#### The Data Resource Center for Child and Adolescent Health: Using Data for Action

www.childhealthdata.org



Family Voices National Conference May 25, 2007 Presented by: Christina Bethell, PhD, MPH, MBA





- Why is data useful?
- Overview of the Two National Surveys
- Overview of the Data Resource Center
- How to Use the Website

# Why is Data Useful?





Family stories give a face and heart to needs.

Data expands family stories to inform policy debates and drive change.

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



#### Application of Data

- Identifying/documenting needs
  - How many children in your state have what needs?
  - How do needs vary across states and why?
  - How do needs vary across subgroups of children within and across states and why?
  - How does data support your assumptions or what you're hearing from the field (providers, families, other agencies)?
- Building partnerships
  - What partners could use this data: Public Programs, Health plans, Hospitals, Providers, community groups, faith based organizations?
  - How can you share data to support common efforts, improve care?



### Application of Data

- > Educating Policymakers
  - What are key policy issues for your initiative ?
  - What programs or groups need what information?
  - What data could help them learn about child health needs?
- > Advocacy
  - Are there key pressure points in program budgets or priorities coming up?
  - What methods would be most effective in presenting your case?
  - How could you use data in Fact Sheets, Testimony, the media, along with family stories?
- > Grant Writing
  - How can you use data to strengthen your proposal?

## Survey Data Included in the Data Resource Center



National Survey of Children's Health (NSCH), 2003



National Survey of Children with Special Health Care Needs (NS-CSHCN), 2001



Sponsored by the Maternal and Child Health Bureau

Use <u>SLAITS</u> (State & Local Area Integrated Telephone Survey) sampling mechanism

- National Center for Health Statistics/CDC oversees sampling and administration
- Designed and collected in a manner that allows valid state-to-state and national comparisons

Weighted data yield prevalence estimates for noninstitutionalized child population ages 0-17 in <u>each</u> <u>state</u>, and <u>nationally</u>



### Both surveys identify Children with Special Health Care Needs (CSHCN)

"Children with special health care needs . . . a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

— Maternal and Child Health Bureau, July 1998



> Both use the same method to identify CSHCN

National Survey of CSHCN, 2001Prevalence = 12.8%

National Survey of Children's Health, 2003
• Prevalence = 17.6%

## **CSHCN Screener**



Asks about 5 different health consequences:

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

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

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



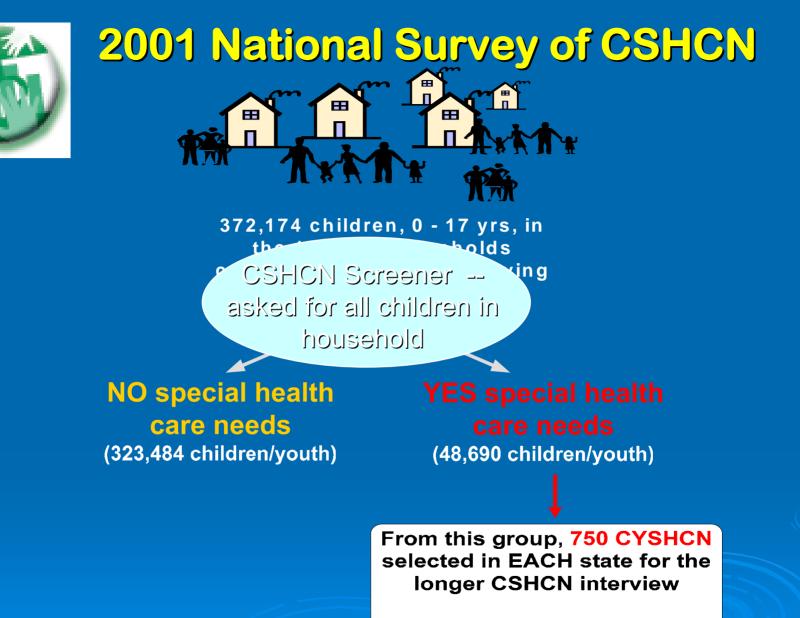
#### National Survey of Children with Special Health Care Needs (NS-CSHCN)

Conducted for the first time during 2000 – 2001

Screening method identifies CSHCN according to MCHB definition

> Was repeated in 2005-06 with some revisions & additional items on functional difficulties and conditions

Public release data expected Fall 2007

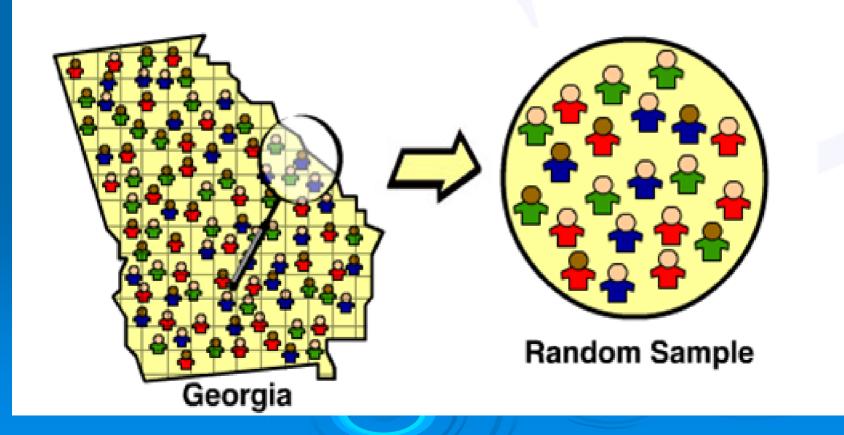


38,866 CSHCN interviews completed

## Random sampling:

 allows certain characteristics to be estimated with precision

larger sample sizes achieve more precision.





# In-depth CSHCN interview collects information on:

- > Child health and functional status
- > Child health insurance status and adequacy of coverage
- Access to health care needed services & unmet needs
- > Care coordination
- Impact of child's health on family
- MCHB core outcomes for CYSHCN and

Key indicators of CSHCN health & system performance



Increased sample size: 850 CSHCN interviews collected per state

- Added items asking about current health conditions & specific functional difficulties
- Revised, improved questions on care coordination & transition to adulthood
- > National referent sample of Non-CSHCN ( $n \approx 5000$ )
- Datasets publicly available Fall 2007; Data Resource Center website access October 1 2007



## National Survey of Children's Health

- Conducted for the first time during 2003 2004. Repeated in 2007.
- One child randomly selected in each household subject of survey for a total of 102,353 interviews
- Same CSHCN screening method as NS-CSHCN
- Information on children's health and well-being collected in combination with data on child's family/neighborhood context
- First time such a broad range of info collected in manner that allow state-to-state and national comparisons

#### National Survey of Children's Health

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

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

102.353

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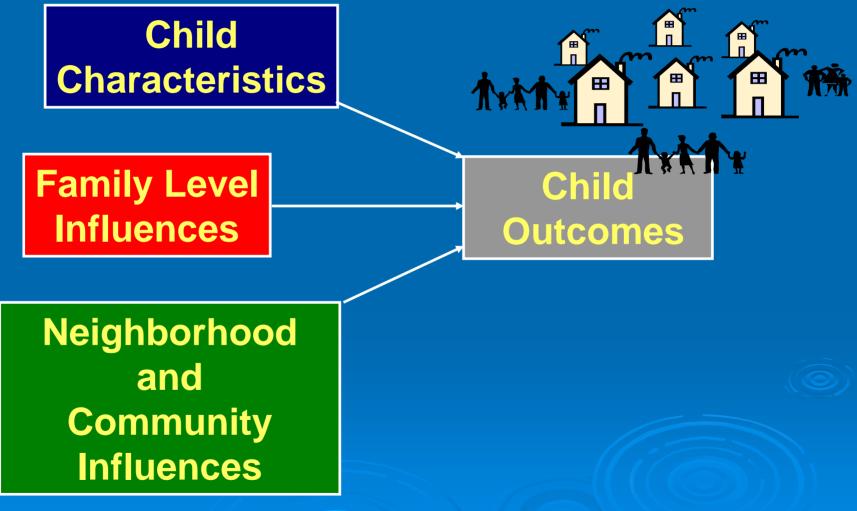
Early Childhood

questions ask childrer

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



#### **National Survey of Children's Health**





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

- Child's <u>health status</u>: physical, emotional, dental
- Child's health care including medical home
- > Child's <u>school & activities</u>
- Child's <u>family</u> & <u>neighborhood</u> -- including maternal health status
- Early childhood (ages 0-5)
- School-age (ages 6-17)

# Two Surveys - What Are the Differences?



All children

#### Population

#### **Topic Areas**

#### Health, Family, Neighborhood

#### Health, Unmet Needs, Family Impact

**CYSHCN** 

#### Sample Size per state

2,000 (300 CSHCN)

750



## Always Anchor to Children!

The denominator for ALL results in both surveys is <u>always CHILDREN</u> -- never parents!

- <u>Correct</u> -- % of children ages 0-17, or ages 0-5, or ages 6-17, etc.
- Never! % of parents, families, mothers ....

The Data Resource Center for Child and Adolescent Health Website





#### WEBSITE - <u>www.childhealthdata.org</u> serves as an umbrella site for national survey data

www.childhealthdata.org

Data Resource Center for Child & Adolescent Health

www.cshcndata.org

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

Nat. Survey of Children's Health HOMEPAGE



#### What is the DRC?

### Interactive Data Resource Center providing:

1. Hands-on, User-Friendly Access to Data

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

#### 2. Resources and Information about Data

 Examples of how other state and family leaders are using these data findings, background about the national surveys, resources about health of children



## What is the DRC?

# Interactive Data Resource Center providing:

#### 3. Education

 Obtain technical assistance for understanding, interpreting and using data, online workshops, and opportunities to partner with other stakeholders to discuss, interpret and act on data findings



## What is the Purpose of the DRC?

#### Centralize Data

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

#### Increase Knowledge

Build common knowledge and capacity for using data to stimulate and inform system change locally and nationally and opportunities to partner with other stakeholders to discuss, interpret and act on data findings



- Developed and led by CAHMI -- Child and Adolescent Health Measurement Initiative based at the Oregon Health & Science University in Portland OR
- National advisory group provides ongoing guidance and development of standardized indicators
- Sponsored by the federal Maternal and Child Health Bureau

## How to Use the DRC Website



#### Data Resource Center for Child & Adolescent Health

×

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Online Tour NEW!

Ask a Question

Tell a Friend

E-Updates

Answer Our Brief User Poll

NSCH Survey

NS-CSHCN Survey



#### Welcome to the Data Resource Center online tour!

The Data Resource Center online tour is designed to help users learn more about the website's features and options for obtaining data results. Each interactive session provides step-by-step instructions and easy to follow guidelines for conducting data searches and using the results. The content in each session builds on learning from previous sessions and we recommend starting with Part 1 the first time you take the tour.

WHAT DO I NEED? The online tour uses Macromedia Flash. Newer browsers come with built-in support for Flash; older browsers sometimes require a plug-in that can be downloaded at no cost from the <u>Macromedia Flash Player</u> site.

WHAT IF MY COMPUTER DOESN'T HAVE SPEAKERS? If your computer doesn't have the ability to play audio, you can still take the tour by following along using the written transcript for each session.

#### Part 1: Getting Started

Learn to conduct a basic data search, how to interpret the results, and where to access additional information about specific child health indicators.

Download written transcript (PDF)

#### Part 2: Comparing Subgroups and Saving Search Results

Practice comparing data results for children from different demographic subgroups, learn how to read the bar chart display, and find out where to save search results for easy reference later.

Download written transcript (PDF)

#### • Part 3: Ranking and Comparing State Results

Learn about the website's State Profile feature, practice comparing data search results for different states or regions, and use the "All States" table option to rank states according to their child health indicator results.

Download written transcript (PDF)

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Ask a Question Tell a Friend Sign Up for E-Updates Link To Us Answer Our Brief User Poll NSCH Survey NS-CSHCN Survey	Your Email Address:           Subject:           Message:	
	Send	

# Three Types of Data

### State Profile Tables

- "All States" Comparison Tables
- Data Graphs and Tables for Every Indicator
  - Comparing an indicator across any two geographic areas and
  - Comparing indicators across subgroups of children by age, race, insurance status, income, family structure, health status, etc.

#### **Example of State Profile**

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

#### National Survey of Children with Special Health Car California

Children ages 0-17 years old

Hispanic

Prevalence Statistics			Indicator	
<b>Child-Level Prevalence:</b>	State %	Nation %	Child Health:	State
Percentage of Children & Youth with Special Health Care Needs, 0 - 17 yrs old	10.3	12.8	<ol> <li>% of CYSHCN whose health conditions consistently and often greatly affect their daily activities.</li> </ol>	24.0
Household-Level Prevale	ence:		<ol> <li>% of CYSHCN with 11 or more days of school absences due to illness.</li> </ol>	16.2
Percentage of Households with Children that have one or more	17.0	20.0	Health Insurance Coverage:	
CYSHCN, 0 - 17 yrs old			<ol> <li>% of CYSHCN without insurance at some point during the past year.</li> </ol>	9.9
Prevalence by Age:			<ol> <li>4) % of CYSHCN currently uninsured.</li> </ol>	4.3
Children 0-5 years of age	5.7	7.8	5) % of currently insured CYSHCN with	36.5
Children 6-11 years of age	11.2	14.6	coverage that is not adequate.	30.5
Children 12-17 years of age	14.0	15.8		
Prevalence by Sex:			Access to Care:	00.4
Female	8.3	10.5	<ol> <li>% of CYSHCN with 1 or more unmet needs for specific health care services.</li> </ol>	23.1
Male	12.3	15.0	7b) % of CYSHCN whose families	25.1
Prevalence by Poverty L	evel:		needed but did not get all respite care, genetic counseling and/or mental health	
0% - 99% FPL	7.5	13.6	services.	
100% - 199% FPL	9.7	13.6	8) % of CYSHCN needing specialty care	27.3
200% - 399% FPL	11.0	12.8	who had problems getting a referral.	
400% FPL or greater	13.8	13.6	9) % of CYSHCN without a usual source	9.5
Prevalence by Race/Ethr	nicity:		of care (or who rely on the emergency room).	

7.6

8.5

Child Health:	State %	Nation %
<ol> <li>% of CYSHCN whose health conditions consistently and often greatly affect their daily activities.</li> </ol>	24.0	23.2
<ol> <li>% of CYSHCN with 11 or more days of school absences due to illness.</li> </ol>	16.2	15.8
Health Insurance Coverage:		
<ol> <li>% of CYSHCN without insurance at some point during the past year.</li> </ol>	9.9	11.6
4) % of CYSHCN currently uninsured.	4.3	5.2
<ol> <li>% of currently insured CYSHCN with coverage that is not adequate.</li> </ol>	36.5	33.8
Access to Care:		
<ol> <li>% of CYSHCN with 1 or more unmet needs for specific health care services.</li> </ol>	23.1	17.7
7b) % of CYSHCN whose families needed but did not get all respite care, genetic counseling and/or mental health services.	25.1	23.1
8) % of CYSHCN needing specialty care	27.3	21.9

% of CYSHCN without a personal

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Needs, 20 1

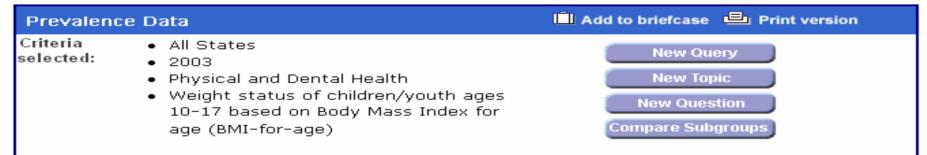
Close

9.3

11.0

13.2

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



Question: Indicator 1.4 What is the weight status of children/youth ages 10-17 based on Body Mass Index for age (BMI-for-age)? (derived)

Notes: Click on the Column Header to sort the results by ascending or descending order. To get a detailed explanation of the data HOVER over the text in the table.

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

## Example of Data Table Comparing Two Geographic Areas

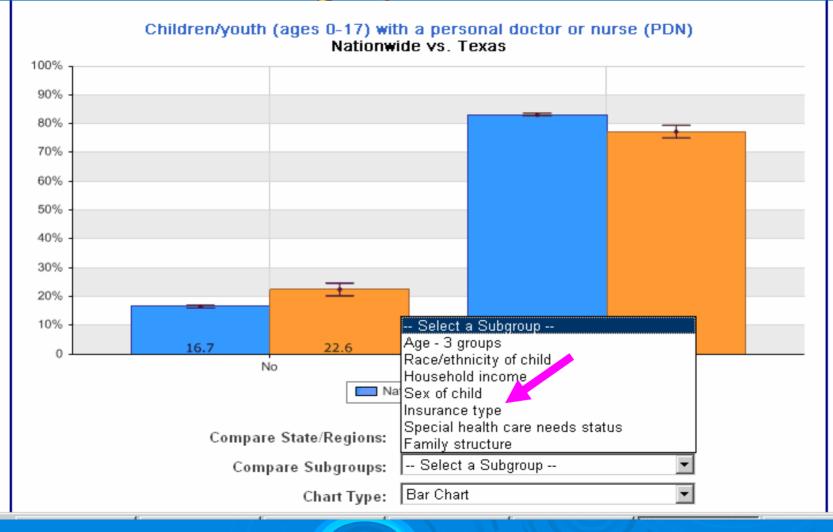
Question: Indicator 4.9: A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. Do you have one or more person(s) you think of as (child's name)'s personal doctor or nurse? (S5Q01)

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

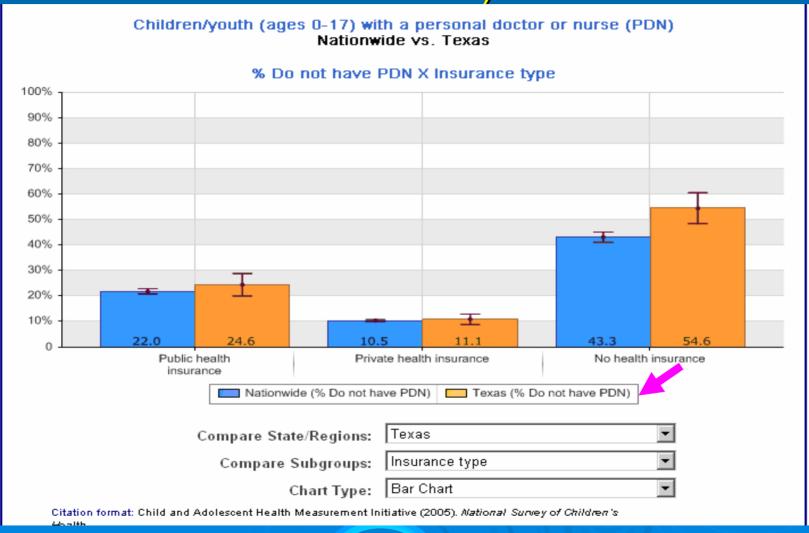
For a detailed explanation of the data MOVE your cursor over the text in the table or the bold text below C.I. = 95% Confidence Interval. Percentages are <u>weighted to population characteristics</u>.

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

## Example of Graph Comparing Two Geographic Areas



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





- Start with your State Profile
- Search the data for single topics and indicators



ational Survey of Children with Special Health Care Needs Data Resource Center — Your Data... Your story

Link to Us DRC Home Contact Us Glossarv Search

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

### Start HERE!



1. Learn about the survey

2. Search the

data

 Report your results

On Its Way!

2005 NS-CSHCN Data Coming Fall 2007

To Preview Content Guide **Click Here** 

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





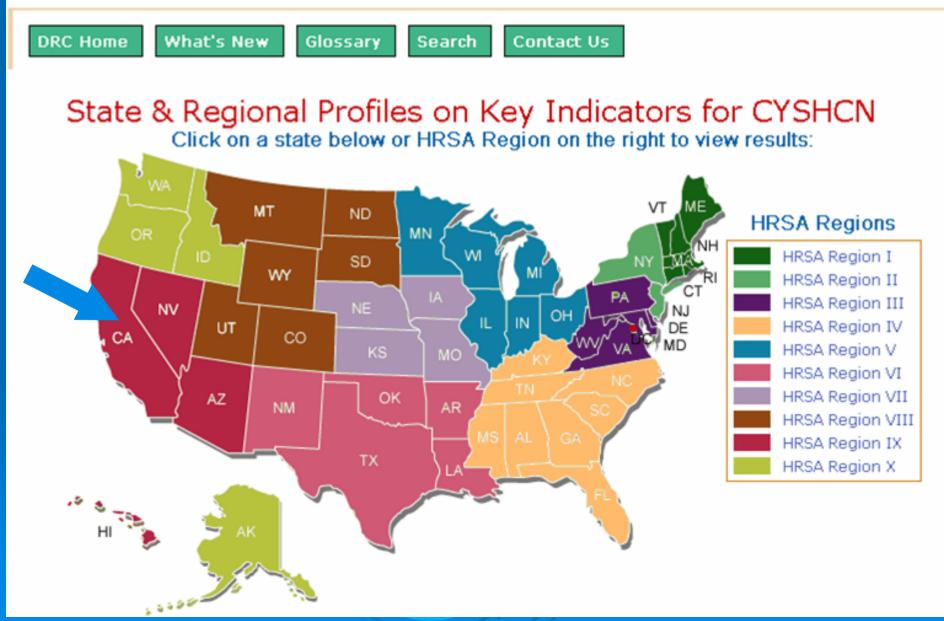
CLICK HERE

- CSHCN Survey Home Start Data Query
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National Survey of Children with Special Health Care Needs Data Resource Center — Your Data... Your story



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

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

Children ages 0-17 years old

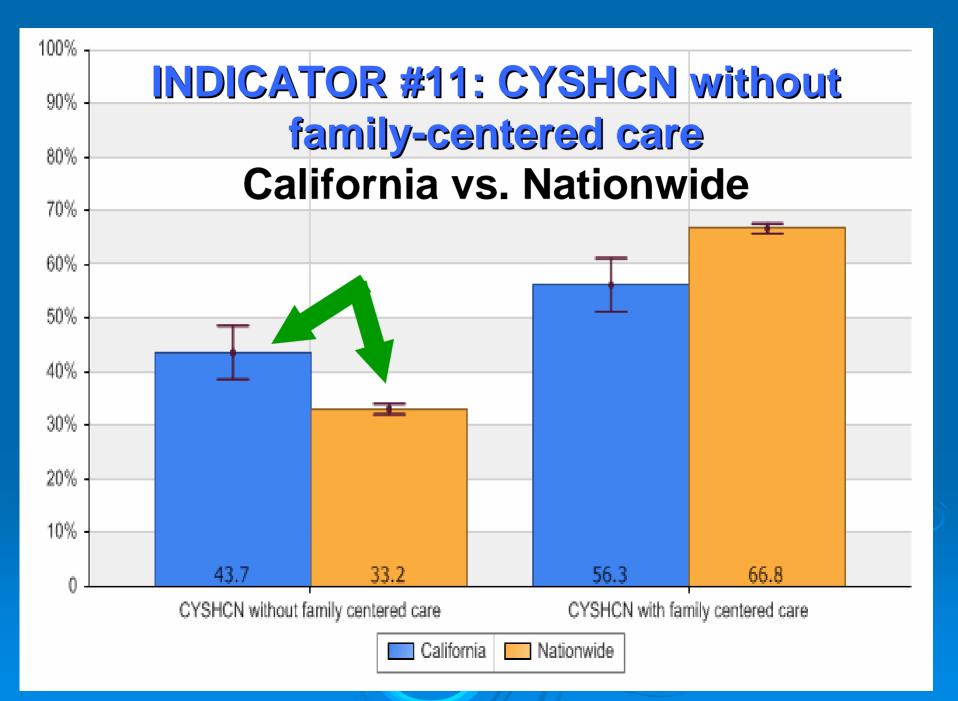
### Prevalence Statistics

Child-Level Prevalence:	State %	Nation %	
Percentage of Children & Youth with Special Heatth Care Needs, 0 - 17 yrs old	10.3	12.8	
Household-Level Prevale	ence:		
Percentage of Households with Children that have one or more CYSHCN, 0 - 17 yrs old	17.0	20.0	
Prevalence by Age:			
Children <b>0-5</b> years of age	5.7	7.8	
Children 6-11 years of age	11.2	14.6	
Children 12-17 years of age	14.0	15.8	
Prevalence by Sex:			
Female	8.3	10.5	
Male	12.3	15.0	
Prevalence by Poverty L	evel:		
0% - 99% FPL	7.5	13.6	
100% - 199% FPL	9.7	13.6	
200% - 399% FPL	11.0	12.8	
400% FPL or greater	13.8	13.6	
Prevalence by Race/Ethr	nicity:		
Hispanic	7.6	8.5	

### Indicator

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

<ol> <li>% of CYSHCN needing specialty care who had problems getting a referral.</li> </ol>	27.3	21.9	
9) % of CYSHCN without a usual source of care (or who rely on the emergency room).	9.5	9.3	
<ol> <li>% of CYSHCN without a personal doctor or nurse.</li> </ol>	13.2	11.0	
Family-Centered Care:			
11) CYSHCN without family- centered are.	43.7	33.2	
Impact on Family:			
<ol> <li>% of CYSHCN whose families pay \$1,000 or more in medical expenses per year.</li> </ol>	11.8	11.2	
13) % of CYSHCN whose families	19.2	20.9	





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### NSCH Survey Home

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OR

# Data Resource Center — Your Data... Your story

DRC Home Link to Us

Glossary

Search Contact Us

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

To begin an interactive deta search:

Select a starting point from the list below

- O Child Health Measures (Content Map) Over 60 indicators of child health and well-being
- O State Profile (Content Map) Compare State Profile results for different groups of children

### • Healthy People 2010 (Content Map) Survey content pertaining to Healthy People 2010 goals

### **Survey Sections** (Content Map)

Responses to questions asked in each section of the survey

Enter a word, phrase or topic to look for:

Find: 
 All the words 
 Any of the words 
 Exact phrase

	Examples of available		
2. Select a Topic	information	Select	
Physical and Dental He	0		
Emotional and Mental Health		C	
Health Insurance Coverage		0	
Health Care Access and Quality		С	
Community and School Activities		0	
Family Health and Activities		С	
Neighborhood Safety and Support		O	



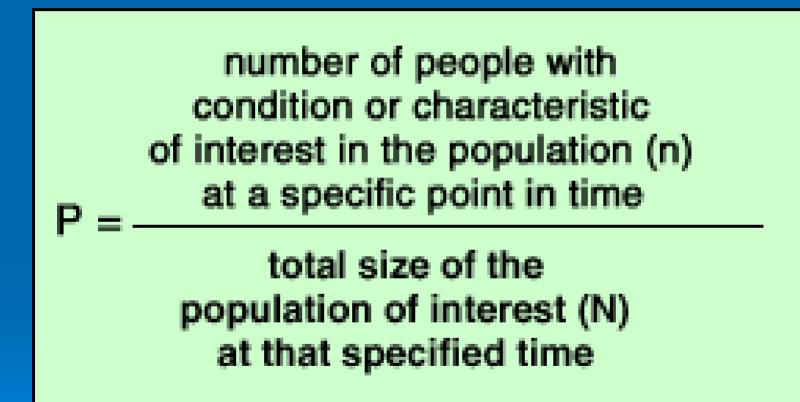
## > Prevalence

## > Weighted estimate



> 95% Confidence interval

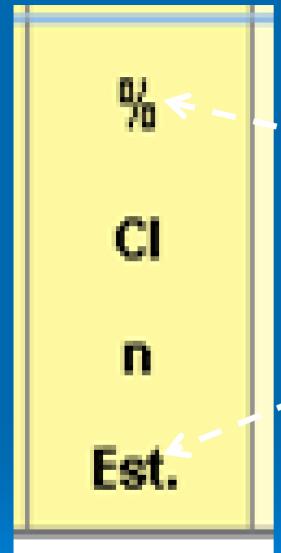
## **Prevalence:**



From: http://apps.nccd.cdc.gov/brfssdatasystems/prevalence.asp

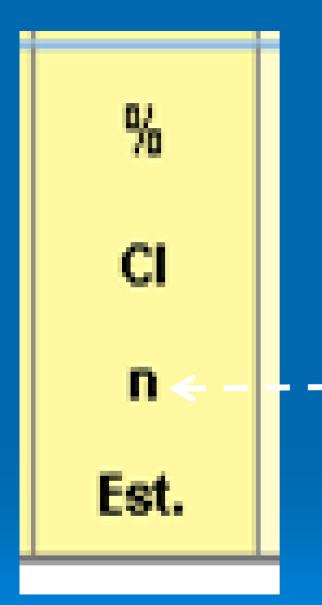
Question: How many hours per week do families of CYSHCN spend providin health care? [derived from C9q03 and C9q04]

	$\frown$	Less than 1 hour	1 - 4 hours per week	5 - 10 hours p
Functional limitations	%	24.2	33.6	14.2
	СІ	(22.5 - 25.8)	(31.6 - 35.5)	(12.9 - 15
	n	2,025	2,593	1,131
	Est.	456,672	634,256	269,13
Managed by Rx meds	<b>%</b> 6	58.7	29.6	5.4
	СІ	(57.3 - 60.2)	(28.2 - 30.9)	(4.8 - 6.
	n	8,727	4,132	728
	Est.	1,957,891	986,373	179,24
Above routine need/use of services	%	42.6	35.9	10.0



## Weighted prevalence estimate

Estimated number or % of people with the characteristic or response of interest after adjusting (weighting) to represent total population in the sampled area.



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

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

# 95% Confidence Interval

- Provides information about the precision of the prevalence estimate
- Width of CI influenced by sample size

   Generally: the larger the sample, the smaller width of the CI -- and the more precise the prevalence estimate.

# Making Data Useful?



## Select data facts that:

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



- Find positive stats to show progress
- Use personal stories to illustrate data
- Be consistent !!!
- Less is often "MORE"

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

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State Data Sets

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### Data in Action

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

### Massachusetts Mom Storms the State House

Carrie Howland included data from the Data Resource Center in a presentation at the National Respite Coalition event in Washington DC, in support of the National Lifespan Respite Care Act.

### Alaska's Covering Kids Coalition Meeting

Presented by Barbara Hale October 4, 2005

Massachusetts Office of Medicaid: Helping Families of Children with Special Health Care Needs Get Back to Work. A Cost Neutral Approach to Family Empowerment 2006

### Save the CDRC

Dr. Brian Rogers used state-by-state comparisons from the National Survey of Children with Special Health Care Needs in is preparation for a legislative hearing on proposed budget cuts to the Child Development and Rehabilitation Center (CDRC).

### Family Voices Leader in North Dakota

Donene Feist, a parent activist, understands the power of data to support and strengthen the stories parents and caregivers have to tell about the challenges of caring for children with special needs.

### Racial/Ethnic Disparities in Adolescent and Young Adult Health

The Center for Applied Research and Technical Assistance (CARTA) used data from the DRC in a report on racial/ethnic disparities in adolescent and young adult health.

### Substance abuse treatment duration for Medicaid versus commercial clients in an HMO

Presented by Frances Lynch February 14th, 2006

### Children's Health, The Nation's Wealth: Assessing and Improving Child Health

The National Academies of Science used data from the National Survey of Children's Health in a report that offers a new framework for the health measurement of children.

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

Chartbooks, Presentations, and Publications related to the National Survey of Children with Special Health Care Needs

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USER POLL

ANSWER OUR BRIEF

YOUR BRIEFCASE

Especially for Families

Ational Survey of Children with Special Health Care Needs Data Resource Center — Your Data... Your story

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### Tell Us What You Think

1. How easy was it for you to find what you needed from the Data Resource Center website? (check one)

Very easy
 Easy
 Somewhat easy
 Not easy, but I was able to find what I needed
 Did not find what I needed (if you would like assistance, please provide your e-mail address in the comment box at the bottom of this page and we will contact you)

2. How do you plan to use information from this website? (check all that apply)

- Research
- Policy
- Presentation
- Paper/Document I am writing
- To educate self or others
- Other (please describe in the comment box at the bottom of this page)

3. How likely are you to visit the Data Resource Center website again? (check one)

Very likely
 Likely
 Somewhat likely
 Not likely at all
 Don't know





# General Questions or Inquiries cahmi@ohsu.edu

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