

Putting Data Into Action: Accessing and Using Data from the National Survey of Children with Special Health Care Needs

Plus Findings on Children with Special Health Care Needs and Autism Spectrum Disorders

SPHARC Technical Assistance Webinar
March 21, 2012



The Data Resource Center is supported by the federal Maternal and Child Health Bureau

The Data Resource Center for Child and Adolescent Health www.childhealthdata.org



Learning Objectives

- Increase your understanding of the National Survey of Children with Special Health Care Needs and the National Survey of Children's Health.
- Understand how you can easily access these survey data on the Data Resource Center website.
- Become aware of resources available to you through the Data Resource Center.
- Learn about initial findings from the 2009/10 NS-CSHCN and 2007 NSCH on CSHCN with autism spectrum disorders.
- Discover more ways that you can effectively use the data available on the DRC website.

Why We Need Data!

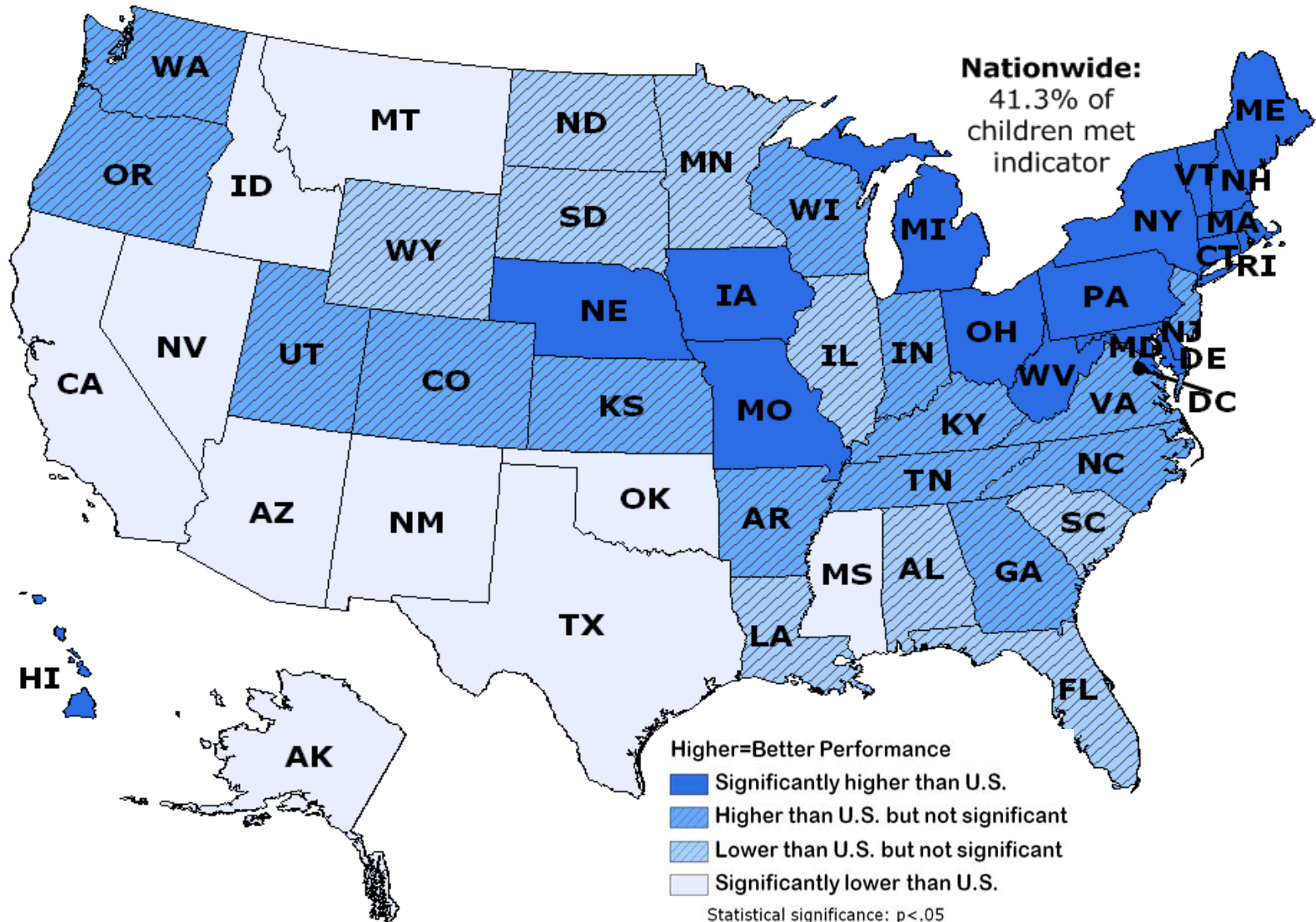
- **Identifying/documenting needs and performance**
- **Building partnerships**
- **Educating Ourselves and Policymakers**
- **Advocacy**
- **Grant Writing**
- **Research**

Myth Busting is Essential

Assumption: Most Children in the U.S. Get Adequate Health Care.

Minimal Quality of Care Composite Measure (Insurance usually or always adequate, at least 1 preventive care visit in previous 12 months, and care meets medical home criteria)

Nationwide:
41.3% of children met indicator



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Resource Center

Learn About
the Surveys

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Survey Fast Facts

Quick Data Search

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How to Use This Site

Keyword Search



Go

Data at a Glance

At your fingertips—easy-to-read data snapshots for each state



State/Region Nationwide

Browse Data Snapshots

Welcome to the Data Resource Center for Child & Adolescent Health!

Welcome to the newly redesigned DRC website. Take a [tour](#) of the site and give us your feedback.

The mission of the Data Resource Center (DRC) is to take the voices of parents, gathered through the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN), and share the results through this online resource so they can be used by researchers, policymakers, family advocates and consumers to promote a higher quality health care system for children, youth and families. [Learn more about the DRC](#)

DRC Highlights

- Child Obesity State Report Cards
- New NS-CSHCN Data Trends
- New chartbook comparing CSHCN with children who do not have special health care needs

Most Popular Topics

What you can do on the DRC website?

- Learn about** the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs
- Browse** national and state findings on hundreds of child health indicators
- Search** data based on numerous important topics and subgroups of children
- Download** and print snapshot profiles on key

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Data Sets Available on the Data Resource Center (DRC) Web Site





National Survey of Children with Special Health Care Needs (NS-CSHCN)

- Conducted to produce national and state-based prevalence estimates of children with special health care needs (CSHCN), their health and experiences with the health care system.
- First conducted in 2001.
- Repeated in 2005/06 and in 2009/10.



NS-CSHCN Main Topic Areas

- Child's Health and Functional Status
- Access to Care—Use of Services and Unmet Needs
- Care Coordination
- Family-Centered Care and Shared Decision Making
- Transition Issues
- Developmental Screening
- Health Insurance
- Adequacy of Health Insurance
- Impact on Family



The NS-CSHCN and System of Care

Maternal and Child Health Bureau (MCHB) Core Outcomes Covered by NS-CSHCN Survey Measures:

1. Families are Partners in Health Care Decision-Making
2. Care is Received within Medical Home
3. Adequate Insurance to Cover Needed Health Services
4. Early, Continuous Screening for Special Health Care Needs
5. Community-based Service Systems Easily Used by Families
6. YSHCN Receive Services for Successful Transitions into Adulthood



National Survey of Children's Health (NSCH)

- Conducted to produce national and state estimates of the health and well-being of children, youth and families.
- First conducted in 2003 and again in 2007.
- The 2011 NSCH is “in the field.”

The NSCH and Healthy People

Healthy People 2020 Objective Areas with Relevant 2007 NSCH and/or 2009/10 NS-CSHCN Measures

- Access to Health Services
- Adolescent Health
- Disability and Health
- Early and Middle Childhood
- Hearing and Other Sensory or Communication Disorders
- Immunization and Infectious Diseases
- Injury and Violence Prevention
- Maternal, Infant and Child Health
- Mental Health and Mental Disorders
- Nutrition and Weight Status
- Oral Health
- Physical Activity
- Respiratory Diseases
- Sleep Health
- Substance Abuse
- Tobacco Use
- Vision



Both the NSCH and NS-CSHCN

- Are administered using State and Local Area Integrated Telephone Survey (SLAITS) methodology.
- Include independent random-digit-dial samples for all 50 states plus D.C.
- Screen households for children under 18 years of age.
 - Both surveys use the CSHCN screener, but the NS-CSHCN ONLY includes CSHCN.

CSHCN Screener Overview

CSHCN are identified in the NS-CSHCN and the NSCH using the CSHCN Screener: a five-item, parent-reported tool designed to operationalize the federal Maternal and Child Health Bureau (MCHB) consequences-based definition of CSHCN.

- The CSHCN Screener focuses on the health consequences rather than on the presence of a specific diagnosis or type of disability.
- The screener assesses children's health care needs status by using questions that ask about need or use of services, prescription medications, specialized therapies, and having functional difficulties due to an ongoing condition.
- The non-condition specific approach used by the CSHCN Screener identifies children across the range and diversity of childhood chronic conditions and special needs, allowing a more comprehensive assessment of health needs and health care system performance.



Final 2009/10 NS-CSHCN Sample including CSHCN with ASDs

- Data were collected from July 2009 to March 2011.
- 40,242 total interviews were completed throughout the U.S.
 - Minimum: 751 in District of Columbia
 - Maximum: 878 in Texas
- 3,055 CSHCN, age 2-17 years, were reported to have current autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder.

Weighting and Estimation

- Sampling weights permit national and state estimates of child health and well-being.
 - For example, an estimated 4.8% to 7.9% of CSHCN age 2-17 years have current autism spectrum disorders (ASD) nationwide.
 - According to the 2009/10 NS-CSHCN, current prevalence of ASD among CSHCN age 2-17 years ranges across states, from a low of 4.5% in Mississippi to a high of 14.3% in New Jersey.
- Sampling weights are adjusted for potential non-response biases and to account for non-coverage of non-telephone households.
 - Sampling weights are further adjusted to match American Community Survey (ACS) population totals for various demographic groups.

On the DRC Website...

What normally would have to be done to get data findings:

1. Download raw data from study content and re-size survey select topics, upload into statistical analysis software including missing (household, clean, code for missing computation if needed,
2. Determine scoring, construct variables, construct concepts and coding, coding
3. Subpopulation construct subgroup variables
4. Compute with adjustment to standard errors for sampling
5. Present data findings in format into tables and graphs.

Now people can:

1. Click on a topic
2. Get tables and graphs already made
3. Compare across all states and subgroups of children with a point and a click!
4. Download and use in presentations, reports, data briefs, etc.



What Features are Available?

➤ Learn

- Search and compare national, state, and regional survey results for subgroups of children (age, race, sex, income, insurance and health status, etc.)
- Get topically focused data snapshots and profiles
- Get expert help – by e-mailing us your questions, plus get links to other data sets and resources



DRC Technical Assistance



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Ask Us a Question

Have a question? We're here to help.

- Perhaps there is an answer in our [Frequently Asked Questions](#).
- Take an [Online Tour](#) of the DRC website to learn how to search for data and use this site.
- Get [Fast Facts](#) about the NSCH and NS-CSHCN surveys.
- Review [Guides to Topics and Questions](#) in the surveys.

Still have a question? Please [email us](#).

Our goal is to provide quick, thorough replies to your questions and requests for information. DRC staff members make every effort to respond within 2 to 3 business days.

To ensure delivery to your inbox (not junk mail) please add donotreply@childhealthdata.org to your email address book.

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Common Technical Assistance Requests

- Website Assistance/Where to Find Information
- Indicator/Measurement Development
- Downloadable Data Sets and Variable Codebooks
- Conceptualizing Research and Application of the Data
- Interpretation of Data
- Understanding the Surveys
- Resource Location
- New Data Analysis Needs

Other Features Available

➤ Get resources

findings in a valid and effective manner

➤ Download cleaned, labeled state-specific national survey datasets with pre-constructed indicators and additional variables (SAS & SPSS)

➤ Sign up for regular e-updates, twitter and Facebook posts

➤ Find out about and access the latest publications, reports and abstracts using the national survey data

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Keyword Search



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Your Profile Settings

[Profile Overview](#)

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Your Data Briefcase

An online "briefcase" allows you to save your data query results, state data snapshots, and content pages in a folder for future reference. You can return to this folder at any time to view and print saved briefcase items. Any page on the Data Resource Center (DRC) can be added to your briefcase by clicking on "Save to Briefcase" on the left column of each page.

Note: You will need to be logged into your account to save items into your briefcase. The "Save to Briefcase" data tool will not be available if you are not logged into your account.

- ✘ [Browse by Survey and Topic--Data Resource Center for Child and Adolescent Health](#)
- ✘ [Examples of Data Use--Data Resource Center for Child and Adolescent Health](#)
- ✘ [CSHCN 2005/06: % of children/youth \(ages 0-17\) with special health care needs, Nationwide](#)
- ✘ [NSCH Mental Health Profile](#)
- ✘ [State-Specific Survey Results for Title V Needs Assessment](#)
- ✘ [How to Use Data Effectively--Data Resource Center for Child and Adolescent Health](#)

About the Data Resource Center

Learn About the Surveys

Browse the Data

- National Survey of Children's Health (NSCH)
- National Survey of Children with Special Health Care Needs (CSHCN)
- Guide to Survey Topics and

National Survey of Children with Special Health Care Needs (2009/10 NS-CSHCN)

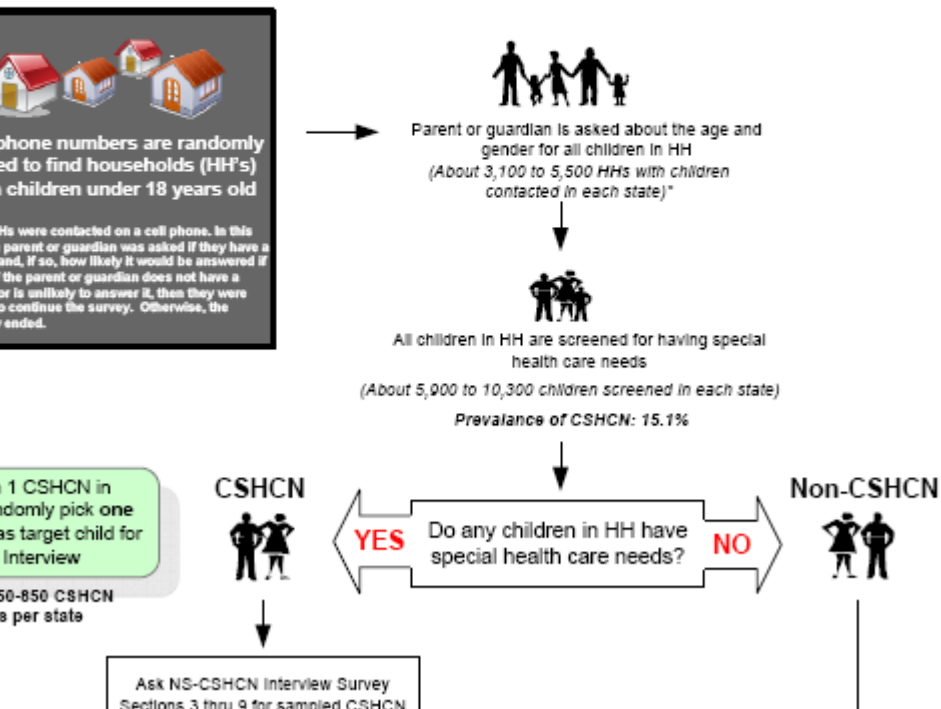
FAST FACTS about the SURVEY

What is the National Survey of CSHCN?

- A national telephone survey conducted for a third time during 2009-2010; previous administrations of the survey took place in 2000-2001 and 2005-2006
- Independent random samples taken in all 50 states and the District of Columbia
- Telephone numbers are randomly generated and called to find households with one or more children under 18 years old. Trained interviewers ask parents or guardians a series of questions for children in the household to identify those with special health care needs

2010 National Survey of Children with Special Health Care Needs (2009/10 NS-CSHCN)

Sampling and Survey Administration Process



0, a total of 372,698 children under 18 years old from 196,159 households were identified to participate in the survey. Final Screener datasets have 371,000 children under 18 years old, in order to maintain confidentiality of respondents.

7,242 detailed CSHCN interviews were collected during 2009-2010; at least 750 interviews were conducted in EACH state and the District of Columbia

It takes about 33 minutes, on average, to complete an interview.

The 2010 NS-CSHCN was administered in English, Spanish, Mandarin, Cantonese, Vietnamese, and Tagalog.

What information is available for EACH state?

Estimated prevalence and number of CSHCN in the state population, and the estimated number of children with children having one or more CSHCN under 18 years old

CSHCN interviews providing detailed information about each state's CSHCN population for subgroups such as age, race/ethnicity, family structure, household income, and insurance status

What are covered by the CSHCN Interview?

Current and functional status; including current conditions and functioning difficulties due to health conditions

Health insurance status and adequacy of coverage

Health care — including types of health care services needed and any unmet needs for medical and dental care, and specialty services received

About the Data Resource Center

Learn About the Surveys

Browse by Topic

National Survey of Children's Health (NSCH)

National Survey of Children with Special Health Care Needs (CSHCN)

Guide to Survey Topics and Questions

Survey FAQs

Fast Facts about the Surveys

Survey Methods and Documentation

Guide to Topics & Questions Asked

National Survey of Children with Special Health Care Needs, 2009/10

NOTE: Telephones are dialed at random to identify households with one or more children under 18 years old. The interviewers speak to the parent or guardian who knows the most about the child's or children's health and health care. If he or she is not available, multiple call back attempts are made to reach them. If the parent or guardian's language is not English, arrangements are made to call back later to administer the survey in another language.

**Denotes that original version of the variable is not released publicly. Variable may be recoded or omitted in public use data.

CLICK on the question numbers in blue text below to view the full text of the question and its response options.

- SECTION 1: NIS/SLAITS Eligibility
- SECTION 2: Initial Demographics

CSHCN2009

Section 2. INITIAL SCREENING

INTRODUCTION The next questions are about any kind of health problems, concerns, or conditions that may affect your (child/children)'s physical health, behavior, learning, growth, or physical development. Some of these health problems may affect your (child/children)'s abilities and activities at school or at play. Some of these problems affect the kind or amount or services your (child/children) may need or use.

CSHCN1 (IF S_UNDR18=1, INSERT 'Does your child?' IF S_UNDR18 > 1, INSERT 'Do any of your children') currently need or use medicine prescribed by a doctor, other than vitamins?

(01) YES

(02) NO [SKIP TO CSHCN2]

(77) DONT KNOW [SKIP TO CSHCN2]

(99) REFUSED [SKIP TO CSHCN2]

READ IF NECESSARY: This applies to ANY medications prescribed by a doctor. Do not include over-the-counter medications such as cold or headache medications, or any vitamins, minerals, or supplements that can be purchased without a prescription. THESE QUESTIONS REFER ONLY TO A CURRENT CONDITION. THE RESPONDENT SHOULD ONLY REPLY WITH "YES" IF THE CHILD CURRENTLY HAS A SPECIAL HEALTH CARE NEED

Health and Functional Status

Care – Use of Services and Unmet Needs

Medication

Parental Care and Shared Decision Making

Special Issues

Mental Screening (6-17 years)

Insurance

History of Health Care Coverage

Family

Additional Questions

Demographics

Demographics

SLAITS Eligibility

Are there any children under 18 years old live in this household? (S_UNDR18)

Demographics

Do you currently need or use medicine prescribed by a doctor, other than vitamins? (CSHCN1)



Data Available on the DRC Website

➤ Interactive Data Snapshots

- View Topic Specific Snapshots

➤ Interactive State Ranking Tables

- View and compare all states at the same time
- Get maps comparing each state to the nation

➤ Interactive Query for Individual Outcomes, Indicators and Single Items

- Search by state, region, and nationwide
- Stratify by numerous population subgroups
- Compare all states on individual items, indicators or outcomes
- Trend across survey years where possible

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Survey Fast Facts

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State/Region Nationwide

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 childhealthdata 1 in 5 high school students meets the medical criteria for addiction, according to a Columbia study. Read an article at <http://t.co/a3ox4H2>
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OPTION 1: The DRC 360 “Get Started” Tour

Step 1: Just click on your state.



Data Tools

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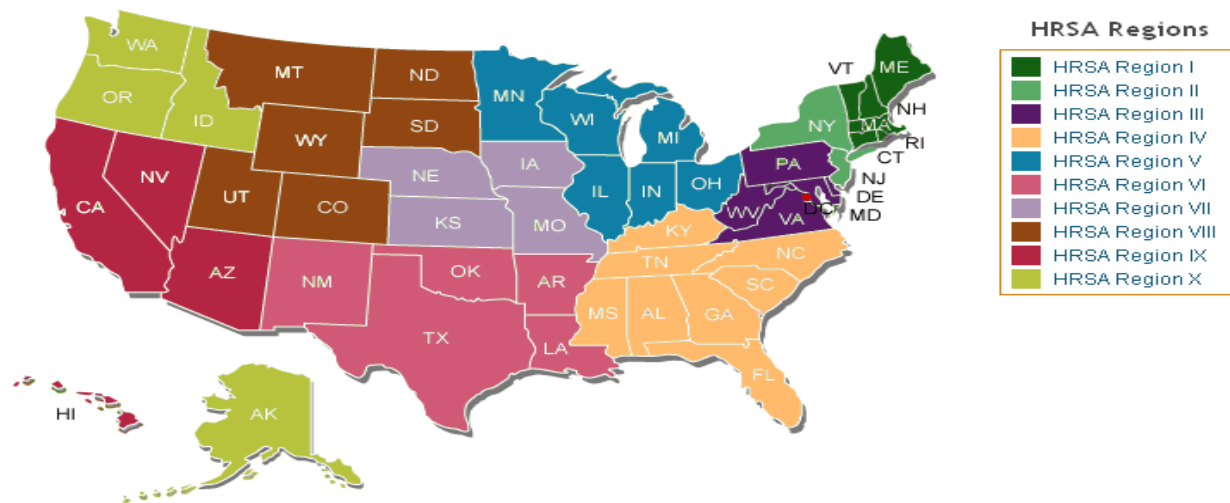
Step 2: Select a profile of interest.

Data Snapshots can view and choose your

To view your data snapshot, follow the two easy steps below:

1. Click on the map (a state, region or nationwide) to view your snapshot.
2. Select a snapshot from the list of categories below.

1. Click on your state, HRSA Region, or Nationwide to view your snapshot.



2. Select a Snapshot from the Categories below. Customizable profiles, where you can choose your own indicators, are marked with an asterisk*.

Nationwide

Overall Health and Health Care Topics

Key Indicators of child health status, insurance and health care access, and family/social content

2007 NSCH National and State Chartbook Pages

2007 NSCH Child Health Indicators Customizable Snapshot*

2003 NSCH National and State Chartbook Pages

2003 NSCH Child Health Indicators Customizable Snapshot*

2003-2007 NSCH Comparison National and State Chartbook Pages

2009/10 NS-CSHCN National and State Profile Pages

2005/06 NS-CSHCN National and State Chartbook Pages

2001 NS-CSHCN National and State Chartbook Pages

2005/06-2009/10 NS-CSHCN Comparison National and State Profile Pages

2001-2005/06 NS-CSHCN Comparison National and State Chartbook Pages

Health Care System Quality and Performance

Topic-Specific: Quality indicators, Medical Home & Health People 2010

Disparities in Child Health Across Populations

Topic-Specific: CSHCN vs. Non-CSHCN, Race/Ethnicity & Rural-Urban Status



Step 3: Then view a range of measures and select any.

2009/10 National Survey of Children with Special Health Care Needs

Nationwide Profile

Return to Snapshot Selection
 Compare Survey Years 2001-05/06
 Compare Survey Years 2005-09/10
[2001 Profile](#)
[2005/06 Profile](#)

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

Prevalence of CSHCN	State %	Nation %	National Chartbook Indicators	State %	Nation %
CSHCN Prevalence			Child Health		
Percent of children who have special health care needs	15.1	15.1	CSHCN whose conditions affect their activities usually, always, or a great deal	27.1	27.1
CSHCN Prevalence by Age			Health Insurance Coverage		
Age 0-5 years	9.3	9.3	CSHCN with 11 or more days of school absences due to illness	15.5	15.5
Age 6-11 years	17.7	17.7	Access to Care		
Age 12-17 years	18.4	18.4	CSHCN without insurance at some point in past year	9.3	9.3
CSHCN Prevalence by Sex			CSHCN without insurance at time of survey	3.5	3.5
Male	17.4	17.4	Currently insured CSHCN whose insurance is inadequate	34.3	34.3
Female	12.7	12.7	Family Centered Care		
CSHCN Prevalence by Hispanic Origin and Race			CSHCN with any unmet need for specific health care services	23.6	23.6
Non-Hispanic	14.5	14.5	CSHCN with any unmet need for family support services	7.2	7.2
White	14.6	14.6	CSHCN needing a referral who have difficulty getting it	23.4	23.4
Black	15.9	15.9	CSHCN without a usual source of care when sick (or who rely on the emergency room)	9.5	9.5
Other	11.8	11.8	CSHCN without any personal doctor or nurse	6.9	6.9
Hispanic	9.6	9.6	Impact on Family		
Spanish Language Household	6.4	6.4	CSHCN without family-centered care	35.4	35.4

MCHB Core Outcomes	State %	Nation %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	70.3	70.3
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	43.0	43.0
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	60.6	60.6
CSHCN who are screened early and continuously for special health care needs	78.6	78.6
CSHCN whose services are organized in ways that families can use them easily	65.1	65.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	40.0	40.0
CSHCN whose services are organized in ways that families can use them easily	65.1	65.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	40.0	40.0

Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than or equal to 30%.



This takes you to your state's findings for that measure.

Current Search Criteria

Survey: 2009/10 National Survey of Children with

Special Health Ca

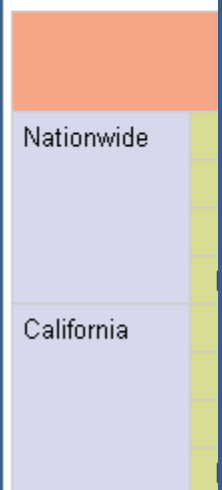
Starting Point: M
Indicators

State/Region: Na

Topic: MCHB Cor

Question: Outcor
coordinated, ongo
medical home (de

Outcome #2: CS
comprehensive



C.I. = 95% Confiden

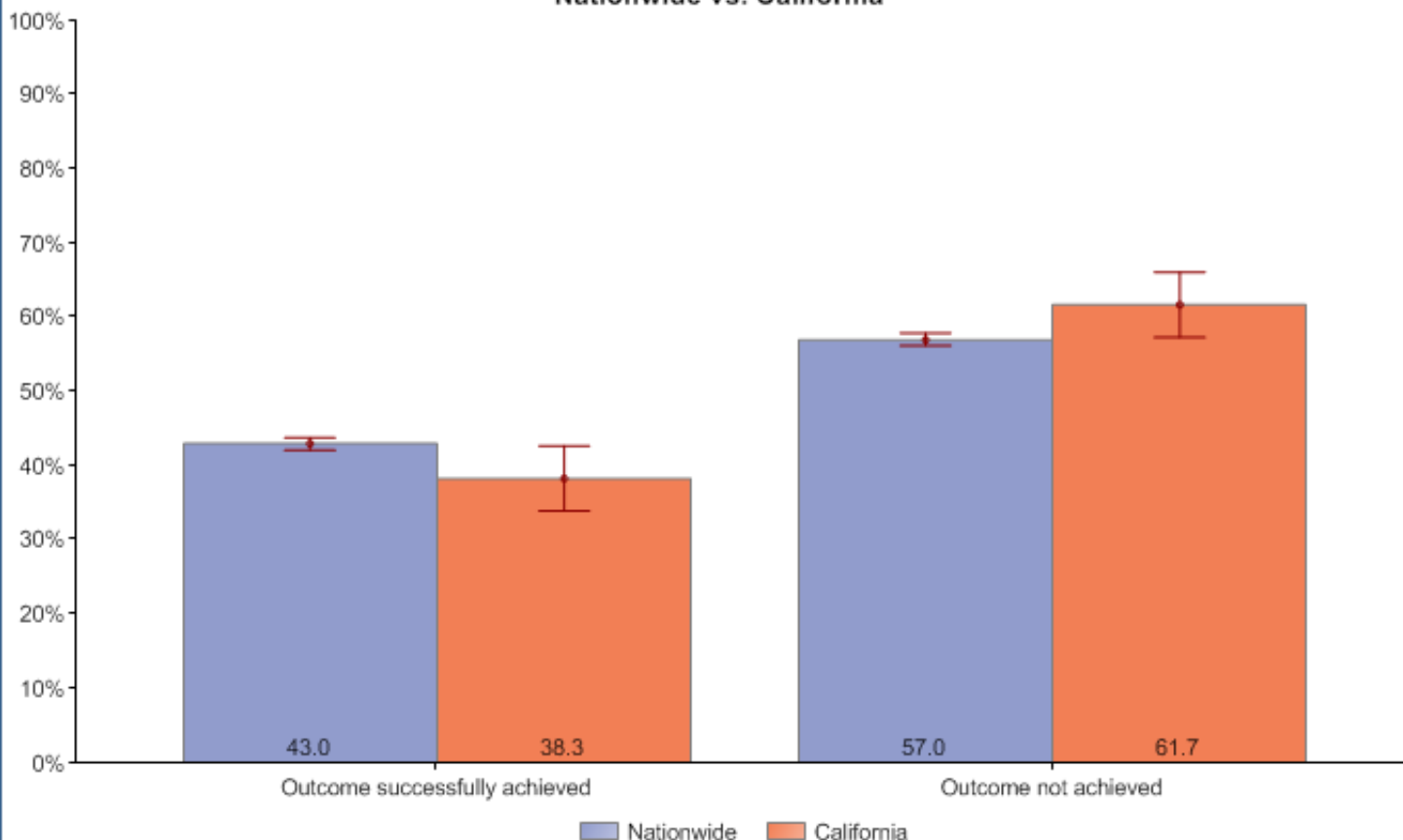
n = Cell size. Use caution in interpreting Cell sizes less than 50.

Edit Search Criteria

MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home

CSHCN age 0 -17 years

Nationwide vs. California



Step 4: Select a subgroup to view your state findings.

Current Search Criteria

Survey: 2009/10 National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide vs. California

Topic: MCHB Core Outcomes for CSHCN

Question: Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

Edit Search Criteria

Compare States:

California

Compare Subgroups:

- Select a Subgroup
- Select a Subgroup
- Age - 3 groups
- Sex of child
- Race/ethnicity
- Primary language for Hispanic CSHCN
- Specific types of special health needs
- Emotional/behavioral/developmental issues
- Family structure
- Insurance status
- Type of insurance
- Consistency of insurance coverage
- Adequacy of current health insurance

		Outcome successfully achieved	Outcome not achieved	
Nationwide	%	43.0	57.0	100.0
	C.I.	(42.1 - 43.8)	(56.2 - 57.9)	
	n	18,279	20,671	
	Pop. Est.	4,613,661	6,126,183	
California	%	38.3	61.7	100.0
	C.I.	(33.9 - 42.7)	(57.3 - 66.1)	
	n	299	492	
	Pop. Est.	365,908	589,751	

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
n = Cell size. Use caution in interpreting Cell sizes less than 50.

This takes you to your state's Medical Home findings by insurance type.

Current Search Criteria

Survey: 2009/10 National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide vs. California

Topic: MCHB Core Outcome

Question: Outcome #2: CS coordinated, ongoing, comprehensive medical home ([details](#))

Sub Group: Outcome success of insurance

Outcome #2: CSHCN with within a medical home ([details](#))

Select a response category

		Private insurance only	Public insurance only
Nationwide	%	51.2	34.0
	C.I.	(50.1 - 52.4)	(32.4 - 35.5)
	n	12,129	4,115
	Pop. Est.	2,810,201	1,252,062
California	%	47.0	25.4
	C.I.	(41.2 - 52.8)	(17.4 - 33.4)
	n	212	52
	Pop. Est.	260,211	64,798

		Private insurance only	Public insurance only
Nationwide	%	51.2	34.0
	C.I.	(50.1 - 52.4)	(32.4 - 35.5)
	n	12,129	4,115
	Pop. Est.	2,810,201	1,252,062
California	%	47.0	25.4
	C.I.	(41.2 - 52.8)	(17.4 - 33.4)
	n	212	52
	Pop. Est.	260,211	64,798

C.I. = 95% Confidence Interval.

n = Cell size. Use caution in interpreting estimates based on small cell sizes.

Estimates based on sample data.

The relative standard error is greater than 30%.



Full Menu of Subgroups Available

- All 50 states, D.C., and 10 HRSA regions
- Age
- Sex of child
- Race/ethnicity of child
- Primary household language
- Household income level
- Household income (SCHIP)
- Family structure
- Special health care needs status (NSCH only) and/or type
- Type of insurance
- Consistency of insurance
- Presence of a medical home
- Presence of an emotional, behavioral or developmental problem
- Adequacy of health insurance

Step 5: See where your state ranks across all states by selecting “all states” as the comparison group.

Current Search Criteria

Survey: 2009/10 National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide vs. California

Topic: MCHB Core Outcomes for CSHCN

Question: Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

Sub Group: Outcome successfully achieved x Type of insurance

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

Select a response category

		Private insurance only	Public insurance only	Both public and private insurance	
Nationwide	%	51.2	34.0	35.3	24.2
	C.I.	(50.1 - 52.4)	(32.4 - 35.5)	(32.1 - 38.6)	(19.9 - 28.5)
	n	12,129	4,115	1,011	318

Compare States:

- All States
- Unselect State or Region
- All States
- All Regions
- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas

Current Search Criteria

Survey: 2009/10 National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Indicators

State/Region: All States

Topic: MCHB Core Indicators

Outcome #2: CSHCN who receive care at home (details)

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.

	State	Outcome successfully achieved %	Outcome not achieved %	Total %
1	Alabama	50.7	49.3	100.0
2	Kentucky	50.2	49.8	100.0
3	Kansas	49.4	50.6	100.0
4	New Hampshire	49.4	50.6	100.0
5	Indiana	48.5	51.5	100.0
6	Nebraska	48.2	51.8	100.0
7	Minnesota	48.0	52.0	100.0
8	Pennsylvania	48.0	52.0	100.0
9	North Dakota	47.8	52.2	100.0
10	Maine	47.5	52.5	100.0

Step 6: Click on your state to get back to querying by other subgroups in your state

Top 10 States

Outcome #2: CSHCN who receive care at home (details)

Notes: Click on the HOVER over the text

	State
1	Alabama
2	Kentucky
3	Kansas
4	New Hampshire
5	Indiana
6	Nebraska

41	Texas	40.1	59.9	100.0
42	Montana	39.1	60.9	100.0
43	New York	38.4	61.6	100.0
44	California	38.3	61.7	100.0
45	New Jersey	38.3	61.7	100.0
46	Mississippi	36.8	63.2	100.0
47	Nevada	36.8	63.2	100.0
48	Florida	36.2	63.8	100.0
49	Arizona	36.1	63.9	100.0
50	New Mexico	34.9	65.1	100.0
51	District of Columbia	34.2	65.8	100.0

Bottom 10 States

Then you are back to CA versus the nation. Continue searching subgroups on this measure or...

Current Search Criteria

Survey: 2009/10 National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide vs. California

Topic: MCHB Core Outcomes for CSHCN

Question: Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

Compare States:

California

Compare Subgroups:

Select a Subgroup

» [Change question, topic or survey](#)

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

		Outcome successfully achieved	Outcome not achieved	Total %
Nationwide	%	43.0	57.0	100.0
	C.I.	(42.1 - 43.8)	(56.2 - 57.9)	
	n	18,279	20,671	
	Pop. Est.	4,613,661	6,126,183	
California	%	38.3	61.7	100.0
	C.I.	(33.9 - 42.7)	(57.3 - 66.1)	
	n	299	492	
	Pop. Est.	365,908	589,751	

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
n = Cell size. Use caution in interpreting Cell sizes less than 50.

Trending Across Survey Years

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Current Search Criteria

Survey: 2009/10 National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide

Topic: CSHCN Health and Functional Status

Question: Indicator 1: CSHCN whose health conditions consistently affect their daily activities (details)

Edit Search Criteria

Compare States:

Select a State or Region

Compare Subgroups:

Select a Subgroup

» Compare this measure across years

» Change question, topic or survey

Indicator 1: CSHCN whose health conditions consistently and often greatly affect their daily activities (details)

	Daily activities consistently affected, often a great deal	Daily activities moderately affected some of the time	Daily activities never affected	Total %
%	27.1	38.5	34.4	100.0
C.I.	(26.2 - 27.9)	(37.7 - 39.4)	(33.6 - 35.2)	
n	9,730	15,611	14,795	
Pop. Est.	2,996,614	4,265,089	3,806,433	

Trending Across Survey Years with Subgroups

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Home > Browse the Data > Browse by Survey > Survey Results

Current Search Criteria

Survey: Compare all years - National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide

Topic: CSHCN Health and Functional Status

Question: Indicator 1: CSHCN whose health conditions consistently affect their daily activities [\(details\)](#)

Edit Search Criteria

Compare States:

Select a State or Region

Compare Subgroups:

Select a Subgroup

Select a Subgroup

Age - 3 groups

Insurance status

Sex of child

Indicator 1: CSHCN whose health conditions consistently and often greatly affect their daily activities [\(details\)](#)

Select a Response Category: Consistently affected

		2001	2005/06	2009/10
Nationwide	%	23.2	24.0	27.1
	C.I.	(22.4 - 24.0)	(23.2 - 24.7)	(26.2 - 27.9)

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

Trending Across Survey Years with Subgroups by State

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Home > Browse the Data > Browse by Survey > Survey Results

Current Search Criteria

Survey: Compare all years - National Survey of Children with Special Health Care Needs

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: Nationwide vs. District of Columbia

Topic: CSHCN Health and Functional Status

Question: Indicator 1: CSHCN whose health conditions consistently affect their daily activities [\(details\)](#)

Sub Group: Consistently affected x Currently insured

Edit Search Criteria

Compare States:

District of Columbia

Compare Subgroups:

Insurance status

» Return to single year data results

» Change question, topic or survey

Indicator 1: CSHCN whose health conditions consistently and often greatly affect their daily activities [\(details\)](#)

Select a Response Category: Consistently affected

Select a Sub Group Category: Currently insured

		2001	2005/06	2009/10
Nationwide	%	22.8	23.6	26.8
	C.I.	(21.9 - 23.6)	(22.9 - 24.4)	(25.9 - 27.6)
District of Columbia	%	23.5	21.1	21.7
	C.I.	(19.0 - 27.9)	(17.5 - 24.6)	(17.4 - 25.9)

OPTION 2: The DRC “Full Search”

Step 1: Click on “Browse by Survey & Topic”



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Data Resource Center for Child & Adolescent Health

A project of the Child and Adolescent Health Measurement Initiative

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Current

Survey:

Special

Starting

Indicators

State/Region: California

Topic: MCHB Core Outcomes for CSHCN

Question: Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

Edit Search Criteria

Compare States:

Select a State or Region

Compare Subgroups:

Select a Subgroup

» Change question, topic or survey

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ([details](#))

	Outcome successfully achieved	Outcome not achieved	Total %
%	38.3	61.7	100.0
C.I.	(33.9 - 42.7)	(57.3 - 66.1)	
n	299	492	
Pop. Est.	365,908	589,751	

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
n = Cell size. Use caution in interpreting Cell sizes less than 50.

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Step 2: Select a survey, a survey year and geographic area.

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Home > Browse the Data > Browse by Survey

Browse by Survey & Topic

To begin your interactive data search: 1) Select a Survey, Survey Year, and State or Region. 2) Select your desired Topic/Starting Point. 3) Select your indicator or measure.

This will direct you to a results page where you can compare across states, regions and by numerous subgroups.

1. Select a Survey, Year, and Geographic Area

Select a Survey: National Survey of Children with Special Health Care Needs

Select a Year: 2009/10

Select a State/Region: Nationwide

2. Select a Starting Point

MCHB Core Outcomes

CSHCN performance me

- MCHB Core Outcomes
- CSHCN Health and Fur
- Health Insurance Cove
- Health Care Needs and
- Care Coordination and
- Impact on Families

CSHCN Prevalence an

Child or household level

Subcomponents and D

Additional measures, subcomponents and details on each of the Core Outcomes

2009/10 NS-CSHCN Survey Sections

Responses to questions asked in each section of the CSHCN Interview

- Nationwide
- All States
- All Regions
- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas



2. Select a Starting Point/Topic

- MCHB Core Outcomes and Key Indicators** (Content Map)
CSHCN performance measures and key indicator results
- CSHCN Prevalence and Demographics** (Content Map)
Child or household level data for children with and without special needs
- Subcomponents and Details for Core Outcomes**
Additional measures, subcomponents and details on each of the Core Outcomes
- 2009/10 NS-CSHCN Survey Sections**
Responses to questions asked in each section of the CSHCN Interview
 - Initial Screening for Special Needs (Survey Section 2)
 - CSHCN Health and Functional Status (Survey Section 3)
 - CSHCN Access to Care: Use of Services and Unmet Needs (Survey Section 4)
 - CSHCN Care Coordination (Survey Section 5)
 - CSHCN Family Centered Care and Shared Decision Making (Survey Section 6a)
 - CSHCN Transition Issues (Survey Section 6b)
 - CSHCN Developmental Screening (Survey Section 6c)
 - CSHCN Health Insurance (Survey Section 7)
 - CSHCN Adequacy of Health Care Coverage (Survey Section 8)
 - CSHCN Impact on the Family (Survey Section 9)
 - CSHCN ADD/ADHD Questions (Survey Section 9.5)
 - CSHCN Family Composition and Income (Survey Sections 10 & 11)

Step 3: Select a measurement topic and measure.

3. Select a Survey Question (click the **i** for more information on the question)

Developmental Screening, age 1-5 years only **i**

Parent filled out questionnaire about specific developmental or behavioral concerns, CSHCN age 1-5 years



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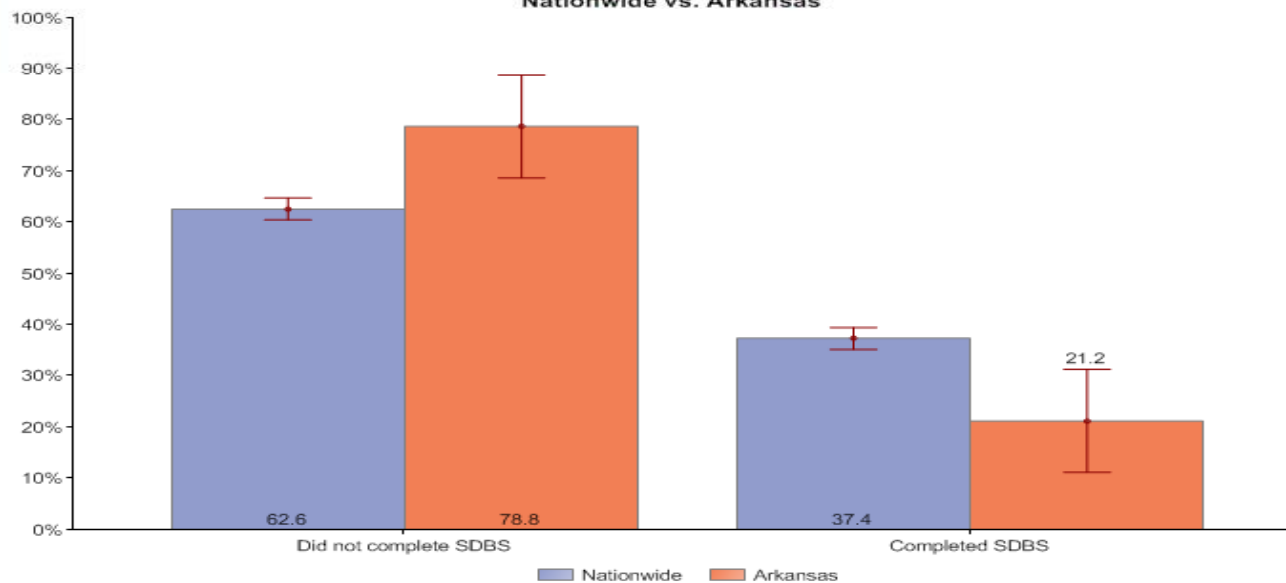
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During the past 12 months, was [child's name] screened for being at risk for developmental, behavioral and social delays using a parent-reported standardized developmental behavioral screening (SDBS) tool during a health care visit? (details)

		Did not complete SDBS	Completed SDBS	Total %
Nationwide	%	62.6	37.4	100.0
	C.I.	(60.5 - 64.8)	(35.2 - 39.5)	
	n	4,375	2,289	
	Pop. Est.	1,327,069	791,341	
Arkansas	%	78.8	21.2	100.0
	C.I.	(68.7 - 88.8)	(11.2 - 31.3)	
	n	82	26	
	Pop. Est.	22,361	6,030	

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
n = Cell size. Use caution in interpreting Cell sizes less than 50.

Parent completed standardized developmental screening tool CSHCN age 12 months-5 years Nationwide vs. Arkansas



Edit Search Criteria

Compare States:

Arkansas

Compare Subgroups:

State Subgroup data not available



Other Data Snapshots and Topical Profiles Available through the DRC

1. Across Year Comparisons Data Snapshots

2. Title V Needs Assessment

3. Core Outcomes Profiles

4. Family to Family Profiles

5. Medical Home Profiles

6. Conditions-Specific Profiles

7. Disparities Profiles

**2009/10 NS-
CSHCN Versions
Coming Soon!**

Who Are CSHCN? Profile

Who Are Children with Special Health Care Needs?

Definition

The federal Maternal and Child Health Bureau defines children with special health care needs (CSHCN) as:

*"those who have or are at increased 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."*¹

This definition is used to guide the development of family-centered, coordinated systems of care for children and families for children with special needs served by the state Title V block grants administered by the Maternal and Child Health Bureau.

The National Survey of CSHCN (NS-CSHCN) and the National Survey of Children's Health (NSCH) – two child health prevalence surveys – use a validated non-condition specific, consequences based screening tool to identify children meeting the Maternal and Child Health definition of CSHCN with the exception that the "at risk" component is not included.^{2,3}

Demographic Profile

- Compared to children not meeting CSHCN criteria (non-CSHCN), CSHCN are more likely to be male (17.4% vs. 12.7%) and older, 12–17 years (18.4%) compared to 0–5 years (9.3%) and 6–11 years (17.7%).⁴
- While estimated by the NS-CSHCN to be about 15.1% of the child population, CSHCN account for 40% or more of medical expenditures for children overall.⁴

Health Status Profile Among CSHCN

All CSHCN currently have a condition with health and related service consequences. In the 2009/10 NS-CSHCN, prevalence of twenty specific conditions was included in the survey. 87.7% of CSHCN have at least 1 condition on the list and 29.1% of CSHCN have 3 or more of these conditions.

Condition	%	Condition	%
ADD/ADHD	30.2	Headaches	9.8
Depression	10.3	Head Injury	1.4
Anxiety	17.1	Heart Problem	3.0
Behavioral problems	13.5	Blood Problems	1.5
Autism, ASD	7.9	Cystic Fibrosis	0.3
Developmental Delay	17.6	Cerebral Palsy	1.6
Intellectual Disability	5.8	Muscular Dystrophy	0.3
Asthma	35.3	Down Syndrome	1.1
Diabetes	1.7	Arthritis	2.9
Epilepsy	3.1	Allergies	48.6

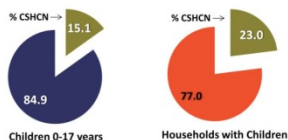
¹Condition prevalence in 2009/10 was asked using two questions: prevalence of conditions ever or currently. Only current prevalence was asked in 2005/06.
²Condition was either not asked about in the 2005/06 NS-CSHCN or was not comparable. Note: This is prevalence among CSHCN.

Functional difficulties are difficulties that impact the day-to-day life of CSHCN. 91.2% of CSHCN experience at least 1 of the following functional difficulties and 45.6% of CSHCN have 4 or more of the difficulties listed.

Functional Difficulty	%
Breathing or other respiratory problems	46.5
Swallowing, digesting food, or metabolism	19.1
Blood Circulation	6.1
Repeated or chronic physical pain, including headaches	29.0
Seeing even when wearing glasses or contact lenses	15.6
Hearing even when using a hearing aid or other device	6.3
Taking care of self, such as eating, dressing or bathing	19.8
Coordination or moving around	19.6
Using his/her hands	16.1
Learning, understanding or paying attention	51.1
Speaking, communicating, or being understood	32.9
Feeling anxious or depressed	42.9
Behavior problems	41.4
Making and keeping friends	32.4

Prevalence Profile

Source: 2009–2010 National Survey of Children with Special Health Care Needs, www.nchs.gov/data/whi/whi0910.htm



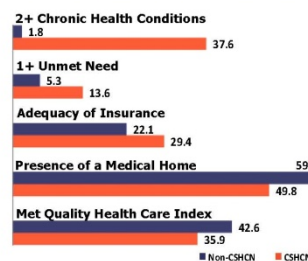
According to the 2009/10 National Survey of Children with Special Health Care Needs:

- Approximately 11.2 million children ages 0–17 years in the United States (15.1%) have special health care needs.
- Prevalence of CSHCN ranges from 10.6% to 19.8% across the 50 states and the District of Columbia.
- Over 1 in 5 households with children in the United States have at least one child with special health care needs. This translates into almost 9 million households nationally.

¹ McPherson M, Arango P, Fox H, et al. "A new definition of children with special health care needs". *Pediatrics*. 1998; 102: 137-140.
² Behrle CO, Reed D, Sherr R, Blumberg E, Newacheck P. Identifying Children with Special Health Care Needs: Development and Evaluation of a Short Screening Tool. *Annals of Pediatrics*. 2002.
³ Behrle CO, Reed D, Blumberg E, Newacheck P. What is the Role of Children with Special Health Care Needs? Towards an Understanding of Variations in Prevalence and Methods across Three National Surveys. *MCH Journal*. July 2007.
⁴ Newacheck P, Vitiello A, et al. A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*. 2005; 159: 10-17.

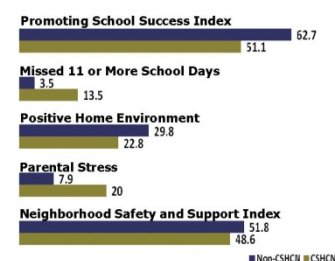
Data Resource Center (DRC) is a project of the Child and Adolescent Health Measurement Initiative at Oregon Health & Science University. DRC is sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration.

Comparing CSHCN to Children without Special Health Care Needs (Non-CSHCN) Health Status and Utilization



Source: 2007 National Survey of Children's Health, www.childhealthdata.org

School and Home Profile



Source: 2007 National Survey of Children's Health, www.childhealthdata.org

Identifying CSHCN

CSHCN are identified in the NS-CSHCN and the NSCH using the CSHCN Screener[®] – a five item, parent-reported tool designed to reflect the federal Maternal and Child Health Bureau's consequences-based definition of children with special health care needs.⁴

- The CSHCN Screener[®] operationalizes the MCHB definition of CSHCN by focusing on the health consequences a child experiences as a result of having an on-going health condition rather than on the presence of a specific diagnosis or type of disability.
- The screener assesses children's health care needs status by using questions that ask about need or use of services, prescription medications, specialized therapies, and having functional difficulties due to an ongoing condition.
- The non-condition specific approach used by the CSHCN Screener[®] identifies children across the range and diversity of childhood chronic conditions and special needs, allowing a more comprehensive assessment of health needs and health care system performance.

Developed by The Child & Adolescent Health Measurement Initiative (CAHMI at www.cahmi.org), National Data Resource Center for Child and Adolescent Health, Oregon Health & Science University, School of Medicine, Department of Pediatrics

Visit the Data Resource Center
to learn more about CSHCN in your state



¹ McPherson M, Arango P, Fox H, et al. "A new definition of children with special health care needs". *Pediatrics*. 1998; 102: 137-140.

² Behrle CO, Reed D, Sherr R, Blumberg E, Newacheck P. Identifying Children with Special Health Care Needs: Development and Evaluation of a Short Screening Tool. *Annals of Pediatrics*. 2002.

³ Behrle CO, Reed D, Blumberg E, Newacheck P. What is the Role of Children with Special Health Care Needs? Towards an Understanding of Variations in Prevalence and Methods across Three National Surveys. *MCH Journal*. July 2007.

⁴ Newacheck P, Vitiello A, et al. A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*. 2005; 159: 10-17.

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Condition Specific Profiles

Part I: % of CSHCN with **Autism or autism spectrum disorder**

% of CSHCN overall with condition: 5.4
Estimated number with condition: 544,181

% of CSHCN with Condition

By Age Group **Nationwide**

0 - 5 years	5.2
6 - 11 years	6.0
12 - 17 years	4.9

By Sex

Male	7.2
Female	2.8

% of CSHCN with Condition

By Insurance

Private insurance only	4.3
Public insurance only	6.2
Both public and private	11.0
Uninsured	5.3

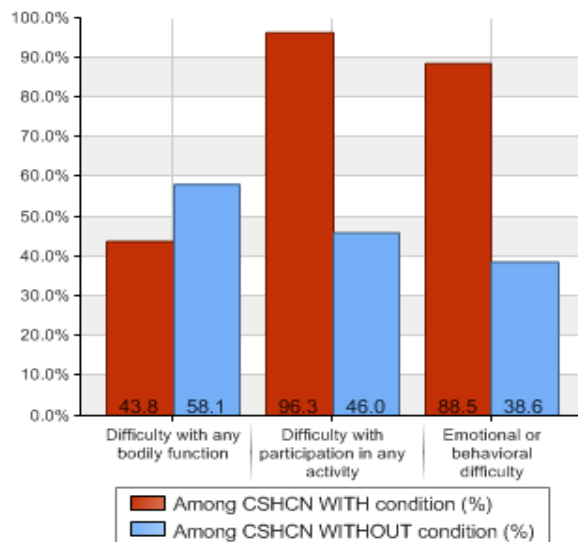
Nationwide

By SSI Status

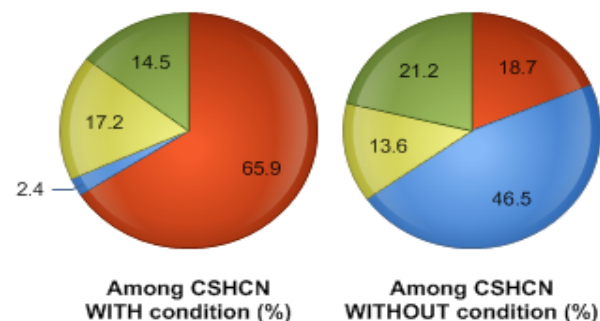
Receives SSI for disability	19.4
-----------------------------	------

Part II: Selected Health Characteristics among CSHCN with **Autism or autism spectrum disorder -- NATIONWIDE**

Type of functional difficulties for CSHCN with and without condition¹



% of CSHCN with and without condition qualifying on specific types of special health needs criteria²



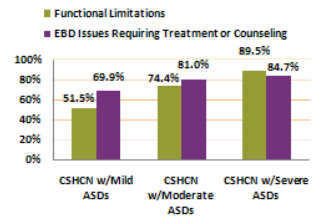
- Functional limitations (alone or with any other type)
- Managed by prescription medications
- Above routine need/use of services only
- Rx medications AND elevated service use

National Profile of CSHCN with ASD

National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN & 2007 NSCH

Who Are Children with Autism Spectrum Disorders?
According to the Centers for Disease Control and Prevention (CDC): "Autism Spectrum Disorders (ASDs) are a group of developmental disabilities that can cause significant social, communication and behavioral challenges. ... ASDs are 'spectrum disorders.' That means ASDs affect each person in different ways, and can range from very mild to severe."¹ Consequently, nearly all children with ASDs qualify as children with special health care needs (CSHCN), because they experience at least one type of ongoing condition that results in an above routine need for health and related services.² The CSHCN Screener, which operationalizes this definition, was used in both the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN) and the 2007 National Survey of Children's Health (NSCH) to identify CSHCN. Based on findings from the 2009/10 NS-CSHCN and the 2007 National Survey of Children's Health (NSCH), 4.8% to 7.9% of U.S. CSHCN currently experience ASDs.³ Prevalence of CSHCN with ASDs ranges across states, from 4.5% in Mississippi to 14.3% in New Jersey according to data from the 2009/10 NS-CSHCN.

Figure 1. Prevalence of Functional Limitations and Emotional, Behavioral or Developmental Issues among CSHCN with ASDs by Severity

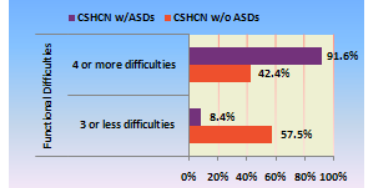


Data Source: 2009/10 NS-CSHCN

¹Variations in sampling and administration between the 2009/10 NS-CSHCN and 2007 NSCH lead to expected variations in prevalence.

Four in five (80.6%) CSHCN with ASDs are boys, and 71.6% of CSHCN with ASDs were diagnosed between 0 – 5 years of age. Among CSHCN with ASDs, parents described approximately half (49.5%) as having mild ASDs, 36.2% as having moderate ASDs and 14.3% as having severe ASDs. Positivity bias in parent reports of child functioning may lessen the severity of conditions described despite notable health impacts.³ As depicted in Figure 1, a larger proportion of CSHCN with moderate or severe ASDs have functional limitations and/or emotional, behavioral or developmental (EBD) issues requiring treatment or counseling compared to CSHCN with mild ASDs. Most CSHCN with ASDs (93.2%) also have at least one other condition from a list of 20 conditions asked about in the 2009/10 NS-CSHCN, and 91.6% of CSHCN with ASDs experience four or more functional difficulties from a list of 14 specific difficulties related to bodily functions, activities or participation, and emotional or behavioral factors (Figure 2).

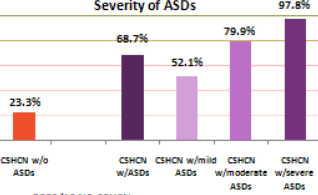
Figure 2. Prevalence of Functional Difficulties among CSHCN with ASDs compared to CSHCN without ASDs



Data Source: 2009/10 NS-CSHCN

The complexity of health care needs that many CSHCN with ASDs experience may influence their overall health status and daily activities. In the 2007 NSCH, a lower proportion of CSHCN with ASDs (54.6%) were reported by their parents to have excellent or very good overall health status compared to CSHCN without ASDs (70.3%) and non-CSHCN (87.4%). Further, in the 2009/10 NS-CSHCN, over two-thirds (68.7%) of CSHCN with ASDs had health conditions that consistently affected their activities often a great deal compared to only 23.3% of CSHCN without ASDs (Figure 3). Among CSHCN with severe ASDs, 97.8% had conditions that consistently affected their daily activities often a great deal relative to 79.9% of CSHCN with moderate ASDs and 52.1% of CSHCN with mild ASDs.

Figure 3. Daily Activities Consistently Affected, Often a Great Deal among CSHCN without ASDs compared to CSHCN with ASDs & by Severity of ASDs

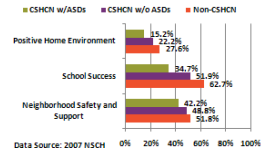


Data Source: 2009/10 NS-CSHCN

Home, School and Neighborhood Environments
The health and well-being of each child is influenced by his or her interconnected home, school and neighborhood environments. Contextual factors from these environments and other child level factors may interact during certain periods of a child's lifespan ultimately promoting resiliency and healthy development or increasing risk for adverse health outcomes. Together, several summary measures from the 2007 NSCH provide a more comprehensive picture of how CSHCN, including those with ASDs, compare to non-CSHCN in terms of their home, school and neighborhood environments.



Figure 6. CSHCN with ASDs in Home, School and Neighborhood Environments Relative to CSHCN without ASDs and Non-CSHCN



Data Source: 2007 NSCH

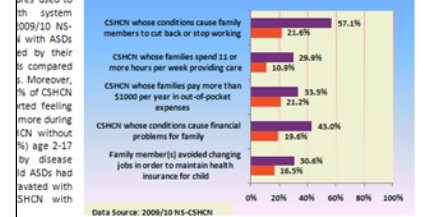
- Takeaways**
- CSHCN with ASDs generally experience a greater burden of illness in terms of the types of special health care needs they have as well as the number of comorbid conditions and functional difficulties that they experience compared to CSHCN without ASDs.
 - The impact on families of CSHCN with ASDs is greater than that experienced by families of CSHCN without ASDs.
 - CSHCN with ASDs are less likely to meet each system of care core outcome and all age-relevant core outcomes compared to CSHCN without ASDs.
 - CSHCN with ASDs are also less likely to experience a positive home environment, school success and neighborhood safety and support compared to CSHCN without ASDs and non-CSHCN.
 - System-wide improvements are needed to enhance the health and well-being of CSHCN with ASDs.

As reflected in Figure 6, CSHCN with less likely to meet age-relevant - positive home environment⁴ or CSHCN without ASDs and non-CSHCN with ASDs age 6-17 years were also less likely to meet school success criteria⁵ than CSHCN without ASDs and non-CSHCN neighborhood safety and support measures.⁶ CSHCN with ASDs were than CSHCN without ASDs and non-CSHCN meet all age-relevant criteria.

Positive Home, School Success and Safety and Support Criteria
⁴Positive home environment was measured following age-relevant criteria: (1) household smoking; (2) family shares in more days per week; (3) children watch hours of television per day (age 1-17); (4) television in bedroom (age 6-17); (5) breastfed ever (age 0-5); (6) children was required homework (age 6-17); and children have met most/all of child's friend.
⁵School success was measured only age 6-17 years using the following criteria: (1) usually/always engaged in school; (2) participated in extracurricular activity usually/always felt safe at school.
⁶Neighborhood safety and support were the following age-relevant criteria: (1) usually/always safe; neighborhood is neighborhood includes three or more to childhood; and (4) school-age child schools (age 6-17).

References
1. CDC. 2010. Autism Spectrum Disorders (ASDs). "Signs and Symptoms" Web page. Retrieved from <http://www.cdc.gov/nbdds/autism/sign>
2. Motherson, M., Arango, P., Fox, H. et al. "A new definition of children with special health care needs." Pediatrics. 1998. 102:137-140.
3. Simon, A.G., Chan, H.S., & Forest, C.B. "Assessment of children's health-related quality of life in the United States with a multidimensional index." Suggested Citation: Child and Adolescent Health Measurement Initiative (2012). "National Profile of Children with Special Health Care Needs: Key Findings from the 2009/10 NS-CSHCN and 2007 NSCH." Data Resource Center, supported by Cooperative Agreement 1-U59-AC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at www.childhealthdata.org. Revised 3/21/12.

Figure 4. Family Impacts among CSHCN with ASDs compared to CSHCN without ASDs



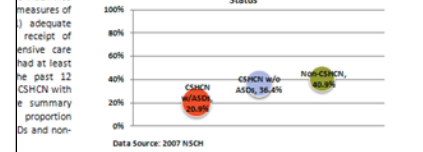
Data Source: 2009/10 NS-CSHCN

The Bureau (MCHB) assesses health system performance for CSHCN with six core outcomes. To see how CSHCN with ASDs compare to CSHCN without ASDs on each of the six core outcomes based on SHCN with ASDs, only 7.4% met all age-relevant core outcomes compared to 18.7% of non-CSHCN.

Table 1. System of Care Core Outcomes

System of Care Core Outcomes	CSHCN w/ASDs	CSHCN w/o ASDs
Partners in decision-making	56.7%	71.2%
Visit a medical home	23.9%	44.7%
Adequate health insurance for needed services	49.4%	61.3%
Timely and continuously for special health care needs	78.5%	80.2%
Health care systems are easy for families of CSHCN to use	42.8%	67.1%
Health care needs receive transition to adulthood services	21.1%	41.4%

Figure 5. Children Meeting All Minimal Quality Summary Measure Criteria by CSHCN and ASD Status

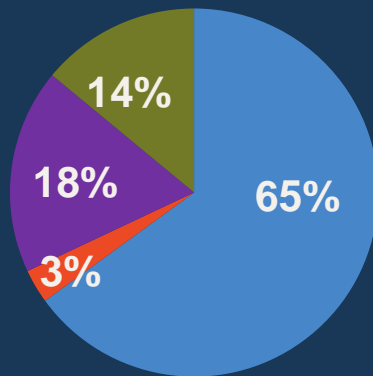


Data Source: 2007 NSCH

Suggested Citation: Child and Adolescent Health Measurement Initiative (2012). "National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN and 2007 NSCH." Data Resource Center, supported by Cooperative Agreement 1-U59-AC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at www.childhealthdata.org. Revised 3/21/12.

Who are CSHCN with ASD?

Prevalence of Special Health Care Needs Type among CSHCN with ASD

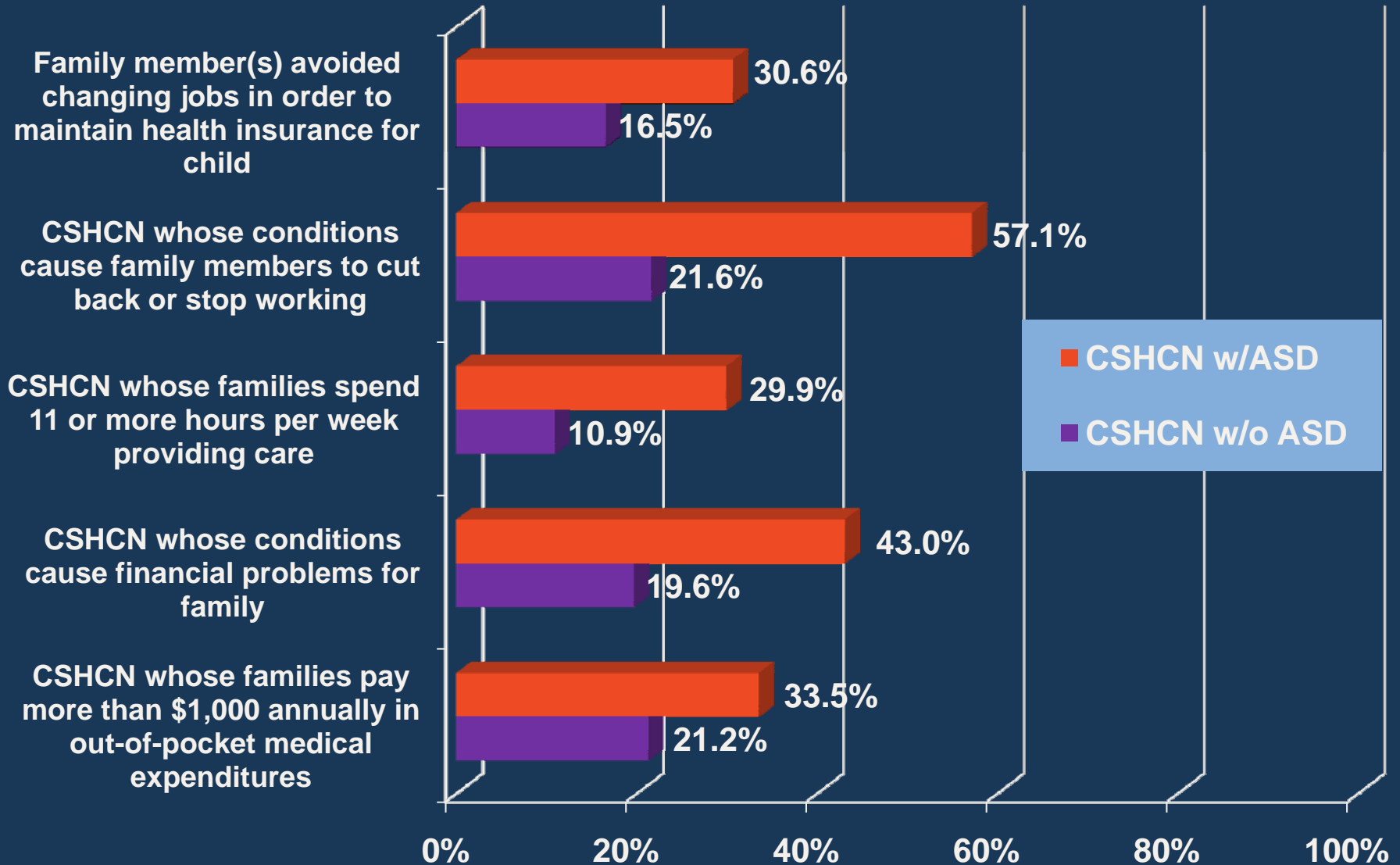


- Functional Limitations (with any other)
- Managed by Rx Medications Only
- Above Routine Need/Use of Services Only
- Prescription Medication Use AND Elevated Services Use

- 4 in 5 (80.6%) CSHCN with ASD are boys.
- 71.6% of CSHCN with ASD were diagnosed between 0 – 5 years of age.
- Nearly half (49.5%) of CSHCN with ASD have ASDs reported as mild compared to 36.2% with moderate ASD and 14.3% with severe ASD.
- Over 9 in 10 (91.6%) CSHCN with ASD have 4 or more functional difficulties.
- 93.2% of CSHCN with ASD have at least one other condition.



Impact on Families of CSHCN with ASD based on 2009/10 NS-CSHCN data



Data Source: 2009/10 NS-CSHCN



System of Care Performance among CSHCN with ASD

MCHB Core Outcomes	CSHCN with ASD	CSHCN without ASD
1) Shared Decision-Making	56.7%	71.2%
2) Medical Home	23.9%	44.7%
3) Adequate Health Insurance Coverage	49.4%	61.3%
4) Early and Continuous Screening for Special Health Care Needs	78.5%	80.2%
5) Ease of Use of Community Services Systems	42.8%	67.1%
6) Youth with Special Health Care Needs receive Needed Transition to Adulthood Services	21.1%	41.4%



MCHB Core Outcome Profiles

(Could be tailored to your state for CSHCN w/ASDs)



www.childhealthdata.org

Outcome #1: Families are partners in decision making at all levels

Effective promotion of health and health services for children with special health care needs (CSHCN) requires a system of care that is integrated, comprehensive, coordinated and family centered. Ideally, these systems are easy to navigate and foster positive experiences between families and health service providers. Advancing integrated systems of care for CSHCN and their families is a national mandate under Public Law 101-239 and is a priority reflected in the Healthy People goals set forth by the U.S. Department of Health and Human Services from 2000 to 2020. To help determine progress towards these goals, the Federal Maternal and Child Health Bureau established the following six core outcomes that facilitate integrated systems of care for CSHCN:

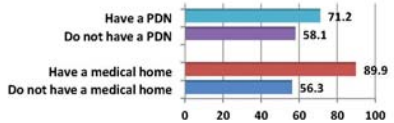
1. Partners in Decision-Making
2. Adequate Health Insurance
3. Early and Continuous Screening
4. Medical Home
5. Ease of Community-Based Service Use
6. Transition to Adulthood

The National Survey of Children with Special Health Care Needs (NS-CSHCN), which has been conducted every four years since 2001, is designed to provide information on the CSHCN population and to assist in the measurement of these core outcomes. The survey measures each core outcome with low-threshold criteria. Outcome #1 is measured through questions that assess the extent to which health professionals engage families in decision-making about their child's health care. Based on data from the 2009/10 NS-CSHCN, 70.3% of CSHCN nationwide meet Outcome #1, with states ranging from 61.8% - 77.6%. Assessment of the variation between states and within demographic or other subgroups of CSHCN is critical to developing appropriate interventions and policy responses.

Measurement

CSHCN meet Outcome 1 when the respondent answers usually or always to all four of the following questions:
We want to know about how [S.C.]'s doctors or other health care providers work with you to make decisions about [his/her] health care services and treatment. During the past 12 months...
CSQ21 How often did [S.C.]'s doctors or other health care providers discuss with you the range of options to consider for [his/her] health care or treatment?
CSQ22 How often did they encourage you to ask questions or raise concerns?
CSQ23 How often did they make it easy for you to ask questions or raise concerns?
CSQ24 How often did they consider and respect what health care and treatment choices you thought would work best for [S.C.]?
 ...Would you say never, sometimes, usually, or always?

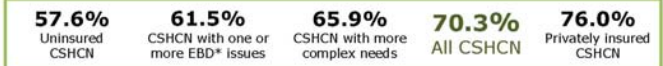
Proportion of CSHCN Meeting Outcome #1 by Presence of a Medical Home and Personal Doctor or Nurse



• CSHCN with a personal doctor or nurse (PDN) are more likely to receive care where their families are partners in decision making than CSHCN without a PDN.

• CSHCN with a medical home are more likely to meet Outcome #1 than CSHCN without a medical home.

**National and state-level prevalence of all outcomes by demographics & subgroups are available online at childhealthdata.org



Data Resource Center (DRC) is a project of the Child and Adolescent Health Measurement Initiative at Oregon Health & Science University. DRC is sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration. Created November 2011.



www.childhealthdata.org

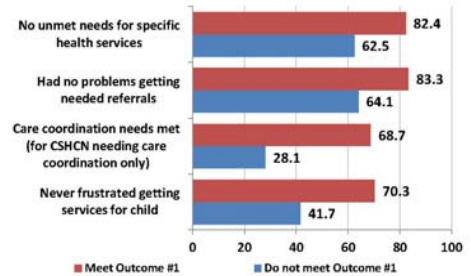


Setting the stage for optimal health trajectories.

A partnership between a child's family and their health care providers allows for an open and intentional dialogue about his or her unique health needs. This leads to individualization of care and the ability to identify factors that may negatively affect his or her health. It also gives children and their families the support they need during critical periods of development. However, only about 70% of CSHCN meet this core outcome. Vulnerable CSHCN, especially those with functional limitations and those living in poverty, are even less likely to receive care in which families are partners in decision making.

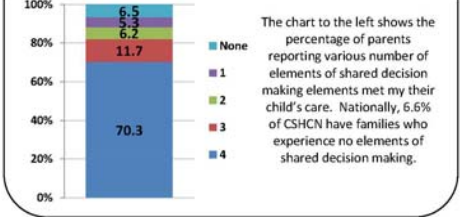
Trending Across Survey Years: Measurement changed significantly for 2009/10 NS-CSHCN, and therefore cannot be compared to 2001 or 2005/06 NS-CSHCN survey findings.

Experience with care for CSHCN who do and do not meet Outcome #1



- CSHCN who meet Outcome #1 have a lower probability of experiencing frustration seeking services or having unmet needs for specific health services than CSHCN who do not meet Outcome #1
- CSHCN who meet Outcome #1 have a higher probability of having their care coordination needs met and having no problems getting needed referrals than CSHCN who do not meet Outcome #1

Number of Shared Decision Making Elements Met



The chart to the left shows the percentage of parents reporting various number of elements of shared decision making elements met by their child's care. Nationally, 6.6% of CSHCN have families who experience no elements of shared decision making.

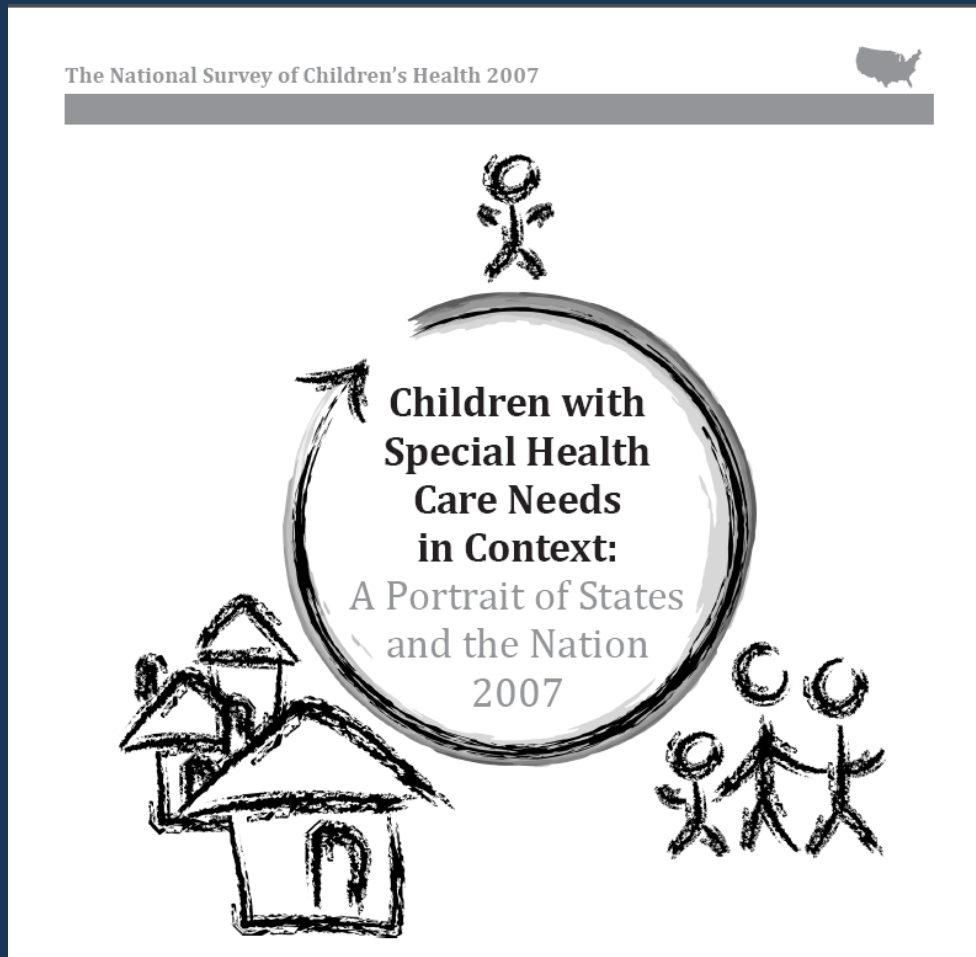
Taking it a Step Further

The following are questions relating to Outcome #1 that cannot be answered by this national survey data but are important to consider when evaluating how early and continuous screening can best work to improve the health and well-being of CSHCN:

- Current measurement is physician-focused -- are families working to encourage these critical conversations?
- Do families have the support they need to play the most positive role possible in their child's development?
- What do health care providers do to educate families on how they can best support their child's development?
- What is the family doing in the day-to-day life of their child to promote or maintain health?
- Are families involved in the policy decisions that affect them?



To Understand the Context of CSHCN with ASDs compared to CSHCN without ASDs and Non-CSHCN—**2007 NSCH Data** Can Also be Used



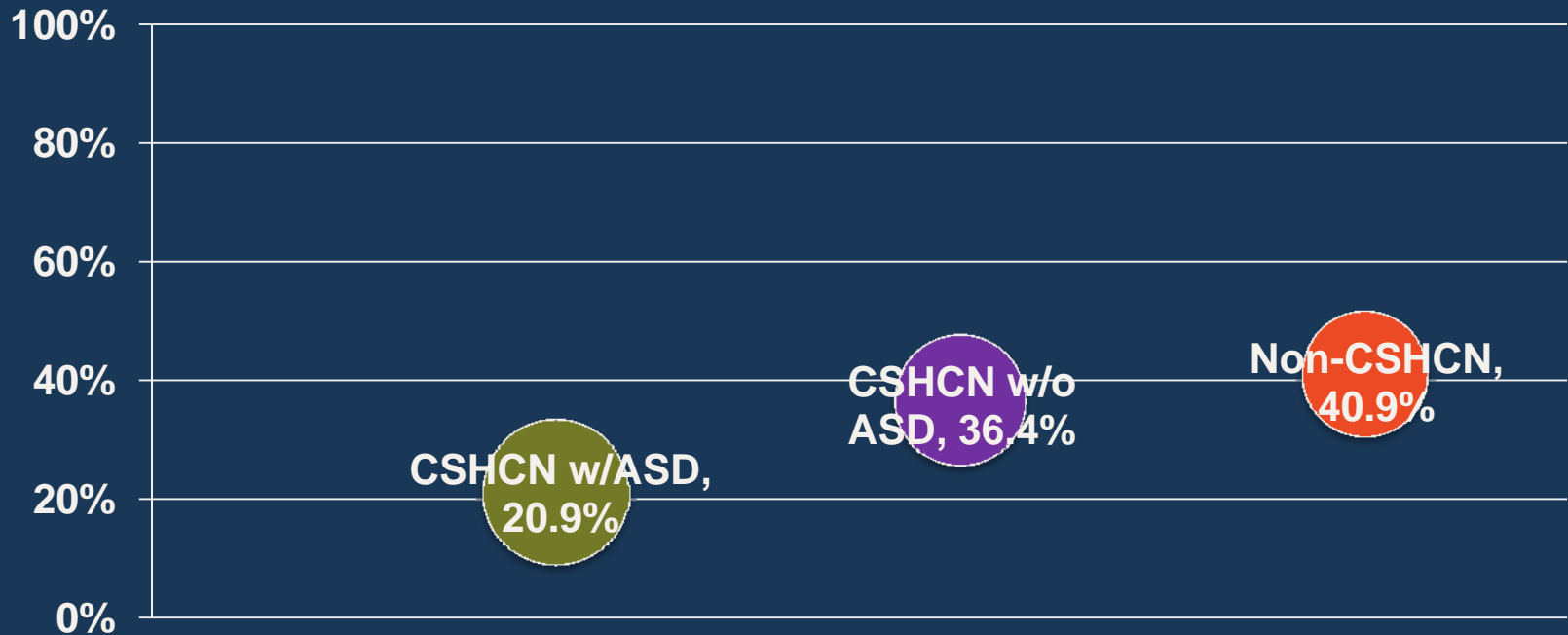


Sample CSHCN in Context Chartbook Page, includes National and State Level Data

Indicator	Explanation	State % non- CSHCN	State % CSHCN	National % CSHCN
THE CHILD'S HEALTH AND HEALTH CARE				
Physical Activity	percent of children aged 6-17 who exercise 4 or more days per week	67.2	57.1	60.9
Overweight/Obesity Status	percent of children aged 10-17 who are overweight or obese (BMI ≥ 85 th percentile)	27.0	33.2	36.3
Inadequate Insurance	percent of children with current insurance that is not adequate to meet health needs	19.7	23.7	29.4
Preventive Medical Care	percent of children with 1 or more preventive medical visits in the past year	92.8	96.1	91.4
Preventive Dental Care	percent of children with 2 or more preventive dental visits in the past year	49.6	59.6	57.1
Specialist Access	percent of children who have problems receiving specialist care when needed	20.3	33.0	27.0
Medical Home	percent of children who receive comprehensive, ongoing, and coordinated care within a medical home	60.0	53.1	49.8
Personal Doctor or Nurse	percent of children with at least one personal doctor or nurse	92.0	94.9	94.7
Usual Source of Care	percent of children with a usual source of care when sick	93.2	96.4	94.8
Family-Centered Care	percent of children who receive family-centered care	69.6	71.3	65.5
THE CHILD'S HOME AND FAMILY				
Smoking in the Home	percent of children who live in households where someone smokes inside the home	6.9	8.6	10.1
Television and Media	percent of children aged 1-17 who watch more than 1 hour of TV per weekday	49.5	50.1	54.3
Family Meals	percent of children who share meals with their family on 4 or more days per week	73.8	72.8	76.0
Inadequate Sleep	percent of children aged 6-17 who do not get adequate sleep every night of the week	39.4	56.6	41.1
Maternal Health	percent of children who live with mothers who are in excellent or very good health	65.5	54.5	47.8
Parental Coping	percent of children whose parents feel they are coping very well with demands of parenthood	63.1	48.5	51.9
Parent-Child Relationship	percent of children who share ideas with their parents very well	70.0	55.5	62.6
Parental Stress	percent of children whose parents usually or always feel stress due to parenting	6.5	24.1	20.0
THE CHILD AT SCHOOL AND IN THE COMMUNITY				
School Engagement	percent of children aged 6-17 who are adequately engaged in school	82.3	71.0	69.5
Missed School Days	percent of children aged 6-17 who missed 11 or more days of school in the past year	2.9	12.0	13.5
Repeating a Grade	percent of children aged 6-17 who have repeated one or more grades since kindergarten	8.3	15.2	18.5
Neighborhood Resources	percent of children who live in neighborhoods with a park, sidewalks, a library, and a community center	48.5	57.9	47.9
Safety of Child in Neighborhood	percent of children who live in neighborhoods that are always safe	52.4	47.8	49.2
SUMMARY MEASURES				
Quality of Care Summary	percent of children who meet a minimum quality of care index	47.5	43.0	35.9
Home Environment Summary	percent of children who meet criteria for a home environment summary measure	31.6	24.8	22.7
Neighborhood & School Summary	percent of children who meet criteria for a neighborhood/ school safety and support measure	54.3	54.9	48.6



Minimum Quality of Care Summary Measure using 2007 NSCH Data



Data Source: 2007 NSCH

The minimum quality of care summary measure is based on the following 3 criteria:

- (1) Adequate health insurance coverage;
- (2) Receipt of coordinated, ongoing, comprehensive care within a medical home; and
- (3) Had at least one preventive medical visit in the past 12 months.

Home, School and Neighborhood Environments of CSHCN with ASD

The 2007 NSCH
includes the
following summary
measures of:

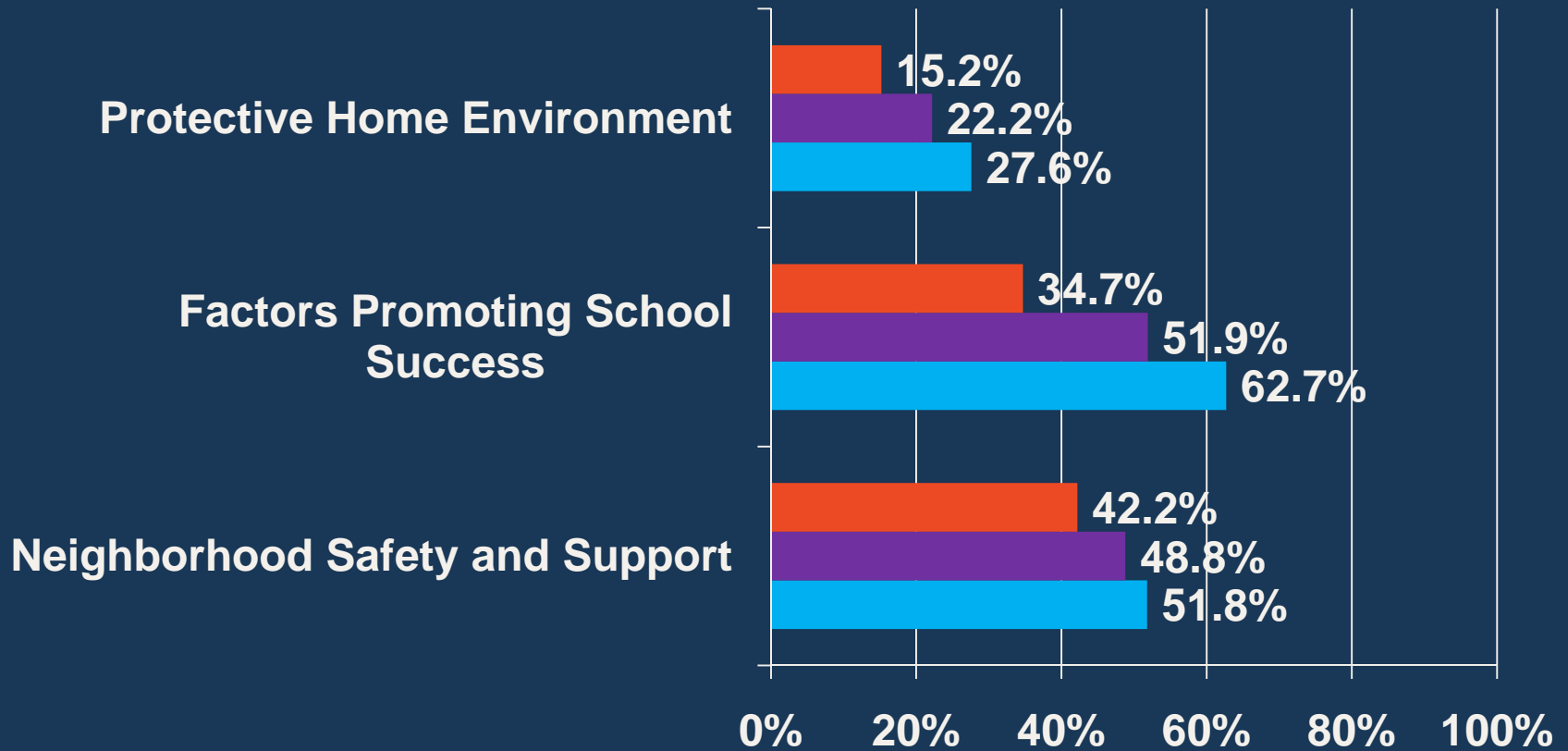
- Protective Home Environment
- Factors Promoting School Success
- Neighborhood and School Safety and Support





Home, School and Neighborhood Summary Measures among CSHCN with ASD

■ CSHCN with ASD ■ CSHCN without ASD ■ Non-CSHCN



Data Source: 2007 NSCH

Other Ideas for Maximizing the Use of Your Data

1. Use the data to motivate and inform partnerships
2. Leverage data points provided to conduct more in depth analyses and tell a story!
3. Local area synthetic estimates
4. More ideas provided in the additional slides section



How the DRC can Support Program Improvement Partnerships

Understand Your Population

User generated tables, bar and pie charts, and customizable reports supply prevalence estimates and population counts to help define your population of CSCHN and their health needs

Assess System Performance

Immediate access to over 100 state-specific indicators of child health and well-being and system performance for children overall and children with special health care needs (CSHCN).

Examine Improvement Opportunities

“Point and click” menu allows users to explore disparities and gaps in access and services for different population subgroups of children and CSHCN.



How the DRC can Support Programs Improvement Partnerships

Select Priorities

User generated tables, bar and pie charts, and customizable reports supply prevalence estimates and population counts to help guide selection of priority needs.

Set Targets

“All States” ranking maps and tables provide benchmark data to assist in identifying state-negotiated performance measure targets.

Identify Promising Improvement Models

Information on national, within and across States variation using standardized indicators helps identify where quality is better and can help in cross-state learning for purposes of identifying promising models for improvement as well as identify key collaborators for improvement.

Monitor Progress

Centralized resource for standardized, population-based survey questions to use in collecting child health and health care quality data locally.

Make the Data Come Alive



All of the CSHCN living in California would fill 24,927 school buses and stretch 170 miles

How far would the buses span if they were filled with subgroups of California CSHCN?

- White: 52 miles
- Non-white: 92 miles

Tell and Enhance the Human Story

- Of CSHCN that are insured:
 - Over 1 in 3 (34.3%) have insurance that does not adequately meet their needs.
 - This ranges from 1 in 4 [25.5% -DE] to almost 1 in 2 [44.8%-CO] across states.



This translates into nearly 90,825 school buses filled with CSHCN with inadequate health insurance – enough to span the entire length of California.

All of this data was obtained in less than one minute on the CAHMI Data Resource Center –www.childhealthdata.org



Local Area Estimates Something to Consider

Race/Ethnicity Adjusted	California	Marin County	Fresno County
Prevalence of CSHCN	14.5%	15.8%	14.5%
Prevalence of Inadequate Insurance	24.9%	24.1%	24.9%
Prevalence of Grade Repetition	10.6%	9.9%	13.5%
Prevalence of a “Home Environment” Summary Measure	29.6%	31.6%	20.8%
Prevalence of Medical Home	49.6%	52.0%	46.9%

Data Sources: 2007 NSCH and kidsdata.org

The Importance of Standardization

Standardize



Compare



Learn



Be Bold!

- ❑ The NSCH and NS-CSHCN are unprecedented resources!
- ❑ State data provides a basis for across-area learning and building shared understanding of priorities and impact.



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Thank You!

□ ADDITIONAL SLIDES TO FOLLOW



DRC Goals

- 1) Provide centralized, user-friendly interactive access to standardized national, regional and state-level findings from national surveys on child and adolescent health and well-being.
- 2) Build common knowledge, capacity, and passion for using data to stimulate and inform system change locally and nationally—especially among state health agency leaders and staff, family advocates and policy leaders.



NSCH and NS-CSHCN Measures Endorsed by the National Quality Forum

Measures Endorsed by NQF—Awaiting final Board ratification

- Number of school days missed due to illness
- Adequacy of insurance for optimal health
- Problems obtaining needed referrals
- Medical home
- Communities perceived as safe
- Schools perceived as safe
- Effective care coordination

Measures Recommended for Endorsement Pending Public Comment and Final Vote

- Usual source of sick care
- Developmental screening
- Obesity status based on parent report of BMI
- Preventive dental care
- Exposure to secondhand smoke inside the home
- Transition services to adult health care for CSHCN
- Weekly physical activity
- Consistency of health insurance coverage
- Family-centered care



More Profiles with NS-CSHCN and NSCH Data are Available on the DRC Website

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2009/10 National Survey of Children with Special Health Care Needs

Nationwide Profile

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[2001 Profile](#)
[2005/06 Profile](#)

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

Prevalence of CSHCN	State %	Nation %	National Chartbook Indicators	State %	Nation %
CSHCN Prevalence			Child Health		
Percent of children who have special health care needs	15.1	15.1	CSHCN whose conditions affect their activities usually, always, or a great deal	27.1	27.1
CSHCN Prevalence by Age			CSHCN with 11 or more days of school absences due to illness		
Age 0-5 years	9.3	9.3		15.5	15.5
Age 6-11 years	17.7	17.7	Health Insurance Coverage		
Age 12-17 years	18.4	18.4	CSHCN without insurance at some point in past year	9.3	9.3
CSHCN Prevalence by Sex			CSHCN without insurance at time of survey	3.5	3.5
Male	17.4	17.4	Currently insured CSHCN whose insurance is inadequate	34.3	34.3
Female	12.7	12.7	Access to Care		
CSHCN Prevalence by Hispanic Origin and Race			CSHCN with any unmet need for specific health care services	23.6	23.6
Non-Hispanic	14.5	14.5	CSHCN with any unmet need for family support services	7.2	7.2
White	14.6	14.6	CSHCN needing a referral who have difficulty getting it	23.4	23.4
Black	15.9	15.9	CSHCN without a usual source of care when sick (or who rely on the emergency room)	9.5	9.5
Other	11.8	11.8	CSHCN without any personal doctor or nurse	6.9	6.9
Hispanic	9.6	9.6	Family Centered Care		
Spanish Language Household	6.4	6.4	CSHCN without family-centered care	35.4	35.4
English Language Household	12.7	12.7	Impact on Family		
			CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child	22.1	22.1
			CSHCN whose conditions cause financial problems for the family	21.6	21.6
			CSHCN whose families spend 11 or more hours per week providing or coordinating child's health care	13.1	13.1
			CSHCN whose conditions cause family members to cut back or stop working	25.0	25.0
			MCHB Core Outcomes		
			CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	70.3	70.3
			CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	43.0	43.0
			CSHCN whose families have adequate private and/or public insurance to pay for the services they need	60.6	60.6
			CSHCN who are screened early and continuously for special health care needs	78.6	78.6
			CSHCN whose services are organized in ways that families can use them easily	65.1	65.1

State 2009/10 NS-CSHCN Profiles include the MCHB Core Outcomes

TEST



Your Data ... Your Story

Data Resource Center for Child & Adolescent Health

A project of the Child and Adolescent Health Measurement Initiative

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Male	17.4	17.4	Currently insured CSHCN whose insurance is inadequate	34.3	34.3
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Non-Hispanic	14.5	14.5	CSHCN with any unmet need for family support services	7.2	7.2
White	14.6	14.6	CSHCN needing a referral who have difficulty getting it	23.4	23.4
Black	15.9	15.9	CSHCN without a usual source of care when sick (or who rely on the emergency room)	9.5	9.5
Other	11.8	11.8	CSHCN without any personal doctor or nurse	6.9	6.9
Hispanic	9.6	9.6	Family Centered Care		
Spanish Language Household	6.4	6.4	CSHCN without family-centered care	35.4	35.4
English Language Household	12.7	12.7	Impact on Family		
MCHB Core Outcomes			CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child	22.1	22.1
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	70.3	70.3	CSHCN whose conditions cause financial problems for the family	21.6	21.6
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	43.0	43.0	CSHCN whose families spend 11 or more hours per week providing or coordinating child's health care	13.1	13.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	60.6	60.6	CSHCN whose conditions cause family members to cut back or stop working	25.0	25.0
CSHCN who are screened early and continuously for special health care needs	78.6	78.6			
CSHCN whose services are organized in ways that families can use them easily	65.1	65.1			



See Whether You Can Compare Outcomes Across Survey Years

TEST



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2005/06 vs. 2009/10 National Survey of Children with Special Health Care Needs

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[2005/06 Profile](#)
[2009/10 Profile](#)

Nationwide Profile

✓ = Indicator comparable across survey years, ⊘ = Indicator NOT comparable across survey years

Prevalence of CSHCN	2005/06 %	2009/10 %
CSHCN Prevalence		
Percent of children who have special health care needs	13.9	15.1
CSHCN Prevalence by Age		
Age 0-5 years	8.8	9.3
Age 6-11 years	16.0	17.7
Age 12-17 years	16.8	18.4
CSHCN Prevalence by Sex		
Male	16.1	17.4
Female	11.6	12.7
CSHCN Prevalence by Hispanic Origin and Race		
Non-Hispanic	15.0	14.5
White	15.5	14.6
Black	15.0	15.9
Other	N/A	11.8
Hispanic	8.3	9.6
Spanish Language Household	4.6	6.4
English Language Household	13.1	12.7

National Chartbook Indicators	2005/06 %	2009/10 %
Child Health		
CSHCN whose conditions affect their activities usually, always, or a great deal	✓ 24.0	27.1
CSHCN with 11 or more days of school absences due to illness	✓ 14.3	15.5
Health Insurance Coverage		
CSHCN without insurance at some point in past year	✓ 8.8	9.3
CSHCN without insurance at time of survey	✓ 3.5	3.5
Currently insured CSHCN whose insurance is inadequate	✓ 33.1	34.3
Access to Care		
CSHCN with any unmet need for specific health care services	✓ 16.1	23.6
CSHCN with any unmet need for family support services	✓ 4.9	7.2
CSHCN needing a referral who have difficulty getting it	⊘ 21.1	23.4
CSHCN without a usual source of care when sick (or who rely on the emergency room)	✓ 5.7	9.5
CSHCN without any personal doctor or nurse	⊘ 6.5	6.9
Family Centered Care		
CSHCN without family-centered care	✓ 35.4	35.4
Impact on Family		
CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child	✓ 20.0	22.1

Whole System, Whole Child View

Understanding how many CSHCN meet each age-relevant MCHB Core Outcome provides a clearer picture of how the system of care are performing.

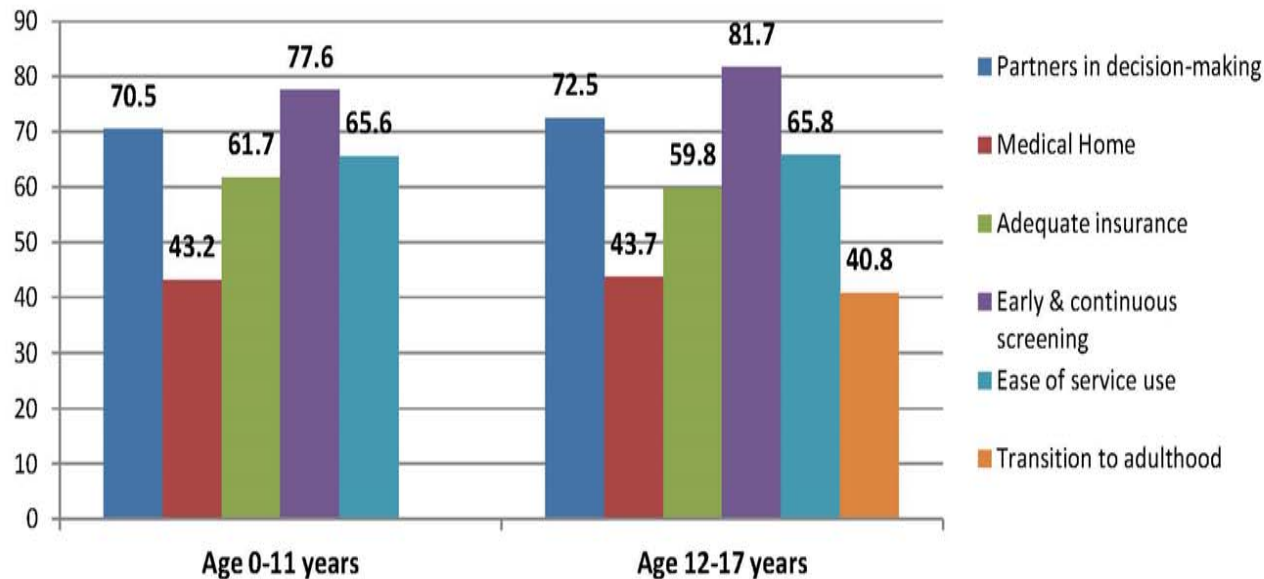
Age 0-11

12.1%
CSHCN with
more EBI

Age 12-17

6.2%
Publicly
insured
CSHCN

Percentage of CSHCN Meeting the Each Core Outcome



- Core Outcome #2: Medical Home and core Outcome #6: Transition to Adulthood (CSHCN age 12-17 years only) are the two outcomes least likely to be met.
- For both age groups, more CSHCN meet Outcome #4: Early and Continuous Screening than any other outcome.

12.3%
Publicly
insured
CSHCN

6.2%
Publicly
insured
CSHCN

Other Options: Obtain U.S. Maps and State Ranking Tables for Measures



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Current

Survey:

Special

Starting

Indicators

State/Region: Nationwide vs. California

Topic: MCHB Core Outcomes for CSHCN

Question: Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home (details)

Edit Search Criteria

Compare States:

California

Compare Subgroups:

Select a Subgroup

Change question, topic or survey

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home (details)

		Outcome successfully achieved	Outcome not achieved	Total %
Nationwide	%	43.0	57.0	100.0

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Browse State Ranking Maps

State Ranking Maps provide a visual display of the nation, comparing each individual state's performance to the national average on key Child Health Indicators in the National Survey of Children's Health (NSCH) and MCHB Core Outcomes and Indicators in the National Survey of Children with Special Health Care Needs (NS-CSHCN).

Click on any state within the state ranking map to compare performances on the indicator.

NSCH State Ranking Maps

CSHCN State Ranking Maps

CORE OUTCOMES/PERFORMANCE MEASURES

- Outcome #1: CSHCN whose families are partners in decision making and satisfied with services
- Outcome #2: CSHCN have a medical home
- Outcome #3: CSHCN have adequate private and/or public insurance
- Outcome #4: CSHCN who are screened early and continuously for special health care needs
- Outcome #5: Community-based services are organized for ease of use
- Outcome #6: CSHCN Youth receive services needed for transition to adulthood (ages 12-17 only)
- Met All 5 Core Outcomes (CSHCN ages 0-11 only)
- Met All 6 Core Outcomes (ages 12-17 only)

NATIONAL CHARTBOOK INDICATORS

- Indicator #1: CSHCN whose conditions affect their activities
- Indicator #2: CSHCN with 11 or more days of school absences due to illness
- Indicator #3: CSHCN without insurance at some point during past year
- Indicator #4: CSHCN without insurance at time of survey
- Indicator #5: Currently insured CSHCN whose insurance is inadequate
- Indicator #6: CSHCN with any unmet need for specific health care services
- Indicator #7: CSHCN with any unmet need for family support services

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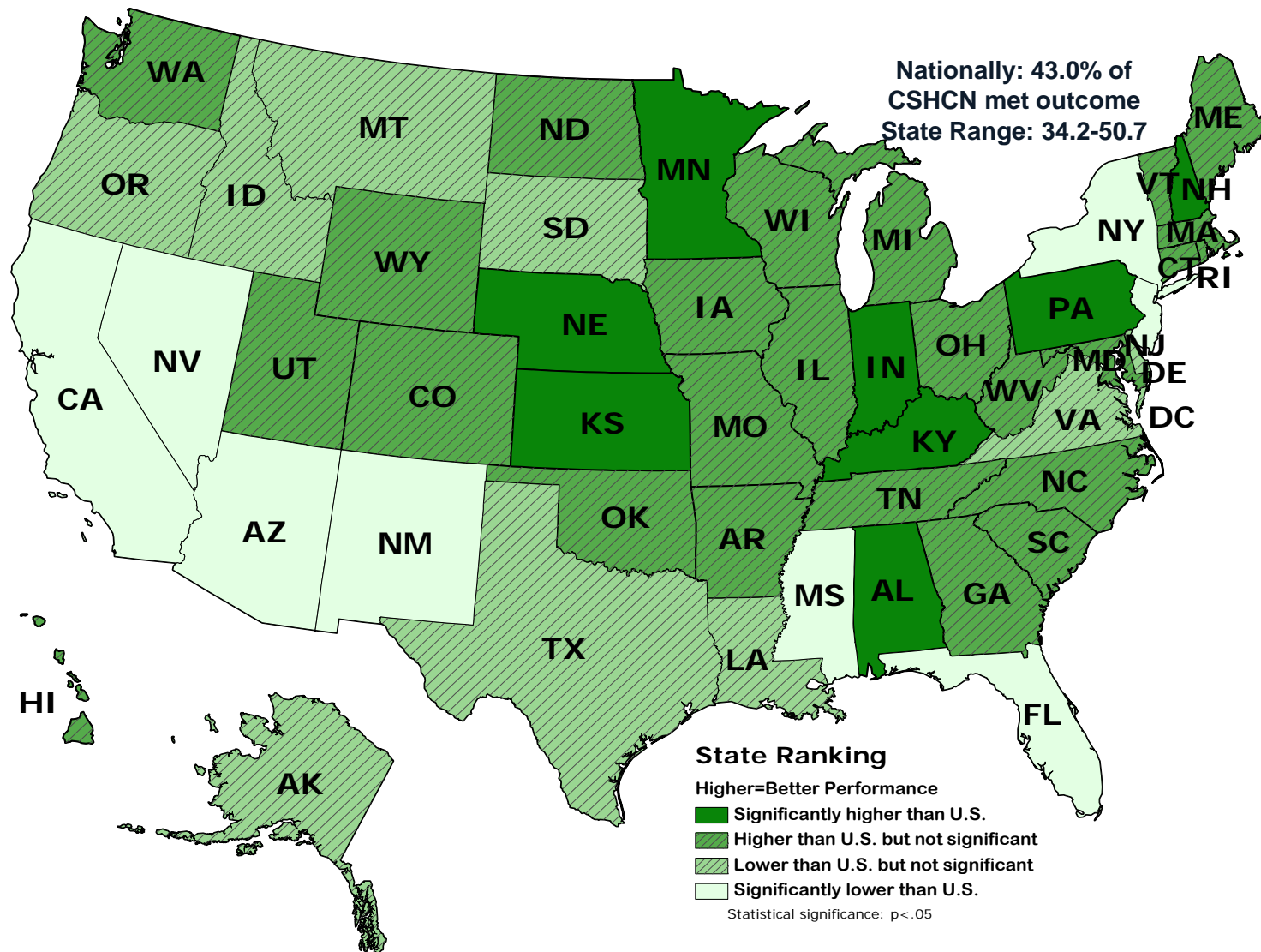


Browse the Data

Home > Browse the Data

MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing comprehensive care within a medical home

2009/10 National Survey of Children with Special Health Care Needs



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Title V Needs Assessment State Profiles



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Home > Browse the Data > Title V > Title V Needs Assessment Data

Guide to Using the DRC for Title V Needs Assessment

Quickly find state estimates for your Title V needs assessment!

1. Select your state.
2. Select your population of interest (All Children or Children with Special Health Care Needs).
3. Click on "view data" for your state estimates. State estimates can be examined further by subgroups or compared to other states on the data query pages.

1. Choose a geographic area

State/Region/Nation:

2. Choose a population for the State, Region or Nation

Measures for Population of All Children [click to show](#)

Measures for Children with Special Health Care Needs [click to hide](#)

	Measure	Among CSHCN only, 2009/10 NS-CSHCN	Among CSHCN (vs. non)*, 2007 NSCH
Health Status and Outcomes			
Morbidity Rates Prevalence rates for CSHCN may differ between the two national surveys due to sampling methods. Click here to find out more information.	Population prevalence of CSHCN (from NS-CSHCN)	View Data	
	Population prevalence of CSHCN (from NSCH)		View Data
Severity of condition	Severity of conditions		View Data
	School days missed	View Data	View Data
	Provider visits (coming soon)	View Data	View Data
	Emergency room visits (coming soon)	View Data	
Functional limitations	Health conditions interfere with activity and social participation, age 6-17		View Data
	Health conditions consistently affect daily activities	View Data	
	Number of functional difficulties reported from list of 15 difficulties	View Data	
Prevalence of preventable disease and chronic diseases	Overall prevalence of chronic health conditions		View Data
	Prevalence of individual chronic health conditions (e.g., asthma; diabetes)	Keyword Condition	Keyword Condition
Obesity/overweight	BMI (for CSHCN)		View Data
Mental Health	Delayed care	View Data	

Medical Home Profiles



Data Resource Center for Child & Adolescent Health
Your Data... Your story A project of the Child and Adolescent Health Measurement Initiative (CAHMI)

www.childhealthdata.org

LOUISIANA

Medical Home Performance Profile for ALL CHILDREN
Data Source: 2007 National Survey of Children's Health

Medical Home Profile at a Glance

Louisiana: 55.3%

National Rate: 57.5%

Range across States: 45.4% - 69.3%

Prevalence of Medical Home in Louisiana

All Children (age 0-17)	State	HRSA Region VI	Nation
Met All Medical Home Criteria	55.3%	52.0%	57.5%

Age of Child

0 - 5 years old	61.4%	60.1%	64.0%
6 - 11 years old	53.8%	46.0%	55.2%
12 - 17 years old	50.9%	49.4%	53.4%

Sex of Child

Male	57.0%	52.7%	56.8%
Female	53.6%	51.2%	58.2%

Household Poverty Level (Federal Poverty Level [FPL] Guidelines)*

0 - 99% FPL	36.5%	32.0%	39.4%
100 - 199% FPL	48.6%	42.3%	49.4%
200 - 399% FPL	65.0%	57.0%	62.5%
400% FPL or higher	70.7%	75.9%	69.3%

* For more information on FPL guidelines please visit: <http://aspe.hhs.gov/poverty/07Poverty.shtml>

Race/Ethnicity of Child

Hispanic	46.5%	37.7%	38.5%
White, Non-Hispanic	66.4%	68.6%	68.0%
Black, Non-Hispanic	40.9%	36.6%	44.2%
Multi-Racial/Other, Non-Hispanic	47.9%	53.6%	55.6%

Type of Insurance

Public insurance such as Medicaid or SCHIP	44.9%	38.6%	45.4%
Private health insurance	68.6%	66.7%	66.5%
Currently uninsured	31.1%	29.5%	35.7%

Children with Special Health Care Needs (CSHCN) Status

CSHCN	51.3%	49.1%	49.8%
Non-CSHCN	56.6%	52.7%	59.4%

Components of Medical Home

Accessibility	State	HRSA Region VI	Nation
Has a personal doctor or nurse	91.2%	89.3%	92.2%

Family-Centered Care (% who report "usually" or "always")

Doctor spends enough time	76.6%	73.6%	79.3%
Doctor listens carefully	88.8%	86.0%	89.4%
Doctor provides specific needed information	84.9%	80.6%	84.8%
Doctor helps parent feel like partner in care	88.8%	84.4%	87.6%

Comprehensive

Has a problem getting referrals when needed	27.6%	20.2%	17.7%
Has a usual source for both sick and well care	92.9%	90.7%	93.1%

Coordinated (% among children receiving 2 or more types of services)

Received any help arranging or coordinating care	20.4%	22.3%	20.7%
Reported getting all help needed arranging care for child	66.6%	70.3%	68.7%
Very satisfied with communication between doctors, when needed	72.9%	76.8%	72.3%
Very satisfied with communication between doctors and school, when needed	49.8%	63.3%	62.3%

Culturally Effective (% who report "usually" or "always")

Doctor is sensitive to family customs and values	89.4%	86.5%	89.2%
Availability of interpreter, when needed	NA**	64.1%	64.2%

Citation format: Child and Adolescent Health Measurement Initiative. 2007 National Survey of Children's Health Medical Home State Profile. Data Resource Center for Child and Adolescent Health website. Retrieved [mm/dd/yy] from www.medicalhomedata.org.

** NA Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than or equal to 30% and/or the number of responses is less than 25.

For more information on the Medical Home concept, resources related to Medical Home, or more Medical Home data, please go to www.medicalhomedata.org.



Disparity Profiles

- 2009/10 Disparity Profiles Coming Soon
- 2007 Disparity Profiles
 - Special Health Care Needs Status
 - Health Insurance
 - Race/Ethnicity
 - Rural-Urban Commuting Areas
- *Disparity Profiles are customizable, in which you can choose your own indicators



Examples of Variation (e.g. Information) to Look For

Example:

Met Transition to Adulthood Criteria: 40.0%

➤ **Variations Across States**

State Range: 31.7% (NV) to 52.7% (KS)

➤ **Disparities Nationwide (and variation in disparities!)**

Private: 50.2%; Public: 25.8%; Uninsured: 19.6%

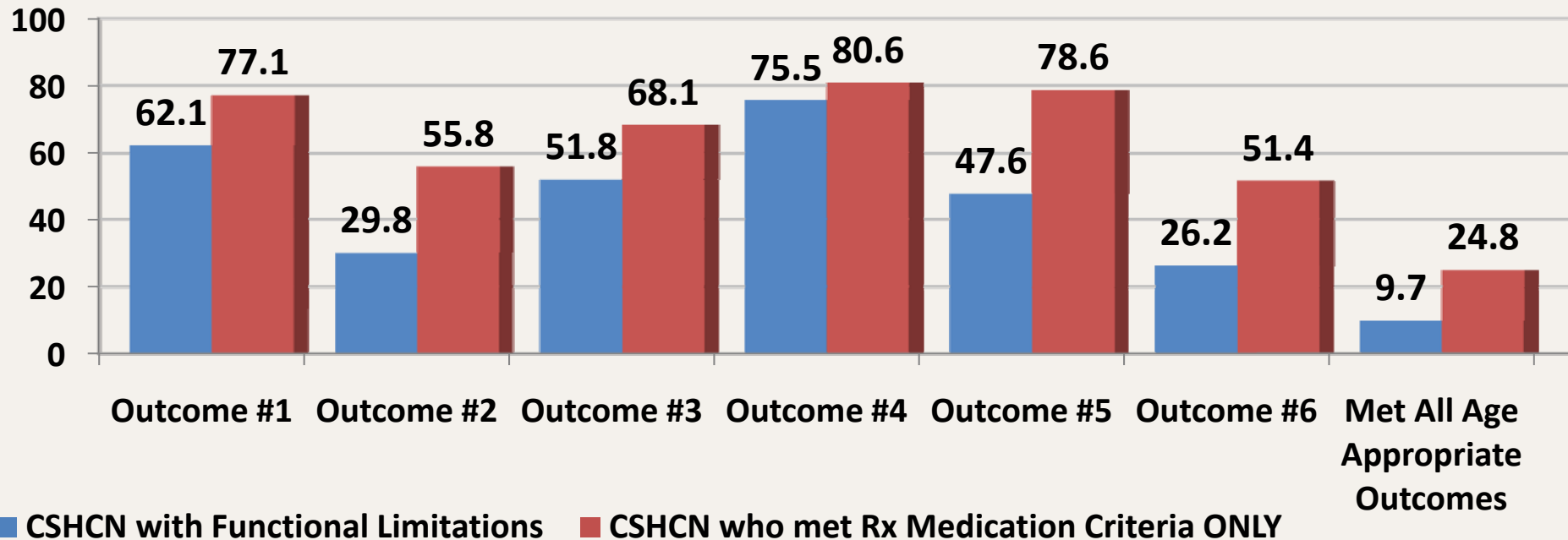
Among Insured – Adequate Insurance: 46.2%

Inadequate Insurance: 31.7%

Myth Busting Is Essential

Myth: CSHCN are a homogeneous population.

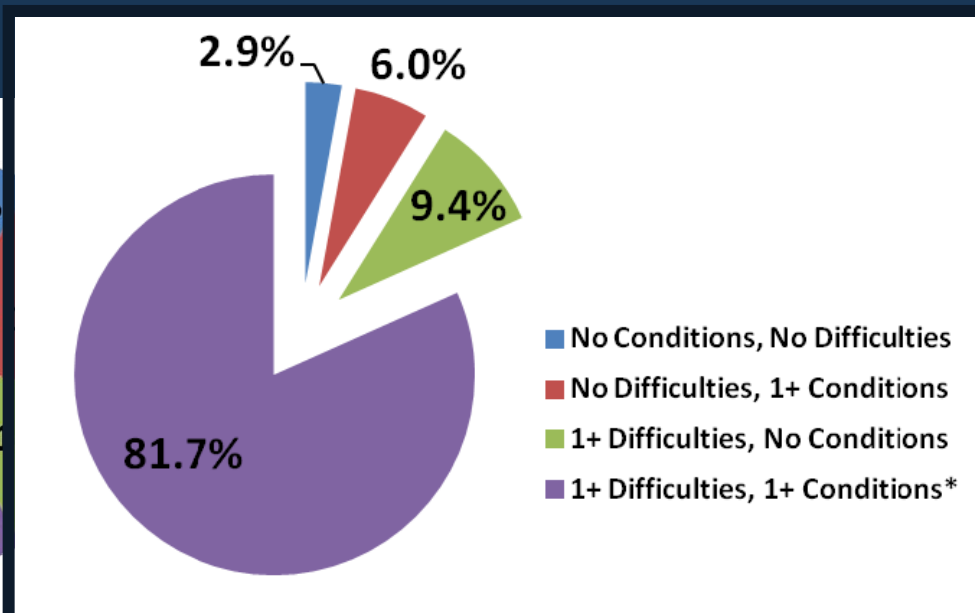
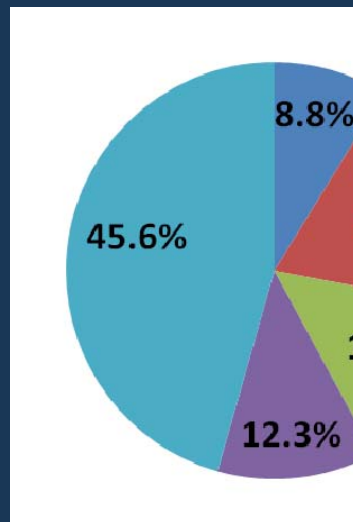
Fact: CSHCN have diverse needs and experiences with care. Differences are exemplified by comparing CSHCN with functional limitation to those who need or use prescription medications only.



Myth Busting Is Essential

Myth: Some children identified by the CSHCN Screener don't have any ongoing health conditions or functional difficulties.

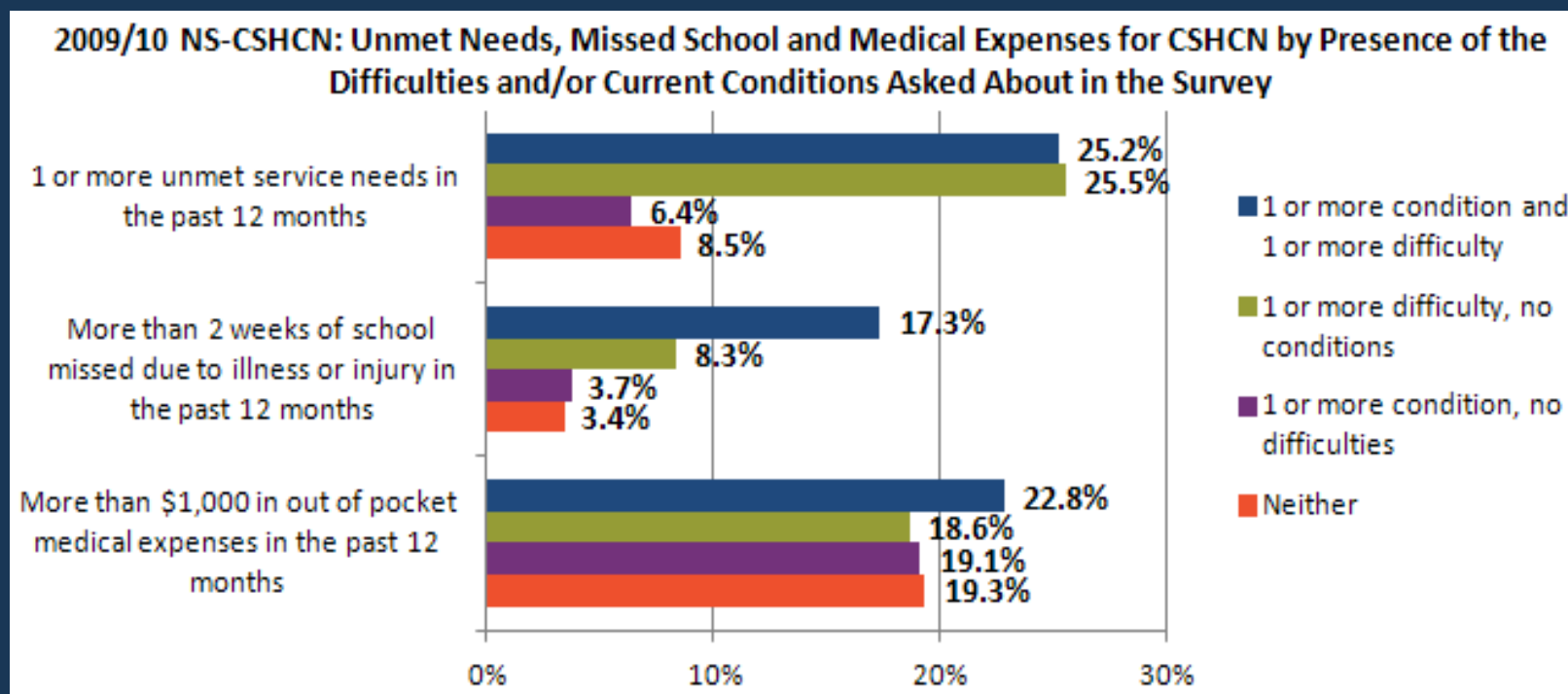
Fact: All CSHCN identified by the CSHCN Screener experience at least one ongoing health condition resulting in above routine need for health and related services. 90.8% of CSHCN reporting no functional difficulties state that this is because their conditions are being treated and are under control.



* Of the 14 difficulties and 20 conditions asked about in the 2009/10 NS-CSHCN
Data Source: 2009/10 National Survey of Children with Special Health Care Needs

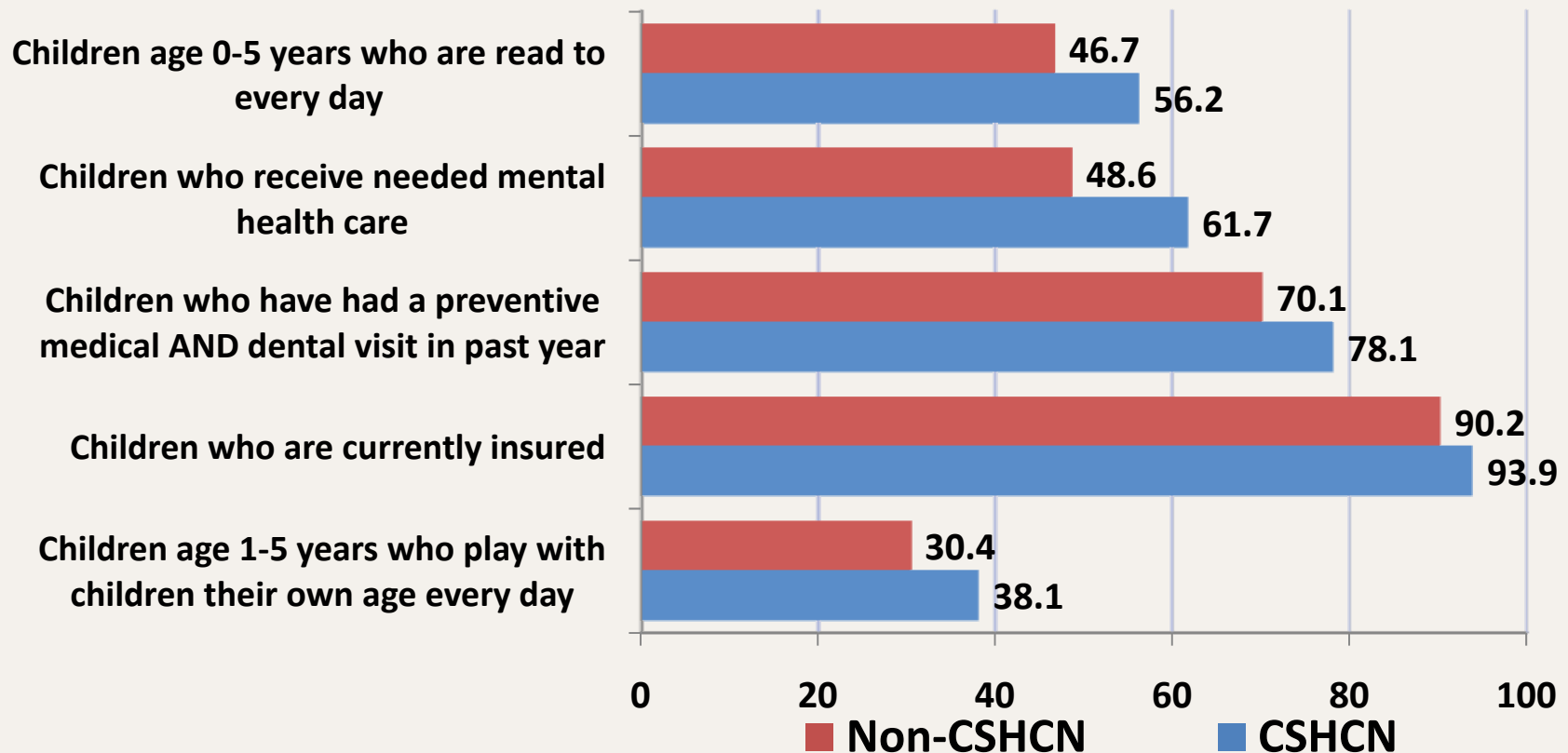
Who are the 2.9% of CSHCN reporting none of the conditions or difficulties asked about in the survey?

- 91.3% report their conditions are under control due to medication or treatment
- 65.7% qualified as CSHCN on the prescription medication criterion only
- 19.3% had over \$1,000 in out-of-pocket medical expenses in the prior year



Myth Busting Is Essential

Myth: Children with Special Health Care Needs always have worse outcomes compared to non-CSHCN.



Data Source: 2007 National Survey of Children's Health

Myth Busting Is Essential

Myth: All states are essentially the same with regard to prevalence and type of CSHCN.

Nationwide	Variation Across States
Among all Children	
CYSHCN (15.1%)	1.87 fold (10.6%-19.8%)
Among CYSHCN	
Ongoing Emotional, Behavioral, Developmental Problems (31.8%)	1.69 fold (24.0%-40.6%)
Health Conditions Consistently and Often Greatly Affect Daily Activities (27.1%)	2.11 fold (21.9%-46.2%)

Myth Busting Is Essential

Myth: Only CSHCN with rare conditions, such as Cerebral Palsy and Muscular Dystrophy, experience a lot of functional difficulties.

Fact: CSHCN with common conditions are likely to experience multiple difficulties too. Those with the most commonly reported condition (allergies) experience a mean of 3.8 difficulties.

Note that CSHCN with each condition are likely to have at least one of the other conditions as well. For example, 80.0% of CSHCN with current asthma also have one or more of the other conditions asked about.

Health Issue Asked About* (prevalence among CSHCN)	Mean # of Difficulties – A Little or A Lot	Mean # of Difficulties – A Lot Only
Cerebral Palsy (1.6%)	7.7	4.4
Intellectual Disability (5.8%)	7.6	4.0
Head Injury (1.4%)	7.3	3.8
Autism, ASD (7.9%)	6.9	3.3
Developmental Delay (17.6%)	6.9	3.2
Muscular Dystrophy (0.3%)	6.8	3.9
Down Syndrome (1.1%)	6.8	2.8
Epilepsy (3.1%)	6.4	3.3
Behavioral problems (13.5%)	6.4	3.0
Depression (10.3%)	6.3	2.9
Arthritis (2.9%)	6.3	2.7
Anxiety (17.1%)	6.1	2.7
Headaches (9.8%)	5.5	2.2
Heart Problem (3.0%)	5.1	2.0
ADD/ADHD (30.2%)	4.9	1.8
Blood Problems (1.5%)	4.9	1.8
Cystic Fibrosis (0.3%)	4.1	1.9
Allergies (48.6%)	3.8	1.2
Asthma (35.3%)	3.6	1.1
Diabetes (1.7%)	3.3	0.9

* Condition prevalence in 2009/10 was asked using two questions: prevalence of conditions ever or currently. Only current prevalence is included here.

Motivating and Informing Partnerships

- Partnerships falter or proceed on faulty ground as assumptions go unannounced and unchecked
 - How are we doing?
 - What and who should we focus on?
 - How do we know if anything improved?



Making the Data Come Alive



school buses span if they were filled with subgroups of California CSHCN?

- 2+ of 16 more common conditions: 89 miles
- Complex needs: 109 miles
- Functional difficulties: 44 miles

Make the Data Come Alive

asthma, which is the equivalent
of enough children to fill 20
Staples Centers!

- 11.5 for ADHD
- 1.9 for Autism/ASD
- 1 for Cerebral Palsy
- 1 for Diabetes
- 3.9 for Depression



Use the NSCH too!

Leverage both the NS-CSHCN and NSCH to create a unique synthesis of nationally comparable data



Lucile Packard
FOUNDATION for Children's Health

Children with Special Health Care Needs

A Profile of Key Issues in California



Prepared by



CAHMI
The Child and Adolescent
Health Measurement Initiative

June 2010





Synthetic Estimate

- Prevalence estimates for local areas by using descriptive/demographic data of local areas combined with state prevalence values
- Can calculate county-level estimates based on demographic distribution of local area
- Similar in concept to an “indirect adjustment”



Synthetic Estimate: What do you need?

- Prevalence of an indicator by selected demographic category (at state level)
 - Examples:** prevalence of CSHCN, adequate insurance, medical home, asthma, etc.
 - Can be anything for which you have state-level data
- Can access at www.childhealthdata.org
- Prevalence of children in your county for the demographic characteristic you wish to “adjust” for
 - Examples:** Age, Sex, Race/Ethnicity, Income
- **Access Census Demographics**



How to Calculate a Synthetic Estimate

1. Select indicator of interest:
Prevalence of CSHCN
2. Select geographic area for calculation:
Need State and Local Area:
California (Marin & Fresno Counties)
3. Select demographic category
Race/Ethnicity: Latino/Hispanic, White, Black and Multi-racial/Other

*Must match to your state-level data



How to Calculate a Synthetic Estimate

4. Identify distribution of demographic categories in local area

Race/Ethnicity Category	Distribution in Local Area (Marin County)	Distribution in Local Area (Fresno County)
Latino/Hispanic	18,468	163,560
White	29,394	66,283
Black	1,268	14,411
Multiracial	2,441	6,119
Other	1,942	28,157
TOTAL # of Children	53,513	278,530

*Data Source: KidsData.org. Combined prevalence of Asian, Native American, and Multi-racial to match categories in 2009/10 NS-CSHCN data set.



How to Calculate a Synthetic Estimate

5. Identify prevalence of selected indicator by demographic categories (at state level)

Race/Ethnicity Category	Prevalence of CSHCN by Race (State of California)
Latino/Hispanic	8.0
White	11.6
Black	14.8
Other	7.8
TOTAL % of Children	10.6

***Data Source: 2009 NS-CSHCN Screener File. Obtained from Data Resource Center for Child and Adolescent Health, www.childhealthdata.org.**



How to Calculate a Synthetic Estimate

6. Calculate synthetic estimate: Marin County

Race/Ethnicity Category	Distribution in Local Area (Marin County)	Prevalence of CSHCN by Race (State of CA)	# of Children in Marin County within Race/Ethnicity category who are CSHCN
Latino/Hispanic	18,468	8.0	1477.44
White	29,394	11.6	3409.70
Black	1,268	14.8	187.66
Other	4,383	7.8	341.874
TOTAL # of Children	53,513		5416.67

$$5,417/53,513=10.1\%$$