

Putting Data Into Action: Accessing and Using Data from the National Survey of Children with Special Health Care Needs

The Data Resource Center for Child and Adolescent Health
www.childhealthdata.org



The Data Resource Center is supported by the federal Maternal and Child Health Bureau



Why We Need Data!

- **Identifying/documenting needs and performance**
- **Building partnerships**
- **Educating Ourselves and Policymakers**
- **Advocacy**
- **Grant Writing**
- **Research**

About the Data Resource Center

Learn About the Surveys

Browse the Data

Put Data into Action

Get Help



Survey Fast Facts

Quick Data Search

Browse by State

How to Use This Site

Keyword Search



Go

Data at a Glance

At your fingertips—easy-to-read data snapshots for each state



State/Region Nationwide

Browse Data Snapshots

Welcome to the Data Resource Center for Child & Adolescent Health!

Welcome to the newly redesigned DRC website. Take a [tour](#) of the site and give us your feedback.

The mission of the Data Resource Center (DRC) is to take the voices of parents, gathered through the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN), and share the results through this online resource so they can be used by researchers, policymakers, family advocates and consumers to promote a higher quality health care system for children, youth and families. [Learn more about the DRC](#)

DRC Highlights

- Child Obesity State Report Cards
- New NS-CSHCN Data Trends
- New chartbook comparing CSHCN with children who do not have special health care needs

Most Popular Topics

What you can do on the DRC website?

- Learn about** the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs
- Browse** national and state findings on hundreds of child health indicators
- Search** data based on numerous important topics and subgroups of children
- Download** and print snapshot profiles on key

Connect with the DRC

Sign up for email updates

email address

Submit

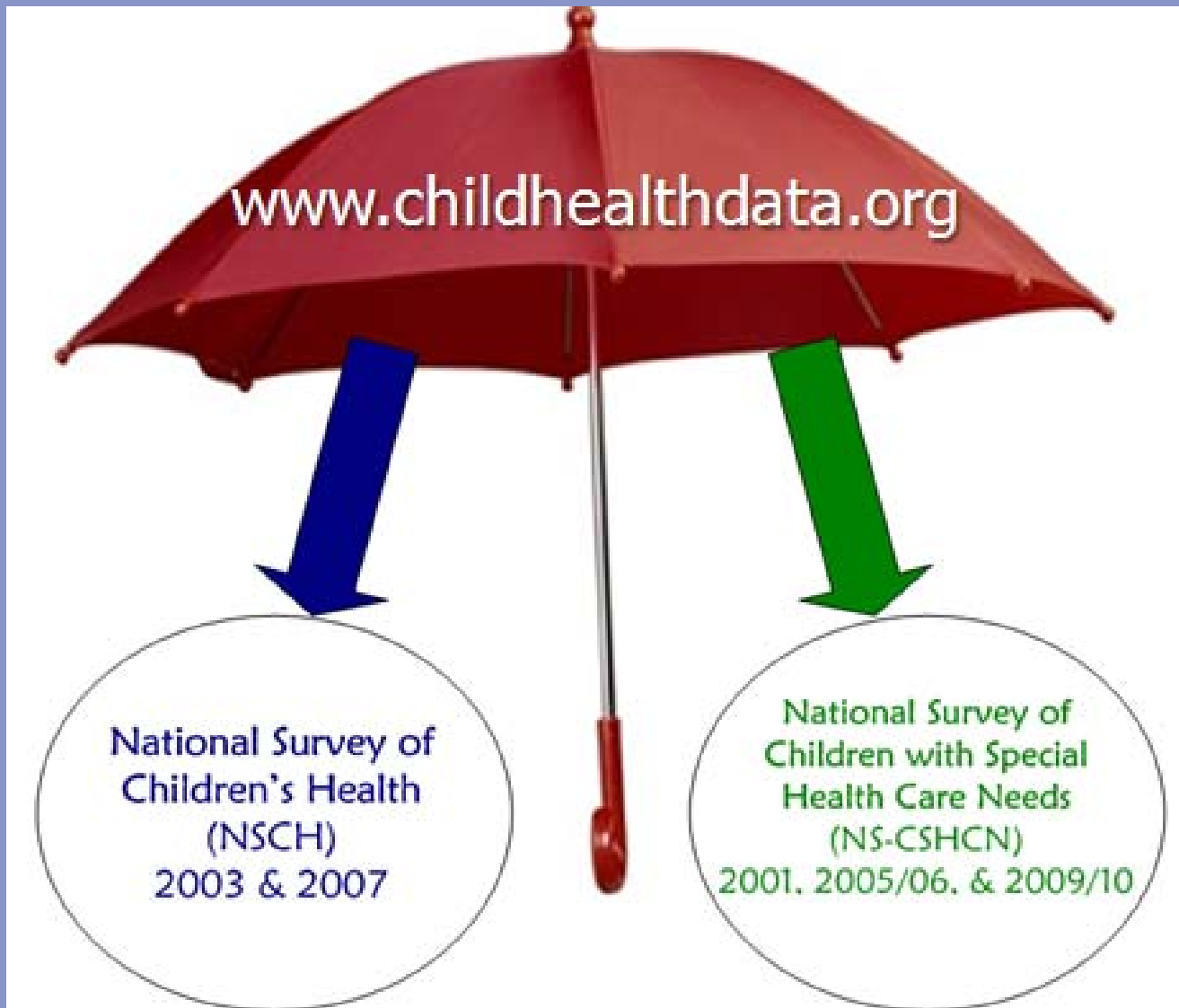


childhealthdata National study finds that providing insurance to the poor helps them maintain both health and financial stability: <http://t.co/y0X8H1b>
4 days ago · reply · retweet · favorite



childhealthdata 1 in 5 high school students meets the medical criteria for addiction, according to a Columbia study. Read an article at <http://t.co/a3ox4H2>
6 days ago · reply · retweet · favorite

Available Datasets on the DRC Website





What Features are Available?

- **Learn** about the surveys
- **Search and compare** national, state, and regional survey results for subgroups of children (age, race, sex, income, insurance and health status, etc.)
 - Over 100 indicators and each survey item, including:
 - Each CSHCN Systems of Care Core Outcomes
 - Data relevant to 34 of 45 Title V Block Grant/Needs Assessment Focus Areas
 - 18 Healthy People 2020 Measures
 - 16 Outcomes and Quality Measures Endorsed by NQF

National Survey of Children with Special Health Care Needs (2009/10 NS-CSHCN)

FAST FACTS about the SURVEY

About the Data Resource Center

Learn About the Surveys

Browse

National Survey of Children's Health (NSCH)

National Survey of Children with Special Health Care Needs (NS-CSHCN)

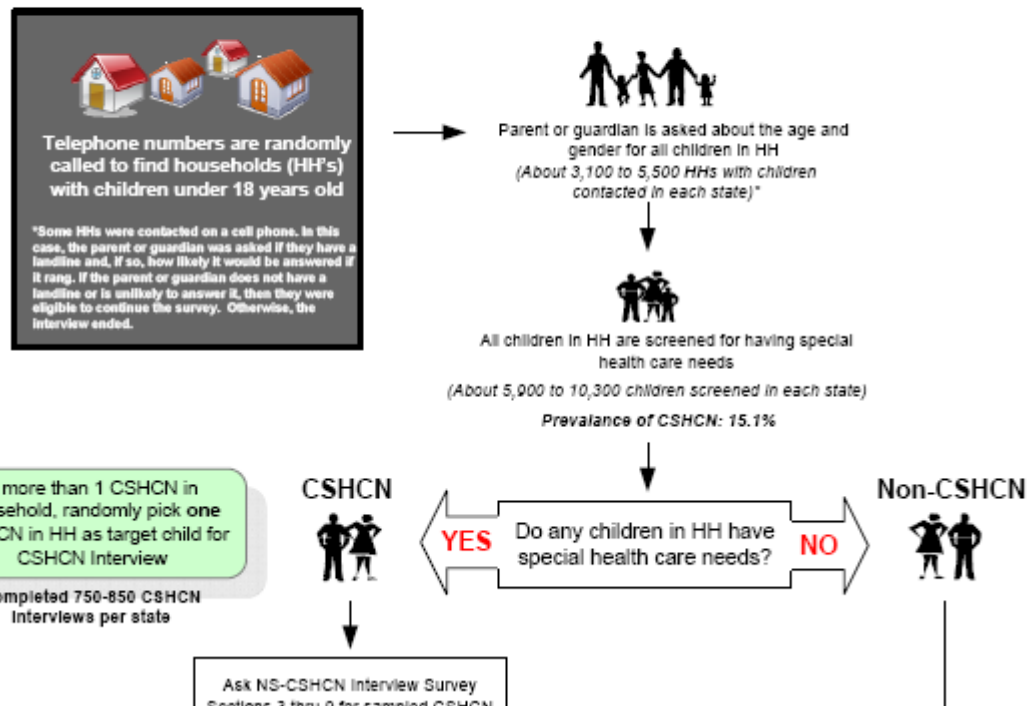
Guide to Survey Topics and

What is the National Survey of CSHCN?

- A national telephone survey conducted for a third time during 2009-2010; previous administrations of the survey took place in 2000-2001 and 2005-2006
- Independent random samples taken in all 50 states and the District of Columbia
- Telephone numbers are randomly generated and called to find households with one or more children under 18 years old. Trained interviewers ask parents or guardians a series of questions for all children in the household to identify those with special health care needs

2009/10 National Survey of Children with Special Health Care Needs (2009/10 NS-CSHCN)

Sampling and Survey Administration Process



children under 18 years old from 196,159 households were identified with special health care needs. Final Screener datasets have 371,617 records in order to maintain confidentiality of respondents.

Interviews were collected during 2009-2010; at least 750 interviews were completed in each state and the District of Columbia

Interviews, on average, took 15 minutes, on average, to complete

The survey was administered in English, Spanish, Mandarin, Cantonese, Vietnamese

How many CSHCN in the state population, and the estimated percent of children with one or more CSHCN under 18 years old

providing detailed information about each state's CSHCN population as age, race/ethnicity, family structure, household income, etc.

What types of health care services needed and any unmet needs for care, and specialty services received

including current conditions and functioning difficulties

and adequacy of coverage

types of health care services needed and any unmet needs for care

care, and specialty services received

Guide to Topics & Questions Asked

National Survey of Children with Special Health Care Needs, 2009/10

NOTE: Telephones are dialed at random to identify households with one or more children under 18 years old. The interviewer asks to speak to the parent or guardian who knows the most about the child's or children's health and health care. If he or she is not available, multiple call back attempts are made to reach them. If the parent or guardian's language is not English, arrangements are made to call back later to administer the survey in another language.

**Denotes that original version of the variable is not released publicly. Variable may be recoded or omitted in public use data files.

CLICK on the question numbers in blue text below to view the full text of the question and its response options.

- SECTION 1: NIS/SLAITS Eligibility
- SECTION 2: Initial Demographics

About the Data Resource Center

Learn About the Surveys

National Survey of Children's (NSCH)

National Survey of Children with Special Health Care Needs (NS-CSHCN)

Guide to Survey Topics and Questions

Survey FAQs

Fast Facts about the Surveys



CSHCN2009

CSHCN2009

Section 2. INITIAL SCREENING

INTRODUCTION The next questions are about any kind of health problems, concerns, or conditions that may affect your (child/children)'s physical health, behavior, learning, growth, or physical development. Some of these health problems may affect your (child/children)'s abilities and activities at school or at play. Some of these problems affect the kind or amount or services your (child/children) may need or use.

CSHCN1 (IF S_UNDR18=1, INSERT 'Does your child'? IF S_UNDR18 > 1, INSERT 'Do any of your children') currently need or use medicine prescribed by a doctor, other than vitamins?

- (01) YES
- (02) NO [SKIP TO CSHCN2]
- (77) DONT KNOW [SKIP TO CSHCN2]
- (99) REFUSED [SKIP TO CSHCN2]

READ IF NECESSARY: This applies to ANY medications prescribed by a doctor. Do not include over-the-counter medications such as cold or headache medications, or any vitamins, minerals, or supplements that can be purchased without a prescription. THESE QUESTIONS REFER ONLY TO A CURRENT CONDITION. THE RESPONDENT SHOULD ONLY REPLY WITH "YES" IF THE CHILD CURRENTLY HAS A SPECIAL HEALTH CARE NEED.

[top](#)

[top](#)

han vitamins? (CSHCN1)
services that is usual for most children



What data can you get on the DRC Website?

- Interactive Data Snapshots
 - View Topic Specific Snapshots
- Interactive State Ranking Tables
 - View and compare all states at the same time
 - Get maps comparing each state to the nation
- Interactive Query for Individual Outcomes, Indicators and Single Items
 - Search by state, region, and nationwide
 - Stratify by numerous population subgroups
 - Compare all states on individual items, indicators or outcomes
 - Trend across survey years where possible

About the Data Resource Center

Learn About the Surveys

Browse the Data

Put Data into Action

Get Help



Survey Fast Facts

Quick Data Search

Browse by State

How to Use This

Data at a Glance

At your fingertips—easy-to-read data snapshots for each state



State/Region Nationwide

Browse Data Snapshots

Welcome to the Data Resource Center for Child & Adolescent Health!

Welcome to the newly redesigned DRC website. Take a tour of the site and give us your feedback.

The mission of the Data Resource Center (DRC) is to take the voices of parents, gathered through the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN), and share the results through this online resource so they can be used by researchers, policymakers, family advocates and consumers to promote a higher quality health care system for children, youth and families. [Learn more about the DRC](#)

DRC Highlights

- Child Obesity State Report Cards
- New NS-CSHCN Data Trends
- New chartbook comparing CSHCN with children who do not have special health care needs

Most Popular Topics

What you can do on the DRC website?


- Learn about** the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs
- Browse** national and state findings on hundreds of child health indicators
- Search** data based on numerous important topics and subgroups of children
- Download** and print snapshot profiles on key

Sign up for our newsletter

email address

Submit

 childhealthdata National study finds that providing insurance to the poor helps them maintain both health and financial stability: <http://t.co/y0X8H1b>
4 days ago · reply · retweet · favorite

 childhealthdata 1 in 5 high school students meets the medical criteria for addiction, according to a Columbia study. Read an article at <http://t.co/a3ox4H2>
6 days ago · reply · retweet · favorite

OPTION 1: The DRC 360 “Get Started” Tour

Step 1: Just click on your state



Step 2: View a range of measures and select any of your choice

2009/10 National Survey of Children with Special Health Care Needs

Nationwide Profile

[Return to Snapshot Selection](#)
[Compare Survey Years 2001-05/06](#)
[Compare Survey Years 2005-09/10](#)
[2001 Profile](#)
[2005/06 Profile](#)

Click on any row of data in the table below to view detailed results by age, race/ethnicity, household income and other subgroups.

Prevalence of CSHCN	State %	Nation %	National Chartbook Indicators	State %	Nation %
CSHCN Prevalence			Child Health		
Percent of children who have special health care needs	15.1	15.1	CSHCN whose conditions affect their activities usually, always, or a great deal	27.1	27.1
CSHCN Prevalence by Age			CSHCN with 11 or more days of school absences due to illness		
Age 0-5 years	9.3	9.3		15.5	15.5
Age 6-11 years	17.7	17.7	Health Insurance Coverage		
Age 12-17 years	18.4	18.4	CSHCN without insurance at some point in past year	9.3	9.3
CSHCN Prevalence by Sex			CSHCN without insurance at time of survey	3.5	3.5
Male	17.4	17.4	Currently insured CSHCN whose insurance is inadequate	34.3	34.3
Female	17.7	17.7	Access to Care		
			CSHCN with unmet need for specific health care services	22.6	22.6

MCHB Core Outcomes	State %	Nation %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	70.3	70.3
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	43.0	43.0
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	60.6	60.6
CSHCN who are screened early and continuously for special health care needs	78.6	78.6
CSHCN whose services are organized in ways that families can use them easily	65.1	65.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	40.0	40.0

CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child	22.1	22.1
CSHCN whose conditions cause financial problems for the family	21.6	21.6
CSHCN whose families spend 11 or more hours per week providing or coordinating child's health care	13.1	13.1



...takes you to your state's findings for that measure

Current Search Criteria

Survey: 2009/10 National Survey of Children with

Special Health Ca

Starting Point: M

Indicators

State/Region: Na

Topic: MCHB Cor

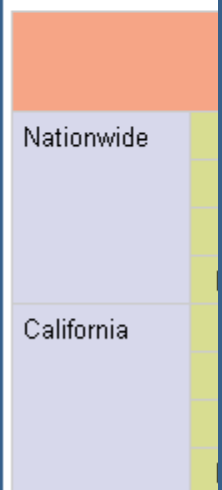
Question: Outcor

coordinated, ongo

medical home (de

Outcome #2: CS

comprehensive



C.I. = 95% Confiden

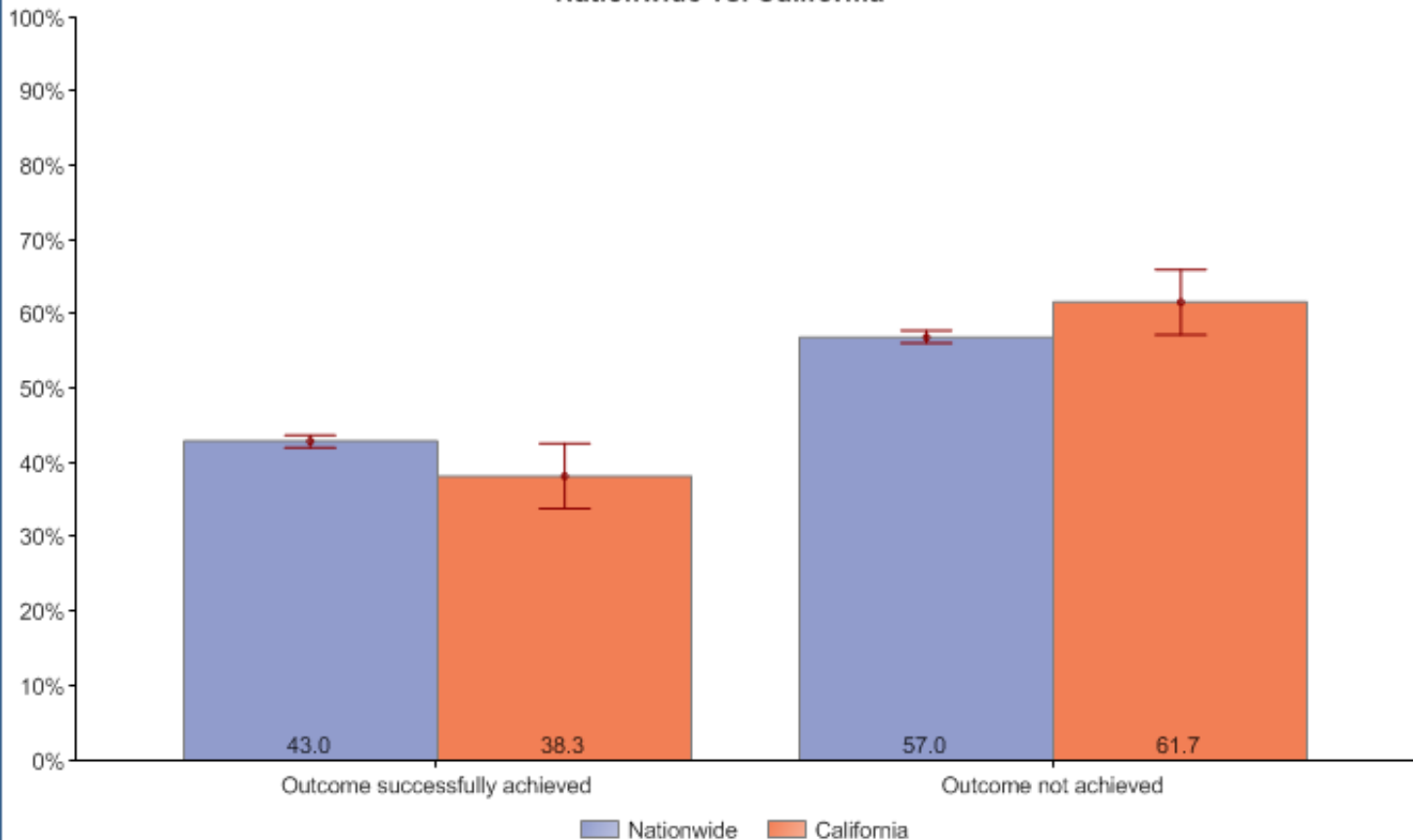
n = Cell size. Use caution in interpreting Cell sizes less than 50.

Edit Search Criteria

Compare States:

MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home

CSHCN age 0 -17 years
Nationwide vs. California



Step 3: Select a subgroup to view your state findings for

Current Search Criteria

Survey: 2009/10 National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide vs. California

Topic: MCHB Core Outcomes for CSHCN

Question: Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

Edit Search Criteria

Compare States:

California

Compare Subgroups:

Select a Subgroup

- Select a Subgroup
- Age - 3 groups
- Sex of child
- Race/ethnicity
- Primary language for Hispanic CSHCN
- Specific types of special health needs
- Emotional/behavioral/developmental issues
- Family structure
- Insurance status
- Type of insurance
- Consistency of insurance coverage
- Adequacy of current health insurance

		Outcome successfully achieved	Outcome not achieved	
Nationwide	%	43.0	57.0	100.0
	C.I.	(42.1 - 43.8)	(56.2 - 57.9)	
	n	18,279	20,671	
	Pop. Est.	4,613,661	6,126,183	
California	%	38.3	61.7	100.0
	C.I.	(33.9 - 42.7)	(57.3 - 66.1)	
	n	299	492	
	Pop. Est.	365,908	589,751	

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
n = Cell size. Use caution in interpreting Cell sizes less than 50.

...takes you to your state's Medical Home findings by insurance type

Current Search Criteria

Survey: 2009/10 National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide

Topic: MCHB Core Outcomes

Question: Outcome #2: CS coordinated, ongoing, comprehensive medical home ([details](#))

Sub Group: Outcome success of insurance

Outcome #2: CSHCN with within a medical home

Select a response category

		Private insurance only	Public insurance only
Nationwide	%	51.2	34.0
	C.I.	(50.1 - 52.4)	(32.4 - 35.5)
	n	12,129	4,115
	Pop. Est.	2,810,201	1,252,062
California	%	47.0	25.4
	C.I.	(41.2 - 52.8)	(17.4 - 33.4)
	n	212	52
	Pop. Est.	260,211	64,798

C.I. = 95% Confidence Interval.

n = Cell size. Use caution in interpretation.

Estimates based on sample sizes too small to meet standards for reliability or precision.

The relative standard error is greater than 30%.

Compare Subgroups:

Type of insurance

		Private insurance only	Public insurance only
Nationwide	%	51.2	34.0
	C.I.	(50.1 - 52.4)	(32.4 - 35.5)
	n	12,129	4,115
	Pop. Est.	2,810,201	1,252,062
California	%	47.0	25.4
	C.I.	(41.2 - 52.8)	(17.4 - 33.4)
	n	212	52
	Pop. Est.	260,211	64,798



Subgroup Comparison Options

- All 50 states, D.C., & 10 HRSA regions
- Age
- Sex of child
- Race/ethnicity of child
- Primary household language
- Household income level
- Household income (SCHIP)
- Family structure
- Special Health Care Needs Status
- Type of insurance
- Consistency of insurance
- Presence of a medical home
- Presence of an emotional, behavioral or developmental problem
- Adequacy of health insurance

Step 4: See where your state ranks across all states by selecting "all states" as comparison group

Current Search Criteria

Survey: 2009/10 National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide vs. California

Topic: MCHB Core Outcomes for CSHCN

Question: Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

Sub Group: Outcome successfully achieved x Type of insurance

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

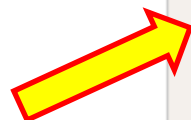
Select a response category

		Private insurance only	Public insurance only	Both public and private insurance	
Nationwide	%	51.2	34.0	35.3	24.2
	C.I.	(50.1 - 52.4)	(32.4 - 35.5)	(32.1 - 38.6)	(19.9 - 28.5)
	n	12,129	4,115	1,011	318

Edit Search Criteria

Compare States:

- All States
- Unselect State or Region
- All States
- All Regions
- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas



Current Search Criteria

Survey: 2009/10 National Survey of Children with

Special Health Ca

Starting Point: M

Indicators

State/Region: All

Topic: MCHB Cor

Question: Outcom

coordinated, ongoi

medical home (det

Outcome #2: CSHCN who receive coordi
home (details)

Notes: Click on the Column Header to sort the results
HOVER over the text in the table.

	State	Outcome successfully achieved %	Outcome not achieved %	Total %
1	Alabama	50.7	49.3	100.0
2	Kentucky	50.2	49.8	100.0
3	Kansas	49.4	50.6	100.0
4	New Hampshire	49.4	50.6	100.0
5	Indiana	48.5	51.5	100.0
6	Nebraska	48.2	51.8	100.0
7	Minnesota	48.0	52.0	100.0
8	Pennsylvania	48.0	52.0	100.0
9	North Dakota	47.8	52.2	100.0
10	Maine	47.5	52.5	100.0

Top 10
States

Notes: Click on the
HOVER over the tex

	State
1	Ala
2	Ker
3	Ka

Bottom
10
States

9	North
10	M
11	Massa
12	Id

41	Texas	40.1	59.9	100.0
42	Montana	39.1	60.9	100.0
43	New York	38.4	61.6	100.0
44	California	38.3	61.7	100.0
45	New Jersey	38.3	61.7	100.0
46	Mississippi	36.8	63.2	100.0
47	Nevada	36.8	63.2	100.0
48	Florida	36.2	63.8	100.0
49	Arizona	36.1	63.9	100.0
50	New Mexico	34.9	65.1	100.0
51	District of Columbia	34.2	65.8	100.0

Step 5: Click on your state to
get back to querying by other
subgroups in your state

...and back to CA vs. Nation... continue searching subgroups on this measure..or...

Current Search Criteria

Survey: 2009/10 National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide vs. California

Topic: MCHB Core Outcomes for CSHCN

Question: Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home [\(details\)](#)

Edit Search Criteria

Compare States:

California

Compare Subgroups:

Select a Subgroup

» [Change question, topic or survey](#)

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home [\(details\)](#)

		Outcome successfully achieved	Outcome not achieved	Total %
Nationwide	%	43.0	57.0	100.0
	C.I.	(42.1 - 43.8)	(56.2 - 57.9)	
	n	18,279	20,671	
	Pop. Est.	4,613,661	6,126,183	
California	%	38.3	61.7	100.0
	C.I.	(33.9 - 42.7)	(57.3 - 66.1)	
	n	299	492	
	Pop. Est.	365,908	589,751	

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
n = Cell size. Use caution in interpreting Cell sizes less than 50.

Trending Across Survey Years

About the Data
Resource Center

Learn About
the Surveys

Browse the Data

Put Data
into Action

Get Help

Keyword Search



Go

Browse the Data

Browse by Survey & Topic

Get State Snapshots

Get US Data Maps

Medical Home Data Portal

Browse Title V Topics

Data Tools

Get Print Version

Download PDF

Email Page

Share Page

Tweet Page

Home > Browse the Data > Browse by Survey > Survey Results

Current Search Criteria

Survey: 2009/10 National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide

Topic: CSHCN Health and Functional Status

Question: Indicator 1: CSHCN whose health conditions consistently affect their daily activities (details)

Edit Search Criteria

Compare States:

Select a State or Region

Compare Subgroups:

Select a Subgroup

» Compare this measure across years

» Change question, topic or survey

Indicator 1: CSHCN whose health conditions consistently and often greatly affect their daily activities (details)

	Daily activities consistently affected, often a great deal	Daily activities moderately affected some of the time	Daily activities never affected	Total %
%	27.1	38.5	34.4	100.0
C.I.	(26.2 - 27.9)	(37.7 - 39.4)	(33.6 - 35.2)	
n	9,730	15,611	14,795	
Pop. Est.	2,996,614	4,265,089	3,806,433	

Other Options: Obtain US Maps and State Ranking Tables for Measures

TEST



Your Data ... Your Story

Data Resource Center for Child & Adolescent Health

A project of the Child and Adolescent Health Measurement Initiative

Ask us a question | Request a dataset
Sign In to Access Your Briefcase

Keyword Search



Go

About the Data Resource Center

Learn About the Surveys

Browse the Data

Put Data into Action

Get Help

Browse the Data

Browse by Survey & Topic

Get State Snapshots

Get US Data Maps

Medical Home Data Portal

Browse Title V Topics

Data Tools

Get Print Version

Download PDF

Email Page

Share Page

Twitter Page

Home > Browse the Data > Results

Current

Survey:

Special

Starting

Indicators

State/Region: Nationwide vs. California

Topic: MCHB Core Outcomes for CSHCN

Question: Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home (details)

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home (details)

		Outcome successfully achieved	Outcome not achieved	Total %
Nationwide	%	43.0	57.0	100.0

Edit Search Criteria

Compare States:

California

Compare Subgroups:

Select a Subgroup

Change question, topic or survey

Browse the Data

Home > Browse the Data

MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing comprehensive care within a medical home

2005 National Survey of Children with Special Health Care Needs

Browse by Survey

Browse by Topic

Browse by State

Browse State Rankings

Data Snapshots

Data Trends

Browse by Medical Home

Browse by Title V

Data Tools

Add to Your Briefcase

Get Print Version

Download PDF

Share This Link



MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing comprehensive care within a medical home

	District of Columbia	Nationwide
%	36.9	47.1
C.I.	(32.6 - 41.1)	(46.3 - 48.0)
n	314	18,977
Pop. Est.	5,701	4,588,731

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
n = Cell size. Use caution in interpreting Cell sizes less than 50.



- Significantly higher than U.S.
- Higher than U.S. but not significant
- Lower than U.S. but not significant
- Significantly lower than U.S.

Statistical significance: $p < .05$



What Other Features Are Available?

- Get topically focused data snapshots and profiles
- Get expert help – by e-mailing us your questions, plus get links to other data sets and resources
- Get resources and ideas on how to report your findings in a valid and effective manner



Core Outcome Profiles

(could be tailored to your state)



Data Resource Center for Child & Adolescent Health
A project of the Child and Adolescent Health Measurement Initiative

www.childhealthdata.org

Outcome #1: Families are partners in decision making at all levels

Effective promotion of health and health services for children with special health care needs (CSHCN) requires a system of care that is integrated, comprehensive, coordinated and family centered. Ideally, these systems are easy to navigate and foster positive experiences between families and health service providers. Advancing integrated systems of care for CSHCN and their families is a national mandate under Public Law 101-239 and is a priority reflected in the Healthy People goals set forth by the U.S. Department of Health and Human Services from 2000 to 2020. To help determine progress towards these goals, the Federal Maternal and Child Health Bureau established the following six core outcomes that facilitate integrated systems of care for CSHCN:

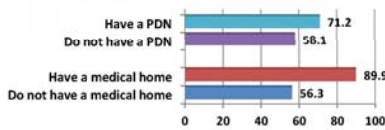
1. Partners in Decision-Making
2. Medical Home
3. Adequate Health Insurance
4. Early and Continuous Screening
5. Ease of Community-Based Service Use
6. Transition to Adulthood

The National Survey of Children with Special Health Care Needs (NS-CSHCN), which has been conducted every four years since 2001, is designed to provide information on the CSHCN population and to assist in the measurement of these core outcomes. The survey measures each core outcome with low-threshold criteria. Outcome #1 is measured through questions that assess the extent to which health professionals engage families in decision-making about their child's health care. Based on data from the 2009/10 NS-CSHCN, 70.3% of CSHCN nationwide meet Outcome #1, with states ranging from 61.8% - 77.6%. Assessment of the variation between states and within demographic or other subgroups of CSHCN is critical to developing appropriate interventions and policy responses.

Measurement

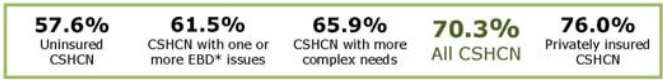
CSHCN meet Outcome 1 when the respondent answers usually or always to all four of the following questions:
We want to know about how [S.C.]'s doctors or other health care providers work with you to make decisions about [his/her] health care services and treatment. During the past 12 months...
C6Q21 How often did [S.C.]'s doctors or other health care providers discuss with you the range of options to consider for [his/her] health care or treatment?
C6Q22 How often did they encourage you to ask questions or raise concerns?
C6Q23 How often did they make it easy for you to ask questions or raise concerns?
C6Q24 How often did they consider and respect what health care and treatment choices you thought would work best for [S.C.]?
...Would you say never, sometimes, usually, or always?

Proportion of CSHCN Meeting Outcome #1 by Presence of a Medical Home and Personal Doctor or Nurse



- CSHCN with a personal doctor or nurse (PDN) are more likely to receive care where their families are partners in decision making than CSHCN without a PDN.
- CSHCN with a medical home are more likely to meet Outcome #1 than CSHCN without a medical home.

**National and state-level prevalence of all outcomes by demographics & subgroups are available online at childhealthdata.org



Data Resource Center (DRC) is a project of the Child and Adolescent Health Measurement Initiative at Oregon Health & Science University. DRC is sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration. *Created November 2011.



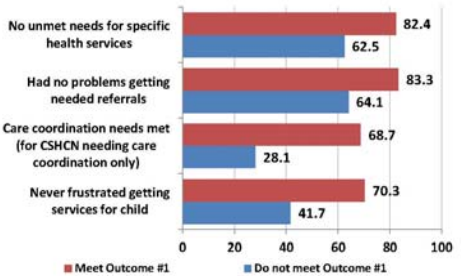
Data Resource Center for Child & Adolescent Health
A project of the Child and Adolescent Health Measurement Initiative

www.childhealthdata.org

Setting the stage for optimal health trajectories.
A partnership between a child's family and their health care providers allows for an open and intentional dialogue about his or her unique health needs. This leads to individualization of care and the ability to identify factors that may negatively affect his or her health. It also gives children and their families the support they need during critical periods of development. However, only about 70% of CSHCN meet this core outcome. Vulnerable CSHCN, especially those with functional limitations and those living in poverty, are even less likely to receive care in which families are partners in decision making.

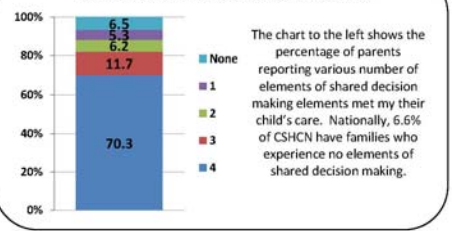
Trending Across Survey Years:
Measurement changed significantly for 2009/10 NS-CSHCN, and therefore cannot be compared to 2001 or 2005/06 NS-CSHCN survey findings.

Experience with care for CSHCN who do and do not meet Outcome #1



- CSHCN who meet Outcome #1 have a lower probability of experiencing frustration seeking services or having unmet needs for specific health services than CSHCN who do not meet Outcome #1
- CSHCN who meet Outcome #1 have a higher probability of having their care coordination needs met and having no problems getting needed referrals than CSHCN who do not meet Outcome #1

Number of Shared Decision Making Elements Met



Taking it a Step Further

The following are questions relating to Outcome #1 that cannot be answered by this national survey data but are important to consider when evaluating how early and continuous screening can best work to improve the health and well-being of CSHCN:

- Current measurement is physician-focused -- are families working to encourage these critical conversations?
- Do families have the support they need to play the most positive role possible in their child's development?
- What do health care providers do to educate families on how they can best support their child's development?
- What is the family doing in the day-to-day life of their child to promote or maintain health?
- Are families involved in the policy decisions that affect them?

Who Are CSHCN Profile

Who Are Children with Special Health Care Needs?

Definition

The federal Maternal and Child Health Bureau defines children with special health care needs (CSHCN) as:
*"those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."*¹

This definition is used to guide the development of family-centered, coordinated systems of care for children and families for children with special needs served by the state Title V block grants administered by the Maternal and Child Health Bureau.

The National Survey of CSHCN (NS-CSHCN) and the National Survey of Children's Health (NSCH) – two child health prevalence surveys – use a validated non-condition specific, consequences based screening tool to identify children meeting the Maternal and Child Health definition of CSHCN with the exception that the "at risk" component is not included.^{2,3}

Demographic Profile

- Compared to children not meeting CSHCN criteria (non-CSHCN), CSHCN are more likely to be male (17.4% vs. 12.7%) and older, 12–17 years (18.4%) compared to 0–5 years (9.3%) and 6–11 years (17.7%).
- While estimated by the NS-CSHCN to be about 15.1% of the child population, CSHCN account for 40% or more of medical expenditures for children overall.⁴

Health Status Profile Among CSHCN

All CSHCN currently have a condition with health and related service consequences. In the 2009/10 NS-CSHCN, prevalence of twenty specific conditions was included in the survey. 87.7% of CSHCN have at least 1 condition on the list and 29.1% of CSHCN have 3 or more of these conditions.

Condition	%	Condition	%
ADD/ADHD	30.2	Headaches	9.8
Depression	10.3	Head Injury	1.4
Anxiety	17.1	Heart Problem	3.0
Behavioral problems	13.5	Blood Problems	1.5
Autism, ASD	7.9	Cystic Fibrosis	0.3
Developmental Delay	17.6	Cerebral Palsy	1.6
Intellectual Disability	5.8	Muscular Dystrophy	0.3
Asthma	35.3	Down Syndrome	1.1
Diabetes	1.7	Arthritis	2.9
Epilepsy	3.1	Allergies	48.6

¹Condition prevalence in 2009/10 was asked using two questions: prevalence of conditions ever or currently. Only current prevalence was asked in 2005/06.
²Condition was either not asked about in the 2005/06 NS-CSHCN or was not comparable. Note: This is prevalence among CSHCN.

Functional difficulties are difficulties that impact the day-to-day life of CSHCN. 91.2% of CSHCN experience at least 1 of the following functional difficulties and 45.6% of CSHCN have 4 or more of the difficulties listed.

Functional Difficulty	%
Breathing or other respiratory problems	46.5
Swallowing, digesting food, or metabolism	19.1
Blood Circulation	6.1
Repeated or chronic physical pain, including headaches	29.0
Seeing even when wearing glasses or contact lenses	15.6
Hearing even when using a hearing aid or other device	6.3
Taking care of self, such as eating, dressing or bathing	19.8
Coordination or moving around	19.6
Using his/her hands	16.1
Learning, understanding or paying attention	51.1
Speaking, communicating, or being understood	32.9
Feeling anxious or depressed	42.9
Behavior problems	41.4
Making and keeping friends	32.4

Prevalence Profile

Source: 2009-2010 National Survey of Children with Special Health Care Needs; www.nchsdata/naahc/naahc.htm



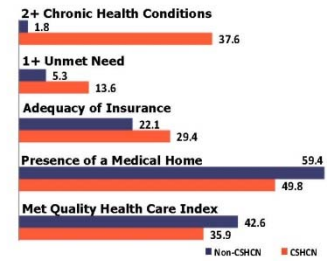
According to the 2009/10 National Survey of Children with Special Health Care Needs:

- Approximately 11.2 million children ages 0–17 years in the United States (15.1%) have special health care needs.
- Prevalence of CSHCN ranges from 10.6% to 19.8% across the 50 states and the District of Columbia.
- Over 1 in 5 households with children in the United States have at least one child with special health care needs. This translates into almost 9 million households nationally.

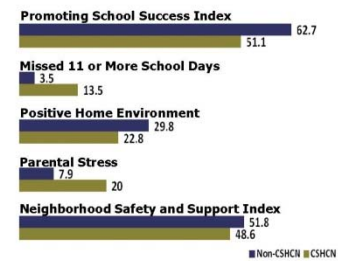
¹ McPherson M, Arango P, Fox H, et al. "A new definition of children with special health care needs". *Pediatrics*. 1998; 102: 137-140.
² Bethel, CO, Reed, D, Stern, R, Blumberg, S, Newacheck, P. Identifying Children with Special Health Care Needs: Development and Evaluation of a Short Screening Tool. *Annals of Pediatrics*. 2002
³ Bethel, CO, Reed, D, Blumberg, S, Newacheck, P. What is the Role of Children with Special Health Care Needs: Development and Evaluation of Variants in Prevalence and Methods across Three National Surveys. *MCH Journal*. July 2007
⁴ Newacheck, PV & Kay, SE. A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*. 2005; 159: 10-17.

Data Resource Center (DRC) is a project of the Child and Adolescent Health Measurement Initiative at Oregon Health & Science University. DRC is sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration.

Comparing CSHCN to Children without Special Health Care Needs (Non-CSHCN) Health Status and Utilization School and Home Profile



Source: 2007 National Survey of Children's Health; www.childhealthdata.org



Source: 2007 National Survey of Children's Health; www.childhealthdata.org

Identifying CSHCN

CSHCN are identified in the NS-CSHCN and the NSCH using the CSHCN Screener[®] – a five item, parent-reported tool designed to reflect the federal Maternal and Child Health Bureau's consequences-based definition of children with special health care needs.^{5,6}

- The CSHCN Screener[®] operationalizes the MCHB definition of CSHCN by focusing on the health consequences a child experiences as a result of having an on-going health condition rather than on the presence of a specific diagnosis or type of disability.
- The screener assesses children's health care needs status by using questions that ask about need or use of services, prescription medications, specialized therapies, and having functional difficulties due to an ongoing condition.
- The non-condition specific approach used by the CSHCN Screener[®] identifies children across the range and diversity of childhood chronic conditions and special needs, allowing a more comprehensive assessment of health needs and health care system performance.

Developed by The Child & Adolescent Health Measurement Initiative (CAHMI at www.cahmi.org); National Data Resource Center for Child and Adolescent Health, Oregon Health & Science University, School of Medicine, Department of Pediatrics

Visit the Data Resource Center to learn more about CSHCN in your state



⁵ McPherson M, Arango P, Fox H, et al. "A new definition of children with special health care needs". *Pediatrics*. 1998; 102: 137-140.
⁶ Bethel, CO, Reed, D, Stern, R, Blumberg, S, Newacheck, P. Identifying Children with Special Health Care Needs: Development and Evaluation of a Short Screening Tool. *Annals of Pediatrics*. 2002
⁷ Bethel, CO, Reed, D, Blumberg, S, Newacheck, P. What is the Role of Children with Special Health Care Needs: Development and Evaluation of Variants in Prevalence and Methods across Three National Surveys. *MCH Journal*. July 2007
⁸ Newacheck, PV & Kay, SE. A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*. 2005; 159: 10-17.

Data Resource Center (DRC) is a project of the Child and Adolescent Health Measurement Initiative at Oregon Health & Science University. DRC is sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration.

Condition-Specific Profiles

Part I: % of CSHCN with **Autism or autism spectrum disorder**

% of CSHCN overall with condition: 5.4
Estimated number with condition: 544,181

% of CSHCN with Condition

By Age Group **Nationwide**

0 - 5 years	5.2
6 - 11 years	6.0
12 - 17 years	4.9

By Sex

Male	7.2
Female	2.8

% of CSHCN with Condition

By Insurance

Private insurance only	4.3
Public insurance only	6.2
Both public and private	11.0
Uninsured	5.3

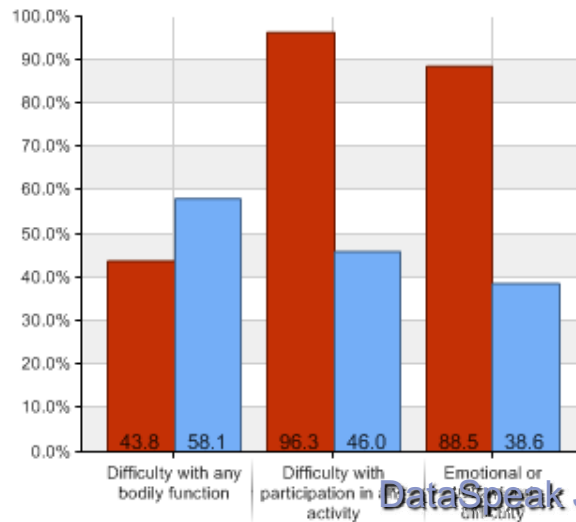
Nationwide

By SSI Status

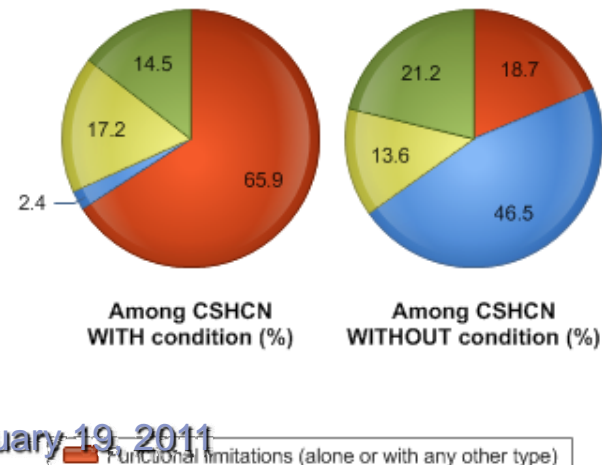
Receives SSI for disability	19.4
-----------------------------	------

Part II: Selected Health Characteristics among CSHCN with **Autism or autism spectrum disorder -- NATIONWIDE**

Type of functional difficulties for CSHCN with and without condition¹



% of CSHCN with and without condition qualifying on specific types of special health needs criteria²





Data Resource Center Technical Assistance



[? Ask us a question](#) | [Request a dataset](#)
[» Sign In to Access Your Briefcase](#)

About the Data Resource Center

Learn About the Surveys

Browse the Data

Put Data into Action

Get Help

Keyword Search



Go

Get Help

[How to Use This Site](#)

[Ask Us a Question](#)

[Request a Dataset](#)

[Glossary](#)

[Additional Resources](#)

[Home](#) > [Get Help](#) > [Ask Us a Question](#)

Ask Us a Question

Have a question? We're here to help.

- Perhaps there is an answer in our [Frequently Asked Questions](#).
- Take an [Online Tour](#) of the DRC website to learn how to search for data and use this site.
- Get [Fast Facts](#) about the NSCH and NS-CSHCN surveys.
- Review [Guides to Topics and Questions](#) in the surveys.

Still have a question? Please [email us](#).

Our goal is to provide quick, thorough replies to your questions and requests for information. DRC staff members make every effort to respond within 2 to 3 business days.

To ensure delivery to your inbox (not junk mail) please add donotreply@childhealthdata.org to your email address book.

Data Tools

 [Get Print Version](#)

 [Download PDF](#)

 [Email Page](#)

 [Share Page](#)

 [Tweet Page](#)



Example Technical Assistance Questions

Profile of Technical Assistance

- Website Assistance/Where to Find Information
- Indicator/M Measurement Development
- Downloadable Data sets and variable codebooks
- Conceptualizing Research and Application of the Data
- Interpretation of Data
- Understanding the Surveys
- Resource Location
- New Data Analysis Needs



What Other Features Are Available?

- **Download** cleaned, labeled state-specific national survey datasets with pre-constructed indicators and additional variables (SAS & SPSS)
- **Sign up** for regular e-updates, twitter and discussions on Facebook
- **Find out** about and access the latest publications, reports & abstracts using the national survey data



Contact Us

- Visit us at www.childhealthdata.org
- Email us at cahmi@ohsu.edu
- Connect with the DRC to Join the Conversation!
 - Like us on Facebook:
<http://www.facebook.com/childhealthdata>
 - Follow us on Twitter: @childhealthdata