National and State Findings and Resources for Assessing School-Related Functioning, Health Needs and Coordination of Care for Children and Youth with Special Health Care Needs (CYSHCN)

Using Data for Action

www.childhealthdata.org

National Assembly on School-Based Health Centers National Convention
June 30, 2007
Presented by: Christina Bethell, PhD, MPH, MBA
Agenda

9:00-9:15  Rationale, Definition and Tools for Identifying CYSHCN (PART A)

9:15-9:45  National and cross-State findings on CYSHCN and demonstration of the Data Resource Center for Child and Adolescent Health (www.childhealthdata.org) (PART B)

9:45-10:00  Application of data to inform and stimulate programs and policies (PART C)

10:00-10:15  Local application of methods to identify and measure health and health care quality (PART D)
Desired Take Home Messages

- **Identify CYSHCN in School-Based health centers**
- **Access available data** to identify and stimulate action to improve health and health care for CYSHCN
- **Conduct targeted measurement** locally drawing on nationally standardized tools
Part A: 
Rationale, Definition and Tools to Identify CYSHCN
Once upon a time in a galaxy far, far away...

There was great need to identify children and youth with special health care needs .........
Motivation for Identification of Children and Youth with Special Health Care Needs in School-Based Settings

- **Impact on School Performance and Development:** Having a special health care need impacts school performance, effects the probability of having specific risk and protective factors and influences healthy development and transition to adulthood.

- **Health Care Needs:** Distinct in terms of the type, scope, duration and complexity of health care needs.

- **Quality Assessment:** Given increased exposure, experiences of children and youth with special health care needs are more sensitive indicator of quality.

- **Costs:** Children and youth with special health care needs account for majority of health care costs and represent group for which greatest savings may occur.

- **Improvement Opportunities:** Information about quality shows tremendous need and opportunity for improvement.
Identification Purposes

- Evaluate Service Requirements
- Quality Measurement
- Assess Resource Requirements
- Early Identification at Point of Enrollment
- Early identification at point of service
- Prescreen for case management
Defining Special Health Needs – WHO do we want to identify?

NARROWER DEFINITIONS
include only those with very severe conditions or highly complex needs
(C only)

BROADER DEFINITIONS
include those with wider array of conditions, levels of severity and service use needs
(B + C)

MOST INCLUSIVE DEFINITIONS
include “at risk” groups
(A + B + C)

GROUP A
At risk for developing a special health care need

GROUP B
On going health conditions; above average service use needs; few to moderate functional limitations

GROUP C
On going health conditions; high or complex service use needs; moderate to severe functional limitations

Special Health Needs Continuum
Defining CSHCN

- **Conceptual Approaches**
  - Program-based
  - Diagnosis-based
  - Consequences-based

- **Specific Criteria**
  - Level and types of functional limitations
  - Level, frequency and types of services needed
  - Types of conditions
  - Diagnostic status
  - Duration of condition status
“Children with special health care needs are those who have or are at-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.”

— Maternal and Child Health Bureau, July 1998
Rationale for selecting a **non-condition specific, consequences-based** method?

- The **epidemiology** of children and youth with chronic conditions makes condition by condition assessments impractical for comparison purposes.

- Single condition monitoring provides an inadequate view of overall health, health needs and system performance for CYSHCN, who **share many common needs and often have more than one condition**.

- Many children and youth **experience consequences long before they receive a diagnosis** or the correct diagnosis, especially for children
  - with conditions for which clear diagnostic criteria do not exist are not routinely applied
  - with mental, behavioral or developmental problems.
What is the CSHCN Screener?

- A Non-Condition Specific, Health and Health Care Need Consequences-Based **Method for Identifying Children with Special Health Care Needs Targeting Categories B and C.**

- **Designed in 1998-2000 by CAHMI** to operationalize MCHB definition of CSHCN

- **Developed through a national process** involving physician leaders, state leaders, families, methods experts, and policymakers

- **Tested with over 36,000 children / youth** during development & testing phases and over 600,000 cases analyzed since 2000

- **Several versions tested,** leading to final screener, which takes 1 minute to complete.
What was the need for a short, parent/youth completed tool

- Parent/youth report most amendable to uniform data collection (vs. administrative records or medical chart data)
- Per survey item costs of national survey data collection high
- Longer surveys threaten participation rate.
What was the need for a short, parent/youth completed tool

- **Limits of condition checklists, medical records and administrative, diagnostic data**
  - Comprehensive condition check-lists need to be extraordinarily long
  - **Verbatim responses** to condition questions difficult to code and score
  - Condition check-list results difficult to interpret due small numbers for most conditions and high rates of co-morbidity
  - **Parent/patient report of conditions** show many over and under-identification problems as do administrative/medical record data.
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 ongoing 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
CYSHCN
Children meeting 1 or more of the above qualifying screening criteria
Sample question:

Q3) Is (child’s name) limited or prevented in any way in his/her ability to the things that most children of the same age can do?

**IF YES:**

Q3a) Is (child’s name) limitation in abilities because of ANY medical, behavioral or other health condition?

**IF YES:**

Q3b) Is this a condition that has lasted or is expected to last for at least 12 months?

All three parts of question 3 must be answered YES for a child to qualify on the functional limitations consequences criteria.
NO GOLD STANDARD? “Triangulate” to Validate

**SURVEY PARENTS**
- Ask about specific health services children need or use
- Ask about child health status & impact of any health problems

**MEDICAL RECORDS**
- Examine encounter & claims data for diagnoses listed in children’s records

**SURVEY PARENTS**
- Ask to name any specific diagnoses or health conditions children have

**CLINICAL EVALUATION**
- Review of children’s medical charts by pediatric clinicians

**COMPARE TO:**
- CYSHCN identified by other methods or definitions such as program eligibility
- Children not identified

Group id’ed by CSHCN Screener
How is the CSHCN Screener being used today in the US?

- Is used in many health plans, pediatric practices and hospital care environments

  - To identify CSHCN for purposes of follow-up and further assessment of health needs
  
  - To evaluate utilization, unmet needs, costs of care, health care services quality and outcomes for CSHCN.

- Is used in the US in at least five national, state and local surveys related to children’s health and health care to assess the prevalence of CSHCN.
National surveys using the federal MCHB definition and CSHCN Screener to identify CSHCN:

- National Survey of CSHCN
- National Survey of Children’s Health
- Medical Expenditure Panel Survey
- Consumer Assessment of Health Plans Survey—Child with Chronic Conditions
20.8% or 10.17 Million Children and Youth Age 6-17 in the US Qualified as Having a Special Health Care Need in 2003 Using the CSHCN Screener
Proportion of Children and Youth with Special Health Care Needs: Nation and Range Across States

<table>
<thead>
<tr>
<th>Age 0-5</th>
<th>Age 6-11</th>
<th>Age 12-17</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>NV; CA; LA; WV; NH</td>
<td>20.2%</td>
</tr>
<tr>
<td>Lowest State</td>
<td>CA</td>
<td>11.1%</td>
</tr>
<tr>
<td>Highest State</td>
<td>NH</td>
<td>27.4%</td>
</tr>
</tbody>
</table>

Proportion of Children and Youth Experiencing Specific Types of Special Health Care Needs: By Age

- **Dependent on Medications**: Age 0-5 (5.0%), Age 6-11 (16.4%), Age 12-17 (6.8%)
- **Experiences Functional Limitation**: Age 0-5 (4.6%), Age 6-11 (2.5%), Age 12-17 (0.0%)
- **Requires Specialized Therapies**: Age 0-5 (0.0%), Age 6-11 (5.0%), Age 12-17 (10.0%)
- **Requires Treatment for Emotional, Behavioral Issue**: Age 0-5 (0.0%), Age 6-11 (2.5%), Age 12-17 (15.0%)

Part B: National and State Findings on School-Age CYSHCN
Proportion of School-Age Children with Parent-Reported Excellent/Very Good Health Status: By CYSHCN Status

Children and Youth Age 6 to 17

<table>
<thead>
<tr>
<th>CYSHCN</th>
<th>Non-CYSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>National</td>
<td>67.4%</td>
</tr>
<tr>
<td>Lowest State</td>
<td>52.7%</td>
</tr>
<tr>
<td>Highest State</td>
<td>96.5%</td>
</tr>
</tbody>
</table>

Proportion of School-Age Children Reporting Connection with School and Confidence in Life: By CYSHCN Status

Children and Youth Age 13 to 18

Proportion of School-Age CYSHCN Active Outside School: By Poverty Status

CYSHCN Age 6 to 17

Proportion of School-Age Children and Youth Whose Mothers Report Excellent/Very Good Health Status: By CYSHCN Status

**Children and Youth Age 6 to 17**

- **National**: 57.80%
- **Lowest State**: 43.40%
- **Highest State**: 78.60%
- **KY**: 53.60%
- **CA**: 43.40%
- **MI**: 68.10%
- **VT**: 78.60%

Proportion of School-Age CYSHCN Whose Mothers Report Excellent/Very Good Health Status: By Race/Ethnicity

CYSHCN Age 6 to 17

White: 63.50%
Hispanic: 40.30%
Black: 44.00%

Proportion of School-Age CYSHCN With Healthy Mothers: By Poverty Status

Proportion of CYSHCN Whose Parent(s) Cut Back or Stopped Working Due to Child's Health Needs: By Age

- **30.5%** for National Age 6-11
- **24.4%** for National Age 12-17
- **24.3%** for Lowest State Age 6-11
- **15.3%** for Lowest State Age 12-17
- **38.9%** for Highest State Age 6-11
- **32.2%** for Highest State Age 12-17

**SOURCE:** 2001 National Survey of Children with Special Health Care Needs; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health (www.childhealthdata.org)
Proportion Missing Two or More Weeks of School in Last Year: CYSHCN vs. Non-CYSHCN

Children and Youth Age 6 to 17

<table>
<thead>
<tr>
<th></th>
<th>CYSHCN</th>
<th>Non-CYSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>National</strong></td>
<td>13.5%</td>
<td>8.9%</td>
</tr>
<tr>
<td><strong>Lowest State</strong></td>
<td>3.0%</td>
<td>1.8%</td>
</tr>
<tr>
<td><strong>Highest State</strong></td>
<td>22.7%</td>
<td>5.5%</td>
</tr>
</tbody>
</table>

Proportion of Children and Youth Repeating a Grade in School: CYSHCN vs. Non-CYSHCN

*Children and Youth Age 6 to 17*

- **National**
  - CYSHCN: 17.7%
  - Non-CYSHCN: 9.6%
- **Lowest State**
  - CYSHCN: 4.0%
  - Non-CYSHCN: 2.2%
- **Highest State**
  - CYSHCN: 37.9%
  - Non-CYSHCN: 21.1%

Proportion of School-Age CYSHCN Missing School or Repeating a Grade: By Poverty Status

CYSHCN Age 6 to 17

Two+ Weeks of School Missed

- Below Poverty Level: 19.9%
- 400%+ of Poverty Level: 9.0%

Repeated 1+ Grades in School

- Below Poverty Level: 30.7%
- 400%+ of Poverty Level: 10.2%

Proportion of School-Age Children and Youth Whose School Contacted Parents About Concerns: CYSHCN vs. Non-CYSHCN

Proportion of School-Age Children and Youth Whose School Contacted Parents About Concerns: By Race/Ethnicity

Children and Youth Age 6 to 17

- White: 32.70%
- Hispanic: 42.60%
- Black: 52.90%

Proportion with Emotional Difficulties: CYSHCN vs. Non-CYSHCN

Children and Youth Age 6 to 17

Moderate/Severe Socioemotional Difficulties
- CYSHCN: 33.0%
- Non-CYSHCN: 4.3%

Usually/Always Unhappy, Sad or Depressed
- CYSHCN: 5.2%
- Non-CYSHCN: 1.2%

Usually/Always Withdrawn and Uninvolved with Others
- CYSHCN: 4.9%
- Non-CYSHCN: 2.2%

CYSHCN STATE RANGE: 2.3% (WY) to 10.4% (MT)
CYSHCN STATE RANGE: .4% (UT) to 3.9% (TX)

Proportion of School-Age CYSHCN With Socio-Emotional Difficulties and School-Related Issues: By Poverty Status

CYSHCN Age 6 to 17

Proportion of School-Age Children and Youth with Public Health Insurance: CYSHCN vs. Non-CYSHCN

Children and Youth Age 6 to 17

- National:
  - CYSHCN: 32.00%
  - Non-CYSHCN: 23.20%

- Lowest State:
  - CYSHCN: 17.30%
  - Non-CYSHCN: 8.60%

- Highest State:
  - CYSHCN: 55.90%
  - Non-CYSHCN: 47.30%

Proportion of School Age CYSHCN with Public Health Insurance: By Race/Ethnicity

Proportion of CYSHCN Whose Parents Report Insurance is NOT Adequate to Meet Needs: By Age

<table>
<thead>
<tr>
<th>Age</th>
<th>National</th>
<th>Lowest State</th>
<th>Highest State</th>
</tr>
</thead>
<tbody>
<tr>
<td>6-11 Years</td>
<td>32.8%</td>
<td>22.2%</td>
<td>42.5%</td>
</tr>
<tr>
<td>12-17 Years</td>
<td>34.8%</td>
<td>25.2%</td>
<td>45.4%</td>
</tr>
</tbody>
</table>

Proportion of School-Age CYSHCN Whose Parents Report Health Insurance is Adequate to Meet Needs: By Household Income

Proportion of School-Age Children Meeting AAP Criteria for Having a Medical Home: By CYSHCN Status

Children and Youth Age 6 to 17

National

CYSHCN: 43.00%
Non-CYSHCN: 40.10%

Lowest State

AZ; NV
CYSHCN: 29.70%
Non-CYSHCN: 27.80%

Highest State

NH; MA
CYSHCN: 51.50%
Non-CYSHCN: 61.70%

Youth Reported Quality of Care: By CYSHCN Status

Children and Youth Age 13 to 18

<table>
<thead>
<tr>
<th></th>
<th>CYSHCN</th>
<th>Non-CSYSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth Reports Having Private/Confidential Visit</td>
<td>39%</td>
<td>24%</td>
</tr>
<tr>
<td>Youth Reports Providers Spend Enough Time</td>
<td>53%</td>
<td>50%</td>
</tr>
</tbody>
</table>

Proportion of School-Age CYSHCN Whose Parents Report Satisfaction with Communication Between the Child's Provider(s) and the School

CYSHCN Age 6 to 17

Proportion of School-Age CYSHCN With A Medical Home and Good Coordination with School: By Insurance Type

**Proportion of CYSHCN Age 6 to 17**

- **Has a Medical Home**
  - Public Insurance: 39.4%
  - Private Insurance: 46.2%

- **Satisfied with Provider-School Communication**
  - Public Insurance: 43.4%
  - Private Insurance: 40.2%

National Survey of Children with Special Health Care Needs

- 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
2001 National Survey of CSHCN

372,174 children, 0 - 17 yrs, in the 196,888 households contacted screened for having CSHCN

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
National Survey of Children’s Health

Child Characteristics

Family Level Influences

Neighborhood and Community Influences

Child Outcomes
NSCH 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)
National Survey of Children’s Health

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

Early Childhood questions (Section 6) asked for children ages 0-5.

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

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

102,353
How to Use the DRC Website
WEBSITE - www.childhealthdata.org
serves as an umbrella site for national survey data
Data Resource Center for Child & Adolescent Health
Your Data… Your story

National, state and regional survey data right at your fingertips!

Select a survey to search:

National Survey of Children’s Health (NSCH), 2003
- Compare results for your state, the nation, or subgroups of children.
- View state and regional profiles on key measures.
- Explore survey content relevant to Healthy People 2010.

OR

National Survey of Children with Special Health Care Needs (NS-CSHCN), 2001
- Search and compare national, state or regional prevalence estimates.
- Look for national, state or regional results on key indicators and MCHB outcomes.
- Compare findings for CSHCN from different age, race, income, or health status groups.

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

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

### Prevalence Statistics

<table>
<thead>
<tr>
<th>Child-Level Prevalence</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<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>
</tr>
</tbody>
</table>

### Household-Level Prevalence:

Percentage of Households with Children that have one or more CYSHCN, 0 - 17 yrs old | 17.0 | 20.0 |

### Prevalence by Age:

- Children 0-5 years of age | 5.7 | 7.8 |
- Children 6-11 years of age | 11.2 | 14.6 |
- Children 12-17 years of age | 14.0 | 15.8 |

### Prevalence by Sex:

- Female | 8.3 | 10.5 |
- Male | 12.3 | 15.0 |

### Prevalence by Poverty Level:

- 0% - 99% FPL | 7.5 | 13.6 |
- 100% - 199% FPL | 9.7 | 13.6 |
- 200% - 399% FPL | 11.0 | 12.8 |
- 400% FPL or greater | 13.8 | 13.6 |

### Prevalence by Race/Ethnicity:

- Hispanic | 7.6 | 8.5 |

### Indicator

<table>
<thead>
<tr>
<th>Indicator</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<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>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>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>
### Prevalence Data

Criteria selected:
- All States
- 2003
- Physical and Dental Health
- Weight status of children/youth ages 10-17 based on Body Mass Index for age (BMI-for-age)

**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>
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<tr>
<td>Alabama</td>
<td>6.1</td>
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<td>16.7</td>
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<td>16.4</td>
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<td>65.3</td>
<td>17.5</td>
<td>12.2</td>
<td>100.0</td>
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<tr>
<td>California</td>
<td>4.7</td>
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<td>16.8</td>
<td>13.2</td>
<td>100.0</td>
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<tr>
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<td>72.0</td>
<td>12.0</td>
<td>9.9</td>
<td>100.0</td>
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<td>Connecticut</td>
<td>4.8</td>
<td>67.9</td>
<td>15.0</td>
<td>12.3</td>
<td>100.0</td>
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<td>District of Columbia</td>
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<td>54.8</td>
<td>16.7</td>
<td>22.8</td>
<td>100.0</td>
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<tr>
<td>Delaware</td>
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<td>59.7</td>
<td>20.7</td>
<td>14.8</td>
<td>100.0</td>
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<td>6.0</td>
<td>61.5</td>
<td>13.0</td>
<td>14.4</td>
<td>100.0</td>
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<td>15.3</td>
<td>16.4</td>
<td>100.0</td>
</tr>
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<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>
**Example of Data Table Comparing Two Geographic Areas**

**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>No</th>
<th>Yes</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nationwide</strong></td>
<td>16.7</td>
<td>83.3</td>
<td>100.0</td>
</tr>
<tr>
<td>%</td>
<td>(16.2 - 17.1)</td>
<td>(82.9 - 83.8)</td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>14,568</td>
<td>87,491</td>
<td></td>
</tr>
<tr>
<td>Est.</td>
<td>12,077,887</td>
<td>60,397,961</td>
<td></td>
</tr>
<tr>
<td><strong>Texas</strong></td>
<td>22.6</td>
<td>77.4</td>
<td>100.0</td>
</tr>
<tr>
<td>%</td>
<td>(20.4 - 24.8)</td>
<td>(75.2 - 79.6)</td>
<td></td>
</tr>
<tr>
<td>n</td>
<td>433</td>
<td>1,740</td>
<td></td>
</tr>
<tr>
<td>Est.</td>
<td>1,400,973</td>
<td>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
Graph Comparing Two Geographic Areas and Three Subgroups of Children (by Type of Health Insurance)
Three Ways to Get Your Data

- Start with your state’s standard profile
- Start by creating your own customized state profile
- Search the data for single topics and indicators
Begin by selecting one of these three steps - and don't forget to check out the State Profiles option below.

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

Want to view your state's data profile?
- Chartbooks
- Publications & Presentations
- Data in Action
- Frequently Asked Questions
- E-Updates

On Its Way!
2005 NS-CSHCN Data Coming Fall 2007
To Preview Content Guide Click Here
### 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>Indicator</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child-Level Prevalence:</strong></td>
<td></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>
<td></td>
</tr>
<tr>
<td><strong>Household-Level Prevalence:</strong></td>
<td></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>
<td></td>
</tr>
</tbody>
</table>

<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>
<td>5.7</td>
<td>7.8</td>
</tr>
<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>
</tr>
</tbody>
</table>

<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>

<table>
<thead>
<tr>
<th>Prevalence by Poverty Level:</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>0% - 99% FPL</td>
<td>7.5</td>
<td>13.6</td>
</tr>
<tr>
<td>100% - 199% FPL</td>
<td>9.7</td>
<td>13.6</td>
</tr>
<tr>
<td>200% - 399% FPL</td>
<td>11.0</td>
<td>12.8</td>
</tr>
<tr>
<td>400% FPL or greater</td>
<td>13.8</td>
<td>13.6</td>
</tr>
</tbody>
</table>

<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>

### Child Health:

1) % of CYSHCN whose health conditions consistently and often greatly affect their daily activities.  
   State: 24.0 | Nation: 23.2

2) % of CYSHCN with 11 or more days of school absences due to illness.  
   State: 16.2 | Nation: 15.8

### Health Insurance Coverage:

3) % of CYSHCN without insurance at some point during the past year.  
   State: 9.9  | Nation: 11.6

4) % of CYSHCN currently uninsured.  
   State: 4.3  | Nation: 5.2

5) % of currently insured CYSHCN with coverage that is not adequate.  
   State: 36.5 | Nation: 33.8

### Access to Care:

6) % of CYSHCN with 1 or more unmet needs for specific health care services.  
   State: 23.1 | Nation: 17.7

7b) % of CYSHCN whose families needed but did not get all respite care, genetic counseling and/or mental health services.  
    State: 25.1 | Nation: 23.1

8) % of CYSHCN needing specialty care who had problems getting a referral.  
   State: 27.3 | Nation: 21.9

9) % of CYSHCN without a usual source of care (or who rely on the emergency room).  
   State: 9.5  | Nation: 9.3

10) % of CYSHCN without a personal
<table>
<thead>
<tr>
<th></th>
<th>% of CYSHCN needing specialty care</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>who had problems getting a referral.</td>
<td>27.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>% of CYSHCN without a usual source</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>of care (or who rely on the emergency room).</td>
<td>9.5</td>
</tr>
</tbody>
</table>

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

**Family-Centered Care:**

<table>
<thead>
<tr>
<th></th>
<th>% of CYSHCN without family-centered care.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td></td>
<td>43.7</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>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td></td>
<td>11.8</td>
</tr>
</tbody>
</table>

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

California vs. Nationwide

43.7 33.2 56.3 66.8

CYSHCN without family centered care
CYSHCN with family centered care
National Survey of Children's Health
Data Resource Center — Your Data... Your story

Create Your Own Profile...

1. Choose one or two geographic areas to compare

State/Region/Nation for Profile:   State/Region/Nation for Comparison:

2. Select a profile format

- Demographic Profile
- Chartbook State Profile
- Healthy People 2010 Profile
- Key Child Health Indicators Customized Profile

Next >
Create Your Own Profile...

**Selected Criteria:**

**Step 1:** Nationwide vs. District of Columbia  
**Step 2:** Key Child Health Indicators Customized Profile

3. Choose the Indicators for your profile

**Physical and Dental Health**
- [ ] All
- [ ] Indicator 1.1: Child health status
- [ ] Indicator 1.2: Healthy teeth
- [ ] Indicator 1.3: Breastfed ever
- [ ] Indicator 1.4: BMI for age
- [ ] Indicator 1.5: Physical activity
- [ ] Indicator 1.6: Lost school days
- [ ] Indicator 1.7: Childhood injuries
- [ ] Indicator 1.8: Accidental poisoning (National Data Only)
- [ ] Indicator 1.9: Moderate or severe health conditions
- [ ] Indicator 1.10: Impact of asthma on child
- [ ] Indicator 1.10a: Impact of current asthma on child

**Community and School Activities**
- [ ] All
- [ ] Indicator 5.1: Early childhood school
- [ ] Indicator 5.2: Repeating grades in school
- [ ] Indicator 5.3: Activities outside of school
- [ ] Indicator 5.4: Volunteer activities
- [ ] Indicator 5.5: Work for pay
- [ ] Indicator 5.6: Reading for pleasure
- [ ] Indicator 5.7: Religious services attendance

**Family Health and Activities**
- [ ] All
- [ ] Indicator 6.1: Maternal physical health status
- [ ] Indicator 6.2: Maternal mental health status
- [ ] Indicator 6.3: Overall maternal health status
# National Survey of Children's Health, 2003

## Key Child Health Indicators Customized Profile for Nationwide vs. District of Columbia

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

Shaded estimates do not meet the National Center for Health Statistics standard for reliability or precision because the relative standard error (RSE) is \( \geq 30\% \).

<table>
<thead>
<tr>
<th>Physical and Dental Health</th>
<th>Nationwide Pop. Est</th>
<th>Nationwide (95% CI)</th>
<th>District of Columbia (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicator 1.1: Children/youth ages 0-17 who are overweight based on Body Mass Index-for-age</td>
<td>4,607,912</td>
<td>(14.0, 15.4)</td>
<td>(18.8, 26.3)</td>
</tr>
<tr>
<td>Indicator 1.5: Children/youth ages 6-17 who exercised vigorously every day during the past week</td>
<td>12,561,056</td>
<td>(26.0, 26.6)</td>
<td>(23.7, 30.4)</td>
</tr>
<tr>
<td>Indicator 1.6: Children/youth ages 6-17 who missed 11 or more days of school because of illness or injury in the past 12 months</td>
<td>2,486,464</td>
<td>(5.2, 5.5)</td>
<td>(2.9, 5.7)</td>
</tr>
</tbody>
</table>

## Emotional and Mental Health

<table>
<thead>
<tr>
<th>Emotional and Mental Health</th>
<th>Nationwide Pop. Est</th>
<th>Nationwide (95% CI)</th>
<th>District of Columbia (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicator 2.3: Children/youth ages 3-17 who have moderate or severe difficulties with emotions, concentration, behavior, or ability to get along with others</td>
<td>5,620,307</td>
<td>(9.2, 9.9)</td>
<td>(8.6, 12.6)</td>
</tr>
<tr>
<td>Indicator 2.5: Children/youth ages 6-17 who inconsistently exhibit positive social skills</td>
<td>10,712,114</td>
<td>(21.9, 22.5)</td>
<td>(29.9, 37)</td>
</tr>
<tr>
<td>Indicator 2.6: Children/youth ages 6-17 who often exhibit problematic behaviors</td>
<td>3,814,253</td>
<td>(7.8, 8.2)</td>
<td>(9.6, 14.8)</td>
</tr>
</tbody>
</table>

## Health Care Access and Quality

<table>
<thead>
<tr>
<th>Health Care Access and Quality</th>
<th>Nationwide Pop. Est</th>
<th>Nationwide (95% CI)</th>
<th>District of Columbia (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicator 4.1: Children/youth ages 1-17 who received needed mental health care or services</td>
<td>58.7</td>
<td>(58.6, 58.7)</td>
<td>(58.6, 58.7)</td>
</tr>
</tbody>
</table>
National Survey of Children’s Health, 2003  
Key Child Health Indicators Customized Profile for Nationwide vs. District of Columbia

<table>
<thead>
<tr>
<th>Physical and Dental Health</th>
<th>Nationwide Pop. Est</th>
<th>Nationwide (95% CI)</th>
<th>District (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicator 1.4: Children/youth ages 0-17 who are overweight based on Body Mass Index-for-age</td>
<td>4,607,912</td>
<td>14.8 (14.2 - 15.4)</td>
<td>22.8 (18.8 - 26.8)</td>
</tr>
<tr>
<td>Indicator 1.5: Children/youth ages 6-17 who exercised vigorously every day during the past week</td>
<td>12,561,056</td>
<td>25.0 (25.4 - 26.6)</td>
<td>27.0 (23.7 - 30.4)</td>
</tr>
<tr>
<td>Indicator 1.6: Children/youth ages 6-17 who missed 11 or more days of school because of illness or injury in the past 12 months</td>
<td>2,486,464</td>
<td>5.2 (4.9 - 5.5)</td>
<td>4.3 (2.9 - 5.7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotional and Mental Health</th>
<th>Nationwide Pop. Est</th>
<th>Nationwide (95% CI)</th>
<th>District (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicator 2.3: Children/youth ages 3-17 who have moderate or severe difficulties with emotions, concentration, behavior, or ability to get along with others</td>
<td>5,620,307</td>
<td>9.2 (8.8 - 9.5)</td>
<td>10.6 (8.6 - 12.6)</td>
</tr>
<tr>
<td>Indicator 2.5: Children/youth ages 6-17 who inconsistently exhibit positive social skills</td>
<td>10,712,114</td>
<td>21.9 (21.3 - 22.5)</td>
<td>33.4 (29.3 - 37.7)</td>
</tr>
<tr>
<td>Indicator 2.6: Children/youth ages 6-17 who often exhibit problematic behaviors</td>
<td>3,814,253</td>
<td>7.8 (7.4 - 8.2)</td>
<td>12.2 (9.6 - 14.8)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health Care Access and Quality</th>
<th>Nationwide Pop. Est</th>
<th>Nationwide (95% CI)</th>
<th>District (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicator 4.5: Children/youth ages 1-17 who received needed mental health care or counseling during the past 12 months (children/youth who needed mental health care)</td>
<td>2,712,215</td>
<td>58.7 (56.5 - 61)</td>
<td>66.1 (56.2 - 76)</td>
</tr>
<tr>
<td>Indicator 4.8: Children/youth ages 0-17 who receive health care that meets the American Academy of Pediatrics definition of Medical Home</td>
<td>33,118,954</td>
<td>45.1 (45.6 - 46.7)</td>
<td>45.2 (42.4 - 48)</td>
</tr>
<tr>
<td>Indicator 4.12: Children/youth who had problems getting specialty care or services recommended by their personal doctor or nurse (PDTN) during the past 12 months (ages 0-17 who have a PDTN and needed specialty care, services, or equipment)</td>
<td>2,561,525</td>
<td>15.5 (14.7 - 16.3)</td>
<td>21.2 (16.2 - 26.2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Health and Activities</th>
<th>Nationwide Pop. Est</th>
<th>Nationwide (95% CI)</th>
<th>District (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicator 6.2: Children/youth ages 0-17 whose mothers' emotional health is excellent or very good</td>
<td>48,502,912</td>
<td>71.4 (70.3 - 72)</td>
<td>69.4 (66.6 - 72.2)</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?
CLICK HERE

- 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></td>
</tr>
<tr>
<td>Emotional and Mental Health</td>
<td></td>
</tr>
<tr>
<td>Health Insurance Coverage</td>
<td></td>
</tr>
<tr>
<td>Health Care Access and Quality</td>
<td></td>
</tr>
<tr>
<td>Community and School Activities</td>
<td></td>
</tr>
<tr>
<td>Family Health and Activities</td>
<td></td>
</tr>
<tr>
<td>Neighborhood Safety and Support</td>
<td></td>
</tr>
</tbody>
</table>
Terms to Know

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

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

From: http://apps.nccd.cdc.gov/brfssdataset/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</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 - 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>
Random sampling:

• allows certain characteristics to be estimated with precision

• larger sample sizes achieve more precision.
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.
\[ n = \text{actual number of people in the sample with a specific characteristic or response to a survey question} \]

before weighting to reflect population of the sampled area
“Margin of Error” --- the statistical price you pay for not interviewing EVERYONE!

95% Confidence Interval

- 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.
National and State Findings and Resources for Assessing School-Related Functioning, Health Needs and Coordination of Care for Children and Youth with Special Health Care Needs (CYSHCN)

PART C AND PART D
www.childhealthdata.org

National Assembly on School-Based Health Centers National Convention
June 30, 2007
Presented by: Christina Bethell, PhD, MPH, MBA
Agenda

9:00-9:15  Rationale, Definition and Tools for Identifying CYSHCN (PART A)

9:15-9:45  National and cross-State findings on CYSHCN and demonstration of the Data Resource Center for Child and Adolescent Health (www.childhealthdata.org) (PART B)

9:45-10:00  Application of data to inform and stimulate programs and policies (PART C)

10:00-10:15  Local application of methods to identify and measure health and health care quality (PART D)
PART C: Application of Data to Inform and Drive Evidence-Based Program and Policy Improvements
Why is Data Useful?
Why is Data Useful?

- **Identifying/documenting needs**
  - How many children have what needs?
  - How do needs vary across areas and programs?
  - How do needs vary across subgroups of children within and across areas and programs 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: Other School-Based Health Centers, Public Programs, Health plans, Hospitals, Providers, community groups, faith based organizations?
  - How can you share data to support common efforts, improve care?
Why is Data Useful?

- **Educating Policymakers**
  - What are key policy issues?
  - What programs or groups need what information?
  - What data could help them learn about needs and potential policies to consider?

- **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?
Why is Data Useful?

1. ADVOCACY: Data strengthens your position that change is needed.

2. REPRESENTATION: Data describes who you are and why your views are important.

3. JUSTIFICATION: Data supports your assertion that your program is worthwhile.
Data Impact

Stories give a face and heart to needs.

Data expands your stories to inform policy debates and drive change.
Knowledge of Audience

3 Scenarios:

1. DON'T KNOW basic stats
2. KNOW BUT DON'T CARE compelling stats
3. KNOW BUT DON'T BELIEVE stats from credible source

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

Kristin Grimm, Spitfire Strategies
Select data facts that:

- Support your goal
- Are persuasive and resonate with audience
- Are believable
- Make social sense
- Overcome barriers or skepticism
Make social sense:
There are more gun shops in California than McDonald’s.

Find positive stats to show progress:
Our school health center was so successful that it increased the rate of youth with private and confidential preventive care visits by 50%.
Ground findings in real people:

If all states performed like the best state, 1.3 million more youth with special needs would have health insurance that meets their needs.
Create a compelling analogy:

If all school-age CYSHCN with inadequate provider-school coordination were loaded into school buses, there would be a line of school buses about 830 miles long—nearly 200 miles longer than the entire state of California.
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 Feist, 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
Illustration on How Has DRC Data Been Used?
Program Example

ADVOCACY: Medicaid Buy-In
**Goal:** Convince state policy makers that a change is needed

Why should we implement a Medicaid buy-in program?
ADVOCACY: Medicaid Buy-In

Strategy:

National Survey of CSHCN data

+ 

Local system data

+ 

Photos of real Kids
ADVOCACY: Medicaid Buy-In

Audience:

• state Medicaid program mgmt
• Medicaid contracted providers
• Health Dept mgmt
• Governor’s office
• legislators
• advocates
Arizona’s Children with Special Health Care Needs

Options to Expand Coverage via the Deficit Reduction Act
Who are our CSHCN?

- 10.8% of Arizona’s children have a special health care need.
Insurance Coverage

- 13.6% of Arizona’s CSHCN were uninsured at some point during 2001.
19.1% of Arizona’s CSHCN had 1 or more unmet needs for specific health care services.
Insurance Coverage

- 25.6% of Arizona’s CSHCN needing specialty care had problems getting a referral.
18.3% of Arizona’s CSHCN had health needs that caused family financial problems.
Family Financial Impact

- 30.3% of Arizona’s CSHCN had health needs that caused a family member to cut back or stop working.
Part D: Tips and strategies to implement measurement
Why Measure?

- Goal for measurement is to influence:
  - Practice-level improvement
  - Policy-level improvement

- What is measured is what is focused on
  - Valid and standardized measures can speak volumes
    - Testimonies can actually increase in value and saliency when proceeded with quantitative data
Why Measure?

- Measures answer the questions “why is this activity important”
  - Measurement will enable/empower informed policy level improvement
  - Measurement can empower practice-level improvement.
  - Evaluation measurement informs improvements to implementation

- Measurement needs to be a primary component of a project, FROM THE START
  - Reliable and valid measures only collected if the measurement strategy is thoughtfully and carefully designed at the beginning
  - Measurement needs to be feasible
“Not everything that can be counted counts, and not everything that counts can be counted.”

Albert Einstein
What is a “measure?”

- A concept is not a measure!
- A measure has:
  - A denominator
  - A numerator
  - A clearly specified, standardized strategy for collecting the data
  - Clearly specified scoring methodology
  - Mechanisms for reporting and interpreting results
Desirable Measure Attributes:

- Valid
- Reliable
- Standardized Methodology
- Feasible
- Sustainable

May be valuable to think about measures used to evaluate the practices that could be incorporated into other state activities:

- Req. performance measure
- Measure to assess performance improvement project activities
CAVEATS

- Quality measurement is complex
  - No perfect measures
  - No perfect method or source for data
  - All data sources have benefits and drawbacks.
  - All approaches have strengths and weaknesses.

Goal:
Chose the measurement approach that feasibly yields the most valid and reliable measure possible.
Key Parameters for a Child and Youth Centered Measurement Strategy

- **Adopt a broad quality framework**
- Identify consumer-relevant quality measures that taken together **fill each component of the framework** and produce information relevant and actionable for all key partners (providers, families, health plan leaders, community, etc.)

  - **Cycle measures** from year to year so as to reduce burden in any one year and allow time for improvement.

- Emphasis communication of information to be sure to **tell the relevant and actionable story** each partner needs to hear.

- **Continuously monitor** the value of information and adjust as evolution occurs
Example of a Broad Framework

### National Healthcare Quality Report Framework

**Components of Health Care Quality**

<table>
<thead>
<tr>
<th>Health care needs</th>
<th>Effectiveness</th>
<th>Safety</th>
<th>Timeliness</th>
<th>Patient centeredness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staying healthy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting better</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with illness or disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>End of life care</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

- Equity is a component of health care quality that applies to all cells in the matrix
- Resource generation is another component discussed in the National Healthcare Report
- The first NHQR is due to Congress in 2003
Sources of data for quality measurement:

**Claims Data**

- **Pros**
  - Codes are tied to costs
  - Diagnostic specific codes
  - Can be relatively easy to obtain

- **Cons**
  - Claims data limited to the “owner” of the claim
    - Practice-level data can be difficult given the multiple payers
  - Completeness, quality and accuracy of data vary
  - Just because a code is there, does not mean it is used
  - Time lag in availability of data for new enrollees
  - “Carve outs”
  - Limited to “users” -- tells if service used not if those who needed it “got it” or those who “got it” needed it or if those who “got it and needed it got good care”
  - Denominator of children will vary depending upon type & number of codes chosen for inclusion
Sources of data for quality measurement:

Non-Electronic Medical record

- **Pros**
  - High level of clinical detail about diagnostic data, provider assessment and plan
  - Condition-specific information, if the condition has been identified
  - May contain info not available thru administrative or patient reported data

- **Cons**
  - Limited to events that occurs where the record is held
  - Can be expensive & time consuming to collect, requires practice participation
  - Clinician variability
  - Not a reliable, valid source of specific information about the discussions that happened during a visit
Data Source #3: PARENT REPORT

PATIENT EXPERIENCE of CARE

STRUCTURE of the HEALTH CARE SYSTEM

PROCESSES OF CARE

OUTCOMES OF CARE
Sources of data for quality measurement: Patient or youth survey

- **Pros**
  - Parents/youth most often the most valid reporter about 1) what happened during the visit and 2) child/youth health characteristics and 3) functioning, burden of illness and quality of life outcomes
  - Care experiences from patient/youth perspective can be highly relevant information
  - Can ask the parent/youth about multiple processes of care in multiple settings
  - For many relevant survey items/scale, national and state level data will be available via the national surveys

- **Cons**
  - Can only assess what is communicated with the parent/youth and/or involves their experience
  - Require infrastructure and processes beyond medical charts and billing data
  - Response rates can be a challenge
  - Misconceptions about the validity of parent/youth report about processes of care
Examples of Relevant CAHMI Quality Tools Developed (compliment HEDIS and others)

- **Early childhood health promotion, prevention & development (PHDS)**
  - Survey-based measures for use in quality evaluations, quality improvement & national assessment of Bright Futures guidelines
  - 8+ quality measures
  - Measure of standardized developmental screening under development

- **Young adult/adolescent health promotion and prevention (YAHCS)**
  - Survey-based measures for use in quality evaluations, quality improvement and national assessment of Bright Futures guidelines
  - 7+ quality measures
Examples of Relevant CAHMI Quality Tools Developed (compliment HEDIS and others)

- **Children with special health care needs (CSHCN module)**
  - screener, sampling strategy and question supplement -- for use with CAHPS and other surveys (e.g. BRFSS, MEPS, SLAITS...)
  - 10-15 quality measures with CAHPS CCC
  - Mental, behavioral and emotional health care quality measures also possible to derive from data

- **Medical Home Measurement Module**

- **Avoidable hospitalization for young children with acute conditions**

- **Hospital quality: communication, quality and safety of care (focus on LEP clients)**
Youth vs. Parent Report of Excellent/Very Good Health Status: Comparison From Two National Surveys

Children and Youth Age 13 to 18

Youth Report: 43.0%
Parent Report: 67.4%

CHILD HEALTH TOOLBOX

Measuring Performance in Child Health Programs
Access, Quality, and Health Service Delivery

Concepts, tips, and tools for evaluating Medicaid, the State Children’s Health Insurance Program (SCHIP), Title V, and other health care service programs for children.

How can you tell whether children are receiving quality health care?
How do you know when a health program is functioning effectively?
Where can you find tools to help answer these questions?
If the right tool is not available, how can you develop your own?

This online resource can help State and local policymakers and program directors and staff to answer these and related questions about measuring health care performance in child health programs.

Major Sections
- Understanding Performance Measurement
- Uses of Performance Measurement
- Why Child Health Measures?
- Established Child Health Measures
- Emerging Measures
- Choosing Performance Measures
Four basic functions required for implementation

- Convening key stakeholders and identifying partnerships
- Developing Quality Measures and Gathering Quality Information
- Effectively communicating to engage and influence
- Educating on Methods and Communicating Quality Information
**Additional General Measurement Issues**

- **Importance of child/youth-level measures**
  - Measures of how one child/youth experiences multiple components of care
- **Measurement strategies need to be specific for each unit of analysis**
  - For example, if there are multiple practice sites
    - Sample size and data collection need to be adjusted per site, but standardized methods maintained.
- **(Even small) Pilot testing of measurement approach is crucial**
  - Avoids measures with incomplete, non-valid data
  - Identifies areas of confusion in measurement approach.
- **Continued technical assistance and periodic quality checks necessary**
- **Periodic reporting of measurement findings is essential to continue participation and buy in about the value of measurement**
Closing Summary

- **Identify CYSHCN in School-Based health centers**
- **Access available data to identify and stimulate action to improve health and health care for CYSHCN**
- **Conduct targeted measurement locally drawing on nationally standardized tools**
Thank You

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