Data for Action:
Using the Data Resource Center
To Strengthen Your Story!

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Agenda

- Introduction and Overview – Nora Wells
- Tips on How Data Helps – Becky Adelmann
- How to Use the Website—Christina Bethell
- Real Data in Action — Wendy Benz
Introduction and Overview

Nora Wells
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?

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

2. 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
Tips on How Data Helps

Becky Adelmann
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
Family stories give a face and heart to needs.

Data expands family stories to inform policy debates and drive change.
Strengthening 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”
Make social sense:
There are more gun shops in California than McDonald’s.

Find positive stats to show progress:
Title IX was so successful that it increased young women’s participation in high school sports by 847%.
How has the DRC Has Been Used?

Identifying/documenting needs

- How many children in your state have unmet needs?
- How does data support what you’re hearing from 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?
How has the DRC Has Been Used?

Educating Policymakers

- Key policy issues for your state
- Programs needs for information
- Data to educate about child health needs

Advocacy

- Pressure points in program budgets, priorities
- Effective methods to present your case
- Use of data in Fact Sheets, testimony, the media, to strengthen family stories

Grant Writing

- Use of data to strengthen your proposal
Medicaid Waiver
for medically-involved children

FAST FACTS
- HB 2406 will create a Medically Involved Home Care Program in the Department of Human Services.
- Up to 200 children will be eligible for Medicaid Waiver services irrespective of family income.
- Services may include home nursing care, durable medical equipment, and respite care.

Oregon families caring for medically involved children receive very little, if any, support or assistance. Many families are forced to place their children in foster care or nursing homes. Others impoverish themselves to access Medicaid services. Many more simply exhaust themselves physically and financially as they provide demanding care 24 hours a day, putting their entire families at risk. Oregon is one of the few states in the nation that does not provide access to a Medicaid Waiver for medically-involved children.

Who are "medically involved children"? These are children whose level of disability requires total assistance with eating, dressing, toileting, and mobility. They may use feeding tubes, incontinence supplies, require durable medical equipment, and often require frequent repositioning over a 24 hour period.

What would a Medicaid Waiver do? A waiver would allow medically-involved children to receive help and support in their family home even if their family is not eligible for Medicaid.

Why should Oregon seek a Medicaid Waiver for medically-involved children?
- Children should have the opportunity to grow up in their own home with families who love them.
- Families should not be forced to choose out-of-home placement to meet their children’s needs.
- It costs less to support a child in their family home than in a nursing home or foster care.
Family Opportunity Act
Expanded access to healthcare for children with disabilities

Families of children with disabilities often face extraordinary out-of-pocket expenses to meet their children’s health needs. Even with private insurance, families may not have coverage available for items such as therapies, durable medical equipment, and/or procedures related to the child’s disability diagnosis. Many families incur tremendous medical expenses in caring for their children, and some families impoverish themselves in order to maintain eligibility for Medicaid coverage. Over 42% of Oregon families of children with special healthcare needs have inadequate insurance coverage.

HB 2407 would allow Oregon to take advantage of the Federal Family Opportunity Act (FOA), providing families of children with disabilities the opportunity to buy into the State Medicaid Program.

Who would be eligible in Oregon?
Data in Action

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

Family Opportunity Act
The Oregon Developmental Disabilities Coalition used data from the DRC to write a Fact Sheet on expanding access to healthcare for children and their families. The Fact Sheet was provided to state legislators by family advocates.

Arizona’s Children with Special Health Care Needs
Wendy Benz, Coordinator of Family Health Information with Raising Special Kids, used data from the DRC to communicate stories and statistics to policymakers, while working to improve Arizona’s health care delivery system.

Medicaid Waiver
The Oregon Developmental Disabilities Coalition used data from the DRC to write a Fact Sheet for state legislators to encourage support of a Medicaid waiver for medically involved children. The one page document provides a quick overview that clearly outlines facts and how proposed legislation will benefit children and their families.

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
How to Use the Website

Christina Bethell
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.

Want to view your state's data profile?

CLICK HERE

Want to view your state's data profile?

CLICK HERE

www.childhealthdata.org
What Are the Differences?

Population

NSCH

All children

NS-CYSHCN

CYSHCN

Topic Areas

Health, Family, Neighborhood

Health, Unmet Needs, Family Impact

Sample Size per state

2,000 (300 CYSHCN)

750
Child Health Measures

Over 60 measures of child health and well-being derived from the survey

Physical and Dental Health
- 1.1 Child health status
- 1.2 Healthy teeth
- 1.3 Breathing issues
- 1.4 BMI for age
- 1.5 Physical activity
- 1.6 Lost school days
- 1.7 Childhood injuries
- 1.8 Accidental poisoning
- 1.9 Moderate or severe health conditions
- 1.10 Impact of asthma on child
- 1.11 Impact of asthma on family
- 1.12 Hospitalization for asthma

Emotional and Mental Health
- 2.1 Parent-reported concerns
- 2.2 At risk for developmental delay
- 2.3 Socio-emotional difficulties
- 2.4 Impact of children's socio-emotional difficulties on family
- 2.5 Social competence
- 2.6 Problematic behaviors
- 2.7 Medication for ADD/ADHD
- 2.8 Autism ever

Health Insurance Coverage
- 3.1 Currently insured
- 3.2 Consistent health insurance coverage
- 3.3 Insurance type

Health Care Access and Quality
- 4.1 Preventive medical care
- 4.2 Getting needed preventive dental care
- 4.3 Medical and dental preventive care
- 4.4 Emergency room visits
- 4.5 Getting needed mental health care
- 4.6 Getting needed medical care
- 4.7 Getting needed prescription medications
- 4.8 Medical home
- 4.9 Personal doctor or nurse (PDN)
- 4.10 Communication with PDN
- 4.11 Getting needed care from PDN
- 4.12 Access to specialty care or services
- 4.13 Care coordination from PDN
- 4.14 Doctor asks about concerns
- 4.15 Getting needed information

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

Family Health and Activities
- 6.1 Maternal physical health status
- 6.2 Maternal mental health status
- 6.3 Overall maternal health status
- 6.4 Household smoking
- 6.5 Working poor households
- 6.6 Outings with family
- 6.7 Reading to young children
- 6.8 Shared meals
- 6.9 Adequate sleep
- 6.10 TV watching
- 6.11 Staying home alone
- 6.12 Parental aggravation with child
- 6.13 Last minute child care changes
- 6.14 Impact of child care on family work life
- 6.15 Child care issues
- 6.16 Non-parental child care

Neighborhood Safety and Support
- 7.1 Supportive neighborhoods
- 7.2 Safe neighborhoods
- 7.3 Safe schools
2005-2006 National Survey of Children with Special Health Care Needs
Data Resource Center – Your Data... Your story

Key Indicators and Core Outcomes

5 Core Outcomes Possible to Assess (organized by degree of expected comparability to 2001)

- Comparability Not Impacted
  Outcome #1: Families partners in decision-making/satisfied with services
  Outcome #3: Adequate insurance

- Comparability Likely Impacted
  Outcome #2: Medical Home (four of five components had significant changes in survey items used)
  Outcome #5: Community-based services organized so families can use them easily
  Outcome #6: Transition to Adulthood

Key Indicators with No Changes Expected to Substantially Impact Comparability to 2001

- Indicator #1: % with health conditions consistently and often greatly affecting daily activities
- Indicator #2: % school-age children and youth with 11 or more days of school absences due to illness
- Indicator #3: % with any gap in insurance
- Indicator #4: % currently uninsured
- Indicator #5: % with currently insured with adequate insurance
- Indicator #6: % with unmet needs for range of specific services
- Indicator #7: % with family-centered care
- Indicator #13: % with families experiencing financial problems due to child’s health
- Indicator #14: % with families spending 11+ hours per wk providing/coordinating care for child

Key Indicators with Substantial Changes that May Impact Comparison with 2001

- Indicator #7b: % whose families with unmet family support services (respite, genetic counseling or mental health services)
- Indicator #8: % problems getting needed referral(s)
- Indicator #9: % without usual source of care or who rely on the ER
- Indicator #10: % without a personal doctor or nurse
- Indicator #12: % with families paying more than $1000 for child’s medical expenses
- Indicator #15: % with family members who cut back or stopped working due to child’s health needs

Health and functioning
1. 18 items on specific physical, social and communication functioning issues child experiences
2. 18 items on the name of specific health conditions or problems child currently has

Health care access and utilization
1. Number of ER visits
2. Problems getting referrals for doctors or other services

Other Topics
1. Primary household language
2. Need and get interpreter
3. Family composition

*There are many other “new” items. However, these are in topical areas also represented in 2001 survey. Go to www.childhealthdata.org for more information.
Three Types of Data

1. State Profile Tables
2. “All States” Comparison Tables
3. 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, 2011

### 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>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>

<table>
<thead>
<tr>
<th>Prevalence by Sex</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of Children &amp; Youth with Special Health Care Needs, 0 - 17 yrs old</td>
<td>8.3</td>
<td>12.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Prevalence by Poverty Level</th>
<th>0% - 99% FPL</th>
<th>100% - 199% FPL</th>
<th>200% - 399% FPL</th>
<th>400% FPL or greater</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of Children &amp; Youth with Special Health Care Needs, 0 - 17 yrs old</td>
<td>7.5</td>
<td>9.7</td>
<td>11.0</td>
<td>13.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Prevalence by Race/Ethnicity</th>
<th>Hispanic</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of Children &amp; Youth with Special Health Care Needs, 0 - 17 yrs old</td>
<td>7.6</td>
<td>8.5</td>
</tr>
</tbody>
</table>

#### Indicator

<table>
<thead>
<tr>
<th>Child Health</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>
</tbody>
</table>

**Health Insurance Coverage:**

<table>
<thead>
<tr>
<th>Child Health</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<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>
</tbody>
</table>

**Access to Care:**

<table>
<thead>
<tr>
<th>Child Health</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<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 care plan.</td>
<td>13.2</td>
<td>11.0</td>
</tr>
</tbody>
</table>
Example of “All State” Comparison Table
(Option to Sort by Rank)

<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>18.0</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>

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.
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>Nationwide</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></td>
<td>14,568</td>
<td>87,491</td>
<td></td>
</tr>
<tr>
<td></td>
<td>12,077,887</td>
<td>60,397,981</td>
<td></td>
</tr>
<tr>
<td>Texas</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></td>
<td>433</td>
<td>1,740</td>
<td></td>
</tr>
<tr>
<td></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)

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

% Do not have PDN × Insurance type

[Bar chart with data and comparison between Nationwide and Texas for each insurance type]

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)
Two Ways to Look at Data

1. Start with your State Profile
2. 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.

**Start HERE!**

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

**On Its Way!**

2005 NS-CSHCN Data Coming Fall 2007
To Preview Content Guide
Click Here

Want to view your state's data profile?

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

Click Here
# National Survey of Children with Special Health Care Needs, 2001

**California**

Children ages 0-17 years old

## Prevalence Statistics

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Child-Level Prevalence:</th>
<th>Household-Level Prevalence:</th>
</tr>
</thead>
<tbody>
<tr>
<td>State %</td>
<td>Nation %</td>
<td>State %</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>
</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>
</tr>
</tbody>
</table>

## Prevalence by Age:

<table>
<thead>
<tr>
<th>Age Group</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>

## Prevalence by Sex:

<table>
<thead>
<tr>
<th>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:

<table>
<thead>
<tr>
<th>FPL 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>

## Prevalence by Race/Ethnicity:

<table>
<thead>
<tr>
<th>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>Child Health:</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>
</tbody>
</table>

## Health Insurance Coverage:

<table>
<thead>
<tr>
<th>Coverage</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<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>
</tbody>
</table>

## Access to Care:

<table>
<thead>
<tr>
<th>Access</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<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>
8) % of CYSHCN needing specialty care who had problems getting a referral.

9) % of CYSHCN without a usual source of care (or who rely on the emergency room).

10) % of CYSHCN without a personal doctor or nurse.

Family-Centered Care:

<table>
<thead>
<tr>
<th>Impact on Family:</th>
</tr>
</thead>
<tbody>
<tr>
<td>12) % of CYSHCN whose families pay $1,000 or more in medical expenses per year.</td>
</tr>
<tr>
<td>13) % of CYSHCN whose families</td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>11.8</td>
<td>11.2</td>
</tr>
<tr>
<td>19.2</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>43.7</td>
<td>56.3</td>
</tr>
<tr>
<td>33.2</td>
<td>66.8</td>
</tr>
</tbody>
</table>

[Bar chart showing comparison between California and nationwide data]
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.

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

Start HERE!

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

CLICK HERE

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
<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>
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
Real Data in Action

Wendy Benz
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.
How Have We Used the DRC?

1. Medicaid Buy-In
   General State Demographic data

2. Electronic Health Records System
   Parent-Professional Partnership data

3. Health Care Provider Trainings
   Family-Centered Care data
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

+ Catalyst Center data analysis

+ Photos of our 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?

1. 10.8% of Arizona’s children have a special health care need.
Insurance Coverage

1. 13.6% of Arizona’s CSHCN were uninsured at some point during 2001.
Insurance Coverage

1. 19.1% of Arizona’s CSHCN had 1 or more unmet needs for specific health care services.
1. 25.6% of Arizona’s CSHCN needing specialty care had problems getting a referral.
1. 18.3% of Arizona’s CSHCN had health needs that caused family financial problems.
1. 30.3% of Arizona’s CSHCN had health needs that caused a family member to cut back or stop working.
REPRESENTATION:
Electronic Health Records System
Goal: Convince policymakers that family representatives should be included.

Why should we consider your views in the design of our state’s electronic health records system?
Strategy:

Personal story & data

+ National Survey of CSHCN data
Audience:

• state EHRS committee
• state Medicaid program
• Governor’s office
• hospital systems
• doctor practices & other providers
• insurance companies/health plans
• computer systems designers
• attorneys
“My daughter Allison was born two months premature. She spent her first six weeks in the NICU. At discharge, we received her hospital medical records file – it was 3” thick; I know because I measured it...
REPRESENTATION: EHRS
“In the 13 years since Allison was born, we have moved six times across three different states. We have collected medical records -- all paper -- from:
9 pediatricians
5 neurologists
4 orthopedists
6 ENTs
7 audiologists
10 speech therapists
12 physical therapists
8 occupational therapists
7 oral motor therapists
3 child psychologists...
Allison’s medical records file is now a file cabinet.
11% of Arizona’s kids have special health care needs.
70% of Arizona’s families of kids with special needs do not believe they are receiving effective care coordination.
75% of our families do not believe that doctors & other programs share information effectively.
Program Example

**JUSTIFICATION:** Health Care Provider Training
Goal: Convince educators & health care students of the value of family-centered care

Why should future health care providers learn (and care) about family-centered care practices?
JUSTIFICATION: Provider Training

Strategy:

Family-Centered Care Curriculum

+  

Personal stories from Family Faculty

+  

National Survey of CSHCN data
Audience:

- education program coordinators
- medical residents
- dental students
- student nurses
Needs Statement

To effectively coordinate care and achieve improved health outcomes for children, providers need an adequate understanding of family-centered care principles and related concepts.
JUSTIFICATION: Provider Training
Supporting Data for Arizona

70% families do not receive effective care coordination.

75% families do not believe that doctors and other programs share information effectively.

36% families do not receive family-centered care.
JUSTIFICATION: Provider Training
49% families are not partners in decision-making and satisfied with their child’s care.

66% Hispanic families are not partners in decision-making and satisfied with their child’s care.
JUSTIFICATION: Provider Training
64% Arizona children do not have a Medical Home (national average is 54%).

50% Arizona’s CSHCN do not have a Medical Home.

66% Arizona’s CSHCN with public insurance do not have a Medical Home.
Data Resource Center for Child & Adolescent Health

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