

# 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](http://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](http://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**





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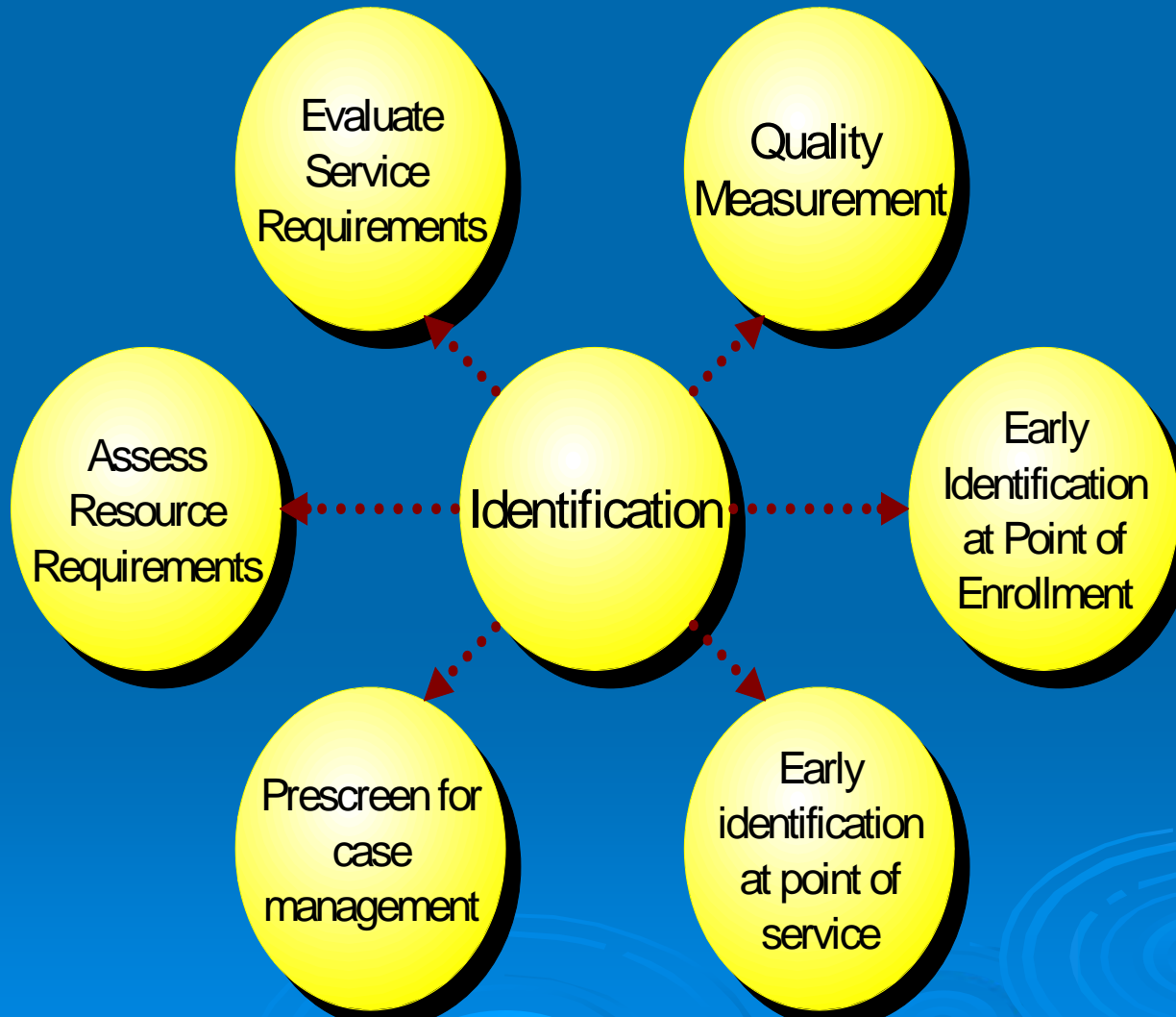
Once upon a time in a  
galaxy far, far away...

**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



# Defining Special Health Needs – WHO do we want to identify?

## NARROWER DEFINITIONS

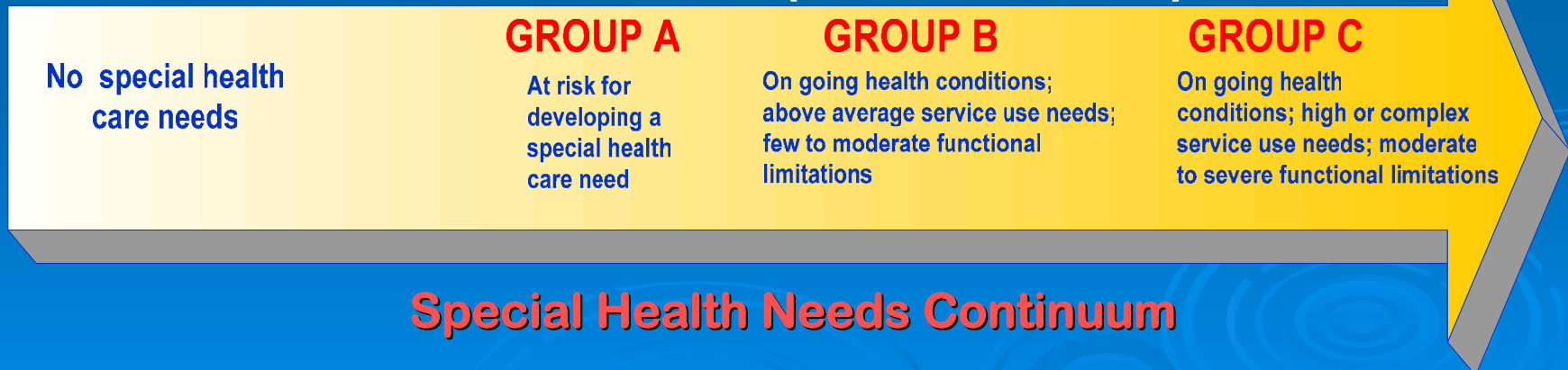
include only those with very severe conditions or highly complex needs  
**(C only)**

## 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)**



**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

## Federal Maternal and Child Health Bureau Definition of Children With Special Health Care Needs

*“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.

# CSHCN Screener

Asks about 5 different health consequences:

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

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

**AND**

*b) Condition has lasted or is expected to last for at least 12 months*

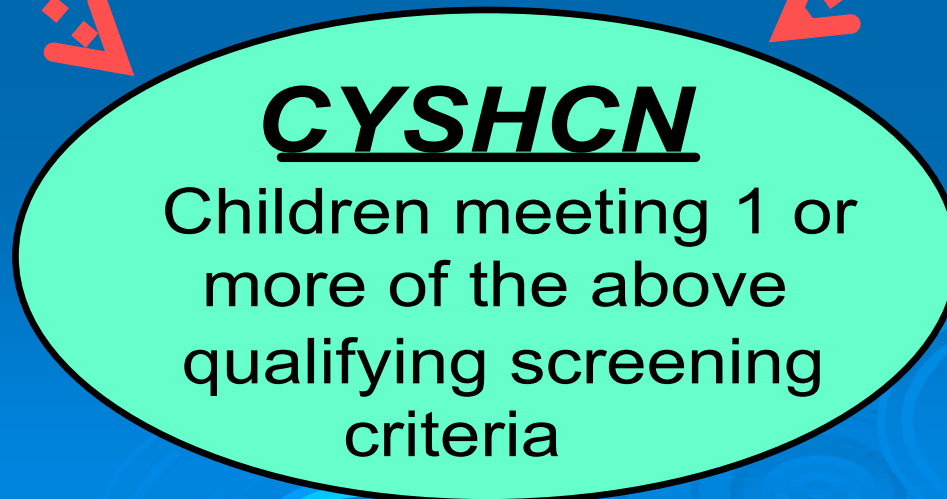
**Q1:**  
**PRESCRIPTION  
(RX) MEDS**

**Q2: ABOVE  
ROUTINE  
SERVICE USE**

**Q3:**  
**FUNCTIONAL  
LIMITATIONS**

**Q4:**  
**SPECIALIZED  
THERAPIES**

**Q5:**  
**MENTAL  
HEALTH**





# CSHCN Screener

Sample question:

**Q3)** Is **(child's name)** limited or prevented in any way in his/her ability to do 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?

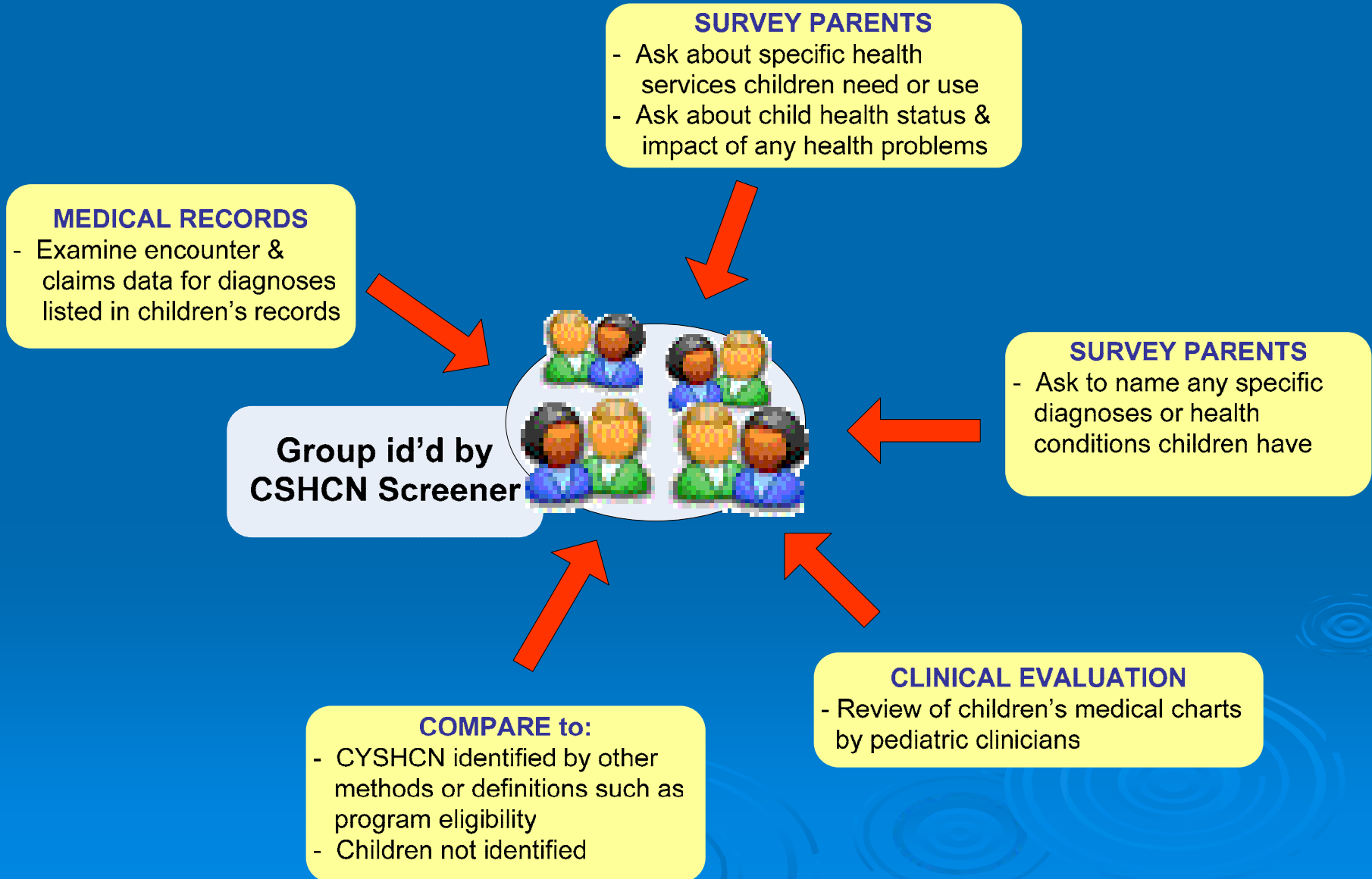
**IF YES:**

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

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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



# How is the CSHCN Screener being used today in the US?

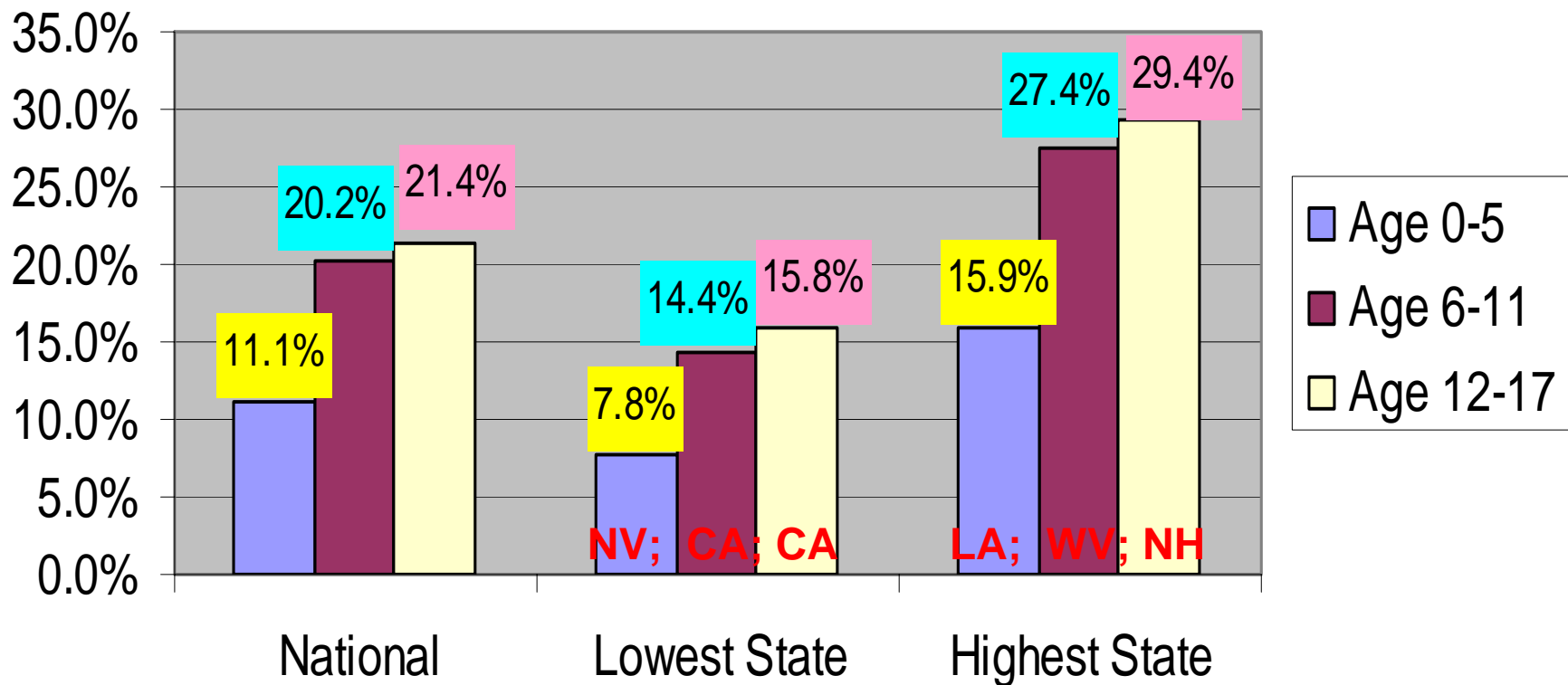
- Is used in many health plans, pediatric practices and hospital care environments
  - To identify CSHCN for purposes of **follow-up and further assessment of health needs**
  - To **evaluate utilization, unmet needs, costs of care, health care services quality and outcomes** for CSHCN.
- Is used in 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**

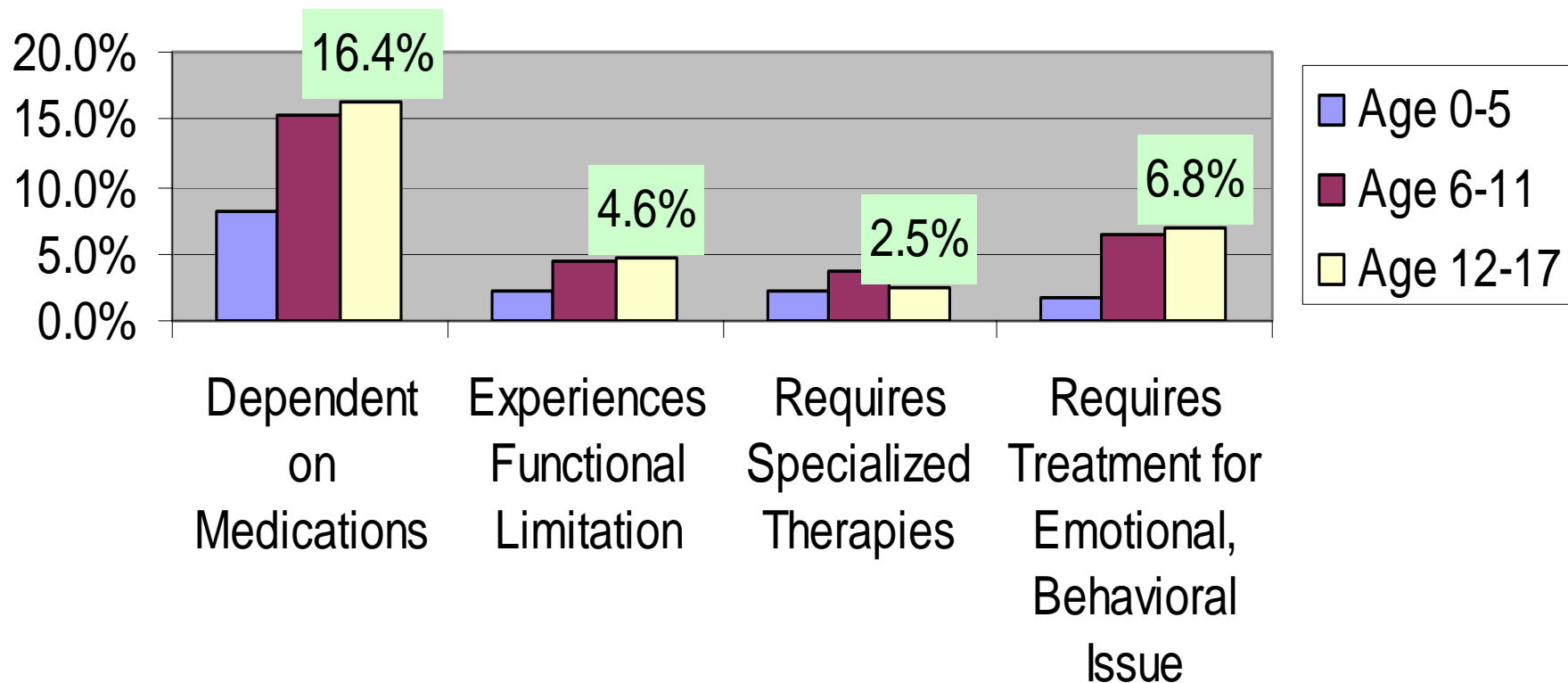
**20.8% or 10.17 Million  
Children and Youth Age 6-17  
in the US Qualified as Having  
a Special Health Care Need in  
2003 Using the CSHCN  
 Screener**

# Proportion of Children and Youth with Special Health Care Needs: Nation and Range Across States



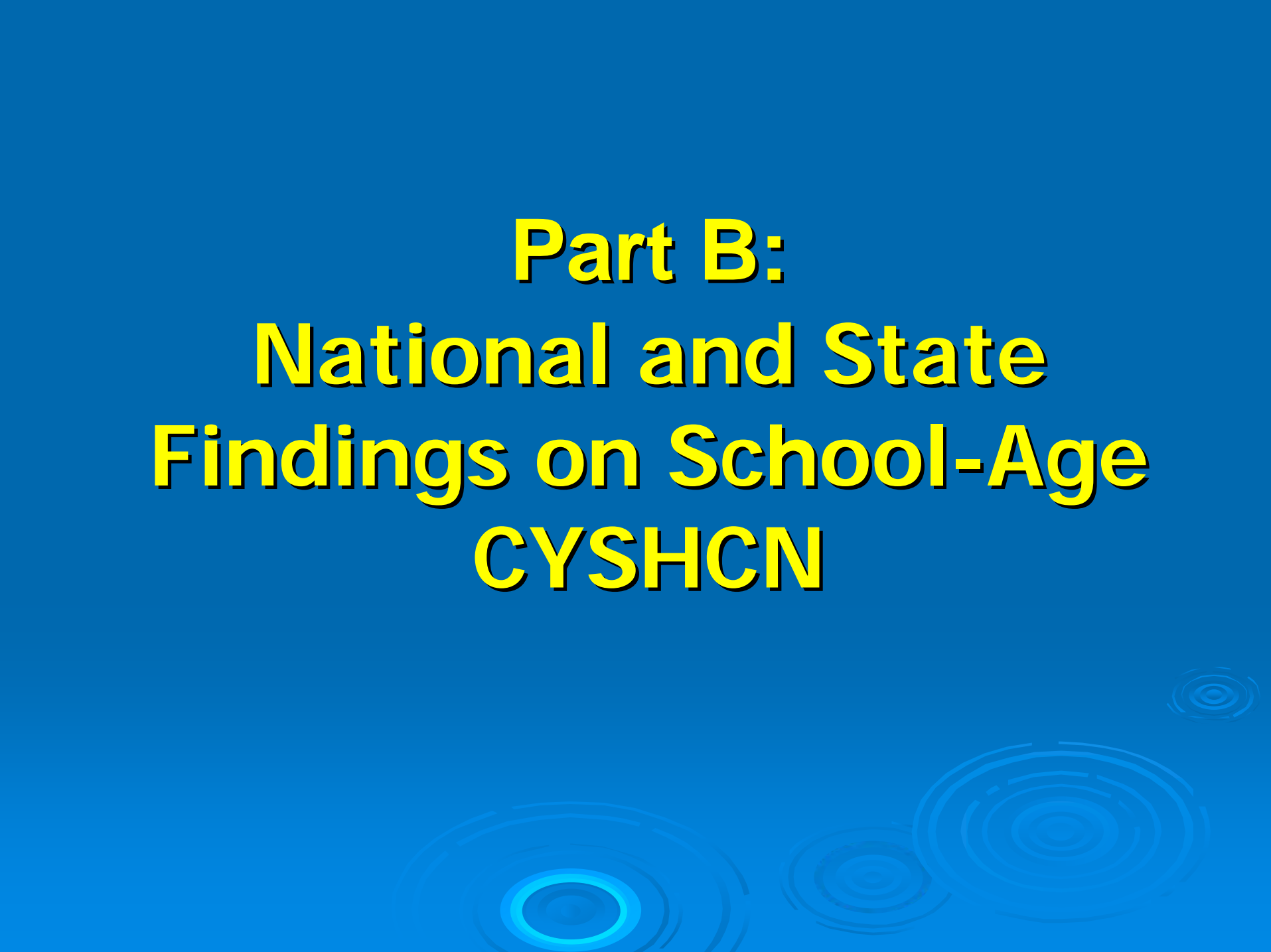
SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.

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



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

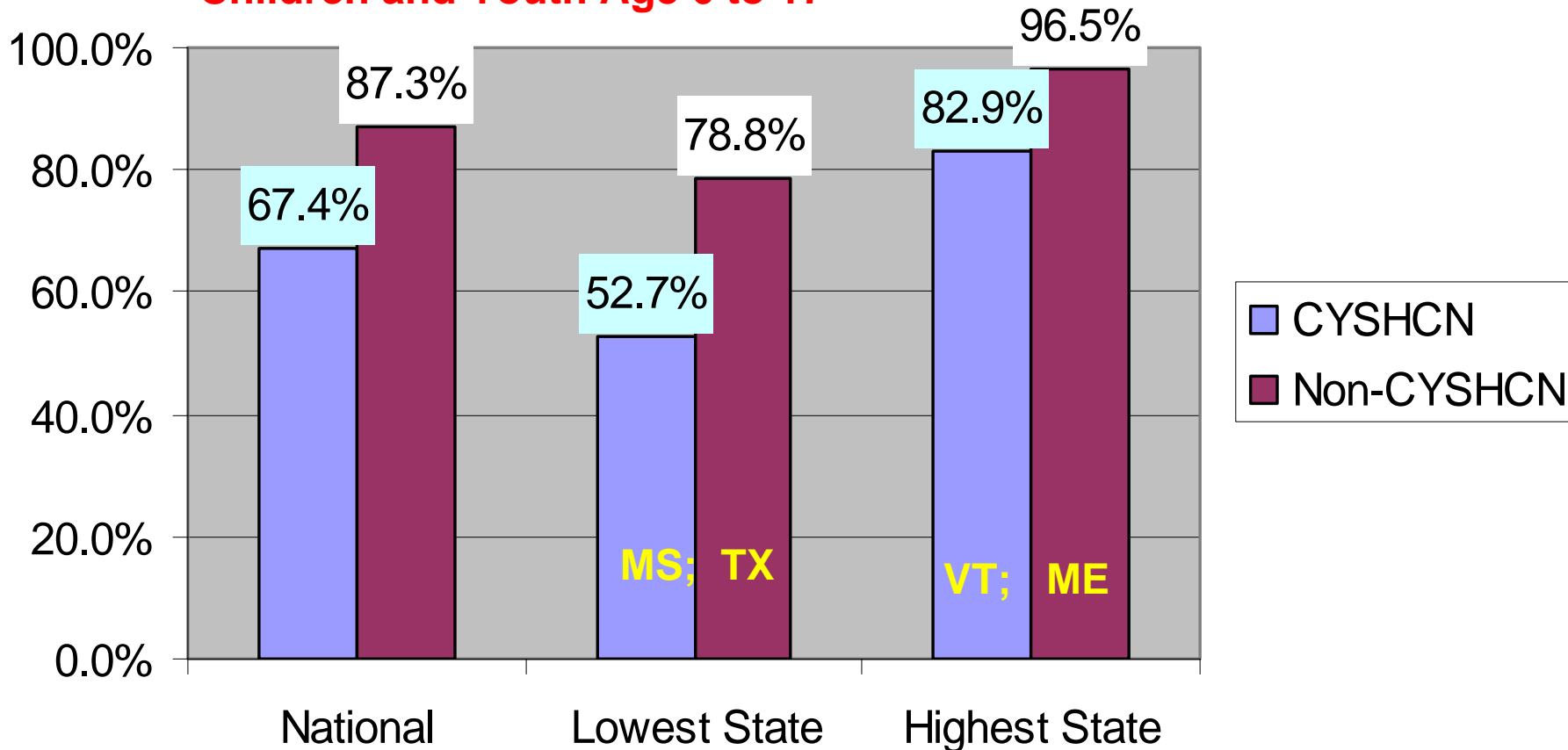
**Part B:**  
**National and State**  
**Findings on School-Age**  
**CYSHCN**





# Proportion of School-Age Children with Parent-Reported Excellent/Very Good Health Status: By CYSHCN Status

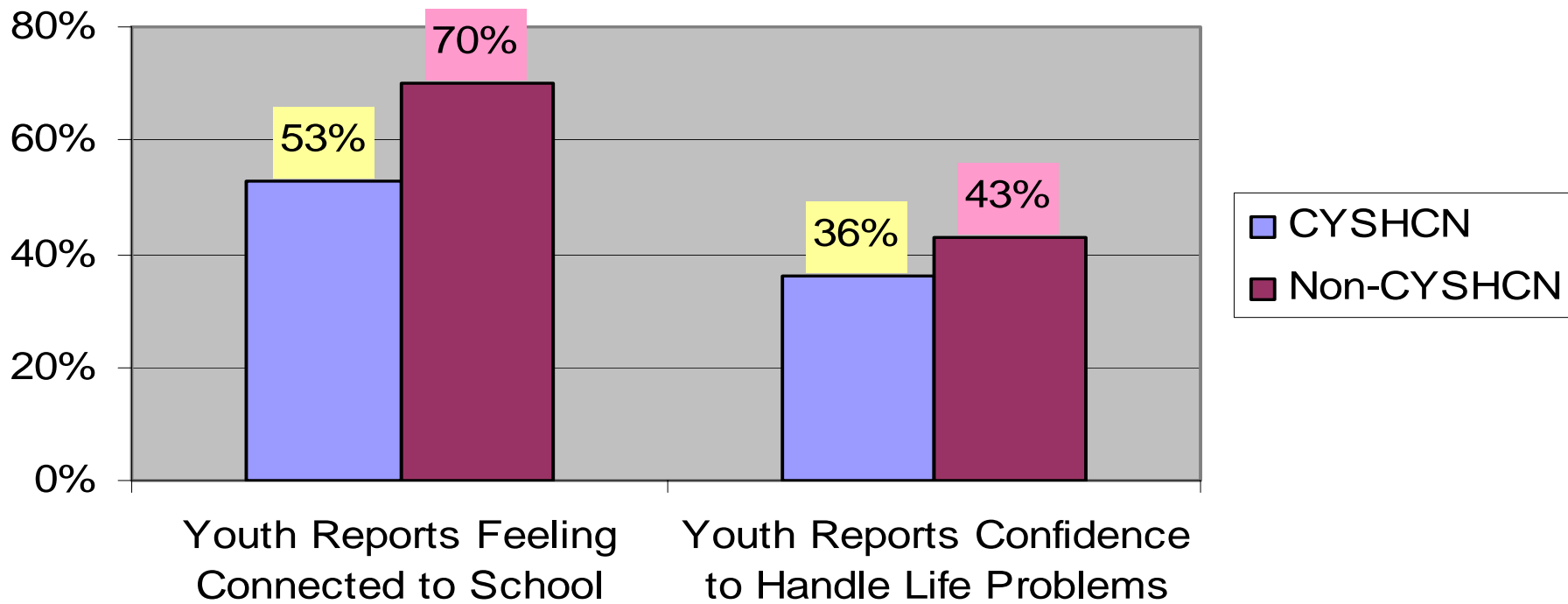
Children and Youth Age 6 to 17



SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.

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

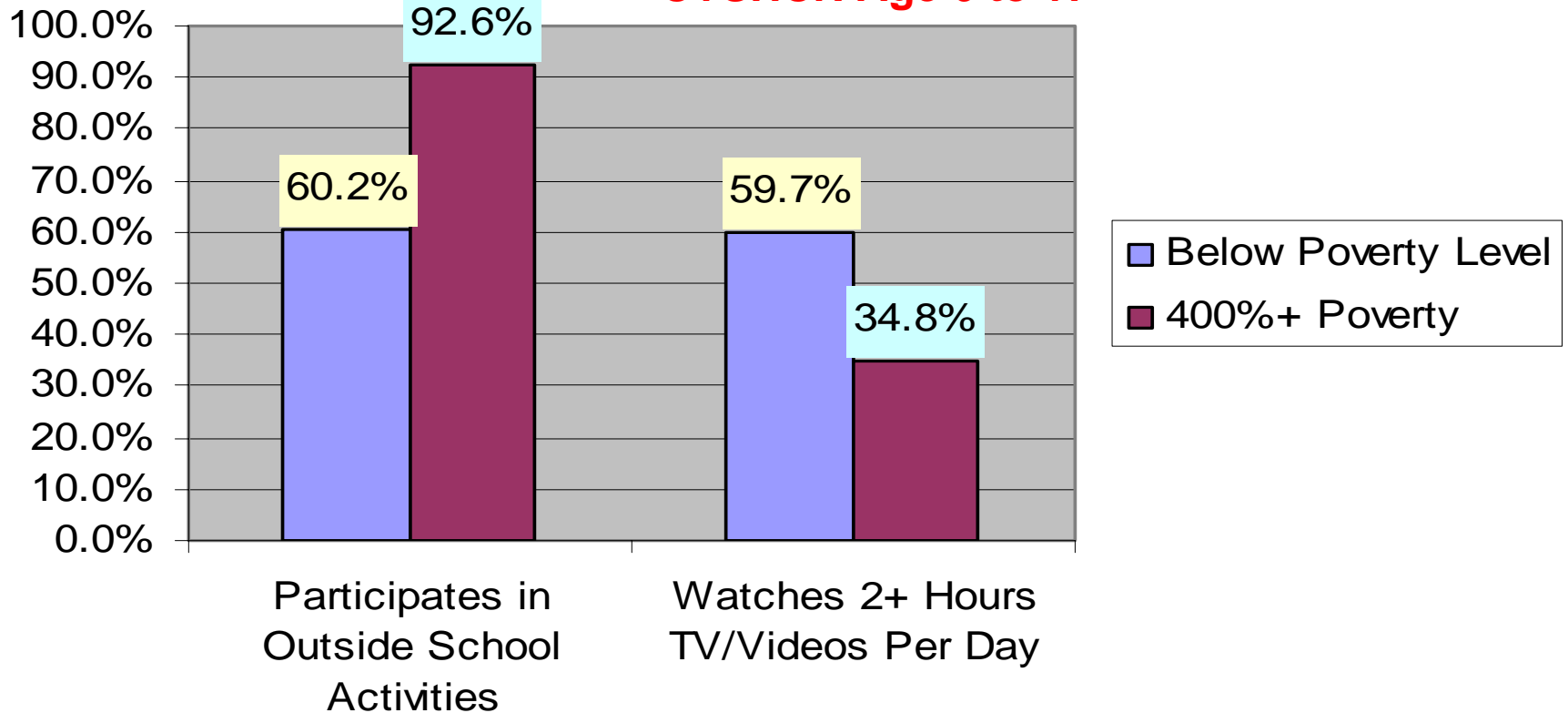
Children and Youth Age 13 to 18



**SOURCE: 2002 National Online Youth Survey. The Child and Adolescent Health Measurement Initiative. Funding by the Robert Wood Johnson Foundation.**

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

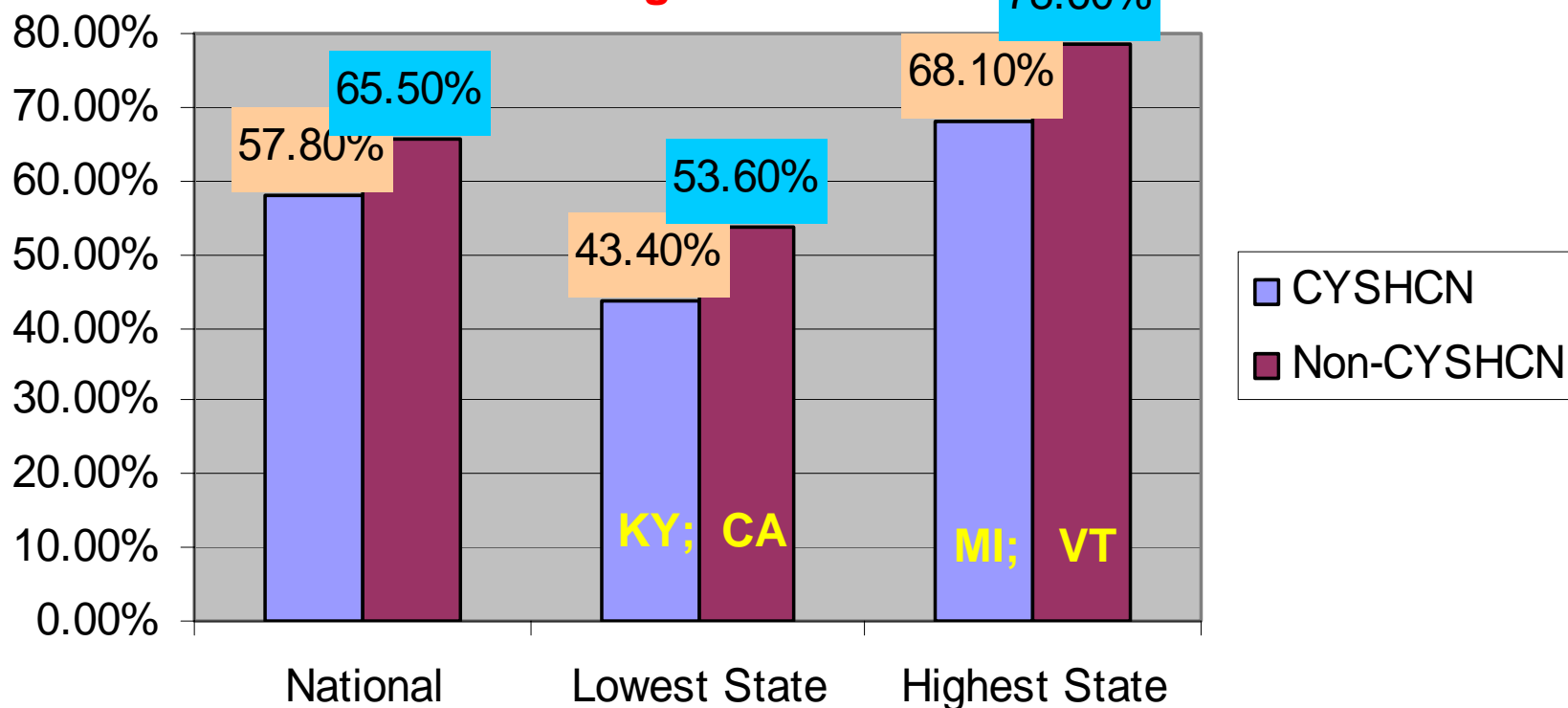
CYSHCN Age 6 to 17



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

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

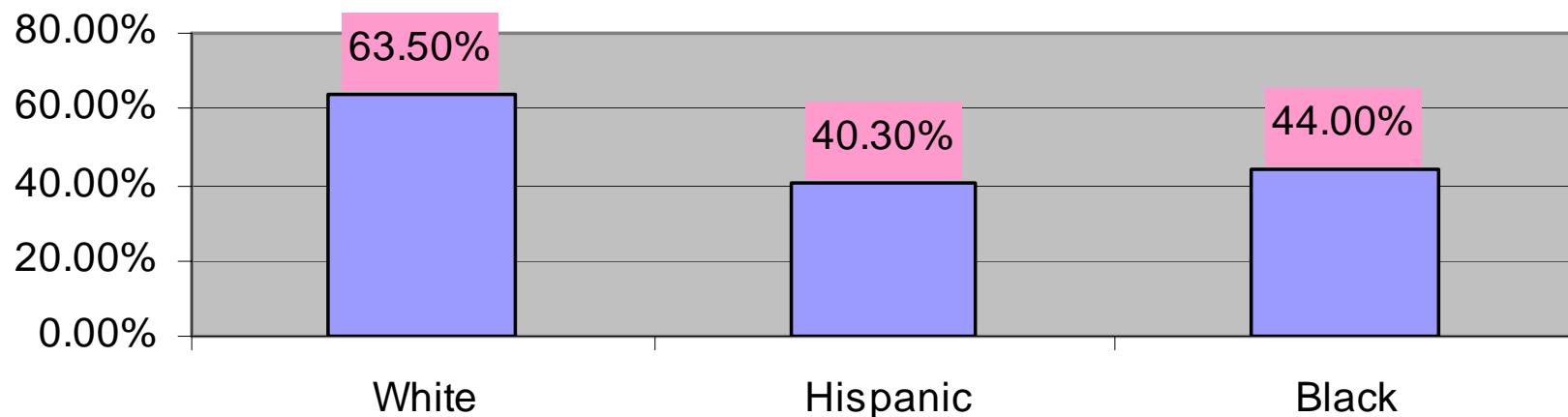
Children and Youth Age 6 to 17



SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.

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

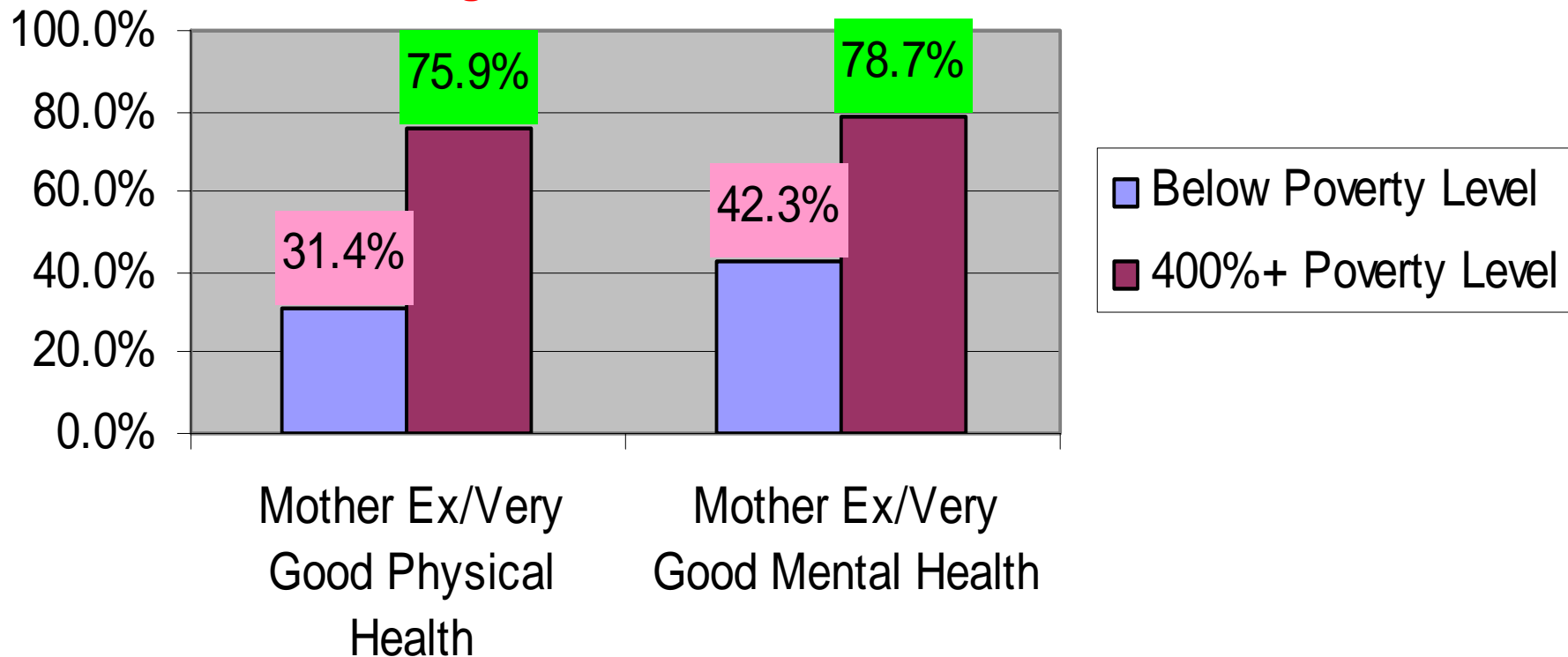
**CYSHCN Age 6 to 17**



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

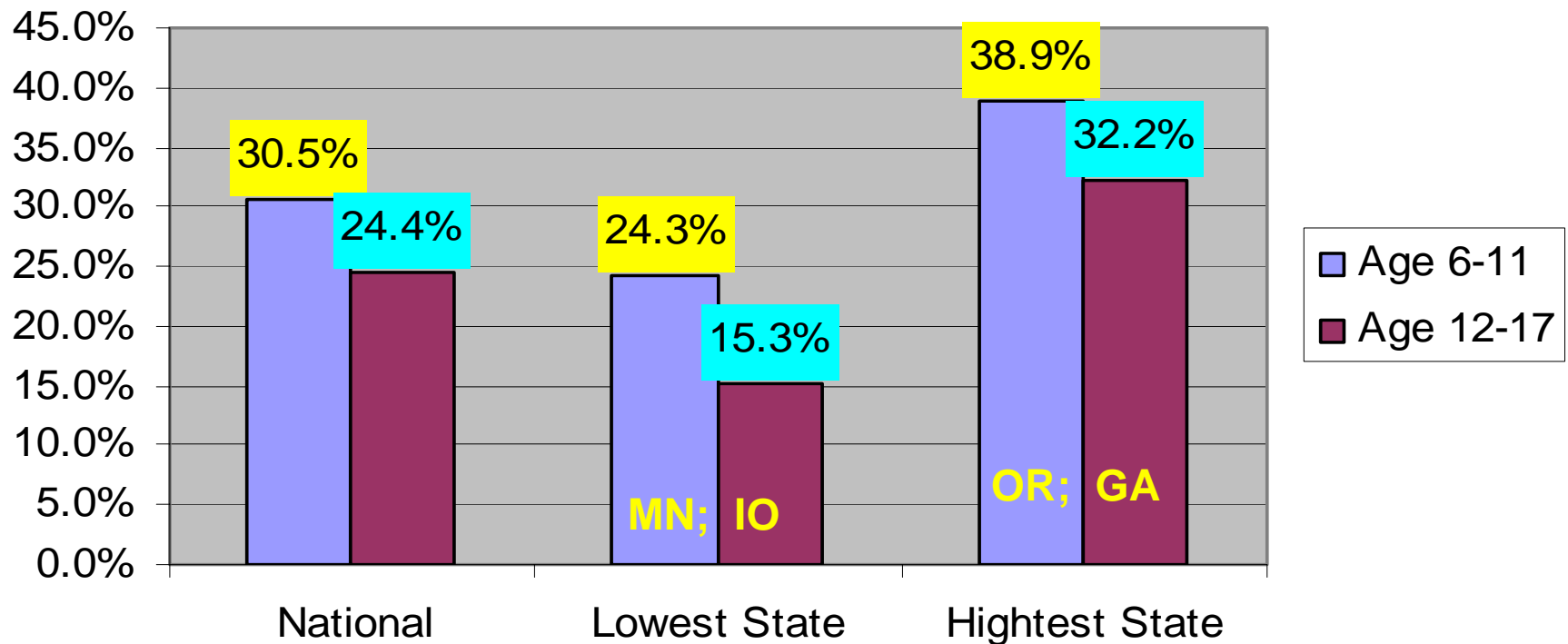
# Proportion of School-Age CYSHCN With Healthy Mothers: By Poverty Status

**CYSHCN Age 6 to 17**



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

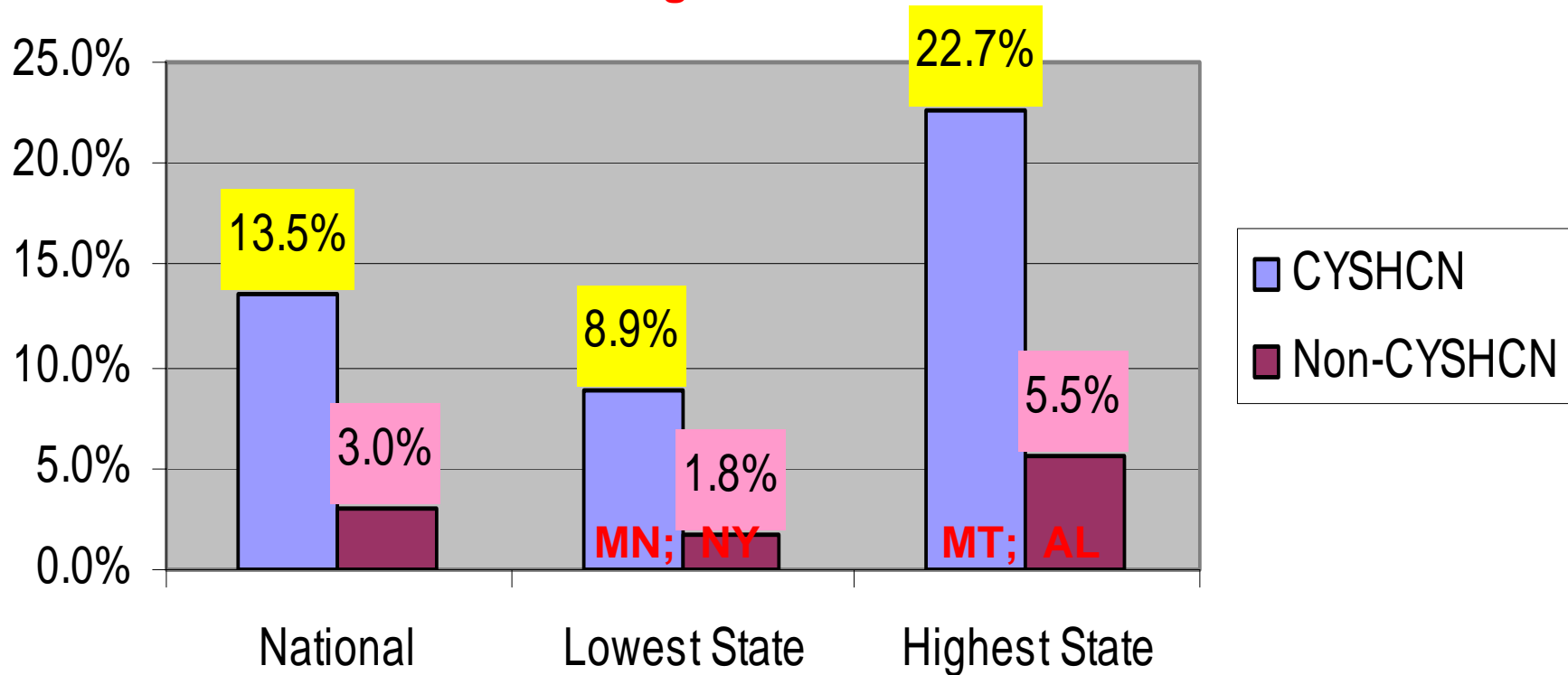
## Proportion of CYSHCN Whose Parent(s) Cut Back or Stopped Working Due to Child's Health Needs: By Age



**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](http://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

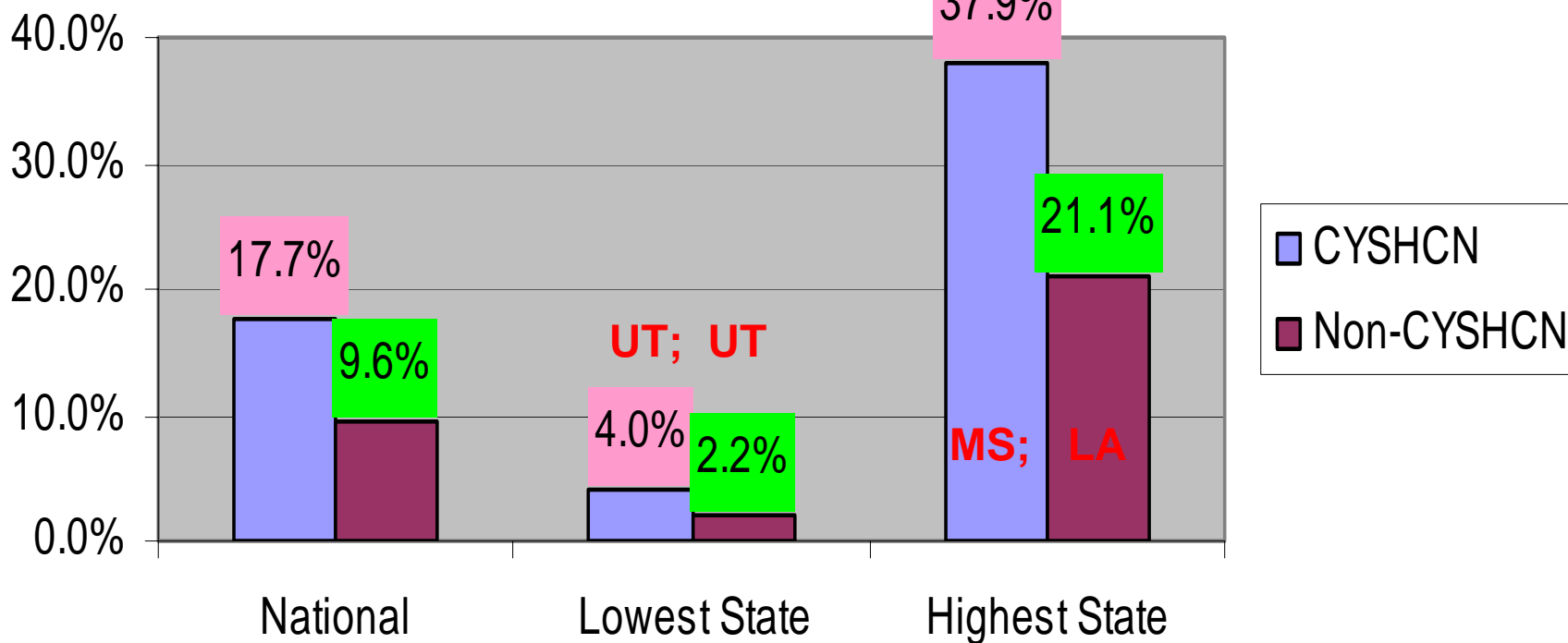


SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.



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

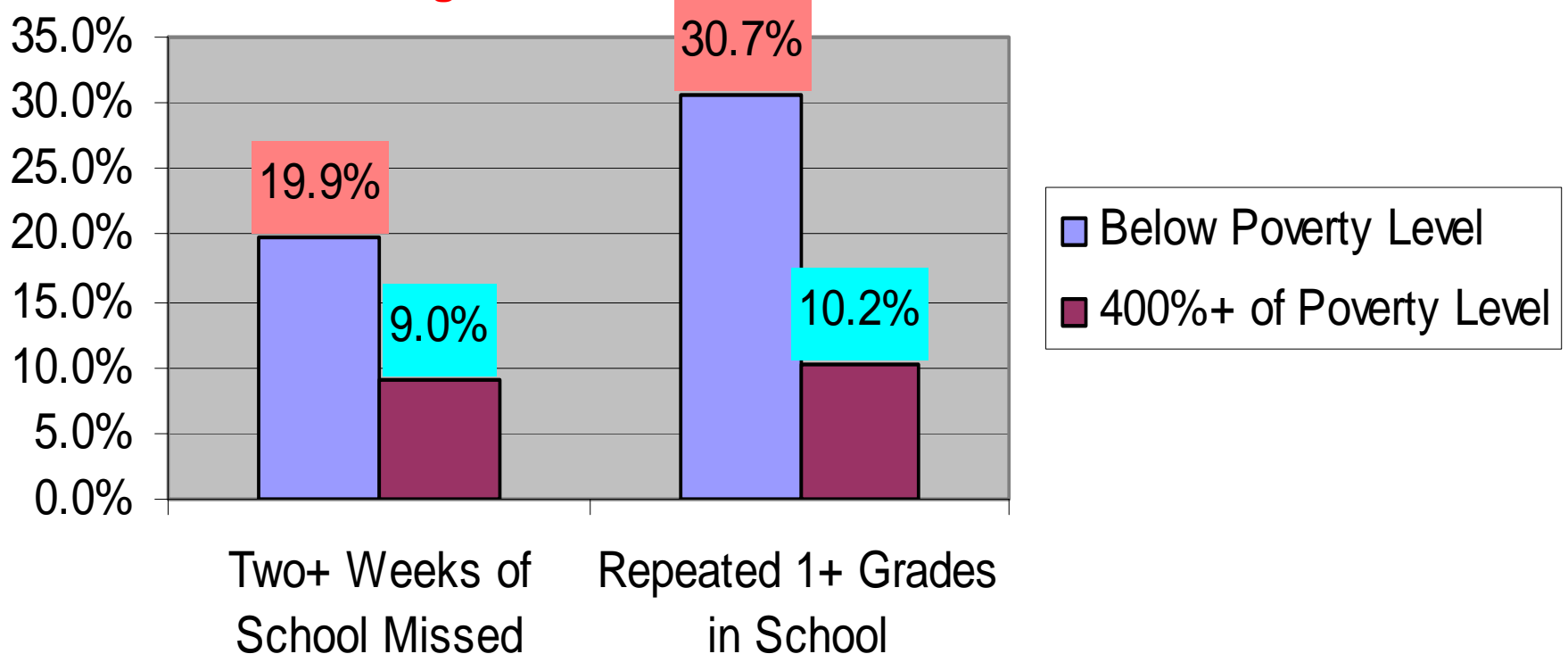
Children and Youth Age 6 to 17



SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.

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

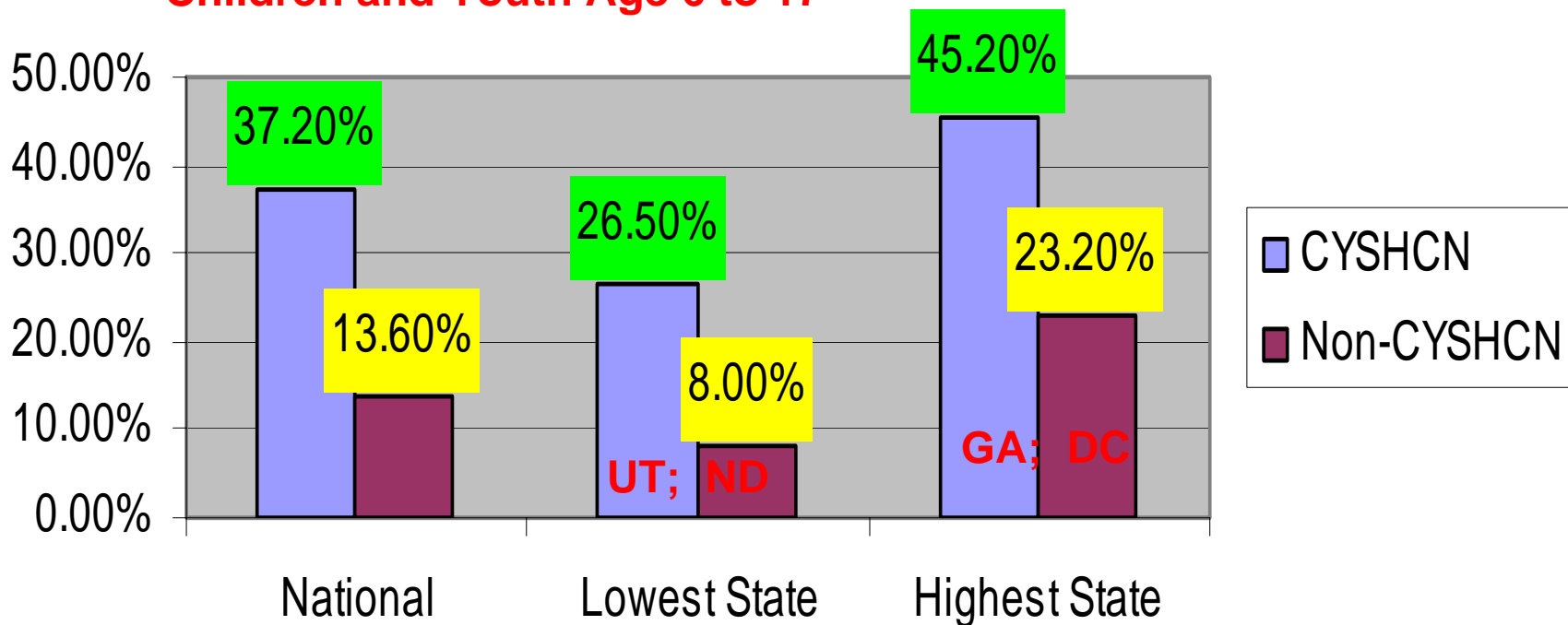
**CYSHCN Age 6 to 17**



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

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

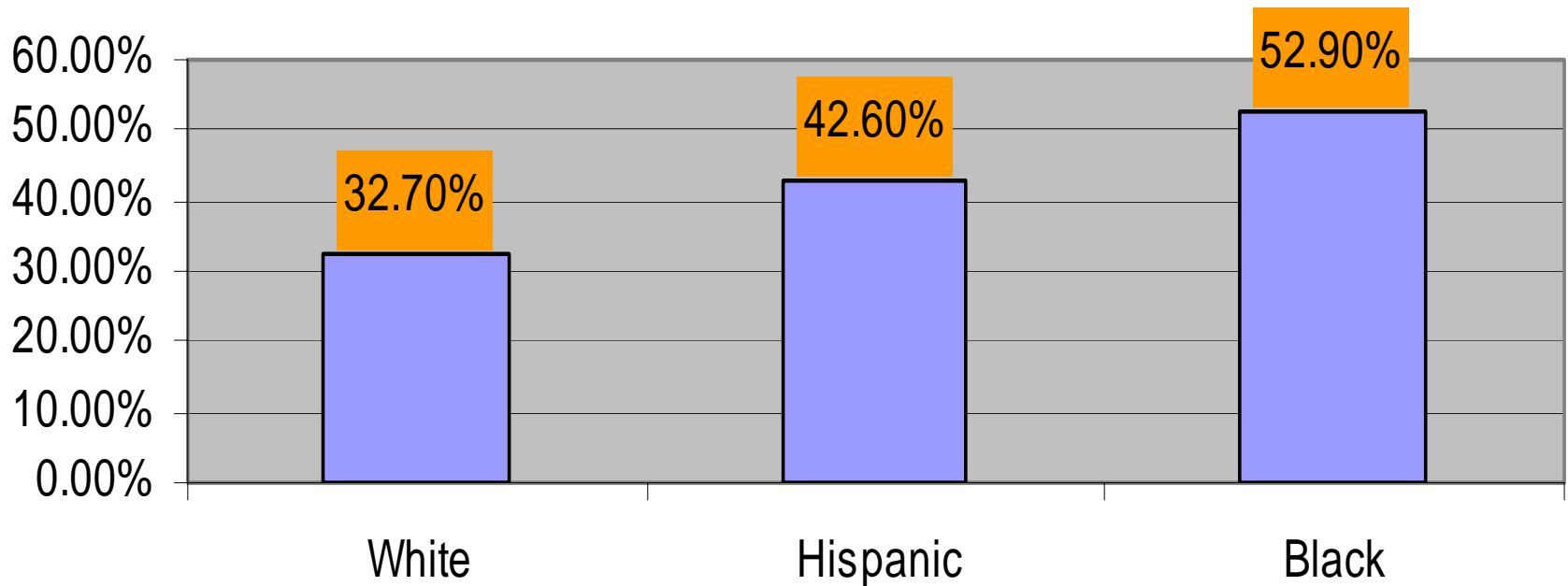
Children and Youth Age 6 to 17



SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.

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

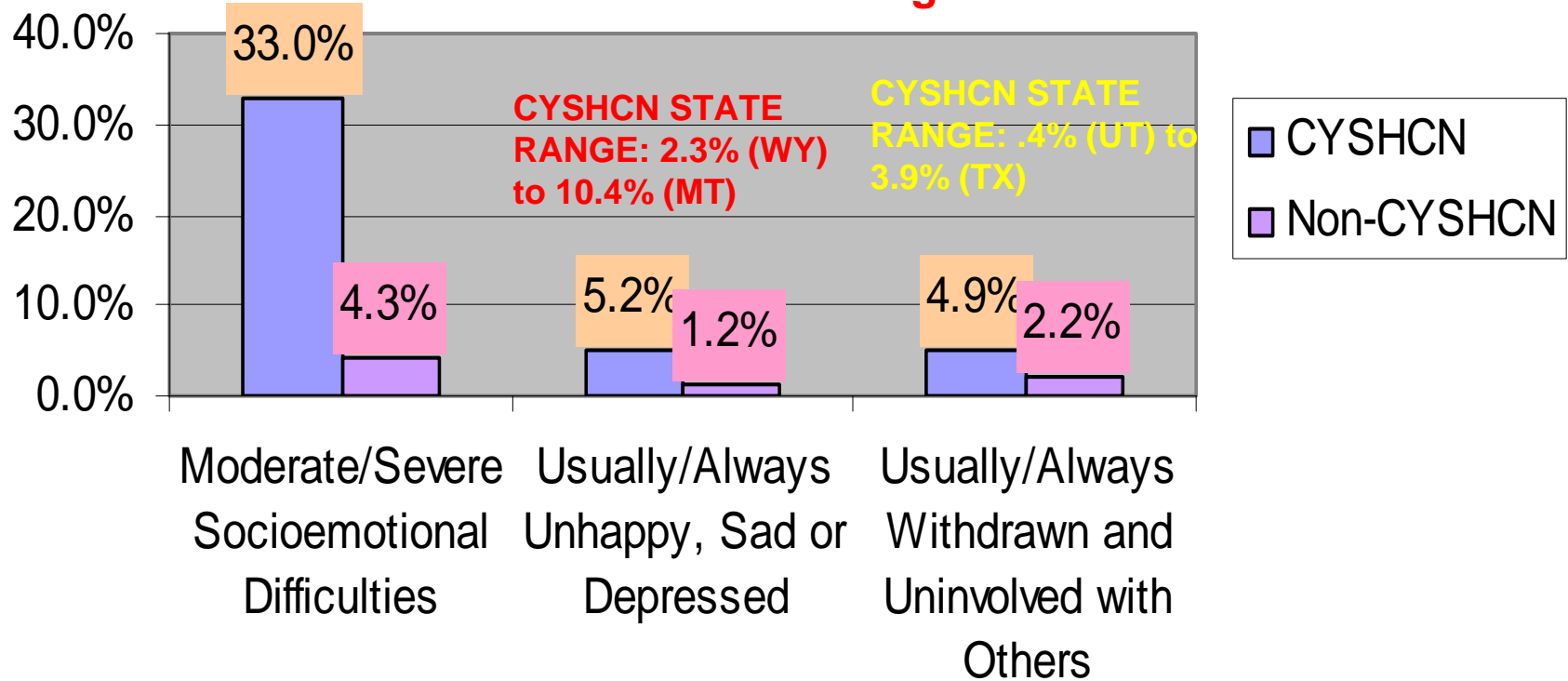
Children and Youth Age 6 to 17



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

# Proportion with Emotional Difficulties: CYSHCN vs. Non-CYSHCN

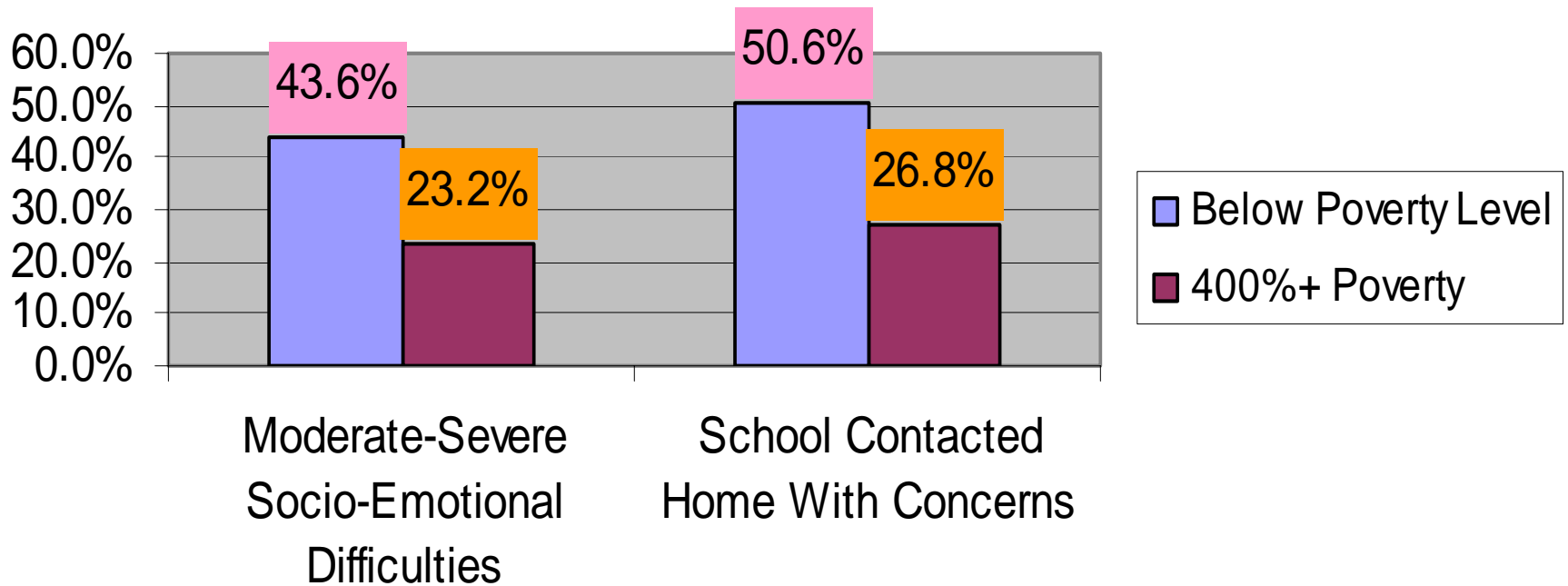
**Children and Youth Age 6 to 17**



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

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

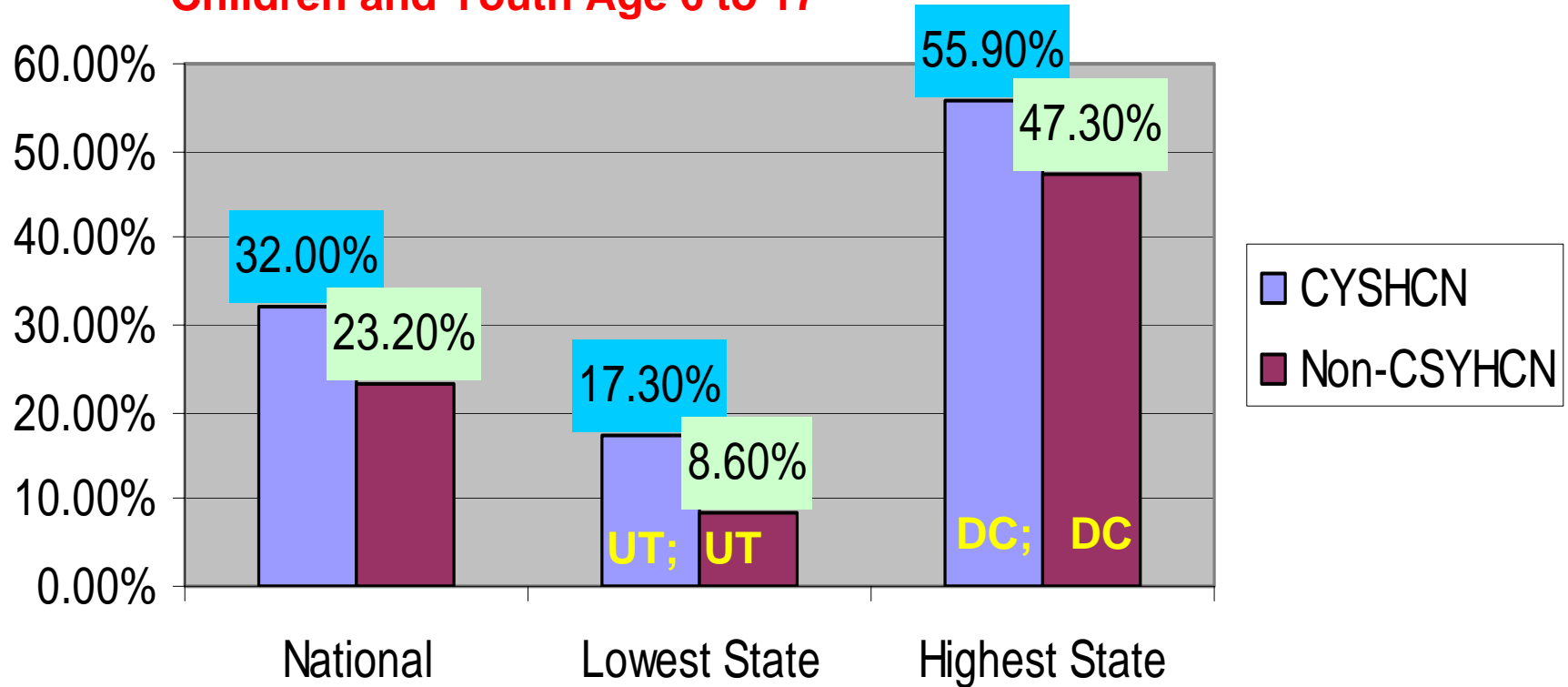
**CYSHCN Age 6 to 17**



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

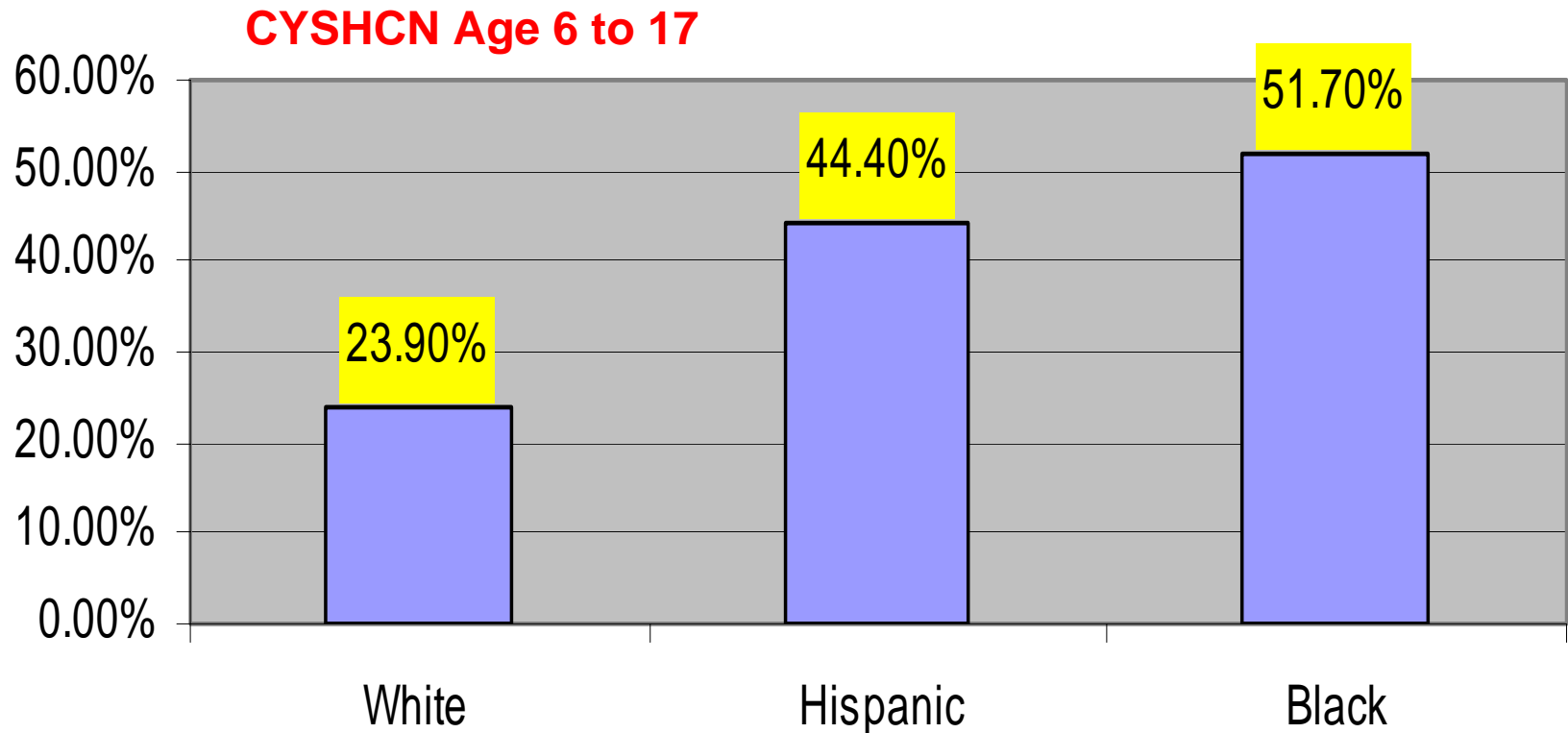
# Proportion of School-Age Children and Youth with Public Health Insurance: CYSHCN vs. Non-CYSHCN

Children and Youth Age 6 to 17



SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.

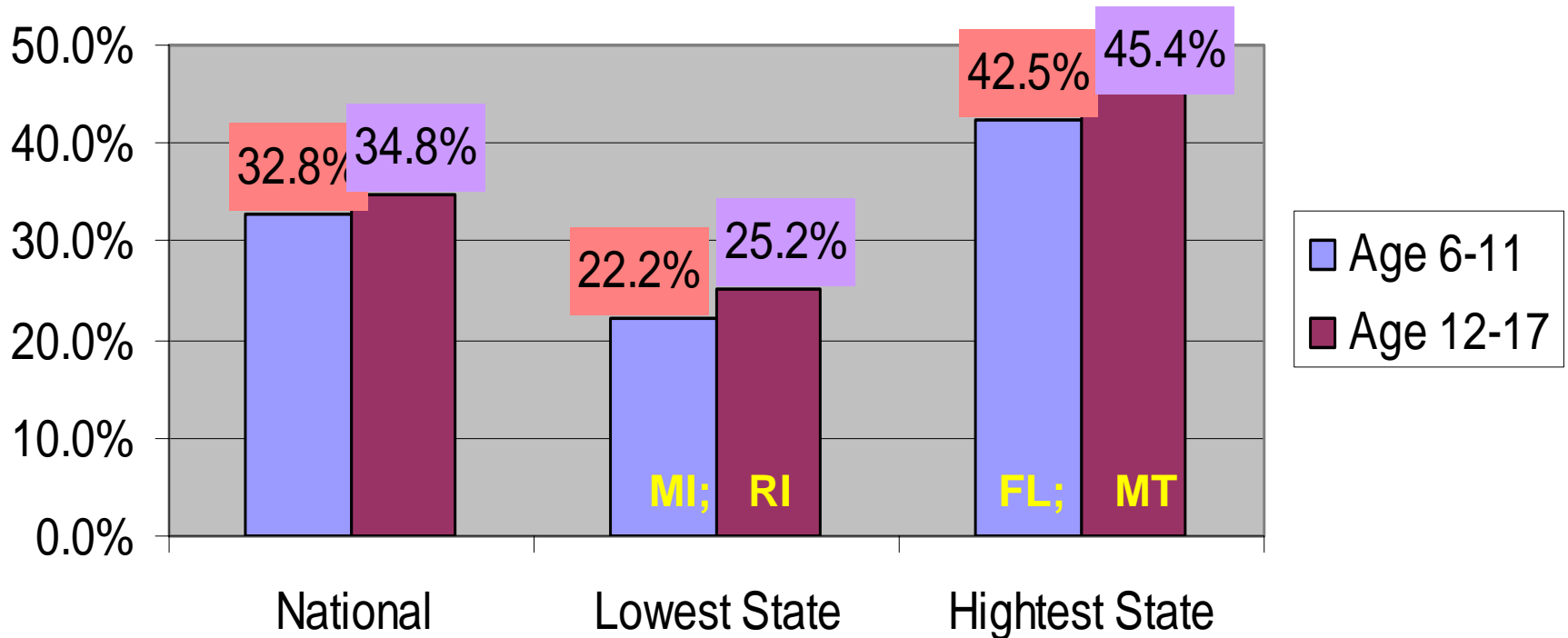
# Proportion of School Age CYSHCN with Public Health Insurance: By Race/Ethnicity



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

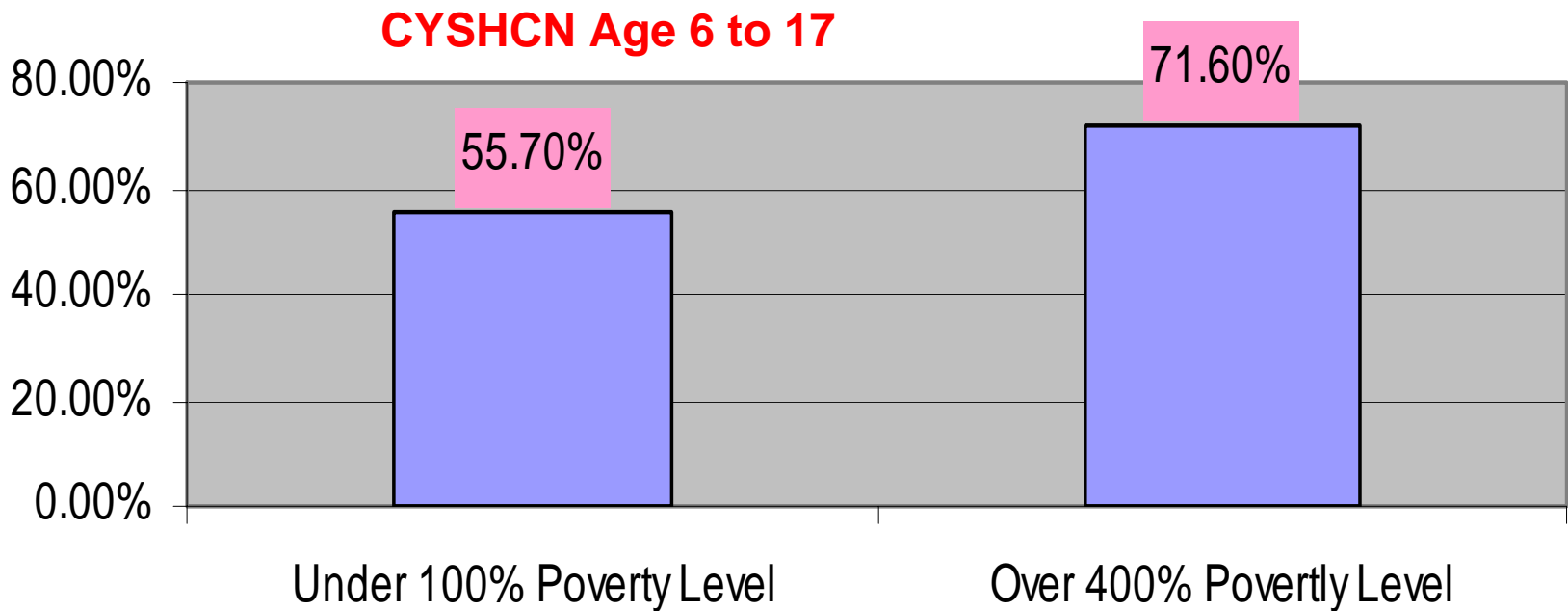


# Proportion of CYSHCN Whose Parents Report Insurance is NOT Adequate to Meet Needs: By Age



**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](http://www.childhealthdata.org))**

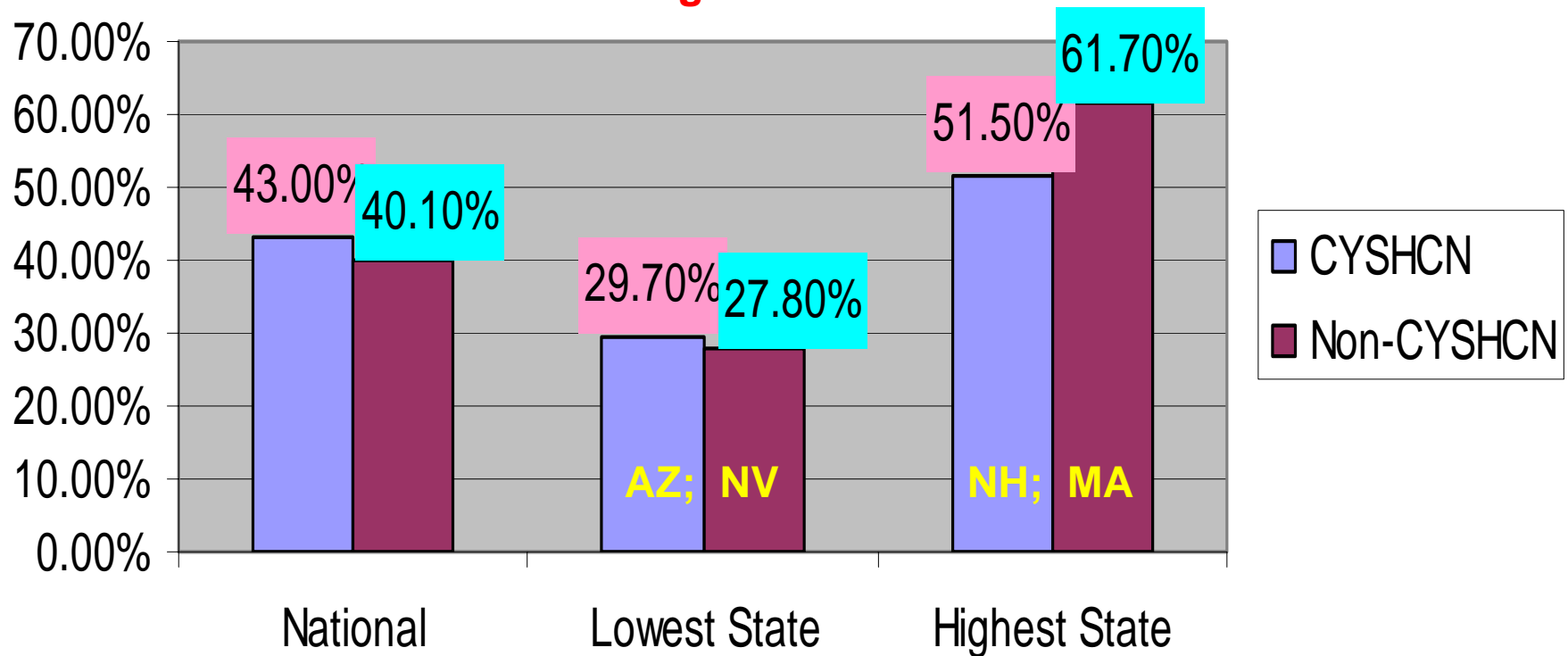
## Proportion of School-Age CYSHCN Whose Parents Report Health Insurance is Adequate to Meet Needs: By Household Income



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

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

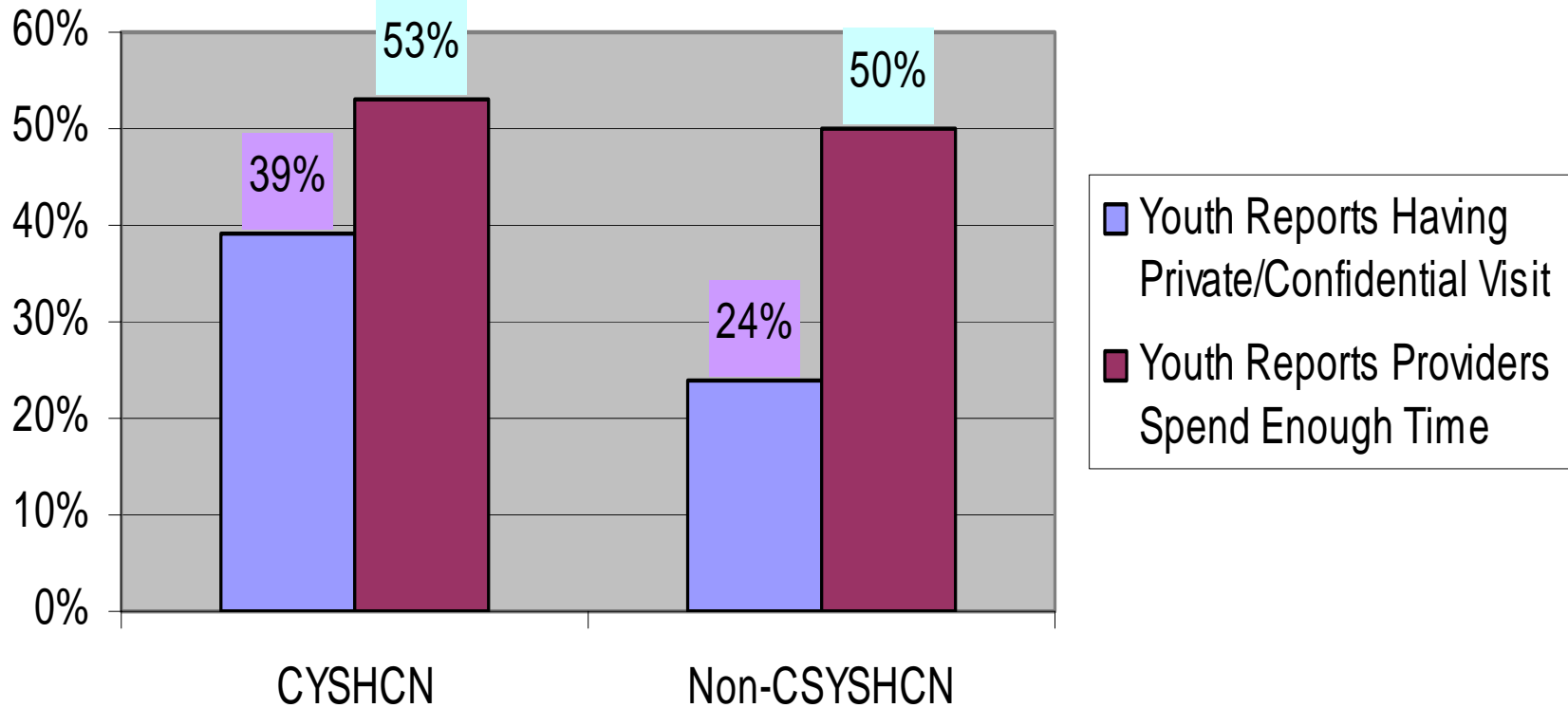
**Children and Youth Age 6 to 17**



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

# Youth Reported Quality of Care: By CYSHCN Status

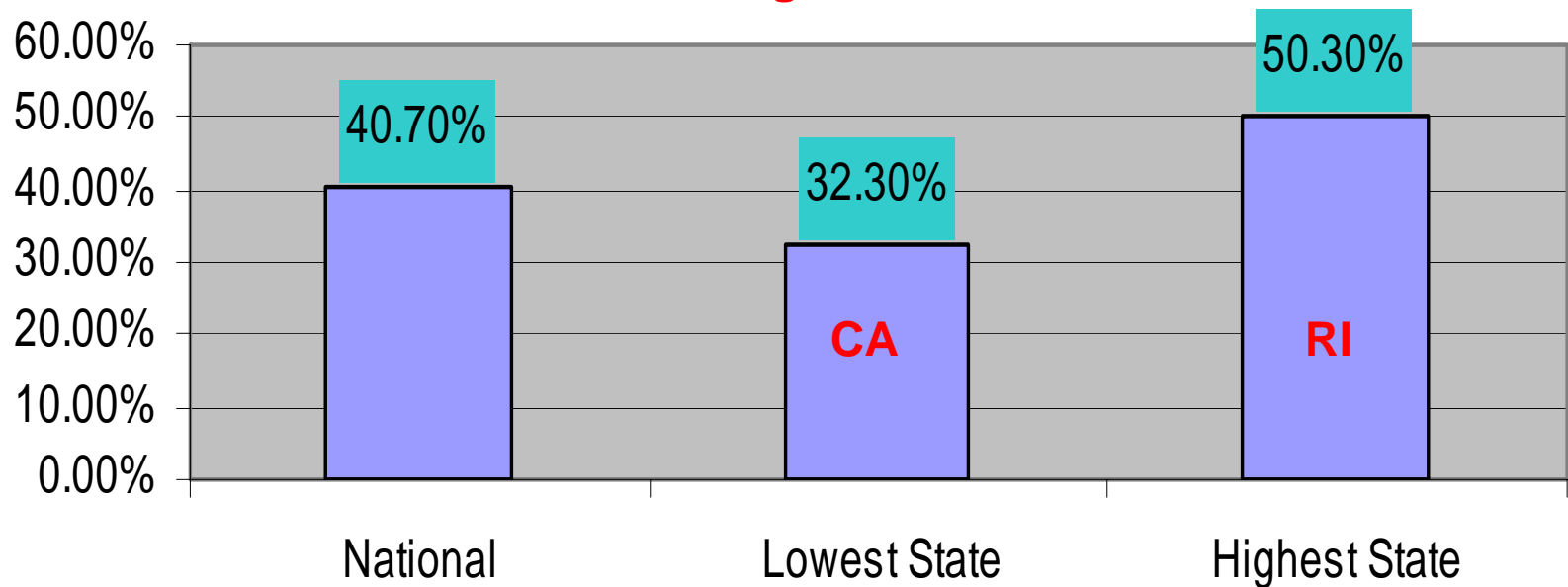
**Children and Youth Age 13 to 18**



**SOURCE: 2002 National Online Youth Survey. The Child and Adolescent Health Measurement Initiative. Funding by the Robert Wood Johnson Foundation.**

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

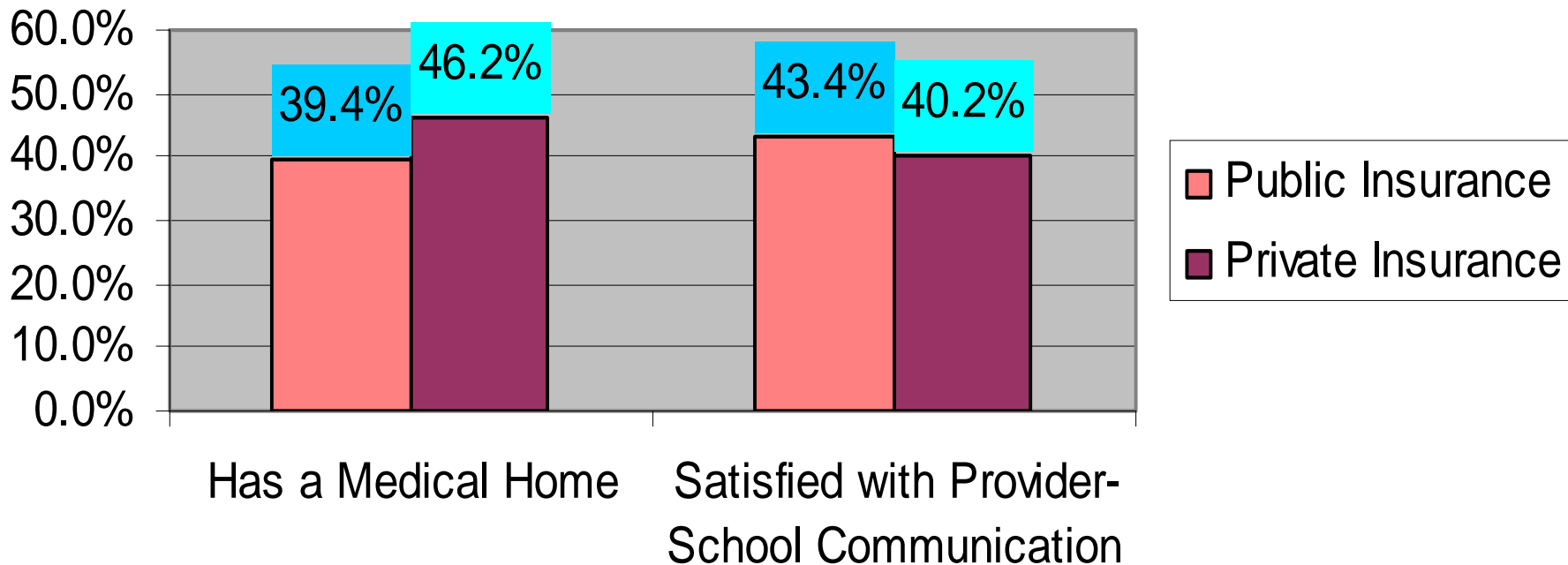
**CYSHCN Age 6 to 17**



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**

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

**CYSHCN Age 6 to 17**



**SOURCE: 2003 National Survey of Children's Health; Analysis by The Child and Adolescent Health Measurement Initiative Data Resource Center for Child and Adolescent Health.**



# 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 United States were asked for all children in  
household

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**



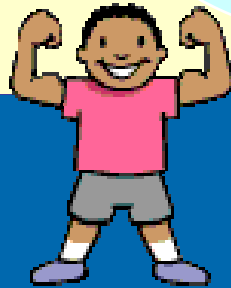
## NSCH yields over 100 indicators of child health & well-being in the following areas:

- 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**



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

**102,353**

**Early Childhood  
questions (Sections 1-5)  
asked for  
children**

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

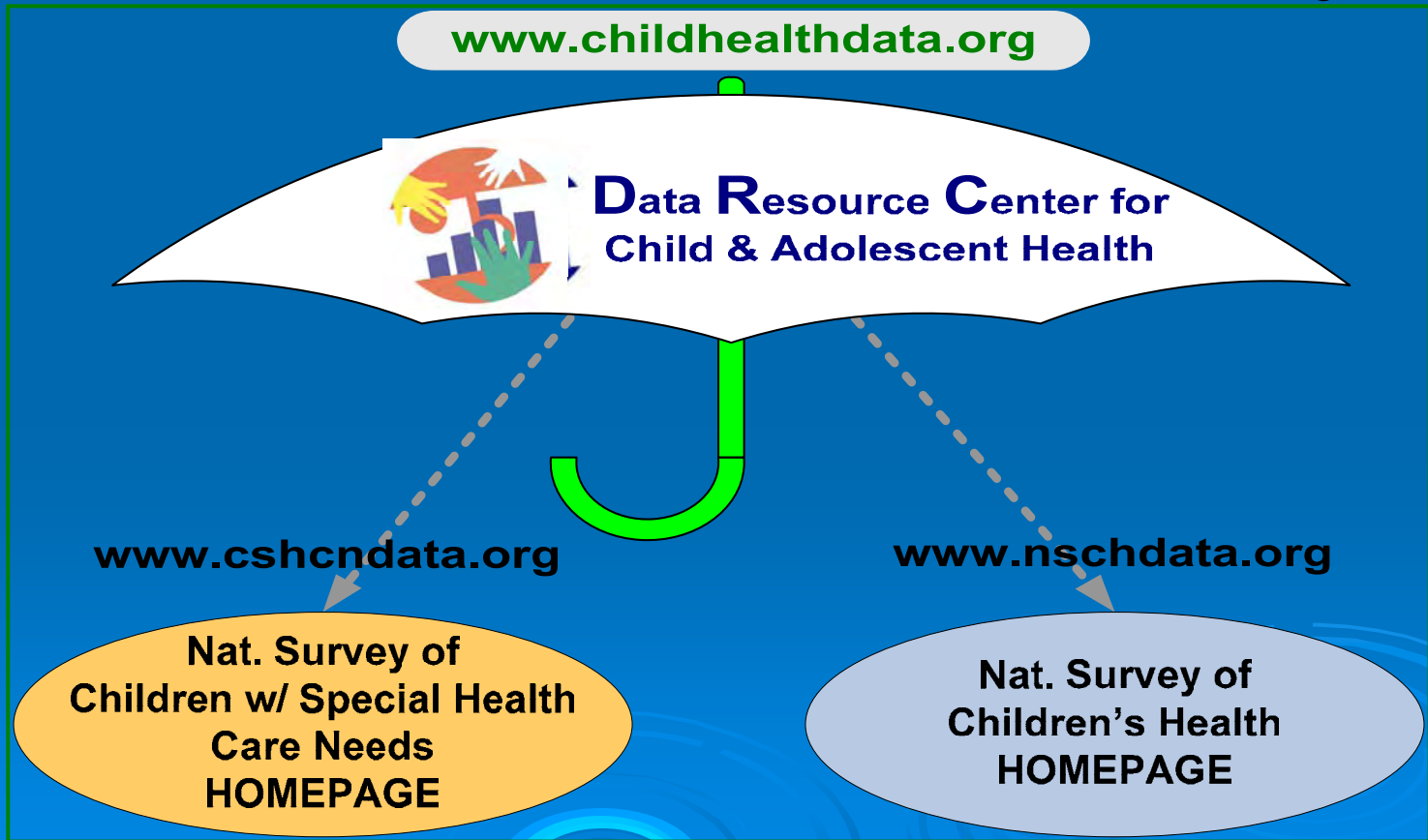
# How to Use the DRC Website





# DRC Website

**WEBSITE** - [www.childhealthdata.org](http://www.childhealthdata.org)  
serves as an umbrella site for national survey data





# Data Resource Center for Child & Adolescent Health

Your Data... Your story


- [DRC Home](#)
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- [Glossary](#)
- [Search](#)
- [Contact Us](#)

- Online Tour **NEW!**
- Ask a Question
- Tell a Friend
- E-Updates
- Answer Our Brief User Poll

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

## Select a survey to search:

**N**ational 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**

**N**ational 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](#)

This site is a project of  
**CAHMI**  
The Child and Adolescent Health Measurement Initiative





# National Survey of Children with Special Health Care Needs

Data Resource Center — Your Data... Your story

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- [CSHCN Survey Home](#)
- [Start Data Query](#)
- [State Profiles](#)
- [Quick Guides](#)
- [Resources for Data Users](#)
- [Especially for Families](#)
- [State Data Sets](#)

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

## Start **HERE!**



**1.** Learn about the survey



**2.** Search the data



**3.** Report your results

## On Its Way!

2005 NS-CSHCN Data  
Coming Fall 2007

To Preview Content  
Guide

[Click Here](#)

Want to view your state's  
data profile?




[CLICK HERE](#)

- [Chartbooks](#)
- [Publications & Presentations](#)
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- [Frequently Asked Questions](#)
- [E-Updates](#)

This site is a project of

**CAHMI**

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- [ANSWER OUR BRIEF USER POLL](#)
- [TELL A FRIEND](#)

 [YOUR BRIEFCASE](#)



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This site is a project of



## 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 \(PDF\)](#)





# Data Resource Center for Child & Adolescent Health

*Your Data... Your story*

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## Ask a Question

**Your Email Address:**

**Subject:**

**Message:**



# 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.

# Example of State Profile

## 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 %

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

#### Household-Level Prevalence:

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

#### Prevalence by Age:

Age Group	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:

Sex	State %	Nation %
Female	8.3	10.5
Male	12.3	15.0

#### Prevalence by Poverty Level:

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:

Race/Ethnicity	State %	Nation %
Hispanic	7.6	8.5

### Indicator

#### Child Health: State % Nation %

Indicator	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 %
<b>Nationwide</b>	4.9	64.6	15.7	14.8	100.0
<a href="#">Alaska</a>	5.7	63.6	19.6	11.1	100.0
<a href="#">Alabama</a>	6.1	59.3	17.9	16.7	100.0
<a href="#">Arkansas</a>	6.3	60.8	16.4	16.4	100.0
<a href="#">Arizona</a>	5.0	65.3	17.5	12.2	100.0
<a href="#">California</a>	4.7	65.3	16.8	13.2	100.0
<a href="#">Colorado</a>	6.0	72.0	12.0	9.9	100.0
<a href="#">Connecticut</a>	4.8	67.9	15.0	12.3	100.0
<a href="#">District of Columbia</a>	5.6	54.8	16.7	22.8	100.0
<a href="#">Delaware</a>	4.8	59.7	20.7	14.8	100.0
<a href="#">Florida</a>	6.0	61.5	18.0	14.4	100.0
<a href="#">Georgia</a>	3.5	64.8	15.3	16.4	100.0
<a href="#">Hawaii</a>	6.6	66.5	13.5	13.3	100.0
<a href="#">Iowa</a>	5.1	69.4	13.0	12.5	100.0
<a href="#">Idaho</a>	6.0	68.4	15.5	10.1	100.0

# 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 %
<b>Nationwide</b>	%	<b>16.7</b>	<b>83.3</b>	<b>100.0</b>
	C.I.	(16.2 - 17.1)	(82.9 - 83.8)	
	n	14,568	87,491	
	Est.	12,077,887	60,397,981	
<b>Texas</b>	%	<b>22.6</b>	<b>77.4</b>	<b>100.0</b>
	C.I.	(20.4 - 24.8)	(75.2 - 79.6)	
	n	433	1,740	
	Est.	1,400,973	4,799,550	



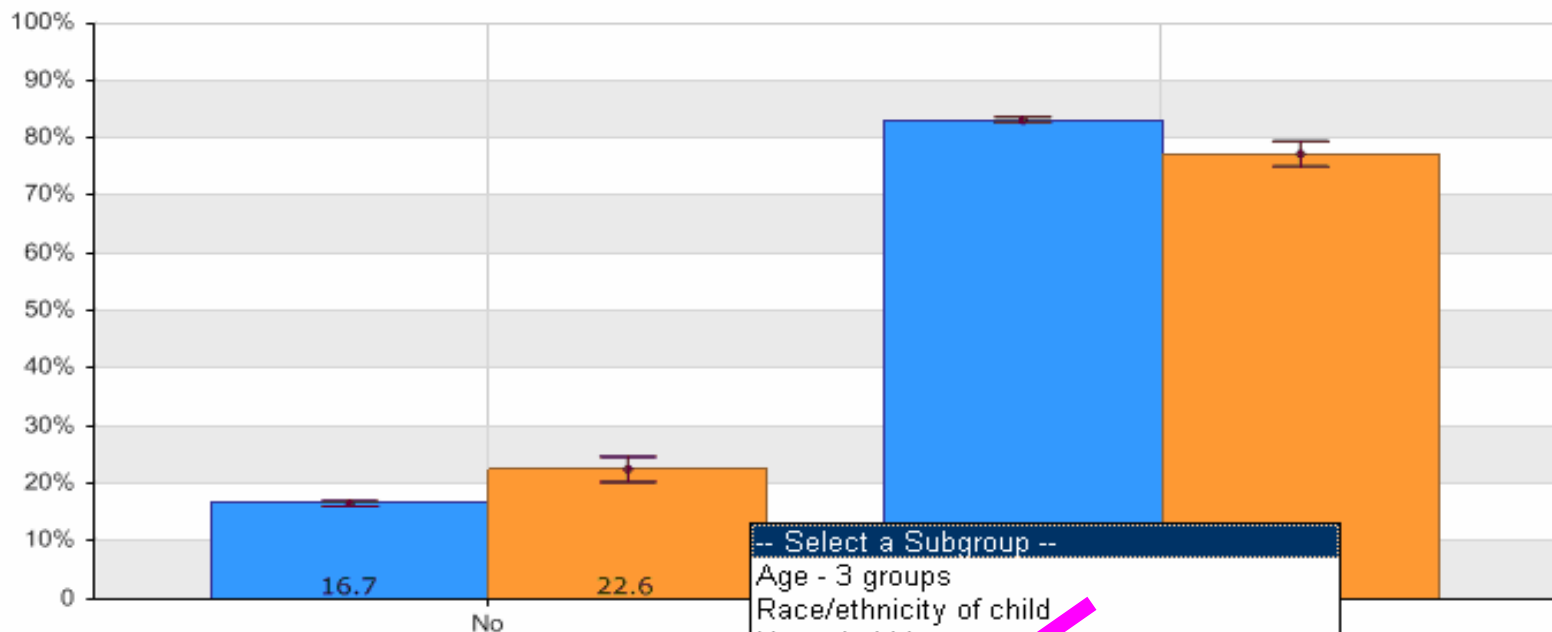
For a detailed explanation of the data **MOVE** your cursor over the text in the table or the bold text below

**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



Legend: Na

Compare State/Regions:

Compare Subgroups:

Chart Type:

-- Select a Subgroup --

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

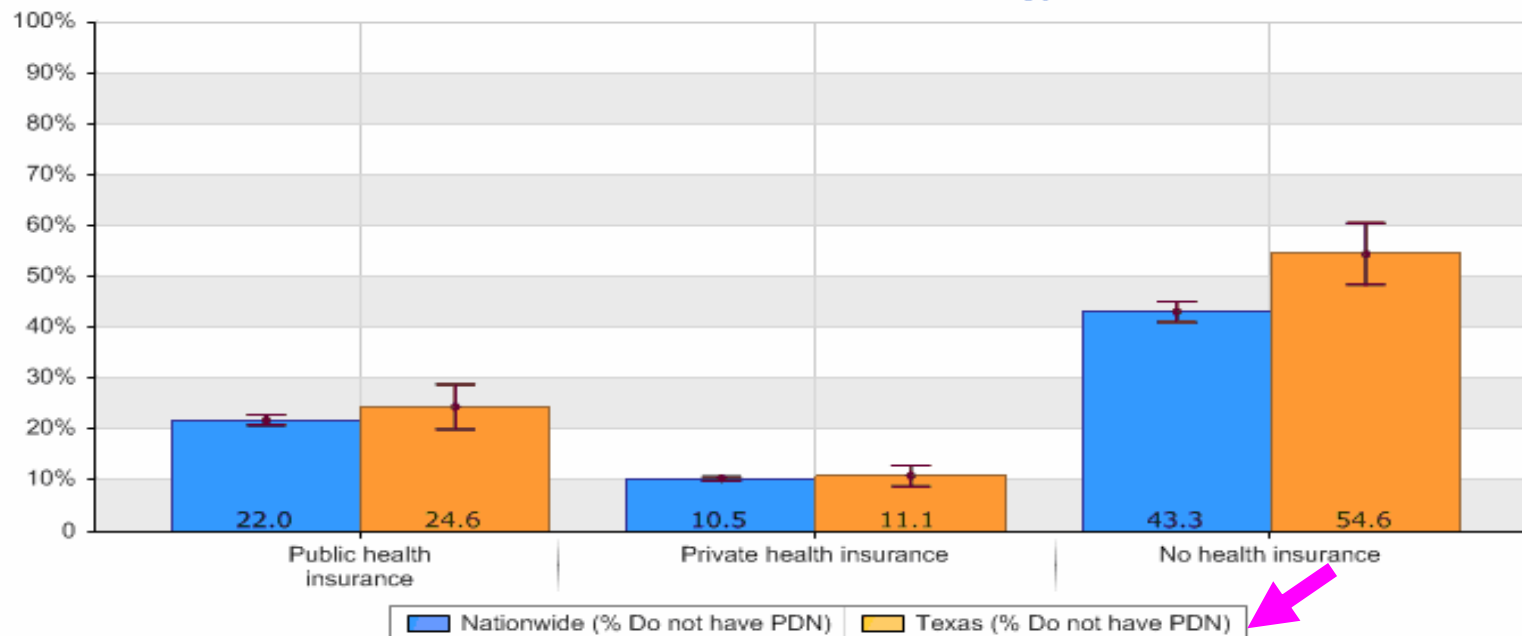
-- Select a Subgroup --

Bar Chart

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

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

% Do not have PDN X Insurance type



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*





# 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





# National Survey of Children with Special Health Care Needs

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## Start **HERE!**



**1.** Learn about the survey



**2.** Search the data



**3.** Report your results

## On Its Way!

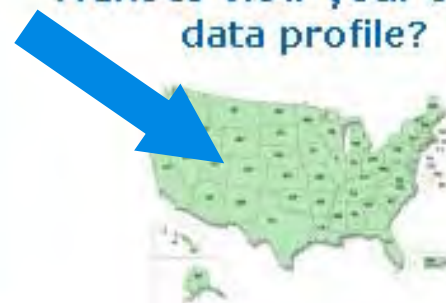
2005 NS-CSHCN Data  
Coming Fall 2007

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## State & Regional Profiles on Key Indicators for CYSHCN

Click on a state below or HRSA Region on the right to view results:





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

## California

Children ages 0-17 years old

[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 <b>0-5</b> years of age	5.7	7.8
Children <b>6-11</b> years of age	11.2	14.6
Children <b>12-17</b> years of age	14.0	15.8

#### Prevalence by Sex:

<b>Female</b>	8.3	10.5
<b>Male</b>	12.3	15.0

#### Prevalence by Poverty Level:

<b>0% - 99%</b> FPL	7.5	13.6
<b>100% - 199%</b> FPL	9.7	13.6
<b>200% - 399%</b> FPL	11.0	12.8
<b>400%</b> FPL or greater	13.8	13.6

#### Prevalence by Race/Ethnicity:

<b>Hispanic</b>	7.6	8.5
-----------------	-----	-----

### Indicator

#### Child Health: State % Nation %

<b>1)</b> % of CYSHCN whose health conditions consistently and often greatly affect their daily activities.	24.0	23.2
<b>2)</b> % of CYSHCN with 11 or more days of school absences due to illness.	16.2	15.8

#### Health Insurance Coverage:

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

#### Access to Care:

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

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

### Family-Centered Care:

---

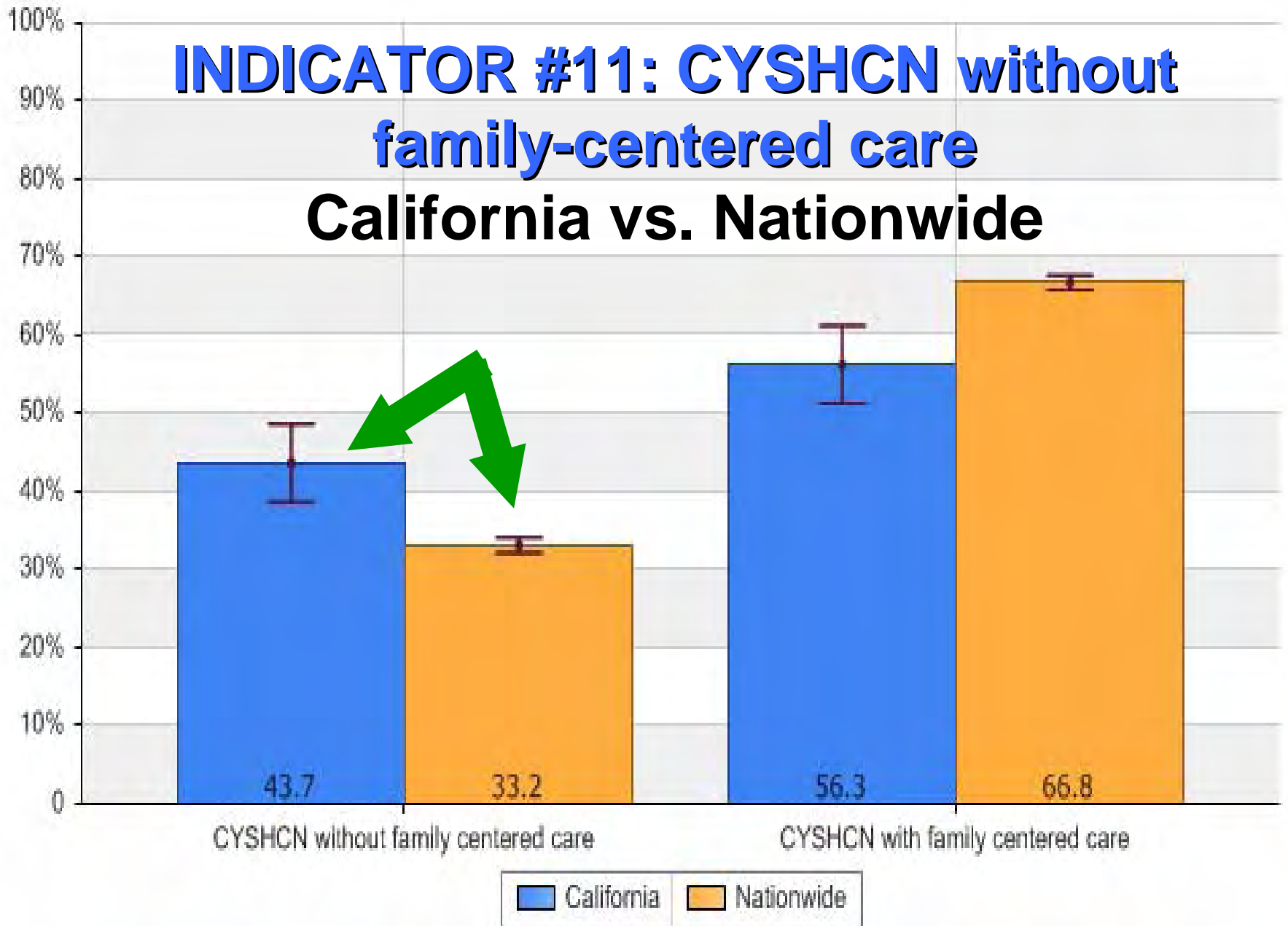
<b>11)</b> % of CYSHCN without family-centered care.	43.7	33.2
--	------	------

### Impact on Family:

---

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

# INDICATOR #11: CYSHCN without family-centered care California vs. Nationwide





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## 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

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## Create Your Own Profile...

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

- [< Previous](#)
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### 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





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## National Survey of Children's Health, 2003

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

**Note:** 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  $\geq 30\%$ .

	Nationwide Pop. Est	% Nationwide (95% CI)	% District of Columbia (95% CI)
<b>Physical and Dental Health</b>			
Indicator 1.4: Children/youth ages 0-17 who are overweight based on Body Mass Index-for-age	4,607,912	14.8 (14.2 - 15.4)	22.8 (18.8 - 26.8)
Indicator 1.5: Children/youth ages 6-17 who exercised vigorously every day during the past week	12,561,056	26.0 (25.4 - 26.6)	27.0 (23.7 - 30.4)
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	2,486,464	5.2 (4.9 - 5.5)	4.3 (2.9 - 5.7)
<b>Emotional and Mental Health</b>			
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	5,620,307	9.2 (8.8 - 9.5)	10.6 (8.6 - 12.6)
Indicator 2.5: Children/youth ages 6-17 who inconsistently exhibit positive social skills	10,712,114	21.9 (21.3 - 22.5)	33.4 (29.9 - 37)
Indicator 2.6: Children/youth ages 6-17 who often exhibit problematic behaviors	3,814,253	7.8 (7.4 - 8.2)	12.2 (9.6 - 14.8)
<b>Health Care Access and Quality</b>			
Indicator 4.5: Children/youth ages 1-17 who reported needed mental health services	5,000,000	50.0	66.7

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# National Survey of Children's Health, 2003

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Indicator 2.6: Children/youth ages 6-17 who often exhibit problematic behaviors	3,814,253	7.8 (7.4 - 8.2)	12.2 (9.6 - 14.8)
<b>Health Care Access and Quality</b>			
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)	2,712,215	58.7 (56.5 - 61)	66.1 (56.2 - 76)
Indicator 4.8: Children/youth ages 0-17 who receive health care that meets the American Academy of Pediatrics definition of Medical Home	33,118,954	46.1 (45.6 - 46.7)	45.2 (42.4 - 48)
Indicator 4.12: Children/youth who had problems getting specialty care or services recommended by their personal doctor or nurse (PDN) during the past 12 months (ages 0-17 who have a PDN and needed specialty care, services, or equipment)	2,561,525	15.5 (14.7 - 16.3)	21.2 (16.2 - 26.2)
<b>Family Health and Activities</b>			
Indicator 6.2: Children/youth ages 0-17 whose mothers' emotional health is excellent or very good	48,502,912	71.4 (70.9 - 72)	69.4 (66.6 - 72.2)
Indicator 6.10: Children/youth ages 6-17 who spend four or more hours		7.0	14.1



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### JUST RELEASED!



Overweight and Physical Activity Among Children

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- Chartbooks
- Publications & Presentations
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- Frequently Asked Questions
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Want to view your state's data profile?



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**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	<input type="radio"/>
Emotional and Mental Health	<input type="radio"/>
Health Insurance Coverage	<input type="radio"/>
Health Care Access and Quality	<input type="radio"/>
Community and School Activities	<input type="radio"/>
Family Health and Activities	<input type="radio"/>
Neighborhood Safety and Support	<input type="radio"/>



# Terms to Know

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

# Prevalence:

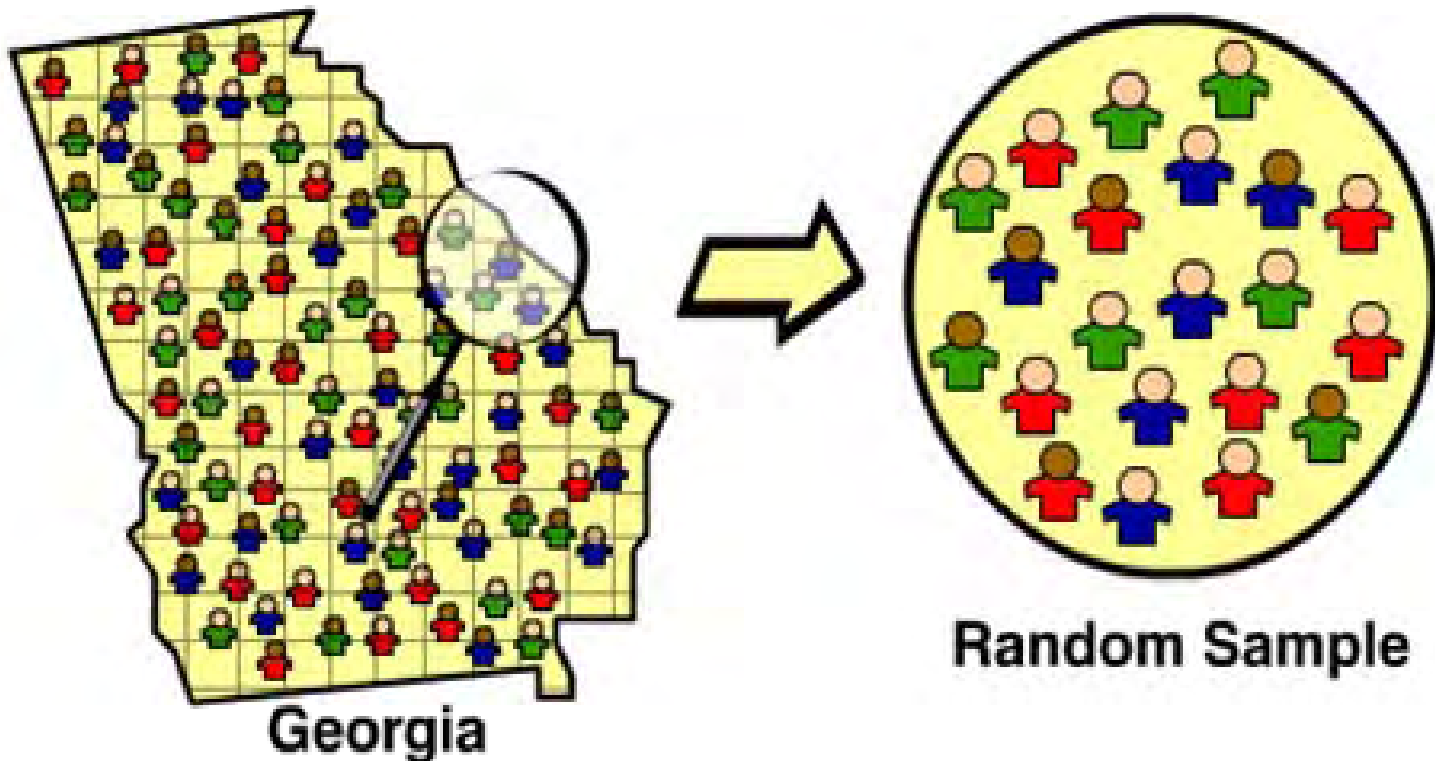
$$P = \frac{\text{number of people with condition or characteristic of interest in the population (n) at a specific point in time}}{\text{total size of the population of interest (N) at that specified time}}$$

**Question:** How many hours per week do families of CYSHCN spend providing health care? [derived from C9q03 and C9q04]

		Less than 1 hour	1 - 4 hours per week	5 - 10 hours per week
<b>Functional limitations</b>	<b>%</b>	<b>24.2</b>	<b>33.6</b>	<b>14.2</b>
	<b>CI</b>	(22.5 - 25.8)	(31.6 - 35.5)	(12.9 - 15.5)
	<b>n</b>	2,025	2,593	1,131
	<b>Est.</b>	456,672	634,256	269,133
<b>Managed by Rx meds</b>	<b>%</b>	<b>58.7</b>	<b>29.6</b>	<b>5.4</b>
	<b>CI</b>	(57.3 - 60.2)	(28.2 - 30.9)	(4.8 - 6.0)
	<b>n</b>	8,727	4,132	728
	<b>Est.</b>	1,957,891	986,373	179,244
<b>Above routine need/use of services</b>	<b>%</b>	<b>42.6</b>	<b>35.9</b>	<b>10.0</b>

# Random sampling:

- allows certain characteristics to be estimated with precision
- larger sample sizes achieve more precision.





%

CI

n

Est.

**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.**

%

CI

n



Est.

**n** = actual number of people in the sample with a specific characteristic or response to a survey question ----

before weighting to reflect population of the sampled area

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

## 95% Confidence Interval

%

CI ←

n

Est.

- 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](http://www.childhealthdata.org)



National Assembly on School-Based Health Centers National Convention

June 30, 2007

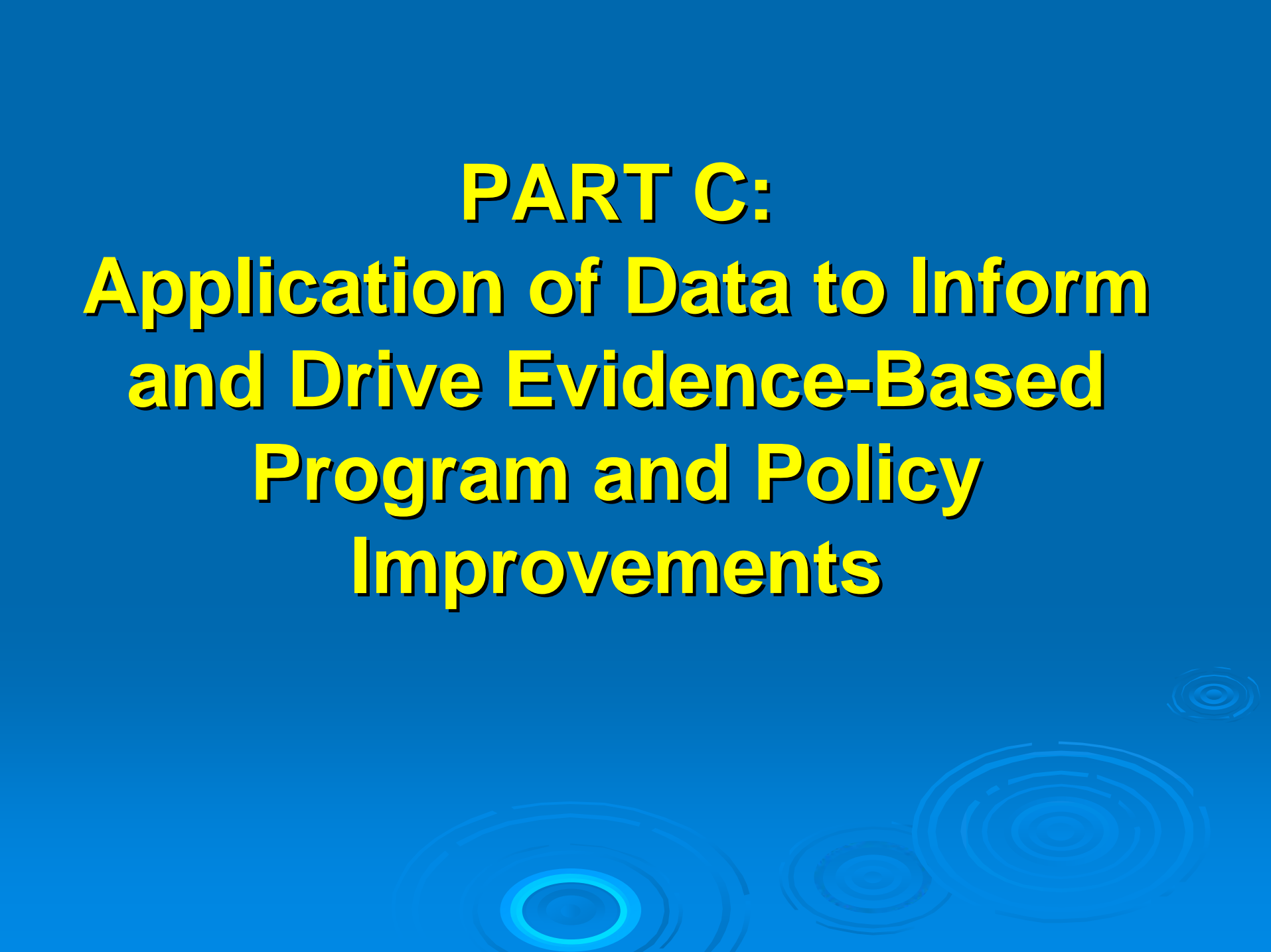
Presented by: Christina Bethell, PhD, MPH, MBA



# 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](http://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*



# Data Strengthens Your Message

## Select data facts that:

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



# Interpreting Data

## **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%.



# Interpreting Data

## **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.**



# Interpreting Data

## **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.**





# National Survey of Children with Special Health Care Needs

Data Resource Center — Your Data... Your story

- [DRC Home](#)
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- [State Data Sets](#)

- [ONLINE TOUR](#)
- [ASK A QUESTION](#)
- [ANSWER OUR REEFF USER POLL](#)
- [TELL A FRIEND](#)
- [YOUR BRIEFCASE](#)



## 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

### Massachusetts Office of Medicaid: Helping Families of Children with Special Health Care Needs Get Back to Work. A Cost Neutral Approach to Family Empowerment

2006

### Save the CDRC

Dr. Brian Rogers used state-by-state comparisons from the National Survey of Children with Special Health Care Needs in is 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





# 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

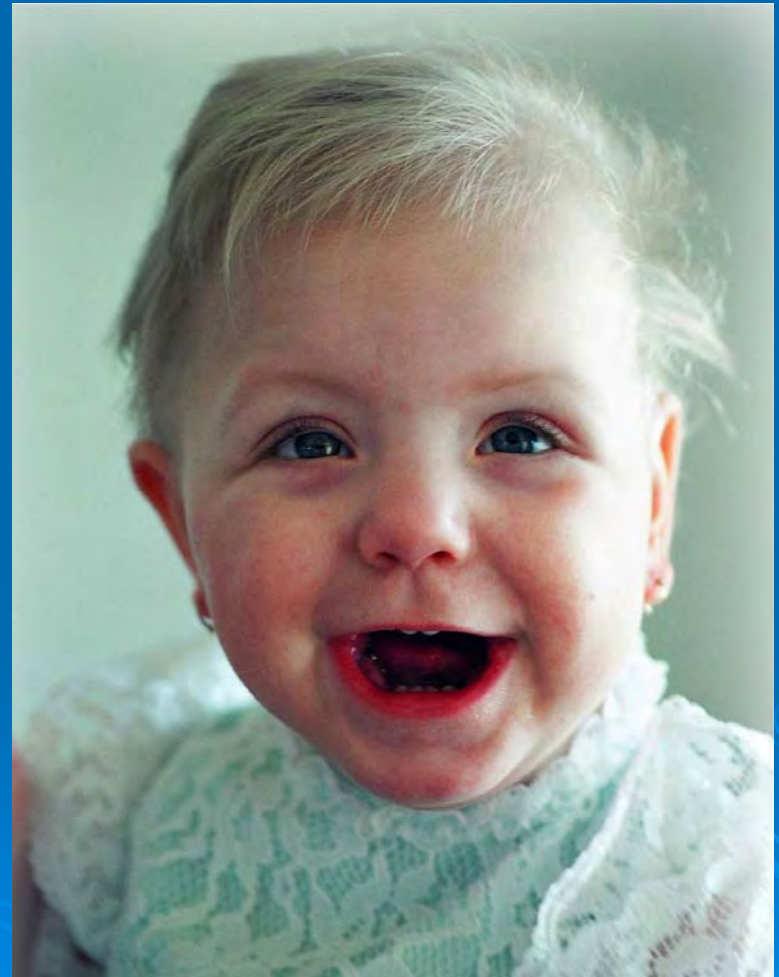
Options to Expand Coverage  
via the Deficit Reduction Act

The background of the slide features several decorative elements consisting of concentric circles in shades of blue, resembling ripples in water. These circles are scattered across the lower half of the slide, with some being more prominent than others.



# 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.



# Insurance Coverage

- 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.



# Family Financial Impact

- 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



Agency for Healthcare Research and Quality

Quality Research for Quality Healthcare

## National Healthcare Quality Report Framework

### Components of Health Care Quality

#### Health care needs

#### Effectiveness

#### Safety

#### Timeliness

#### Patient centeredness

Staying healthy

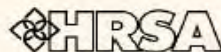
Getting better

Living with illness or disability

End of life care

	Effectiveness	Safety	Timeliness	Patient centeredness
Staying healthy				
Getting better				
Living with illness or disability				
End of life care				

- 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

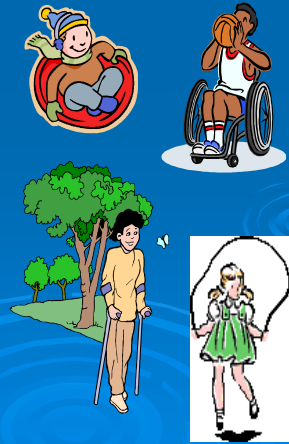
STRUCTURE of the HEALTH CARE SYSTEM



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



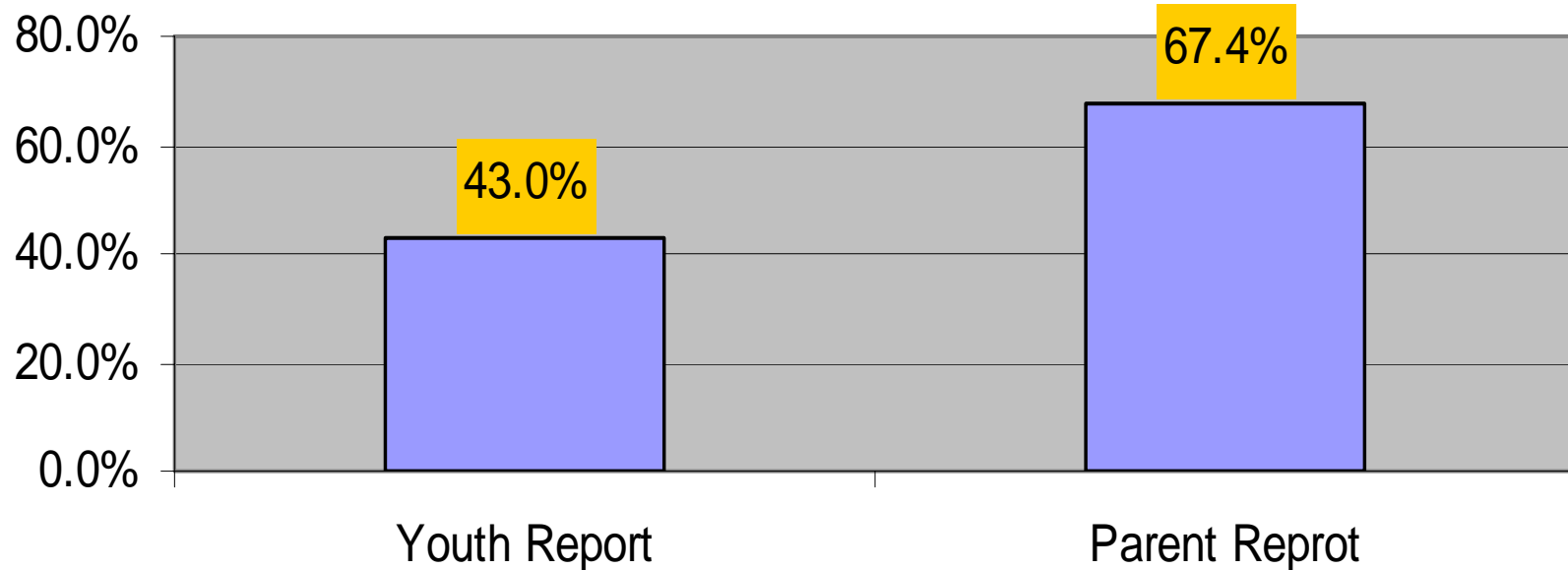
# Examples of Relevant CAHMI Quality Tools Developed (compliment HEDIS and others)

- **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**



**SOURCE: 2002 National Online Youth Survey. The Child and Adolescent Health Measurement Initiative. Funding by the Robert Wood Johnson Foundation AND 2003 National Survey of Children's Health (Parent Report), CAHMI DRC.**



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**Resource Links**

[CONQUEST](#)  
Computerized Needs-Oriented  
Quality Measurement Evaluation  
System

[HCUPnet](#)  
Interactive Tool for

# 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



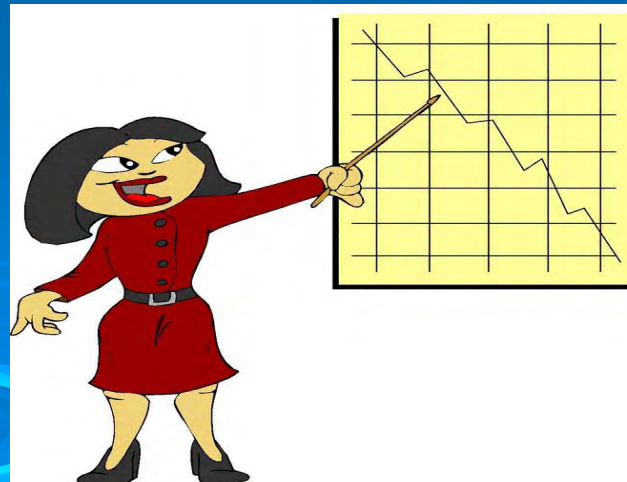
Developing Quality Measures and Gathering Quality Information



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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