96 dev_age_11=99.

IF DE_DEV2=95 dev_age_11=95.

IF (SYSMIS(DE_DEV2)) dev_age_11=90.

VARIABLE LABELS dev_age_11 "Age when parent was first told by Dr that child had developmental delay (ever and current diagnosis)".

VALUE LABELS dev_age_11

1 "0-2 years"

2 "3-5 years"

3 "6-17 years"

90 "System missing"

95 "No one ever told child has DD"

99 "DK".

FORMATS dev_age_11 (F4.0).

MISSING VALUES dev_age_11(90,95,99).

EXECUTE.

COMPUTE int_age_all=999.

IF DE_INT2A=2 int_age_all=DE_INT2*1.

IF DE_INT2A=1 int_age_all=DE_INT2/12.

RECODE int_age_all

(0 thru 2.99=1) (3.0 thru 5.9=2) (6.0 thru 17=3) (else=copy) into int_age_11.

IF DE_INT2=96 int_age_11=99.

IF DE_INT2=95 int_age_11=95.

IF (SYSMIS(DE_INT2)) int_age_11=90.

VARIABLE LABELS int_age_11 "Age when parent was first told by Dr that child had intellectual disability (ever and current diagnosis)".

VALUE LABELS int_age_11

1 "0-2 years"

2 "3-5 years"

3 "6-17 years"

90 "System missing"

95 "No one ever told child has ID"

99 "DK".

FORMATS int_age_11 (F4.0).

MISSING VALUES int_age_11(90,95,99).

EXECUTE.

COMPUTE any_age_11 = 999.

IF aut_age_11 = 3 or int_age_11 = 3 or dev_age_11 = 3 any_age_11 = 3.

IF aut_age_11 = 2 or int_age_11 = 2 or dev_age_11 = 2 any_age_11 = 2.

IF aut_age_11 = 1 or int_age_11 = 1 or dev_age_11 = 1 any_age_11 = 1.

IF aut_age_11 >89 and int_age_11 >89 and dev_age_11 >89 any_age_11 = 99.

VARIABLE LABELS any_age_11 "Age when parent was first told by Dr that child EVER had any of 3 developmental condition (ASD, ID, or DD)".

VALUE LABELS any_age_11

1 "0-2 years"

2 "3-5 years"

3 "6-7 years"

99 "No one ever told child has ASD, ID, or DD/SYSMIS/DK".

FORMATS any_age_11(f4.0).

MISSING VALUES any_age_11(90,95,99).

EXECUTE.

Type of ASD diagnosis	
Description	Did the doctors, health care providers, or school professionals ever tell you that child had any of the 3 conditions: Asperger's, pervasive developmental disorder or autistic disorder?
Survey Items Used	DE_AUT5A: DE_AUT5B; DE_AUT5C
Denominator	CSHCN 6-17 years old with current autism spectrum disorder
Numerator	Types of ASD diagnosis: Asperger's Disorder; Pervasive Developmental Disorder; Autistic Disorder; Multiple diagnosis

Notes for Data-Users
N/A

SPSS Syntax and Annotation

COMPUTE dx_autyp_11 = 999.

IF (DE_AUT5A=6=0 or DE_AUT5A=6 or DE_AUT5A=7 or (SYSMIS(DE_AUT5A))) or (DE_AUT5B=0 or DE_AUT5B=6 or DE_AUT5B=7 or (SYSMIS(DE_AUT5B))) or

(DE_AUT5C=0 or DE_AUT5C=6 or DE_AUT5C=7 or (SYSMIS(DE_AUT5C))) dx_autyp_11=99.

IF DE_AUT5A = 1 dx_autyp_11 = 1.

IF DE_AUT5B = 1 dx_autyp_11 = 2.

IF DE_AUT5C = 1 dx_autyp_11 = 3.

IF (DE_AUT5A = 1 and DE_AUT5B = 1) or (DE_AUT5A = 1 and DE_AUT5C = 1) or (DE_AUT5B = 1 and DE_AUT5C = 1) dx_autyp_11 = 4.

IF (SYSMIS(DE_AUT5A)) dx_autyp_11 = 90.

VARIABLE LABELS dx_autyp_11 "Among CSHCN w/autism, was ever told child had Asperger's, Pervasive Developmental Disorder (PDD), Autistic Disorder, or multiple diagnosis".

VALUE LABELS dx_autyp_11

1 "Asperger's Disorder"

2 "Pervasive Developmental Disorder "

3 "Autistic Disorder"

4 "Multiple diagnosis"

90 "No ASD"

99 "DK/Ref/Missing in error".

FORMATS dx_autyp_11(f4.0).

MISSING VALUES dx_autyp_11(90,99).

EXECUTE.

Ever had Asperger's Disorder

Description	Did doctors, health care providers, or school professionals ever tell you the child had Asperger's Disorder?
Survey Items Used	DE_AUT5A
Denominator	CSHCN 6-17 years old with current autism spectrum disorder
Numerator	Yes, have been told they have Asperger's Disorder; No, have not been told they have Asperger's Disorder

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE DE_AUT5A (0=2) (1=1) (6 thru 7=99) (SYSMIS=90) into asperger_11. VARIABLE LABELS asperger_11 "Among CSHCN with autism, parent was ever told child had Asperger's". VALUE LABELS asperger_11 1 "Yes, parent was ever told child had Asperger's" 2 "No, parent never told child had Asperger's" 90 "CSHCN without autism" 99 "DK/Ref". FORMATS asperger_11(f4.0). MISSING VALUES asperger_11(90,99). EXECUTE

Ever had pervasive development disorder	
Description	Did doctors, health care providers, or school professionals ever tell you the child had pervasive development disorder (PDD)?
Survey Items Used	DE_AUT5B
Denominator	CSHCN 6-17 years old with current autism spectrum disorder
Numerator	Yes, have been told they have PDD; No, have not been told they have PDD
Notes for Data-Users	
N/A	
SPSS Syntax and Annotation	

RECODE DE_AUT5B

(0=2) (1=1) (6 thru 7=99) (SYSMIS=90) into pdd_11.

VARIABLE LABELS pdd_11 "Among CSHCN with autism, parent was ever told child had Pervasive Developmental Disorder (PDD)".

VALUE LABELS pdd_11

1 "Yes, parent was ever told child had PDD"

2 "No, parent never told child had PDD"

90 "CSHCN without PDD"

99 "DK/Ref".

FORMATS pdd_11(f4.0).

MISSING VALUES pdd_11(90,99).

EXECUTE.

Ever had autism disorder

Description	Did doctors, health care providers, or school professionals ever tell you the child had autism disorder?
Survey Items Used	DE_AUT5C
Denominator	CSHCN 6-17 years old with current autism spectrum disorder
Numerator	Yes, have been told they have autism disorder; No, have not been told they have autism disorder

Notes for Data-Users

N/A

SPSS Syntax and Annotation

RECODE DE_AUT5C

 (0=2) (1=1) (6 thru 7=99) (SYSMIS=90) into autdisrd_11.

VARIABLE LABELS autdisrd_11 "Among CSHCN with autism, parent was ever told child had Autistic Disorder".

VALUE LABELS autdisrd_11

1 "Yes, parent was ever told child had Autistic Disorder"

2 "No, parent never told child had Autistic Disorder"

90 "CSHCN without PDD"

99 "DK/Ref".

FORMATS autdisrd_11(f4.0).

MISSING VALUES autdisrd_11(90,99).

EXECUTE.

Age when parent was first told child had ASD

Description	How old was child when you were first told he/she had ASD?
Survey Items Used	DE_AUT2; DE_AUT2A
Denominator	CSHCN age 6-17 years with current autism spectrum disorder
Numerator	Child's age when parent first told: 0-2 years old; 3-5 years old; 6-17 years old

Notes for Data-Users
N/A

SPSS Syntax and Annotation

COMPUTE aut_age_all=999.
IF DE_AUT2A=2 aut_age_all=DE_AUT2*1.
IF DE_AUT2A=1 aut_age_all=DE_AUT2/12.

RECODE aut_age_all
(0 thru 2.99=1) (3.0 thru 5.9=2) (6.0 thru 17=3) (else=copy) into aut_age_11.
IF DE_AUT2=96 aut_age_11=99.
IF DE_AUT2=95 aut_age_11=95.
IF (SYSMIS(DE_AUT2)) aut_age_11=90.
VARIABLE LABELS aut_age_11 "Age when parent was first told by Dr that child had ASD (ever and current diagnosis)".
VALUE LABELS aut_age_11
1 "0-2 years"
2 "3-5 years"
3 "6-17 years"
90 "System missing"
95 "No one ever told child has ASD"
99 "DK".
FORMATS aut_age_11 (F4.0).
MISSING VALUES aut_age_11(90,95,99).
EXECUTE.

Child's parents were told child did not have ASD

Description	Has a doctor, health care provider, or school professional ever told you that child did not have autism spectrum disorder (ASD) since learning he/she had ASD?
Survey Items Used	DE_AUT6
Denominator	CSHCN 6-17 years old with current autism spectrum disorder
Numerator	Yes, have been told since having ASD that they do not have ASD; No, have never been told they do not have ASD

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE no_aut_11 = 999.

IF DE_AUT6 = 1 no_aut_11 = 1.

IF DE_AUT6 = 0 no_aut_11 = 2.

IF DE_AUT6 = 6 or DE_AUT6=7 no_aut_11 = 99.

IF (SYSMIS(DE_AUT6)) no_aut_11=90.

VARIABLE LABELS no_aut_11 " Parents who were ever told by a doctor, health care provider, or school professional that child did not have autism or ASD since child was first diagnosed".

VALUE LABELS no_aut_11

1 "Yes have been told since having ASD that they do not have ASD"

2 "No, have never been told that they do not have ASD"

90 "System missing"

99 "DK/Ref".

FORMATS no_aut_11(f3.0).

MISSING VALUES no_aut_11(90,99).

EXECUTE.

Type of doctor who first diagnosed ASD

Description	What type of doctor first diagnosed child with autism spectrum disorder?
Survey Items Used	DE_AUT1R
Denominator	CSHCN ages 6-17 years with current autism spectrum disorder
Numerator	Type of health care provider: Pediatrician or family health care practitioner; Psychologist; Specialist; Multidisciplinary team/Other

Notes for Data-Users
N/A

SPSS Syntax and Annotation

COMPUTE drdx_aut_11 = 999.

IF DE_AUT1R =1 or DE_AUT1R=2 drdx_aut_11 = 1.

IF DE_AUT1R =4 or DE_AUT1R=5 drdx_aut_11 = 2.

IF DE_AUT1R =3 or DE_AUT1R=6 or DE_AUT1R=7 or DE_AUT1R=10 drdx_aut_11 = 3.

IF DE_AUT1R = 13 drdx_aut_11 = 4.

IF DE_AUT1R =8 or DE_AUT1R=9 or DE_AUT1R=11 or DE_AUT1R=12 drdx_aut_11 = 4.

IF DE_AUT1R=96 drdx_aut_11=99.

IF DE_AUT1R=14 drdx_aut_11=95.

IF (SYSMIS(DE_AUT1R)) drdx_aut_11 = 90.

VARIABLE LABELS drdx_aut_11 "Health care provider who first gave Autism diagnosis (ever & current diagnosis)".

VALUE LABELS drdx_aut_11

1 "Pediatrician or Pediatric/Family HCP"

2 "Psychologist"

3 "Specialist Dr"

4 "Multidisciplinary Team/Other"

90 "System missing"

95 "Never told child had condition"

99 "DK".

FORMATS drdx_aut_11(f4.0).

MISSING VALUES drdx_aut_11(90,95,99).

Diagnostic Experiences

Age at which parent was first told child had developmental delay	
Description	How old was child when you were first told he/she had developmental delay?
Survey Items Used	DE_DEV2; DE_DEV2A
Denominator	CSHCN age 6-17 years with current developmental delay
Numerator	CSHCN who were first told they had developmental delay: 0-2 years old; 3-5 years old; 6-17 years old
Notes for Data-Users	
N/A	
SPSS Syntax and Annotation	

COMPUTE dev_age_all=999.
IF DE_DEV2A=2 dev_age_all=DE_DEV2*1.
IF DE_DEV2A=1 dev_age_all=DE_DEV2/12.

RECODE dev_age_all
(0 thru 2.99=1) (3.0 thru 5.9=2) (6.0 thru 17=3) (else=copy) into dev_age_11.
IF DE_DEV2=96 dev_age_11=99.
IF DE_DEV2=95 dev_age_11=95.
IF (SYSMIS(DE_DEV2)) dev_age_11=90.
VARIABLE LABELS dev_age_11 "Age when parent was first told by Dr that child had developmental delay (ever and current diagnosis)".
VALUE LABELS dev_age_11
1 "0-2 years"
2 "3-5 years"
3 "6-17 years"
90 "System missing"
95 "No one ever told child has DD"
99 "DK".
FORMATS dev_age_11 (F4.0).
MISSING VALUES dev_age_11(90,95,99).
EXECUTE.

Child's parents were told child did not have developmental delay

Description	Has a doctor, health care provider, or school professional ever told you that child did not have developmental delay since learning he/she had developmental delay?
Survey Items Used	DE_DEV6
Denominator	CSHCN 6-17 years old with current developmental delay
Numerator	Yes, have been told since having developmental delay (DD) that they do not have DD; No, have never been told that they do not have DD

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE no_dev_11 = 999.

IF DE_DEV6 = 1 no_dev_11 = 1.

IF DE_DEV6 = 0 no_dev_11 = 2.

IF DE_DEV6 =6 or DE_DEV6=7 no_dev_11 = 99.

IF (SYSMIS(DE_DEV6)) no_dev_11=90.

VARIABLE LABELS no_dev_11 "Parents who were ever told by a doctor, health care provider, or school professional that child did not have developmental delay since child was first diagnosed".

VALUE LABELS no_dev_11

1 "Yes have been told since having DD that they do not have DD"

2 "   No, have never been told that they do not have DD"

90 "System missing"

99 "DK/Ref".

FORMATS no_dev_11(f3.0).

MISSING VALUES no_dev_11(90,99).

EXECUTE.

Type of doctor who first diagnosed developmental delay

Description	What type of doctor first diagnosed child with developmental delay?
Survey Items Used	DE_DEV1R
Denominator	CSHCN 6-17 years old with current developmental delay
Numerator	Type of health care provider: Pediatrician or family health care practitioner; Psychologist; Specialist; Multidisciplinary team/Other

Notes for Data-Users
N/A

SPSS Syntax and Annotation

COMPUTE drdx_dev_11 = 999.

IF DE_DEV1R =1 or DE_DEV1R=2 drdx_dev_11 = 1.

IF DE_DEV1R =4 or DE_DEV1R=5 drdx_dev_11 = 2.

IF DE_DEV1R =3 or DE_DEV1R=6 or DE_DEV1R=7 or DE_DEV1R=10 drdx_dev_11 = 3.

IF DE_DEV1R = 13 drdx_dev_11 = 4.

IF DE_DEV1R =8 or DE_DEV1R=9 or DE_DEV1R=11 or DE_DEV1R=12 drdx_dev_11 = 4.

IF DE_DEV1R=96 or DE_DEV1R=97 drdx_dev_11=99.

IF DE_DEV1R=14 drdx_dev_11=95.

IF (SYSMIS(DE_DEV1R)) drdx_dev_11 = 90.

VARIABLE LABELS drdx_dev_11 "Health care provider who first gave developmental delay diagnosis (ever & current diagnosis)".

VALUE LABELS drdx_dev_11

1 "Pediatrician or Pediatric/Family HCP"

2 "Psychologist"

3 "Specialist Dr"

4 "Multidisciplinary Team/Other"

90 "System missing"

95 "Never told child had condition"

99 "DK".

FORMATS drdx_dev_11(f4.0).

MISSING VALUES drdx_dev_11().

Age at which parent was first told child had intellectual disability

Description	How old was child when you were first told he/she had intellectual disability?
Survey Items Used	DE_INT2; DE_INT2A
Denominator	CSHCN age 6-17 years with current intellectual disability
Numerator	CSHCN who were first told they had intellectual disability at: 0-2 years old; 3-5 years old; 6-17 years old

Notes for Data-Users

N/A

SPSS Syntax and Annotation

```
COMPUTE int_age_all=999.
IF DE_INT2A=2 int_age_all=DE_INT2*1.
IF DE_INT2A=1 int_age_all=DE_INT2/12.

RECODE int_age_all
(0 thru 2.99=1) (3.0 thru 5.9=2) (6.0 thru 17=3) (else=copy) into int_age_11.
IF DE_INT2=96 int_age_11=99.
IF DE_INT2=95 int_age_11=95.
IF (SYSMIS(DE_INT2)) int_age_11=90.
VARIABLE LABELS int_age_11 "Age when parent was first told by Dr that child had intellectual disability
(ever and current diagnosis)".
VALUE LABELS int_age_11
1 "0-2 years"
2 "3-5 years"
3 "6-17 years"
90 "System missing"
95 "No one ever told child has ID"
99 "DK".
FORMATS int_age_11 (F4.0).
MISSING VALUES int_age_11(90,95,99).
EXECUTE.
```

Child's parents were told child did not have intellectual disability

Description	Has a doctor, health care provider, or school professional ever told you that child did not have intellectual disability since learning he/she had intellectual disability?
Survey Items Used	DE_INT6
Denominator	CSHCN 6-17 years old with current intellectual disability
Numerator	Yes, have been told since having intellectual disability (ID) that they do not have ID; No, have never been told that they do not have ID

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE no_int_11 = 999.

IF DE_INT6 = 1 no_int_11 = 1.

IF DE_INT6 = 0 no_int_11 = 2.

IF DE_INT6 =6 or DE_INT6=7 no_int_11 =99.

IF (SYSMIS(DE_INT6)) no_int_11 =90.

VARIABLE LABELS no_int_11 "Parents who were ever told by a doctor, health care provider, or school professional that child did not have intellectual disability since child was first diagnosed".

VALUE LABELS no_int_11

1 "Yes have been told since having DD that they do not have ID"

2 "No, have never been told that they do not have ID"

90 "System missing"

99 "DK/Ref".

FORMATS no_int_11(f3.0).

MISSING VALUES no_int_11(90,99).

EXECUTE.

Type of doctor who first diagnosed intellectual disability
Description	What type of doctor first diagnosed child with intellectual disability?
Survey Items Used	DE_INT1R
Denominator	CSHCN ages 6-17 years with current intellectual disability
Numerator	Type of health care provider: Pediatrician or family health care practitioner; Psychologist; Specialist; Multidisciplinary team/Other
Notes for Data-Users	
N/A	
SPSS Syntax and Annotation	

COMPUTE drdx_int_11 = 999.

IF DE_INT1R =1 or DE_INT1R=2 drdx_int_11 = 1.

IF DE_INT1R =4 or DE_INT1R=5 drdx_int_11 = 2.

IF DE_INT1R =3 or DE_INT1R=6 or DE_INT1R=7 or DE_INT1R=10 drdx_int_11 = 3.

IF DE_INT1R = 13 drdx_int_11 = 4.

IF DE_INT1R =8 or DE_INT1R=9 or DE_INT1R=11 or DE_INT1R=12 drdx_int_11 = 4.

IF DE_INT1R=96 drdx_int_11=99.

IF DE_INT1R=14 drdx_int_11=95.

IF (SYSMIS(DE_INT1R)) drdx_int_11 = 90.

VARIABLE LABELS drdx_int_11 "Health care provider ho first gave Intellectual Disability diagnosed (ever & current diagnosis)".

VALUE LABELS drdx_int_11

1 "Pediatrician or Pediatric/Family HCP"

2 "Psychologist"

3 "Specialist Dr"

4 "Multidisciplinary Team/Other"

90 "System missing"

95 "Never told child had condition"

99 "DK".

FORMATS drdx_int_11(f4.0).

MISSING VALUES drdx_int_11(90,95,99).

Health and Education Services

Number of health and related services used	

Description	How many CSHCN currently use one or more health care services on regular basis to meet their developmental needs, out of 7 types of health services?
Survey Items Used	HCS1_A; HCS1_A_2; HCS1_B; HCS1_B_2; HCS1_C; HCS1_C_2; HCS1_D; HCS1_D_2; HCS1_F; HCS1_F_2; HCS1_G; HCS1_G_2; HCS1_H; HCS1_H_2; HCS1_I; HCS1_I_2; HCS1_J; HCS1_J_2; HCS1_K; HCS1_K_2
Denominator	CSHCN ages 6-17 years with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	No health care services used; 1 health care service used; 2 health care services used; 3+ health care services used

Notes for Data-Users
15% of survey respondents had missing values for between 1 and 6 of the 7 possible services from the list

SPSS Syntax and Annotation

COMPUTE hcs_bi_11=999.

IF HCS1_A_2=1 hcs_bi_11=1.

IF HCS1_A=0 or HCS1_A_2=0 hcs_bi_11=2.

IF HCS1_A=6 or HCS1_A_2=6 or HCS1_A_2=7 hcs_bi_11=99.

VARIABLE LABELS hcs_bi_11 "Currently use behavioral intervention or modification services on a regular basis?".

VALUE LABELS hcs_bi_11

1 "Yes, child currently use the services"

2 "No, child does not currently use the services"

99 "DK/Ref".

FORMATS hcs_bi_11(f2.0).

*MISSING VALUES hcs_bi_11(99).

COMPUTE hcs_si_11=999.

IF HCS1_B_2=1 hcs_si_11=1.

IF HCS1_B=0 or HCS1_B_2=0 hcs_si_11=2.

IF HCS1_B=6 or HCS1_B=7 or HCS1_B_2=6 or HCS1_B_2=7 hcs_si_11=99.

VARIABLE LABELS hcs_si_11 "Currently use sensory integration therapy on a regular basis?".

VALUE LABELS hcs_si_11

1 "Yes, child currently uses the therapy"

2 "No, child does not currently use the therapy"

99 "DK/Ref".

FORMATS hcs_si_11(f2.0).

*MISSING VALUES hcs_si_11(99).

COMPUTE hcs_ct_11=999.

IF HCS1_C_2=1 hcs_ct_11=1.

IF HCS1_C=0 or HCS1_C_2=0 hcs_ct_11=2.

IF HCS1_C=6 or HCS1_C=7 or HCS1_C_2=6 or HCS1_C_2=7 hcs_ct_11=99.

VARIABLE LABELS hcs_ct_11 "Currently use cognitive based therapy on a regular basis?".

VALUE LABELS hcs_ct_11

1 "Yes, child currently uses the therapy"

2 "No, child does not currently use the therapy"

99 "DK/Ref".

FORMATS hcs_ct_11(f2.0).

*MISSING VALUES hcs_ct_11(99).

COMPUTE hcs_ot_11=99.

IF HCS1_D_2=1 or HCS1_E_2=1 hcs_ot_11=1.

IF (HCS1_D=0 or HCS1_D_2=0) and (HCS1_E=0 or HCS1_E_2=0) hcs_ot_11=2.

VARIABLE LABELS hcs_ot_11 "Currently use occupational therapy (school-based or other) on a regular basis?".

VALUE LABELS hcs_ot_11

1 "Yes, child currently uses the therapy"

2 "No, child does not currently use the therapy"

99 "DK/Ref".

FORMATS hcs_ot_11(f2.0).

*MISSING VALUES hcs_ot_11(99).

COMPUTE hcs_pt_11=99.

IF HCS1_F_2=1 or HCS1_G_2=1 hcs_pt_11=1.

IF (HCS1_F=0 or HCS1_F_2=0) and (HCS1_G=0 or HCS1_G_2=0) hcs_pt_11=2.

VARIABLE LABELS hcs_pt_11 "Currently use physical therapy (school-based or other) on a regular basis?".

VALUE LABELS hcs_pt_11

1 "Yes, child currently uses the therapy"

2 "Child does not currently use the therapy"

99 "DK/Ref".

FORMATS hcs_pt_11(f2.0).

*MISSING VALUES hcs_pt_11(99).

RECODE HCS1_F_2 HCS1_G_2

(SYSMIS=999) (else=copy) into HCS1_F_2R HCS1_G_2R.

COMPUTE hcs_st_11=99.

IF HCS1_H_2=1 or HCS1_I_2=1 hcs_st_11=1.

IF (HCS1_H=0 or HCS1_H_2=0) and (HCS1_I=0 or HCS1_I_2=0) hcs_st_11=2.

VARIABLE LABELS hcs_st_11 "Currently use social skills training (school-based or other) on a regular basis?".

VALUE LABELS hcs_st_11

1 "Yes, child currently uses the services"

2 "No, child does not currently use the services"

99 "DK/Ref".

FORMATS hcs_st_11(f2.0).

*MISSING VALUES hcs_st_11(99).

COMPUTE hcs_lt_11=99.

IF HCS1_J_2=1 or HCS1_K_2=1 hcs_lt_11=1.

IF (HCS1_J=0 or HCS1_J_2=0) and (HCS1_K=0 or HCS1_K_2=0) hcs_lt_11=2.

VARIABLE LABELS hcs_lt_11 "Currently use speech or language therapy (school-based or other) on a regular basis?".

VALUE LABELS hcs_lt_11

1 "Yes, child currently uses the therapy"

2 "No, child does not currently use the therapy"

99 "DK/Ref".

FORMATS hcs_lt_11(f2.0).

*MISSING VALUES hcs_lt_11(99).

COUNT hcs_num_11=hcs_bi_11 hcs_si_11 hcs_ct_11 hcs_ot_11 hcs_pt_11 hcs_st_11 hcs_lt_11(1).

IF hcs_bi_11=99 and hcs_si_11=99 and hcs_ct_11=99 and hcs_ot_11=99 and hcs_pt_11=99 and hcs_st_11=99 and hcs_lt_11=99 hcs_num_11=99.

VARIABLE LABELS hcs_num_11 "Number of services CSHCN currently use".

COMPUTE hcscount_11=999.

IF hcs_num_11=0 hcscount_11=0.

IF hcs_num_11=1 hcscount_11=1.

IF hcs_num_11=2 hcscount_11=2.

IF hcs_num_11>2 hcscount_11=3.

IF hcs_num_11=99 hcscount_11=99.

VARIABLE LABELS hcscount_11 "Currently use 3 or more of 7 types of health care services to meet their developmental needs".

VALUE LABELS hcscount_11

0 "Do not use any services"

1 "One service"

2 "Two services"

3 "Three or more services"

99 "DK/Ref to all".

MISSING VALUES hcscount_11(99).

FORMATS hcscount_11(f2.0).

Currently use behavioral intervention or modification services	
Description	Does child currently use behavioral intervention or modification services on a regular basis?
Survey Items Used	HCS1_A; HCS1_A_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, uses this type of service; No, does not use this type of service

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE hcs_bi_11=999.

IF HCS1_A_2=1 hcs_bi_11=1.

IF HCS1_A=0 or HCS1_A_2=0 hcs_bi_11=2.

IF HCS1_A=6 or HCS1_A_2=6 or HCS1_A_2=7 hcs_bi_11=99.

VARIABLE LABELS hcs_bi_11 "Currently use behavioral intervention or modification services on a regular basis?".

VALUE LABELS hcs_bi_11

1 "Yes, child currently use the services"

2 "No, child does not currently use the services"

99 "DK/Ref".

FORMATS hcs_bi_11(f2.0).

*MISSING VALUES hcs_bi_11(99).

EXECUTE.

Currently use sensory integration therapy
Description	Does child currently use sensory integration therapy on a regular basis?
Survey Items Used	HCS1_B; HCS1_B_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, uses this type of service; No, does not use this type of service

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE hcs_si_11=999.
IF HCS1_B_2=1 hcs_si_11=1.
IF HCS1_B=0 or HCS1_B_2=0 hcs_si_11=2.
IF HCS1_B=6 or HCS1_B=7 or HCS1_B_2=6 or HCS1_B_2=7 hcs_si_11=99.
VARIABLE LABELS hcs_si_11 "Currently use sensory integration therapy on a regular basis?".
VALUE LABELS hcs_si_11
1 "Yes, child currently uses the therapy"
2 "No, child does not currently use the therapy"
99 "DK/Ref".
FORMATS hcs_si_11(f2.0).
*MISSING VALUES hcs_si_11(99).
EXECUTE.

Currently use cognitive based therapy

Description	Does child currently use cognitive based therapy on a regular basis?
Survey Items Used	HCS1_C; HCS1_C_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, uses this type of service; No, does not use this type of service

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE hcs_ct_11=999.
IF HCS1_C_2=1 hcs_ct_11=1.
IF HCS1_C=0 or HCS1_C_2=0 hcs_ct_11=2.
IF HCS1_C=6 or HCS1_C=7 or HCS1_C_2=6 or HCS1_C_2=7 hcs_ct_11=99.
VARIABLE LABELS hcs_ct_11 "Currently use cognitive based therapy on a regular basis?".
VALUE LABELS hcs_ct_11
1 "Yes, child currently uses the therapy"
2 "No, child does not currently use the therapy"
99 "DK/Ref".
FORMATS hcs_ct_11(f2.0).
*MISSING VALUES hcs_ct_11(99).
EXECUTE.

Currently use occupational therapy

Description	Does child currently use occupational therapy on a regular basis?
Survey Items Used	HCS1_D; HCS1_D_2
Denominator	CSHCN ages 6-17 years with current ASD, ID and/or DD
Numerator	Yes, uses this type of service; No, does not use this type of service

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE hcs_ot_11=99. IF HCS1_D_2=1 or HCS1_E_2=1 hcs_ot_11=1. IF (HCS1_D=0 or HCS1_D_2=0) and (HCS1_E=0 or HCS1_E_2=0) hcs_ot_11=2. VARIABLE LABELS hcs_ot_11 "Currently use occupational therapy (school-based or other) on a regular basis?". VALUE LABELS hcs_ot_11 1 "Yes, child currently uses the therapy" 2 "No, child does not currently use the therapy" 99 "DK/Ref". FORMATS hcs_ot_11(f2.0). *MISSING VALUES hcs_ot_11(99). EXECUTE.

Currently use physical therapy
Description	Does child currently use physical therapy on a regular basis?
Survey Items Used	HCS1_F; HCS1_F_2; HCS1_G; HCS1_G_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, uses this type of service; No, does not use this type of service

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE hcs_pt_11=99.
IF HCS1_F_2=1 or HCS1_G_2=1 hcs_pt_11=1.
IF (HCS1_F=0 or HCS1_F_2=0) and (HCS1_G=0 or HCS1_G_2=0) hcs_pt_11=2.
VARIABLE LABELS hcs_pt_11 "Currently use physical therapy (school-based or other) on a regular basis?".
VALUE LABELS hcs_pt_11
1 "Yes, child currently uses the therapy"
2 "Child does not currently use the therapy"
99 "DK/Ref".
FORMATS hcs_pt_11(f2.0).
*MISSING VALUES hcs_pt_11(99).
EXECUTE.

Currently use social skills training	
Description	Does child currently use social skills training on a regular basis?
Survey Items Used	HCS1_H; HCS1_H_2; HCS1_I; HCS1_I_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder (ASD), developmental delay (DD), and/or intellectual disability (ID)
Numerator	Yes, uses this type of service; No, does not use this type of service

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE hcs_st_11=99. IF HCS1_H_2=1 or HCS1_I_2=1 hcs_st_11=1. IF (HCS1_H=0 or HCS1_H_2=0) and (HCS1_I=0 or HCS1_I_2=0) hcs_st_11=2. VARIABLE LABELS hcs_st_11 "Currently use social skills training (school-based or other) on a regular basis?". VALUE LABELS hcs_st_11 1 "Yes, child currently uses the services" 2 "No, child does not currently use the services" 99 "DK/Ref". FORMATS hcs_st_11(f2.0). *MISSING VALUES hcs_st_11(99). EXECUTE.

Currently use speech or language therapy
Description	Does child currently use speech or language therapy on a regular basis?
Survey Items Used	HCS1_J; HCS1_J_2; HCS1_K; HCS1_K_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, uses this type of service; No, does not use this type of service

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE hcs_lt_11=99.

IF HCS1_J_2=1 or HCS1_K_2=1 hcs_lt_11=1.

IF (HCS1_J=0 or HCS1_J_2=0) and (HCS1_K=0 or HCS1_K_2=0) hcs_lt_11=2.

VARIABLE LABELS hcs_lt_11 "Currently use speech or language therapy (school-based or other) on a regular basis?".

VALUE LABELS hcs_lt_11

1 "Yes, child currently uses the therapy"

2 "No, child does not currently use the therapy"

99 "DK/Ref".

FORMATS hcs_lt_11(f2.0).

*MISSING VALUES hcs_lt_11(99).

EXECUTE.

Number of providers children currently work with	
Description	How many CSHCN currently work with one or more providers of health and related services to meet their developmental needs out of 8 types of providers?
Survey Items Used	HCS2_A; HCS2_A_2; HCS2_B; HCS2_B_2; HCS2_C; HCS2_C_2; HCS2_D: HCS2_D_2; HCS2_E; HCS2_E_2; HCS2_E; HCS2_E_2; HCS2_F; HCS2_F_2; HCS2_G; HCS2_G_2; HCS2_H; HCS2_H_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	No providers currently seen; 1 provider currently seen; 2 or more providers currently seen

Notes for Data-Users
N/A

SPSS Syntax and Annotation

```
COMPUTE audiolog_11 = 999.
IF HCS2_A = 0 or HCS2_A_2 = 0 audiolog_11 = 2.
IF HCS2_A_2 = 1 audiolog_11 = 1.
IF HCS2_A=6 or HCS2_A_2=6 audiolog_11 =99.
VARIABLE LABELS audiolog_11 "Currently work with an audiologist on a regular basis".
VALUE LABELS audiolog_11
1 "Yes, child works with audiologist"
2 "No, child does not work with audiologist"
99 "DK".
FORMATS audiolog_11(f2.0).
*MISSING VALUES audiolog_11(99).
EXECUTE.


COMPUTE devped_11 = 999.
IF HCS2_B = 0 or HCS2_B_2 = 0 devped_11 = 2.
IF HCS2_B_2 = 1 devped_11 = 1.
IF HCS2_B=6 or HCS2_B_2=6 or HCS2_B_2=7 devped_11=99.
VARIABLE LABELS devped_11 "Currently work with a developmental pediatrician on a regular basis".
VALUE LABELS devped_11
1 "Yes, child works with developmental pediatricians"
2 "No, child does not work with developmental pediatricians"
99 "DK".
FORMATS devped_11(f2.0).
*MISSING VALUES devped_11(99).
EXECUTE.
```

COMPUTE neurolog_11 = 999.

IF HCS2_C = 0 or HCS2_C_2 = 0 neurolog_11 = 2.

IF HCS2_C_2 = 1 neurolog_11 = 1.

IF HCS2_C=6 or HCS2_C_2=6 or HCS2_C_2=7 neurolog_11=99.

VARIABLE LABELS neurolog_11 "Currently work with a neurologist on a regular basis".

VALUE LABELS neurolog_11

1 "Yes, child works with neurologist"

2 "No, child does not work with neurologist"

99 "DK".

FORMATS neurolog_11(f2.0).

*MISSING VALUES neurolog_11(99).

EXECUTE.

COMPUTE nutritn_11 = 999.

IF HCS2_D = 0 or HCS2_D_2 = 0 nutritn_11 = 2.

IF HCS2_D_2 = 1 nutritn_11 = 1.

IF HCS2_D=6 or HCS2_D_2=6 or HCS2_D_2=7 nutritn_11=99.

VARIABLE LABELS nutritn_11 "Currently work with a nutritionist on a regular basis".

VALUE LABELS nutritn_11

1 "Yes, child works with nutritionist"

2 "No, child does not work with nutritionist"

99 "DK".

FORMATS nutritn_11(f2.0).

*MISSING VALUES nutritn_11(99).

EXECUTE.

COMPUTE nurse_11 = 999.

IF HCS2_E = 0 or HCS2_E_2 = 0 nurse_11 = 2.

IF HCS2_E_2 = 1 nurse_11 = 1.

IF HCS2_E=6 nurse_11 = 99.

VARIABLE LABELS nurse_11 "Currently work with an at home/long-term nurse on a regular basis".

VALUE LABELS nurse_11

1 "Yes, child works with an at home/long-term nurse"

2 "No, child does not work with an at home/long-term nurse"

99 "DK".

FORMATS nurse_11(f2.0).

*MISSING VALUES nurse_11(99).

EXECUTE.

COMPUTE psychiat_11 = 999.

IF HCS2_F = 0 or HCS2_F_2 = 0 psychiat_11= 2.

IF HCS2_F_2 = 1 psychiat_11 = 1.

IF HCS2_F=6 or HCS2_F_2=6 or HCS2_F_2=7 psychiat_11=99.

VARIABLE LABELS psychiat_11 "Currently work with a psychiatrist on a regular basis".

VALUE LABELS psychiat_11

1 "Yes, child works with psychiatrist"

2 "No, child does not work with psychiatrist"

99 "DK".

FORMATS psychiat_11(f2.0).

*MISSING VALUES psychiat_11(99).

EXECUTE.

COMPUTE psychlog_11 = 999.

IF HCS2_G = 0 or HCS2_G_2 = 0 psychlog_11 = 2.

IF HCS2_G_2 = 1 psychlog_11 = 1.

IF HCS2_G=6 or HCS2_G_2=6 or HCS2_G_2=7 psychlog_11=99.

VARIABLE LABELS psychlog_11 "Currently work with a psychologist/psychotherapist on a regular basis".

VALUE LABELS psychlog_11

1 "Yes, child works with psychologist/psychotherapist"

2 "No, child does not work with psychologist/psychotherapist"

99 "DK".

FORMATS psychlog_11(f2.0).

*MISSING VALUES psychlog_11(99).

EXECUTE.

COMPUTE socwork_11 = 999.

IF HCS2_H = 0 or HCS2_H_2 = 0 socwork_11 = 2.

IF HCS2_H_2 = 1 socwork_11 = 1.

IF HCS2_H=6 or HCS2_H_2=6 or HCS2_H_2=7 socwork_11=99.

VARIABLE LABELS socwork_11 "Currently work with a social worker on a regular basis".

VALUE LABELS socwork_11

1 "Yes, child works with a social worker"

2 "No, child does not work with a social worker"

99 "DK".

FORMATS socwork_11(f2.0).

*MISSING VALUES socwork_11(99).

EXECUTE.

COUNT dr_num_11 = audiolog_11 devpediat_11 neurolog_11 nutrition_11 nurse_11 psychiat_11 psycholog_11 socwork_11(1).

VARIABLE LABELS dr_num_11 "Number of providers CSHCN currently work with on a regular basis".

COMPUTE dr_count_11=999.

IF dr_num_11=0 dr_count_11 = 0.

IF dr_num_11=1 dr_count_11 = 1.

IF dr_num_11 > 1 dr_count_11 = 2.

IF audiolog_11=99 and devpediat_11=99 and neurolog_11=99 and nutrition_11=99 and nurse_11=99 and psychiat_11=99 and psycholog_11=99 and socwork_11=99 dr_count_11 = 99.

VARIABLE LABELS dr_count_11 "Currently see 2 or more out of 8 types of providers of health and related services to meet their developmental needs".

VALUE LABELS dr_count_11

0 "Child does not work with any provider"

1 "Child works with one provider"

2 "Child works with 2 or more providers"

99 "DK/Ref to all".

FORMATS dr_count_11(f2.0).

MISSING VALUES dr_count_11(99).

EXECUTE.

Currently work with audiologist	
Description	Does child currently work with audiologist on a regular basis?
Survey Items Used	HCS2_A; HCS2_A_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, works with this type of provider; No, does not work with this type of provider

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE audiolog_11 = 999. IF HCS2_A = 0 or HCS2_A_2 = 0 audiolog_11 = 2. IF HCS2_A_2 = 1 audiolog_11 = 1. IF HCS2_A=6 or HCS2_A_2=6 audiolog_11 =99. VARIABLE LABELS audiolog_11 "Currently work with an audiologist on a regular basis". VALUE LABELS audiolog_11 1 "Yes, child works with audiologist" 2 "No, child does not work with audiologist" 99 "DK". FORMATS audiolog_11(f2.0). *MISSING VALUES audiolog_11(99). EXECUTE.

Currently work with developmental pediatricians	
Description	Does child currently work with developmental pediatricians on a regular basis?
Survey Items Used	HCS2_B; HCS2_B_2
Denominator	Children 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, works with this type of provider; No, does not work with this type of provider
Notes for Data-Users	
N/A	
SPSS Syntax and Annotation	

COMPUTE devped_11 = 999.

IF HCS2_B = 0 or HCS2_B_2 = 0 devped_11 = 2.

IF HCS2_B_2 = 1 devped_11 = 1.

IF HCS2_B=6 or HCS2_B_2=6 or HCS2_B_2=7 devped_11=99.

VARIABLE LABELS devped_11 "Currently work with a developmental pediatrician on a regular basis".

VALUE LABELS devped_11

1 "Yes, child works with developmental pediatricians"

2 "No, child does not work with developmental pediatricians"

99 "DK".

FORMATS devped_11(f2.0).

*MISSING VALUES devped_11(99).

EXECUTE

Currently work with neurologist

Description	Does child currently work with neurologist on a regular basis?
Survey Items Used	HCS2_C; HCS2_C_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, works with this type of provider; No, does not work with this type of provider

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE neurolog_11 = 999.

IF HCS2_C = 0 or HCS2_C_2 = 0 neurolog_11 = 2.

IF HCS2_C_2 = 1 neurolog_11 = 1.

IF HCS2_C=6 or HCS2_C_2=6 or HCS2_C_2=7 neurolog_11=99.

VARIABLE LABELS neurolog_11 "Currently work with a neurologist on a regular basis".

VALUE LABELS neurolog_11

1 "Yes, child works with neurologist"

2 "No, child does not work with neurologist"

99 "DK".

FORMATS neurolog_11(f2.0).

*MISSING VALUES neurolog_11(99).

EXECUTE.

Currently work with nutritionist	
Description	Does child currently work with nutritionist on a regular basis?
Survey Items Used	HCS2_D: HCS2_D_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, works with this type of provider; No, does not work with this type of provider
Notes for Data-Users	
N/A	
SPSS Syntax and Annotation	

COMPUTE nutritn_11 = 999.
IF HCS2_D = 0 or HCS2_D_2 = 0 nutritn_11 = 2.
IF HCS2_D_2 = 1 nutritn_11 = 1.
IF HCS2_D=6 or HCS2_D_2=6 or HCS2_D_2=7 nutritn_11=99.
VARIABLE LABELS nutritn_11 "Currently work with a nutritionist on a regular basis".
VALUE LABELS nutritn_11
1 "Yes, child works with nutritionist"
2 "No, child does not work with nutritionist"
99 "DK".
FORMATS nutritn_11(f2.0).
*MISSING VALUES nutritn_11(99).
EXECUTE.

Currently work with an at home/long-term nurse	
Description	Does child currently work with an at home/long-term nurse on a regular basis?
Survey Items Used	HCS2_E; HCS2_E_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, works with this type of provider; No, does not work with this type of provider

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE nurse_11 = 999. IF HCS2_E = 0 or HCS2_E_2 = 0 nurse_11 = 2. IF HCS2_E_2 = 1 nurse_11 = 1. IF HCS2_E=6 nurse_11 = 99. VARIABLE LABELS nurse_11 "Currently work with an at home/long-term nurse on a regular basis". VALUE LABELS nurse_11 1 "Yes, child works with an at home/long-term nurse" 2 "No, child does not work with an at home/long-term nurse" 99 "DK". FORMATS nurse_11(f2.0). *MISSING VALUES nurse_11(99). EXECUTE.

Currently work with psychiatrist	
Description	Does child currently work with psychiatrist on a regular basis?
Survey Items Used	HCS2_E; HCS2_E_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, works with this type of provider; No, does not work with this type of provider

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE psychiat_11 = 999. IF HCS2_F = 0 or HCS2_F_2 = 0 psychiat_11= 2. IF HCS2_F_2 = 1 psychiat_11 = 1. IF HCS2_F=6 or HCS2_F_2=6 or HCS2_F_2=7 psychiat_11=99. VARIABLE LABELS psychiat_11 "Currently work with a psychiatrist on a regular basis". VALUE LABELS psychiat_11 1 "Yes, child works with psychiatrist" 2 "No, child does not work with psychiatrist" 99 "DK". FORMATS psychiat_11(f2.0). *MISSING VALUES psychiat_11(99). EXECUTE.

Currently work with psychologist/ psychotherapist

Description	Does child currently work with psychologist/ psychotherapist on a regular basis?
Survey Items Used	HCS2_G; HCS2_G_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, works with this type of provider; No, does not work with this type of provider

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE psychlog_11 = 999. IF HCS2_G = 0 or HCS2_G_2 = 0 psychlog_11 = 2. IF HCS2_G_2 = 1 psychlog_11 = 1. IF HCS2_G=6 or HCS2_G_2=6 or HCS2_G_2=7 psychlog_11=99. VARIABLE LABELS psychlog_11 "Currently work with a psychologist/psychotherapist on a regular basis". VALUE LABELS psychlog_11 1 "Yes, child works with psychologist/psychotherapist" 2 "No, child does not work with psychologist/psychotherapist" 99 "DK". FORMATS psychlog_11(f2.0). *MISSING VALUES psychlog_11(99). EXECUTE.

Currently work with a social worker	
Description	Does child currently work with a social worker on a regular basis?
Survey Items Used	HCS2_H; HCS2_H_2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, works with this type of provider; No, does not work with this type of provider

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE socwork_11 = 999. IF HCS2_H = 0 or HCS2_H_2 = 0 socwork_11 = 2. IF HCS2_H_2 = 1 socwork_11 = 1. IF HCS2_H=6 or HCS2_H_2=6 or HCS2_H_2=7 socwork_11=99. VARIABLE LABELS socwork_11 "Currently work with a social worker on a regular basis". VALUE LABELS socwork_11 1 "Yes, child works with a social worker" 2 "No, child does not work with a social worker" 99 "DK". FORMATS socwork_11(f2.0). *MISSING VALUES socwork_11(99). EXECUTE.

Number of medications children currently use

Description	How many medications child currently uses on a regular basis?
Survey Items Used	HCS3_AR; HCS3_A_2R; HCS3_BR; HCS3_B_2R; HCS3_CR; HCS3_C_2R; HCS3_DR; HCS3_D_2R; HCS3_ER; HCS3_E_2R; HCS3_FR; HCS3_F_2R
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Child takes 1 or more medications; Child does not take any medications asked about

Notes for Data-Users
N/A

SPSS Syntax and Annotation

COMPUTE rx_stmlnt_11 = 999.

IF HCS3_A_2R = 1 rx_stmlnt_11 = 1.

IF HCS3_AR = 0 or HCS3_A_2R = 0 rx_stmlnt_11 = 2.

IF HCS3_AR = 6 or HCS3_A_2R = 6 rx_stmlnt_11 = 99.

IF HCS3_AR = 1 and (SYSMIS(HCS3_A_2R)) rx_stmlnt_11 = 99.

VARIABLE LABELS rx_stmlnt_11 "Currently uses stimulant medications to meet developmental needs".

VALUE LABELS rx_stmlnt_11

1 "Yes, child currently uses stimulant medications"

2 "No, child does not currently use stimulant medications"

99 "DK/Missing in error".

MISSING VALUES rx_stmlnt_11(99).

FORMATS rx_stmlnt_11(f2.0).

EXECUTE.

RECODE HCS3_AR HCS3_A_2R

(SYSMIS=999) (else=copy) into HCS3_ARR HCS3_A_2RR.

COMPUTE rx_dprss_11 = 999.

IF HCS3_B_2R = 1 rx_dprss_11 = 1.

IF HCS3_BR = 0 or HCS3_B_2R = 0 rx_dprss_11 = 2.

IF HCS3_BR = 6 or HCS3_B_2R = 6 rx_dprss_11 = 99.

IF HCS3_BR = 1 and (SYSMIS(HCS3_B_2R)) rx_dprss_11 = 99.

VARIABLE LABELS rx_dprss_11 "Currently uses anti-depressant medications to meet developmental needs".

VALUE LABELS rx_dprss_11

1 "Yes, child currently uses anti-depressant medications"

2 "No, child does not currently use anti-depressant medications"

99 "DK/Missing in error".
MISSING VALUES rx_dprss_11(99).
FORMATS rx_dprss_11(f2.0).
EXECUTE.

COMPUTE rx_anxiet_11 = 999.
IF HCS3_C_2R = 1 rx_anxiet_11 = 1.
IF HCS3_CR = 0 or HCS3_C_2R = 0 rx_anxiet_11 = 2.
IF (HCS3_CR =6) or (HCS3_C_2R = 6 or HCS3_C_2R=7) rx_anxiet_11 = 99.
VARIABLE LABELS rx_anxiet_11 "Currently uses anti-anxiety or mood stabilizing medications to meet developmental needs".
VALUE LABELS rx_anxiet_11
1 "Yes, child currently uses anti-anxiety/mood medications"
2 "No, child does not currently use anti-anxiety/mood medications"
99 "DK/Ref".
MISSING VALUES rx_anxiet_11(99).
FORMATS rx_anxiet_11(f2.0).
EXECUTE.

COMPUTE rx_seiz_11 = 999.
IF HCS3_D_2R = 1 rx_seiz_11 = 1.
IF HCS3_DR = 0 or HCS3_D_2R = 0 rx_seiz_11 = 2.
IF HCS3_DR = 6 or HCS3_D_2R = 6 rx_seiz_11 = 99.
VARIABLE LABELS rx_seiz_11 "Currently uses anti-seizure medications to meet developmental needs".
VALUE LABELS rx_seiz_11
1 "Yes, child currently uses anti-seizure medications"
2 "No, child does not currently use anti-seizure medications"
99 "DK".
MISSING VALUES rx_seiz_11(99).
FORMATS rx_seiz_11(f2.0).
EXECUTE.

COMPUTE rx_psych_11 = 999.
IF HCS3_E_2R = 1 rx_psych_11 = 1.
IF HCS3_ER = 0 or HCS3_E_2R = 0 rx_psych_11 = 2.
IF (HCS3_ER = 6 or HCS3_ER = 7) or (HCS3_E_2R=6) rx_psych_11 = 99.
IF HCS3_ER = 1 and (SYSMIS(HCS3_E_2R)) rx_psych_11 = 99.
VARIABLE LABELS rx_psych_11 "Currently uses anti-psychotic medications to meet developmental needs".
VALUE LABELS rx_psych_11
1 "Yes, child currently uses anti-psychotic medications"
2 "No, child does not currently use anti-psychotic medications"
99 "DK/Ref/Missing in error".

MISSING VALUES rx_psych_11(99).

FORMATS rx_psych_11(f2.0).

EXECUTE.

COMPUTE rx_sleep_11 = 999.

IF HCS3_F_2R = 1 rx_sleep_11 = 1.

IF HCS3_FR = 0 OR HCS3_F_2R = 0 rx_sleep_11 = 2.

IF HCS3_FR=6 or HCS3_F_2R = 6 rx_sleep_11 = 99.

IF HCS3_FR=1 and (SYSMIS(HCS3_F_2R)) rx_sleep_11 = 99.

VARIABLE LABELS rx_sleep_11 "Currently uses sleep medications to meet developmental needs".

VALUE LABELS rx_sleep_11

1 "Yes, child currently uses sleep medications"

2 "No, child does not currently use sleep medications"

99 "DK/Missing in error".

MISSING VALUES rx_sleep_11(99).

FORMATS rx_sleep_11(f2.0).

EXECUTE.

Count Rxnum_11=rx_stmlnt_11 rx_dprss_11 rx_anxiet_11 rx_seiz_11 rx_psych_11 rx_sleep_11(1).

If rx_stmlnt_11 = 99 and rx_dprss_11=99 and rx_anxiet_11=99 and rx_seiz_11=99 and rx_psych_11=99 Rxnum_11=99.

VARIABLE LABELS Rxnum_11 "Number of medications CSHCN currently use".

COMPUTE Rxcount_11=999.

IF Rxnum_11=0 Rxcount_11=0.

IF Rxnum_11=1 Rxcount_11=1.

IF Rxnum_11>1 Rxcount_11=2.

IF Rxnum_11=99 Rxcount_11=99.

VARIABLE LABELS Rxcount_11 "Currently uses none, one, or two/more types of medications to meet developmental needs".

VALUE LABELS Rxcount_11

0 "Does not use any medication"

1 "Curretly uses 1 medication"

2 "Curretly uses 2+ medications"

99 "DK/Ref/Missing in error to all".

MISSING VALUES Rxcount_11(99).

FORMATS Rxcount_11(f2.0).

EXECUTE.

Currently use stimulant medications	
Description	Does child currently use stimulant medications to meet his/her developmental needs?
Survey Items Used	HCS3_AR; HCS3_A_2R
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child currently use stimulant medications ; No, child does use stimulant medications

Notes for Data-Users
N/A

SPSS Syntax and Annotation

```
COMPUTE rx_stmlnt_11 = 999.
IF HCS3_A_2R = 1  rx_stmlnt_11 = 1.
IF HCS3_AR = 0 or HCS3_A_2R = 0  rx_stmlnt_11 = 2.
IF HCS3_AR = 6 or HCS3_A_2R = 6  rx_stmlnt_11 = 99.
IF HCS3_AR = 1 and (SYSMIS(HCS3_A_2R)) rx_stmlnt_11 = 99.
VARIABLE LABELS rx_stmlnt_11 "Currently uses stimulant medications to meet developmental needs".
VALUE LABELS rx_stmlnt_11
1 "Yes, child currently uses stimulant medications"
2 "No, child does not currently use stimulant medications"
99 "DK/Missing in error".
MISSING VALUES rx_stmlnt_11(99).
FORMATS rx_stmlnt_11(f2.0).
EXECUTE.
```

Currently use anti-depressant medication	
Description	Does child currently use anti-depressant medications on a regular basis?
Survey Items Used	HCS3_BR; HCS3_B_2R
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child currently uses anti-depressant medications; No, child does not use anti-depressant medications

Notes for Data-Users
N/A

SPSS Syntax and Annotation

RECODE HCS3_AR HCS3_A_2R

(SYSMIS=999) (else=copy) into HCS3_ARR HCS3_A_2RR.

COMPUTE rx_dprss_11 = 999.

IF HCS3_B_2R = 1 rx_dprss_11 = 1.

IF HCS3_BR = 0 or HCS3_B_2R = 0 rx_dprss_11 = 2.

IF HCS3_BR = 6 or HCS3_B_2R = 6 rx_dprss_11 = 99.

IF HCS3_BR = 1 and (SYSMIS(HCS3_B_2R)) rx_dprss_11 = 99.

VARIABLE LABELS rx_dprss_11 "Currently uses anti-depressant medications to meet developmental needs".

VALUE LABELS rx_dprss_11

1 "Yes, child currently uses anti-depressant medications"

2 "No, child does not currently use anti-depressant medications"

99 "DK/Missing in error".

MISSING VALUES rx_dprss_11(99).

FORMATS rx_dprss_11(f2.0).

EXECUTE.

Currently use anti-anxiety or mood stabilizing medications	
Description	Does child currently use anti-anxiety or mood stabilizing medications on a regular basis?
Survey Items Used	HCS3_CR; HCS3_C_2R
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child currently uses anti-anxiety or mood stabilizing medications; No, child does not use anti-anxiety or mood stabilizing medications

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE rx_anxiet_11 = 999. IF HCS3_C_2R = 1 rx_anxiet_11 = 1. IF HCS3_CR = 0 or HCS3_C_2R = 0 rx_anxiet_11 = 2. IF (HCS3_CR =6) or (HCS3_C_2R = 6 or HCS3_C_2R=7) rx_anxiet_11 = 99. VARIABLE LABELS rx_anxiet_11 "Currently uses anti-anxiety or mood stabilizing medications to meet developmental needs". VALUE LABELS rx_anxiet_11 1 "Yes, child currently uses anti-anxiety/mood medications" 2 "No, child does not currently use anti-anxiety/mood medications" 99 "DK/Ref". MISSING VALUES rx_anxiet_11(99). FORMATS rx_anxiet_11(f2.0). EXECUTE.

Currently use anti-seizure medications	
Description	Does child currently use anti-seizure medications on a regular basis?
Survey Items Used	HCS3_DR; HCS3_D_2R
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child currently uses anti-seizure medications; No, child does not use anti-seizure medications

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE rx_seiz_11 = 999. IF HCS3_D_2R = 1 rx_seiz_11 = 1. IF HCS3_DR = 0 or HCS3_D_2R = 0 rx_seiz_11 = 2. IF HCS3_DR = 6 or HCS3_D_2R = 6 rx_seiz_11 = 99. VARIABLE LABELS rx_seiz_11 "Currently uses anti-seizure medications to meet developmental needs". VALUE LABELS rx_seiz_11 1 "Yes, child currently uses anti-seizure medications" 2 "No, child does not currently use anti-seizure medications" 99 "DK". MISSING VALUES rx_seiz_11(99). FORMATS rx_seiz_11(f2.0). EXECUTE.

Currently use anti-psychotic medications	
Description	Does child currently use anti-psychotic medications on a regular basis?
Survey Items Used	HCS3_ER; HCS3_E_2R
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child currently uses anti-psychotic medications; No, child does not use anti-psychotic medications

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE rx_psych_11 = 999. IF HCS3_E_2R = 1 rx_psych_11 = 1. IF HCS3_ER = 0 or HCS3_E_2R = 0 rx_psych_11 = 2. IF (HCS3_ER = 6 or HCS3_ER = 7) or (HCS3_E_2R=6) rx_psych_11 = 99. IF HCS3_ER = 1 and (SYSMIS(HCS3_E_2R)) rx_psych_11 = 99. VARIABLE LABELS rx_psych_11 "Currently uses anti-psychotic medications to meet developmental needs". VALUE LABELS rx_psych_11 1 "Yes, child currently uses anti-psychotic medications" 2 "No, child does not currently use anti-psychotic medications" 99 "DK/Ref/Missing in error". MISSING VALUES rx_psych_11(99). FORMATS rx_psych_11(f2.0). EXECUTE.

Currently use sleep medications	
Description	Does child currently use sleep medications on a regular basis?
Survey Items Used	HCS3_FR; HCS3_F_2R
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child currently uses sleep medications; No, child does not use sleep medications

Notes for Data-Users
N/A

SPSS Syntax and Annotation
COMPUTE rx_sleep_11 = 999. IF HCS3_F_2R = 1 rx_sleep_11 = 1. IF HCS3_FR = 0 OR HCS3_F_2R = 0 rx_sleep_11 = 2. IF HCS3_FR=6 or HCS3_F_2R = 6 rx_sleep_11 = 99. IF HCS3_FR=1 and (SYSMIS(HCS3_F_2R)) rx_sleep_11 = 99. VARIABLE LABELS rx_sleep_11 "Currently uses sleep medications to meet developmental needs". VALUE LABELS rx_sleep_11 1 "Yes, child currently uses sleep medications" 2 "No, child does not currently use sleep medications" 99 "DK/Missing in error". MISSING VALUES rx_sleep_11(99). FORMATS rx_sleep_11(f2.0). EXECUTE.

Type of school child currently enrolled in	
Description	What kind of school does he/she attend?
Survey Items Used	ES1
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Public school; Private school; Home-schooled

Notes for Data-Users
Children not enrolled in school were legitimately skipped from this question

SPSS Syntax and Annotation
RECODE ES1   (6 thru 7=99) (4=95) (else=copy) into es_schl_11.   VARIABLE LABELS es_schl_11 "Type of school CSHCN currently enrolled in".   VALUE LABELS es_schl_11   1 "Public"   2 "Private"   3 "Home-schooled"   95 "Not enrolled in school"   99 "DK/Ref".   MISSING VALUES es_schl_11(95,99).   FORMATS es_schl_11(f2.0).   EXECUTE.

Had an Individualized Education Program

Description	Does child have a written intervention plan called an Individualized Education Program or IEP?
Survey Items Used	ES6
Denominator	CSHCN ages 6-17 years with current autism spectrum disorder, developmental delay, and/or intellectual disability who are currently enrolled in public or private school
Numerator	Yes, child has an IEP; No, child does not have IEP

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE ES6

RECODE ES6

(0=2) (1=1) (6=99) (SYSMIS=90) into es_iep_11.

VARIABLE LABELS es_iep_11 "Among those enrolled in public or private school, children had a written intervention plan called an Individualized Education Program (IEP)".

VALUE LABELS es_iep_11

1 "Yes, child has an IEP"

2 "No, child does not have an IEP"

90 "Home-schooled/Not enrolled in school/DK or Ref to ES1"

99 "DK".

MISSING VALUES es_iep_11(90,99).

FORMATS es_iep_11(f2.0).

EXECUTE.

<table>
<tr><td colspan="2">

Adequacy of Individualized Education Program

</td></tr>
<tr><td>

Description

</td><td>

Does child's Individualized Education Program address all of concerns about his/her development and education?

</td></tr>
<tr><td>

Survey Items Used

</td><td>

ES8

</td></tr>
<tr><td>

Denominator

</td><td>

CSHCN ages 6-17 years with current autism spectrum disorder, developmental delay, and/or intellectual disability who enrolled in public or private school and have an Individualized Education Program

</td></tr>
<tr><td>

Numerator

</td><td>

Yes, child's IEP addresses all of the parent's concerns; No child's IEP does not address all of the parent's concerns

</td></tr>
<tr><td colspan="2">

Notes for Data-Users

</td></tr>
<tr><td colspan="2">

N/A

</td></tr>
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Revisions

</td></tr>
<tr><td colspan="2">

N/A

</td></tr>
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SPSS Syntax and Annotation

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<tr><td colspan="2">

RECODE ES8

(0=2) (1=1) (6 thru 7=99) (SYSMIS=90) into es_iepnd_11.

VARIABLE LABELS es_iepnd_11 "Among those enrolled in public or private school, IEP addresses all of the parent's concerns about their child's development and education ".

VALUE LABELS es_iepnd_11

1 "Yes"

2 "No"

90 "Child does not have an IEP/Not enrolled in public or private school"

99 "DK/Ref".

MISSING VALUES es_iepnd_11(90,99).

FORMATS es_iepnd_11(f2.0).

EXECUTE.

</td></tr>
</table>

Received services from an Early Intervention Service	
Description	Before age 3, did child receive services from an Early Intervention Services?
Survey Items Used	ES9
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability who are currently enrolled in private or public school
Numerator	Yes, child received EIS; No, child did not receive EIS

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE ES9 (0=2) (1=1) (6=99) (SYSMIS=90) into es_eis_11. VARIABLE LABELS es_eis_11 "Among those enrolled in public or private school, received Early Intervention Services (EIS) before they were 3 years old". VALUE LABELS es_eis_11 1 "Yes, child received services from EIS" 2 "No, child did not receive services" 90 "Home-schooled/Not enrolled in school/DK or Ref to ES1" 99 "DK". MISSING VALUES es_eis_11(90,99). FORMATS es_eis_11(f2.0). EXECUTE.

Ever told that child was not eligible for Early Intervention Services	
Description	Were you ever told Early Intervention Services (EIS) was not available to you?
Survey Items Used	ES10
Denominator	CSHCN ages 6-17 years with current autism spectrum disorder, developmental delay, and/or intellectual disability who are currently enrolled in public or private school
Numerator	Yes, ever told child was not eligible for EIS; No, never told hat child was not eligible for EIS
Notes for Data-Users	
N/A	
SPSS Syntax and Annotation	

RECODE ES10

(1=1) (0=2) (6=99) (SYSMIS=90) into es_eisne_11.

VARIABLE LABELS es_eisne_11 "Among those enrolled in public or private school, parent was told their child was not eligible for Early Intervention Services ".

VALUE LABELS es_eisne_11

1 "Yes"

2 "No"

90 "Home-schooled/Not enrolled in school/DK or Ref to ES1"

99 "DK".

MISSING VALUES es_eisne_11(90,99).

FORMATS es_eisne_11(f2.0).

EXECUTE.

Any unmet need for care

Description	Did child receive all necessary treatments, services and saw all service providers needed to care for child's developmental needs during the past 12 months?
Survey Items Used	INS1: INS2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	No, child did not receive all necessary services; Yes, child received all necessary services

Notes for Data-Users
N/A

SPSS Syntax and Annotation

COMPUTE in_unmet_11=999.

IF (INS1=6 or INS1=7 or (SYSMIS(INS1))) or (INS2=6 or (SYSMIS(INS2))) in_unmet_11=99.

IF INS1=0 or INS2=0 in_unmet_11=1.

IF INS1=1 and INS2=1 in_unmet_11=2.

VARIABLE LABELS in_unmet_11 "DID NOT receive all necessary treatments, services, or service providers needed to care for child's developmental needs during the past 12 months".

VALUE LABELS in_unmet_11

1 "Child has unmet needs"

2 "Child does not have unmet needs"

99 "DK/Ref/Partial Interview".

MISSING VALUES in_unmet_11().

FORMATS in_unmet_11(f2.0).

EXECUTE.

Received all needed treatments and services	
Description	During the past 12 months, did child receive all the treatments and services necessary to meet his/her developmental needs?
Survey Items Used	NS1
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child received all necessary services; No, child did not receive all necessary services

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE INS1 (0=2) (1=1) (6 thru 7=99) (SYSMIS=99) into in_serv_11. VARIABLE LABELS in_serv_11 "Received all the treatments and services necessary to meet their developmental needs during the past 12 months". VALUE LABELS in_serv_11 1 "Yes, child received all treatment and services" 2 "Child did not receive all treatment and services" 99 "DK/Ref/Partial Interview". FORMATS in_serv_11(f2.0). MISSING VALUES in_serv_11(99). EXECUTE.

<table>
<tr><td colspan="2" align="center">**Saw all needed service providers**</td></tr>
<tr><td>**Description**</td><td>During the past 12 months, did child see all the service providers needed to care for his/her developmental needs?</td></tr>
<tr><td>**Survey Items Used**</td><td>INS2</td></tr>
<tr><td>**Denominator**</td><td>CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability</td></tr>
<tr><td>**Numerator**</td><td>Yes, child saw all providers needed; No, child did not see all providers needed</td></tr>
<tr><td colspan="2">**Notes for Data-Users**</td></tr>
<tr><td colspan="2">N/A</td></tr>
<tr><td colspan="2">**SPSS Syntax and Annotation**</td></tr>
<tr><td colspan="2">

RECODE INS2

(0=2) (1=1) (6 thru 7=99) (SYSMIS=99) into in_prov_11.

VARIABLE LABELS in_prov_11 "Saw all the service providers needed to care for their developmental needs during the past 12 months".

VALUE LABELS in_prov_11

1 "Yes, child saw all service providers needed to care"

2 "Child did not see all service providers needed to care"

99 "DK/Ref/Partial Interview".

FORMATS in_prov_11(f2.0).

MISSING VALUES in_prov_11(99).

EXECUTE.

</td></tr>
</table>

Health insurance coverage

Description	Does child have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?
Survey Items Used	INS3
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child has health insurance; No, child does not have health insurance

Notes for Data-Users

Estimates may vary compared to similar indicators of other surveys provided elsewhere on the DRC website because of difference in survey wording and survey administration.

SPSS Syntax and Annotation

RECODE INS3

(0=2) (1=1) (6 thru 7=99) (SYSMIS=99) into in_ins_11.

VARIABLE LABELS in_ins_11 "Has any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid".

VALUE LABELS in_ins_11

1 "Yes, child has health insurance"

2 "Child does not have health insurance"

99 "DK/Ref/Partial Interview".

FORMATS in_ins_11(f2.0).

MISSING VALUES in_ins_11(99).

EXECUTE.

Inadequate current health insurance	
Description	Is child's health insurance adequate for his/her needs?
Survey Items Used	National Survey of Children with Special Health Care Needs (NS-CSHCN) items: C8Q01_A, C8Q01_B, C8Q01_C
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability who were insured at the time of the survey
Numerator	Current insurance is adequate; Current insurance is not adequate

Notes for Data-Users
To be scored as having inadequate insurance children have responses of never or sometimes to each item. That is their current insurance coverage never/sometimes covers services and/or never/sometimes has reasonable out of pocket expenses and/or never/sometimes allows CSHCN to see needed health providers. Valid responses on all three items are required. If any item is don't know or refused, then child is set to missing.

SPSS Syntax and Annotation

****from the 2009/2010 NS-CSHCN

COMPUTE metneeds_09 = 99.
IF (SYSMIS (C8Q01_A)) metneeds_09 = 3.
IF (hasins_09 = 1) metneeds_09 = 2.
IF (C8Q01_A = 1) or (C8Q01_A = 2) metneeds_09 = 0.
IF (C8Q01_A = 3) or (C8Q01_A = 4) metneeds_09 = 1.
EXECUTE.
VARIABLE LABELS metneeds_09 'Health insurance benefits meet child needs'.
VALUE LABELS metneeds_09
0 'Never/sometimes'
1 'Usually/always'
2 'Legit skip b/c uninsured'
3 'Sys missing'
99 'DK/Ref'.

COMPUTE reasonable_09 = 99.
IF (SYSMIS (C8Q01_B)) reasonable_09 = 3.
IF (hasins_09 = 1) reasonable_09 = 2.
IF (C8Q01_B = 1) or (C8Q01_B = 2) reasonable_09 = 0.
IF (C8Q01_B = 3) or (C8Q01_B = 4) reasonable_09 = 1.
IF (C8Q01_B = 5) reasonable_09 = 1.
EXECUTE.
VARIABLE LABELS reasonable_09 'Non-covered insurance charges reasonable'.
VALUE LABELS reasonable_09

0 'Never/sometimes'

1 'Usually/always'

2 'Legit skip b/c uninsured'

3 'Sys missing'

99 'DK/Ref'.

COMPUTE providers_09 = 99.

IF (SYSMIS (C8Q01_C)) providers_09 = 3.

IF (hasins_09 = 1) providers_09 = 2.

IF (C8Q01_C = 1) or (C8Q01_C = 2) providers_09 = 0.

IF (C8Q01_C = 3) or (C8Q01_C = 4) providers_09 = 1.

EXECUTE.

VARIABLE LABELS providers_09 'Insurance allows child to see needed providers'.

VALUE LABELS providers_09

0 'Never/sometimes'

1 'Usually/always'

2 'Legit skip b/c uninsured'

3 'Sys missing'

99 'DK/Ref'.

COMPUTE indic5_09=99.

IF (indic4_09=1) indic5_09=999.

IF (metneeds_09=1) and (reasonable_09=1) and (providers_09=1) indic5_09=1.

IF (metneeds_09=0) or (reasonable_09=0) or (providers_09=0) indic5_09=0.

IF (metneeds_09>2) or (reasonable_09>2) or (providers_09>2) indic5_09=99.

EXECUTE.

VARIABLE LABELS indic5_09 'Currently insured CSHCN whose insurance is not adequate'.

VALUE LABELS indic5_09

0 'Current insurance is NOT adequate'

1 'Current insurance IS adequate'

99 'DK or Ref to any item'

999 "uninsured".

MISSING VALUES indic5_09 (99,999).

FORMATS indic5_09 (f2.0).

Current health insurance benefits meet child's needs	
Description	Does child's health insurance offer benefits or cover services that meet his/her needs?
Survey Items Used	National Survey of Children with Special Health Care Needs (NS-CSHCN) item: C8Q01_A
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability who were insured at the time of the survey
Numerator	Never/sometimes meet needs; Usually/always meets needs

Notes for Data-Users
N/A

Revisions
These items are the same as in the 2005/06 NS-CSHCN.

SPSS Syntax and Annotation

****from the 2009/2010 NS-CSHCN
 	
COMPUTE metneeds_09 = 99.
IF (SYSMIS (C8Q01_A)) metneeds_09 = 3.
IF (hasins_09 = 1) metneeds_09 = 2.
IF (C8Q01_A = 1) or (C8Q01_A = 2) metneeds_09 = 0.
IF (C8Q01_A = 3) or (C8Q01_A = 4) metneeds_09 = 1.
EXECUTE.
VARIABLE LABELS metneeds_09 'Health insurance benefits meet child needs'.
VALUE LABELS metneeds_09
0 'Never/sometimes'
1 'Usually/always'
2 'Legit skip b/c uninsured'
3 'Sys missing'
99 'DK/Ref'.

Costs not covered by health insurance are reasonable

Description	Are the costs not covered by child's health insurance reasonable?
Survey Items Used	National Survey of Children with Special Health Care Needs (NS-CSHCN) item: C8Q01_B
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability who were insured at the time of the survey
Numerator	Usually/always reasonable; Never/sometimes reasonable

Notes for Data-Users
N/A

Revisions
These items are the same as in the 2005/06 NS-CSHCN.

SPSS Syntax and Annotation

****from the 2009/2010 NS-CSHCN

COMPUTE reasonable_09 = 99.
IF (SYSMIS (C8Q01_B)) reasonable_09 = 3.
IF (hasins_09 = 1) reasonable_09 = 2.
IF (C8Q01_B = 1) or (C8Q01_B = 2) reasonable_09 = 0.
IF (C8Q01_B = 3) or (C8Q01_B = 4) reasonable_09 = 1.
IF (C8Q01_B = 5) reasonable_09 = 1.
EXECUTE.
VARIABLE LABELS reasonable_09 'Non-covered insurance charges reasonable'.
VALUE LABELS reasonable_09
0 'Never/sometimes'
1 'Usually/always'
2 'Legit skip b/c uninsured'
3 'Sys missing'
99 'DK/Ref'.

Health insurance let child see needed providers	
Description	Does child's health insurance allow him/her to see the health care providers he/she needs?
Survey Items Used	National Survey of Children with Special Health Care Needs (NS-CSHCN) item: C8Q01_C
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability who were insured at the time of the survey
Numerator	Usually/always; Never/sometimes

Notes for Data-Users
N/A

Revisions
The item is the same as in the 2005/06 NS-CSHCN.

SPSS Syntax and Annotation

****from the 2009/2010 NS-CSHCN
 	
COMPUTE providers_09 = 99.
IF (SYSMIS (C8Q01_C)) providers_09 = 3.
IF (hasins_09 = 1) providers_09 = 2.
IF (C8Q01_C = 1) or (C8Q01_C = 2) providers_09 = 0.
IF (C8Q01_C = 3) or (C8Q01_C = 4) providers_09 = 1.
EXECUTE.
VARIABLE LABELS providers_09 'Insurance allows child to see needed providers'.
VALUE LABELS providers_09
0 'Never/sometimes'
1 'Usually/always'
2 'Legit skip b/c uninsured'
3 'Sys missing'
99 'DK/Ref'.

Any unmet need due to insurance coverage	
Description	Are there treatments, services, or service providers that child's needs that are not covered by his/her health insurance in the past 12 months?
Survey Items Used	INS4
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability who were insured at the time of the survey
Numerator	Not all treatments/services covered by insurance; All needed treatments/services covered by insurance

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE INS4

RECODE INS4

(0=2) (1=1) (6=99) (SYSMIS=99) into in_cover_11.

IF INS3=0 or INS3=6 in_cover_11=90.

VARIABLE LABELS in_cover_11 "Health insurance DID NOT cover all the treatments, services, or service providers needed to care for child's developmental needs".

VALUE LABELS in_cover_11

1 "Not all treatments/services covered by insurance"

2 "All needed treatments/services covered by insurance"

90 "Child does not have health insurance or DK/Missing to INS3"

99 "DK/Partial interview".

FORMATS in_cover_11(f2.0).

*MISSING VALUES in_cover_11(90,99).

EXECUTE.

Any speech or language therapy not covered by health insurance

Description	Are speech or language therapies not covered by child's health insurance?
Survey Items Used	Any speech or language therapy not covered by health insurance
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability who were insured at the time of the survey
Numerator	Not covered by insurance; Covered by insurance

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE INS5R01 (0=2) (1=1) (6 thru 7=99) (SYSMIS=99) into in_spch_11. IF INS4=0 in_spch_11=2. IF (INS4=6 or (SYSMIS(INS4))) in_spch_11=99. IF INS3=0 or INS3=6 in_spch_11 =90. VARIABLE LABELS in_spch_11 "Among those who have health insurance, any speech or language therapy not covered by health insurance". VALUE LABELS in_spch_11 1 "Not covered by insurance" 2 "All needed treatments/services covered by insurance" 90 "Child does not have health insurance or DK to INS3" 99 "DK/Ref/Partial interview/Missing in error". FORMATS in_spch_11(f2.0). *MISSING VALUES in_spch_11(90,99). EXECUTE

Any occupational therapy not covered by health insurance

Description	Are occupational therapies not covered by health insurance?
Survey Items Used	INS5R02
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability who were insured at the time of the survey
Numerator	Not covered by insurance; Covered by insurance

Notes for Data-Users

N/A

SPSS Syntax and Annotation

RECODE INS5R02

(0=2) (1=1) (SYSMIS=99) (6 thru 7=99) into in_occup_11.

IF INS4=0 in_occup_11=2.

IF (INS4=6 or (SYSMIS(INS4))) in_occup_11=99.

IF INS3=0 or INS3=6 in_occup_11 =90.

VARIABLE LABELS in_occup_11 "Among those who have health insurance, any occupational therapy not covered by health insurance".

VALUE LABELS in_occup_11

1 "Not covered by insurance"

2 "All needed treatments/services covered by insurance"

90 "Child does not have health insurance or DK to INS3"

99 "DK/Ref/Partial interview/Missing in error".

*MISSING VALUES in_occup_11(90,99).

FORMATS in_occup_11(f2.0).

EXECUTE.

Any behavioral management services not covered by health insurance	
Description	Are behavioral management services not covered by health insurance?
Survey Items Used	INS5R03
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability who were insured at the time of the survey
Numerator	Not covered by insurance; Covered by insurance

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE INS5R03 (0=2) (1=1) (SYSMIS=99) (6 thru 7=99) into in_beh_11. IF INS4=0 in_beh_11=2. IF (INS4=6 or (SYSMIS(INS4))) in_beh_11=99. IF INS3=0 or INS3=6 in_beh_11 =90. VARIABLE LABELS in_beh_11 "Among those who have health insurance, any behavioral management services not covered by health insurance". VALUE LABELS in_beh_11 1 "Not covered by insurance" 2 "All needed treatments/services covered by insurance" 90 "Child does not have health insurance or DK to INS3" 99 "DK/Ref/Partial interview/Missing in error". *MISSING VALUES in_beh_11(90,99). FORMATS in_beh_11(f2.0). EXECUTE.

Any psychological services not covered by health insurance

Description	Are psychological services not covered by health insurance?
Survey Items Used	INS5R04
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability who were insured at the time of the survey
Numerator	Not covered by insurance; Covered by insurance

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE INS5R04 (0=2) (1=1) (SYSMIS=99) (6 thru 7=99) into in_psych_11. IF INS4=0 in_psych_11=2. IF (INS4=6 or (SYSMIS(INS4))) in_psych_11=99. IF INS3=0 or INS3=6 in_psych_11 =90. VARIABLE LABELS in_psych_11 "Among those who have health insurance, any psychological services not covered by health insurance". VALUE LABELS in_psych_11 1 "Not covered by insurance" 2 "All needed treatments/services covered by insurance" 90 "Child does not have health insurance or DK to INS3" 99 "DK/Ref/Partial interview/Missing in error". *MISSING VALUES in_psych_11(90,99). FORMATS in_psych_11(f2.0). EXECUTE.

Any alternative medicine/therapies not covered by health insurance

Description	Are alternative medicine/therapies not covered by health insurance?
Survey Items Used	INS5R08
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability who were insured at the time of the survey
Numerator	Not covered by insurance; Covered by insurance

Notes for Data-Users
N/A

SPSS Syntax and Annotation

RECODE INS5R08

(0=2) (1=1) (SYSMIS=99) (6 thru 7=99) into in_alt_11.

IF INS4=0 in_alt_11=2.

IF (INS4=6 or (SYSMIS(INS4))) in_alt_11=99.

IF INS3=0 or INS3=6 in_alt_11 =90.

VARIABLE LABELS in_alt_11 "Among those who have health insurance, any alternative medicine/therapies not covered by health insurance".

VALUE LABELS in_alt_11

1 "Not covered by insurance"

2 "All needed treatments/services covered by insurance"

90 "Child does not have health insurance or DK to INS3"

99 "DK/Ref/Partial interview/Missing in error".

MISSING VALUES in_alt_11().

FORMATS in_alt_11(f2.0).

EXECUTE.

Strengths and Difficulties Questionnaire composite score	
Description	Did child receive a high score on the Strengths and Difficulties Questionnaire?
Survey Items Used	FSD5_A; FSD5_B; FSD5_C; FSD5_D; FSD5_E
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	High score; Medium score; Low score

Notes for Data-Users
The Strength and Difficulties Questionnaire (SDQ) questions are copyrighted by Robert Goodman, Ph.D., FRCPSYCH, MRCP and included in the Pathways survey with permission. These questions may be used without charge and without seeking separate permission provided the wording is not modified, all the questions are retained, and Dr. Goodman's copyright is acknowledged.

The Pathways telephone interview included 5 items that comprise the modified SDQ. For negative questions (FSD5_B; FSD5_C; and FSD5_D) "Not True" is scored as zero, "Somewhat True" as 1 and "Certainly True" as 2. For positive questions (FSD5_A and FSD5_E) "Not True" is scored as 2, "Somewhat True" as 1 and "Certainly True" as zero. Summing each item generates the total difficulties score. Those whose score ranges from zero to two have normal scores, three to five have borderline scores, and six to ten have abnormal scores. A higher score indicates greater difficulties or fewer strengths.

Revisions
N/A

SPSS Syntax and Annotation

RECODE FSD5_A FSD5_B FSD5_C FSD5_D FSD5_E

(1=0) (2=1) (3=2) (6 thru 7=SYSMIS) into SDQ_1 SDQ_2 SDQ_3 SDQ_4 SDQ_5.

COMPUTE sdq_count=SDQ_1+SDQ_2+SDQ_3+SDQ_4+SDQ_5.

EXECUTE.

COMPUTE sdq_CATI_11 =999.

IF sdq_count <=2 sdq_CATI_11 = 3.

IF sdq_count > 2 and sdq_count < 6 sdq_CATI_11 = 2.

IF sdq_count > 5 sdq_CATI_11 = 1.

IF (FSD5_A=6 or FSD5_A=7 or (SYSMIS(FSD5_A))) or (FSD5_B=6 or FSD5_B=7 or (SYSMIS(FSD5_B))) or (FSD5_C=6 or FSD5_C=7 or (SYSMIS(FSD5_C))) or

 (FSD5_D=6 or FSD5_D=7 or (SYSMSI(FSD5_D))) or (FSD5_E=6 or FSD5_E=7 or (SYSMIS(FSD5_E))) sdq_CATI_11=99.

VARIABLE LABELS sdq_CATI_11 "Scoring results of brief Strengths and Difficulties Questionnaire (5 items)".

VALUE LABELS sdq_CATI_11

1 "High score: 6-10"

```
2 "Medium score: 3-5"
3 "Low score: 0-2"
99 "DK/Ref/Partial interview".
MISSING VALUES sdq_CATI_11(99).
FORMATS sdq_CATI_11(f2.0).
EXECUTE.
```

Child generally well behaved	
Description	Was child generally well behaved and did what adults requested during the past six months?
Survey Items Used	FSD5_A
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Not true; Somewhat true; Certainly true

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SPSS Syntax and Annotation
RECODE FSD5_A
(6 thru 7=99) (SYSMIS=99) (else=copy) into sdq_beh_11.
VARIABLE LABELS sdq_beh_11 "Child was generally well behaved and usually do what adults request during the past six months".
VALUE LABELS sdq_beh_11
1 "Not true"
2 "Somewhat true"
3 "Certainly true"
99 "DK/Ref/Partial interview".
FORMATS sdq_beh_11(f2.0).
MISSING VALUES sdq_beh_11(99).
EXECUTE.

Child has many worries, or often seems worried	
Description	Did child have many worries, or often seems worried during the past six months?
Survey Items Used	FSD5_B
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Not true; Somewhat true; Certainly true

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SPSS Syntax and Annotation
RECODE FSD5_B (6 thru 7=99) (SYSMIS=99) (else=copy) into sdq_wrry_11. VARIABLE LABELS sdq_wrry_11 "Child had many worries, or often seems worried during the past six months". VALUE LABELS sdq_wrry_11 1 "Not true" 2 "Somewhat true" 3 "Certainly true" 99 "DK/Ref/Partial interview". FORMATS sdq_wrry_11(f2.0). MISSING VALUES sdq_wrry_11(99). EXECUTE.

Functioning, Strengths, and Difficulties

<table>
<tr><td colspan="2" align="center">Child often unhappy, depressed, or tearful</td></tr>
<tr><td>Description</td><td>Was child often unhappy, depressed, or tearful during the past six months</td></tr>
<tr><td>Survey Items Used</td><td>FSD5_C</td></tr>
<tr><td>Denominator</td><td>CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability</td></tr>
<tr><td>Numerator</td><td>Not true; Somewhat true; Certainly true</td></tr>
</table>

Notes for Data-Users

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SPSS Syntax and Annotation

RECODE FSD5_C

(6 thru 7=99) (SYSMIS=99) (else=copy) into sdq_dep_11.

VARIABLE LABELS sdq_dep_11 "Child was often unhappy, depressed, or tearful during the past six months".

VALUE LABELS sdq_dep_11

1 "Not true"

2 "Somewhat true"

3 "Certainly true"

99 "DK/Ref/Partial interview".

FORMATS sdq_dep_11(f2.0).

MISSING VALUES sdq_dep_11(99).

EXECUTE.

Child gets along better with adults than with other children/youth	
Description	Was child get along better with adults than with other children or youth during the past six months?
Survey Items Used	FSD5_D
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Not true; Somewhat true; Certainly true

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SPSS Syntax and Annotation
RECODE FSD5_D
(6 thru 7=99) (SYSMIS=99) (else=copy) into sdq_adlt_11.
VARIABLE LABELS sdq_adlt_11 "Child got along better with adults than with other children or youth during the past six months".
VALUE LABELS sdq_adlt_11
1 "Not true"
2 "Somewhat true"
3 "Certainly true"
99 "DK/Ref/Partial interview".
FORMATS sdq_adlt_11(f2.0).
MISSING VALUES sdq_adlt_11(99).
EXECUTE.

	Child has good attention span
Description	During the last six months, did child have a good attention span, sees chores or homework through to the end?
Survey Items Used	FSD5_E
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Not true; Somewhat true; Certainly true

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SPSS Syntax and Annotation

RECODE FSD5_E

(6 thru 7=99) (SYSMIS=99) (else=copy) into sdq_attn_11.

VARIABLE LABELS sdq_attn_11 "Child had a good attention span, sees chores or homework through to the end during the past six months".

VALUE LABELS sdq_attn_11

1 "Not true"

2 "Somewhat true"

3 "Certainly true"

99 "DK/Ref/Partial interview".

FORMATS sdq_attn_11(f2.0).

MISSING VALUES sdq_attn_11(99).

EXECUTE.

School professionals at child's school are able to meet child's needs	
Description	Do parents believe that the teachers and other professionals at the child's school are able to meet their needs?
Survey Items Used	PP1_A
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree; Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE PP1_A
(1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_tchn_11.
VARIABLE LABELS pp_tchn_11 "Parent agrees with following statement: the teachers and other professionals at the child's school are able to meet their needs".
VALUE LABELS pp_tchn_11
1 "Definitely agree"
2 "Somewhat agree"
3 "Definitely/Somewhat disagree"
99 "DK/Ref/Partial interview".
MISSING VALUES pp_tchn_11(99).
FORMATS pp_tchn_11(f2.0).
EXECUTE.

Satisfaction with school services

Description	Do parents agree that they are satisfied with the services child receives from teachers and other school professionals?
Survey Items Used	PP1_B
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree; Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation

RECODE PP1_B

(1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_tchs_11.

VARIABLE LABELS pp_tchs_11 "Parent agrees with following statement: they are satisfied with the services that their child receives from teachers and other school professionals".

VALUE LABELS pp_tchs_11

1 "Definitely agree"

2 "Somewhat agree"

3 "Definitely/Somewhat Disagree"

99 "DK/Ref/Partial interview".

MISSING VALUES pp_tchs_11(99).

FORMATS pp_tchs_11(f2.0).

EXECUTE.

Health care providers are able to meet child's needs	
Description	Do parents believe that the doctors and other health care providers that child sees are able to meet their needs?
Survey Items Used	PP1_C
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree; Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE PP1_C
(1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_drn_11.
VARIABLE LABELS pp_drn_11 "Parent agrees with following statement: the doctors and other health care providers that child sees are able to meet their needs".
VALUE LABELS pp_drn_11
1 "Definitely agree"
2 "Somewhat agree"
3 "Definitely/Somewhat Disagree"
99 "DK/Ref/Partial interview".
MISSING VALUES pp_drn_11(99).
FORMATS pp_drn_11(f2.0).
EXECUTE.

Satisfaction with health care providers	
Description	Do parents agree that they are satisfied with the services child receives from doctors and other health care providers?
Survey Items Used	PP1_D
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree: Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE PP1_D

(1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_drs_11.

VARIABLE LABELS pp_drs_11 "Parent agrees with following statement: they are satisfied with the services that their child receives from doctors and other health care providers".

VALUE LABELS pp_drs_11

1 "Definitely agree"

2 "Somewhat agree"

3 "Definitely/Somewhat Disagree"

99 "DK/Ref/Partial interview".

MISSING VALUES pp_drs_11(99).

FORMATS pp_drs_11(f2.0).

EXECUTE.

Condition is lifelong	
Description	Do parents agree that condition is likely to be lifelong rather than temporary?
Survey Items Used	PP2_A
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree: Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation

RECODE PP2_A

(1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_life_11.

VARIABLE LABELS pp_life_11 "Parent agrees with following statement: condition is likely to be lifelong rather than temporary".

VALUE LABELS pp_life_11

1 "Definitely agree"

2 "Somewhat agree"

3 "Definitely/Somewhat Disagree"

99 "DK/Ref/Partial interview".

MISSING VALUES pp_life_11(99).

FORMATS pp_life_11(f2.0).

EXECUTE.

Treatment can prevent or decrease condition related problems

Description	Do parents believe that the problems related to their child's condition can be prevented or decreased with treatment?
Survey Items Used	PP2_B
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree; Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE PP2_B   (1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_prev_11.   VARIABLE LABELS pp_prev_11 "Parent agrees with following statement: the problems related to their child's condition can be prevented or decreased with treatment".   VALUE LABELS pp_prev_11   1 "Definitely agree"   2 "Somewhat agree"   3 "Definitely/Somewhat Disagree"   99 "DK/Ref/Partial interview".   MISSING VALUES pp_prev_11(99).   FORMATS pp_prev_11(f2.0).   EXECUTE.

Parent has the power to change the condition
Description — Do parents believe that they have the power to change their child's condition?
Survey Items Used — PP2_C
Denominator — CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator — Definitely agree; Somewhat agree; Definitely/Somewhat disagree

Notes for Data-Users

N/A

SPSS Syntax and Annotation

RECODE PP2_C

(1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_chnge_11.

VARIABLE LABELS pp_chnge_11 "Parent agrees with following statement: they have the power to change their child's condition".

VALUE LABELS pp_chnge_11

1 "Definitely agree"

2 "Somewhat agree"

3 "Definitely/Somewhat Disagree"

99 "DK/Ref/Partial interview".

MISSING VALUES pp_chnge_11(99).

FORMATS pp_chnge_11(f2.0).

EXECUTE.

Condition is a mystery	
Description	Do parents believe that condition is a mystery to them?
Survey Items Used	PP2_D
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree; Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE PP2_D   (1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_myst_11.   VARIABLE LABELS pp_myst_11 "Parent agrees with following statement: condition is a mystery to them".   VALUE LABELS pp_myst_11   1 "Definitely agree"   2 "Somewhat agree"   3 "Definitely/Somewhat Disagree"   99 "DK/Ref/Partial interview".   MISSING VALUES pp_myst_11(99).   FORMATS pp_myst_11(f2.0).   EXECUTE.

Child's symptoms come and go	
Description	Do parents believe that the child's symptoms come and go?
Survey Items Used	PP2_E
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree; Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE PP2_E (1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_go_11. VARIABLE LABELS pp_go_11 "Parent agrees with following statement: the child's symptoms come and go". VALUE LABELS pp_go_11 1 "Definitely agree" 2 "Somewhat agree" 3 "Definitely/Somewhat Disagree" 99 "DK/Ref/Partial interview". MISSING VALUES pp_go_11(99). FORMATS pp_go_11(f2.0). EXECUTE.

Parent gets upset when they think about their child's condition

Description	Do parents get upset when they think about their child's condition?
Survey Items Used	PP2_F
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree; Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation

RECODE PP2_F

(1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_upset_11.

VARIABLE LABELS pp_upset_11 "Parent agrees with following statement: when they think about their child's condition they get upset".

VALUE LABELS pp_upset_11

1 "Definitely agree"

2 "Somewhat agree"

3 "Definitely/Somewhat Disagree"

99 "DK/Ref/Partial interview".

MISSING VALUES pp_upset_11(99).

FORMATS pp_upset_11(f2.0).

EXECUTE.

Condition is genetic or hereditary	
Description	Do parents believe that the child's condition is genetic or hereditary?
Survey Items Used	PP2_G
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree; Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE PP2_G

RECODE PP2_G

(1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_gen_11.

VARIABLE LABELS pp_gen_11 "Parent agrees with following statement: the child's condition is genetic or hereditary".

VALUE LABELS pp_gen_11

1 "Definitely agree"

2 "Somewhat agree"

3 "Definitely/Somewhat Disagree"

99 "DK/Ref/Partial interview".

MISSING VALUES pp_gen_11(99).

FORMATS pp_gen_11(f2.0).

EXECUTE.

Condition caused by exposure before birth

Description	Do parents believe that the child's condition was caused by something the child was exposed to in utero, that is, before he/she was born?
Survey Items Used	PP2_H
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree; Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation

RECODE PP2_H

(1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_inutr_11.

VARIABLE LABELS pp_inutr_11 "Parent agrees with following statement: the child's condition was caused by something the child was exposed to in utero, that is, before they was born".

VALUE LABELS pp_inutr_11

1 "Definitely agree"

2 "Somewhat agree"

3 "Definitely/Somewhat Disagree"

99 "DK/Ref/Partial interview".

MISSING VALUES pp_inutr_11(99).

FORMATS pp_inutr_11(f2.0).

EXECUTE.

Condition caused by exposure after birth	
Description	Do parents believe that the child's condition was caused by something the child was exposed to after he/she was born?
Survey Items Used	PP2_I
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree: Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE PP2_I

(1=1) (2=2) (3 thru 4=3) (6 thru 7=99) (SYSMIS=99) into pp_expsd_11.

VARIABLE LABELS pp_expsd_11 "Parent agrees with following statement: the child's condition was caused by something the child was exposed to after they was born".

VALUE LABELS pp_expsd_11

1 "Definitely agree"

2 "Somewhat agree"

3 "Definitely/Somewhat Disagree"

99 "DK/Ref/Partial interview".

MISSING VALUES pp_expsd_11(99).

FORMATS pp_expsd_11(f2.0).

EXECUTE.

Injury affected child's behavior or development	
Description	Has child experienced an accident, injury, or illness that the parent feels has had an effect on the child's behavior or development?
Survey Items Used	PP3
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Definitely agree; Somewhat agree; Definitely/Somewhat disagree

Notes for Data-Users
N/A

SPSS Syntax and Annotation
RECODE PP3
(0=2) (1=1) (6 thru 7=99) (SYSMIS=99) into pp_injry_11.
VARIABLE LABELS pp_injry_11 "Experienced an accident, injury, or illness that the parent feels has had an effect on the child's behavior or development".
VALUE LABELS pp_injry_11
1 "Yes"
2 "No"
99 "DK/Ref/Partial interview".
MISSING VALUES pp_injry_11(99).
FORMATS pp_injry_11(f2.0).
EXECUTE.

Parental Views and Safety Concerns

Wandered or became lost	
Description	Did your child wander off or become lost in the past year?
Survey Items Used	WWP1_A; WWP1_B; WWP1_C; WWP1_D
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child wandered off or became lost; No, child did not wander off or become lost

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE WWP1_AR = WWP1_A.

IF (WWP1_A = 6 or WWP1_A = 7) WWP1_AR = 99.

IF (SYSMIS(WWP1_A)) WWP1_AR = 99.

EXECUTE.

COMPUTE ww_home_11 = 999.

IF (WWP1_AR = 99) ww_home_11 = 99.

IF (WWP1_A = 1) ww_home_11 = 1.

IF (WWP1_A = 0) ww_home_11 = 2.

VARIABLE LABELS ww_home_11 "Wandered off or became lost from their home in the past year".

VALUE LABELS ww_home_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

COMPUTE WWP1_BR = WWP1_B.

IF (WWP1_B = 6 or WWP1_B = 7) WWP1_BR = 99.

IF (SYSMIS(WWP1_B)) WWP1_BR = 99.

EXECUTE.

COMPUTE ww_res_11 = 999.

VARIABLE LABELS ww_res_11 "Wandered off or became lost from someone else's home such as a relative, friend, neighbor, or babysitter in the past year".

IF (WWP1_BR = 99) ww_res_11 = 99.

IF (WWP1_B = 1) ww_res_11 = 1.

IF (WWP1_B = 0) ww_res_11 = 2.

VALUE LABELS ww_res_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

COMPUTE WWP1_CR = WWP1_C.

IF (WWP1_C = 6 or WWP1_C = 7) WWP1_CR = 99.

IF (SYSMIS(WWP1_C)) WWP1_CR = 99.

EXECUTE.

COMPUTE ww_sch_11 = 999.

VARIABLE LABELS ww_sch_11 "Wandered off or became lost from school, day care, or summer camp in the past year in the past year".

IF (WWP1_CR = 99) ww_sch_11 = 99.

IF (WWP1_C = 1) ww_sch_11 = 1.

IF (WWP1_C = 0) ww_sch_11 = 2.

VALUE LABELS ww_sch_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

COMPUTE WWP1_DR = WWP1_D.

IF (WWP1_D = 6 or WWP1_D = 7) WWP1_DR = 99.

IF (SYSMIS(WWP1_D)) WWP1_DR = 99.

EXECUTE.

COMPUTE ww_publc_11 = 999.

VARIABLE LABELS ww_publc_11 "Wandered off or became lost from a store, restaurant, playground, campsite, or any other public place in the past year".

IF (WWP1_DR = 99) ww_publc_11 = 99.

IF (WWP1_D = 1) ww_publc_11 = 1.

IF (WWP1_D= 0) ww_publc_11 = 2.

VALUE LABELS ww_publc_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE.

COMPUTE COUNT_WW = 999.

COUNT COUNT_WW = WW_HOME_11 WW_RES_11 WW_SCH_11 WW_PUBLC_11 (1).

```
COMPUTE COUNT_NOWW = 999.
COUNT COUNT_NOWW = WW_HOME_11 WW_RES_11 WW_SCH_11 WW_PUBLC_11 (2).


COMPUTE WW_COUNT_11 = 999.
IF (WW_HOME_11 = 99 and WW_RES_11 = 99 and WW_SCH_11 = 99 and WW_PUBLC_11 = 99)
WW_COUNT_11 = 99.
IF (COUNT_NOWW GE 4) or (COUNT_NOWW GE 3 and (WW_HOME_11 = 99 or WW_RES_11 = 99 or
WW_SCH_11 = 99 or WW_PUBLC_11 = 99)) WW_COUNT_11 = 0.
IF (COUNT_WW = 1) WW_COUNT_11 = 1.
IF (COUNT_WW GE 2 and COUNT_WW < 80) WW_COUNT_11 = 2.


VARIABLE LABELS WW_COUNT_11 "In the past year, child wandered off or became lost in none, 1, 2 or
more places".
VALUE LABELS  WW_COUNT_11
0 "None"
1 "1"
2 "2+"
99 "Missing"
90 "Skip".
EXECUTE.
COMPUTE ww_any_11 = WW_COUNT_11.
IF (WW_COUNT_11 GE 1 and WW_COUNT_11 < 80) WW_ANY_11 = 1.
VARIABLE LABELS ww_any_11 "Wandered off or became lost in the past year".
VALUE LABELS  ww_any_11
0 "No"
1 "Yes"
99 "Missing"
90 "Skip".
EXECUTE.
```

Wandered off or became lost from home

Description	Did your child wander off or become lost from home in the past year?
Survey Items Used	WWP1_A
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child wandered off or became lost from their home; No, child did not wander off or became lost from their home

Notes for Data-Users
N/A

SPSS Syntax and Annotation

COMPUTE WWP1_AR = WWP1_A.
IF (WWP1_A = 6 or WWP1_A = 7) WWP1_AR = 99.
IF (SYSMIS(WWP1_A)) WWP1_AR = 99.
EXECUTE.
 	
COMPUTE ww_home_11 = 999.
IF (WWP1_AR = 99) ww_home_11 = 99.
IF (WWP1_A = 1) ww_home_11 = 1.
IF (WWP1_A = 0) ww_home_11 = 2.
VARIABLE LABELS ww_home_11 "Wandered off or became lost from their home in the past year ".
VALUE LABELS ww_home_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".

Wandered off or became lost from someone else's home	
Description	Did your child wander off or become lost from someone else's home such as a relative, friend, neighbor or babysitter in the past year?
Survey Items Used	WWP1_B
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, wandered off or became lost; No, child did not wander off or become lost

Notes for Data-Users
N/A

SPSS Syntax and Annotation

```
COMPUTE WWP1_BR = WWP1_B.
IF (WWP1_B = 6 or WWP1_B = 7) WWP1_BR = 99.
IF (SYSMIS(WWP1_B)) WWP1_BR = 99.
EXECUTE.


COMPUTE ww_res_11 = 999.
VARIABLE LABELS ww_res_11 "Wandered off or became lost from someone else's home such as a
relative, friend, neighbor, or babysitter in the past year ".
IF (WWP1_BR = 99) ww_res_11 = 99.
IF (WWP1_B = 1) ww_res_11 = 1.
IF (WWP1_B = 0) ww_res_11 = 2.
VALUE LABELS ww_res_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".
EXECUTE.
```

Wandered off or became lost from school, day care, or camp	
Description	Did your child wander off or become lost from school, day care, or summer camp in the past year?
Survey Items Used	WWP1_C
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child wandered off or became lost; No, child did not wander off or become lost

Notes for Data-Users
N/A

SPSS Syntax and Annotation

COMPUTE WWP1_CR = WWP1_C.
IF (WWP1_C = 6 or WWP1_C = 7) WWP1_CR = 99.
IF (SYSMIS(WWP1_C)) WWP1_CR = 99.
EXECUTE.
 	
COMPUTE ww_sch_11 = 999.
VARIABLE LABELS ww_sch_11 "Wandered off or became lost from school, day care, or summer camp in the past year in the past year".
IF (WWP1_CR = 99) ww_sch_11 = 99.
IF (WWP1_C = 1) ww_sch_11 = 1.
IF (WWP1_C = 0) ww_sch_11 = 2.
VALUE LABELS ww_sch_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".
EXECUTE.

Wandered off or became lost from a public place

Description	Did your child wander off or become lost from a store, restaurant, playground, campsite or any other public place in the past year?
Survey Items Used	WWP1_D
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes, child wandered off or became lost from a public place; No, child did not wander off or become lost from a public place

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE WWP1_DR = WWP1_D.
IF (WWP1_D = 6 or WWP1_D = 7) WWP1_DR = 99.
IF (SYSMIS(WWP1_D)) WWP1_DR = 99.
EXECUTE.

COMPUTE ww_publc_11 = 999.
VARIABLE LABELS ww_publc_11 "Wandered off or became lost from a store, restaurant, playground, campsite, or any other public place in the past year ".
IF (WWP1_DR = 99) ww_publc_11 = 99.
IF (WWP1_D = 1) ww_publc_11 = 1.
IF (WWP1_D= 0) ww_publc_11 = 2.
VALUE LABELS ww_publc_11
1 "Yes"
2 "No"
99 "Missing"
90 "Skip".
EXECUTE.

Barriers added to home due to wandering	
Description	Were barriers added to your home to prevent child from wandering off or becoming lost in the past year?
Survey Items Used	WWP2
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes; No

Notes for Data-Users

N/A

SPSS Syntax and Annotation

COMPUTE ww_barr_11 = 999.

VARIABLE LABELS ww_barr_11 "Barriers were added to home to prevent child from wandering off or becoming lost in the past year".

IF (WWP2R = 99) ww_barr_11 = 99.

IF (WWP2 = 1) ww_barr_11 = 1.

IF (WWP2 = 0) ww_barr_11 = 2.

VALUE LABELS ww_barr_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

EXECUTE

Tracking device added due to wandering	
Description	Did child wear a tracking device to help find them if they wandered off in the past year?
Survey Items Used	WWP3
Denominator	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
Numerator	Yes; No
Notes for Data-Users	
N/A	
SPSS Syntax and Annotation	

COMPUTE ww_track_11 = 999.

VARIABLE LABELS ww_track_11 "Children wore a tracking device to help find them if they wandered off in the past year ".

IF (WWP3R = 99) ww_track_11 = 99.

IF (WWP3 = 1) ww_track_11 = 1.

IF (WWP3 = 0) ww_track_11 = 2.

VALUE LABELS ww_track_11

1 "Yes"

2 "No"

99 "Missing"

90 "Skip".

Age

Description	Age 2 groups (6-17 years)
Survey Items Used	AGE_P
Denominator	CSHCN ages 6-17 years with current ASD, ID and/or DD
Numerator	6-11 yrs; 12-17 yrs

Notes for Data-Users

Current age of child in years at the time of Pathways Interview

SPSS Syntax and Annotation

RECODE AGE_P
(6 thru 11=1) (12 thru 17=2) into age2_11.
VARIABLE LABELS age2_11 "Current age in 6-11 years or 12-17 years".
VALUE LABELS age2_11
1 "6-11 years old"
2 "12-17 years old".
EXECUTE.

Sex of child

Description	Sex of child
Survey Items Used	SEX_P
Denominator	CSHCN ages 6-17 years with current ASD, ID and/or DD
Numerator	Male; Female

Notes for Data-Users

N/A

SPSS Syntax and Annotation

RECODE SEX_P
(7=99) (else=copy) into sex_11.
VARIABLE LABELS sex_11 "Sex of the child".
VALUE LABELS sex_11
1 "Male"
2 "Female"
99 "Refused".
MISSING VALUES sex_11(99).
EXECUTE.

Race/ethnicity

Description	Race/ethnicity of child
Survey Items Used	HISPANIC_IMP_Pv3; RACER_IMP_Pv3
Denominator	CSHCN ages 6-17 years with current ASD, ID and/or DD
Numerator	Hispanic; White, Non-Hispanic; Black, non-Hispanic; Other, non-Hispanic

Notes for Data-Users

The telephone interview questionnaire was only conducted in English. Therefore, estimates are not generalizable to all Hispanic/Latino CSHCN, primarily households who do not speak English. Unknown values for race and ethnicity were calculated using single imputation methods. The race/ethnicity estimates and confidence intervals based on single imputation may differ slightly from those obtained using multiple imputation methods.

SPSS Syntax and Annotation

COMPUTE race4_11 = 99.
IF (HISPANIC_IMP_Pv3 = 1) race4_11 = 1.
IF (HISPANIC_IMP_Pv3 = 0 and RACER_IMP_Pv3 = 1) race4_11 = 2.
IF (HISPANIC_IMP_Pv3 = 0 and RACER_IMP_Pv3 = 2) race4_11 = 3.
IF (HISPANIC_IMP_Pv3 = 0 and RACER_IMP_Pv3 = 3) race4_11 = 4.
VARIABLE LABELS race4_11 "Race/ethnicity categories - 4 categories based on Pathways imputed file - imputation v3".
VALUE LABELS race4_11
1 "Hispanic"
2 "White, non-Hisp"
3 "Black, non-Hisp"
4 "Other, non-Hisp"
99 'DK/REF/SYSMIS to Hispanic or Race or both '.
MISSING VALUES race4_11 (99).
FORMATS race4_11 (f3.0).

COMPUTE race2_11 = 99.
IF (HISPANIC_IMP_Pv3 = 1) race2_11 = 2.
IF (HISPANIC_IMP_Pv3 = 0 and RACER_IMP_Pv3 = 1) race2_11 = 1.
IF (HISPANIC_IMP_Pv3 = 0 and RACER_IMP_Pv3 = 2) race2_11 = 2.
IF (HISPANIC_IMP_Pv3 = 0 and RACER_IMP_Pv3 = 3) race2_11 = 2.
VARIABLE LABELS race2_11 "Race/ethnicity categories - 4 categories based on Pathways imputed file - imputation v3".
VALUE LABELS race2_11
1 "White, non-Hisp"
2 "Other, non-Hispanic"
99 'DK/REF/SYSMIS to Hispanic or Race or both '.

MISSING VALUES race2_11 (99).

FORMATS race2_11 (f3.0).

Household income level

Description	Household income level
Survey Items Used	POVLEVEL_IMP_Pv3
Denominator	CSHCN ages 6-17 years with current ASD, ID and/or DD
Numerator	0-99% FPL; 100-199% FPL; 200-399% FPL, 400% FPL or higher

Notes for Data-Users

Unknown values for income, household size, or both were calculated using single imputation methods. The household poverty level estimates and confidence intervals based on single imputed poverty level may differ slightly from those obtained using multiple imputation methods.

SPSS Syntax and Annotation

RECODE POVLEVEL_IMP_Pv3

(1 thru 2=1) (3 thru 6=2) (7 thru 8=3) (9=4) (SYSMIS=99) INTO povlev4_11.

VARIABLE LABELS povlev4_11 "Levels of income according to Federal Poverty Level (FPL) guidelines - based on imputation v3".

VALUE LABELS povlev4_11

1 "0% - 99% FPL"

2 "100% - 199% FPL"

3 "200% - 399% FPL"

4 "400% FPL or greater"

FORMATS povlev4_11 (f2.0).

EXECUTE.

Household income level (SCHIP)	
Description	Household income level (SCHIP)
Survey Items Used	POVLEVEL_IMP_Pv3
Denominator	CSHCN ages 6-17 years with current ASD, ID and/or DD
Numerator	0-99% FPL; 100-199% FPL; 200-399% FPL, 400% FPL or higher

Notes for Data-Users

Unknown values for income, household size, or both were calculated using single imputation methods. The household poverty level estimates and confidence intervals based on single imputed poverty level may differ slightly from those obtained using multiple imputation methods.

SPSS Syntax and Annotation

RECODE POVLEVEL_IMP_Pv3

(1 thru 6=1) (7=2) (8=3) (9=4) (SYSMIS=99) INTO pov_chip_11.

VARIABLE LABELS pov_chip_11 "Levels of income according to Federal Poverty Level (FPL) guidelines (CHIP) - based on imputation v3".

VALUE LABELS pov_chip_11

1 "0% - 199% FPL"

2 "200% - 299% FPL"

3 "300% - 399% FPL"

4 "400% FPL or greater"

FORMATS pov_chip_11 (f2.0).

EXECUTE.

Highest education of adults in household	
Description	Highest education of adult in household
Survey Items Used	EDUCR_IMP_Pv3
Denominator	CSHCN ages 6-17 years with current ASD, ID and/or DD
Numerator	Less than high school or HS graduate; More than high school education

Notes for Data-Users

Unknown values for household education were calculated using single imputation methods. The highest level of education estimates and confidence intervals based on single imputation may differ slightly from those obtained using multiple imputation methods.

SPSS Syntax and Annotation

RECODE EDUCR_IMP_Pv3

(6 thru 7=99) (1=1) (2=1) (3=2) into educ2_11.

VARIABLE LABELS educ2_11 "Highest parent education in the household (>HS vs. HS or less)?".

VALUE LABELS educ2_11

1 "Less than HS or HS graduate"

2 "More than high school"

99 "DK/Ref".

FORMATS educ2_11 (F4.0).

MISSING VALUES educ2_11 (99).

Insurance type	
Description	Type of health insurance at time of survey
Survey Items Used	National Survey of Children with Special Health Care Needs (NS-CSHCN) items: TYPEINS
Denominator	CSHCN ages 6-17 years with current ASD, ID and/or DD
Numerator	Private insurance only; public insurance only; Both public & private insurance; Uninsured

Notes for Data-Users

The 20009/10 NS-CSHCN item

SPSS Syntax and Annotation

RECODE TYPEINS

(SYSMIS=99) (4=99) (5=4) (else=copy) INTO instype_09.

VARIABLE LABELS instype_09 "Type of Insurance Coverage".

VALUE LABELS instype_09

1 'Private only'

2 'Public only'

3 'Both Public and Private'

4 'Uninsured'

99 "Missing or comprehensive other insurance".

MISSING VALUES instype_09 (99).

FORMATS instype_09 (f2.0).

EXECUTE.

Condition groups – 3 categories

Description	CSHCN who currently have ASD, ID (w/o ASD), DD only, and w/o ASD ID DD
Survey Items Used	DE_AUT11; DE_INT11; DE_DEV11
Denominator	CSHCN ages 6-17 years with current ASD, ID and/or DD
Numerator	CSHCN currently have ASD; CSHCN currently have ID with/without ASD; CSHCN currently have DD only

Notes for Data-Users

N/A

SPSS Syntax and Annotation

RECODE DE_AUT11

(0=2) (1=1) (SYSMIS=2) (6=99) into dx_aut_11.

VARIABLE LABELS dx_aut_11 "CSHCN currently has Autism/ASD".

VALUE LABELS dx_aut_11

1 "CSHCN currently has autism/AS"

2 "CSHCN does not currently have autism/ASD"

99 "DK".

FORMATS dx_aut_11(f2.0).

*MISSING VALUES dx_aut_11(90,99).

RECODE DE_DEV11

(0=2) (1=1) (SYSMIS=2) (6=99) into dx_dev_11.

VARIABLE LABELS dx_dev_11 "CSHCN currently has a developmental delay".

VALUE LABELS dx_dev_11

1 "CSHCN currently has DD"

2 "CSHCN does not currently have DD"

99 "DK".

FORMATS dx_dev_11(f2.0).

*MISSING VALUES dx_dev_11(90,99).

RECODE DE_INT11

(0=2) (1=1) (SYSMIS=2) (6=99) into dx_int_11.

VARIABLE LABELS dx_int_11 "CSHCN currently has an intellectual disability".

VALUE LABELS dx_int_11

1 "CSHCN currently has ID"

2 "CSHCN does not currently have ID"

99 "DK".

FORMATS dx_int_11(f2.0).

*MISSING VALUES dx_int_11(90,99).

COMPUTE dx_grp3_11 = 999.

IF Dx_dev_11 = 1 dx_grp3_11 = 3.

IF Dx_aut_11 = 1 dx_grp3_11= 1.

IF (Dx_aut_11 =2 or Dx_aut_11 =99) and Dx_int_11 = 1 dx_grp3_11 = 2.

IF Dx_aut_11 =99 and Dx_dev_11=99 and Dx_int_11=99 dx_grp3_11=99.

IF Dx_curr_11=2 dx_grp3_11 = 90.

VARIABLE LABELS dx_grp3_11 "CSHCN who currently have ASD, ID (w/o ASD), DD only".

VALUE LABELS dx_grp3_11

1 "CSHCN currently have ASD"

2 "CSHSN currently have ID with/without ASD"

3 "CSHCN currently have DD only"

90 "No current condition"

99 DK to all.

FORMATS dx_grp3_11(f2.0).

MISSING VALUES dx_grp3_11().

EXECUTE.

Condition groups – 2 categories

Description	CSHCN who currently have Autism Spectrum Disorder without Intellectual Disability and/or Developmental Delay
Survey Items Used	DE_AUT11; DE_INT11; DE_DEV11
Denominator	CSHCN ages 6-17 years with current ASD, ID and/or DD
Numerator	CSHCN currently have ASD; CSHCN currently have DD and/or ID

Notes for Data-Users

N/A

SPSS Syntax and Annotation

RECODE DE_AUT11

(0=2) (1=1) (SYSMIS=2) (6=99) into dx_aut_11.

VARIABLE LABELS dx_aut_11 "CSHCN currently has Autism/ASD".

VALUE LABELS dx_aut_11

1 "CSHCN currently has autism/AS"

2 "CSHCN does not currently have autism/ASD"

99 "DK".

FORMATS dx_aut_11(f2.0).

*MISSING VALUES dx_aut_11(90,99).

RECODE DE_DEV11

(0=2) (1=1) (SYSMIS=2) (6=99) into dx_dev_11.

VARIABLE LABELS dx_dev_11 "CSHCN currently has a developmental delay".

VALUE LABELS dx_dev_11

1 "CSHCN currently has DD"

2 "CSHCN does not currently have DD"

99 "DK".

FORMATS dx_dev_11(f2.0).

*MISSING VALUES dx_dev_11(90,99).

RECODE DE_INT11

(0=2) (1=1) (SYSMIS=2) (6=99) into dx_int_11.

VARIABLE LABELS dx_int_11 "CSHCN currently has an intellectual disability".

VALUE LABELS dx_int_11

1 "CSHCN currently has ID"

2 "CSHCN does not currently have ID"

99 "DK".

FORMATS dx_int_11(f2.0).

*MISSING VALUES dx_int_11(90,99).

COMPUTE dx_grp2_11 = 999.

IF Dx_dev_11 = 1 or Dx_int_11 = 1 dx_grp2_11 = 2.

IF DX_AUT_11 = 1 dx_grp2_11 = 1.

IF Dx_aut_11 =99 and Dx_dev_11=99 and Dx_int_11=99 dx_grp2_11=99.

IF Dx_curr_11=2 dx_grp2_11 = 90.

VARIABLE LABELS dx_grp2_11 "CSHCN who currently have Autism Spectrum Disorder w/o Intellectual Disability and /or Developmental Delay".

VALUE LABELS dx_grp2_11

1 "CSHCN currently have ASD"

2 "CSHCN currently have DD or ID"

90 "No current condition"

99 DK to all.

Appendix A:

Unweighted Frequency Tables for Codebook Variables

Developmental Concern

pc_age_11 Age when parents were first concerned about their child's development

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Condition/concern at or before birth	547	13.6	13.9	13.9
	2.00 1 - 23 months	1128	28.0	28.7	42.7
	3.00 24 - 47 months	1092	27.1	27.8	70.5
	4.00 48+ months	1158	28.7	29.5	100.0
	Total	3925	97.3	100.0	
Missing	90.00 Skip	87	2.2		
	99.00 Missing	20	.5		
	Total	107	2.7		
Total		4032	100.0		

pc_count_11 Parents who had 0-1, 2-3, or 4+ of the 7 types of developmental concerns

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 0-1 concerns	359	8.9	10.6	10.6
	2.00 2-3 concerns	1106	27.4	32.6	43.2
	3.00 4+ concerns	1925	47.7	56.8	100.0
	Total	3390	84.1	100.0	
Missing	90.00 Skip	642	15.9		
Total		4032	100.0		

pc_vrbl_11 Parent was concerned that child had problems talking later, not talking at all, or loosing speech skills

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	1998	49.6	67.0	67.0
	2.00 No	984	24.4	33.0	100.0
	Total	2982	74.0	100.0	
Missing	90.00 Skip	1043	25.9		
	99.00 Missing	1	.0		
	999.00	6	.1		
	Total	1050	26.0		
Total		4032	100.0		

pc_beh_11 Parent was concerned that child had difficulties playing with others, difficulties with change, or any other behavior difficulties (sleeping/eating, hyper, wandering, tantrums, aggressive/destructive)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	2657	65.9	78.8	78.8
	2.00 No	716	17.8	21.2	100.0
	Total	3373	83.7	100.0	
Missing	90.00 Skip	654	16.2		
	99.00 Missing	5	.1		
	Total	659	16.3		
Total		4032	100.0		

pc_motor_11 Parent was concerned that child had problems with coordination/gross motor skills, or fine motor skills

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	2013	49.9	59.8	59.8
	2.00 No	1356	33.6	40.2	100.0
	Total	3369	83.6	100.0	
Missing	90.00 Skip	654	16.2		
	99.00 Missing	9	.2		
	Total	663	16.4		
Total		4032	100.0		

pc_nonvr_11 Parent concerned that child had problems making eye contact, responding when called/to sounds, or with other forms of non-verbal communication (tone of voice, facial expressions, body language)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	2181	54.1	64.7	64.7
	2.00 No	1190	29.5	35.3	100.0
	Total	3371	83.6	100.0	
Missing	90.00 Skip	654	16.2		
	99.00 Missing	7	.2		
	Total	661	16.4		
Total		4032	100.0		

pc_learn_11 Parent was concerned that child had problems understanding what others say or difficulty learning new things or skills

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	2180	54.1	74.9	74.9
	2.00 No	731	18.1	25.1	100.0
	Total	2911	72.2	100.0	
Missing	90.00 Skip	1117	27.7		
	99.00 Missing	4	.1		
	Total	1121	27.8		
Total		4032	100.0		

pc_gest_11 Parent was concerned that child had unusual gestures or movements such as hand flapping, toe walking, or self-spinning

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	905	22.4	33.8	33.8
	2.00 No	1769	43.9	66.2	100.0
	Total	2674	66.3	100.0	
Missing	90.00 Skip	1355	33.6		
	99.00 Missing	3	.1		
	Total	1358	33.7		
Total		4032	100.0		

pc_med_11 Parent was concerned that child had medical problems such as seizures, lack of physical growth, or stomach problems

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	802	19.9	23.7	23.7
	2.00 No	2575	63.9	76.3	100.0
	Total	3377	83.8	100.0	
Missing	90.00 Skip	654	16.2		
	99.00 Missing	1	.0		
	Total	655	16.2		
Total		4032	100.0		

talk_1st_11 Among parents with any developmental concern, person who first had concern that something was not right with child's development

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Parent	2448	60.7	72.9	72.9
	2.00 Health Care Professional	154	3.8	4.6	77.4
	3.00 Teacher, School Counselor, or Nurse	307	7.6	9.1	86.6
	4.00 Other	451	11.2	13.4	100.0
	Total	3360	83.3	100.0	
Missing	90.00 Skip	634	15.7		
	99.00 Missing	38	.9		
	Total	672	16.7		
Total		4032	100.0		

talk_age_11 Child's age when parent first talked to a doctor/health care provider about her/his concerns

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Before birth - <1 yr	993	24.6	26.9	26.9
	2.00 1 - < 2yrs old	525	13.0	14.2	41.1
	3.00 2 - <4yrs old	979	24.3	26.5	67.6
	4.00 4+ yrs old	1196	29.7	32.4	100.0
	Total	3693	91.6	100.0	
Missing	90.00 Skip	324	8.0		
	99.00 Missing	15	.4		
	Total	339	8.4		
Total		4032	100.0		

talk_dr_11 Parent talked to a doctor or health care provider about their concern

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	3708	92.0	92.3	92.3
	2.00 No	308	7.6	7.7	100.0
	Total	4016	99.6	100.0	
Missing	90.00 Skip	12	.3		
	99.00 Missing	4	.1		
	Total	16	.4		
Total		4032	100.0		

dr_test_11 Doctor or health care provider conducted a developmental test when parent had a developmental concern

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	1931	47.9	52.3	52.3
	2.00 No	1760	43.7	47.7	100.0
	Total	3691	91.5	100.0	
Missing	90.00 Skip	324	8.0		
	99.00 Missing	17	.4		
	Total	341	8.5		
Total		4032	100.0		

dr_refer_11 Doctor or healthcare provider made a referral to a special when parent had developmental concerns

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	2267	56.2	61.4	61.4
	2.00 No	1424	35.3	38.6	100.0
	Total	3691	91.5	100.0	
Missing	90.00 Skip	324	8.0		
	99.00 Missing	17	.4		
	Total	341	8.5		
Total		4032	100.0		

dr_sch_11 Doctor or healthcare provider suggested that parent talk with the school when parent had a developmental concern

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	1437	35.6	38.9	38.9
	2.00 No	2254	55.9	61.1	100.0
	Total	3691	91.5	100.0	
Missing	90.00 Skip	324	8.0		
	99.00 Missing	17	.4		
	Total	341	8.5		
Total		4032	100.0		

dr_norm_11 Doctor or healthcare provider said nothing was wrong or behavior was normal when parent had a developmental concern

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	879	21.8	23.8	23.8
	2.00 No	2812	69.7	76.2	100.0
	Total	3691	91.5	100.0	
Missing	90.00 Skip	324	8.0		
	99.00 Missing	17	.4		
	Total	341	8.5		
Total		4032	100.0		

dr_early_11 Doctor or healthcare provider said 'it's too early to tell' when parent had a developmental concern

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	1335	33.1	36.2	36.2
	2.00 No	2356	58.4	63.8	100.0
	Total	3691	91.5	100.0	
Missing	90.00 Skip	324	8.0		
	99.00 Missing	17	.4		
	Total	341	8.5		
Total		4032	100.0		

dr_grow_11 Doctor or healthcare provider said child might 'grow out of it' when parent had a developmental concern

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	1584	39.3	42.9	42.9
	2.00 No	2107	52.3	57.1	100.0
	Total	3691	91.5	100.0	
Missing	90.00 Skip	324	8.0		
	99.00 Missing	17	.4		
	Total	341	8.5		
Total		4032	100.0		

talk_sch_11 Parent talked to teacher, school nurse, school counselor, or other school professional about their concern

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	3727	92.4	92.8	92.8
	2.00 No	290	7.2	7.2	100.0
	Total	4017	99.6	100.0	
Missing	90.00 Skip	12	.3		
	99.00 Missing	3	.1		
	Total	15	.4		
Total		4032	100.0		

pc_scr_11 Developmental screening or assessment completed by parent/health provider

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Completed screening	2029	50.3	50.5	50.5
	2.00 No screening	1047	26.0	26.1	76.6
	3.00 Didn't talk to provider	942	23.4	23.4	100.0
	Total	4018	99.7	100.0	
Missing	99.00 Missing	14	.3		
Total		4032	100.0		

scr_dr_11 Physician completed screener/assessment

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	1920	47.6	62.9	62.9
	2.00 No	1131	28.1	37.1	100.0
	Total	3051	75.7	100.0	
Missing	90.00 Skip	942	23.4		
	99.00 Missing	39	1.0		
	Total	981	24.3		
Total		4032	100.0		

scr_p_11 Parent completed screener/assessment

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	1042	25.8	36.3	36.3
	2.00 No	1825	45.3	63.7	100.0
	Total	2867	71.1	100.0	
Missing	90.00 Skip	942	23.4		
	99.00 Missing	223	5.5		
	Total	1165	28.9		
Total		4032	100.0		

Diagnostic Experiences

any_age_11 Age when parent was first told by Dr that child EVER had any of 3 developmental condition (ASD, ID, or DD)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0-2 years	1340	33.2	34.0	34.0
	2 3-5 years	1320	32.7	33.5	67.6
	3 6-7 years	1277	31.7	32.4	100.0
	Total	3937	97.6	100.0	
Missing	99 No one ever told child has ASD, ID, or DD/Sysmis/DK	95	2.4		
Total		4032	100.0		

dx_autyp_11 Among CSHCN w/Autism, was ever told child had Asperger's, Pervasive Developmental Disorder (PDD), Autistic Disorder or multiple diagnosis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Asperger's Disorder	317	7.9	21.8	21.8
	2.00 Pervasive Developmental Disorder	209	5.2	14.4	36.2
	3.00 Autistic Disorder	277	6.9	19.0	55.2
	4.00 Multiple diagnosis	652	16.2	44.8	100.0
	Total	1455	36.1	100.0	
Missing	90.00 No ASD	2392	59.3		
	99.00 DK/Ref/Missing in error	185	4.6		
	Total	2577	63.9		
Total		4032	100.0		

asperger_11 Among CSHCN with autism, parent was ever told child had Asperger's

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, parent was ever told child had Asperger's	728	18.1	44.7	44.7
	2 No, parent never told child had Asperger's	901	22.3	55.3	100.0
	Total	1629	40.4	100.0	
Missing	90 CSHCN without autism	2392	59.3		
	99 DK/Ref	11	.3		
	Total	2403	59.6		
Total		4032	100.0		

pdd_11 Among CSHCN with autism, parent was ever told child had Pervasive Developmental Disorder (PDD)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, parent was ever told child had PDD	729	18.1	46.0	46.0
	2 No, parent never told child had PDD	855	21.2	54.0	100.0
	Total	1584	39.3	100.0	
Missing	90 CSHCN without PDD	2392	59.3		
	99 DK/Ref	56	1.4		
	Total	2448	60.7		
Total		4032	100.0		

autdisrd_11 Among CSHCN with autism, parent was ever told child had Autistic Disorder

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, parent was ever told child had Autistic Disorder	801	19.9	49.9	49.9
	2 No, parent never told child had Autistic Disorder	805	20.0	50.1	100.0
	Total	1606	39.8	100.0	
Missing	90 CSHCN without PDD	2392	59.3		
	99 DK/Ref	34	.8		
	Total	2426	60.2		
Total		4032	100.0		

aut_age_11 Age when parent was first told by Dr that child had ASD (ever and current diagnosis)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0-2 years	280	6.9	17.2	17.2
	2 3-5 years	651	16.1	39.9	57.0
	3 6-17 years	701	17.4	43.0	100.0
	Total	1632	40.5	100.0	
Missing	90 System missing	2384	59.1		
	95 No one ever told child has ASD	8	.2		
	99 DK	8	.2		
	Total	2400	59.5		
Total		4032	100.0		

no_aut_11 Parents who were ever told by a doctor, health care provider, or school professional that child did not have autism or ASD since child was first diagnosed

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes have been told since having ASD that they do not have ASD	302	7.5	18.5	18.5
	2 No, have never been told that they do not have ASD	1334	33.1	81.5	100.0
	Total	1636	40.6	100.0	
Missing	90 System missing	2392	59.3		
	99 DK/Ref	4	.1		
	Total	2396	59.4		
Total		4032	100.0		

drdx_aut_11 Health care provider who first gave Autism diagnosis (ever & current diagnosis)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Pediatrician or Pediatric/Family HCP	253	6.3	15.5	15.5
	2 Psychologist	416	10.3	25.5	41.0
	3 Specialist Dr	668	16.6	41.0	82.0
	4 Multidisciplinary Team/Other	293	7.3	18.0	100.0
	Total	1630	40.4	100.0	
Missing	90 System missing	2293	56.9		
	95 Never told child had condition	89	2.2		
	99 DK	20	.5		
	Total	2402	59.6		
Total		4032	100.0		

dev_age_11 Age when parent was first told by Dr that child had developmental delay (ever and current diagnosis)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0-2 years	1252	31.1	37.1	37.1
	2 3-5 years	1142	28.3	33.9	71.0
	3 6-17 years	979	24.3	29.0	100.0
	Total	3373	83.7	100.0	
Missing	90 System missing	636	15.8		
	95 No one ever told child has DD	3	.1		
	99 DK	20	.5		
	Total	659	16.3		
Total		4032	100.0		

no_dev_11 Parents who were ever told by a doctor, health care provider, or school professional that child did not have developmental delay since child was first diagnosed

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes have been told since having DD that they do not have DD	312	7.7	9.2	9.2
	2 No, have never been told that they do not have DD	3069	76.1	90.8	100.0
	Total	3381	83.9	100.0	
Missing	90 System missing	639	15.8		
	99 DK/Ref	12	.3		
	Total	651	16.1		
Total		4032	100.0		

drdx_dev_11 Health care provider who first gave developmental delay diagnosis (ever & current diagnosis)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Pediatrician or Pediatric/Family HCP	1263	31.3	37.9	37.9
	2 Psychologist	565	14.0	16.9	54.8
	3 Specialist Dr	1003	24.9	30.1	84.9
	4 Multidisciplinary Team/Other	503	12.5	15.1	100.0
	Total	3334	82.7	100.0	
Missing	90 System missing	550	13.6		
	95 Never told child had condition	85	2.1		
	99 DK	63	1.6		
	Total	698	17.3		
Total		4032	100.0		

int_age_11 Age when parent was first told by Dr that child had intellectual disability (ever and current diagnosis)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0-2 years	398	9.9	39.8	39.8
	2 3-5 years	332	8.2	33.2	73.0
	3 6-17 years	270	6.7	27.0	100.0
	Total	1000	24.8	100.0	
Missing	90 System missing	3008	74.6		
	95 No one ever told child has ID	10	.2		
	99 DK	14	.3		
	Total	3032	75.2		
Total		4032	100.0		

no_int_11 Parents who were ever told by a doctor, health care provider, or school professional that child did not have intellectual disability since child was first diagnosed

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes have been told since having ID that they do not have ID	58	1.4	5.7	5.7
	2 No, have never been told that they do not have ID	953	23.6	94.3	100.0
	Total	1011	25.1	100.0	
Missing	90 System missing	3018	74.9		
	99 DK/Ref	3	.1		
	Total	3021	74.9		
Total		4032	100.0		

drdx_int_11 Health care provider who first gave intellectual disability diagnosed (ever & current diagnosis)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Pediatrician or Pediatric/Family HCP	278	6.9	28.0	28.0
	2 Psychologist	203	5.0	20.4	48.4
	3 Specialist Dr	375	9.3	37.8	86.2
	4 Multidisciplinary Team/Other	137	3.4	13.8	100.0
	Total	993	24.6	100.0	
Missing	90 System missing	2963	73.5		
	95 Never told child had condition	46	1.1		
	99 DK	30	.7		
	Total	3039	75.4		
Total		4032	100.0		

<u>Health and Education Services</u>

hcscount_11 Currently use 3 or more of 7 types of health care services to meet their developmental needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Do not use any services	1103	27.4	27.4	27.4
	1 One service	765	19.0	19.0	46.3
	2 Two services	690	17.1	17.1	63.4
	3 Three or more services	1474	36.6	36.6	100.0
	Total	4032	100.0	100.0	

hcs_bi_11 Currently use behavioral intervention or modification services on a regular basis?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently use the services	1062	26.3	27.0	27.0
	2 No, child does not currently use the services	2875	71.3	73.0	100.0
	Total	3937	97.6	100.0	
Missing	99 DK/Ref	95	2.4		
Total		4032	100.0		

hcs_si_11 Currently use sensory integration therapy on a regular basis?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses the therapy	506	12.5	13.2	13.2
	2 No, child does not currently use the therapy	3341	82.9	86.8	100.0
	Total	3847	95.4	100.0	
Missing	99 DK/Ref	185	4.6		
Total		4032	100.0		

hcs_ct_11 Currently use cognitive based therapy on a regular basis?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses the therapy	810	20.1	22.1	22.1
	2 No, child does not currently use the therapy	2857	70.9	77.9	100.0
	Total	3667	90.9	100.0	
Missing	99 DK/Ref	365	9.1		
Total		4032	100.0		

hcs_ot_11 Currently use occupational therapy (school-based or other) on a regular basis?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses the therapy	1544	38.3	39.1	39.1
	2 No, child does not currently use the therapy	2406	59.7	60.9	100.0
	Total	3950	98.0	100.0	
Missing	99 DK/Ref	82	2.0		
Total		4032	100.0		

hcs_pt_11 Currently use physical therapy (school-based or other) on a regular basis?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses the therapy	768	19.0	19.3	19.3
	2 Child does not currently use the therapy	3221	79.9	80.7	100.0
	Total	3989	98.9	100.0	
Missing	99 DK/Ref	43	1.1		
Total		4032	100.0		

hcs_st_11 Currently use social skills training (school-based or other) on a regular basis?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses the services	1689	41.9	42.7	42.7
	2 No, child does not currently use the services	2263	56.1	57.3	100.0
	Total	3952	98.0	100.0	
Missing	99 DK/Ref	80	2.0		
Total		4032	100.0		

hcs_lt_11 Currently use speech or language therapy (school-based or other) on a regular basis?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses the therapy	1787	44.3	44.5	44.5
	2 No, child does not currently use the therapy	2227	55.2	55.5	100.0
	Total	4014	99.6	100.0	
Missing	99 DK/Ref	18	.4		
Total		4032	100.0		

dr_count_11 CSHCN who currently see 2 or more out of 8 types of providers of health and related services to meet their developmental needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Child does not work with any provider	1819	45.1	45.1	45.1
	1 Child works with one provider	1158	28.7	28.7	73.8
	2 Child works with 2 or more providers	1055	26.2	26.2	100.0
	Total	4032	100.0	100.0	

audiolog_11 Currently work with an audiologist on a regular basis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child works with audiologist	214	5.3	5.4	5.4
	2 No, child does not work with audiologist	3764	93.4	94.6	100.0
	Total	3978	98.7	100.0	
Missing	99 DK	54	1.3		
Total		4032	100.0		

devped_11 Currently work with a developmental pediatrician on a regular basis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child works with developmental pediatricians	423	10.5	10.6	10.6
	2 No, child does not work with developmental pediatricians	3573	88.6	89.4	100.0
	Total	3996	99.1	100.0	
Missing	99 DK	36	.9		
Total		4032	100.0		

neurolog_11 Currently work with a neurologist on a regular basis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child works with neurologist	510	12.6	12.7	12.7
	2 No, child does not work with neurologist	3493	86.6	87.3	100.0
	Total	4003	99.3	100.0	
Missing	99 DK	29	.7		
Total		4032	100.0		

nutritn_11 Currently work with a nutritionist on a regular basis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child works with nutritionist	215	5.3	5.3	5.3
	2 No, child does not work with nutritionist	3804	94.3	94.7	100.0
	Total	4019	99.7	100.0	
Missing	99 DK	13	.3		
Total		4032	100.0		

nurse_11 Currently work with an at home/long-term nurse on a regular basis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child works with an at home/long-term nurse	65	1.6	1.6	1.6
	2 No, child does not work with an at home/long-term nurse	3964	98.3	98.4	100.0
	Total	4029	99.9	100.0	
Missing	99 DK	3	.1		
Total		4032	100.0		

psychiat_11 Currently work with a psychiatrist on a regular basis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child works with psychiatrist	956	23.7	23.8	23.8
	2 No, child does not work with psychiatrist	3055	75.8	76.2	100.0
	Total	4011	99.5	100.0	
Missing	99 DK	21	.5		
Total		4032	100.0		

psychlog_11 Currently work with a psychologist/psychotherapist on a regular basis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child works with psychologist/psychotherapist	870	21.6	21.8	21.8
	2 No, child does not work with psychologist/psychotherapist	3117	77.3	78.2	100.0
	Total	3987	98.9	100.0	
Missing	99 DK	45	1.1		
Total		4032	100.0		

socwork_11 CSHCN who currently work with a social worker on a regular basis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child works with a social worker	593	14.7	14.8	14.8
	2 No, child does not work with a social worker	3416	84.7	85.2	100.0
	Total	4009	99.4	100.0	
Missing	99 DK	23	.6		
Total		4032	100.0		

Rxcount_11 Currently uses none, one, or two/more types of medications to meet developmental needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Does not use any medication	2059	51.1	51.1	51.1
	1 Curretly uses 1 medication	1051	26.1	26.1	77.1
	2 Curretly uses 2+ medications	922	22.9	22.9	100.0
	Total	4032	100.0	100.0	

Appendix A: Unweighted Frequency Tables

rx_stmlnt_11 Currently uses stimulant medications to meet developmental needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses stimulant medications	1182	29.3	29.6	29.6
	2 No, child does not currently use stimulant medications	2813	69.8	70.4	100.0
	Total	3995	99.1	100.0	
Missing	99 DK/Missing in error	37	.9		
Total		4032	100.0		

rx_dprss_11 Currently uses anti-depressant medications to meet developmental needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses anti-depressant medications	563	14.0	14.0	14.0
	2 No, child does not currently use anti-depressant medications	3449	85.5	86.0	100.0
	Total	4012	99.5	100.0	
Missing	99 DK/Missing in error	20	.5		
Total		4032	100.0		

rx_anxiet_11 Currently uses anti-anxiety or mood stabilizing medications to meet developmental needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses anti-anxiety/mood medications	655	16.2	16.3	16.3
	2 No, child does not currently use anti-anxiety/mood medications	3352	83.1	83.7	100.0
	Total	4007	99.4	100.0	
Missing	99 DK/Ref	25	.6		
Total		4032	100.0		

rx_seiz_11 Currently uses anti-seizure medications to meet developmental needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses anti-seizure medications	335	8.3	8.3	8.3
	2 No, child does not currently use anti-seizure medications	3688	91.5	91.7	100.0
	Total	4023	99.8	100.0	
Missing	99 DK	9	.2		
Total		4032	100.0		

rx_psych_11 Currently uses anti-psychotic medications to meet developmental needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses anti-psychotic medications	314	7.8	7.8	7.8
	2 No, child does not currently use anti-psychotic medications	3688	91.5	92.2	100.0
	Total	4002	99.3	100.0	
Missing	99 DK/Ref/Missing in error	30	.7		
Total		4032	100.0		

rx_sleep_11 Currently uses sleep medications to meet developmental needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child currently uses sleep medications	530	13.1	13.3	13.3
	2 No, child does not currently use sleep medications	3455	85.7	86.7	100.0
	Total	3985	98.8	100.0	
Missing	99 DK/Missing in error	47	1.2		
Total		4032	100.0		

es_schl_11 Type of school CSHCN currently enrolled in

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Public	3460	85.8	86.3	86.3
	2 Private	377	9.4	9.4	95.7
	3 Home-schooled	173	4.3	4.3	100.0
	Total	4010	99.5	100.0	
Missing	95 Not enrolled in school	14	.3		
	99 DK/Ref	8	.2		
	Total	22	.5		
Total		4032	100.0		

es_iep_11 Among those enrolled in public or private school, children had a written intervention plan called an Individualized Education Program (IEP)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child has an IEP	3028	75.1	79.3	79.3
	2 No, child does not have an IEP	792	19.6	20.7	100.0
	Total	3820	94.7	100.0	
Missing	90 Home-schooled/Not enrolled in school/DK or Ref to ES1	195	4.8		
	99 DK	17	.4		
	Total	212	5.3		
Total		4032	100.0		

es_iepnd_11 Among those enrolled in public or private school, IEP addresses all of the parent's concerns about their child's development and education

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes	2575	63.9	85.2	85.2
	2 No	447	11.1	14.8	100.0
	Total	3022	75.0	100.0	
Missing	90 Child does not have an IEP/Not enrolled in public or private school	1004	24.9		
	99 DK/Ref	6	.1		
	Total	1010	25.0		
Total		4032	100.0		

es_eis_11 Among those enrolled in public or private school, received Early Intervention Services (EIS) before they were 3 years old

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child received services from EIS	1419	35.2	38.1	38.1
	2 No, child did not receive services	2310	57.3	61.9	100.0
	Total	3729	92.5	100.0	
Missing	90 Home-schooled/Not enrolled in school/DK or Ref to ES1	195	4.8		
	99 DK	108	2.7		
	Total	303	7.5		
Total		4032	100.0		

es_eisne_11 Among those enrolled in public or private school, parent was told their child was not eligible for Early Intervention Services

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes	296	7.3	7.8	7.8
	2 No	3498	86.8	92.2	100.0
	Total	3794	94.1	100.0	
Missing	90 Home-schooled/Not enrolled in school/DK or Ref to ES1	195	4.8		
	99 DK	43	1.1		
	Total	238	5.9		
Total		4032	100.0		

Unmet Needs and Insurance Adequacy

in_unmet_11 DID NOT receive all necessary treatments, services, or service providers needed to care for child's developmental needs during the past 12 months

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Child has unmet needs	1053	26.1	26.4	26.4
	2 Child does not have unmet needs	2939	72.9	73.6	100.0
	Total	3992	99.0	100.0	
Missing	99 DK/Ref/Partial Interview	40	1.0		
Total		4032	100.0		

in_serv_11 Received all the treatments and services necessary to meet their developmental needs during the past 12 months

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child received all treatment and services	3053	75.7	76.5	76.5
	2 Child did not receive all treatment and services	939	23.3	23.5	100.0
	Total	3992	99.0	100.0	
Missing	99 DK/Ref/Partial Interview	40	1.0		
Total		4032	100.0		

in_prov_11 Saw all the service providers needed to care for their developmental needs during the past 12 months

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child saw all service providers needed to care	3257	80.8	81.5	81.5
	2 Child did not see all service providers needed to care	740	18.4	18.5	100.0
	Total	3997	99.1	100.0	
Missing	99 DK/Ref/Partial Interview	35	.9		
Total		4032	100.0		

in_ins_11 Has any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes, child has health insurance	3877	96.2	96.3	96.3
	2 Child does not have health insurance	149	3.7	3.7	100.0
	Total	4026	99.9	100.0	
Missing	99 DK/Ref/Partial Interview	6	.1		
Total		4032	100.0		

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

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 Current insurance is NOT adequate	1607	39.9	41.5	41.5
	1 Current insurance IS adequate	2264	56.2	58.5	100.0
	Total	3871	96.0	100.0	
Missing	99 DK or Ref to any item	39	1.0		
	999 Uninsured	122	3.0		
	Total	161	4.0		
Total		4032	100.0		

metneeds_09 Health insurance benefits meet child needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 Never/sometimes	753	18.7	18.7	18.7
	1.00 Usually/always	3141	77.9	77.9	96.6
	2.00 Legit skip b/c uninsured	122	3.0	3.0	99.6
	3.00 Sys missing	4	.1	.1	99.7
	99.00 DK/Ref	12	.3	.3	100.0
	Total	4032	100.0	100.0	

reasonable_09 Non-covered insurance charges reasonable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 Never/sometimes	1364	33.8	33.8	33.8
	1.00 Usually/always	2517	62.4	62.4	96.3
	2.00 Legit skip b/c uninsured	122	3.0	3.0	99.3
	3.00 Sys missing	4	.1	.1	99.4
	99.00 DK/Ref	25	.6	.6	100.0
	Total	4032	100.0	100.0	

providers_09 Insurance allows child to see needed providers

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 Never/sometimes	592	14.7	14.7	14.7
	1.00 Usually/always	3312	82.1	82.1	96.8
	2.00 Legit skip b/c uninsured	122	3.0	3.0	99.9
	3.00 Sys missing	4	.1	.1	100.0
	99.00 DK/Ref	2	.0	.0	100.0
	Total	4032	100.0	100.0	

in_cover_11 Health insurance DID NOT cover all the treatments, services, or service providers needed to care for child's developmental needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Not all treatments/services covered by insurnace	1065	26.4	28.2	28.2
	2 All needed treatments/services covered by insurance	2708	67.2	71.8	100.0
	Total	3773	93.6	100.0	
Missing	90 Child does not have health insurance or DK/Missing to INS3	152	3.8		
	99 DK/Partial interview	107	2.7		
	Total	259	6.4		
Total		4032	100.0		

in_spch_11 Among those who have health insurance, any speech or language therapy not covered by health insurance

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Not covered by insurance	145	3.6	3.9	3.9
	2 All needed treatments/services covered by insurance	3607	89.5	96.1	100.0
	Total	3752	93.1	100.0	
Missing	90 Child does not have health insurance or DK to INS3	152	3.8		
	99 DK/Ref/Partial interview/Missing in error	128	3.2		
	Total	280	6.9		
Total		4032	100.0		

in_occup_11 Among those who have health insurance, any occupational therapy not covered by health insurance

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Occupational therapy not covered by insurance	109	2.7	2.9	2.9
	2 All needed treatments/services covered by insurance	3643	90.4	97.1	100.0
	Total	3752	93.1	100.0	
Missing	90 Child does not have health insurance or DK to INS3	152	3.8		
	99 DK/Ref/Partial interview/Missing in error	128	3.2		
	Total	280	6.9		
Total		4032	100.0		

in_beh_11 Among those who have health insurance, any behavioral management services not covered by health insurance

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Not covered by insurance	109	2.7	2.9	2.9
	2 All needed treatments/services covered by insurance	3643	90.4	97.1	100.0
	Total	3752	93.1	100.0	
Missing	90 Child does not have health insurance or DK to INS3	152	3.8		
	99 DK/Ref/Partial interview/Missing in error	128	3.2		
	Total	280	6.9		
Total		4032	100.0		

in_psych_11 Among those who have health insurance, any psychological services not covered by health insurance

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Not covered by insurance	185	4.6	4.9	4.9
	2 All needed treatments/services covered by insurance	3567	88.5	95.1	100.0
	Total	3752	93.1	100.0	
Missing	90 Child does not have health insurance or DK to INS3	152	3.8		
	99 DK/Ref/Partial interview/Missing in error	128	3.2		
	Total	280	6.9		
Total		4032	100.0		

in_alt_11 Among those who have health insurance, any alternative medicine/therapies not covered by health insurance

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Not covered by insurance	144	3.6	3.8	3.8
	2 All needed treatments/services covered by insurance	3608	89.5	96.2	100.0
	Total	3752	93.1	100.0	
Missing	90 Child does not have health insurance or DK to INS3	152	3.8		
	99 DK/Ref/Partial interview/Missing in error	128	3.2		
	Total	280	6.9		
Total		4032	100.0		

Functioning, Strengths and Difficulties

sdq_CATI_11 Scoring results of brief Strengths and Difficulties Questionnaire (5 items)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 High score: 6-10	1202	29.8	30.3	30.3
	2 Medium score: 3-5	1844	45.7	46.5	76.7
	3 Low score: 0-2	923	22.9	23.3	100.0
	Total	3969	98.4	100.0	
Missing	99 DK/Ref/Partial interview	63	1.6		
Total		4032	100.0		

sdq_beh_11 Child was generally well behaved and usually do what adults request during the past six months

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Not true	366	9.1	9.1	9.1
	2 Somewhat true	1763	43.7	43.9	53.0
	3 Certainly true	1886	46.8	47.0	100.0
	Total	4015	99.6	100.0	
Missing	99 DK/Ref/Partial interview	17	.4		
Total		4032	100.0		

sdq_wrry_11 Child had many worries, or often seems worried during the past six months

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Not true	1332	33.0	33.2	33.2
	2 Somewhat true	1638	40.6	40.8	74.0
	3 Certainly true	1041	25.8	26.0	100.0
	Total	4011	99.5	100.0	
Missing	99 DK/Ref/Partial interview	21	.5		
Total		4032	100.0		

sdq_dep_11 Child was often unhappy, depressed, or tearful during the past six months

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Not true	2328	57.7	58.0	58.0
	2 Somewhat true	1348	33.4	33.6	91.5
	3 Certainly true	341	8.5	8.5	100.0
	Total	4017	99.6	100.0	
Missing	99 DK/Ref/Partial interview	15	.4		
Total		4032	100.0		

sdq_adlt_11 Child got along better with adults than with other children or youth during the past six months

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Not true	1527	37.9	38.2	38.2
	2 Somewhat true	1337	33.2	33.5	71.7
	3 Certainly true	1131	28.1	28.3	100.0
	Total	3995	99.1	100.0	
Missing	99 DK/Ref/Partial interview	37	.9		
Total		4032	100.0		

sdq_attn_11 Child had a good attention span, sees chores or homework through to the end during the past six months

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Not true	1919	47.6	47.8	47.8
	2 Somewhat true	1556	38.6	38.8	86.6
	3 Certainly true	538	13.3	13.4	100.0
	Total	4013	99.5	100.0	
Missing	99 DK/Ref/Partial interview	19	.5		
Total		4032	100.0		

Parental Views and Safety Concerns

pp_tchn_11 Parent agrees with following statement: the teachers and other professionals at the child's school are able to meet their needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	1777	44.1	44.3	44.3
	2 Somewhat agree	1634	40.5	40.7	85.0
	3 DefinitelySomewhat disagree	600	14.9	15.0	100.0
	Total	4011	99.5	100.0	
Missing	99 DK/Ref/Partial interview	21	.5		
Total		4032	100.0		

pp_tchs_11 Parent agrees with following statement: they are satisfied with the services that their child receives from teachers and other school professionals

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	1764	43.8	44.0	44.0
	2 Somewhat agree	1516	37.6	37.8	81.8
	3 Definitely/Somewhat Disagree	729	18.1	18.2	100.0
	Total	4009	99.4	100.0	
Missing	99 DK/Ref/Partial interview	23	.6		
Total		4032	100.0		

pp_drn_11 Parent agrees with following statement: the doctors and other health care providers that child sees are able to meet their needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	2364	58.6	58.8	58.8
	2 Somewhat agree	1308	32.4	32.6	91.4
	3 Definitely/Somewhat Disagree	346	8.6	8.6	100.0
	Total	4018	99.7	100.0	
Missing	99 DK/Ref/Partial interview	14	.3		
Total		4032	100.0		

pp_drs_11 Parent agrees with following statement: they are satisfied with the services that their child receives from doctors and other health care providers

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	2472	61.3	61.5	61.5
	2 Somewhat agree	1201	29.8	29.9	91.4
	3 Definitely/Somewhat Disagree	346	8.6	8.6	100.0
	Total	4019	99.7	100.0	
Missing	99 DK/Ref/Partial interview	13	.3		
Total		4032	100.0		

pp_life_11 Parent agrees with following statement: condition is likely to be lifelong rather than temporary

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	2630	65.2	65.7	65.7
	2 Somewhat agree	920	22.8	23.0	88.7
	3 Definitely/Somewhat Disagree	451	11.2	11.3	100.0
	Total	4001	99.2	100.0	
Missing	99 DK/Ref/Partial interview	31	.8		
Total		4032	100.0		

pp_prev_11 Parent agrees with following statement: the problems related to their child's condition can be prevented or decreased with treatment

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	1375	34.1	34.6	34.6
	2 Somewhat agree	1574	39.0	39.6	74.3
	3 Definitely/Somewhat Disagree	1021	25.3	25.7	100.0
	Total	3970	98.5	100.0	
Missing	99 DK/Ref/Partial interview	62	1.5		
Total		4032	100.0		

pp_chnge_11 Parent agrees with following statement: they have the power to change their child's condition

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	422	10.5	10.6	10.6
	2 Somewhat agree	1163	28.8	29.2	39.8
	3 Definitely/Somewhat Disagree	2396	59.4	60.2	100.0
	Total	3981	98.7	100.0	
Missing	99 DK/Ref/Partial interview	51	1.3		
Total		4032	100.0		

pp_myst_11 Parent agrees with following statement: condition is a mystery to them

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	573	14.2	14.3	14.3
	2 Somewhat agree	882	21.9	22.0	36.4
	3 Definitely/Somewhat Disagree	2546	63.1	63.6	100.0
	Total	4001	99.2	100.0	
Missing	99 DK/Ref/Partial interview	31	.8		
Total		4032	100.0		

pp_go_11 Parent agrees with following statement: the child's symptoms come and go

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	416	10.3	10.4	10.4
	2 Somewhat agree	773	19.2	19.3	29.7
	3 Definitely/Somewhat Disagree	2819	69.9	70.3	100.0
	Total	4008	99.4	100.0	
Missing	99 DK/Ref/Partial interview	24	.6		
Total		4032	100.0		

pp_upset_11 Parent agrees with following statement: when they think about their child's condition they get upset

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	950	23.6	23.7	23.7
	2 Somewhat agree	1214	30.1	30.2	53.9
	3 Definitely/Somewhat Disagree	1851	45.9	46.1	100.0
	Total	4015	99.6	100.0	
Missing	99 DK/Ref/Partial interview	17	.4		
Total		4032	100.0		

pp_gen_11 Parent agrees with following statement: the child's condition is genetic or hereditary

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	1444	35.8	37.7	37.7
	2 Somewhat agree	1177	29.2	30.7	68.5
	3 Definitely/Somewhat Disagree	1208	30.0	31.5	100.0
	Total	3829	95.0	100.0	
Missing	99 DK/Ref/Partial interview	203	5.0		
Total		4032	100.0		

pp_inutr_11 Parent agrees with following statement: the child's condition was caused by something the child was exposed to in utero, that is, before they was born

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	568	14.1	15.2	15.2
	2 Somewhat agree	708	17.6	18.9	34.1
	3 Definitely/Somewhat Disagree	2468	61.2	65.9	100.0
	Total	3744	92.9	100.0	
Missing	99 DK/Ref/Partial interview	288	7.1		
Total		4032	100.0		

pp_expsd_11 Parent agrees with following statement: the child's condition was caused by something the child was exposed to after they was born

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Definitely agree	483	12.0	12.6	12.6
	2 Somewhat agree	612	15.2	15.9	28.5
	3 Definitely/Somewhat Disagree	2748	68.2	71.5	100.0
	Total	3843	95.3	100.0	
Missing	99 DK/Ref/Partial interview	189	4.7		
Total		4032	100.0		

pp_injry_11 Experienced an accident, injury, or illness that the parent feels has had an effect on the child's behavior or development

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Yes	783	19.4	19.6	19.6
	2 No	3205	79.5	80.4	100.0
	Total	3988	98.9	100.0	
Missing	99 DK/Ref/Partial interview	44	1.1		
Total		4032	100.0		

ww_any_11 Wandered off or became lost in the past year

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00 No	3164	78.5	78.7	78.7
	1.00 Yes	857	21.3	21.3	100.0
	Total	4021	99.7	100.0	
Missing	99.00 Missing	11	.3		
Total		4032	100.0		

ww_home_11 Wandered off or became lost from their home in the past year

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	293	7.3	7.3	7.3
	2.00 No	3728	92.5	92.7	100.0
	Total	4021	99.7	100.0	
Missing	99.00 Missing	11	.3		
Total		4032	100.0		

Appendix A: Unweighted Frequency Tables

ww_res_11 Wandered off or became lost from someone else's home such as a relative, friend, neighbor, or babysitter in the past year

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	140	3.5	3.5	3.5
	2.00 No	3878	96.2	96.5	100.0
	Total	4018	99.7	100.0	
Missing	99.00 Missing	14	.3		
Total		4032	100.0		

ww_sch_11 Wandered off or became lost from school, day care, or summer camp in the past year in the past year

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	227	5.6	5.6	5.6
	2.00 No	3792	94.0	94.4	100.0
	Total	4019	99.7	100.0	
Missing	99.00 Missing	13	.3		
Total		4032	100.0		

ww_publc_11 Wandered off or became lost from a store, restaurant, playground, campsite, or any other public place in the past year

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	579	14.4	14.4	14.4
	2.00 No	3441	85.3	85.6	100.0
	Total	4020	99.7	100.0	
Missing	99.00 Missing	12	.3		
Total		4032	100.0		

ww_barr_11 Barriers were added to home to prevent child from wandering off or becoming lost in the past year

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	743	18.4	18.5	18.5
	2.00 No	3278	81.3	81.5	100.0
	Total	4021	99.7	100.0	
Missing	99.00 Missing	11	.3		
Total		4032	100.0		

ww_track_11 Children wore a tracking device to help find them if they wandered off in the past year

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Yes	83	2.1	2.1	2.1
	2.00 No	3938	97.7	97.9	100.0
	Total	4021	99.7	100.0	
Missing	99.00 Missing	11	.3		
Total		4032	100.0		

Stratifiers

age2P_11 Age of the child in Pathways - 2 age groups

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 6-11 years old	1953	48.4	48.4	48.4
	2.00 12-17 years old	2079	51.6	51.6	100.0
	Total	4032	100.0	100.0	

sexP_11 Sex of the child

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 Male	2780	68.9	69.0	69.0
	2.00 Female	1249	31.0	31.0	100.0
	Total	4029	99.9	100.0	
Missing	99.00 Refused	3	.1		
Total		4032	100.0		

race4P_11 Race/ethnicity categories - 4 categories based on Pathways imputed file - imputation v3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Hispanic	358	8.9	8.9	8.9
	2 White, non-Hisp	2914	72.3	72.3	81.2
	3 Black, non-Hisp	346	8.6	8.6	89.7
	4 Other, non-Hisp	414	10.3	10.3	100.0
	Total	4032	100.0	100.0	

povlev4P_11 Version 1: Income level of CSHCN's household (% of Federal Poverty Level) based on imputation v3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0% - 99% FPL	708	17.6	17.6	17.6
	2 100% - 199% FPL	824	20.4	20.4	38.0
	3 200% - 399% FPL	1281	31.8	31.8	69.8
	4 400% FPL or greater	1219	30.2	30.2	100.0
	Total	4032	100.0	100.0	

povschip_11 Version 2: SCHIP relevant income level of CSHCN's household (% of Federal Poverty Level) based on imputation v3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 0% - 199% FPL	1532	38.0	38.0	38.0
	2 200% - 299% FPL	718	17.8	17.8	55.8
	3 300% - 399% FPL	563	14.0	14.0	69.8
	4 400% FPL or greater	1219	30.2	30.2	100.0
	Total	4032	100.0	100.0	

educ2_11 Highest parent education in the household (>HS vs. HS or less)?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Less than HS or HS graduate	779	19.3	19.3	19.3
	2 More than high school	3253	80.7	80.7	100.0
	Total	4032	100.0	100.0	

instype_09 Type of Insurance Coverage

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Private only	1965	48.7	50.3	50.3
	2 Public only	1291	32.0	33.1	83.4
	3 Both Public and Private	528	13.1	13.5	96.9
	4 Uninsured	122	3.0	3.1	100.0
	Total	3906	96.9	100.0	
Missing	99 Missing or comprehensive other insurance	126	3.1		
Total		4032	100.0		

Appendix A: Unweighted Frequency Tables

REGION_P Region of residence

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 1 - NORTHEAST	778	19.3	19.3	19.3
	2 2 - MIDWEST	926	23.0	23.0	42.3
	3 3 - SOUTH	1180	29.3	29.3	71.5
	4 4 - WEST	1148	28.5	28.5	100.0
	Total	4032	100.0	100.0	

DX_aut_11 CSHCN who currently have Autism/ASD

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 CSHCN currently has autism/AS	1420	35.2	35.5	35.5
	2 CSHCN does not currently have autism/ASD	2578	63.9	64.5	100.0
	Total	3998	99.2	100.0	
Missing	99 DK/Missing in error	34	.8		
Total		4032	100.0		

DX_int_11 CSHCN who currently have intellectual disability

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 CSHCN currently has ID	960	23.8	23.9	23.9
	2.00 CSHCN does not currently have ID	3062	75.9	76.1	100.0
	Total	4022	99.8	100.0	
Missing	99.00 DK	10	.2		
Total		4032	100.0		

DX_dev_11 CSHCN who currently have developmental delay

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 CSHCN currently has DD	2965	73.5	73.5	73.5
	2.00 CSHCN does not currently have DD	1046	25.9	25.9	99.5
	99.00 DK	21	.5	.5	100.0
	Total	4032	100.0	100.0	

Dx_curr_11 CSHCN currently have ASD, ID and/or DD

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 CSHCN currently has ASD, ID and/or ID	3518	87.3	87.3	87.3
	2 CSHCN does not currently have any of the 3 conditions	514	12.7	12.7	100.0
	Total	4032	100.0	100.0	

Dx_grp2_11 CSHCN who currently have Autism Spectrum Disorder w/o Intellectual Disability and /or Developmental Delay

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00 CSHCN currently have ASD	1420	35.2	40.4	40.4
	2.00 CSHCN currently have DD or ID	2098	52.0	59.6	100.0
	Total	3518	87.3	100.0	
Missing	90.00 No current condition	514	12.7		
Total		4032	100.0		

Dx_grp3_11 CSHCN who currently have ASD, ID (w/o ASD), DD only

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 CSHCN currently have ASD	1420	35.2	40.4	40.4
	2 CSHSN currently have ID with/without ASD	657	16.3	18.7	59.0
	3 CSHCN currently have DD only	1441	35.7	41.0	100.0
	Total	3518	87.3	100.0	
Missing	90 No current condition	514	12.7		
Total		4032	100.0		

Appendix B: Methods Notes on Imputation of Missing Values

The 2011 Survey of Pathways to Diagnosis and Services (Pathways) is a follow-up survey of children with special health care needs (CSHCN) whose parents reported that they had been told that their child ever had autism spectrum disorder (ASD), intellectual disability, and/or developmental delay from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). The Pathways survey provides a rich source of data for studying the relationships between socio-economic characteristics and parental concerns, diagnostic experience, and other health and services measures for CSHCN with ASD and related conditions. However, as is common for most household interview surveys, nonresponse rates can occasionally be higher for certain demographic questions. For the 2011 Pathways survey, socio-economic information of each Pathways-interviewed child was extracted from the 2009/10 NS-CSHCN. The following variables were observed to have more missing cases than desired and imputations were calculated: household income, race/ethnicity, highest education level of any parent in the household, household language and total number of adults in the household.

Imputation is one commonly used method for handling nonresponse data in a survey – especially when the proportion of missing, refused, or "don't know" responses exceed 5% or more of the total. Imputation accomplishes three things. First, it adjusts for observed differences between non-respondents and respondents to an item. Second, imputed response values permit bivariate and multivariate statistical analysis without the need to exclude cases that are missing a value for the imputed variable yet have valid responses on other items. Finally, imputation offers a standardized approach to resolving non-response issues and contributes to improved consistency and comparability of analyses conducted by many researchers. The National Center for Health Statistics (NCHS) website offers a downloadable file with multiple imputed income values for the 2011 Pathways survey. Interested users can access this file and accompanying instructions free of charge at: **http://www.cdc.gov/nchs/slaits/imputed_data.htm**. The datasets provided by NCHS contain five sets of imputed values for each imputed variable in Pathways survey. These files are appropriate for use with software able to accommodate multiple imputation analyses and are available free of charge. All imputed variables in the DRC 2011 Pathways Dataset were generated using a single imputation value from the imputed data file. Analyses based upon single imputation procedures tend to underestimate standard error because they do not fully account for the inherent uncertainty resulting from lack of knowledge about the true values. The DRC Indicator Dataset also contains the non-imputed versions of each imputed variable in addition to the imputation flag for each variable indicating which cases were imputed and which were not.

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

Income: An index of income relative to the Department of Health and Human Services Federal Poverty Guidelines (FPL) is constructed based on reported household income and the reported number of people (adults and children) living in the household. To determine household income level, the parent survey (2009/10 NS-CSHCN) for Pathways contains a question about the total combined household income for the previous calendar year (C11Q01 from the 2009/10 NS-CSHCN). If the survey respondent answers "don't know" or "refused" to C11Q01, they are then asked a series of 'cascade' questions, assessing if their combined household income falls within certain ranges (C11Q01_DON'TKNOW or C11Q01_REFUSED and W9Q03-W9Q12A from the 2009/10 NS-CSHCN). If the respondent did not provide any income information either from the original question or the cascade series following it, they were assigned an imputed income value. If the respondent did not answer C11Q01 but provided a household income range based upon the cascade questions, they were also assigned an

income value using an imputation procedure that anchored their imputed income value to the range they provided. The income variables are at the household level. In the Pathways interview file, 16.9% of 4032 interviewed cases were missing on income altogether, which resulted in imputed income. Please note that the process used to impute income for the Pathways parent survey, the 2009/10 NS-CSHCN, differs slightly from prior survey years of the NS-CSHCN.

Other Imputed Variables: Variables other than income were imputed in the 2009/10 NS-CSHCN. Below lists each imputed variable and the number of cases in the Pathways interview file that were missing and therefore imputed for that variable. RACER (child's race): 20 imputed cases; HISPANIC (Hispanic ethnicity of child):16 imputed cases; PLANGUAGE (primary household language): 1 imputed case; EDUCR (highest education level of any parent in the household): 23 imputed cases; TOTADULTR (total number of adults living in the household): 1 imputed case.

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

The Data Resource Center chose to use imputation 3 for all of the imputed variables from Pathways imputation file. This choice was randomly made.