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
Why We Need Data!

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

Association of Maternal & Child Health Programs Annual Conference, 2012
Myth Busting Is Essential
Assumption: Most Children in the US Get Adequate Health Care:
Minimal Quality of Care Composite Measure (Insurance usually or always adequate, at least 1 preventive care visit in previous 12 months, and care meets medical home criteria)

Nationwide: 41.3% of children met indicator

Higher=Better Performance
- 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
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 topics
Available Datasets on the DRC

www.childhealthdata.org


Association of Maternal & Child Health Programs Annual Conference, 2012
What normally would have to be done to get data findings:

1. Download raw data files, study content and sample size, select topics, upload into statistical analysis software, conducting file linking (household, family, state), clean, code for missing, conduct imputation, etc.
2. Determine measure scoring, construct variables, learn about concepts and coding, test with sampling
3. Subpop to your state, construct subgroup variables
4. Conduct weighting and adjustment to standard errors for complex sampling
5. Produce data findings and format into tables and graphs.

Now people can:

1. Click on a topic
2. Get tables and graphs already made
3. Compare across all states and subgroups of children with a point and a click!
4. Download and use in presentations, reports, one pagers, etc.

Association of Maternal & Child Health Programs Annual Conference, 2012
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.)
- **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
Data Resource Center Technical Assistance

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.
Example Technical Assistance Questions

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

Association of Maternal & Child Health Programs Annual Conference, 2012
What Other Features Are Available?

- **Get resources** and ideas on how to report your findings in a valid and effective manner
- **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
Your Data Briefcase

An online "briefcase" allows you to save your data query results, state data snapshots, and content pages in a folder for future reference. You can return to this folder at any time to view and print saved briefcase items. Any page on the Data Resource Center (DRC) can be added to your briefcase by clicking on "Save to Briefcase" on the left column of each page.

Note: You will need to be logged into your account to save items into your briefcase. The "Save to Briefcase" data tool will not be available if you are not logged into your account.

- Browse by Survey and Topic--Data Resource Center for Child and Adolescent Health
- Examples of Data Use--Data Resource Center for Child and Adolescent Health
- CSHCN 2005/06: % of children/youth (ages 0-17) with special health care needs, Nationwide
- NSCH Mental Health Profile
- State-Specific Survey Results for Title V Needs Assessment
- How to Use Data Effectively--Data Resource Center for Child and Adolescent Health
National Survey of Children with Special Health Care Needs (2009/10 NS-CSHCN)

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

Sampling and Survey Administration Process

Children under 18 years old from 196,159 households were identified as having special health care needs. Final Screener datasets have 371,617 cases.

4 interviews were collected during 2009-2010; at least 750 interviews are needed, on average, to complete the survey. The survey is administered in English, Spanish, Mandarin, Cantonese, Vietnamese.

Available for EACH state?
- Number CSHCN in the state population, and the estimated percent of children with special health care needs
- Information about each state’s CSHCN population by age, race/ethnicity, family structure, household income, etc.

Interviews are conducted by the CSHCN Interviewer.
- Including current conditions and functioning difficulties
- Adequacy of coverage
- Types of health care services needed and any unmet needs for care, and specialty services received
Welcome to the Data Resource Center for Child & Adolescent Health

The mission of the Data Resource Center for Child & Adolescent Health is to provide researchers, policymakers, and caregivers with access to data and resources related to child health and development.

Annual Maternal and Child Health Epidemiology Meeting, 2011

Guide to Topics & Questions Asked

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

NOTE: Telephone numbers 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/SLATS 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 or services your (child/children) may need or use.

CSHCN1: (IF $UNDRE18=1, INSERT “Does your child?” IF $UNDRE18 > 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 your children receive services that are usual in 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
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- 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
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- Download and print snapshot profiles on key child health issues

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

datahealthdata National study finds that providing insurance to the poor helps them maintain both health and financial stability: http://f.tw/y0X5Hlb
4 days ago · reply · retweet · favorite

datahealthdata 1 in 5 high school students meets the medical criteria for addiction, according to a Columbia study. Read an article at http://f.tw/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**

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

<table>
<thead>
<tr>
<th>Prevalence of CSHCN</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN Prevalence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percent of children who have special health care needs</td>
<td>15.1</td>
<td>15.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CSHCN Prevalence by Age</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 0-5 years</td>
<td>9.3</td>
<td>9.3</td>
</tr>
<tr>
<td>Age 6-11 years</td>
<td>17.7</td>
<td>17.7</td>
</tr>
<tr>
<td>Age 12-17 years</td>
<td>18.4</td>
<td>18.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CSHCN Prevalence by Sex</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>17.4</td>
<td>17.4</td>
</tr>
<tr>
<td>Female</td>
<td>18.7</td>
<td>18.7</td>
</tr>
</tbody>
</table>

### National Chartbook Indicators

<table>
<thead>
<tr>
<th>Indicator</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child Health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN whose conditions affect their activities usually, always, or a great deal</td>
<td>27.1</td>
<td>27.1</td>
</tr>
<tr>
<td>CSHCN with 11 or more days of school absences due to illness</td>
<td>15.5</td>
<td>15.5</td>
</tr>
<tr>
<td><strong>Health Insurance Coverage</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN without insurance at some point in past year</td>
<td>9.3</td>
<td>9.3</td>
</tr>
<tr>
<td>CSHCN without insurance at time of survey</td>
<td>3.5</td>
<td>3.5</td>
</tr>
<tr>
<td>Currently insured CSHCN whose insurance is inadequate</td>
<td>34.3</td>
<td>34.3</td>
</tr>
<tr>
<td><strong>Access to Care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN with unmet need for specific healthcare services</td>
<td>33.6</td>
<td>33.6</td>
</tr>
</tbody>
</table>

### MCHE Core Outcomes

<table>
<thead>
<tr>
<th>Outcome</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive</td>
<td>70.3</td>
<td>70.3</td>
</tr>
<tr>
<td>CSHCN who receive coordinated, ongoing, comprehensive care within a medical home</td>
<td>43.0</td>
<td>43.0</td>
</tr>
<tr>
<td>CSHCN whose families have adequate private and/or public insurance to pay for the services they need</td>
<td>60.6</td>
<td>60.6</td>
</tr>
<tr>
<td>CSHCN who are screened early and continuously for special health care needs</td>
<td>78.6</td>
<td>78.6</td>
</tr>
<tr>
<td>CSHCN whose services are organized in ways that families can use them easily</td>
<td>65.1</td>
<td>65.1</td>
</tr>
<tr>
<td>Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence</td>
<td>40.0</td>
<td>40.0</td>
</tr>
<tr>
<td>CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child</td>
<td>22.1</td>
<td>22.1</td>
</tr>
<tr>
<td>CSHCN whose conditions cause financial problems for the family</td>
<td>21.6</td>
<td>21.6</td>
</tr>
<tr>
<td>CSHCN whose families spend 11 or more hours per week providing or coordinating children’s health care</td>
<td>13.1</td>
<td>13.1</td>
</tr>
</tbody>
</table>
…takes you to your state’s findings for that measure
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)

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

Association of Maternal & Child Health Programs Annual Conference, 2012
Step 4: See where your state ranks across all states by selecting “all states” as comparison group.
### 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>49.1</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

- California: Outcome successfully achieved % 38.3

### Notes:
- Click on the Column Header to sort the results.
- Hover over the text in the table.

---

**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  
**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)

<table>
<thead>
<tr>
<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></td>
<td></td>
<td>100.0</td>
</tr>
<tr>
<td>C.I.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pop. Est.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| 27.1 | 38.5 | 34.4 | 100.0 |
| (26.2 - 27.9) | (37.7 - 39.4) | (33.6 - 35.2) |         |
| 9,730 | 15,811 | 14,795 |         |
| 2,998,614 | 4,265,089 | 3,806,433 |         |
## Trending Across Survey Years with Subgroups

### Current Search Criteria

**Survey:** Compare all years - 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
  - [ ] Age - 3 groups
  - [ ] Insurance status
  - [ ] Sex of child

---

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

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>2005/06</th>
<th>2009/10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td>23.2</td>
<td>24.0</td>
<td>27.1</td>
</tr>
<tr>
<td><strong>C.I.</strong></td>
<td>(22.4 - 24.0)</td>
<td>(23.2 - 24.7)</td>
<td>(26.2 - 27.9)</td>
</tr>
</tbody>
</table>

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
Trending Across Survey Years with Subgroups

Current Search Criteria

Survey: Compare all years - National Survey of Children with Special Healthcare 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)

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

Select a Response Category: Consistently affected

Select a Sub Group Category: Not currently insured

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>2005/06</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td>31.0</td>
<td>32.1</td>
</tr>
</tbody>
</table>

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
### Current Search Criteria

**Survey:** Compare all years - National Survey of Children with Special Health Care Needs

**Starting Point:** MCHB Core Outcomes and Key Indicators

**State/Region:** Nationwide vs. District of Columbia

**Topic:** CSHCN Health and Functional Status

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

**Sub Group:** Consistently affected x Currently insured

---

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

Select a Response Category: Consistently affected

Select a Sub Group Category: Currently insured

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>2005/06</th>
<th>2009/10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td>22.8</td>
<td>23.6</td>
<td>26.8</td>
</tr>
<tr>
<td></td>
<td>(21.9 - 23.6)</td>
<td>(22.9 - 24.4)</td>
<td>(25.9 - 27.6)</td>
</tr>
<tr>
<td>District of Columbia</td>
<td>23.5</td>
<td>21.1</td>
<td>21.7</td>
</tr>
<tr>
<td></td>
<td>(19.0 - 27.9)</td>
<td>(17.5 - 24.6)</td>
<td>(17.4 - 25.9)</td>
</tr>
</tbody>
</table>

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
OPTION 2: The DRC “full search”
Step 1: Click on “Browse by Survey & Topic”
Step 2: Select a survey, a survey year and geographic area
Step 3: Select a measurement topic and measure.

2. Select a Starting Point/Topic

- CSHCN Chartbook Indicators and MCHB Core Outcome Indicators
  - MCHB Core Outcomes for CSHCN
    - CSHCN Health and Functional Status
    - Health Insurance Coverage and Program Participation
    - Health Care Needs and Access to Care
    - Care Coordination and Family Centered Care
    - Impact on Families

- CSHCN Prevalence and Demographics (Content Map)
  - Child or household level data for children with & without special health care needs

- Additional Measures of CSHCN Health, Access and Care Quality (Content Map)
  - Includes sub-component results for core outcomes & key indicators

- 2005/06 CSHCN Survey Sections (Content Map)
  - Responses to questions asked in each section of the CSHCN Interview

3. Select a Survey Question

- Outcome #1: CSHCN whose families are partners in decision making and satisfied with services
- Outcome #2: CSHCN have a medical home
- Outcome #3: CSHCN have adequate public or private insurance
- Outcome #4: CSHCN who are screened early and continuously for special health care needs
- Outcome #5: Community-based service systems are organized for ease of use
- Outcome #6: CSHCN youth receive services needed for transition to adulthood
- CSHCN ages 0-11 served by care systems meeting all core outcomes
- CSHCN ages 12-17 served by care systems meeting all core outcomes
Other Options: Obtain US Maps and State Ranking Tables for Measures

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

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

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)

<table>
<thead>
<tr>
<th></th>
<th>Outcome successfully achieved</th>
<th>Outcome not achieved</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td>43.0</td>
<td>57.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>
MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing comprehensive care within a medical home

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

Nationally: 43.0% of CSHCN met outcome
State Range: 34.2-50.7

State Ranking
Higher= Better Performance
- 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<0.05
Examples of Other Data Snapshots and Topical Profiles to Look For

1. Across Year Comparisons Data Snapshots
2. Condition Specific Data Snapshots
3. Core Outcomes Profiles
4. Medical Home Profiles
5. Disparity Profiles
6. Your Data, Your Story Templates
7. Others....
Core Outcome Profiles
(could be tailored to your state)

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 (CSCHN) 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 CSCHN and their families is a national priority under Public Law 108-357 and 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 five core outcomes that facilitate integrated systems of care for CSCHN:

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

The National Survey of Children with Special Health Care Needs (NS-CSCHN), which has been conducted every four years since 2001, is designed to provide information on the CSCHN population and to assist in the measurement of these core outcomes. The survey measures each core outcome with a three-level ordinal scale: Outcome #1 is measured through questions that assess the extent to which health professionals engage families in decision-making about the child’s health care. Based on data from the 2009/10 NS-CSCHN, 26.3% of CSCHN met Outcome #1, with states ranging from 9.1% - 72.5%. Assessment of the variation between states and within demographic or other subgroups of CSCHN is critical to developing appropriate interventions and policy responses.

**Measurement**
CSCHN meet Outcome 1 when the respondent answers ‘always’ or ‘usually’ to all four of the following questions:

1. We want to know about your child’s doctors or other health care providers work with you to make decisions about your child’s health care services and treatment during the past 12 months...
2. How often did they encourage you to ask questions or raise concerns?
3. How often did they encourage you to ask questions or raise concerns?
4. How often did they consider and respect what you thought would be best for your child?

**Performance**
Proportion of CSCHN meeting Outcome #1 by Presence of a Medical Home and Personal Doctor or Nurse

- **Have a POC:** 73.2%
- **Do not have a POC:** 39.3%

**Calculation**

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

**Note:** National and state-level prevalence of all outcomes by demographic subgroups are available online at childhealthdata.org

**57.6% Uninsured CHCN**
**61.5% CHCN with care or more EBB**
**65.9% CHCN with more complex needs**
**70.3% All CHCN**
**76.0% Privately insured CHCN**

**Association of Maternal & Child Health Programs Annual Conference, 2012**
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.”

This definition is used to guide the development of family-centered, coordinated systems of care for children and families with the special needs served by the state Title V Block grants 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 child health prevalence surveys — use a validated, 10-condition specific, consequence-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 (28.8%) compared to 6.5 years (0.2%) 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**
All CSHCN surveys have a condition or related service component. In the 2009 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 25.1% of CSHCN have 5 or more of these conditions.

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

<table>
<thead>
<tr>
<th>Condition</th>
<th>NS-CSHCN</th>
<th>Non-CSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHD</td>
<td>0.2%</td>
<td>0.2%</td>
</tr>
<tr>
<td>Depression</td>
<td>1.8%</td>
<td>1.8%</td>
</tr>
<tr>
<td>Autism</td>
<td>3.4%</td>
<td>3.4%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>1.0%</td>
<td>1.0%</td>
</tr>
<tr>
<td>Add-on Disability</td>
<td>1.9%</td>
<td>1.9%</td>
</tr>
<tr>
<td>Asthma</td>
<td>1.8%</td>
<td>1.8%</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>0.8%</td>
<td>0.8%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>0.7%</td>
<td>0.7%</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>0.6%</td>
<td>0.6%</td>
</tr>
</tbody>
</table>

*Data from 2009 National Survey of Children’s Health, www.childhealthdata.org*
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

<table>
<thead>
<tr>
<th>By 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>% of CSHCN with Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>By Insurance</td>
</tr>
<tr>
<td>Private insurance only</td>
</tr>
<tr>
<td>Public insurance only</td>
</tr>
<tr>
<td>Both public and private</td>
</tr>
<tr>
<td>Uninsured</td>
</tr>
</tbody>
</table>

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

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

![Bar chart showing type of functional difficulties for CSHCN with and without condition]

![Pie charts showing % of CSHCN with and without condition qualifying on specific types of special health needs criteria]
# How the DRC can support Programs Improvement Partnerships

<table>
<thead>
<tr>
<th><strong>Understand your population</strong></th>
<th>User generated tables, bar and pie charts, and customizable reports supply prevalence estimates and population counts to help define your population of CSCHN and their health needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assess system performance</strong></td>
<td>Immediate access to over 100 state-specific indicators of child health and well-being and system performance for children overall and children with special health care needs (CSHCN).</td>
</tr>
<tr>
<td><strong>Examine improvement opportunities</strong></td>
<td>“Point and click” menu allows users to explore disparities and gaps in access and services for different population subgroups of children and CSHCN.</td>
</tr>
<tr>
<td><strong>Select priorities</strong></td>
<td>User generated tables, bar and pie charts, and customizable reports supply prevalence estimates and population counts to help guide selection of priority needs.</td>
</tr>
<tr>
<td>---------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Set targets</strong></td>
<td>“All States” ranking maps and tables provide benchmark data to assist in identifying state-negotiated performance measure targets.</td>
</tr>
<tr>
<td><strong>Identify promising improvement models</strong></td>
<td>Information on national, within and across States variation using standardized indicators helps identify where quality is better and can help in cross-state learning for purposes of identifying promising models for improvement as well as identify key collaborators for improvement.</td>
</tr>
<tr>
<td><strong>Monitor progress</strong></td>
<td>Centralized resource for standardized, population-based survey questions to use in collecting child health and health care quality data locally.</td>
</tr>
</tbody>
</table>
Example:
Met Transition to Adulthood Criteria: 40.0%

- Variations Across States
  State Range: 31.7% (NV) to 52.7% (KS)

- Disparities Nationwide (and variation in disparities!)
  Private: 50.2%; Public: 25.8%; Uninsured: 19.6%
  Among Insured – Adequate Insurance: 46.2%
  Inadequate Insurance: 31.7%

Association of Maternal & Child Health Programs Annual Conference, 2012
Whole System, Whole Child View

Core Outcome #2: Medical Home and core Outcome #6: Transition to Adulthood (CSHCN age 12-17 years only) are the two outcomes least likely to be met.

For both age groups, more CSHCN meet Outcome #4: Early and Continuous Screening than any other outcome.

Association of Maternal & Child Health Programs Annual Conference, 2012
1. Local area synthetic estimates
2. Using the data to motivate and inform partnerships
3. Using the familiar to communicate about the unfamiliar
4. Leveraging data points provided to conduct more in depth analyses and tell a story!
<table>
<thead>
<tr>
<th>Race/Ethnicity Adjusted</th>
<th>California</th>
<th>Marin County</th>
<th>Fresno County</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence of CSHCN</td>
<td>14.5%</td>
<td>15.8%</td>
<td>14.5%</td>
</tr>
<tr>
<td>Prevalence of Inadequate Insurance</td>
<td>24.9%</td>
<td>24.1%</td>
<td>24.9%</td>
</tr>
<tr>
<td>Prevalence of Grade Repetition</td>
<td>10.6%</td>
<td>9.9%</td>
<td>13.5%</td>
</tr>
<tr>
<td>Prevalence of a “Home Environment” Summary Measure</td>
<td>29.6%</td>
<td>31.6%</td>
<td>20.8%</td>
</tr>
<tr>
<td>Prevalence of Medical Home</td>
<td>49.6%</td>
<td>52.0%</td>
<td>46.9%</td>
</tr>
</tbody>
</table>

Data sources: 2007 National Survey of Children’s Health and kidscount.org
All of the CSHCN living in California would fill 24,927 school buses and stretch 170 miles.

How far would the buses span if they were filled with subgroups of California CSHCN?

- White: 52 miles
- Non-white: 92 miles
The Importance of Standardization

Standardize

Compare

Learn

Association of Maternal & Child Health Programs Annual Conference, 2012
The NSCH and NS-CSHCN are unprecedented resources!

State data provides a basis for across-area learning and building shared understanding of priorities and impact.
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