Data Resource Center for Child & Adolescent Health

www.childhealthdata.org

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

Presented by:

Nora Wells

Christina Bethell

Becky Adelmann

Wendy Benz

Moderated by:

Renee Schwalberg

FAMILY VOICES®

CAHMI
The Child and Adolescent
Health Measurement Initiative

Rene Schwalberg
Director, Health Policy
Health Systems Research, Inc.
RSchwalberg@hsrnet.com
207-772-1410

Nora Wells
Family Voices National Office
nwells@familyvoices.org
(617) 399-8323

Becky Adelmann
Family Voices of Oregon
Oregon F2F Health Information & Education Center
adelmann@ohsu.edu
503-494-7657

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

Wendy Benz
Family Voices of Arizona
Raising Special Kids
wendyb@raisingspecialkids.org
602-242-4366

Data Resource Center for Child & Adolescent Health

Agenda

- Introduction and Overview – Nora Wells

- Tips on How Data Helps – Becky Adelmann

- How to Use the Website—Christina Bethell

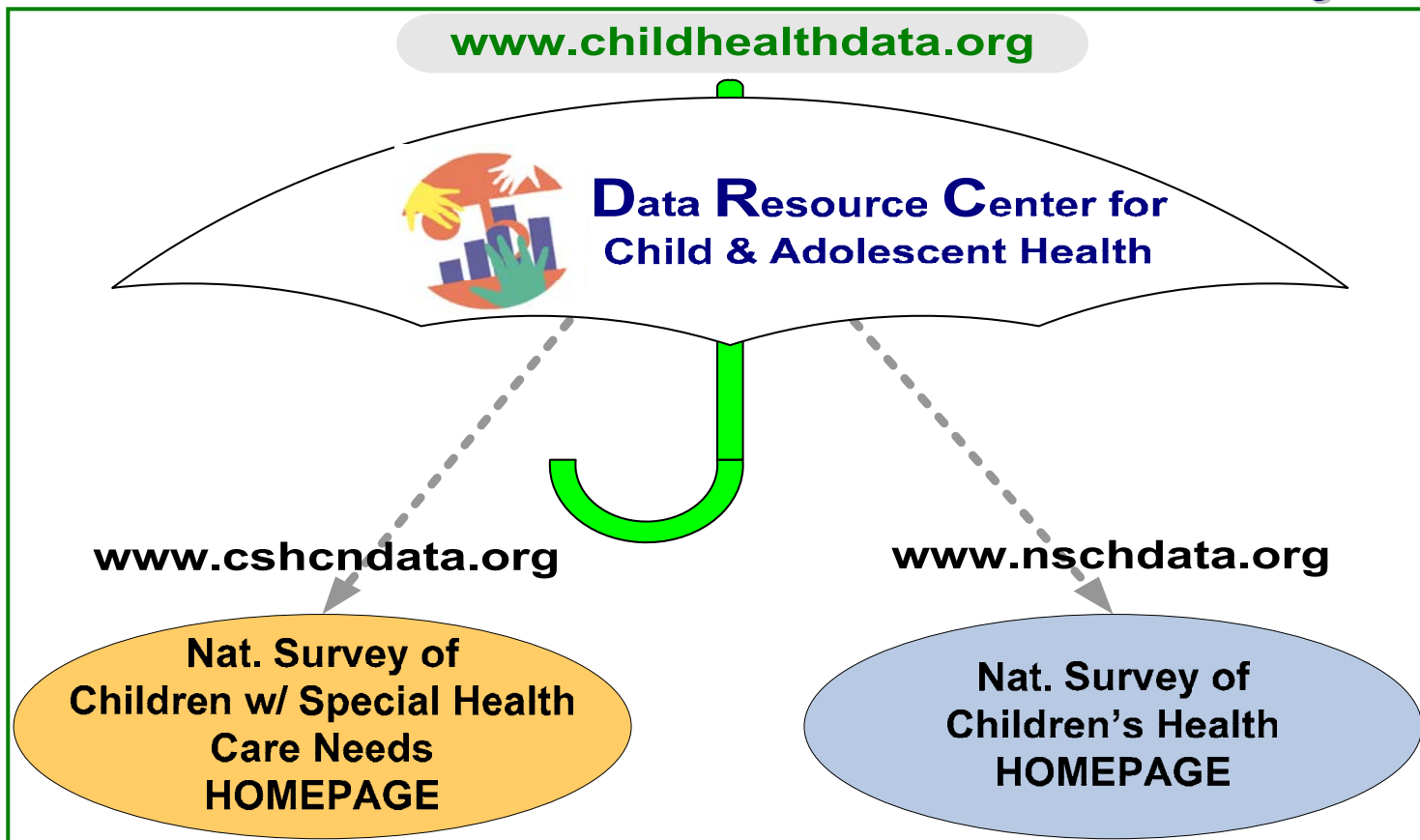- Real Data in Action — Wendy Benz

Introduction and Overview

Nora Wells

DRC Website

WEBSITE - www.childhealthdata.org
serves as an umbrella site for national survey data

www.childhealthdata.org

Data Resource Center for
Child & Adolescent Health

www.cshcndata.org

www.nschdata.org

Nat. Survey of
Children w/ Special Health
Care Needs
HOMEPAGE

Nat. Survey of
Children's Health
HOMEPAGE

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

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*

Data Impact

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

DD COALITION

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.

1/2007 v7

18

DD COALITION

Family Opportunity Act
Expanded access to healthcare for children with disabilities

FAST FACTS

→ Over 24% of Oregon families of children with special healthcare needs report financial problems due to their child's medical expenses.

→ Nearly 33% of Oregon families of children with special healthcare needs have cut back or stopped working in order to meet their child's health needs.

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?

8.5 x 11 in

National Survey of Children with Special Health Care Needs
Data Resource Center — Your Data… Your story

DRC Home   Link to Us   Glossary   Search   Contact Us

- CSHCN Survey Home
- Start Data Query
- State Profiles
- Quick Guides
- Resources for Data Users
- Especially for Families
- State Data Sets

- ONLINE TOUR
- ASK A QUESTION
- ANSWER OUR BRIEF USER POLL
- TELL A FRIEND
- YOUR BRIEFCASE

This site is a project of

CAHMI
The Child and Adolescent
Health Measurement Initiative

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

20

How to Use the Website

Christina Bethell

File   Edit   View   Favorites   Tools   Help

Back   Search   Favorites

Address   http://www.childhealthdata.org/content/Default.aspx   Go   Links

Data Resource Center for Child & Adolescent Health

Your Data… Your story

DRC Home   Link to Us   Glossary   Search   Contact Us

Online Tour NEW!

Ask a Question

Tell a Friend

E-Updates

Answer Our Brief User Poll

- NSCH Survey
- NS-CSHCN Survey
- AWSTATS

This site is a project of

CAHMI

The Child and Adolescent Health Measurement Initiative

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.

Want to view your state's data profile?

CLICK HERE

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

Internet

www.childhealthdata.org

What Are the Differences?

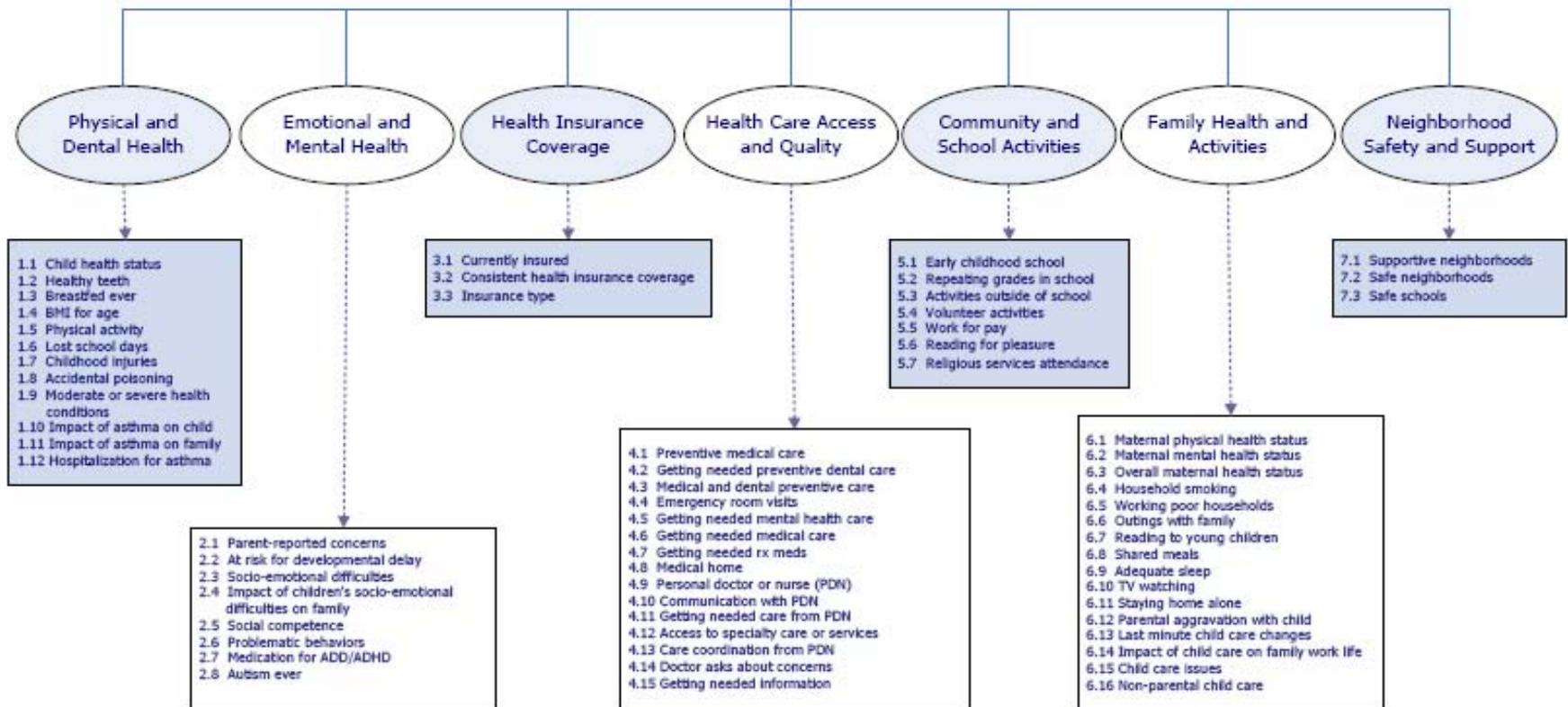|	**NSCH**	**NS-CSHCN**
Population	**All children**	**CYSHCN**
Topic Areas	**Health, Family, Neighborhood**	**Health, Unmet Needs, Family Impact**
Sample Size per state	**2,000 (300 CSHCN)**	**750**

National Survey of Children's Health
Data Resource Center — Your Data... Your story

Child Health Measures

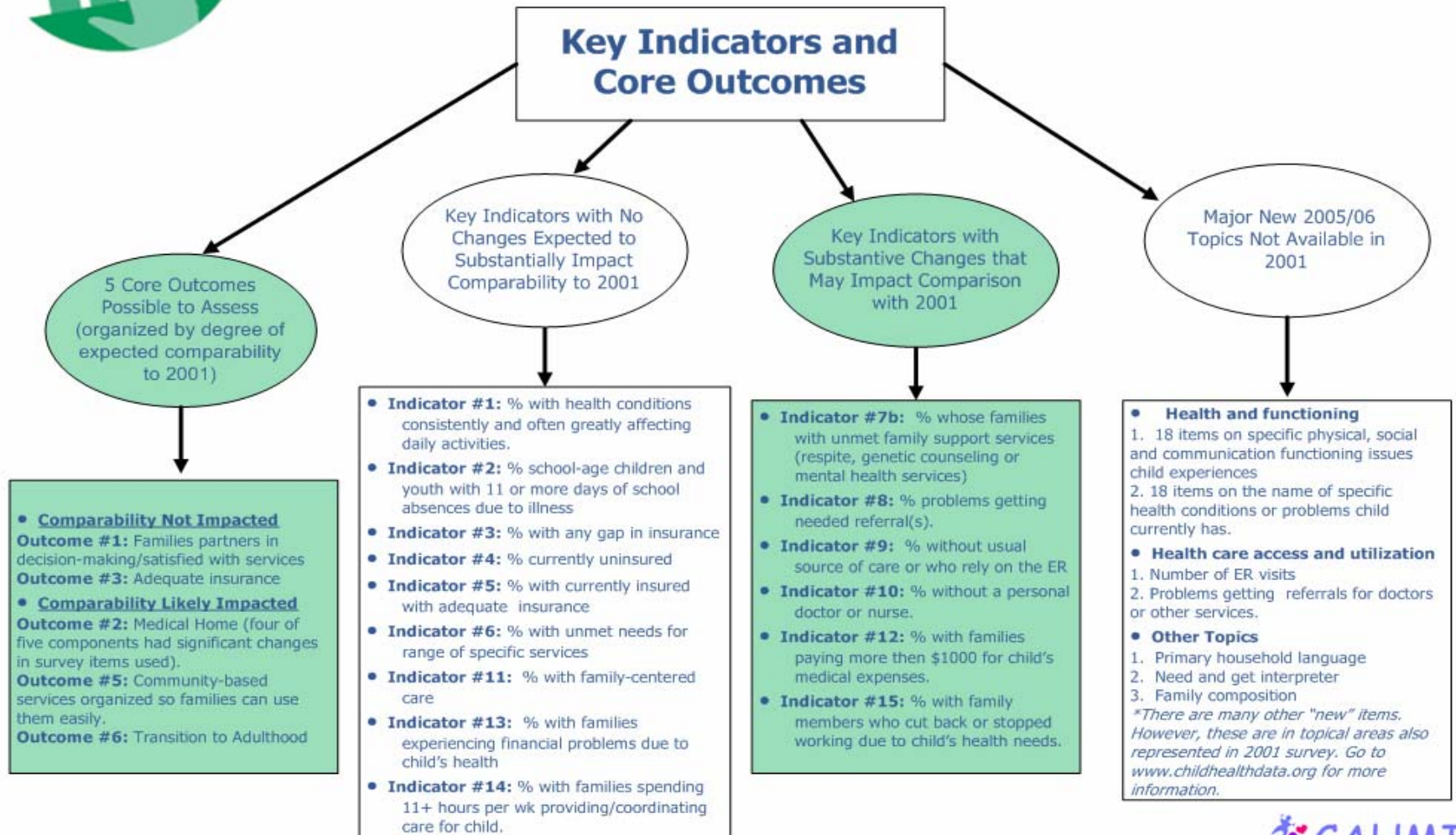Over 60 measures of child health and well-being derived from the survey

- Physical and Dental Health
- Emotional and Mental Health
- Health Insurance Coverage
- Health Care Access and Quality
- Community and School Activities
- Family Health and Activities
- Neighborhood Safety and Support

Physical and Dental Health

1.1 Child health status
1.2 Healthy teeth
1.3 Breastfed ever
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 rx meds
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

CAHMI
The Child and Adolescent
Health Measurement Initiative

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)

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

Key Indicators with Substantive Changes that May Impact Comparison with 2001

Major New 2005/06 Topics Not Available in 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

- **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 #11:** % 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.

- **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 then $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.

Example of State Profile

Children with Special Health Care Needs - State Data - Microsoft Internet Explorer

National Survey of Children with Special Health Care Needs, 2001

California

Children ages 0-17 years old   Print   Close

Prevalence Statistics		
Child-Level Prevalence:	**State %**	**Nation %**
Percentage of Children & Youth with Special Health Care Needs, 0 - 17 yrs old	10.3	12.8
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		
Child Health:	**State %**	**Nation %**
1) % of CYSHCN whose health conditions consistently and often greatly affect their daily activities.	24.0	23.2
2) % of CYSHCN with 11 or more days of school absences due to illness.	16.2	15.8
Health Insurance Coverage:		
3) % of CYSHCN without insurance at some point during the past year.	9.9	11.6
4) % of CYSHCN currently uninsured.	4.3	5.2
5) % of currently insured CYSHCN with coverage that is not adequate.	36.5	33.8
Access to Care:		
6) % of CYSHCN with 1 or more unmet needs for specific health care services.	23.1	17.7
7b) % of CYSHCN whose families needed but did not get all respite care, genetic counseling and/or mental health services.	25.1	23.1
8) % of CYSHCN needing specialty care who had problems getting a referral.	27.3	21.9
9) % of CYSHCN without a usual source of care (or who rely on the emergency room).	9.5	9.3
10) % of CYSHCN without a personal	13.2	11.0

Example of "All State" Comparison Table (Option to Sort by Rank)

Prevalence Data   📁 **Add to briefcase**   🖨 **Print version**

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)

[New Query]
[New Topic]
[New Question]
[Compare Subgroups]

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.

Region	Underweight %	Normal weight %	At risk of overweight %	Overweight %	Total %
Nationwide	4.9	64.6	15.7	14.8	100.0
Alaska	5.7	63.6	19.6	11.1	100.0
Alabama	6.1	59.3	17.9	16.7	100.0
Arkansas	6.3	60.8	16.4	16.4	100.0
Arizona	5.0	65.3	17.5	12.2	100.0
California	4.7	65.3	16.8	13.2	100.0
Colorado	6.0	72.0	12.0	9.9	100.0
Connecticut	4.8	67.9	15.0	12.3	100.0
District of Columbia	5.6	54.8	16.7	22.8	100.0
Delaware	4.8	59.7	20.7	14.8	100.0
Florida	6.0	61.5	18.0	14.4	100.0
Georgia	3.5	64.8	15.3	16.4	100.0
Hawaii	6.6	66.5	13.5	13.3	100.0
Iowa	5.1	69.4	13.0	12.5	100.0
Idaho	6.0	68.4	15.5	10.1	100.0

28

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)

Region		No	Yes	Total %
Nationwide	%	**16.7**	**83.3**	**100.0**
	C.I.	(16.2 - 17.1)	(82.9 - 83.8)	
	n	14,568	87,491	
	Est.	12,077,887	60,397,981	
Texas	%	**22.6**	**77.4**	**100.0**
	C.I.	(20.4 - 24.8)	(75.2 - 79.6)	
	n	433	1,740	
	Est.	1,400,973	4,799,550	

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

Example of Graph Comparing Two Geographic Areas

Children/youth (ages 0–17) with a personal doctor or nurse (PDN)
Nationwide vs. Texas
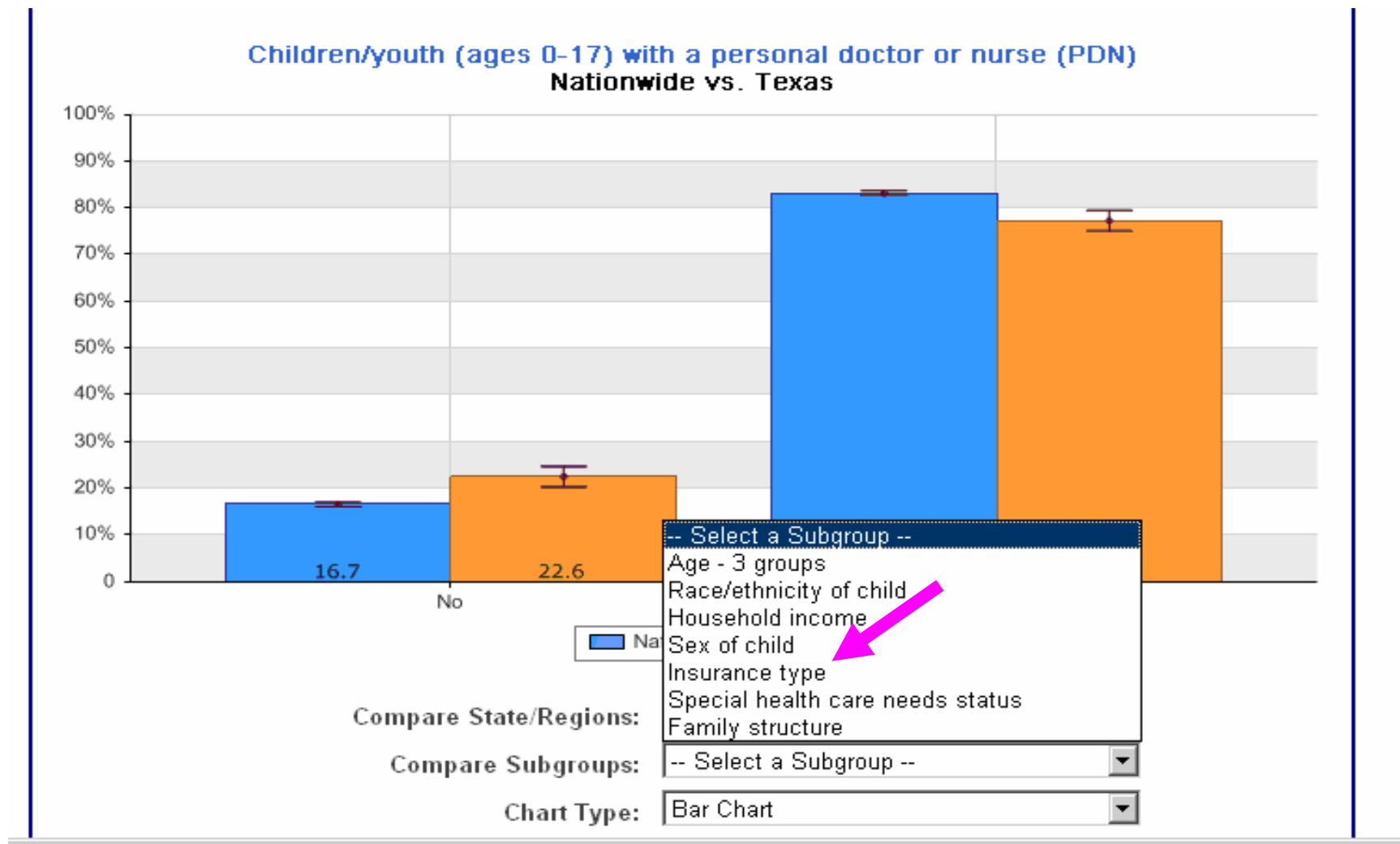
Graph Comparing Two Geographic Areas and Three Subgroups of Children (by Type of Health Insurance)

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

% Do not have PDN X Insurance type

	Public health insurance	Private health insurance	No health insurance
Nationwide (% Do not have PDN)	22.0	10.5	43.3
Texas (% Do not have PDN)	24.6	11.1	54.6

Compare State/Regions: Texas
Compare Subgroups: Insurance type
Chart Type: Bar Chart
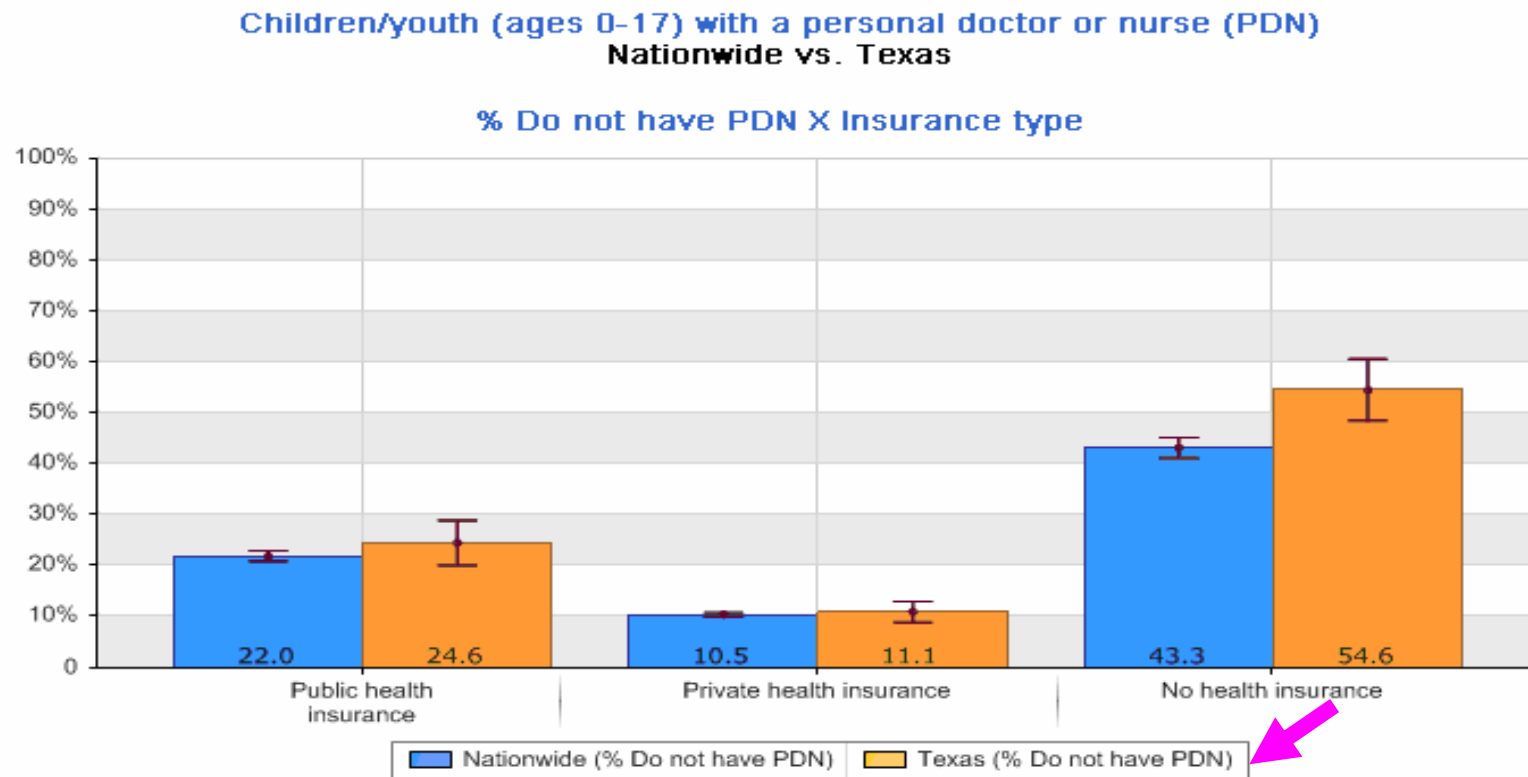
Citation format: Child and Adolescent Health Measurement Initiative (2005). *National Survey of Children's Health*

Data Resource Center for Child & Adolescent Health
Your Data... Your story

line Tour **NEW!**

a Question

a Friend

Jpdates

swer Our Brief
er Poll

CH Survey

CSHCN Survey

is site is a project of

AHMI
Child and Adolescent
Measurement Initiative

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**

National Survey of Children with Special Health Care Needs

Data Resource Center — Your Data... Your story

- CSHCN Survey Home
- Start Data Query
- State Profiles
- Quick Guides
- Resources for Data Users
- Especially for Families
- State Data Sets

- SIGN IN
- AWSTATS
- ONLINE TOUR NEW!
- ASK A QUESTION
- ANSWER OUR BRIEF USER POLL
- TELL A FRIEND

- YOUR BRIEFCASE

This site is a project of

CAHMI

Begin by selecting one of theses three 3 steps — and don't forget to check out the State Profiles option below.

Start HERE!

1. Learn about the survey

2. Search the data

3. Report your results

On Its Way!

2005 NS-CSHCN Data Coming Fall 2007

To Preview Content Guide **Click Here**

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

Want to view your state's data profile?

CLICK HERE

National Survey of Children with Special Health Care Needs
Data Resource Center — Your Data… Your story

State & Regional Profiles on Key Indicators for CYSHCN
Click on a state below or HRSA Region on the right to view results:

HRSA Regions

- HRSA Region I
- HRSA Region II
- HRSA Region III
- HRSA Region IV
- HRSA Region V
- HRSA Region VI
- HRSA Region VII
- HRSA Region VIII
- HRSA Region IX
- HRSA Region X

National Survey of Children with Special Health Care Needs, 2001
California

Children ages 0-17 years old

Print Close

Prevalence Statistics

Child-Level Prevalence:	State %	Nation %
Percentage of Children & Youth with Special Health Care Needs, 0 - 17 yrs old	10.3	12.8

Household-Level Prevalence:

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

Prevalence by Age:

	State %	Nation %
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:

	State %	Nation %
Female	8.3	10.5
Male	12.3	15.0

Prevalence by Poverty Level:

	State %	Nation %
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:

	State %	Nation %
Hispanic	7.6	8.5

Indicator

Child Health:	State %	Nation %
1) % of CYSHCN whose health conditions consistently and often greatly affect their daily activities.	24.0	23.2
2) % of CYSHCN with 11 or more days of school absences due to illness.	16.2	15.8

Health Insurance Coverage:

	State %	Nation %
3) % of CYSHCN without insurance at some point during the past year.	9.9	11.6
4) % of CYSHCN currently uninsured.	4.3	5.2
5) % of currently insured CYSHCN with coverage that is not adequate.	36.5	33.8

Access to Care:

	State %	Nation %
6) % of CYSHCN with 1 or more unmet needs for specific health care services.	23.1	17.7
7b) % of CYSHCN whose families needed but did not get all respite care, genetic counseling and/or mental health services.	25.1	23.1
8) % of CYSHCN needing specialty care who had problems getting a referral.	27.3	21.9
9) % of CYSHCN without a usual source of care (or who rely on the emergency room).	9.5	9.3
10) % of CYSHCN without a personal	13.2	11.0

8) % of CYSHCN needing specialty care who had problems getting a referral.	27.3	21.9
9) % of CYSHCN without a usual source of care (or who rely on the emergency room).	9.5	9.3
10) % of CYSHCN without a personal doctor or nurse.	13.2	11.0

Family-Centered Care:

Impact on Family:

12) % of CYSHCN whose families pay $1,000 or more in medical expenses per year.	11.8	11.2
13) % of CYSHCN whose families	19.2	20.9

INDICATOR #11: CYSHCN without family-centered care
California vs. Nationwide
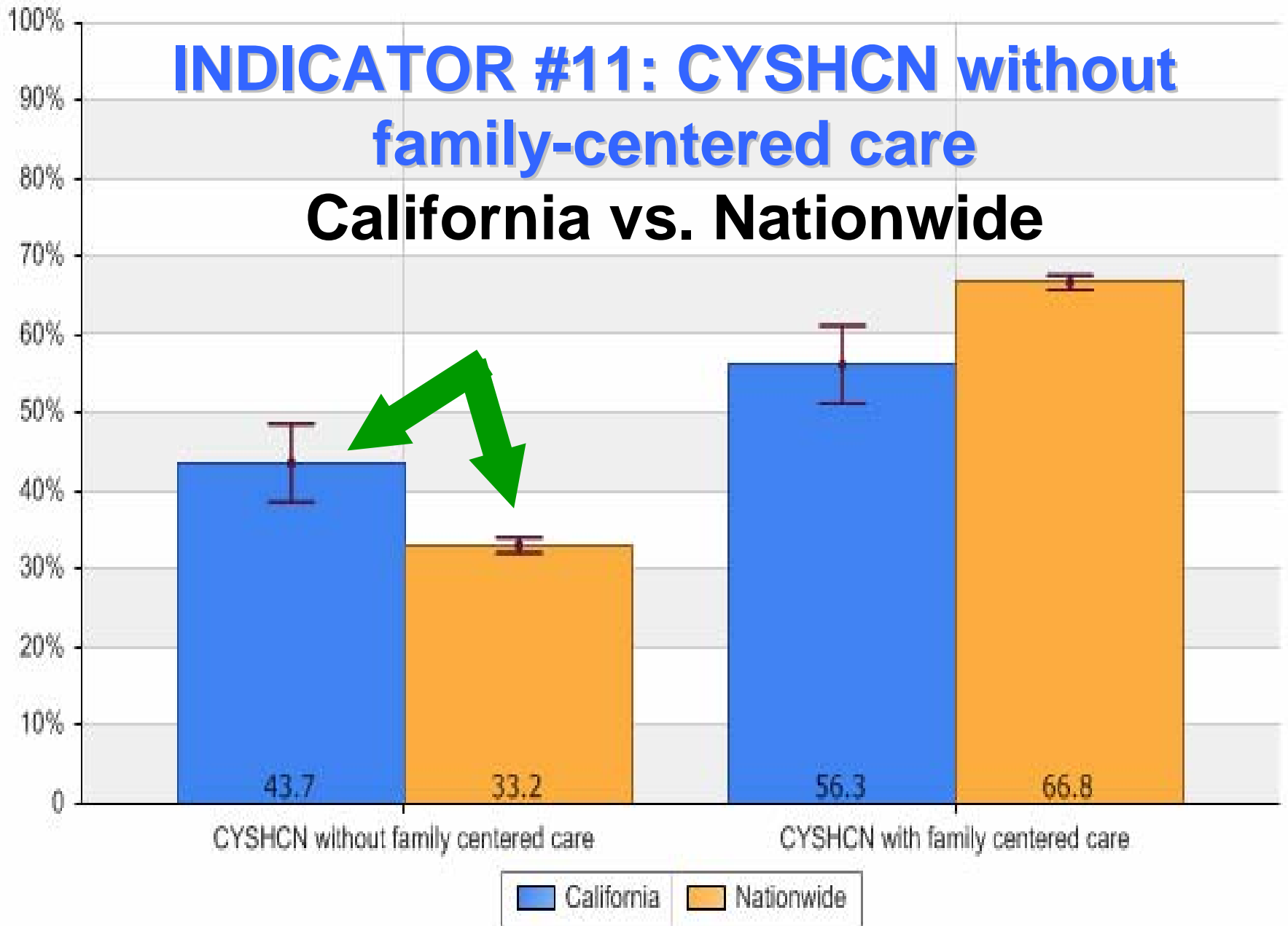
Back ·   ·   ·   Search   Favorites   ·   W ·

National Survey of Children's Health
Data Resource Center — Your Data... Your story

| DRC Home | Link to Us | Glossary | Search | Contact Us |

- NSCH Survey Home
- Start Data Query
- State Profiles
- Quick Guides

- ONLINE TOUR **NEW!**
- ASK A QUESTION
- ANSWER OUR BRIEF USER POLL
- TELL A FRIEND

YOUR BRIEFCASE

This site is a project of

CAHMI
The Child and Adolescent Health Measurement Initiative

Begin by selecting one of theses three 3 steps - and don't forget to check out the State Profiles option below.

Start HERE!

1. Learn about the survey

2. Search the data

3. Report your results

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

JUST RELEASED!

Overweight and Physical Activity Among Children

Want to view your state's data profile?

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.

Internet

National Survey of Children's Health
Data Resource Center — Your Data... Your story

NSCH Survey Home

Start Data Query

State Profiles

Quick Guides

- SIGN IN
- AWSTATS
- ONLINE TOUR NEW!
- ASK A QUESTION
- ANSWER OUR BRIEF USER POLL
- TELL A FRIEND

YOUR BRIEFCASE

This site is a project of

CAHMI
The Child and Adolescent
Health Measurement Initiative

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

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

2. Select a Topic	Select
Physical and Dental Health	○
Emotional and Mental Health	○
Health Insurance Coverage	○
Health Care Access and Quality	○
Community and School Activities	○
Family Health and Activities	○
Neighborhood Safety and Support	○

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

Data Resource Center for Child & Adolescent Health

Your Data... Your story

DRC Home **What's New** **Glossary** **Search** **Contact Us**

Get Connected!

Ask a Question

Tell a Friend

Sign Up for E-Updates

Link To Us

Answer Our Brief User Poll

- NSCH Survey
- NS-CSHCN Survey

Ask a Question

Your Email Address:

Subject:

Message:

Send

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

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?

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.**
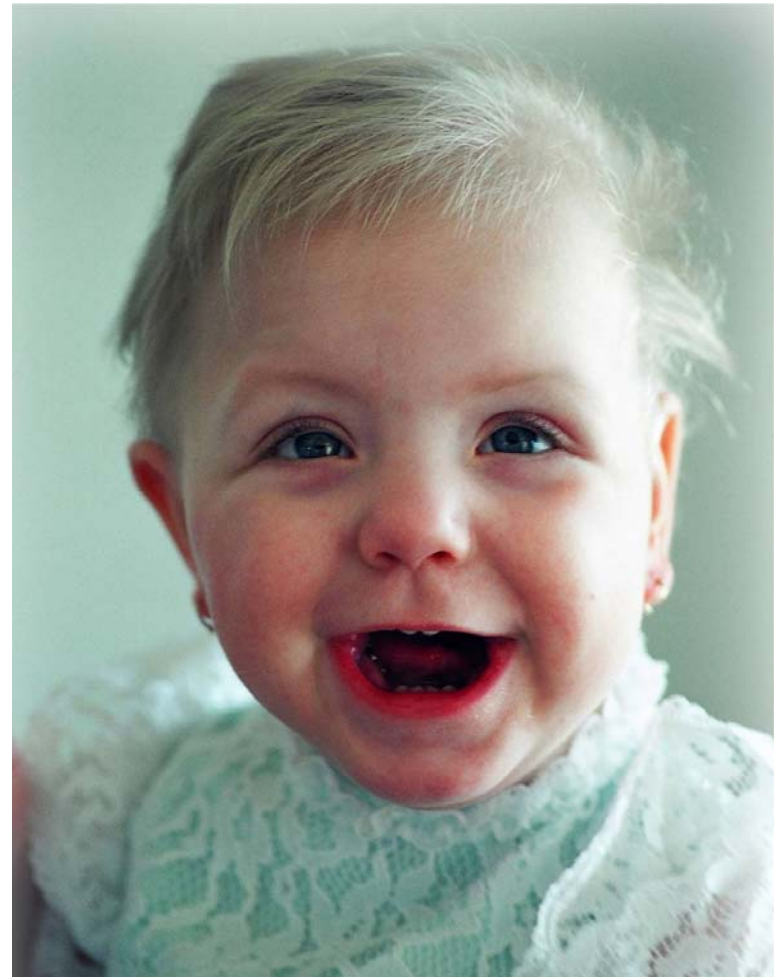
Insurance Coverage

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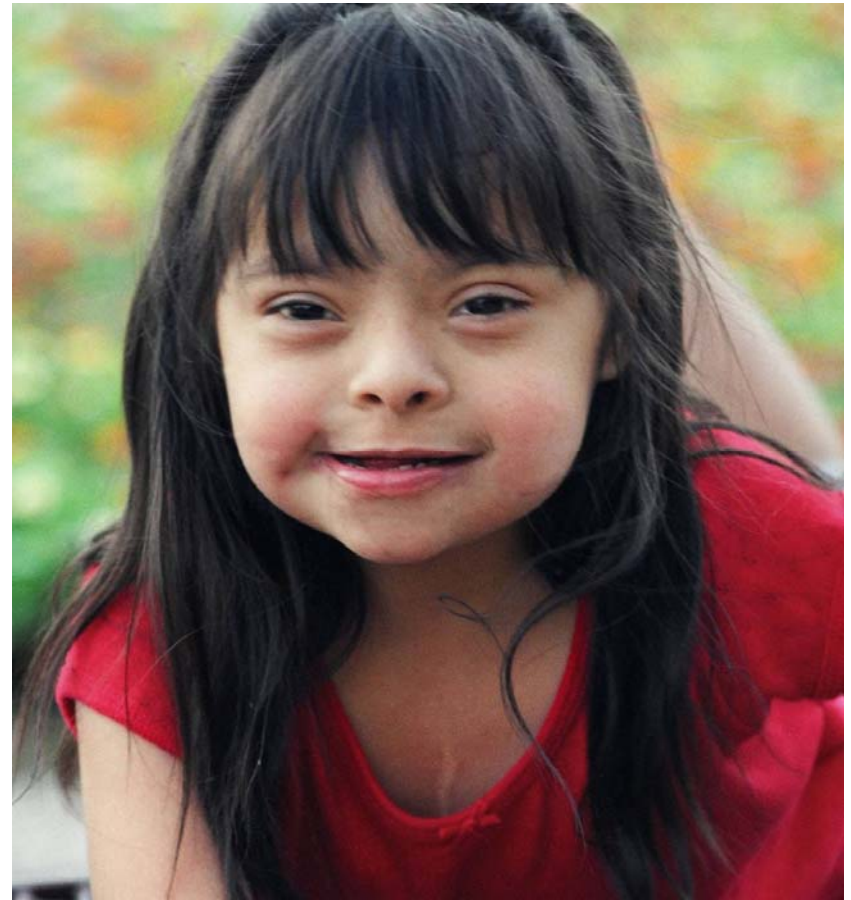
Insurance Coverage

1. **19.1% of Arizona's CSHCN had 1 or more unmet needs for specific health care services.**

Insurance Coverage

1. **25.6% of Arizona's CSHCN needing specialty care had problems getting a referral.**

Family Financial Impact

1. **18.3% of Arizona's CSHCN had health needs that caused family financial problems.**

Family Financial Impact

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
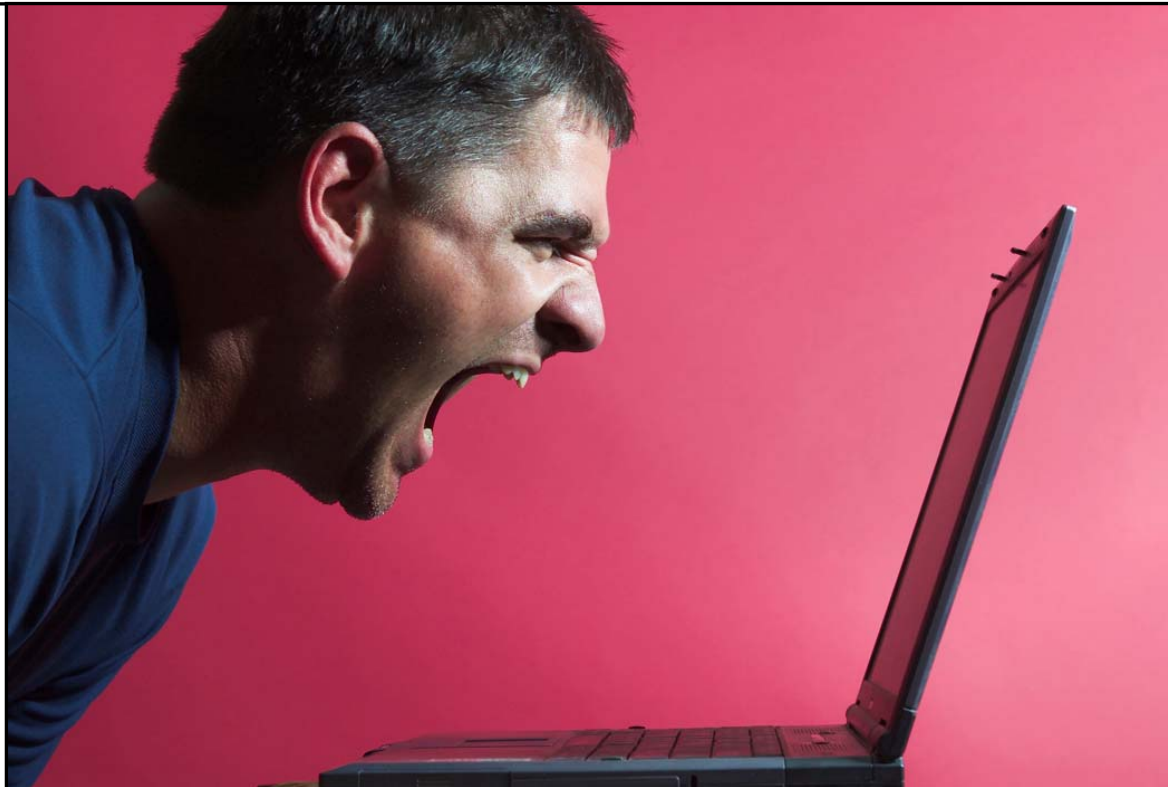
Goal: Convince policymakers that family representatives should be included

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…

"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.

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?

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.

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

Rene Schwalberg
Director, Health Policy
Health Systems Research, Inc.
RSchwalberg@hsrnet.com
207-772-1410

Nora Wells
Family Voices National Office
nwells@familyvoices.org
(617) 399-8323

Becky Adelmann
Family Voices of Oregon
Oregon F2F Health Information & Education Center
adelmann@ohsu.edu
503-494-7657

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

Wendy Benz
Family Voices of Arizona
Raising Special Kids
wendyb@raisingspecialkids.org
602-242-4366

FAMILY VOICES®

CAHMI
The Child and Adolescent
Health Measurement Initiative