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
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

**Data at a Glance**
At your fingertips—easy-to-read data snapshots for each state.

State/Region: Nationwide
Browse Data Snapshots

**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/y0XSHlb
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

DataSpeak January 19, 2011

www.childhealthdata.org


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

DataSpeak January 19, 2011
What is the National Survey of CSHCN?

- 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.

In 2009-2010, children under 18 years old from 196,159 households were identified as having special health care needs. Final Screener datasets have 371,617 records, with each record representing one child. An average of 750 interviews were collected during 2009-2010; at least 750 interviews were collected in each state and the District of Columbia.

The interview was administered in English, Spanish, Mandarin, Cantonese, and Vietnamese.

Use for EACH State?

Number CSHCN in the state population, and the estimated percent of households with one or more CSHCN under 18 years old.

CCHN: Current CSHCN

NCHN: Never CSHCN

NH: CSHCN

CCHN: Current CSHCN

NCHN: Never CSHCN

NH: CSHCN

1. If more than 1 CSHCN in household, randomly pick one as target child for CSHCN Interview.
2. If only 1 CSHCN in household, use that child for CSHCN Interview.
3. If no CSHCN in household, use that household as Non-CSHCN Interview.

CSHCN

1. Do any children in HH have special health care needs?
2. If NO, stop interview.
3. If YES, continue interview.

Non-CSHCN

1. Stop interview.

Compiled 750-850 CSHCN interviews per state.
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: NS/SHST Eligibility
- SECTION 2: Initial Demographics

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 of 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
07 DON'T KNOW
09 REFUSED

READ IF NECESSARY: This applies to ALL 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.

Do any of your children need or use medicine prescribed by a doctor, other than vitamins?
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
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.
...takes you to your state’s findings for that measure
Step 3: Select a subgroup to view your state findings for

Current Search Criteria

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

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

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

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

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

C.I. = 95% Confidence Interval, n = Cell size. Use caution in interpreting estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30%.
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.
Step 5: Click on your state to get back to querying by other subgroups in your state.

# Top 10 States

<table>
<thead>
<tr>
<th>State</th>
<th>Outcome successfully achieved %</th>
<th>Outcome not achieved %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alabama</td>
<td>50.7</td>
<td>49.3</td>
<td>100.0</td>
</tr>
<tr>
<td>Kentucky</td>
<td>50.2</td>
<td>49.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Kansas</td>
<td>49.4</td>
<td>50.6</td>
<td>100.0</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>49.4</td>
<td>50.6</td>
<td>100.0</td>
</tr>
<tr>
<td>Indiana</td>
<td>48.5</td>
<td>51.5</td>
<td>100.0</td>
</tr>
<tr>
<td>Nebraska</td>
<td>48.2</td>
<td>51.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Minnesota</td>
<td>48.0</td>
<td>52.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>48.0</td>
<td>52.0</td>
<td>100.0</td>
</tr>
<tr>
<td>North Dakota</td>
<td>47.8</td>
<td>52.2</td>
<td>100.0</td>
</tr>
<tr>
<td>Maine</td>
<td>47.5</td>
<td>52.5</td>
<td>100.0</td>
</tr>
</tbody>
</table>

# Bottom 10 States

<table>
<thead>
<tr>
<th>State</th>
<th>Outcome successfully achieved %</th>
<th>Outcome not achieved %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>41 Texas</td>
<td>40.1</td>
<td>59.9</td>
<td>100.0</td>
</tr>
<tr>
<td>42 Montana</td>
<td>39.1</td>
<td>60.9</td>
<td>100.0</td>
</tr>
<tr>
<td>43 New York</td>
<td>38.4</td>
<td>61.6</td>
<td>100.0</td>
</tr>
<tr>
<td>44 California</td>
<td>38.3</td>
<td>61.7</td>
<td>100.0</td>
</tr>
<tr>
<td>45 New Jersey</td>
<td>38.3</td>
<td>61.7</td>
<td>100.0</td>
</tr>
<tr>
<td>46 Mississippi</td>
<td>36.8</td>
<td>63.2</td>
<td>100.0</td>
</tr>
<tr>
<td>47 Nevada</td>
<td>36.8</td>
<td>63.2</td>
<td>100.0</td>
</tr>
<tr>
<td>48 Florida</td>
<td>36.2</td>
<td>63.8</td>
<td>100.0</td>
</tr>
<tr>
<td>49 Arizona</td>
<td>36.1</td>
<td>63.9</td>
<td>100.0</td>
</tr>
<tr>
<td>50 New Mexico</td>
<td>34.9</td>
<td>65.1</td>
<td>100.0</td>
</tr>
<tr>
<td>51 District of Columbia</td>
<td>34.2</td>
<td>65.8</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Notes: Click on the Column Header to sort the results.

Hover over the text in the table.
...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  
**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**

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

<table>
<thead>
<tr>
<th></th>
<th>Daily activities consistently affected, often a great deal</th>
<th>Daily activities moderately affected some of the time</th>
<th>Daily activities never affected</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>27.1</td>
<td>38.5</td>
<td>34.4</td>
<td>100.0</td>
</tr>
<tr>
<td>C.I.</td>
<td>(26.2 - 27.9)</td>
<td>(37.7 - 39.4)</td>
<td>(33.6 - 36.2)</td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>9,730</td>
<td>15,911</td>
<td>14,795</td>
<td></td>
</tr>
<tr>
<td>Pop. Est.</td>
<td>2,998,614</td>
<td>4,265,089</td>
<td>3,806,433</td>
<td></td>
</tr>
</tbody>
</table>
Other Options: Obtain US Maps and State Ranking Tables for Measures
### 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

<table>
<thead>
<tr>
<th></th>
<th>District of Columbia</th>
<th>Nationwide</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>36.9</td>
<td>47.1</td>
</tr>
<tr>
<td>C.I.</td>
<td>(32.6 - 41.1)</td>
<td>(46.3 - 48.0)</td>
</tr>
<tr>
<td>n</td>
<td>314</td>
<td>18,977</td>
</tr>
<tr>
<td>Pop. Est.</td>
<td>5,701</td>
<td>4,588,731</td>
</tr>
</tbody>
</table>

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

DataSpeak January 19, 2011
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 one or more chronic physical, developmental, behavioral, or other health-related conditions and who also require health and related services of a type or amount beyond that required by children generally." This definition is used to guide the development of family-centered, coordinated systems of care for children and families of children with special health care needs served by the state Title V programs, administered by the Maternal and Child Health Bureau.

The National Survey of Children’s Health (NS-CSHCN) and the National Survey of Children’s Health (NS-CSHCN) – two-children’s health prevalence surveys – use a validated two-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.

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 6.5 years (5.2%) and 6-11 years (17.9%).
- 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.

Health Status Profile Among CSHCN
- Children with CSHCN are 1.5 times more likely to have a condition than their non-CSHCN counterparts.
- Children with CSHCN are more likely to have a condition than their non-CSHCN counterparts.

Comparing CSHCN to Children without Special Health Care Needs (Non-CSHCN)

<table>
<thead>
<tr>
<th>Health Status</th>
<th>CSHCN</th>
<th>Non-CSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>2+ Chronic Health Conditions</td>
<td>1.5x</td>
<td>1.0x</td>
</tr>
<tr>
<td>Unmet Need</td>
<td>1.5x</td>
<td>1.0x</td>
</tr>
<tr>
<td>Adequacy of Insurance</td>
<td>1.5x</td>
<td>1.0x</td>
</tr>
<tr>
<td>Presence of a Medical Home</td>
<td>1.5x</td>
<td>1.0x</td>
</tr>
</tbody>
</table>

Identifying CSHCN
CSHCN are identified in the NS-CSHCN and the NS-CSHCN using the CSHCN Screener® - a 5-item, parent-report tool designed to reflect the federal Maternal and Child Health Bureau’s consequences-based definition of children with special health care needs.

- The CSHCN Screener® operationalizes the MDHHS definition of CSHCN by focusing on the health consequences of children’s experiences as a result of having an ongoing 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, specialists’ services, and level of 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 children’s 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 (CABMI) at www.cabmi.org; National Data Resource Center for Child and Adolescent Health, Oregon Health & Science University, School of Medicine, Department of Pediatrics.

Who Are CSHCN Profile

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

www.childhealthdata.org

DataSpeak January 19, 2011
Condition-Specific Profiles

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

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Nationwide</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 5 years</td>
<td>5.2</td>
</tr>
<tr>
<td>5 - 11 years</td>
<td>6.0</td>
</tr>
<tr>
<td>12 - 17 years</td>
<td>4.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>By Sex</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>7.2</td>
</tr>
<tr>
<td>Female</td>
<td>2.8</td>
</tr>
</tbody>
</table>

Estimated number with condition: 544,181

% of CSHCN overall with condition: 5.4

<table>
<thead>
<tr>
<th>By Insurance</th>
<th>Nationwide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private insurance only</td>
<td>4.3</td>
</tr>
<tr>
<td>Public insurance only</td>
<td>6.2</td>
</tr>
<tr>
<td>Both public and private</td>
<td>11.0</td>
</tr>
<tr>
<td>Uninsured</td>
<td>5.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>By SSI Status</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Receives SSI for disability</td>
<td>19.4</td>
</tr>
</tbody>
</table>

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

Type of functional difficulties for CSHCN with and without condition:

- Difficulty with any bodily function
- Difficulty with participation in activity
- Emotional or behavioral problems

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

Among CSHCN WITH condition (%):
- Functional limitations (alone or with any other type): 66.0%
- Managed by prescription medications: 46.5%

Among CSHCN WITHOUT condition (%):
- Functional limitations (alone or with any other type): 21.2%
- Managed by prescription medications: 13.6%
Data Resource Center Technical Assistance

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

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.
Profile of Technical Assistance

- Website Assistance/Where to Find Information
- Indicator/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