

# 2011 Survey of Pathways to Diagnosis and Services (Pathways)

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**SAS CODE FOR DATA USERS:  
OUTCOME MEASURES AND SUBGROUPS**

Version 1.0: July 2015



## Recommended Citation

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

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

## Purpose of the 2011 Pathways SAS Codebook

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This codebook contains documentation and SAS 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](http://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 SPSS or SAS 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](mailto:info@cahmi.org).

## The CAHMI Data Resource Center for Child and Adolescent Health

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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](http://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

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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 medications, 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 Pediatrics. 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](http://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/slait/imp/imp\\_data.htm](http://www.cdc.gov/nchs/slait/imp/imp_data.htm). Additional information and results from the 2011 Pathways survey are available on the DRC website at: [www.childhealthdata.org](http://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

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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/CSV 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

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### 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.

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

The 2011 Pathways and NS-CSHCN public use data files provided by the National Center for Health Statistics include special codes to differentiate several types of missing values. Since these values are referred to in code for some of the indicator variables, their definitions are shown in the accompanying table.

Code	Category	Description
.L	LEGITIMATE SKIP	Variable is missing due to valid questionnaire paths based on a previous answer to a root question.
.P	PARTIAL INTERVIEW	Variable is missing because the respondent ended the interview before completing the full interview.
.M	MISSING IN ERROR	Variable is missing due to interviewer or system errors. In cases of interviewer error, the interviewer may have deleted the data by accident or simply may not have entered the response. In cases of system error, the data may not have been collected or saved properly after it was entered by the interviewer in the CATI system.

NOTE: It is important to note that derived variables (i.e., variables created in this codebook that are not in the original public use file) may not include the detailed coding of missing data. All missing values for derived variables received a “.M” code regardless of the reason for the missing data. Similarly, “.M” was used when derived variables were suppressed to protect the confidentiality of the survey participants.

## **Additional Information on Survey Design and Methodology**

The NCHS is currently developing a final *Design and Operation of the 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/slait/PathwaysFAQ.pdf>.



## Developmental Concerns

Pathways Sample	Children with ASD, Intellectual Disability, or Developmental Delay (exclusively)
<b>Description</b>	CSHCN who currently have ASD, intellectual disability, or developmental delay (exclusively)
<b>Survey Items Used</b>	DE_AUT11; DE_DEV11; DE_INT11
<b>Denominator</b>	CSHCN age 6-17 years who ever have ASD, intellectual disability, and/or developmental delay
<b>Numerator</b>	CSHCN who currently have ASD, Intellectual Disability, or Developmental Delay (exclusively)
<b>Notes for Data-Users</b>	
<p>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.</p>	
<b>SAS Code and Annotation</b>	
<pre> EVER_AUT = .; if DE_AUT11 = .L then EVER_AUT = .L; if DE_AUT12 = 1 or ((CSHCN_K2Q35A=1 and COND_CONFIRM=1) or COND_A=1) then EVER_AUT = 2; /* and DE_AUT11 in (0,6,7,.L) Ever autism; */ if DE_AUT11 = 1 then EVER_AUT = 1; * Current autism; if DE_AUT11 in (.M,6,7) then EVER_AUT = .; LABEL EVER_AUT = 'CSHCN who currently or ever were told that child had Autism/ASD';  EVER_INT = .; if DE_INT11 = .L then EVER_INT = .L; if DE_INT12 = 1 or ((CSHCN_K2Q37A=1 and COND_Confirm=1) or COND_C=1) then EVER_INT = 2; * Ever intellectual disability; if DE_INT11=1 then EVER_INT = 1; * Current intellectual disability; if DE_INT11 in (.M,6,7) then EVER_INT = .; LABEL EVER_INT = 'CSHCN who currently or ever were told that child had Intellectual Disability';  EVER_DEV = .; if DE_DEV11 = .L then EVER_DEV = .L; if DE_DEV12 = 1 or ((cshcn_k2q36a=1 and COND_confirm=1) or COND_B=1) then EVER_DEV = 2; * Ever developmental delay; if DE_DEV11=1 then EVER_DEV = 1; * Current developmental delay; if DE_DEV11 in (.M,6,7) then EVER_DEV = .; LABEL EVER_DEV = 'CSHCN who currently or ever were told that child had Developmental Delay';  DX_AUT_11 = .; if DE_AUT11 in (0,.L) then DX_AUT_11 = 2; if DE_AUT11 = 1 then DX_AUT_11 = 1; label DX_AUT_11 = "CSHCN currently has Autism/ASD";  DX_DEV_11 = .; if DE_DEV11 in (0,.L) then DX_DEV_11 = 2; if DE_DEV11 = 1 then DX_DEV_11 = 1; </pre>	



## Developmental Concerns

label DX\_DEV\_11 = "CSHCN currently has a developmental delay";

DX\_INT\_11 = .;

if DE\_INT11 in (0,.L) then DX\_INT\_11 = 2;

if DE\_INT11 = 1 then DX\_INT\_11 = 1;

label DX\_INT\_11 = "CSHCN currently has an intellectual disability";

DX\_CURR\_11 = .;

if DX\_AUT\_11 in (1,2) OR DX\_INT\_11 in (1,2) OR DX\_DEV\_11 in (1,2) then DX\_CURR\_11 = 2;  
/\*Ever\*/

if DX\_AUT\_11 = 1 OR DX\_INT\_11 = 1 OR DX\_DEV\_11 = 1 then DX\_CURR\_11 = 1; /\*Current\*/

Label DX\_CURR\_11 = "CSHCN currently has ASD, ID or DD";

value cond\_status

1 = "currently has condition"

2 = "does not have condition";

## Developmental Concerns

Age of child when parent first concerned	
<b>Description</b>	How old was child when you first noticed something was not quite right with child's development?
<b>Survey Items Used</b>	PC1; PC1A
<b>Denominator</b>	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
<b>Numerator</b>	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
<b>Notes for Data-Users</b>	
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.	
<b>SAS Code and Annotation</b>	
<pre> PC_AGE_all = .; IF PC1_A = 2 THEN PC_AGE_all = PC1; /*Age in yrs*/ IF PC1_A = 1 THEN PC_AGE_all = PC1/12; /*Age in months into yrs*/ IF PC1 = 94 THEN PC_AGE_all = 0; /*Condition before birth = 0*/  PC_AGE_11 = .; IF PC_AGE_all = 0 THEN PC_AGE_11 = 1; /*At/Before birth*/ IF PC_AGE_all &gt; 0 THEN PC_AGE_11 = 2; /* 1 - 23 months old*/ IF PC_AGE_all GE 2 THEN PC_AGE_11 = 3; /* 24 - 47 months old*/ IF PC_AGE_all GE 4 THEN PC_AGE_11 = 4; /* 48+ months old*/ IF PC1 IN (93,95) THEN PC_AGE_11 = .L; /*Concern present before child/parent entered fam or never cocerned*/ LABEL PC_AGE_11 = "Age when parents were first concerned about their development";  value PC_AGE 1 = "Condition/concern at or before birth" 2 = "1 - 23 months" 3 = "24 - 47 months" 4 = "48+ months"; </pre>	

## Developmental Concerns

Number of developmental concerns out of 7 types	
<b>Description</b>	How many parents had one or more concerns about their child's development, out of 7 types of developmental domains?
<b>Survey Items Used</b>	PC_VRBL_11; PC_BEH_11; PC_MOTOR_11; PC_NONVR_11; PC_LEARN_11; PC_GEST_11; PC_MED_11
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	CSHCN whose parents had 0-1 concerns; 2-3 concerns; 4 or more concerns in any of the developmental domains.
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> array var_pct {*} PC_VRBL_11 PC_BEH_11 PC_MOTOR_11 PC_NONVR_11 PC_LEARN_11 PC_GEST_11 PC_MED_11; anypct = 0; misst_m = 0; misst_l = 0; do i = 1 to dim(var_pct);     if var_pct(i) = 1 then anypct = anypct + 1;     if var_pct(i) = . then misst_m = misst_m + 1;     if var_pct(i) = .L then misst_l = misst_l + 1; end; drop i;  PC_COUNT_11 = anypct; /*.L include PC1 = 93,94,96*/ IF anypct = 0 THEN PC_COUNT_11 = 1; /*0-1 concerns*/ IF anypct in (2,3) THEN PC_COUNT_11 = 2; /*2-3 concerns*/ IF anypct GE 4 THEN PC_COUNT_11 = 3; /*4+ concerns*/ IF misst_l = 7 THEN PC_COUNT_11 = .L; /*had .L for all types of concerns*/ IF misst_m = 7 THEN PC_COUNT_11 = .; /*missing if any DK/REF*/ IF PC1 = 95 THEN PC_COUNT_11 = 1; LABEL PC_COUNT_11 = "Parents who had 0-1, 2-3, 4 or more of the 7 types of developmental concerns";  value PC_COUNT 1 = "0-1 concerns" 2 = "2-3 concerns" 3 = "4 or more concerns"; </pre>	

## Developmental Concerns

Parent concerned that child had problems talking or communicating	
<b>Description</b>	Among CSHCN whose parents had a developmental concern, was parent concerned that child had problems talking, communicating, or loosing speech skills?
<b>Survey Items Used</b>	PC_2G; PC_2H; PC_2I; PC_2J
<b>Denominator</b>	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
<b>Numerator</b>	Yes, parent concerned that child had speech/communication problems; No, parent did not have this concern
<b>Notes for Data-Users</b>	
<p>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.</p>	
<b>SAS Code and Annotation</b>	
<pre> PC_VRBL_11 = .; /*PC2_G = .L if PC1=93,94,95,96 OR PC_AGE &lt; 9mo; PC2_H,I,J = .L if PC1=93,94,95,96 OR PC_AGE &lt;= 9mo*/ IF PC2_G = 1 OR PC2_H = 1 OR PC2_I = 1 OR PC2_J = 1 THEN PC_VRBL_11 = 1; IF PC2_G = 0 AND PC2_H in (0,.L) AND PC2_I in (0,.L) AND PC2_J in (0,.L) THEN PC_VRBL_11 = 2; IF PC2_G = .L THEN PC_VRBL_11 = .L; LABEL PC_VRBL_11 = "Parent was concerned that child had problems talking later, not talking at all, not talking as well, or loosing speech skills";  value yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Parent concerned that child had behavioral problems	
<b>Description</b>	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)?
<b>Survey Items Used</b>	PC2_E; PC2_M; PC2_N
<b>Denominator</b>	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
<b>Numerator</b>	Yes, parent concerned that child had behavioral difficulties; No, parent did not have this concern
Notes for Data-Users	
<p>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.</p>	
SAS Code and Annotation	
<pre> PC_BEH_11 = .; /*PC2_E = .L if PC1=93,94,95,96 OR PC_AGE = 0; PC2_M,N = .L if PC1=93,94,95,96 OR PC_AGE &lt;= 12mo */ IF PC2_E = 1 OR PC2_M = 1 OR PC2_N = 1 THEN PC_BEH_11 = 1; IF PC2_E = 0 AND PC2_M in (0,.L) AND PC2_N in (0,.L) THEN PC_BEH_11 = 2; IF PC2_E = .L AND PC2_M = .L AND PC2_N = .L THEN PC_BEH_11 = .L; LABEL 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 yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Parent concerned that child had problems with motor skills	
<b>Description</b>	Among CSHCN whose parents had a developmental concern, was parent concerned that child had problems with coordination, gross motor skills, or fine motor skills?
<b>Survey Items Used</b>	PC2_F, PC2_L
<b>Denominator</b>	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
<b>Numerator</b>	Yes, parent concerned that child had problems with coordination, gross motor skills, or fine motor skills; No, parent did not have this concern
<b>Notes for Data-Users</b>	
<p>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.</p>	
<b>SAS Code and Annotation</b>	
<pre> PC_MOTOR_11 = .; /*PC2_F = .L if PC1=93,94,95,96 OR PC_AGE = 0; PC2_L = .L if PC1=93,94,95,96 OR PC_AGE &lt;= 12mo */ IF PC2_F = 1 OR PC2_L = 1 THEN PC_MOTOR_11 = 1; IF PC2_F = 0 AND PC2_L in (0,.L) THEN PC_MOTOR_11 = 2; IF PC2_F = .L THEN PC_MOTOR_11 = .L; LABEL PC_MOTOR_11 = "Parent was concerned that child had problems with coordination/gross motor skills, or fine motor skills";  value yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Parent concerned that child had problems with non-verbal communication	
<b>Description</b>	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?
<b>Survey Items Used</b>	PC2_B; PC2_C; PC2_D
<b>Denominator</b>	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
<b>Numerator</b>	Yes, parent concerned that child had problems with non-verbal communication; No, parent did not have this concern
<b>Notes for Data-Users</b>	
<p>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.</p>	
<b>SAS SAS and Annotation</b>	
<pre> PC_NONVR_11 = .; /*PC2_B,C,D = .L if PC1=93,94,95,96 OR PC_AGE = 0 */ IF PC2_B = 1 OR PC2_C = 1 OR PC2_D = 1 THEN PC_NONVR_11 = 1; IF PC2_B = 0 AND PC2_C = 0 AND PC2_D = 0 THEN PC_NONVR_11 = 2; IF PC2_B = .L AND PC2_C = .L AND PC2_D = .L THEN PC_NONVR_11 = .L; LABEL 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 yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Parent concerned that child had problems with learning or understanding	
<b>Description</b>	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?
<b>Survey Items Used</b>	PC2_K,; PC2_O; PC2_P
<b>Denominator</b>	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.
<b>Numerator</b>	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.
<b>Notes for Data-Users</b>	
<p>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.</p>	
<b>SAS Code and Annotation</b>	
<pre> PC_LEARN_11 = .; /*PC2_K = .L if PC1=93,94,95,96 OR PC_AGE &lt;= 9mo; PC2_O,P = .L if PC1=93,94,95,96 OR PC_AGE &lt;= 12mo */ IF PC2_K = 1 OR PC2_O = 1 OR PC2_P = 1 THEN PC_LEARN_11 = 1; IF PC2_K = 0 AND PC2_O in (0,.L) AND PC2_P in (0,.L) THEN PC_LEARN_11 = 2; IF PC2_K = .L AND PC2_O = .L AND PC2_P = .L THEN PC_LEARN_11 = .L; LABEL PC_LEARN_11 = "Parent was concerned that child had problems understanding what others say or difficulty learning new things or skills";  value yn 1 = "yes" 2 = "no"; </pre>	



## Developmental Concerns

Parent concerned that child had unusual gestures or movements	
<b>Description</b>	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?
<b>Survey Items Used</b>	PC2_Q
<b>Denominator</b>	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.
<b>Numerator</b>	Yes, parent was concerned that child had unusual gestures or movements; No, parent did not have this concern
<b>Notes for Data-Users</b>	
<p>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.</p>	
<b>SAS Code and Annotation</b>	
<pre> PC_GEST_11=PC2_Q; /*PC2_q = .L if PC1=93,94,95,96 OR PC_AGE &lt;= 12mo */ IF PC2_Q in (6,7) then PC_GEST_11 = .; IF PC2_Q = 0 then PC_GEST_11 = 2; LABEL PC_GEST_11 = "Parent was concerned that child had unusual gestures or movements such as hand-flapping, toe-walking, or self-spinning?";  value yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Parent concerned that child had medical problems	
<b>Description</b>	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?
<b>Survey Items Used</b>	PC2_A
<b>Denominator</b>	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.
<b>Numerator</b>	Yes, parent concerned that child had medical problems; No, parent did not have this concern
<b>Notes for Data-Users</b>	
<p>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.</p>	
<b>Revisions</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PC_MED_11=PC2_A; /*PC2_A = .L if PC1=93,94,95,96 OR PC_AGE = 0*/ IF PC2_A in (6,7) then PC_MED_11 = .; IF PC2_A = 0 then PC_MED_11 = 2; LABEL PC_MED_11 = "Parent was concerned that child had medical problems such as seizures, lack of physical growth, or stomach problems";  value yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Person first concerned with child's development	
<b>Description</b>	Who first had concerns that something was not right with child's development?
<b>Survey Items Used</b>	PC3, PC4
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability whose parents had a developmental concern
<b>Numerator</b>	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
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> TALK_1ST_11 = .; /*Among those with concern if PC1&gt;1*/ IF PC3 = 1 AND RELATIONR IN (1,2) THEN TALK_1ST_11 = 1; /*PARENT*/ IF PC4R IN (1,2) THEN TALK_1ST_11 = 1; IF PC4R = 4 THEN TALK_1ST_11 = 2; /*DR/HCP*/ IF PC4R IN (5,6) THEN TALK_1ST_11 = 3; /*TEACHER SCHOOL COUNCELOR NURSE*/ IF PC3 = 1 AND RELATIONR = 3 THEN TALK_1ST_11 = 4; /*OTHER*/ IF PC4R IN (3,7,8) THEN TALK_1ST_11 = 4; /*OTHER*/ IF PC3 = .L then TALK_1ST_11 = .L; /*Respondent not concerned/concern present before child/parent entered fam, condition/concern present at/before birth*/ LABEL TALK_1ST_11 = "Among parents with any developmental concern, person who first had concern that something was not right with child's development";  value TALK_1ST 1 = "Parent" 2 = "Health Care Professional" 3 = "Teacher, Councilor, or Nurse at school" 4 = "Other"; </pre>	

## Developmental Concerns

Age first talked to doctor	
<b>Description</b>	What was child's age when parent first talked to a doctor or health care provider about their concerns?
<b>Survey Items Used</b>	PC6; PC6A
<b>Denominator</b>	CSHCN ages 6-17 years with current autism spectrum disorder, developmental delay, and/or intellectual disability whose parents had a developmental concern
<b>Numerator</b>	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
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> TALK_YR = .; IF PC6_A = 2 THEN TALK_YR = PC6; /*Age in yrs*/ IF PC6_A = 1 THEN TALK_YR = PC6/12; /*Age in months into yrs*/ If PC6 = .L THEN TALK_YR = .L; /*No concern*/  TALK_AGE_11 = .; /*.L includes PC1=95 and PC5 = 0 (no)*/ IF TALK_YR GE 0 THEN TALK_AGE_11 = 1; /* Before birth - &lt;1yr*/ IF TALK_YR GE 1 THEN TALK_AGE_11 = 2; /* 1 - &lt;2yrs old*/ IF TALK_YR GE 2 THEN TALK_AGE_11 = 3; /* 2 - &lt;4yrs old*/ IF TALK_YR GE 4 THEN TALK_AGE_11 = 4; /* 4+ yrs old*/ IF TALK_DR_11 = 2 THEN TALK_AGE_11 = 5; /*Did not see DR*/ IF TALK_YR = .L THEN TALK_AGE_11 = .L; LABEL TALK_AGE_11 = "Child's age when parent talked to a dr/health care provider about their concern";  value TALK_AGE 1 = "Before birth - 11 months" 2 = "12 - 23 months" 3 = "24 - 47 months" 4 = "48+ months"; </pre>	

## Developmental Concerns

Child's parent talked to a doctor about their concerns	
<b>Description</b>	Did parent talk to a doctor or health care provider about their concerns?
<b>Survey Items Used</b>	PC5
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, or intellectual disability whose parents had a developmental concern
<b>Numerator</b>	Yes, parent talked to doctor about concern; Parent did not talk to doctor about concern
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> TALK_DR_11 = PC5; IF PC5&gt;2 THEN TALK_DR_11 = .; IF PC5=0 THEN TALK_DR_11 = 2; Label TALK_DR_11 = "Parent talked to a doctor or health care provider about their concern";  value yn 1 = "yes" 2 = "no";                     </pre>	

## Developmental Concerns

Doctor or health care provider conducted a developmental test	
<b>Description</b>	After parent expressed concerns, did the doctor or health care provider conduct a developmental test?
<b>Survey Items Used</b>	PC7_AR01
<b>Denominator</b>	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.
<b>Numerator</b>	Yes, doctor conducted developmental test; No, developmental test was not conducted
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> /*PC7_AR0X = .L if PC1 = 95 and if PC5 in 0,6*/ DR_TEST_11 = PC7_AR01; IF PC7_AR01 in (6,7) THEN DR_TEST_11 = .; IF PC7_AR01 = 0 THEN DR_TEST_11 = 2; LABEL DR_TEST_11 = "Doctor or health care provider conducted a developmental test when parent had a developmental concern";  value yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Doctor or health care provider referred child to a specialist	
<b>Description</b>	After parent expressed concerns, did doctor or health care provider refer the child to a specialist?
<b>Survey Items Used</b>	PC7_AR02
<b>Denominator</b>	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.
<b>Numerator</b>	Yes, doctor referred child to a specialist; No referral made
Notes for Data-Users	
N/A	
SAS Code and Annotation	
<pre> DR_REFER_11 = PC7_AR02; IF PC7_AR02 in (6,7) THEN DR_REFER_11 = .; IF PC7_AR02 = 0 THEN DR_REFER_11 = 2; LABEL DR_REFER_11 = "Doctor or health care provider made a referral to a specialist when parent had a developmental concern";  value yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Doctor or health care provider suggested parents talk with child's school	
<b>Description</b>	After parent expressed concerns, did the doctor or health care provider suggest that parent talk with the child's school?
<b>Survey Items Used</b>	PC7_AR03
<b>Denominator</b>	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.
<b>Numerator</b>	Yes, doctor suggested parents talk to child's school; No, suggestion was not made
Notes for Data-Users	
N/A	
SAS Code and Annotation	
<pre> DR_SCH_11 = PC7_AR03; IF PC7_AR03 in (6,7) THEN DR_SCH_11 = .; IF PC7_AR03 = 0 THEN DR_SCH_11 = 2; LABEL DR_SCH_11 = "Doctor or health care provider suggested that parent talk with the school when parent had a developmental concern"; value yn 1 = "yes" 2 = "no"; </pre>	



## Developmental Concerns

Doctor or health care provider told parents nothing was wrong	
<b>Description</b>	After parent expressed concerns, did the doctor or health care provider say that nothing was wrong or behavior was normal?
<b>Survey Items Used</b>	PC7_AR04
<b>Denominator</b>	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.
<b>Numerator</b>	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	
SAS Code and Annotation	
<pre> DR_NORM_11 = PC7_AR04; IF PC7_AR04 in (6,7) THEN DR_NORM_11 = .; IF PC7_AR04 = 0 THEN DR_NORM_11 = 2; LABEL DR_NORM_11 = "Doctor or health care provider said 'nothing was wrong' or 'behavior was normal' when parent had a developmental concern";  value yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Doctor or health care provider told parents it was too early to tell	
<b>Description</b>	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?
<b>Survey Items Used</b>	PC7_AR05
<b>Denominator</b>	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.
<b>Numerator</b>	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	
SAS Code and Annotation	
<pre> DR_EARLY_11 = PC7_AR05; IF PC7_AR05 in (6,7) THEN DR_EARLY_11 = .; IF PC7_AR05 = 0 THEN DR_EARLY_11 = 2; LABEL DR_EARLY_11 = "Doctor or health care provider said 'it's too early to tell' when parent had a developmental concern";  value yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Doctor or health care provider said child might grow out of it	
<b>Description</b>	After parent expressed concerns, did the doctor or health care provider tell you that the child might grow out of it?
<b>Survey Items Used</b>	PC7_AR06
<b>Denominator</b>	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.
<b>Numerator</b>	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	
SAS Code and Annotation	
<pre> DR_GROW_11 = PC7_AR06; IF PC7_AR06 in (6,7) THEN DR_GROW_11 = .; IF PC7_AR06 = 0 THEN DR_GROW_11 = 2; LABEL DR_GROW_11 = "Doctor or health care provider said the child might 'grow out of it' when parent had a developmental concern"; /*Don't need to include OTHER*/  value yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Child's parent talked to school about their concerns	
<b>Description</b>	Did parent talk to teacher, school nurse, school counselor, or other school professional about their concern?
<b>Survey Items Used</b>	PC8
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, intellectual disability and/or developmental delay whose parents had a developmental concern
<b>Numerator</b>	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	
SAS Code and Annotation	
<pre> TALK_SCH_11 = PC8; IF PC8&gt;2 THEN TALK_SCH_11 = .; IF PC8=0 THEN TALK_SCH_11 = 2; Label TALK_SCH_11 = "Parent talked to teacher, school nurse, school counselor, or other school professional about their concern";  value yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Developmental screening	
<b>Description</b>	Was a developmental screening or assessment completed by the parent, doctor, or health care provider?
<b>Survey Items Used</b>	PC7_B; PC7_C; PC7_D; PC7_E; PC7_F; PC7_G; PC7_H
<b>Denominator</b>	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.
<b>Numerator</b>	Developmental screening or assessment completed by parent/health provider: Had screening; No screening; Did not talk to doctor or provider
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PC_SCR_11 = .; IF SCR_P_11 = 2 OR SCR_DR_11 = 2 THEN PC_SCR_11 = 2; /*Neither*/ IF SCR_P_11 = 1 OR SCR_DR_11 = 1 THEN PC_SCR_11 = 1; /*Parent and/or Physician completed*/ IF SCR_P_11 = . AND SCR_DR_11 = . THEN PC_SCR_11 = .; /*DK/Ref*/ IF SCR_P_11 = .L AND SCR_DR_11 = .L THEN PC_SCR_11 = .L; /*Legitimate Skip*/ IF PC7_B = .L THEN PC_SCR_11 = 3; /*Didn't talk to Dr/provider about concerns when child was &lt;6yrs old*/  LABEL PC_SCR_11 = "Developmental screening or assessment completed by parent/health provider or none completed";  value PC_SCR 1 = "Completed Screening" 2 = "No Screening" 3 = "Didn't talk to DR/provider" 6 = "DK"; </pre>	

## Developmental Concerns

Physician completed a developmental screener	
<b>Description</b>	Did doctor or health care provider complete a developmental screening or assessment of child?
<b>Survey Items Used</b>	PC7_G; PC7_H
<b>Denominator</b>	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
<b>Numerator</b>	Yes, physician completed screener; No, physician did not complete screener
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> SCR_DR_11 = .; /*Physician completed screener/assessment - among those who talked to a dr/hcp*/ IF PC7_G = 6 OR PC7_H = 6 THEN SCR_DR_11 = .; /*Any DK*/ IF PC7_G = 0 OR PC7_H = 0 THEN SCR_DR_11 = 2; /*No*/ IF PC7_G = 1 OR PC7_H = 1 THEN SCR_DR_11 = 1; /*Yes*/ IF PC7_G = .L AND PC7_H = .L THEN SCR_DR_11 = .L; /*Legitimate Skip*/ Label SCR_DR_11 = "Physician completed screener/assessment";  value yn 1 = "yes" 2 = "no"; </pre>	

## Developmental Concerns

Parent completed a developmental screener	
<b>Description</b>	Did parent complete a developmental screening or assessment of child?
<b>Survey Items Used</b>	PC7_B; PC7_C; PC7_D; PC7_E; PC7_F
<b>Denominator</b>	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
<b>Numerator</b>	Yes, parent completed screener; No parent did not complete screener
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> SCR_P_11 = .; /*Parent completed screener/assessment - among those who talked to a dr/hcp*/ If PC7_B = .L AND PC7_C = .L AND PC7_E = .L AND PC7_D = .L AND PC7_F = .L THEN SCR_P_11 = .L; /*Legitimate Skip*/ If PC7_B in (1,6) OR PC7_C in (1,6) OR PC7_E in (1,6) OR PC7_D in (1,6) OR PC7_F in (1,6) THEN SCR_P_11 = .; /*Completed scr/asses. not sure of content*/ IF PC7_B = 1 AND (PC7_C = 1 OR PC7_E = 1) AND (PC7_D = 1 OR PC7_F = 1) THEN SCR_P_11 = 1; /* Yes*/ IF PC7_B = 0 OR (PC7_C = 0 OR PC7_E = 0) OR (PC7_D = 0 OR PC7_F = 0) THEN SCR_P_11 = 2; /*No*/ Label SCR_P_11 = "Parent completed screener/assessment";  value yn 1 = "yes" 2 = "no"; </pre>	

## Diagnostic Experiences

Child's age when parent first told that child had one of three developmental conditions	
<b>Description</b>	Age at which child was first told they had any of 3 developmental conditions
<b>Survey Items Used</b>	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?
<b>Survey Items Used</b>	DE_AUT2; DE_AUT2A; DE_DEV2; DE_DEV2A; DE_INT2; DE_INT2A
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Child's age when parent first told: 0-2 years old; 3-5 years old; 6-17 years old
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> AUT_AGE_all = .; IF DE_AUT2A = 2 THEN AUT_AGE_all = DE_AUT2; /*Age in yrs*/ IF DE_AUT2A = 1 THEN AUT_AGE_all = DE_AUT2/12; /*Age in yrs*/ AUT_AGE_11 = .; IF AUT_AGE_all GE 0 THEN AUT_AGE_11 = 1; /* Before birth - &lt;1yrs old*/ IF AUT_AGE_all GE 1 THEN AUT_AGE_11 = 1; /* 1 - 2yrs old*/ IF AUT_AGE_all GE 3 THEN AUT_AGE_11 = 2; /* 3 - 5 yrs old*/ IF AUT_AGE_all GE 6 THEN AUT_AGE_11 = 3; /* 6+yrs old*/ IF DE_AUT2 = .L then AUT_AGE_11 = .L; LABEL AUT_AGE_11 = "Age when parent was first told by Dr that child had ASD (ever and current diagnosis)";  DEV_AGE_all = .; IF DE_DEV2A = 2 THEN DEV_AGE_all = DE_DEV2; /*Age in yrs*/ IF DE_DEV2A = 1 THEN DEV_AGE_all = DE_DEV2/12; /*Age in yrs*/ DEV_AGE_11 = .; IF DEV_AGE_all GE 0 THEN DEV_AGE_11 = 1; /* Before birth - &lt;1yrs old*/ IF DEV_AGE_all GE 1 THEN DEV_AGE_11 = 1; /* 1 - 2yrs old*/ IF DEV_AGE_all GE 3 THEN DEV_AGE_11 = 2; /* 3 - 5yrs old*/ IF DEV_AGE_all GE 6 THEN DEV_AGE_11 = 3; /* 6+yrs old*/ IF DE_DEV2 = .L then DEV_AGE_11 = .L; LABEL DEV_AGE_11 = "Age when parent was first told by Dr that child had Developmental Delay (ever and current diagnosis)";  INT_AGE_all = .; IF DE_INT2A = 2 THEN INT_AGE_all = DE_INT2; /*Age in yrs*/ </pre>	



## Diagnostic Experiences

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IF DE_INT2A = 1 THEN INT_AGE_all = DE_INT2/12; /*Age in yrs*/
INT_AGE_11 = .;
IF INT_AGE_all GE 0 THEN INT_AGE_11 = 1; /* Before birth - <1yrs old*/
IF INT_AGE_all GE 1 THEN INT_AGE_11 = 1; /* 1 - 2yrs old*/
IF INT_AGE_all GE 3 THEN INT_AGE_11 = 2; /* 3 - 5yrs old*/
IF INT_AGE_all GE 6 THEN INT_AGE_11 = 3; /* 6+yrs old*/
IF DE_INT2 = .L then INT_AGE_11 = .L;
LABEL INT_AGE_11 = "Age when parent was first told by Dr that child had Intellectual Disability (ever and current diagnosis)";

ANY_AGE_11 = .; /*missing (.) includes all who said DE_X2 = 95, 96 to all conditions child currently has*/
IF AUT_AGE_11 = 3 OR INT_AGE_11 = 3 OR DEV_AGE_11 = 3 THEN ANY_AGE_11 = 3;
IF AUT_AGE_11 = 2 OR INT_AGE_11 = 2 OR DEV_AGE_11 = 2 THEN ANY_AGE_11 = 2;
IF AUT_AGE_11 = 1 OR INT_AGE_11 = 1 OR DEV_AGE_11 = 1 THEN ANY_AGE_11 = 1;
IF AUT_AGE_11 = .L AND INT_AGE_11 = .L AND DEV_AGE_11 = .L THEN ANY_AGE_11 = .L;
LABEL 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 Dx_AGE /* AUT_AGE_11, DEV_AGE_11, INT_AGE_11, ANY_AGER_11*/
1 = "0-2 years"
2 = "3-5 years"
3 = "6+ years";
```

## Diagnostic Experiences

Type of ASD diagnosis	
<b>Description</b>	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?
<b>Survey Items Used</b>	DE_AUT5A; DE_AUT5B; DE_AUT5C
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder
<b>Numerator</b>	Types of ASD diagnosis: Asperger's Disorder; Pervasive Developmental Disorder; Autistic Disorder; Multiple diagnosis
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> DX_AUTYP_11 = .; if DE_AUT5A in (1,0) OR DE_AUT5B in (1,0) OR DE_AUT5C in (1,0) then DX_AUTYP = 5; /*Never told Asperger's, PDD, or Autistic Disorder*/ if DE_AUT5A = 1 then DX_AUTYP_11 = 1; /*Ever told Asperger's Disorder*/ if DE_AUT5B = 1 then DX_AUTYP_11 = 2; /*Ever told PDD*/ if DE_AUT5C = 1 then DX_AUTYP_11 = 3; /*Ever told Autistic Disorder*/ if (DE_AUT5A = 1 and DE_AUT5B = 1) or (DE_AUT5A = 1 and DE_AUT5C = 1) or (DE_AUT5B = 1 and DE_AUT5C = 1) then DX_AUTYP_11 = 4; /*Multiple dx*/ if DE_AUT5A =.L then DX_AUTYP_11 = .L; label DX_AUTYP_11 = "Among CSHCN w/Autism, was ever told child had Asperger's, Pervasive Development Disorder, Autistic Disorder, or multiple diagnoses";  value subtype 1 = "Asperger's Disorder" 2 = "Pervasive Developmental Disorder" 3 = "Autistic Disorder" 4 = "Multiple Diagnosis" 5 = "Never told Asperger's, PDD, or Autistic"; </pre>	

## Diagnostic Experiences

Ever had Asperger's Disorder	
<b>Description</b>	Did doctors, health care providers, or school professionals ever tell you the child had Asperger's Disorder?
<b>Survey Items Used</b>	DE_AUT5A
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder
<b>Numerator</b>	Yes, have been told they have Asperger's Disorder; No, have not been told they have Asperger's Disorder
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> ASPERGER_11 = DE_AUT5A; IF DE_AUT5A = 0 THEN ASPERGER_11 = 2; IF DE_AUT5A in (6,7) THEN ASPERGER_11 = .; label ASPERGER_11 = "Among CSHCN w/Autism, parent was ever told child had Asperger's";  value yn 1 = "yes" 2 = "no"; </pre>	

## Diagnostic Experiences

Ever had pervasive development disorder	
<b>Description</b>	Did doctors, health care providers, or school professionals ever tell you the child had pervasive development disorder (PDD)?
<b>Survey Items Used</b>	DE_AUT5B
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder
<b>Numerator</b>	Yes, have been told they have PDD; No, have not been told they have PDD
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PDD_11 = DE_AUT5B; IF DE_AUT5B = 0 THEN PDD_11 = 2; IF DE_AUT5B in (6,7) THEN PDD_11 = .; label PDD_11 = "Among CSHCN w/Autism, parent was ever told child had Pervasive Development Disorder";  value yn 1 = "yes" 2 = "no"; </pre>	

## Diagnostic Experiences

Ever had autism disorder	
<b>Description</b>	Did doctors, health care providers, or school professionals ever tell you the child had autism disorder?
<b>Survey Items Used</b>	DE_AUT5C
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder
<b>Numerator</b>	Yes, have been told they have autism disorder; No, have not been told they have autism disorder
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> AUTDISRD_11 = DE_AUT5C; IF DE_AUT5C = 0 THEN AUTDISRD_11 = 2; IF DE_AUT5C in (6,7) THEN AUTDISRD_11 = .; label AUTDISRD_11 = "Among CSHCN w/Autism, parent was ever told child had Autistic Disorder";  value yn 1 = "yes" 2 = "no"; </pre>	

## Diagnostic Experiences

Age when parent was first told child had ASD	
<b>Description</b>	How old was child when you were first told he/she had ASD?
<b>Survey Items Used</b>	DE_AUT2; DE_AUT2A
<b>Denominator</b>	CSHCN age 6-17 years with current autism spectrum disorder
<b>Numerator</b>	Child's age when parent first told: 0-2 years old; 3-5 years old; 6-17 years old
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> /* Missing (.) includes those who answered DE_AUT2 as 95= no one told them the child had condition, and 96=DK;*/ AUT_AGE_all = .; IF DE_AUT2A = 2 THEN AUT_AGE_all = DE_AUT2; /*Age in yrs*/ IF DE_AUT2A = 1 THEN AUT_AGE_all = DE_AUT2/12; /*Age in yrs*/ AUT_AGE_11 = .; IF AUT_AGE_all GE 0 THEN AUT_AGE_11 = 1; /* Before birth - &lt;1yrs old*/ IF AUT_AGE_all GE 1 THEN AUT_AGE_11 = 1; /* 1 - 2yrs old*/ IF AUT_AGE_all GE 3 THEN AUT_AGE_11 = 2; /* 3 - 5 yrs old*/ IF AUT_AGE_all GE 6 THEN AUT_AGE_11 = 3; /* 6+yrs old*/ IF DE_AUT2 = .L then AUT_AGE_11 = .L; LABEL AUT_AGE_11 = "Age when parent was first told by Dr that child had ASD (ever and current diagnosis)";  AUT_AGER_11 = AUT_AGE_11; IF DX_AUT_11 = 2 AND AUT_AGE_11 GE 1 THEN AUT_AGER_11 = .M; LABEL AUT_AGER_11 = "Age when parent was first told by Dr that child had ASD (current diagnosis only)";  value Dx_AGE 1 = "0-2 years" 2 = "3-5 years" 3 = "6+ years"; </pre>	

## Diagnostic Experiences

Child's parents were told child did not have ASD	
<b>Description</b>	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?
<b>Survey Items Used</b>	DE_AUT6
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder
<b>Numerator</b>	Yes, have been told since having ASD that they do not have ASD; No, have never been told they do not have ASD
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> NO_AUT_11 = .; if DE_AUT6 = 1 then NO_AUT_11 = 1; if DE_AUT6 = 0 then NO_AUT_11 = 2; if DE_AUT6 = .L then NO_AUT_11 = .L;  Label 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 yn /*NO_AUT_11*/ 1 = "yes" 2 = "no"; </pre>	

## Diagnostic Experiences

Type of doctor who first diagnosed ASD	
<b>Description</b>	What type of doctor first diagnosed child with autism spectrum disorder?
<b>Survey Items Used</b>	DE_AUT1R
<b>Denominator</b>	CSHCN ages 6-17 years with current autism spectrum disorder
<b>Numerator</b>	Type of health care provider: Pediatrician or family health care practitioner; Psychologist; Specialist; Multidisciplinary team/Other
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> DRDX_AUT_11 = .;/*Missing includes (14)never told child had condition, (96)dk*/ if DE_AUT1R in (1,2) then DRDX_AUT_11 = 1;/*(1)Pediatrician/pediatric HCP,NP or PA; (2)Other HCP, Fam practice dr/NP/PA*/ if DE_AUT1R in (4,5) then DRDX_AUT_11 = 2;/*(4)School psychologist/counselor (5)Psychologist, non- school*/ if DE_AUT1R in (3,6,7,10) then DRDX_AUT_11 = 3;/*(3)Pediatric specialist; (6)Psychiatrist, medical dr; (7)Neurologist; (10)Specialist dr (other than dev pediatrician, psychiatrist, neurologist */ if DE_AUT1R = 13 then DRDX_AUT_11 = 4;/*(13)Team of professionals/multidisciplinary team*/ if DE_AUT1R in (8,9,11,12) then DRDX_AUT_11 = 4;/*(8)School nurse, (9) Phys/occ/speech/other therapist, (11)Other*/ if DE_AUT1R = .L then DRDX_AUT_11 = .L; LABEL DRDX_AUT_11 = "Health care provider who first gave Autism diagnosis (ever &amp; current diagnosis)";  DrDxAUTR = DRDX_AUT_11; IF DX_AUT_11 = 2 AND DRDX_AUT_11 GE 1 THEN DrDxAUTR = .M; LABEL DrDxAUTR = "Health care provider who first gave Autism diagnosis (current diagnosis only)";  value DRTYP /*DRDX_AUT_11*/ 1 = "Pediatrician or Pediatric/Family HCP" 2 = "Psychologist" 3 = "Specialist Dr" 4 = "Multidisciplinary Team/Other"; </pre>	



## Diagnostic Experiences

Age at which parent was first told child had developmental delay	
<b>Description</b>	How old was child when you were first told he/she had developmental delay?
<b>Survey Items Used</b>	DE_DEV2; DE_DEV2A
<b>Denominator</b>	CSHCN age 6-17 years with current developmental delay
<b>Numerator</b>	CSHCN who were first told they had developmental delay: 0-2 years old; 3-5 years old; 6-17 years old
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> /* Missing (.) includes those who answered DE_DEV2 as 95= no one told them the child had condition, and 96=DK*/ DEV_AGE_all = .; IF DE_DEV2A = 2 THEN DEV_AGE_all = DE_DEV2; /*Age in yrs*/ IF DE_DEV2A = 1 THEN DEV_AGE_all = DE_DEV2/12; /*Age in yrs*/ DEV_AGE_11 = .; IF DEV_AGE_all GE 0 THEN DEV_AGE_11 = 1; /* Before birth - &lt;1yrs old*/ IF DEV_AGE_all GE 1 THEN DEV_AGE_11 = 1; /* 1 - 2yrs old*/ IF DEV_AGE_all GE 3 THEN DEV_AGE_11 = 2; /* 3 - 5yrs old*/ IF DEV_AGE_all GE 6 THEN DEV_AGE_11 = 3; /* 6+yrs old*/ IF DE_DEV2 = .L then DEV_AGE_11 = .L; LABEL DEV_AGE_11 = "Age when parent was first told by Dr that child had Developmental Delay (ever and current diagnosis)";  DEV_AGER_11 = DEV_AGE_11; IF DX_DEV_11 = 2 AND DEV_AGE_11 GE 1 THEN DEV_AGER_11 = .; LABEL DEV_AGER_11 = "Age when parent was first told by Dr that child had ASD (current diagnosis only)";  value Dx_AGE /*DEV_AGE_11*/ 1 = "0-2 years" 2 = "3-5 years" 3 = "6+ years"; </pre>	

## Diagnostic Experiences

Child's parents were told child did not have developmental delay	
<b>Description</b>	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?
<b>Survey Items Used</b>	DE_DEV6
<b>Denominator</b>	CSHCN 6-17 years old with current developmental delay
<b>Numerator</b>	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
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> NO_DEV_11 = .; if DE_DEV6 = 1 THEN NO_DEV_11 = 1; if DE_DEV6 = 0 THEN NO_DEV_11 = 2; if DE_DEV6 = .L THEN NO_DEV_11 = .L; Label 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 yn /*NO_DEV_11*/ 1 = "yes" 2 = "no"; </pre>	

## Diagnostic Experiences

Type of doctor who first diagnosed developmental delay	
<b>Description</b>	What type of doctor first diagnosed child with developmental delay?
<b>Survey Items Used</b>	DE_DEV1R
<b>Denominator</b>	CSHCN 6-17 years old with current developmental delay
<b>Numerator</b>	Type of health care provider: Pediatrician or family health care practitioner; Psychologist; Specialist; Multidisciplinary team/Other
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> DRDX_DEV_11 = .; /*Missing includes (14)never told child had condition, (96)dk*/ if DE_DEV1R in (1,2) then DRDX_DEV_11 = 1; /*(1)Pediatrician/pediatric HCP,NP or PA; (2)Other HCP, Fam practice dr/NP/PA*/ if DE_DEV1R in (4,5) then DRDX_DEV_11 = 2; /*(4)School psychologist/counselor (5)Psychologist, non-school*/ if DE_DEV1R in (3,6,7,10) then DRDX_DEV_11 = 3; /*(3)Pediatric specialist; (6)Psychiatrist, medical dr; (7)Neurologist; (10)Specialist dr (other than dev pediatrician, psychiatrist, neurologist */ if DE_DEV1R = 13 then DRDX_DEV_11 = 4; /*(13)Team of professionals/multidisciplinary team*/ if DE_DEV1R in (8,9,11,12) then DRDX_DEV_11 = 4; /*(8)School nurse, (9) Phys/occ/speech/other therapist, (11)Other*/ if DE_DEV1R = .L then DRDX_DEV_11 = .L; LABEL DRDX_DEV_11 = "Health care provider who first gave Developmental Delay diagnosis (ever &amp; current diagnosis) ";  DrDxDEVR = DRDX_DEV_11; IF DX_DEV_11 = 2 AND DRDX_DEV_11 GE 1 THEN DrDxDEVR = .M; LABEL DrDxDEVR = "Health care provider who first gave Developmental Delay diagnosis (current diagnosis only)";  value DRTYP /*DRDX_DEV_11*/ 1 = "Pediatrician or Pediatric/Family HCP" 2 = "Psychologist" 3 = "Specialist Dr" 4 = "Multidisciplinary Team/Other"; </pre>	

## Diagnostic Experiences

Age at which parent was first told child had intellectual disability	
<b>Description</b>	How old was child when you were first told he/she had intellectual disability?
<b>Survey Items Used</b>	DE_INT2; DE_INT2A
<b>Denominator</b>	CSHCN age 6-17 years with current intellectual disability
<b>Numerator</b>	CSHCN who were first told they had intellectual disability at: 0-2 years old; 3-5 years old; 6-17 years old
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> /* Missing (.) includes those who answered DE_INT2 as 95= no one told them the child had condition, and 96=DK; should we include 95 as (.), or .L, or does it matter?*/ INT_AGE_all = .; IF DE_INT2A = 2 THEN INT_AGE_all = DE_INT2; /*Age in yrs*/ IF DE_INT2A = 1 THEN INT_AGE_all = DE_INT2/12; /*Age in yrs*/ INT_AGE_11 = .; IF INT_AGE_all GE 0 THEN INT_AGE_11 = 1; /* Before birth - &lt;1yrs old*/ IF INT_AGE_all GE 1 THEN INT_AGE_11 = 1; /* 1 - 2yrs old*/ IF INT_AGE_all GE 3 THEN INT_AGE_11 = 2; /* 3 - 5yrs old*/ IF INT_AGE_all GE 6 THEN INT_AGE_11 = 3; /* 6+yrs old*/ IF DE_INT2 = .L then INT_AGE_11 = .L; LABEL INT_AGE_11 = "Age when parent was first told by Dr that child had Intellectual Disability (ever and current diagnosis)";  INT_AGER_11 = INT_AGE_11; IF DX_INT_11 = 2 AND INT_AGE_11 GE 1 THEN INT_AGER_11 = .M; LABEL INT_AGER_11 = "Age when parent was first told by Dr that child had ASD (current diagnosis only)";  value Dx_AGE /*INT_AGE_11*/ 1 = "0-2 years" 2 = "3-5 years" 3 = "6+ years"; </pre>	

## Diagnostic Experiences

Child's parents were told child did not have intellectual disability	
<b>Description</b>	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?
<b>Survey Items Used</b>	DE_INT6
<b>Denominator</b>	CSHCN 6-17 years old with current intellectual disability
<b>Numerator</b>	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
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> NO_INT_11 = .; if DE_INT6 = 1 then NO_INT_11 = 1; if DE_INT6 = 0 then NO_INT_11 = 2; if DE_INT6 = .L then NO_INT_11 = .L; Label 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 yn /*NO_INT_11*/ 1 = "yes" 2 = "no"; </pre>	

## Diagnostic Experiences

Type of doctor who first diagnosed intellectual disability	
<b>Description</b>	What type of doctor first diagnosed child with intellectual disability?
<b>Survey Items Used</b>	DE_INT1R
<b>Denominator</b>	CSHCN ages 6-17 years with current intellectual disability
<b>Numerator</b>	Type of health care provider: Pediatrician or family health care practitioner; Psychologist; Specialist; Multidisciplinary team/Other
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> DRDX_INT_11 = .; /*Missing includes (14) never told child had condition, (96)dk*/ if DE_INT1R in (1,2) then DRDX_INT_11 = 1; /*(1)Pediatrician/pediatric HCP,NP or PA; (2)Other HCP, Fam practice dr/NP/PA*/ if DE_INT1R in (4,5) then DRDX_INT_11 = 2; /*(4)School psychologist/counselor (5)Psychologist, non-school*/ if DE_INT1R in (3,6,7,10) then DRDX_INT_11 = 3; /*(3)Pediatric specialist; (6)Psychiatrist, medical dr; (7)Neurologist; (10)Specialist dr (other than dev pediatrician, psychiatrist, neurologist */ if DE_INT1R = 13 then DRDX_INT_11 = 4; /*(13)Team of professionals/multidisciplinary team*/ if DE_INT1R in (8,9,11,12) then DRDX_INT_11 = 4; /*(8)School nurse, (9) Phys/occ/speech/other therapist, (11)Other*/ if DE_INT1R = .L then DRDX_INT_11 = .L; LABEL DRDX_INT_11 = "Health care provider who first gave Intellectual Disability diagnosis (ever &amp; current diagnosis)";  DrDxINTR = DRDX_INT_11; IF DX_INT_11 = 2 AND DRDX_INT_11 GE 1 THEN DrDxINTR = .M; LABEL DrDxINTR = "Health care provider who first gave Intellectual Disability diagnosis (current diagnosis only)";  value DRTYP /*DRDX_INT_11*/ 1 = "Pediatrician or Pediatric/Family HCP" 2 = "Psychologist" 3 = "Specialist Dr" 4 = "Multidisciplinary Team/Other"; </pre>	

## Health and Education Services

Number of health and related services used	
<b>Description</b>	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?
<b>Survey Items Used</b>	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
<b>Denominator</b>	CSHCN ages 6-17 years with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	No health care services used; 1 health care service used; 2 health care services used; 3+ health care services used
<b>Notes for Data-Users</b>	
15% of survey respondents had missing values for between 1 and 6 of the 7 possible services from the list	
<b>SAS Code and Annotation</b>	
<pre> /*Revised any concern out of the 7 types of concern with an array*/ array var_hcs {*} HCS_BI_11 HCS_SI_11 HCS_CT_11 HCS_OT_11 HCS_PT_11 HCS_ST_11 HCS_LT_11; anyhcs = 0; missh_m = 0; missh_l = 0; do i = 1 to dim(var_pct);     if var_hcs(i) = 1 then anyhcs = anyhcs + 1;     if var_hcs(i) = . then missh_m = missh_m + 1;     if var_hcs(i) = .L then missh_l = missh_l + 1; end; drop i;  HCS_COUNT_11 = anyhcs; IF anyhcs GE 3 THEN HCS_COUNT_11 = 3; IF missh_m = 7 THEN HCS_COUNT_11 = .; /*missing if any DK/REF*/ IF missh_l = 7 THEN HCS_COUNT_11 = .L; /*had .L for all types of concerns*/ LABEL HCS_COUNT_11 = "Currently use 3 or more of 7 types of health care services to meet their developmental needs";  value count_three /*HCS_COUNT_11*/ 0 = "None" 1 = "One" 2 = "Two" 3 = "Three or more"; </pre>	

## Health and Education Services

Currently use behavioral intervention or modification services	
<b>Description</b>	Does child currently use behavioral intervention or modification services on a regular basis?
<b>Survey Items Used</b>	HCS1_A; HCS1_A_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, uses this type of service; No, does not use this type of service
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> HCS_BI_11 = .; /*No .L's*/ IF HCS1_A_2 = 1 THEN HCS_BI_11 = 1; IF HCS1_A_2 = 0 OR HCS1_A = 0 THEN HCS_BI_11 = 2; LABEL HCS_BI_11 = "Currently use behavioral intervention or modification services on a regular basis";  value yn 1 = "yes" 2 = "no"; </pre>	



## Health and Education Services

Currently use sensory integration therapy	
<b>Description</b>	Does child currently use sensory integration therapy on a regular basis?
<b>Survey Items Used</b>	HCS1_B; HCS1_B_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, uses this type of service; No, does not use this type of service
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> HCS_SI_11 = .; /*No .L's*/ IF HCS1_B_2 = 1 THEN HCS_SI_11 = 1; IF HCS1_B_2 = 0 OR HCS1_B = 0 THEN HCS_SI_11 = 2; LABEL HCS_SI_11 = "Currently use sensory integration therapy on a regular basis";  value yn 1 = "yes" 2 = "no"; </pre>	

## Health and Education Services

Currently use cognitive based therapy	
<b>Description</b>	Does child currently use cognitive based therapy on a regular basis?
<b>Survey Items Used</b>	HCS1_C; HCS1_C_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, uses this type of service; No, does not use this type of service
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> HCS_CT_11 = .; /*No .L's*/ IF HCS1_C_2 = 1 THEN HCS_CT_11 = 1; IF HCS1_C_2 = 0 OR HCS1_C = 0 THEN HCS_CT_11 = 2; LABEL HCS_CT_11 = "Currently use cognitive based therapy on a regular basis";  value yn 1 = "yes" 2 = "no"; </pre>	

## Health and Education Services

Currently use occupational therapy	
<b>Description</b>	Does child currently use occupational therapy on a regular basis?
<b>Survey Items Used</b>	HCS1_D; HCS1_D_2
<b>Denominator</b>	CSHCN ages 6-17 years with current ASD, ID and/or DD
<b>Numerator</b>	Yes, uses this type of service; No, does not use this type of service
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> HCS_OT_11 = .; /*No .L's*/ IF HCS1_D_2 = 1 OR HCS1_E_2 = 1 THEN HCS_OT_11 = 1; IF (HCS1_D_2 = 0 OR HCS1_D = 0) AND (HCS1_E_2 = 0 OR HCS1_E = 0) THEN HCS_OT_11 = 2; LABEL HCS_OT_11 = "Currently use occupational therapy on a regular basis";  value yn 1 = "yes" 2 = "no";                     </pre>	

## Health and Education Services

Currently use physical therapy	
<b>Description</b>	Does child currently use physical therapy on a regular basis?
<b>Survey Items Used</b>	HCS1_F; HCS1_F_2; HCS1_G; HCS1_G_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, uses this type of service; No, does not use this type of service
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> HCS_PT_11 = .; /*No .L's*/ IF HCS1_F_2 = 1 OR HCS1_G_2 = 1 THEN HCS_PT_11 = 1; IF (HCS1_F_2 = 0 OR HCS1_F = 0) AND (HCS1_G_2 = 0 OR HCS1_G = 0) THEN HCS_PT_11 = 2; LABEL HCS_PT_11 = "Currently use physical therapy on a regular basis";  value yn 1 = "yes" 2 = "no"; </pre>	

## Health and Education Services

Currently use social skills training	
<b>Description</b>	Does child currently use social skills training on a regular basis?
<b>Survey Items Used</b>	HCS1_H; HCS1_H_2; HCS1_I; HCS1_I_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder (ASD), developmental delay (DD), and/or intellectual disability (ID)
<b>Numerator</b>	Yes, uses this type of service; No, does not use this type of service
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> HCS_ST_11 = .; /*No .L's*/ IF HCS1_H_2 = 1 OR HCS1_I_2 = 1 THEN HCS_ST_11 = 1; IF (HCS1_H_2 = 0 OR HCS1_H = 0) AND (HCS1_I_2 = 0 OR HCS1_I = 0) THEN HCS_ST_11 = 2; LABEL HCS_ST_11 = "Currently use social skills training on a regular basis";  value yn 1 = "yes" 2 = "no"; </pre>	

## Health and Education Services

Currently use speech or language therapy	
<b>Description</b>	Does child currently use speech or language therapy on a regular basis?
<b>Survey Items Used</b>	HCS1_J; HCS1_J_2; HCS1_K; HCS1_K_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, uses this type of service; No, does not use this type of service
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> HCS_LT_11 = .; /*No .L's*/ IF HCS1_J_2 = 1 OR HCS1_K_2 = 1 THEN HCS_LT_11 = 1; IF (HCS1_J_2 = 0 OR HCS1_J = 0) AND (HCS1_K_2 = 0 OR HCS1_K = 0) THEN HCS_LT_11 = 2; LABEL HCS_LT_11 = "Currently use speech or language therapy on a regular basis";  value yn 1 = "yes" 2 = "no"; </pre>	

Number of providers children currently work with	
<b>Description</b>	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?
<b>Survey Items Used</b>	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_2; HCS2_E_2; HCS2_F; HCS2_F_2; HCS2_G; HCS2_G_2; HCS2_H; HCS2_H_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	No providers currently seen; 1 provider currently seen; 2 or more providers currently seen
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> /*Current DR*/ Dr_NUM = 0; IF AUDIOLOG_11 = 1 THEN Dr_NUM + 1; IF DEVPED_11 = 1 THEN Dr_NUM + 1; IF NEUROLOG_11 = 1 THEN Dr_NUM + 1; IF NUTRITN_11 = 1 THEN Dr_NUM + 1; IF NURSE_11 = 1 THEN Dr_NUM + 1; IF PSYCHIAT_11 = 1 THEN Dr_NUM + 1; IF PSYCHLOG_11 = 1 THEN Dr_NUM + 1; IF SOCWORK_11 = 1 THEN Dr_NUM + 1;  Dr_COUNT_11 = Dr_NUM; IF Dr_COUNT_11 &gt; 2 THEN Dr_COUNT_11 = 2;/* 2 or more*/ IF AUDIOLOG_11 = . AND DEVPED_11 = . AND NEUROLOG_11 = . AND NUTRITN_11 = . AND NURSE_11 = . AND PSYCHIAT_11 = . AND PSYCHLOG_11 = . AND SOCWORK_11 = . THEN Dr_COUNT_11 = .; LABEL Dr_COUNT_11 = "Currently see two or more out of 8 types of providers of health and related services to meet their developmental needs";  value count_two /*Dr_COUNT_11*/ 0 = "None" 1 = "One" 2 = "Two or more"; </pre>	

## Health and Education Services

Currently work with audiologist	
<b>Description</b>	Does child currently work with audiologist on a regular basis?
<b>Survey Items Used</b>	HCS2_A; HCS2_A_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, works with this type of provider; No, does not work with this type of provider
Notes for Data-Users	
N/A	
SAS Code and Annotation	
<pre> AUDIOLOG_11 = .; IF HCS2_A = 0 OR HCS2_A_2 = 0 THEN AUDIOLOG_11 = 2; IF HCS2_A_2 = 1 THEN AUDIOLOG_11 = 1; LABEL AUDIOLOG_11 = "Currently work with an audiologist";  value yn 1 = "yes" 2 = "no"; </pre>	



Currently work with developmental pediatricians	
<b>Description</b>	Does child currently work with developmental pediatricians on a regular basis?
<b>Survey Items Used</b>	HCS2_B; HCS2_B_2
<b>Denominator</b>	Children 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, works with this type of provider; No, does not work with this type of provider
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> DEVPED_11 = .; IF HCS2_B = 0 OR HCS2_B_2 = 0 THEN DEVPED_11 = 2; IF HCS2_B_2 = 1 THEN DEVPED_11 = 1; LABEL DEVPED_11 = "Currently work with a developmental practitioner";  value yn 1 = "yes" 2 = "no";                     </pre>	

Currently work with neurologist	
<b>Description</b>	Does child currently work with neurologist on a regular basis?
<b>Survey Items Used</b>	HCS2_C; HCS2_C_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, works with this type of provider; No, does not work with this type of provider
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> NEUROLOG_11 = .; IF HCS2_C = 0 OR HCS2_C_2 = 0 THEN NEUROLOG_11 = 2; IF HCS2_C_2 = 1 THEN NEUROLOG_11 = 1; LABEL NEUROLOG_11 = "Currently work with a neurologist";  value yn 1 = "yes" 2 = "no"; </pre>	

## Health and Education Services

Currently work with nutritionist	
<b>Description</b>	Does child currently work with nutritionist on a regular basis?
<b>Survey Items Used</b>	HCS2_D: HCS2_D_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, works with this type of provider; No, does not work with this type of provider
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> NUTRITN_11 = .; IF HCS2_D = 0 OR HCS2_D_2 = 0 THEN NUTRITN_11 = 2; IF HCS2_D_2 = 1 THEN NUTRITN_11 = 1; LABEL NUTRITN_11 = "Currently work with a nutritionist";  value yn 1 = "yes" 2 = "no"; </pre>	

Currently work with an at home/long-term nurse	
<b>Description</b>	Does child currently work with an at home/long-term nurse on a regular basis?
<b>Survey Items Used</b>	HCS2_E; HCS2_E_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, works with this type of provider; No, does not work with this type of provider
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> NURSE_11 = .; IF HCS2_E = 0 OR HCS2_E_2 = 0 THEN NURSE_11 = 2; IF HCS2_E_2 = 1 THEN NURSE_11 = 1; LABEL NURSE_11 = "Currently work with an at home/long-term nurse";  value yn 1 = "yes" 2 = "no";                     </pre>	

Currently work with psychiatrist	
<b>Description</b>	Does child currently work with psychiatrist on a regular basis?
<b>Survey Items Used</b>	HCS2_E; HCS2_E_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, works with this type of provider; No, does not work with this type of provider
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PSYCHIAT_11 = .; IF HCS2_F = 0 OR HCS2_F_2 = 0 THEN PSYCHIAT_11 = 2; IF HCS2_F_2 = 1 THEN PSYCHIAT_11 = 1; LABEL PSYCHIAT_11 = "Currently work with a psychiatrist";  value yn 1 = "yes" 2 = "no";                     </pre>	

Currently work with psychologist/ psychotherapist	
<b>Description</b>	Does child currently work with psychologist/ psychotherapist on a regular basis?
<b>Survey Items Used</b>	HCS2_G; HCS2_G_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, works with this type of provider; No, does not work with this type of provider
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PSYCHLOG_11 = .; IF HCS2_G = 0 OR HCS2_G_2 = 0 THEN PSYCHLOG_11 = 2; IF HCS2_G_2 = 1 THEN PSYCHLOG_11 = 1; LABEL PSYCHLOG_11 = "Currently work with a psychologist/psychotherapist";  value yn 1 = "yes" 2 = "no";                     </pre>	

Currently work with a social worker	
<b>Description</b>	Does child currently work with a social worker on a regular basis?
<b>Survey Items Used</b>	HCS2_H; HCS2_H_2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, works with this type of provider; No, does not work with this type of provider
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> SOCWORK_11 = .; IF HCS2_H = 0 OR HCS2_H_2 = 0 THEN SOCWORK_11 = 2; IF HCS2_H_2 = 1 THEN SOCWORK_11 = 1; LABEL SOCWORK_11 = "Currently work with a social worker";  value yn 1 = "yes" 2 = "no";                     </pre>	

Number of medications children currently use	
<b>Description</b>	How many medications child currently uses on a regular basis?
<b>Survey Items Used</b>	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
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Child takes 1 or more medications; Child does not take any medications asked about
<b>Notes for Data-Users</b>	
N/A	
<b>SPSS Syntax and Annotation</b>	
<pre> /*CURRENT MEDS*/ rx_stmlnt_11 = .; /*(.) indicates dk/ref - there are no .Ls for HCS3_XR*/ IF HCS3_AR = 0 OR HCS3_A_2R = 0 THEN rx_stmlnt_11 = 2; IF HCS3_A_2R = 1 THEN rx_stmlnt_11 = 1; LABEL rx_stmlnt_11 = "Current stimulant Rx use"; rx_dprss_11 = .; IF HCS3_BR = 0 OR HCS3_B_2R = 0 THEN rx_dprss_11 = 2; IF HCS3_B_2R = 1 THEN rx_dprss_11 = 1; LABEL rx_dprss_11 = "Current anti-depressant Rx use"; rx_anxiet_11 = .; IF HCS3_CR = 0 OR HCS3_C_2R = 0 THEN rx_anxiet_11 = 2; IF HCS3_C_2R = 1 THEN rx_anxiet_11 = 1; LABEL rx_anxiet_11 = "Current anti-anxiety/mood Rx use"; rx_seiz_11 = .; IF HCS3_DR = 0 OR HCS3_D_2R = 0 THEN rx_seiz_11 = 2; IF HCS3_D_2R = 1 THEN rx_seiz_11 = 1; LABEL rx_seiz_11 = "Current anti-seizure Rx use"; rx_psych_11 = .; IF HCS3_ER = 0 OR HCS3_E_2R = 0 THEN rx_psych_11 = 2; IF HCS3_E_2R = 1 THEN rx_psych_11 = 1; LABEL rx_psych_11 = "Current anti-psychotic Rx use"; rx_sleep_11 = .; IF HCS3_FR = 0 OR HCS3_F_2R = 0 THEN rx_sleep_11 = 2; IF HCS3_F_2R = 1 THEN rx_sleep_11 = 1; LABEL rx_sleep_11 = "Current sleep Rx use";  Rx_NUM = 0; IF rx_stmlnt_11 = 1 THEN Rx_NUM + 1; IF rx_dprss_11 = 1 THEN Rx_NUM + 1; IF rx_anxiet_11 = 1 THEN Rx_NUM + 1; IF rx_seiz_11 = 1 THEN Rx_NUM + 1; IF rx_psych_11 = 1 THEN Rx_NUM + 1; IF rx_sleep_11 = 1 THEN Rx_NUM + 1; </pre>	



## Health and Education Services

```
Rxcount_11 = Rx_NUM;
IF rx_stmlnt_11 = . AND rx_dprss_11 = . AND rx_anxiet_11 = . AND rx_seiz_11 = . AND rx_psych_11 = .
AND rx_sleep_11 = . THEN Rxcount_11 = .;
IF Rxcount_11 > 2 THEN Rxcount_11 = 2;/* 2 AND mANDe*/
LABEL Rxcount_11 = "Currently uses none, one, AND two/mANDe types of medications to meet their
developmental needs";

value yn
1 = "none"
2 = "one";
3 = "two"
```

## Health and Education Services

Currently use stimulant medications	
<b>Description</b>	Does child currently use stimulant medications to meet his/her developmental needs?
<b>Survey Items Used</b>	HCS3_AR; HCS3_A_2R
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child currently use stimulant medications ; No, child does use stimulant medications
<b>Notes for Data-Users</b>	
N/A	
<b>SPSS Syntax and Annotation</b>	
<pre> rx_stmlnt_11 = .; IF HCS3_AR = 0 OR HCS3_A_2R = 0 THEN rx_stmlnt_11 = 2; IF HCS3_A_2R = 1 THEN rx_stmlnt_11 = 1; LABEL rx_stmlnt_11 = "Current stimulant Rx use";  value yn 1 = "yes" 2 = "no";                     </pre>	

Currently use anti-depressant medication	
<b>Description</b>	Does child currently use anti-depressant medications on a regular basis?
<b>Survey Items Used</b>	HCS3_BR; HCS3_B_2R
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child currently uses anti-depressant medications; No, child does not use anti-depressant medications
<b>Notes for Data-Users</b>	
N/A	
<b>SPSS Syntax and Annotation</b>	
<pre> rx_dprss_11 = .; IF HCS3_BR = 0 OR HCS3_B_2R = 0 THEN rx_dprss_11 = 2; IF HCS3_B_2R = 1 THEN rx_dprss_11 = 1; LABEL rx_dprss_11 = "Current anti-depressant Rx use";  value yn 1 = "yes" 2 = "no";                     </pre>	

Currently use anti-anxiety or mood stabilizing medications	
<b>Description</b>	Does child currently use anti-anxiety or mood stabilizing medications on a regular basis?
<b>Survey Items Used</b>	HCS3_CR; HCS3_C_2R
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child currently uses anti-anxiety or mood stabilizing medications; No, child does not use anti-anxiety or mood stabilizing medications
<b>Notes for Data-Users</b>	
N/A	
<b>SPSS Syntax and Annotation</b>	
<pre> rx_anxiet_11 = .; IF HCS3_CR = 0 OR HCS3_C_2R = 0 THEN rx_anxiet_11 = 2; IF HCS3_C_2R = 1 THEN rx_anxiet_11 = 1; LABEL rx_anxiet_11 = "Current anti-anxiety/mood Rx use";  value yn 1 = "yes" 2 = "no";                     </pre>	

Currently use anti-seizure medications	
<b>Description</b>	Does child currently use anti-seizure medications on a regular basis?
<b>Survey Items Used</b>	HCS3_DR; HCS3_D_2R
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child currently uses anti-seizure medications; No, child does not use anti-seizure medications
<b>Notes for Data-Users</b>	
N/A	
<b>SPSS Syntax and Annotation</b>	
<pre>rx_seiz_11 = .; IF HCS3_DR = 0 OR HCS3_D_2R = 0 THEN rx_seiz_11 = 2; IF HCS3_D_2R = 1 THEN rx_seiz_11 = 1; LABEL rx_seiz_11 = "Current anti-seizure Rx use";  value yn 1 = "yes" 2 = "no";</pre>	

Currently use anti-psychotic medications	
<b>Description</b>	Does child currently use anti-psychotic medications on a regular basis?
<b>Survey Items Used</b>	HCS3_ER; HCS3_E_2R
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child currently uses anti-psychotic medications; No, child does not use anti-psychotic medications
<b>Notes for Data-Users</b>	
N/A	
<b>SPSS Syntax and Annotation</b>	
<pre>rx_psych_11 = .; IF HCS3_ER = 0 OR HCS3_E_2R = 0 THEN rx_psych_11 = 2; IF HCS3_E_2R = 1 THEN rx_psych_11 = 1; LABEL rx_psych_11 = "Current anti-psychotic Rx use";  value yn 1 = "yes" 2 = "no";</pre>	

Currently use sleep medications	
<b>Description</b>	Does child currently use sleep medications on a regular basis?
<b>Survey Items Used</b>	HCS3_FR; HCS3_F_2R
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child currently uses sleep medications; No, child does not use sleep medications
<b>Notes for Data-Users</b>	
N/A	
<b>SPSS Syntax and Annotation</b>	
<pre>rx_sleep_11 = .; IF HCS3_FR = 0 OR HCS3_F_2R = 0 THEN rx_sleep_11 = 2; IF HCS3_F_2R = 1 THEN rx_sleep_11 = 1; LABEL rx_sleep_11 = "Current sleep Rx use";  value yn 1 = "yes" 2 = "no";</pre>	

Type of school child currently enrolled in	
<b>Description</b>	What kind of school does he/she attend?
<b>Survey Items Used</b>	ES1
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Public school; Private school; Home-schooled
<b>Notes for Data-Users</b>	
Children not enrolled in school were legitimately skipped from this question	
<b>SAS Code and Annotation</b>	
<pre> ES_SCH = ES1; IF ES1 IN (6,7) THEN ES_SCH = .; IF ES1 = 4 THEN ES_SCH = .L; /*Not enrolled in school*/ Label ES_SCH = "Type of schools currently enrolled in";  value ES_SCH 1 = "Public" 2 = "Private" 3 = "Home-schooled";                     </pre>	



Had an Individualized Education Program	
<b>Description</b>	Does child have a written intervention plan called an Individualized Education Program or IEP?
<b>Survey Items Used</b>	ES6
<b>Denominator</b>	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
<b>Numerator</b>	Yes, child has an IEP; No, child does not have IEP
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> ES_IEP = ES6; IF ES6 IN (6,7) THEN ES_IEP = .; IF ES6 = 0 THEN ES_IEP = 2; /* .L if ES1 in 3,4,6,7 */ Label ES_IEP = "Among those enrolled in public or private school, had a written intervention plan called an Individualized Education Program (IEP)";  value ES_IEP 1 = "With an IEP" 2 = "Without an IEP"; </pre>	

Adequacy of Individualized Education Program	
<b>Description</b>	Does child's Individualized Education Program address all of concerns about his/her development and education?
<b>Survey Items Used</b>	ES8
<b>Denominator</b>	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
<b>Numerator</b>	Yes, child's IEP addresses all of the parent's concerns; No child's IEP does not address all of the parent's concerns
<b>Notes for Data-Users</b>	
N/A	
<b>Revisions</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> ES_IEPND = ES8; IF ES8 IN (6,7) THEN ES_IEPND = .; IF ES8 = 0 THEN ES_IEPND = 2; /* .L if ES1 in 3,4,6,7 OR if ES6 in 2,6,7 */ Label ES_IEPND = "Among those enrolled in public or private school, IEP addresses all of the parent's concerns about their child's development and education";  value yn 1 = "yes" 2 = "no";                     </pre>	

Received services from an Early Intervention Service	
<b>Description</b>	Before age 3, did child receive services from an Early Intervention Services?
<b>Survey Items Used</b>	ES9
<b>Denominator</b>	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
<b>Numerator</b>	Yes, child received EIS; No, child did not receive EIS
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> ES_EIS = ES9; IF ES9 IN (6,7) THEN ES_EIS = .; IF ES9 = 0 THEN ES_EIS = 2; /* .L if ES1 in 3,4,6,7 */ Label ES_EIS = "Among those enrolled in public or private school, received Early Intervention Services (EIS) before they were 3 years old";  value ES_EIS 1 = "Had an EIS" 2 = "Never had an EIS";                     </pre>	

Ever told that child was not eligible for Early Intervention Services	
<b>Description</b>	Were you ever told Early Intervention Services (EIS) was not available to you?
<b>Survey Items Used</b>	ES10
<b>Denominator</b>	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
<b>Numerator</b>	Yes, ever told child was not eligible for EIS; No, never told hat child was not eligible for EIS
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> ES_EISNE = ES10; IF ES10 IN (6,7) THEN ES_EISNE = .; IF ES10 = 0 THEN ES_EISNE = 2; /* .L if ES1 in 3,4,6,7 */ Label ES_EISNE = "Among those enrolled in public or private school, parent was told their child was not eligible for Early Intervention Services";  value yn 1 = "yes" 2 = "no"; </pre>	

## Unmet Needs and Insurance Adequacy

Any unmet need for care	
<b>Description</b>	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?
<b>Survey Items Used</b>	INS1: INS2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	No, child did not receive all necessary services; Yes, child received all necessary services
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> IN_UNMET_11 = .; if INS1 = 0 or INS2 = 0 then IN_UNMET_11 = 1; if INS1 = 1 and INS2 = 1 then IN_UNMET_11 = 2; if INS1 in (6,7) AND INS2 in (6,7) then IN_UNMET_11 = .; LABEL IN_UNMET_11 = "DID NOT receive all the treatments, services, or service providers needed to care for child's developmental needs during the past 12 months";  value yn 1 = "yes" 2 = "no"; </pre>	

## Unmet Needs and Insurance Adequacy

Received all needed treatments and services	
<b>Description</b>	During the past 12 months, did child receive all the treatments and services necessary to meet his/her developmental needs?
<b>Survey Items Used</b>	NS1
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child received all necessary services; No, child did not receive all necessary services
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> IN_SERV_11 = INS1; if INS1 = 0 then IN_SERV_11 = 2; if INS1 in (6,7) then IN_SERV_11 = .; LABEL IN_SERV_11 = "Received all the treatments and services necessary to meet their developmental needs during the past 12 months";  value yn 1 = "yes" 2 = "no"; </pre>	

## Unmet Needs and Insurance Adequacy

Saw all needed service providers	
<b>Description</b>	During the past 12 months, did child see all the service providers needed to care for his/her developmental needs?
<b>Survey Items Used</b>	INS2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child saw all providers needed; No, child did not see all providers needed
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> IN_PROV_11 = INS2; if INS2 = 0 then IN_PROV_11 = 2; if INS2 in (6,7) then IN_PROV_11 = .; LABEL IN_PROV_11 = "Saw all the service providers needed to care for their developmental needs during the past 12 months";  value yn 1 = "yes" 2 = "no"; </pre>	

## Unmet Needs and Insurance Adequacy

Health insurance coverage	
<b>Description</b>	Does child have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?
<b>Survey Items Used</b>	INS3
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child has health insurance; No, child does not have health insurance
<b>Notes for Data-Users</b>	
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.	
<b>SAS Code and Annotation</b>	
<pre>IN_INS_11 = INS3; if INS3 = 0 then IN_INS_11 = 2; if INS3 in (6,7) then IN_INS_11 = .; LABEL 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 yn 1 = "yes" 2 = "no";</pre>	



## Unmet Needs and Insurance Adequacy

Inadequate current health insurance	
<b>Description</b>	Is child's health insurance adequate for his/her needs?
<b>Survey Items Used</b>	National Survey of Children with Special Health Care Needs (NS-CSHCN) items: C8Q01_A, C8Q01_B, C8Q01_C
<b>Denominator</b>	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
<b>Numerator</b>	Current insurance is adequate; Current insurance is not adequate
<b>Notes for Data-Users</b>	
<p>To be scored as having inadequate insurance children have responses of never or sometimes to each item. That is their current insurance coverage never/sometimes covers services and/or never/sometimes has reasonable out of pocket expenses and/or never/sometimes allows CSHCN to see needed health providers. Valid responses on all three items are required. If any item is don't know or refused, then child is set to missing.</p>	
<b>SAS Code and Annotation</b>	
<pre> metneeds_09 = .; if UNINS = 1 then metneeds_09 = 2; else if UNINS in (6,7) then metneeds_09 = .M; else if C8Q01_A in (1,2) then metneeds_09 = 0; else if C8Q01_A in (3,4) then metneeds_09 = 1; else if C8Q01_A = .L then metneeds_09 = 2; else if C8Q01_A in (6,7,.M) then metneeds_09 = .M; else if C8Q01_A = .P then metneeds_09 = .P; label metneeds_09 = 'Health insurance benefits meet child needs (from the 2009/2010 NS-CSHCN)';  reasonable_09 = .; if UNINS = 1 then reasonable_09 = 2; else if UNINS in (6,7) then reasonable_09 = .M; else if C8Q01_B in (1,2) then reasonable_09 = 0; else if C8Q01_B in (3,4,5) then reasonable_09 = 1; else if C8Q01_B = .L then reasonable_09 = 2; else if C8Q01_B in (6,7,.M) then reasonable_09 = .M; else if C8Q01_B = .P then reasonable_09 = .P; label reasonable_09 = 'Non-covered insurance charges reasonable (from the 2009/2010 NS-CSHCN)';  providers_09 = .; if UNINS = 1 then providers_09 = 2; else if UNINS in (6,7) then providers_09 = .M; else if C8Q01_C in (1,2) then providers_09 = 0; else if C8Q01_C in (3,4) then providers_09 = 1; </pre>	

## Unmet Needs and Insurance Adequacy

```
else if C8Q01_C = .L then providers_09 = 2;
else if C8Q01_C in (6,7,.M) then providers_09 = .M;
else if C8Q01_C = .P then providers_09 = .P;
label providers_09 = 'Insurance allows child to see needed providers (from the 2009/2010 NS-CSHCN)';

indic5_09 = .;
if metneeds_09 = 1 and reasonable_09 = 1 and providers_09 = 1 then indic5_09 = 1;
if metneeds_09 = 0 or reasonable_09 = 0 or providers_09 = 0 then indic5_09 = 0;
if metneeds_09 in (.M,.P) or reasonable_09 in (.M,.P) or providers_09 in (.M,.P) then indic5_09 = .;
if metneeds_09 = 2 then indic5_09 = .L;
label indic5_09 = 'INDICATOR 5: Adequacy of Current Insurance Coverage: Currently insured CSHCN
whose insurance coverage is not adequate (from the 2009/2010 NS-CSHCN)';

value adeqins /*metneeds_09 reasonable_09 providers_09*/
0 = 'Never/sometimes'
1 = 'Usually/always'

value insadeq /*indic_5*/
0 = 'Current insurance is NOT adequate'
1 = 'Current insurance IS adequate';
```

## Unmet Needs and Insurance Adequacy

Current health insurance benefits meet child's needs	
<b>Description</b>	Does child's health insurance offer benefits or cover services that meet his/her needs?
<b>Survey Items Used</b>	National Survey of Children with Special Health Care Needs (NS-CSHCN) item: C8Q01_A
<b>Denominator</b>	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
<b>Numerator</b>	Never/sometimes meet needs; Usually/always meets needs
<b>Notes for Data-Users</b>	
N/A	
<b>Revisions</b>	
These items are the same as in the 2005/06 NS-CSHCN.	
<b>SAS Code and Annotation</b>	
<pre> metneeds_09 = .; if UNINS = 1 then metneeds_09 = 2; else if UNINS in (6,7) then metneeds_09 = .M; else if C8Q01_A in (1,2) then metneeds_09 = 0; else if C8Q01_A in (3,4) then metneeds_09 = 1; else if C8Q01_A = .L then metneeds_09 = 2; else if C8Q01_A in (6,7,.M) then metneeds_09 = .M; else if C8Q01_A = .P then metneeds_09 = .P; label metneeds_09 = 'Health insurance benefits meet child needs (from the 2009/2010 NS-CSHCN)';  value adeqins /*metneeds_09*/ 0 = 'Never/sometimes' 1 = 'Usually/always' </pre>	

## Unmet Needs and Insurance Adequacy

Costs not covered by health insurance are reasonable	
<b>Description</b>	Are the costs not covered by child's health insurance reasonable?
<b>Survey Items Used</b>	National Survey of Children with Special Health Care Needs (NS-CSHCN) item: C8Q01_B
<b>Denominator</b>	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
<b>Numerator</b>	Usually/always reasonable; Never/sometimes reasonable
<b>Notes for Data-Users</b>	
N/A	
<b>Revisions</b>	
These items are the same as in the 2005/06 NS-CSHCN.	
<b>SAS Code and Annotation</b>	
<pre> reasonable_09 = .; if UNINS = 1 then reasonable_09 = 2; else if UNINS in (6,7) then reasonable_09 = .M; else if C8Q01_B in (1,2) then reasonable_09 = 0; else if C8Q01_B in (3,4,5) then reasonable_09 = 1; else if C8Q01_B = .L then reasonable_09 = 2; else if C8Q01_B in (6,7,.M) then reasonable_09 = .M; else if C8Q01_B = .P then reasonable_09 = .P; label reasonable_09 = 'Non-covered insurance charges reasonable (from the 2009/2010 NS-CSHCN)';  value adeqins /*reasonable_09*/ 0 = 'Never/sometimes' 1 = 'Usually/always' </pre>	

## Unmet Needs and Insurance Adequacy

Health insurance let child see needed providers	
<b>Description</b>	Does child's health insurance allow him/her to see the health care providers he/she needs?
<b>Survey Items Used</b>	National Survey of Children with Special Health Care Needs (NS-CSHCN) item: C8Q01_C
<b>Denominator</b>	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
<b>Numerator</b>	Usually/always; Never/sometimes
<b>Notes for Data-Users</b>	
N/A	
<b>Revisions</b>	
The item is the same as in the 2005/06 NS-CSHCN.	
<b>SAS Code and Annotation</b>	
<pre> providers_09 = .; if UNINS = 1 then providers_09 = 2; else if UNINS in (6,7) then providers_09 = .M; else if C8Q01_C in (1,2) then providers_09 = 0; else if C8Q01_C in (3,4) then providers_09 = 1; else if C8Q01_C = .L then providers_09 = 2; else if C8Q01_C in (6,7,.M) then providers_09 = .M; else if C8Q01_C = .P then providers_09 = .P; label providers_09 = 'Insurance allows child to see needed providers (from the 2009/2010 NS-CSHCN)';  value adeqins /*providers_09*/ 0 = 'Never/sometimes' 1 = 'Usually/always'</pre>	

## Unmet Needs and Insurance Adequacy

Any unmet need due to insurance coverage	
<b>Description</b>	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?
<b>Survey Items Used</b>	INS4
<b>Denominator</b>	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
<b>Numerator</b>	Not all treatments/services covered by insurance; All needed treatments/services covered by insurance
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> IN_COVER_11 = INS4; /* .L includes INS3 = 6,7,2*/ if INS4 = 0 then IN_COVER_11 = 2; if INS4 in (6,7) then IN_COVER_11 = .; LABEL IN_COVER_11 = "Health insurance DID NOT cover all the treatments, services, or service providers needed to care for child's developmental needs";  value yn 1 = "yes" 2 = "no"; </pre>	

## Unmet Needs and Insurance Adequacy

Any speech or language therapy not covered by health insurance	
<b>Description</b>	Are speech or language therapies not covered by child's health insurance?
<b>Survey Items Used</b>	Any speech or language therapy not covered by health insurance
<b>Denominator</b>	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
<b>Numerator</b>	Not covered by insurance; Covered by insurance
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> /*Treatments/services/providers not covered by insurance/* - .L includes INS3 = 6,7,2 and INS4 = 0*/ IN_SPCH_11 = INS5R01; IF INS5R01 = 0 THEN IN_SPCH_11 = 2; IF INS4 = 0 THEN IN_SPCH_11 = 2; Label IN_SPCH_11 = "Among those who have health insurance, any speech/language therapy not covered by health insurance";  value yn 1 = "yes" 2 = "no"; </pre>	

## Unmet Needs and Insurance Adequacy

Any occupational therapy not covered by health insurance	
<b>Description</b>	Are occupational therapies not covered by health insurance?
<b>Survey Items Used</b>	INS5R02
<b>Denominator</b>	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
<b>Numerator</b>	Not covered by insurance; Covered by insurance
Notes for Data-Users	
N/A	
SAS Code and Annotation	
<pre> IN_OCCUP_11 = INS5R02; IF INS5R02 = 0 THEN IN_OCCUP_11 = 2; IF INS4 = 0 THEN IN_OCCUP_11 = 2; Label IN_OCCUP_11 = "Among those who have health insurance, any occupational therapy not covered by health insurance";  value yn 1 = "yes" 2 = "no"; </pre>	



## Unmet Needs and Insurance Adequacy

Any behavioral management services not covered by health insurance	
<b>Description</b>	Are behavioral management services not covered by health insurance?
<b>Survey Items Used</b>	INS5R03
<b>Denominator</b>	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
<b>Numerator</b>	Not covered by insurance; Covered by insurance
Notes for Data-Users	
N/A	
SAS Code and Annotation	
<pre> IN_BEH_11 = INS5R03; IF INS5R03 = 0 THEN IN_BEH_11 = 2; IF INS4 = 0 THEN IN_BEH_11 = 2; Label IN_BEH_11 = "Among those who have health insurance, any behavioral management services not covered by health insurance";  value yn 1 = "yes" 2 = "no"; </pre>	

## Unmet Needs and Insurance Adequacy

Any psychological services not covered by health insurance	
<b>Description</b>	Are psychological services not covered by health insurance?
<b>Survey Items Used</b>	INS5R04
<b>Denominator</b>	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
<b>Numerator</b>	Not covered by insurance; Covered by insurance
Notes for Data-Users	
N/A	
SAS Code and Annotation	
<pre> IN_PSYCH_11 = INS5R04; IF INS5R04 = 0 THEN IN_PSYCH_11 = 2; IF INS4 = 0 THEN IN_PSYCH_11 = 2; Label IN_PSYCH_11 = "Among those who have health insurance, any psychological services not covered by health insurance";  value yn 1 = "yes" 2 = "no"; </pre>	

## Unmet Needs and Insurance Adequacy

Any alternative medicine/therapies not covered by health insurance	
<b>Description</b>	Are alternative medicine/therapies not covered by health insurance?
<b>Survey Items Used</b>	INS5R08
<b>Denominator</b>	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
<b>Numerator</b>	Not covered by insurance; Covered by insurance
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre>IN_ALT_11 = INS5R08; IF INS4 = 2 THEN IN_ALT_11 = 2; Label IN_ALT_11 = "Among those who have health insurance, any alternative medicine/therapies not covered by health insurance";  value yn 1 = "yes" 2 = "no";</pre>	

Strengths and Difficulties Questionnaire composite score	
<b>Description</b>	Did child receive a high score on the Strengths and Difficulties Questionnaire?
<b>Survey Items Used</b>	FSD5_A; FSD5_B; FSD5_C; FSD5_D; FSD5_E
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	High score; Medium score; Low score
<b>Notes for Data-Users</b>	
<p>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.</p> <p>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.</p>	
<b>Revisions</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> /*Brief SDQ Scoring*/ SDQ_1 = FSD5_A; SDQ_2 = FSD5_B; SDQ_3 = FSD5_C; SDQ_4 = FSD5_D; SDQ_5 = FSD5_E;  IF FSD5_A = 1 then SDQ_1 = 3; IF FSD5_A = 3 then SDQ_1 = 1; IF FSD5_E = 1 then SDQ_5 = 3; IF FSD5_E = 3 then SDQ_5 = 1;  array miss_sdq {*} SDQ_1 -- SDQ_5; do i = 1 to dim(miss_sdq);     if miss_sdq(i) in (1,2,3) then miss_sdq(i) = miss_sdq(i) - 1;     if miss_sdq(i) in (6,7) then miss_sdq(i) = .; end; drop i;  SDQ_COUNT = SDQ_1 + SDQ_2 + SDQ_3 + SDQ_4 + SDQ_5;  SDQ_CATI_11 = .; IF SDQ_COUNT GE 0 THEN SDQ_CATI_11 = 3; /*Low score: 0-2*/ IF SDQ_COUNT &gt; 2 THEN SDQ_CATI_11 = 2; /*Medium score: 3-5*/ IF SDQ_COUNT &gt; 5 THEN SDQ_CATI_11 = 1; /*High score: 6-10*/ Label SDQ_CATI_11 = "Scoring results of brief Strengths and Difficulties Questionnaire (5 items)"; </pre>	

## Functioning, Strengths, and Difficulties

value SDQ\_SCORE

1 = "High score: 6-10"

2 = "Medium score: 3-5"

3 = "Low score: 0-2";

## Functioning, Strengths, and Difficulties

Child generally well behaved	
<b>Description</b>	Was child generally well behaved and did what adults requested during the past six months?
<b>Survey Items Used</b>	FSD5_A
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Not true; Somewhat true; Certainly true
<b>Notes for Data-Users</b>	
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<b>SAS Code and Annotation</b>	
<pre> SDQ_BEH = FSD5_A; if FSD5_A &gt; 3 then SDQ_BEH = .; Label SDQ_BEH = "Child was generally well behaved and usually do what adults request during the past six months";  value SDQ_ITEM 1 = "Not true" 2 = "Somewhat true" 3 = "Certainly true"; </pre>	

## Functioning, Strengths, and Difficulties

Child has many worries, or often seems worried	
<b>Description</b>	Did child have many worries, or often seems worried during the past six months?
<b>Survey Items Used</b>	FSD5_B
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Not true; Somewhat true; Certainly true
<b>Notes for Data-Users</b>	
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<b>SAS Code and Annotation</b>	
<pre>SDQ_WRRY = FSD5_B; if FSD5_B &gt; 3 then SDQ_WRRY = .; Label SDQ_WRRY = "Child had many worries, or often seems worried during the past six months";  value SDQ_ITEM 1 = "Not true" 2 = "Somewhat true" 3 = "Certainly true";</pre>	

## Functioning, Strengths, and Difficulties

Child often unhappy, depressed, or tearful	
<b>Description</b>	Was child often unhappy, depressed, or tearful during the past six months
<b>Survey Items Used</b>	FSD5_C
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Not true; Somewhat true; Certainly true
<b>Notes for Data-Users</b>	
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<b>SAS Code and Annotation</b>	
<pre>SDQ_DEP = FSD5_C; if FSD5_C &gt; 3 then SDQ_DEP = .; Label SDQ_DEP = "Child was often unhappy, depressed, or tearful during the past six months";  value SDQ_ITEM 1 = "Not true" 2 = "Somewhat true" 3 = "Certainly true";</pre>	



## Functioning, Strengths, and Difficulties

Child gets along better with adults than with other children/youth	
<b>Description</b>	Was child get along better with adults than with other children or youth during the past six months?
<b>Survey Items Used</b>	FSD5_D
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Not true; Somewhat true; Certainly true
<b>Notes for Data-Users</b>	
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<b>SAS Code and Annotation</b>	
<pre>SDQ_ADLT = FSD5_D; if FSD5_D &gt; 3 then SDQ_ADLT = .; Label SDQ_ADLT = "Child got along better with adults than with other children or youth during the past six months";  value SDQ_ITEM 1 = "Not true" 2 = "Somewhat true" 3 = "Certainly true";</pre>	

## Functioning, Strengths, and Difficulties

Child has good attention span	
<b>Description</b>	During the last six months, did child have a good attention span, sees chores or homework through to the end?
<b>Survey Items Used</b>	FSD5_E
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Not true; Somewhat true; Certainly true
<b>Notes for Data-Users</b>	
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<b>SAS Code and Annotation</b>	
<pre>SDQ_ATTEN = FSD5_E; if FSD5_E &gt; 3 then SDQ_ATTEN = .; Label SDQ_ATTEN = "Child had a good attention span, sees chores or homework through to the end during the past six months";  value SDQ_ITEM 1 = "Not true" 2 = "Somewhat true" 3 = "Certainly true";</pre>	

## Parental Views and Safety Concerns

School professionals at child's school are able to meet child's needs	
<b>Description</b>	Do parents believe that the teachers and other professionals at the child's school are able to meet their needs?
<b>Survey Items Used</b>	PP1_A
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree; Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_TCHN_11 = PP1_A; if PP1_A in (3,4) then PP_TCHN_11 = 3; if PP_TCHN_11 in (6,7) then PP_TCHN_11 = .; LABEL 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 DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree"; </pre>	

## Parental Views and Safety Concerns

Satisfaction with school services	
<b>Description</b>	Do parents agree that they are satisfied with the services child receives from teachers and other school professionals?
<b>Survey Items Used</b>	PP1_B
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree; Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_TCHS_11 = PP1_B; if PP1_B in (3,4) then PP_TCHS_11 = 3; if PP_TCHS_11 in (6,7) then PP_TCHS_11 = .; LABEL 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 DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree"; </pre>	

## Parental Views and Safety Concerns

Health care providers are able to meet child's needs	
<b>Description</b>	Do parents believe that the doctors and other health care providers that child sees are able to meet their needs?
<b>Survey Items Used</b>	PP1_C
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree; Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_DRN_11 = PP1_C; if PP1_C in (3,4) then PP_DRN_11 = 3; if PP_DRN_11 in (6,7) then PP_DRN_11 = .; LABEL 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 DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree";                     </pre>	

## Parental Views and Safety Concerns

Satisfaction with health care providers	
<b>Description</b>	Do parents agree that they are satisfied with the services child receives from doctors and other health care providers?
<b>Survey Items Used</b>	PP1_D
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree: Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_DRS_11 = PP1_D; if PP1_D in (3,4) then PP_DRS_11 = 3; if PP_DRS_11 in (6,7) then PP_DRS_11 = .; LABEL 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 DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree"; </pre>	

## Parental Views and Safety Concerns

Condition is lifelong	
<b>Description</b>	Do parents agree that condition is likely to be lifelong rather than temporary?
<b>Survey Items Used</b>	PP2_A
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree: Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_LIFE_11 = PP2_A; if PP2_A in (3,4) then PP_LIFE_11 = 3; if PP_LIFE_11 in (6,7) then PP_LIFE_11 = .; LABEL PP_LIFE_11 = "Parent agrees with following statement: condition is likely to be lifelong rather than temporary";  value DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree"; </pre>	

## Parental Views and Safety Concerns

Treatment can prevent or decrease condition related problems	
<b>Description</b>	Do parents believe that the problems related to their child's condition can be prevented or decreased with treatment?
<b>Survey Items Used</b>	PP2_B
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree; Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_PREV_11 = PP2_B; if PP2_B in (3,4) then PP_PREV_11 = 3; if PP_PREV_11 in (6,7) then PP_PREV_11 = .; LABEL PP_PREV_11 = "Parent agrees with following statement: the problems related to their child's condition can be prevented or decreased with treatment";  value DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree"; </pre>	



## Parental Views and Safety Concerns

Parent has the power to change the condition	
<b>Description</b>	Do parents believe that they have the power to change their child's condition?
<b>Survey Items Used</b>	PP2_C
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree; Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_CHNGE_11 = PP2_C; if PP2_C in (3,4) then PP_CHNGE_11 = 3; if PP_CHNGE_11 in (6,7) then PP_CHNGE_11 = .; LABEL PP_CHNGE_11 = "Parent agrees with following statement: they have the power to change their child's condition";  value DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree"; </pre>	

## Parental Views and Safety Concerns

Condition is a mystery	
<b>Description</b>	Do parents believe that condition is a mystery to them?
<b>Survey Items Used</b>	PP2_D
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree; Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_MYST_11 = PP2_D; if PP2_D in (3,4) then PP_MYST_11 = 3; if PP_MYST_11 in (6,7) then PP_MYST_11 = .; LABEL PP_MYST_11 = "Parent agrees with following statement: condition is a mystery to them";  value DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree";                     </pre>	

## Parental Views and Safety Concerns

Child's symptoms come and go	
<b>Description</b>	Do parents believe that the child's symptoms come and go?
<b>Survey Items Used</b>	PP2_E
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree; Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_GO_11 = PP2_E; if PP2_E in (3,4) then PP_GO_11 = 3; if PP_GO_11 in (6,7) then PP_GO_11 = .; LABEL PP_GO_11 = "Parent agrees with following statement: the child's symptoms come and go";  value DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree";                     </pre>	

## Parental Views and Safety Concerns

Parent gets upset when they think about their child's condition	
<b>Description</b>	Do parents get upset when they think about their child's condition?
<b>Survey Items Used</b>	PP2_F
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree; Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_UPSET_11 = PP2_F; if PP2_F in (3,4) then PP_UPSET_11 = 3; if PP_UPSET_11 in (6,7) then PP_UPSET_11 = .; LABEL PP_UPSET_11 = "Parent agrees with following statement: when they think about their child's condition they get upset";  value DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree"; </pre>	

## Parental Views and Safety Concerns

Condition is genetic or hereditary	
<b>Description</b>	Do parents believe that the child's condition is genetic or hereditary?
<b>Survey Items Used</b>	PP2_G
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree; Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_GEN_11 = PP2_G; if PP2_G in (3,4) then PP_GEN_11 = 3; if PP_GEN_11 in (6,7) then PP_GEN_11 = .; LABEL PP_GEN_11 = "Parent agrees with following statement: the child's condition is genetic or hereditary";  value DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree"; </pre>	

## Parental Views and Safety Concerns

Condition caused by exposure before birth	
<b>Description</b>	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?
<b>Survey Items Used</b>	PP2_H
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree; Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_INUTR_11 = PP2_H; if PP2_H in (3,4) then PP_INUTR_11 = 3; if PP_INUTR_11 in (6,7) then PP_INUTR_11 = .; LABEL 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 were born";  value DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree"; </pre>	

## Parental Views and Safety Concerns

Condition caused by exposure after birth	
<b>Description</b>	Do parents believe that the child's condition was caused by something the child was exposed to after he/she was born?
<b>Survey Items Used</b>	PP2_I
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree: Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_EXPSD_11 = PP2_I; if PP2_I in (3,4) then PP_EXPSD_11 = 3; if PP_EXPSD_11 in (6,7) then PP_EXPSD_11 = .; LABEL 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 DEF_SOMEW 1 = "Definitely Agree" 2 = "Somewhat Agree" 3 = "Definitely/Somewhat Disagree"; </pre>	

## Parental Views and Safety Concerns

Injury affected child's behavior or development	
<b>Description</b>	Has child experienced an accident, injury, or illness that the parent feels has had an effect on the child's behavior or development?
<b>Survey Items Used</b>	PP3
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Definitely agree; Somewhat agree; Definitely/Somewhat disagree
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> PP_INJRY = PP3; IF PP3 = 0 THEN PP_INJRY = 2; IF PP3 GT 2 THEN PP_INJRY = .; LABEL PP_INJRY = "Experienced an accident, injury, or illness that the parent felt had an effect on the child's behavior or development";  value yn 1 = "yes" 2 = "no";                     </pre>	



## Parental Views and Safety Concerns

Wandered or became lost	
<b>Description</b>	Did your child wander off or become lost in the past year?
<b>Survey Items Used</b>	WWP1_A; WWP1_B; WWP1_C; WWP1_D
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child wandered off or became lost; No, child did not wander off or become lost
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> array var_wa {*} WWP1_A WWP1_B WWP1_C WWP1_D; validw = 0; missw = 0; nonew = 0; do i = 1 to dim(var_wa);     if var_wa(i) = 0 then nonew = nonew + 1;     if var_wa(i) = 1 then validw = validw + 1;     if var_wa(i) in (6,7) then missw = missw + 1; end; drop i;  WW_ANY_11 = .; if nonew GE 1 then WW_ANY_11 = 2; if validw GE 1 then WW_ANY_11 = 1; if missw = 4 then WW_ANY_11 = .; label WW_ANY_11 = "Wandered off or became lost in the past year";  value yn 1 = "yes" 2 = "no"; </pre>	

## Parental Views and Safety Concerns

Wandered off or became lost from home	
<b>Description</b>	Did your child wander off or become lost from home in the past year?
<b>Survey Items Used</b>	WWP1_A
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child wandered off or became lost from their home; No, child did not wander off or became lost from their home
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> WW_HOME_11 = WWP1_A; if WWP1_A in (6,7) then WW_HOME_11 = .; if WWP1_A = 0 then WW_HOME_11 = 2; LABEL WW_HOME_11 = "Wandered off or became lost from their home in the past year";  value yn 1 = "yes" 2 = "no";                     </pre>	

## Parental Views and Safety Concerns

Wandered off or became lost from someone else's home	
<b>Description</b>	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?
<b>Survey Items Used</b>	WWP1_B
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, wandered off or became lost; No, child did not wander off or become lost
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> WW_RES_11 = WWP1_B; if WWP1_B in (6,7) then WW_RES_11 = .; if WWP1_B = 0 then WW_RES_11 = 2; LABEL 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";  value yn 1 = "yes" 2 = "no";                     </pre>	

## Parental Views and Safety Concerns

Wandered off or became lost from school, day care, or camp	
<b>Description</b>	Did your child wander off or become lost from school, day care, or summer camp in the past year?
<b>Survey Items Used</b>	WWP1_C
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child wandered off or became lost; No, child did not wander off or become lost
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> WW_SCH_11 = WWP1_C; if WWP1_C in (6,7) then WW_SCH_11 = .; if WWP1_C = 0 then WW_SCH_11 = 2; LABEL WW_SCH_11 = "Wandered off or became lost from school, day care, or summer camp in the past year in the past year";  value yn 1 = "yes" 2 = "no"; </pre>	

## Parental Views and Safety Concerns

Wandered off or became lost from a public place	
<b>Description</b>	Did your child wander off or become lost from a store, restaurant, playground, campsite or any other public place in the past year?
<b>Survey Items Used</b>	WWP1_D
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes, child wandered off or became lost from a public place; No, child did not wander off or become lost from a public place
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> WW_PUBLC_11 = WWP1_D; if WWP1_D in (6,7) then WW_PUBLC_11 = .; if WWP1_D = 0 then WW_PUBLC_11 = 2; LABEL WW_PUBLC_11 = "Wandered off or became lost from a store, restaurant, playground, campsite, or any other public place in the past year";  value yn 1 = "yes" 2 = "no";                     </pre>	

## Parental Views and Safety Concerns

Barriers added to home due to wandering	
<b>Description</b>	Were barriers added to your home to prevent child from wandering off or becoming lost in the past year?
<b>Survey Items Used</b>	WWP2
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes; No
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> WW_BARR_11 = WWP2; if WWP2 in (6,7) then WW_BARR_11 = .; if WWP2 = 0 then WW_BARR_11 = 2; LABEL WW_BARR_11 = "Barriers were added to home to prevent child from wandering off or becoming lost in the past year";  value yn 1 = "yes" 2 = "no"; </pre>	

## Parental Views and Safety Concerns

Tracking device added due to wandering	
<b>Description</b>	Did child wear a tracking device to help find them if they wandered off in the past year?
<b>Survey Items Used</b>	WWP3
<b>Denominator</b>	CSHCN 6-17 years old with current autism spectrum disorder, developmental delay, and/or intellectual disability
<b>Numerator</b>	Yes; No
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> WW_TRACK_11 = WWP3; if WWP3 in (6,7) then WW_TRACK_11 = .; if WWP3 = 0 then WW_TRACK_11 = 2; LABEL WW_TRACK_11 = "Child wore a tracking device to help find them if they wandered off in the past year";  value yn 1 = "yes" 2 = "no";                     </pre>	

## Stratifiers

Age	
<b>Description</b>	Age 2 groups (6-17 years)
<b>Survey Items Used</b>	AGE_P
<b>Denominator</b>	CSHCN ages 6-17 years with current ASD, ID and/or DD
<b>Numerator</b>	6-11 yrs; 12-17 yrs
<b>Notes for Data-Users</b>	
Current age of child in years at the time of Pathways Interview	
<b>SAS Code and Annotation</b>	
<pre>AGE2_11 = .; IF AGE &lt; 12 THEN AGE2_11 = 1; IF AGE GE 12 THEN AGE2_11 = 2; LABEL AGE2_11 = "Current age in 6-11 years or 12-17 years";  value AGE 1 = "6-11 yrs" 2 = "12-17 yrs";</pre>	



## Stratifiers

Sex of child	
<b>Description</b>	Sex of child
<b>Survey Items Used</b>	SEX_P
<b>Denominator</b>	CSHCN ages 6-17 years with current ASD, ID and/or DD
<b>Numerator</b>	Male; Female
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre>SEX_11 = SEX; IF SEX &gt; 2 THEN SEX_11 = .M;  value SEX 1 = "Male" 2 = "Female";</pre>	

## Stratifiers

Race/ethnicity	
<b>Description</b>	Race/ethnicity of child
<b>Survey Items Used</b>	HISPANIC_IMP_Pv3; RACER_IMP_Pv3
<b>Denominator</b>	CSHCN ages 6-17 years with current ASD, ID and/or DD
<b>Numerator</b>	Hispanic; White, Non-Hispanic; Black, non-Hispanic; Other, non-Hispanic
<b>Notes for Data-Users</b>	
<p>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.</p>	
<b>SAS Code and Annotation</b>	
<pre> RACE4_11 = .; IF HISPANIC_imp = 1 THEN RACE4_11 = 1; /*Hispanic*/ IF HISPANIC_imp = 0 AND RACER_imp = 2 THEN RACE4_11 = 2; /*NH-Black*/ IF HISPANIC_imp = 0 AND RACER_imp = 1 THEN RACE4_11 = 3; /*NH_White*/ IF HISPANIC_imp = 0 AND RACER_imp = 3 THEN RACE4_11 = 4; /*NH-Other*/ LABEL RACE4_11 = "Race/Ethnicity (4 categories)";  value RACE 1 = "Hispanic" 2 = "Non-Hispanic Black" 3 = "Non-Hispanic White" 4 = "Non-Hispanic Other"; </pre>	

## Stratifiers

Household income level	
<b>Description</b>	Household income level
<b>Survey Items Used</b>	POVLEVEL_IMP_Pv3
<b>Denominator</b>	CSHCN ages 6-17 years with current ASD, ID and/or DD
<b>Numerator</b>	0-99% FPL; 100-199% FPL; 200-399% FPL, 400% FPL or higher
<b>Notes for Data-Users</b>	
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.	
<b>SAS Code and Annotation</b>	
<pre>POV_I = .; if POVLEVEL_IMP in (1,2) then POV_I = 1; /*&lt;100%FPL*/ if POVLEVEL_IMP in (3,4,5,6) then POV_I = 2; /*100-199%FPL*/ if POVLEVEL_IMP in (7,8) then POV_I = 3; /*200-399%FPL*/ if POVLEVEL_IMP = 9 then POV_I = 4; /*400%/more FPL*/ label POV_I = "Levels of income according to Federal Poverty Level (FPL) guidelines?";  value POV 1 = "&lt;100% FPL" 2 = "100-199% FPL" 3 = "200-399% FPL" 4 = "400% or more FPL";</pre>	

## Stratifiers

Household income level (SCHIP)	
<b>Description</b>	Household income level (SCHIP)
<b>Survey Items Used</b>	POVLEVEL_IMP_Pv3
<b>Denominator</b>	CSHCN ages 6-17 years with current ASD, ID and/or DD
<b>Numerator</b>	0-99% FPL; 100-199% FPL; 200-399% FPL, 400% FPL or higher
<b>Notes for Data-Users</b>	
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.	
<b>SAS Code and Annotation</b>	
<pre>POV_CHIP = .; if POVLEVEL_IMP in (1,2,3,4,5,6) then POV_CHIP = 1; /*&lt;200%FPL*/ if POVLEVEL_IMP = 7 then POV_CHIP = 2; /*200-299%FPL*/ if POVLEVEL_IMP = 8 then POV_CHIP = 3; /*300-399%FPL*/ if POVLEVEL_IMP = 9 then POV_CHIP = 4; /*400%/more FPL*/ label POV_CHIP = "Levels of income according to Federal Poverty Level (FPL) guidelines (CHIP)?";</pre> <pre>value POV_CHIP 1 = "&lt;200% FPL" 2 = "200-299% FPL" 3 = "300-399% FPL" 4 = "400% or more FPL";</pre>	

## Stratifiers

Highest education of adults in household	
<b>Description</b>	Highest education of adult in household
<b>Survey Items Used</b>	EDUCR_IMP_Pv3
<b>Denominator</b>	CSHCN ages 6-17 years with current ASD, ID and/or DD
<b>Numerator</b>	Less than high school or HS graduate; More than high school education
<b>Notes for Data-Users</b>	
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.	
<b>SAS Code and Annotation</b>	
<pre>EDU2_11 = .; IF educr_imp = 3 THEN EDU2_11 = 1; IF educr_imp IN (1,2) THEN EDU2_11 = 2; LABEL EDU2_11 = "Highest parent education in the household (&gt; HS vs. HS or less)";  value educr_i   1 = "Less than high school or HS graduate"   2 = "More than high school";</pre>	

## Stratifiers

Insurance type	
<b>Description</b>	Type of health insurance at time of survey
<b>Survey Items Used</b>	National Survey of Children with Special Health Care Needs (NS-CSHCN) items: TYPEINS
<b>Denominator</b>	CSHCN ages 6-17 years with current ASD, ID and/or DD
<b>Numerator</b>	Private insurance only; public insurance only; Both public & private insurance; Uninsured
<b>Notes for Data-Users</b>	
The 2009/10 NS-CSHCN item	
<b>SAS Code and Annotation</b>	
<pre>instype_09 = TYPEINS; if TYPEINS in (4,.M) then instype_09 = .; if TYPEINS = 5 then instype_09 = 4; label instype_09 = 'Type of Insurance Coverage';  value typeins /*instype_09*/ 1 = 'Private only' 2 = 'Public only' 3 = 'Both Public and Private' 4 = 'Uninsured';</pre>	

**Stratifiers**

Condition groups – 3 categories	
<b>Description</b>	CSHCN who currently have ASD, ID (w/o ASD), DD only, and w/o ASD ID DD
<b>Survey Items Used</b>	DE_AUT11; DE_INT11; DE_DEV11
<b>Denominator</b>	CSHCN ages 6-17 years with current ASD, ID and/or DD
<b>Numerator</b>	CSHCN currently have ASD; CSHCN currently have ID with/without ASD; CSHCN currently have DD only
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> EVER_AUT = .; if DE_AUT11 = .L then EVER_AUT = .L; if DE_AUT12 = 1 or ((CSHCN_K2Q35A=1 and COND_CONFIRM=1) or COND_A=1) then EVER_AUT = 2; /* and DE_AUT11 in (0,6,7,.L)) Ever autism; */ if DE_AUT11 = 1 then EVER_AUT = 1; * Current autism; if DE_AUT11 in (.M,6,7) then EVER_AUT = .; LABEL EVER_AUT = 'CSHCN who currently or ever were told that child had Autism/ASD';  EVER_INT = .; if DE_INT11 = .L then EVER_INT = .L; if DE_INT12 = 1 or ((CSHCN_K2Q37A=1 and COND_Confirm=1) or COND_C=1) then EVER_INT = 2; /* Ever intellectual disability; if DE_INT11=1 then EVER_INT = 1; * Current intellectual disability; if DE_INT11 in (.M,6,7) then EVER_INT = .; LABEL EVER_INT = 'CSHCN who currently or ever were told that child had Intellectual Disability';  EVER_DEV = .; if DE_DEV11 = .L then EVER_DEV = .L; if DE_DEV12 = 1 or ((cshcn_k2q36a=1 and COND_confirm=1) or COND_B=1) then EVER_DEV = 2; /* Ever developmental delay; if DE_DEV11=1 then EVER_DEV = 1; /* Current developmental delay; if DE_DEV11 in (.M,6,7) then EVER_DEV = .; LABEL EVER_DEV = 'CSHCN who currently or ever were told that child had Developmental Delay';  DX_AUT_11 = .; if DE_AUT11 in (0,.L) then DX_AUT_11 = 2; if DE_AUT11 = 1 then DX_AUT_11 = 1; label DX_AUT_11 = "CSHCN currently has Autism/ASD";  DX_DEV_11 = .; </pre>	

### Stratifiers

```
if DE_DEV11 in (0,.L) then DX_DEV_11 = 2;
if DE_DEV11 = 1 then DX_DEV_11 = 1;
label DX_DEV_11 = "CSHCN currently has a developmental delay";

DX_INT_11 = .;
if DE_INT11 in (0,.L) then DX_INT_11 = 2;
if DE_INT11 = 1 then DX_INT_11 = 1;
label DX_INT_11 = "CSHCN currently has an intellectual disability";

DX_GRP3_11 = .;
if DX_DEV_11 = 1 then DX_GRP3_11 = 3; /*CSHCN has DD only*/
if DX_AUT_11 = 1 then DX_GRP3_11 = 1; /*CSHCN has ASD*/
if DX_AUT_11 ne 1 and DX_INT_11 = 1 then DX_GRP3_11 = 2; /*CSHCN has ID w/o ASD*/
if DX_GRP3_11 = . then DX_GRP3_11 = 4; /*MISSING*/
label DX_GRP3_11 = "CSHCN who currently have ASD, ID (w/o ASD), DD only, and w/o ASD ID DD";

value DX3_GRPS
1 = "Any ASD"
2 = "ID w/o ASD"
3 = "DD only"
4 = "None";
```



**Stratifiers**

Condition groups – 2 categories	
<b>Description</b>	CSHCN who currently have Autism Spectrum Disorder without Intellectual Disability and/or Developmental Delay
<b>Survey Items Used</b>	DE_AUT11; DE_INT11; DE_DEV11
<b>Denominator</b>	CSHCN ages 6-17 years with current ASD, ID and/or DD
<b>Numerator</b>	CSHCN currently have ASD; CSHCN currently have DD and/or ID
<b>Notes for Data-Users</b>	
N/A	
<b>SAS Code and Annotation</b>	
<pre> EVER_AUT = .; if DE_AUT11 = .L then EVER_AUT = .L; if DE_AUT12 = 1 or ((CSHCN_K2Q35A=1 and COND_CONFIRM=1) or COND_A=1) then EVER_AUT = 2; /* and DE_AUT11 in (0,6,7,.L)) Ever autism; */ if DE_AUT11 = 1 then EVER_AUT = 1; * Current autism; if DE_AUT11 in (.M,6,7) then EVER_AUT = .; LABEL EVER_AUT = 'CSHCN who currently or ever were told that child had Autism/ASD';  EVER_INT = .; if DE_INT11 = .L then EVER_INT = .L; if DE_INT12 = 1 or ((CSHCN_K2Q37A=1 and COND_Confirm=1) or COND_C=1) then EVER_INT = 2; * Ever intellectual disability; if DE_INT11=1 then EVER_INT = 1; * Current intellectual disability; if DE_INT11 in (.M,6,7) then EVER_INT = .; LABEL EVER_INT = 'CSHCN who currently or ever were told that child had Intellectual Disability';  EVER_DEV = .; if DE_DEV11 = .L then EVER_DEV = .L; if DE_DEV12 = 1 or ((cshcn_k2q36a=1 and COND_confirm=1) or COND_B=1) then EVER_DEV = 2; * Ever developmental delay; if DE_DEV11=1 then EVER_DEV = 1; * Current developmental delay; if DE_DEV11 in (.M,6,7) then EVER_DEV = .; LABEL EVER_DEV = 'CSHCN who currently or ever were told that child had Developmental Delay';  DX_AUT_11 = .; if DE_AUT11 in (0,.L) then DX_AUT_11 = 2; if DE_AUT11 = 1 then DX_AUT_11 = 1; label DX_AUT_11 = "CSHCN currently has Autism/ASD";  DX_DEV_11 = .; </pre>	

### Stratifiers

```
if DE_DEV11 in (0,.L) then DX_DEV_11 = 2;
if DE_DEV11 = 1 then DX_DEV_11 = 1;
label DX_DEV_11 = "CSHCN currently has a developmental delay";

DX_INT_11 = .;
if DE_INT11 in (0,.L) then DX_INT_11 = 2;
if DE_INT11 = 1 then DX_INT_11 = 1;
label DX_INT_11 = "CSHCN currently has an intellectual disability";

DX_GRP2_11 = .;
if DX_DEV_11 = 1 or DX_INT_11 = 1 then DX_GRP2_11 = 2; /*CSHCN has DD or ID*/
if DX_AUT_11 = 1 then DX_GRP2_11 = 1; /*CSHCN has ASD*/
if DX_GRP2_11 = . then DX_GRP2_11 = 3; /*MISSING*/
label DX_GRP2_11 = "CSHCN who currently have ASD, ID and/or DD (w/o ASD),and w/o ASD ID DD";

value DX2_GRPS
1 = "Any ASD"
2 = "ID and/or DD"
3 = "None";
```



## Appendix A:

### Unweighted Frequency Tables for Codebook Variables

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**Developmental Concern****Age when parents were first concerned about their development**

	<b>PC_AGE_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
	.	20	0.50	20	0.50
	L	87	2.16	107	2.65
<b>Condition/concern at or before birth</b>		547	13.57	654	16.22
	<b>1 - 23 months</b>	1128	27.98	1782	44.20
	<b>24 - 47 months</b>	1092	27.08	2874	71.28
	<b>48+ months</b>	1158	28.72	4032	100.00

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

	<b>PC_COUNT_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
	L	642	15.92	642	15.92
	<b>0-1 concerns</b>	359	8.90	1001	24.83
	<b>2-3 concerns</b>	1106	27.43	2107	52.26
	<b>4 or more concerns</b>	1925	47.74	4032	100.00

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

	<b>PC_VRBL_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
	.	7	0.17	7	0.17
	L	1043	25.87	1050	26.04
	<b>yes</b>	1998	49.55	3048	75.60
	<b>no</b>	984	24.40	4032	100.00

**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)**

	<b>PC_BEH_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
	.	5	0.12	5	0.12
	L	654	16.22	659	16.34
	<b>yes</b>	2657	65.90	3316	82.24
	<b>no</b>	716	17.76	4032	100.00

**Appendix A: Unweighted Frequency Tables**

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

<b>PC_MOTOR_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	9	0.22	9	0.22
L	654	16.22	663	16.44
<b>yes</b>	2013	49.93	2676	66.37
<b>no</b>	1356	33.63	4032	100.00

**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)**

<b>PC_NONVR_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	7	0.17	7	0.17
L	654	16.22	661	16.39
<b>yes</b>	2181	54.09	2842	70.49
<b>no</b>	1190	29.51	4032	100.00

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

<b>PC_LEARN_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	4	0.10	4	0.10
L	1117	27.70	1121	27.80
<b>yes</b>	2180	54.07	3301	81.87
<b>no</b>	731	18.13	4032	100.00

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

<b>PC_GEST_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	3	0.07	3	0.07
L	1355	33.61	1358	33.68
<b>yes</b>	905	22.45	2263	56.13
<b>no</b>	1769	43.87	4032	100.00

**Appendix A: Unweighted Frequency Tables**

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

<b>PC_MED_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	1	0.02	1	0.02
L	654	16.22	655	16.25
<b>yes</b>	802	19.89	1457	36.14
<b>no</b>	2575	63.86	4032	100.00

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

	<b>TALK_1ST_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
	.	38	0.94	38	0.94
	L	634	15.72	672	16.67
	<b>Parent</b>	2448	60.71	3120	77.38
	<b>Health Care Professional</b>	154	3.82	3274	81.20
	<b>Teacher, Councilor, or Nurse at school</b>	307	7.61	3581	88.81
	<b>Other</b>	451	11.19	4032	100.00

**Child's age when parent talked to a dr/health care provider about their concern**

	<b>TALK_AGE_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
	.	15	0.37	15	0.37
	L	324	8.04	339	8.41
	<b>Before birth - 11 months</b>	993	24.63	1332	33.04
	<b>12 - 23 months</b>	525	13.02	1857	46.06
	<b>24 - 47 months</b>	979	24.28	2836	70.34
	<b>48+ months</b>	1196	29.66	4032	100.00

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

	<b>TALK_DR_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
	.	4	0.10	4	0.10
	L	12	0.30	16	0.40
	<b>yes</b>	3708	91.96	3724	92.36
	<b>no</b>	308	7.64	4032	100.00

**Appendix A: Unweighted Frequency Tables**

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

<b>DR_TEST_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	16	0.40	16	0.40
L	324	8.04	340	8.43
M	1	0.02	341	8.46
yes	1931	47.89	2272	56.35
no	1760	43.65	4032	100.00

**Doctor or health care provider made a referral to a specialist when parent had a developmental concern**

<b>DR_REFERER_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	16	0.40	16	0.40
L	324	8.04	340	8.43
M	1	0.02	341	8.46
yes	2267	56.23	2608	64.68
no	1424	35.32	4032	100.00

**Doctor or health care provider suggested that parent talk with the school when parent had a developmental concern**

<b>DR_SCH_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	16	0.40	16	0.40
L	324	8.04	340	8.43
M	1	0.02	341	8.46
yes	1437	35.64	1778	44.10
no	2254	55.90	4032	100.00

**Doctor or health care provider said 'nothing was wrong' or 'behavior was normal' when parent had a developmental concern**

<b>DR_NORM_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	16	0.40	16	0.40
L	324	8.04	340	8.43
M	1	0.02	341	8.46
yes	879	21.80	1220	30.26
no	2812	69.74	4032	100.00

**Appendix A: Unweighted Frequency Tables**

**Doctor or health care provider said 'it's too early to tell' when parent had a developmental concern**

<b>DR_EARLY_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	16	0.40	16	0.40
L	324	8.04	340	8.43
M	1	0.02	341	8.46
yes	1335	33.11	1676	41.57
no	2356	58.43	4032	100.00

**Doctor or health care provider said the child might 'grow out of it' when parent had a developmental concern**

<b>DR_GROW_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	16	0.40	16	0.40
L	324	8.04	340	8.43
M	1	0.02	341	8.46
yes	1584	39.29	1925	47.74
no	2107	52.26	4032	100.00

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

<b>TALK_SCH_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	3	0.07	3	0.07
L	12	0.30	15	0.37
yes	3727	92.44	3742	92.81
no	290	7.19	4032	100.00

**Developmental screening or assessment completed by parent/health provider or none completed**

<b>PC_SCR_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	14	0.35	14	0.35
<b>Completed Screening</b>	2029	50.32	2043	50.67
<b>No Screening</b>	1047	25.97	3090	76.64
<b>Didn't talk to DR/provider</b>	942	23.36	4032	100.00



## Appendix A: Unweighted Frequency Tables

### Physician completed screener/assessment

SCR_DR_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	39	0.97	39	0.97
L	942	23.36	981	24.33
yes	1920	47.62	2901	71.95
no	1131	28.05	4032	100.00

### Parent completed screener/assessment

SCR_P_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	223	5.53	223	5.53
L	942	23.36	1165	28.89
yes	1042	25.84	2207	54.74
no	1825	45.26	4032	100.00

## Diagnostic Experiences

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

ANY_AGE_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	18	0.45	18	0.45
L	77	1.91	95	2.36
0-2 years	1340	33.23	1435	35.59
3-5 years	1320	32.74	2755	68.33
6+ years	1277	31.67	4032	100.00

**Among CSHCN w/Autism, was ever told child had Asperger's, Pervasive Development Disorder, Autistic Disorder, or multiple diagnoses**

DX_AUTYP_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	186	4.61	186	4.61
L	2391	59.30	2577	63.91
Asperger's Disorder	317	7.86	2894	71.78
Pervasive Developmental Disorder	209	5.18	3103	76.96
Autistic Disorder	277	6.87	3380	83.83
Multiple Diagnosis	652	16.17	4032	100.00

Appendix A: Unweighted Frequency Tables

Among CSHCN w/Autism, parent was ever told child had Asperger's

ASPERGER_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	11	0.27	11	0.27
L	2391	59.30	2402	59.57
M	1	0.02	2403	59.60
yes	728	18.06	3131	77.65
no	901	22.35	4032	100.00

Among CSHCN w/Autism, parent was ever told child had Pervasive Development Disorder

PDD_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	56	1.39	56	1.39
L	2391	59.30	2447	60.69
M	1	0.02	2448	60.71
yes	729	18.08	3177	78.79
no	855	21.21	4032	100.00

Among CSHCN w/Autism, parent was ever told child had Autistic Disorder

AUTDISRD_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	34	0.84	34	0.84
L	2391	59.30	2425	60.14
M	1	0.02	2426	60.17
yes	801	19.87	3227	80.03
no	805	19.97	4032	100.00

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

AUT_AGE_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	17	0.42	17	0.42
L	2383	59.10	2400	59.52
0-2 years	280	6.94	2680	66.47
3-5 years	651	16.15	3331	82.61
6+ years	701	17.39	4032	100.00

**Appendix A: Unweighted Frequency Tables**

**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**

<b>NO_AUT_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	5	0.12	5	0.12
L	2391	59.30	2396	59.42
yes	302	7.49	2698	66.91
no	1334	33.09	4032	100.00

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

<b>DRDX_AUT_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	110	2.73	110	2.73
L	2292	56.85	2402	59.57
<b>Pediatrician or Pediatric/Family HCP</b>	253	6.27	2655	65.85
<b>Psychologist</b>	416	10.32	3071	76.17
<b>Specialist Dr</b>	668	16.57	3739	92.73
<b>Multidisciplinary Team/Other</b>	293	7.27	4032	100.00

**Age when parent was first told by Dr that child had Developmental Delay (ever and current diagnosis)**

<b>DEV_AGE_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	23	0.57	23	0.57
L	636	15.77	659	16.34
<b>0-2 years</b>	1252	31.05	1911	47.40
<b>3-5 years</b>	1142	28.32	3053	75.72
<b>6+ years</b>	979	24.28	4032	100.00

**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**

<b>NO_DEV_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	12	0.30	12	0.30
L	639	15.85	651	16.15
yes	312	7.74	963	23.88
no	3069	76.12	4032	100.00

**Appendix A: Unweighted Frequency Tables**

**Health care provider who first gave Developmental Delay diagnosis (ever & current diagnosis)**

<b>DRDX_DEV_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	148	3.67	148	3.67
L	550	13.64	698	17.31
<b>Pediatrician or Pediatric/Family HCP</b>	1263	31.32	1961	48.64
<b>Psychologist</b>	565	14.01	2526	62.65
<b>Specialist Dr</b>	1003	24.88	3529	87.52
<b>Multidisciplinary Team/Other</b>	503	12.48	4032	100.00

**Age when parent was first told by Dr that child had Intellectual Disability (ever and current diagnosis)**

<b>INT_AGE_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	24	0.60	24	0.60
L	3008	74.60	3032	75.20
<b>0-2 years</b>	398	9.87	3430	85.07
<b>3-5 years</b>	332	8.23	3762	93.30
<b>6+ years</b>	270	6.70	4032	100.00

**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**

<b>NO_INT_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	3	0.07	3	0.07
L	3018	74.85	3021	74.93
<b>yes</b>	58	1.44	3079	76.36
<b>no</b>	953	23.64	4032	100.00

**Health care provider who first gave Intellectual Disability diagnosis (ever & current diagnosis)**

<b>DRDX_INT_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	76	1.88	76	1.88
L	2963	73.49	3039	75.37
<b>Pediatrician or Pediatric/Family HCP</b>	278	6.89	3317	82.27
<b>Psychologist</b>	203	5.03	3520	87.30
<b>Specialist Dr</b>	375	9.30	3895	96.60
<b>Multidisciplinary Team/Other</b>	137	3.40	4032	100.00

**Health and Education Services****Currently use 3 or more of 7 types of health care services to meet their developmental needs**

<b>HCS_COUNT_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>None</b>	1103	27.36	1103	27.36
<b>One</b>	765	18.97	1868	46.33
<b>Two</b>	690	17.11	2558	63.44
<b>Three or more</b>	1474	36.56	4032	100.00

**Currently use behavioral intervention or modification services on a regular basis**

<b>HCS_BI_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	95	2.36	95	2.36
<b>yes</b>	1062	26.34	1157	28.70
<b>no</b>	2875	71.30	4032	100.00

**Currently use sensory integration therapy  
on a regular basis**

<b>HCS_SI_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	185	4.59	185	4.59
<b>yes</b>	506	12.55	691	17.14
<b>no</b>	3341	82.86	4032	100.00

**Currently use cognitive based therapy  
on a regular basis**

<b>HCS_CT_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	365	9.05	365	9.05
<b>yes</b>	810	20.09	1175	29.14
<b>no</b>	2857	70.86	4032	100.00

**Appendix A: Unweighted Frequency Tables**

**Currently use occupational therapy on a regular basis**

HCS_OT_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	82	2.03	82	2.03
<b>yes</b>	1544	38.29	1626	40.33
<b>no</b>	2406	59.67	4032	100.00

**Currently use physical therapy on a regular basis**

HCS_PT_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	43	1.07	43	1.07
<b>yes</b>	768	19.05	811	20.11
<b>no</b>	3221	79.89	4032	100.00

**Currently use social skills training on a regular basis**

HCS_ST_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	80	1.98	80	1.98
<b>yes</b>	1689	41.89	1769	43.87
<b>no</b>	2263	56.13	4032	100.00

**Currently use speech or language therapy on a regular basis**

HCS_LT_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	18	0.45	18	0.45
<b>yes</b>	1787	44.32	1805	44.77
<b>no</b>	2227	55.23	4032	100.00

**Currently see two or more out of 8 types of providers of health and related services to meet their developmental needs**

Dr_COUNT_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
<b>None</b>	1819	45.11	1819	45.11
<b>One</b>	1158	28.72	2977	73.83
<b>Two or more</b>	1055	26.17	4032	100.00

## Appendix A: Unweighted Frequency Tables

### Currently work with an audiologist

AUDIOLOG_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	54	1.34	54	1.34
yes	214	5.31	268	6.65
no	3764	93.35	4032	100.00

### Currently work with a developmental practitioner

DEVPED_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	36	0.89	36	0.89
yes	423	10.49	459	11.38
no	3573	88.62	4032	100.00

### Currently work with a neurologist

NEUROLOG_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	29	0.72	29	0.72
yes	510	12.65	539	13.37
no	3493	86.63	4032	100.00

### Currently work with a nutritionist

NUTRITN_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	13	0.32	13	0.32
yes	215	5.33	228	5.65
no	3804	94.35	4032	100.00

### Currently work with an at home/long-term nurse

NURSE_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	3	0.07	3	0.07
yes	65	1.61	68	1.69
no	3964	98.31	4032	100.00

## Appendix A: Unweighted Frequency Tables

### Currently work with a psychiatrist

PSYCHIAT_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	21	0.52	21	0.52
yes	956	23.71	977	24.23
no	3055	75.77	4032	100.00

### Currently work with a psychologist/psychotherapist

PSYCHLOG_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	45	1.12	45	1.12
yes	870	21.58	915	22.69
no	3117	77.31	4032	100.00

### Currently work with a social worker

SOCWORK_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	23	0.57	23	0.57
yes	593	14.71	616	15.28
no	3416	84.72	4032	100.00

### Currently uses none, one, AND two/more types of medications to meet their developmental needs

Rxcount_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
None	2059	51.07	2059	51.07
One	1051	26.07	3110	77.13
Two or more	922	22.87	4032	100.00

### Current stimulant Rx use

rx_stmlnt_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	37	0.92	37	0.92
yes	1182	29.32	1219	30.23
no	2813	69.77	4032	100.00



Appendix A: Unweighted Frequency Tables

Current anti-depressant Rx use

rx_dprss_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	20	0.50	20	0.50
yes	563	13.96	583	14.46
no	3449	85.54	4032	100.00

Current anti-anxiety/mood Rx use

rx_anxiet_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	25	0.62	25	0.62
yes	655	16.25	680	16.87
no	3352	83.13	4032	100.00

Current anti-seizure Rx use

rx_seiz_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	9	0.22	9	0.22
yes	335	8.31	344	8.53
no	3688	91.47	4032	100.00

Current anti-psychotic Rx use

rx_psych_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	30	0.74	30	0.74
yes	314	7.79	344	8.53
no	3688	91.47	4032	100.00

Appendix A: Unweighted Frequency Tables

Current sleep Rx use

rx_sleep_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	47	1.17	47	1.17
yes	530	13.14	577	14.31
no	3455	85.69	4032	100.00

Type of schools currently enrolled in

ES_SCH	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	8	0.20	8	0.20
L	14	0.35	22	0.55
Public	3460	85.81	3482	86.36
Private	377	9.35	3859	95.71
Home-schooled	173	4.29	4032	100.00

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

ES_IEP	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	17	0.42	17	0.42
L	195	4.84	212	5.26
With an IEP	3028	75.10	3240	80.36
Without an IEP	792	19.64	4032	100.00

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

ES_IEPND	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	6	0.15	6	0.15
L	1004	24.90	1010	25.05
yes	2575	63.86	3585	88.91
no	447	11.09	4032	100.00

## Appendix A: Unweighted Frequency Tables

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

ES_EIS	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	108	2.68	108	2.68
L	195	4.84	303	7.51
Had an EIS	1419	35.19	1722	42.71
Never had an EIS	2310	57.29	4032	100.00

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

ES_EISNE	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	43	1.07	43	1.07
L	195	4.84	238	5.90
yes	296	7.34	534	13.24
no	3498	86.76	4032	100.00

### Unmet Needs and Insurance Adequacy

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

IN_UNMET_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	40	0.99	40	0.99
yes	1053	26.12	1093	27.11
no	2939	72.89	4032	100.00

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

IN_SERV_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	39	0.97	39	0.97
P	1	0.02	40	0.99
yes	3053	75.72	3093	76.71
no	939	23.29	4032	100.00

**Appendix A: Unweighted Frequency Tables**

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

<b>IN_PROV_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	32	0.79	32	0.79
<b>P</b>	3	0.07	35	0.87
<b>yes</b>	3257	80.78	3292	81.65
<b>no</b>	740	18.35	4032	100.00

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

<b>IN_INS_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	3	0.07	3	0.07
<b>P</b>	3	0.07	6	0.15
<b>yes</b>	3877	96.16	3883	96.30
<b>no</b>	149	3.70	4032	100.00

**INDICATOR 5: Adequacy of Current Insurance Coverage: Currently insured CSHCN whose insurance coverage is not adequate (from the 2009/2010 NS-CSHCN)**

	<b>indic5_09</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
	.	39	0.97	39	0.97
	<b>L</b>	122	3.03	161	3.99
<b>Current insurance is NOT adequate</b>		1607	39.86	1768	43.85
<b>Current insurance IS adequate</b>		2264	56.15	4032	100.00

**Health insurance benefits meet child needs (from the 2009/2010 NS-CSHCN)**

	<b>metneeds_09</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
	<b>M</b>	16	0.40	16	0.40
<b>Never/sometimes</b>		753	18.68	769	19.07
<b>Usually/always</b>		3141	77.90	3910	96.97
<b>Uninsured</b>		122	3.03	4032	100.00

**Appendix A: Unweighted Frequency Tables**

**Non-covered insurance charges reasonable (from the 2009/2010 NS-CSHCN)**

<b>reasonable_09</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>M</b>	29	0.72	29	0.72
<b>Never/sometimes</b>	1364	33.83	1393	34.55
<b>Usually/always</b>	2517	62.43	3910	96.97
<b>Uninsured</b>	122	3.03	4032	100.00

**Insurance allows child to see needed providers (from the 2009/2010 NS-CSHCN)**

<b>providers_09</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>M</b>	6	0.15	6	0.15
<b>Never/sometimes</b>	592	14.68	598	14.83
<b>Usually/always</b>	3312	82.14	3910	96.97
<b>Uninsured</b>	122	3.03	4032	100.00

**Health insurance DID NOT cover all the treatments, services, or service providers needed to care for child's developmental needs**

<b>IN_COVER_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>.</b>	104	2.58	104	2.58
<b>L</b>	152	3.77	256	6.35
<b>P</b>	3	0.07	259	6.42
<b>yes</b>	1065	26.41	1324	32.84
<b>no</b>	2708	67.16	4032	100.00

**Among those who have health insurance, any speech/language therapy not covered by health insurance**

<b>IN_SPCH_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>.</b>	20	0.50	20	0.50
<b>L</b>	256	6.35	276	6.85
<b>M</b>	1	0.02	277	6.87
<b>P</b>	3	0.07	280	6.94
<b>yes</b>	145	3.60	425	10.54
<b>no</b>	3607	89.46	4032	100.00

## Appendix A: Unweighted Frequency Tables

**Among those who have health insurance, any occupational therapy not covered by health insurance**

IN_OCCUP_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	20	0.50	20	0.50
L	256	6.35	276	6.85
M	1	0.02	277	6.87
P	3	0.07	280	6.94
<b>yes</b>	109	2.70	389	9.65
<b>no</b>	3643	90.35	4032	100.00

**Among those who have health insurance, any behavioral management services not covered by health insurance**

IN_BEH_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	20	0.50	20	0.50
L	256	6.35	276	6.85
M	1	0.02	277	6.87
P	3	0.07	280	6.94
<b>yes</b>	109	2.70	389	9.65
<b>no</b>	3643	90.35	4032	100.00

**Among those who have health insurance, any psychological services not covered by health insurance**

IN_PSYCH_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	20	0.50	20	0.50
L	256	6.35	276	6.85
M	1	0.02	277	6.87
P	3	0.07	280	6.94
<b>yes</b>	185	4.59	465	11.53
<b>no</b>	3567	88.47	4032	100.00

## Appendix A: Unweighted Frequency Tables

**Among those who have health insurance, any alternative medicine/therapies not covered by health insurance**

IN_ALT_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	20	0.50	20	0.50
L	256	6.35	276	6.85
M	1	0.02	277	6.87
P	3	0.07	280	6.94
yes	144	3.57	424	10.52
no	3608	89.48	4032	100.00

### Functioning, Strengths and Difficulties

**Scoring results of brief Strengths and Difficulties Questionnaire (5 items)**

SDQ_CATI_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	63	1.56	63	1.56
High score: 6-10	1202	29.81	1265	31.37
Medium score: 3-5	1844	45.73	3109	77.11
Low score: 0-2	923	22.89	4032	100.00

**Child was generally well behaved and usually do what adults request during the past six months**

SDQ_BEH	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	11	0.27	11	0.27
P	6	0.15	17	0.42
Not true	366	9.08	383	9.50
Somewhat true	1763	43.73	2146	53.22
Certainly true	1886	46.78	4032	100.00

**Child had many worries, or often seems worried during the past six months**

SDQ_WRRY	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	14	0.35	14	0.35
P	7	0.17	21	0.52
Not true	1332	33.04	1353	33.56
Somewhat true	1638	40.63	2991	74.18
Certainly true	1041	25.82	4032	100.00

## Appendix A: Unweighted Frequency Tables

### Child was often unhappy, depressed, or tearful during the past six months

SDQ_DEP	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	8	0.20	8	0.20
P	7	0.17	15	0.37
Not true	2328	57.74	2343	58.11
Somewhat true	1348	33.43	3691	91.54
Certainly true	341	8.46	4032	100.00

### Child got along better with adults than with other children or youth during the past six months

SDQ_ADLT	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	29	0.72	29	0.72
P	8	0.20	37	0.92
Not true	1527	37.87	1564	38.79
Somewhat true	1337	33.16	2901	71.95
Certainly true	1131	28.05	4032	100.00

### Child had a good attention span, sees chores or homework through to the end during the past six months

SDQ_ATTEN	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	11	0.27	11	0.27
P	8	0.20	19	0.47
Not true	1919	47.59	1938	48.07
Somewhat true	1556	38.59	3494	86.66
Certainly true	538	13.34	4032	100.00

## Parental Views and Safety Concerns

### Parent agrees with following statement: the teachers and other professionals at the child's school are able to meet their needs

PP_TCHN_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	13	0.32	13	0.32
P	8	0.20	21	0.52
Definitely Agree	1777	44.07	1798	44.59
Somewhat Agree	1634	40.53	3432	85.12
Definitely/Somewhat Disagree	600	14.88	4032	100.00



**Appendix A: Unweighted Frequency Tables**

**Parent agrees with following statement: they are satisfied with the services that their child receives from teachers and other school professionals**

<b>PP_TCHS_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	15	0.37	15	0.37
<b>P</b>	8	0.20	23	0.57
<b>Definitely Agree</b>	1764	43.75	1787	44.32
<b>Somewhat Agree</b>	1516	37.60	3303	81.92
<b>Definitely/Somewhat Disagree</b>	729	18.08	4032	100.00

**Parent agrees with following statement: the doctors and other health care providers that child sees are able to meet their needs**

<b>PP_DRN_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	6	0.15	6	0.15
<b>P</b>	8	0.20	14	0.35
<b>Definitely Agree</b>	2364	58.63	2378	58.98
<b>Somewhat Agree</b>	1308	32.44	3686	91.42
<b>Definitely/Somewhat Disagree</b>	346	8.58	4032	100.00

**Parent agrees with following statement: they are satisfied with the services that their child receives from doctors and other health care providers**

<b>PP_DRS_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	5	0.12	5	0.12
<b>P</b>	8	0.20	13	0.32
<b>Definitely Agree</b>	2472	61.31	2485	61.63
<b>Somewhat Agree</b>	1201	29.79	3686	91.42
<b>Definitely/Somewhat Disagree</b>	346	8.58	4032	100.00

<b>PP_LIFE_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	23	0.57	23	0.57
<b>P</b>	8	0.20	31	0.77
<b>Definitely Agree</b>	2630	65.23	2661	66.00
<b>Somewhat Agree</b>	920	22.82	3581	88.81
<b>Definitely/Somewhat Disagree</b>	451	11.19	4032	100.00

## Appendix A: Unweighted Frequency Tables

**Parent agrees with following statement: the problems related to their child's condition can be prevented or decreased with treatment**

PP_PREV_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	54	1.34	54	1.34
P	8	0.20	62	1.54
<b>Definitely Agree</b>	1375	34.10	1437	35.64
<b>Somewhat Agree</b>	1574	39.04	3011	74.68
<b>Definitely/Somewhat Disagree</b>	1021	25.32	4032	100.00

**Parent agrees with following statement: they have the power to change their child's condition**

PP_CHNGE_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	43	1.07	43	1.07
P	8	0.20	51	1.26
<b>Definitely Agree</b>	422	10.47	473	11.73
<b>Somewhat Agree</b>	1163	28.84	1636	40.58
<b>Definitely/Somewhat Disagree</b>	2396	59.42	4032	100.00

**Parent agrees with following statement: condition is a mystery to them**

PP_MYST_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	23	0.57	23	0.57
P	8	0.20	31	0.77
<b>Definitely Agree</b>	573	14.21	604	14.98
<b>Somewhat Agree</b>	882	21.88	1486	36.86
<b>Definitely/Somewhat Disagree</b>	2546	63.14	4032	100.00

**Parent agrees with following statement: the child's symptoms come and go**

PP_GO_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	16	0.40	16	0.40
P	8	0.20	24	0.60
<b>Definitely Agree</b>	416	10.32	440	10.91
<b>Somewhat Agree</b>	773	19.17	1213	30.08
<b>Definitely/Somewhat Disagree</b>	2819	69.92	4032	100.00

**Appendix A: Unweighted Frequency Tables**

**Parent agrees with following statement: when they think about their child's condition they get upset**

<b>PP_UPSET_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	9	0.22	9	0.22
<b>P</b>	8	0.20	17	0.42
<b>Definitely Agree</b>	950	23.56	967	23.98
<b>Somewhat Agree</b>	1214	30.11	2181	54.09
<b>Definitely/Somewhat Disagree</b>	1851	45.91	4032	100.00

**Parent agrees with following statement: the child's condition is genetic or hereditary**

<b>PP_GEN_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	195	4.84	195	4.84
<b>P</b>	8	0.20	203	5.03
<b>Definitely Agree</b>	1444	35.81	1647	40.85
<b>Somewhat Agree</b>	1177	29.19	2824	70.04
<b>Definitely/Somewhat Disagree</b>	1208	29.96	4032	100.00

**Parent agrees with following statement: the child's condition was caused by something the child was exposed to in utero, that is, before they were born**

<b>PP_INUTR_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	280	6.94	280	6.94
<b>P</b>	8	0.20	288	7.14
<b>Definitely Agree</b>	568	14.09	856	21.23
<b>Somewhat Agree</b>	708	17.56	1564	38.79
<b>Definitely/Somewhat Disagree</b>	2468	61.21	4032	100.00

**Parent agrees with following statement: the child's condition was caused by something the child was exposed to after they was born**

<b>PP_EXPSD_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	181	4.49	181	4.49
<b>P</b>	8	0.20	189	4.69
<b>Definitely Agree</b>	483	11.98	672	16.67
<b>Somewhat Agree</b>	612	15.18	1284	31.85
<b>Definitely/Somewhat Disagree</b>	2748	68.15	4032	100.00

**Appendix A: Unweighted Frequency Tables**

**Experienced an accident, injury, or illness that the parent felt had an effect on the child's behavior or development**

<b>PP_INJRY</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	36	0.89	36	0.89
<b>P</b>	8	0.20	44	1.09
<b>yes</b>	783	19.42	827	20.51
<b>no</b>	3205	79.49	4032	100.00

**Wandered off or became lost in the past year**

<b>WW_ANY_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	11	0.27	11	0.27
<b>yes</b>	857	21.25	868	21.53
<b>no</b>	3164	78.47	4032	100.00

**Wandered off or became lost from their home in the past year**

<b>WW_HOME_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	3	0.07	3	0.07
<b>P</b>	8	0.20	11	0.27
<b>yes</b>	293	7.27	304	7.54
<b>no</b>	3728	92.46	4032	100.00

**Wandered off or became lost from someone else's home such as a relative, friend, neighbor, or babysitter in the past year**

<b>WW_RES_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	6	0.15	6	0.15
<b>P</b>	8	0.20	14	0.35
<b>yes</b>	140	3.47	154	3.82
<b>no</b>	3878	96.18	4032	100.00

**Appendix A: Unweighted Frequency Tables**

**Wandered off or became lost from school, day care, or summer camp in the past year in the past year**

<b>WW_SCH_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	5	0.12	5	0.12
<b>P</b>	8	0.20	13	0.32
<b>yes</b>	227	5.63	240	5.95
<b>no</b>	3792	94.05	4032	100.00

**Wandered off or became lost from a store, restaurant, playground, campsite, or any other public place in the past year**

<b>WW_PUBLC_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	4	0.10	4	0.10
<b>P</b>	8	0.20	12	0.30
<b>yes</b>	579	14.36	591	14.66
<b>no</b>	3441	85.34	4032	100.00

**Barriers were added to home to prevent child from wandering off or becoming lost in the past year**

<b>WW_BARR_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	3	0.07	3	0.07
<b>P</b>	8	0.20	11	0.27
<b>yes</b>	743	18.43	754	18.70
<b>no</b>	3278	81.30	4032	100.00

**Child wore a tracking device to help find them if they wandered off in the past year**

<b>WW_TRACK_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	3	0.07	3	0.07
<b>P</b>	8	0.20	11	0.27
<b>yes</b>	83	2.06	94	2.33
<b>no</b>	3938	97.67	4032	100.00

Appendix A: Unweighted Frequency Tables

**Stratifiers**

**Current age in 6-11 years or 12-17 years**

<b>AGE2_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>6-11 yrs</b>	1953	48.44	1953	48.44
<b>12-17 yrs</b>	2079	51.56	4032	100.00

<b>SEX_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>M</b>	3	0.07	3	0.07
<b>Male</b>	2780	68.95	2783	69.02
<b>Female</b>	1249	30.98	4032	100.00

**Race/Ethnicity (4 categories)**

<b>RACE4_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>Hispanic</b>	358	8.88	358	8.88
<b>Non-Hispanic Black</b>	346	8.58	704	17.46
<b>Non-Hispanic White</b>	2914	72.27	3618	89.73
<b>Non-Hispanic Other</b>	414	10.27	4032	100.00

**Levels of income according to Federal Poverty Level (FPL) guidelines?**

<b>POV_I</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>&lt;100% FPL</b>	708	17.56	708	17.56
<b>100-199% FPL</b>	824	20.44	1532	38.00
<b>200-399% FPL</b>	1281	31.77	2813	69.77
<b>400% or more FPL</b>	1219	30.23	4032	100.00

**Levels of income according to Federal Poverty Level (FPL) guidelines (CHIP)?**

<b>POV_CHIP</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>&lt;200% FPL</b>	1532	38.00	1532	38.00
<b>200-299% FPL</b>	718	17.81	2250	55.80
<b>300-399% FPL</b>	563	13.96	2813	69.77
<b>400% or more FPL</b>	1219	30.23	4032	100.00

## Appendix A: Unweighted Frequency Tables

### Highest parent education in the household (>HS vs. HS or less)

EDU2_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
> HS	3253	80.68	3253	80.68
< HS or HS	779	19.32	4032	100.00

### Type of Insurance Coverage

instype_09	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	126	3.13	126	3.13
Private only	1965	48.74	2091	51.86
Public only	1291	32.02	3382	83.88
Both Public and Private	528	13.10	3910	96.97
Uninsured	122	3.03	4032	100.00

### Region of residence

REGION	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Northeast	778	19.30	778	19.30
Midwest	926	22.97	1704	42.26
South	1180	29.27	2884	71.53
West	1148	28.47	4032	100.00

### CSHCN currently has Autism/ASD

DX_AUT_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	34	0.84	34	0.84
currently has condition	1420	35.22	1454	36.06
does not have condition	2578	63.94	4032	100.00

### CSHCN currently has an intellectual disability

DX_INT_11	Frequency	Percent	Cumulative Frequency	Cumulative Percent
.	10	0.25	10	0.25
currently has condition	960	23.81	970	24.06
does not have condition	3062	75.94	4032	100.00

**Appendix A: Unweighted Frequency Tables**

**CSHCN currently has a developmental delay**

<b>DX_DEV_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
.	21	0.52	21	0.52
<b>currently has condition</b>	2965	73.54	2986	74.06
<b>does not have condition</b>	1046	25.94	4032	100.00

**CSHCN currently has ASD, ID or DD**

<b>DX_CURR_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>yes</b>	3518	87.25	3518	87.25
<b>no</b>	514	12.75	4032	100.00

**CSHCN who currently have ASD, ID and/or DD (w/o ASD),and w/o ASD ID DD**

<b>DX_GRP2_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>Any ASD</b>	1420	35.22	1420	35.22
<b>ID and/or DD</b>	2098	52.03	3518	87.25
<b>None</b>	514	12.75	4032	100.00

**CSHCN who currently have ASD, ID (w/o ASD), DD only, and w/o ASD ID DD**

<b>DX_GRP3_11</b>	<b>Frequency</b>	<b>Percent</b>	<b>Cumulative Frequency</b>	<b>Cumulative Percent</b>
<b>Any ASD</b>	1420	35.22	1420	35.22
<b>ID w/o ASD</b>	657	16.29	2077	51.51
<b>DD only</b>	1441	35.74	3518	87.25
<b>None</b>	514	12.75	4032	100.00



## 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/slaitis/imputed\\_data.htm](http://www.cdc.gov/nchs/slaitis/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/slaitis/imputed\\_data.htm](http://www.cdc.gov/nchs/slaitis/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

## Appendix B Methods Notes on Imputation of Missing Values

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.