The Data Resource Center for Child and Adolescent Health:
Using Data for Action

www.childhealthdata.org

Family Voices National Conference
May 25, 2007
Presented by: Christina Bethell, PhD, MPH, MBA
Agenda

- Why is data useful?
- Overview of the Two National Surveys
- Overview of the Data Resource Center
- How to Use the Website
Why is Data Useful?
Family stories give a face and heart to needs.

Data expands family stories to inform policy debates and drive change.

“At the end of the day, people change or support change for emotional reasons. Data helps them then rationalize their decisions.”
Application of Data

- **Identifying/documenting needs**
  - How many children in your state have what needs?
  - How do needs vary across states and why?
  - How do needs vary across subgroups of children within and across states and why?
  - How does data support your assumptions or what you’re hearing from the field (providers, families, other agencies)?

- **Building partnerships**
  - What partners could use this data: Public Programs, Health plans, Hospitals, Providers, community groups, faith based organizations?
  - How can you share data to support common efforts, improve care?
Application of Data

- **Educating Policymakers**
  - What are key policy issues for your initiative?
  - What programs or groups need what information?
  - What data could help them learn about child health needs?

- **Advocacy**
  - Are there key pressure points in program budgets or priorities coming up?
  - What methods would be most effective in presenting your case?
  - How could you use data in Fact Sheets, Testimony, the media, along with family stories?

- **Grant Writing**
  - How can you use data to strengthen your proposal?
Survey Data Included in the Data Resource Center

- National Survey of Children’s Health (NSCH), 2003
- National Survey of Children with Special Health Care Needs (NS-CSHCN), 2001
Two Surveys - What do they have in Common?

- Sponsored by the Maternal and Child Health Bureau

- Use **SLAITS** (State & Local Area Integrated Telephone Survey) sampling mechanism

- National Center for Health Statistics/CDC oversees sampling and administration

- Designed and collected in a manner that allows valid state-to-state and national comparisons

- Weighted data yield prevalence estimates for non-institutionalized child population ages 0-17 in each state, and nationally
Two Surveys – What do they have in Common?

- Both surveys identify **Children with Special Health Care Needs (CSHCN)**

“Children with special health care needs . . . 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.”

— Maternal and Child Health Bureau, July 1998
Two Surveys - What do they have in Common?

- Both use the same method to identify CSHCN

National Survey of CSHCN, 2001
- Prevalence = 12.8%

National Survey of Children’s Health, 2003
- Prevalence = 17.6%
CSHCN Screener

Asks about 5 different health consequences:

1) Limited or prevented in ability to function
2) Prescription medication need/use
3) Specialized therapies (OT, PT, Speech)
4) Above routine use of medical care, mental health or other health services
5) Counseling or treatment for on-going emotional, behavioral or developmental problem

a) Due to medical, behavioral or other health condition
   AND

b) Condition has lasted or is expected to last for at least 12 months
National Survey of Children with Special Health Care Needs (NS-CSHCN)

- Conducted for the first time during 2000 – 2001

- Screening method identifies CSHCN according to MCHB definition

- Was repeated in 2005-06 with some revisions & additional items on functional difficulties and conditions

- Public release data expected Fall 2007
2001 National Survey of CSHCN

372,174 children, 0 - 17 yrs, in 196,888 households

CSHCN Screener asked for all children in household

**NO special health care needs**
(323,484 children/youth)

**YES special health care needs**
(48,690 children/youth)

From this group, 750 CYSHCN selected in EACH state for the longer CSHCN interview

38,866 CSHCN interviews completed
Random sampling:

- allows certain characteristics to be estimated with precision
- larger sample sizes achieve more precision.
In-depth CSHCN interview collects information on:

- Child health and functional status
- Child health insurance status and adequacy of coverage
- Access to health care — needed services & unmet needs
- Care coordination
- Impact of child’s health on family
- MCHB core outcomes for CYSHCN and
- Key indicators of CSHCN health & system performance
Upcoming 2005/06 NS-CSHCN Data

- **Increased sample size:** 850 CSHCN interviews collected per state

- **Added items asking about** current health conditions & specific functional difficulties

- **Revised, improved questions** on care coordination & transition to adulthood

- **National referent sample** of Non-CSHCN \((n \approx 5000)\)

- **Datasets publicly available** Fall 2007; **Data Resource Center website access** October 1 2007
National Survey of Children’s Health


- One child randomly selected in each household subject of survey for a total of 102,353 interviews

- Same CSHCN screening method as NS-CSHCN

- Information on children’s health and well-being collected in combination with data on child’s family/neighborhood context

- First time such a broad range of info collected in manner that allow state-to-state and national comparisons
Early Childhood questions (Section 6) asked for children ages 0-5

Survey Sections 1 – 5 and 8 –11 are asked for children of all ages

Middle childhood/Adolescence questions (Section 7) asked for children ages 6-17

National Survey of Children’s Health

CSHCN Screener -- asked only for target child (1 per HH)

102,353
National Survey of Children’s Health

Child Characteristics

Family Level Influences

Neighborhood and Community Influences

Child Outcomes
Survey yields over 100 indicators of child health & well-being in the following areas:

- Child’s **health status**: physical, emotional, dental
- Child’s **health care** – including medical home
- Child’s **school & activities**
- Child’s **family & neighborhood** -- including maternal health status
- **Early childhood** (ages 0-5)
- **School-age** (ages 6-17)
Two Surveys - What Are the Differences?

Population

All children

NSCH

NS-CSHCN

Topic Areas

Health, Family, Neighborhood

Health, Unmet Needs, Family Impact

Sample Size per state

2,000 (300 CSHCN)

750
Always Anchor to Children!

The denominator for ALL results in both surveys is **always CHILDREN** -- never parents!

- **Correct** -- % of children ages 0-17, or ages 0-5, or ages 6-17, etc.
- **Never!** % of parents, families, mothers . . . .
The Data Resource Center for Child and Adolescent Health Website
WEBSITE - www.childhealthdata.org
serves as an umbrella site for national survey data
What is the DRC?

**Interactive Data Resource Center**

**providing:**

1. **Hands-on, User-Friendly Access to Data**
   - National Survey of Children with Special Health Care Needs (NS-CSHCN)
   - National Survey of Children’s Health (NSCH)

2. **Resources and Information about Data**
   - Examples of how other state and family leaders are using these data findings, background about the national surveys, resources about health of children
What is the DRC? 
Interactive Data Resource Center 

providing:

3. Education 

- Obtain technical assistance for understanding, interpreting and using data, online workshops, and opportunities to partner with other stakeholders to discuss, interpret and act on data findings.
What is the Purpose of the DRC?

- **Centralize Data**
  Provide centralized, user-friendly, web-based access to standardized national and state level survey findings

- **Increase Knowledge**
  Build common knowledge and capacity for using data to stimulate and inform system change locally and nationally and opportunities to partner with other stakeholders to discuss, interpret and act on data findings
Who Built the DRC?

- Developed and led by CAHMI -- Child and Adolescent Health Measurement Initiative based at the Oregon Health & Science University in Portland OR
- National advisory group provides ongoing guidance and development of standardized indicators
- Sponsored by the federal Maternal and Child Health Bureau
How to Use the DRC Website
Welcome to the Data Resource Center online tour!

The Data Resource Center online tour is designed to help users learn more about the website’s features and options for obtaining data results. Each interactive session provides step-by-step instructions and easy to follow guidelines for conducting data searches and using the results. The content in each session builds on learning from previous sessions and we recommend starting with Part 1 the first time you take the tour.

WHAT DO I NEED? The online tour uses Macromedia Flash. Newer browsers come with built-in support for Flash; older browsers sometimes require a plug-in that can be downloaded at no cost from the Macromedia Flash Player site.

WHAT IF MY COMPUTER DOESN’T HAVE SPEAKERS? If your computer doesn’t have the ability to play audio, you can still take the tour by following along using the written transcript for each session.

- **Part 1: Getting Started**
  Learn to conduct a basic data search, how to interpret the results, and where to access additional information about specific child health indicators.

  Download written transcript (PDF)

- **Part 2: Comparing Subgroups and Saving Search Results**
  Practice comparing data results for children from different demographic subgroups, learn how to read the bar chart display, and find out where to save search results for easy reference later.

  Download written transcript (PDF)

- **Part 3: Ranking and Comparing State Results**
  Learn about the website’s State Profile feature, practice comparing data search results for different states or regions, and use the "All States" table option to rank states according to their child health indicator results.

  Download written transcript (PDF)
Ask a Question

Your Email Address: 

Subject: 

Message: 

Send
Three Types of Data

- State Profile Tables
- “All States” Comparison Tables
- Data Graphs and Tables for Every Indicator
  - Comparing an indicator across any two geographic areas and
  - Comparing indicators across subgroups of children by age, race, insurance status, income, family structure, health status, etc.
# National Survey of Children with Special Health Care Needs, 2001

**California**

Children ages 0-17 years old

<table>
<thead>
<tr>
<th>Prevalence Statistics</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child-Level Prevalence:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of Children &amp; Youth with Special Health Care Needs, 0-17 yrs old</td>
<td>10.3</td>
<td>12.8</td>
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<tr>
<td><strong>Household-Level Prevalence:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of Households with Children that have one or more CYSHCN, 0-17 yrs old</td>
<td>17.0</td>
<td>20.0</td>
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<tr>
<td><strong>Prevalence by Age:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children 0-5 years of age</td>
<td>5.7</td>
<td>7.8</td>
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<tr>
<td>Children 6-11 years of age</td>
<td>11.2</td>
<td>14.6</td>
</tr>
<tr>
<td>Children 12-17 years of age</td>
<td>14.0</td>
<td>15.8</td>
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<tr>
<td><strong>Prevalence by Sex:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8.3</td>
<td>10.5</td>
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<tr>
<td>Male</td>
<td>12.3</td>
<td>15.0</td>
</tr>
<tr>
<td><strong>Prevalence by Poverty Level:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0% - 99% FPL</td>
<td>7.5</td>
<td>13.6</td>
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<td>200% - 399% FPL</td>
<td>11.0</td>
<td>12.8</td>
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<td>400% FPL or greater</td>
<td>13.8</td>
<td>13.6</td>
</tr>
<tr>
<td><strong>Prevalence by Race/Ethnicity:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>7.6</td>
<td>8.5</td>
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</tbody>
</table>

<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>1) % of CYSHCN whose health conditions consistently and often greatly affect their daily activities.</td>
<td>24.0</td>
<td>23.2</td>
</tr>
<tr>
<td>2) % of CYSHCN with 11 or more days of school absences due to illness.</td>
<td>16.2</td>
<td>15.8</td>
</tr>
<tr>
<td><strong>Health Insurance Coverage:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) % of CYSHCN without insurance at some point during the past year.</td>
<td>9.9</td>
<td>11.6</td>
</tr>
<tr>
<td>4) % of CYSHCN currently uninsured.</td>
<td>4.3</td>
<td>5.2</td>
</tr>
<tr>
<td>5) % of currently insured CYSHCN with coverage that is not adequate.</td>
<td>36.5</td>
<td>33.8</td>
</tr>
<tr>
<td><strong>Access to Care:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6) % of CYSHCN with 1 or more unmet needs for specific health care services.</td>
<td>23.1</td>
<td>17.7</td>
</tr>
<tr>
<td>7b) % of CYSHCN whose families needed but did not get all respite care, genetic counseling and/or mental health services.</td>
<td>25.1</td>
<td>23.1</td>
</tr>
<tr>
<td>8) % of CYSHCN needing specialty care who had problems getting a referral.</td>
<td>27.3</td>
<td>21.9</td>
</tr>
<tr>
<td>9) % of CYSHCN without a usual source of care (or who rely on the emergency room).</td>
<td>9.5</td>
<td>9.3</td>
</tr>
<tr>
<td>10) % of CYSHCN without a personal</td>
<td>13.2</td>
<td>11.0</td>
</tr>
</tbody>
</table>
Question: Indicator 1.4 What is the weight status of children/youth ages 10-17 based on Body Mass Index for age (BMI-for-age)? *(derived)*

Notes: Click on the Column Header to sort the results by ascending or descending order. To get a detailed explanation of the data Hover over the text in the table.

<table>
<thead>
<tr>
<th>Region</th>
<th>Underweight %</th>
<th>Normal weight %</th>
<th>At risk of overweight %</th>
<th>Overweight %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td>4.9</td>
<td>64.6</td>
<td>15.7</td>
<td>14.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Alaska</td>
<td>5.7</td>
<td>63.6</td>
<td>19.6</td>
<td>11.1</td>
<td>100.0</td>
</tr>
<tr>
<td>Alabama</td>
<td>6.1</td>
<td>59.3</td>
<td>17.9</td>
<td>16.7</td>
<td>100.0</td>
</tr>
<tr>
<td>Arkansas</td>
<td>6.3</td>
<td>60.8</td>
<td>16.4</td>
<td>16.4</td>
<td>100.0</td>
</tr>
<tr>
<td>Arizona</td>
<td>5.0</td>
<td>65.3</td>
<td>17.5</td>
<td>12.2</td>
<td>100.0</td>
</tr>
<tr>
<td>California</td>
<td>4.7</td>
<td>65.3</td>
<td>16.8</td>
<td>13.2</td>
<td>100.0</td>
</tr>
<tr>
<td>Colorado</td>
<td>6.0</td>
<td>72.0</td>
<td>12.0</td>
<td>9.9</td>
<td>100.0</td>
</tr>
<tr>
<td>Connecticut</td>
<td>4.8</td>
<td>67.9</td>
<td>15.0</td>
<td>12.3</td>
<td>100.0</td>
</tr>
<tr>
<td>District of Columbia</td>
<td>5.6</td>
<td>54.8</td>
<td>16.7</td>
<td>22.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Delaware</td>
<td>4.8</td>
<td>59.7</td>
<td>20.7</td>
<td>14.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Florida</td>
<td>6.0</td>
<td>61.5</td>
<td>13.0</td>
<td>14.4</td>
<td>100.0</td>
</tr>
<tr>
<td>Georgia</td>
<td>3.5</td>
<td>64.8</td>
<td>15.3</td>
<td>16.4</td>
<td>100.0</td>
</tr>
<tr>
<td>Hawaii</td>
<td>6.6</td>
<td>66.5</td>
<td>13.5</td>
<td>13.3</td>
<td>100.0</td>
</tr>
<tr>
<td>Iowa</td>
<td>5.1</td>
<td>69.4</td>
<td>13.0</td>
<td>12.5</td>
<td>100.0</td>
</tr>
<tr>
<td>Idaho</td>
<td>6.0</td>
<td>68.4</td>
<td>15.5</td>
<td>10.1</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Question: Indicator 4.9: A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. Do you have one or more person(s) you think of as (child's name)'s personal doctor or nurse? (S5Q01)

<table>
<thead>
<tr>
<th>Region</th>
<th>% (C.I.)</th>
<th>No</th>
<th>Yes (C.I.)</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td>16.7  (16.2 - 17.1)</td>
<td>14,568</td>
<td>83.3  (82.9 - 83.8)</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>n = 12,077,887</td>
<td></td>
<td>n = 60,397,981</td>
<td></td>
</tr>
<tr>
<td>Texas</td>
<td>22.6  (20.4 - 24.8)</td>
<td>433</td>
<td>77.4  (75.2 - 79.6)</td>
<td>100.0</td>
</tr>
<tr>
<td></td>
<td>n = 1,400,973</td>
<td></td>
<td>n = 4,799,550</td>
<td></td>
</tr>
</tbody>
</table>

For a detailed explanation of the data MOVE your cursor over the text in the table or the bold text below. C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics, n = Cell size. Use caution in interpreting Cell sizes less than 50.
Example of Graph Comparing Two Geographic Areas

Children/youth (ages 0-17) with a personal doctor or nurse (PDN)

Nationwide vs. Texas

- Select a Subgroup --
  - Age - 3 groups
  - Race/ethnicity of child
  - Household income
  - Sex of child
  - Insurance type
  - Special health care needs status
  - Family structure

Compare State/Regions:

Compare Subgroups:

Chart Type: Bar Chart
Graph Comparing Two Geographic Areas and Three Subgroups of Children (by Type of Health Insurance)

Children/youth (ages 0-17) with a personal doctor or nurse (PDN)

Nationwide vs. Texas

% Do not have PDN by Insurance type

Compare State/Regions: Texas

Compare Subgroups: Insurance type

Chart Type: Bar Chart

Two Ways to Look at Data

- Start with your State Profile
- Search the data for single topics and indicators
Begin by selecting one of these three 3 steps - and don't forget to check out the State Profiles option below.

**Start HERE!**

1. Learn about the survey
2. Search the data
3. Report your results

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**On Its Way!**

2005 NS-CSHCN Data Coming Fall 2007

To Preview Content Guide Click Here

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Want to view your state's data profile?

- Chartbooks
- Publications & Presentations
- Data in Action
- Frequently Asked Questions
- E-Updates

CLICK HERE
State & Regional Profiles on Key Indicators for CYSHCN

Click on a state below or HRSA Region on the right to view results:
# National Survey of Children with Special Health Care Needs, 2001

**California**

Children ages 0-17 years old

## Prevalence Statistics

<table>
<thead>
<tr>
<th>Prevalence by Age:</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children 0-5 years of age</td>
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<td>Children 12-17 years of age</td>
<td>14.0</td>
<td>15.8</td>
</tr>
</tbody>
</table>

## Prevalence by Sex:

<table>
<thead>
<tr>
<th>Prevalence by Sex:</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>8.3</td>
<td>10.5</td>
</tr>
<tr>
<td>Male</td>
<td>12.3</td>
<td>15.0</td>
</tr>
</tbody>
</table>

## Prevalence by Poverty Level:

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<tr>
<th>Prevalence by Poverty Level:</th>
<th>State %</th>
<th>Nation %</th>
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<tr>
<td>0% - 99% FPL</td>
<td>7.5</td>
<td>13.6</td>
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</tbody>
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## Prevalence by Race/Ethnicity:

<table>
<thead>
<tr>
<th>Prevalence by Race/Ethnicity:</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic</td>
<td>7.6</td>
<td>8.5</td>
</tr>
</tbody>
</table>

## Indicator

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Description</th>
<th>State %</th>
<th>Nation %</th>
</tr>
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<tbody>
<tr>
<td>1)</td>
<td>% of CYSHCN whose health conditions consistently and often greatly affect their daily activities.</td>
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<td>2)</td>
<td>% of CYSHCN with 11 or more days of school absences due to illness.</td>
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<td>3)</td>
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<td>---------------------------------------------------------------------</td>
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<tr>
<td>8</td>
<td>27.3</td>
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<td></td>
<td>21.9</td>
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<tr>
<th></th>
<th>% of CYSHCN without a usual source of care (or who rely on the emergency room).</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>9.5</td>
</tr>
<tr>
<td></td>
<td>9.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>% of CYSHCN without a personal doctor or nurse.</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>13.2</td>
</tr>
<tr>
<td></td>
<td>11.0</td>
</tr>
</tbody>
</table>

**Family-Centered Care:**

<table>
<thead>
<tr>
<th></th>
<th>% of CYSHCN without family-centered care.</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>43.7</td>
</tr>
<tr>
<td></td>
<td>33.2</td>
</tr>
</tbody>
</table>

**Impact on Family:**

<table>
<thead>
<tr>
<th></th>
<th>% of CYSHCN whose families pay $1,000 or more in medical expenses per year.</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>11.8</td>
</tr>
<tr>
<td></td>
<td>11.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>% of CYSHCN whose families</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>19.2</td>
</tr>
<tr>
<td></td>
<td>20.9</td>
</tr>
</tbody>
</table>
INDICATOR #11: CYSHCN without family-centered care

California vs. Nationwide

<table>
<thead>
<tr>
<th>CYSHCN without family centered care</th>
<th>CYSHCN with family centered care</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>Nationwide</td>
</tr>
<tr>
<td>43.7</td>
<td>56.3</td>
</tr>
<tr>
<td>33.2</td>
<td>66.8</td>
</tr>
</tbody>
</table>
National Survey of Children's Health

Data Resource Center — Your Data... Your story

Begin by selecting one of these three steps — and don't forget to check out the State Profiles option below.

Start HERE!

1. Learn about the survey
2. Search the data
3. Report your results

JUST RELEASED!

Overweight and Physical Activity Among Children

Want to view your state’s data profile?

- Chartbooks
- Publications & Presentations
- Data in Action
- Frequently Asked Questions
- E-Updates

The Data Resource Center for Child and Adolescent Health is a project of the CAHMI supported by subcontracts Nos. 03-4205022 and 03-4205015 through cooperative agreement #U42 MC00241-02 from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, U.S. Department of Health and Human Resources, with the Early Intervention Research Institute, Utah State University.
To begin an interactive data search:

Select a starting point from the list below:

- Child Health Measures (Content Map)
  Over 60 indicators of child health and well-being

- State Profile (Content Map)
  Compare State Profile results for different groups of children

- Healthy People 2010 (Content Map)
  Survey content pertaining to Healthy People 2010 goals

- Survey Sections (Content Map)
  Responses to questions asked in each section of the survey

OR

Enter a word, phrase or topic to look for:

Find:  ○ All the words  ○ Any of the words  ○ Exact phrase
### Examples of available information

<table>
<thead>
<tr>
<th>2. Select a Topic</th>
<th>Select</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical and Dental Health</td>
<td>0</td>
</tr>
<tr>
<td>Emotional and Mental Health</td>
<td>0</td>
</tr>
<tr>
<td>Health Insurance Coverage</td>
<td>0</td>
</tr>
<tr>
<td>Health Care Access and Quality</td>
<td>0</td>
</tr>
<tr>
<td>Community and School Activities</td>
<td>0</td>
</tr>
<tr>
<td>Family Health and Activities</td>
<td>0</td>
</tr>
<tr>
<td>Neighborhood Safety and Support</td>
<td>0</td>
</tr>
</tbody>
</table>
Terms to Know

- Prevalence
- Weighted estimate
- $n$
- 95% Confidence interval
Prevalence:

\[ P = \frac{\text{number of people with condition or characteristic of interest in the population (n)} \at \text{a specific point in time}}{\text{total size of the population of interest (N)} \at \text{that specified time}} \]

From: http://apps.nccd.cdc.gov/brfssdatasystems/prevalence.asp
**Question:** How many hours per week do families of CYSHCN spend providing health care? [derived from C9q03 and C9q04]

<table>
<thead>
<tr>
<th></th>
<th>Less than 1 hour</th>
<th>1 - 4 hours per week</th>
<th>5 - 10 hours per week</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Functional limitations</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>24.2</td>
<td>33.6</td>
<td>14.2</td>
</tr>
<tr>
<td>CI</td>
<td>(22.5 - 25.8)</td>
<td>(31.6 - 35.5)</td>
<td>(12.9 - 15.5)</td>
</tr>
<tr>
<td>n</td>
<td>2,025</td>
<td>2,593</td>
<td>1,131</td>
</tr>
<tr>
<td>Est.</td>
<td>456,672</td>
<td>634,256</td>
<td>269,13</td>
</tr>
<tr>
<td><strong>Managed by Rx meds</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>58.7</td>
<td>29.6</td>
<td>5.4</td>
</tr>
<tr>
<td>CI</td>
<td>(57.3 - 60.2)</td>
<td>(28.2 - 30.9)</td>
<td>(4.8 - 5.6)</td>
</tr>
<tr>
<td>n</td>
<td>8,727</td>
<td>4,132</td>
<td>728</td>
</tr>
<tr>
<td>Est.</td>
<td>1,957,891</td>
<td>986,373</td>
<td>179,24</td>
</tr>
<tr>
<td><strong>Above routine need/use of services</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>%</td>
<td>42.6</td>
<td>35.9</td>
<td>10.0</td>
</tr>
</tbody>
</table>
Weighted prevalence estimate

Estimated number or % of people with the characteristic or response of interest after adjusting (weighting) to represent total population in the sampled area.
\( n = \) actual number of people in the sample with a specific characteristic or response to a survey question ----

before weighting to reflect population of the sampled area
95% Confidence Interval

• “Margin of Error” --- the statistical price you pay for not interviewing EVERYONE!

• Provides information about the precision of the prevalence estimate

• Width of CI influenced by sample size
  – Generally: the larger the sample, the smaller width of the CI -- and the more precise the prevalence estimate.
Making Data Useful?
Data Strengthens Your Message

Select data facts that:

- Support your goal
- Are persuasive and resonate with audience
- Are believable
- Make social sense
- Overcome barriers or skepticism
Effective Strategies

- Find positive stats to show progress
- Use personal stories to illustrate data
- Be consistent !!!
- Less is often “MORE”
Data in Action

Compelling stories and examples of ways others are using data from the Data Resource Center to make a difference!

Massachusetts Mom Storms the State House
Carrie Howland included data from the Data Resource Center in a presentation at the National Respite Coalition event in Washington DC, in support of the National Lifespan Respite Care Act.

Alaska’s Covering Kids Coalition Meeting
Presented by Barbara Hale
October 4, 2005

2006

Save the CDRC
Dr. Brian Rogers used state-by-state comparisons from the National Survey of Children with Special Health Care Needs in its preparation for a legislative hearing on proposed budget cuts to the Child Development and Rehabilitation Center (CDRC).

Family Voices Leader in North Dakota
Donene Felix, a parent activist, understands the power of data to support and strengthen the stories parents and caregivers have to tell about the challenges of caring for children with special needs.

Racial/Ethnic Disparities in Adolescent and Young Adult Health
The Center for Applied Research and Technical Assistance (CARTA) used data from the DRC in a report on racial/ethnic disparities in adolescent and young adult health.

Substance abuse treatment duration for Medicaid versus commercial clients in an HMO
Presented by Frances Lynch
February 14th, 2006

Children’s Health, The Nation’s Wealth: Assessing and Improving Child Health
The National Academies of Science used data from the National Survey of Children’s Health in a report that offers a new framework for the health measurement of children.

National Survey of Children with Special Health Care Needs
Chartbooks, Presentations, and Publications related to the National Survey of Children with Special Health Care Needs
Ask a Question

Your Email Address: 

Subject: 

Message: 

Send
Tell Us What You Think

1. How easy was it for you to find what you needed from the Data Resource Center website? (check one)
   - Very easy
   - Easy
   - Somewhat easy
   - Not easy, but I was able to find what I needed
   - Did not find what I needed (if you would like assistance, please provide your e-mail address in the comment box at the bottom of this page and we will contact you)

2. How do you plan to use information from this website? (check all that apply)
   - Research
   - Policy
   - Presentation
   - Paper/Document I am writing
   - To educate self or others
   - Other (please describe in the comment box at the bottom of this page)

3. How likely are you to visit the Data Resource Center website again? (check one)
   - Very likely
   - Likely
   - Somewhat likely
   - Not likely at all
   - Don’t know
Thank You

General Questions or Inquiries
cahmi@ohsu.edu

Christina Bethell, Director,
Child & Adolescent Health Measurement Initiative
bethellc@ohsu.edu
503-494-1862