Maximizing the Use of National Survey Data on Child Health





www.childhealthdata.org

Presented by: Debra Read, MPH



Your Data....Your Story! What did you learn about child health today?

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Your Data... Your story

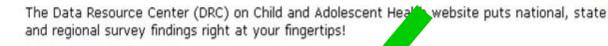


Data Resource Center for Child & Adolescent Health





- Ask a Question
- Tell a Friend
- Sign Up for E-Updates
- Link To Us
- Answer Our Brief User Poll
- NSCH Survey
- NS-CSHCN Survey
- AWSTATS



Start HERE!-click on a survey to begin

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



- Search and compare results on over 60 indicators of child health and well-being.
- View state and regional profiles on key measures.
- Explore survey content relevant to Healthy People 2010 objectives.
- Compare findings at every level for children from different age, race, income, or health status groups.

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

- Search and compare national, state and regional prevalence estimates of children and youth with special health care needs (CYSHCN).
- Find national, state and regional results on key indicators of health and system
 performance and MCHB outcomes for CYSHCN.
- Compare findings for CYSHCN from different age, race, income, or health status groups.

What you'll find:

- Interactive data search tools
- Personalized technical help by email or phone
- Information and examples to help you use data more effectively



Data Resource Center Development / Sponsorship

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



Data Resource Center Features

- Learn about the surveys
- Search and compare national, state, and regional survey results and over 100 child indicators for subgroups of children (age, race, sex, income, insurance and health status, etc.)
- Get resources and ideas on how to report your findings in a valid and effective manner
- Get expert help by e-mailing us your questions, plus get links to other data sets and resources



Data Resource Center Goals

•Provide a high-quality, **publicly accessible and easy to use** webbased resource that allows for **tailored and interactive** state and population subgroup level data searches

•Eliminate barriers faced by policy, program, provider, and advocacy audiences in obtaining information in a real time and user-friendly manner

•Advance evidence-based policy, program development, and advocacy on behalf of children, youth and families

•Build data literacy and the valid use of child health indicators

•Promote integration in the development of national surveys and excellence in the construction and interpretation of child health indicators



Today's Presentation

GOAL: Gain familiarity with the key aspects of the National Survey of CSHCN and National Survey of Children's Health

- Overview of each survey's content & features
- Comparison of similarities and differences
- Status of 2005 NS-CSHCN and next cycle of NSCH
- Things to keep in mind when using these data

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Data Resource Center

for Child & Adolescent Health

www.cshcndata.org

N ational Survey of Children with Special Health Care Needs, 2001

www.nschdata.org



National Survey of Children's Health, 2003

Two Surveys – what do they have in common?

- 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> state, and <u>nationally</u>

What is SLAITS?

- Uses National Immunization Survey sampling frame (which screens for households with children but only samples those w/ children ages 19-35 mos)
- Random Digit Dial telephone design
- Standardized questions produce comparative data across States & for the Nation
- Accommodates modules of customized questions and specific domains of interest
- Estimates are adjusted for non-coverage of HH's without telephones

SLAITS Modules National Survey of Early Childhood Health National sample, 1998-99 • National Asthma Survey National sample + 4 State samples, 2003 National Survey of Children's Health National & State samples, 2003-04 National Survey of Children with Special **Health Care Needs** • National & State samples, 2000-01 & 2005-06 Currently in field, 2005-06 data collection



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
- Being repeated in 2005-06 with some revisions & additional items on functional difficulties and conditions
- Public release data expected Spring 2007



National Survey of CSHCN

372,174 children, 0 - 17 yrs, in the 196,888 households contacted screened for having special health care needs

NO special health care needs (323,484 children/youth)

YES special health

care needs (48,690 children/youth)

From this group, 750 CYSHCN selected in EACH state for the longer CSHCN interview

38,866 CSHCN interviews completed



Nat. Survey of CSHCN uses the MCHB definition as starting point for identification:

"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

CSHCN Screener



Asks about 5 different health consequences:

- 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 CSHCN Denominator #1 Households w/ children

372,174 children, 0 - 17 yrs, in

Denominator #2 Child population, ages 0-17

NO special health care needs (323,484 children/youth)

YES special health care needs (48,690 children/youth)

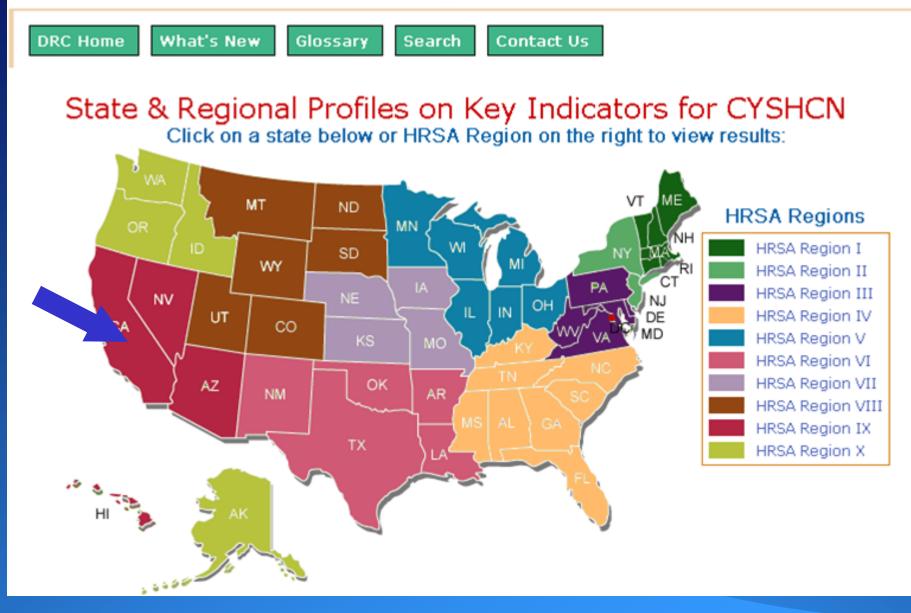
Denominator #3 CSHCN population, ages 0-17 From this group, 750 CYSHCN selected in EACH state for the longer CSHCN interview

38,866 CSHCN interviews completed

In-depth CSHCN interview collects information on:

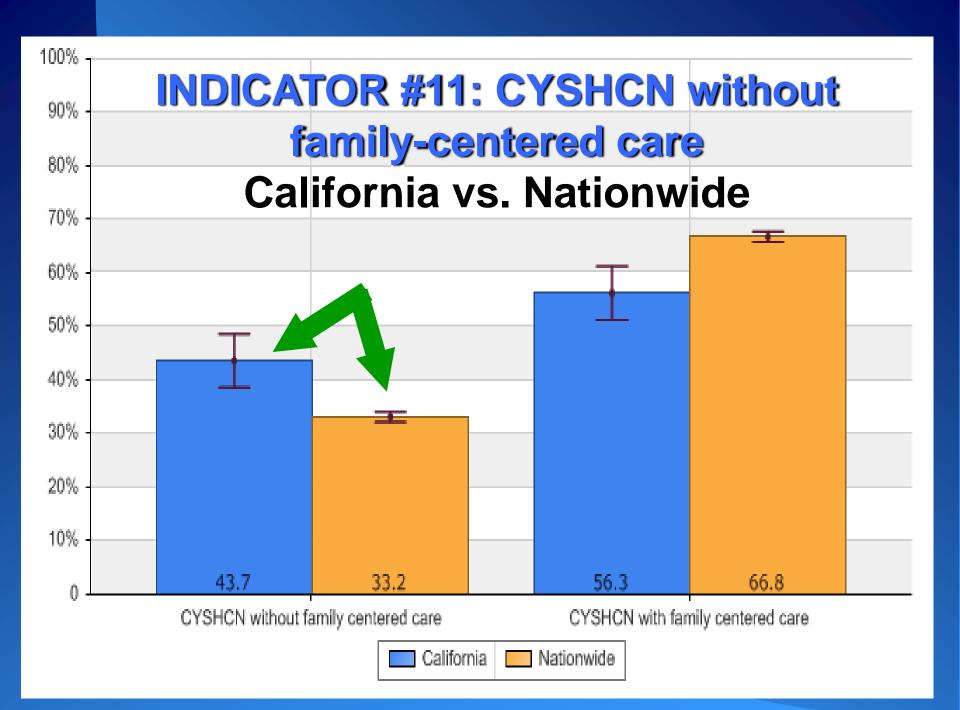
- Child health and functional status
- Child health insurance status and adequacy of coverage
- <u>Access to health care</u> needed services & unmet needs
- <u>Care coordination</u>
- Impact of child's health on family
- MCHB core outcomes for CYSHCN and
- Key indicators of CSHCN health & system performance

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



Califor ia Children age -17 year Prevalence Statistics	s old		Indicato,	a t	<u>Close</u>
Child-Level Prevalence:	State %	Nation %	Child Health:	State %	Nation %
Percentage of Children & Youth with Special Health Care Needs, 0 - 17 yrs old	10.3	12.8	 % of CYSHCN whose health conditions consistently and often greatly affect their daily activities. 	24.0	23.2
Household-Level Prevale	ence:		 % of CYSHCN with 11 or more days of school absences due to illness. 	16.2	15.8
Percentage of Households with Children that have one or more	17.0	20.0	Health Insurance Coverage:		
CYSHCN, 0 - 17 yrs old Prevalence by Age:			 % of CYSHCN without insurance at some point during the past year. 	9.9	11.6
Children 0-5 years of age	5.7	7.8	4) % of CYSHCN currently uninsured.	4.3	5.2
Children 6-11 years of age	11.2	14.6	5) % of currently insured CYSHCN with	36.5	33.8
Children 12-17 years of age	14.0	15.8	coverage that is not adequate.		
Prevalence by Sex:			Access to Care:		
Female	8.3	10.5	 % of CYSHCN with 1 or more unmet needs for specific health care services. 	23.1	17.7
Male	12.3	15.0	7b) % of CYSHCN whose families	25.1	23.1
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	21.9
200% - 399% FPL	11.0	12.8	who had problems getting a referral.		
400% FPL or greater	13.8	13.6	 % of CYSHCN without a usual source of care (or who rely on the emergency 	9.5	9.3
Prevalence by Race/Ethr	nicity:		room).		
Hispanic	7.6	8.5	10) % of CYSHCN without a personal	13.2	11.0

 % of CYSHCN needing specialty care who had problems getting a referral. 	27.3	21.9
 % of CYSHCN without a usual source of care (or who rely on the emergency room). 	9.5	9.3
 % of CYSHCN without a personal 	13.2	11.0
doctor or nurse.		
Vily-Centered Care:		
11) CYSHCN without family- centered care.	43.7	33.2
Centered Cate		
contorea care.		
Impact on Family:		
Impact on Family:	11.8	11.2
Impact on Family: 12) % of CYSHCN whose families pay	11.8	11.2
Impact on Family:	11.8	11.2
Impact on Family: 12) % of CYSHCN whose families pay \$1,000 or more in medical expenses per	11.8	11.2





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

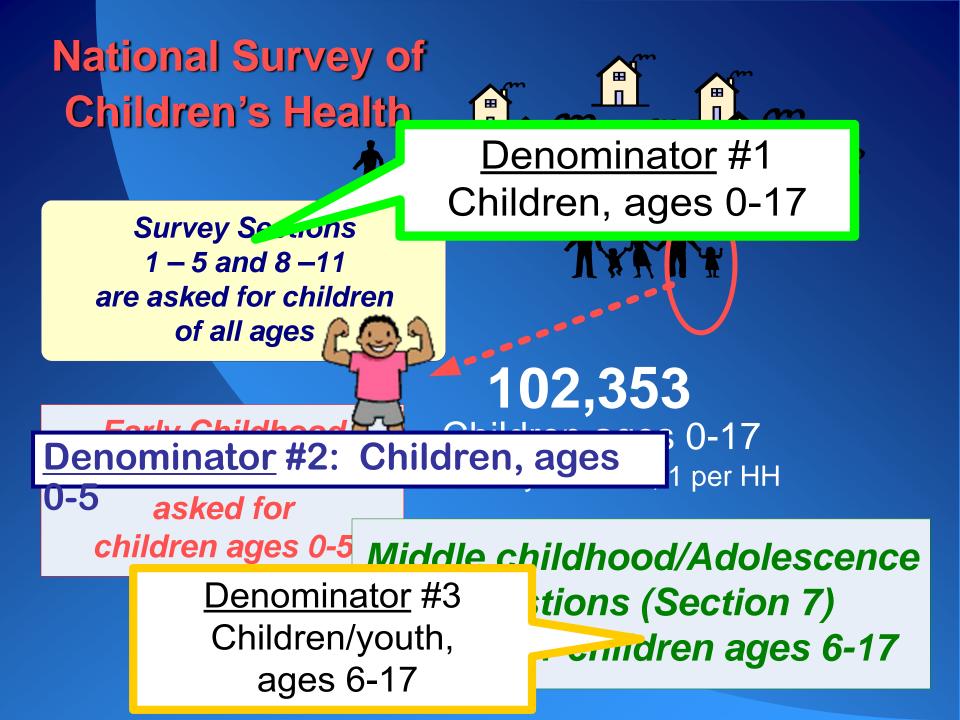
Questions?

Examples of use?



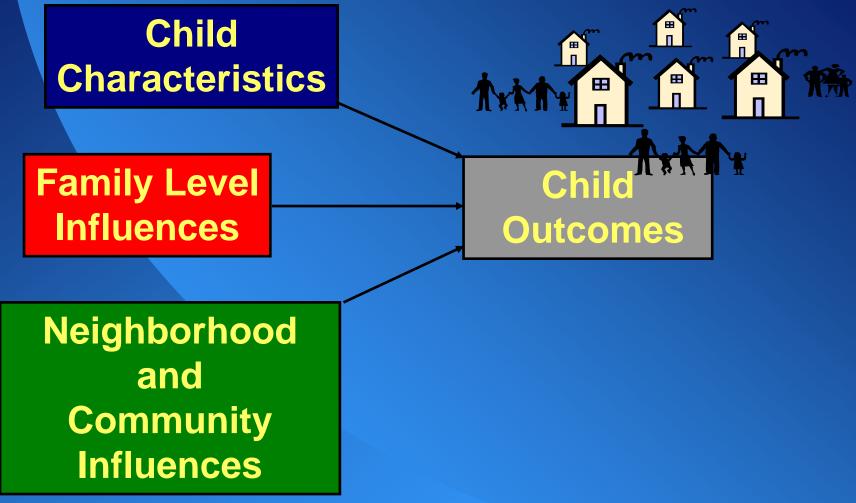
National Survey of Children's Health

- Conducted for the first time during 2003 2004
- 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





NSCH Survey Domains





Survey yields over 100 indicators of child health & wellbeing in the following areas:

- Child's <u>health status</u>: physical, emotional, dental
- Child's <u>health care</u> 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)
- <u>School-age</u> (ages 6-17)

National Survey of Children's Health

Data Resource Center — Your Data... Your story

1. Learn about the survey 2. Start data query-Search the data 3. Report your results STFF 2: Start data dery-Search the data

^C Child Health Measures

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

○ State Profile ²

Compare results from the State Profile pages for children of different ages, race/ethnicity groups, and merce

○ Healthy People 2010⁴

Query the survey content and child health indicators pertaining to Healthy People 2010

^C Survey Sections

Search and compare results for the questions asked in each section of the survey

2. Select a Topic	Select
Physical and Dental Health	0
Emotional and Mental Health Topics to s	
Health Insurance Coverage	- O
Health Care Access and Quality Health Mea	
Community and School Activities	0
Family Health and Activities	0
Neighborhood Safety and Support	0

Examples of available	
2. Select a Topic information	Select
Physical and Dental Health Getting needed preventive dental care	e 0
Emotional and Mental Health	0
Health Insurance Coverage	0
Health Care Access and Quality	0
Community and School Activities	O
Family Health and Activities	0
Neighborhood Safety and Support	O



<u>Print</u> <u>Close</u>

Indicator 4.2: Getting needed preventive dental care

<u>Survey Item(s)</u> :	Derived from: 54Q10 and 54Q13
<u>Denominator</u> :	Children ages 1 -17 years whose parents report that child needed routine preventive dental care during past 12 months (S4209 = Yes) OR (S421C = Yes)
<u>Numerator(s</u>):	Children ages 1-17 whose parents report that child needed rcutine preventive dental care AND did not get all care that was reeded (S4Q10 = Yes) DR (S4Q13 = No)

ADDITIONAL NOTES:

nevada

Routine preventive dental care includes check-ups, screenings, and sealants. About 25% of children/youth ages 1-17 did not need routine preventive dental care during the past 12 months -- this group is not included in the denominator for this indicator.

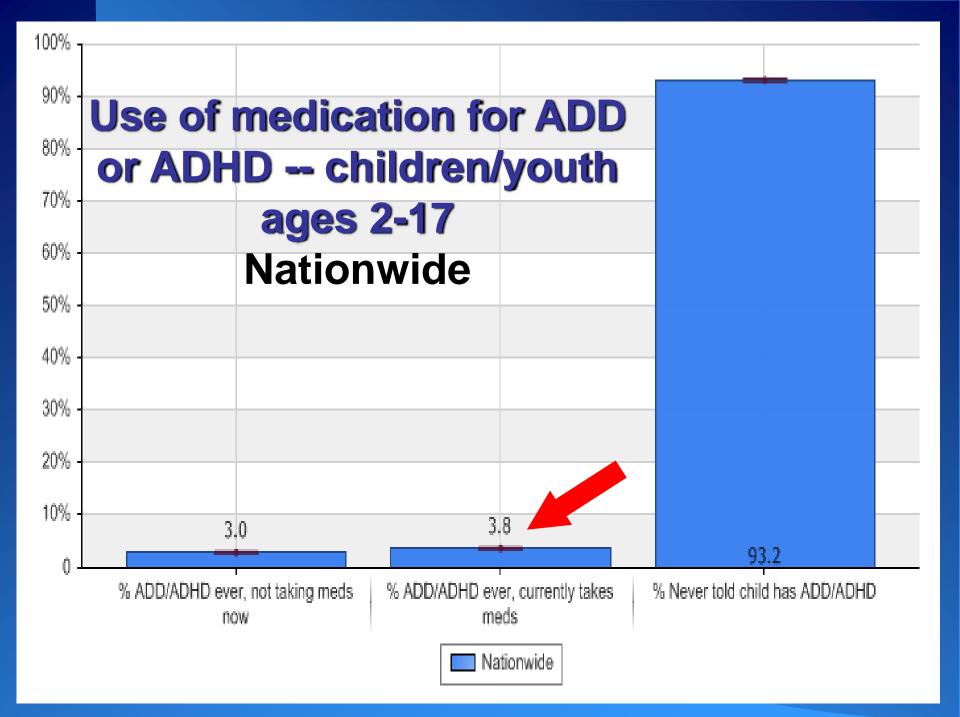
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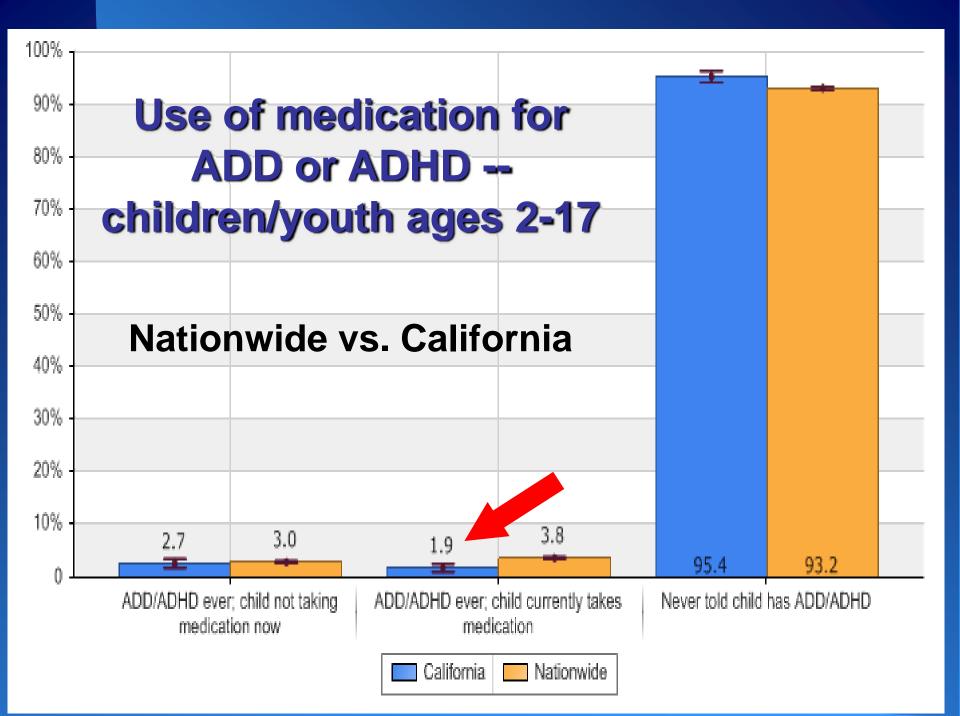
17) with a need for os, screenings and ? <u>(derived)</u>

ded care %	Total %
<u>sueu care 70</u>	TULAL 70
7.7	100.0
7.1	100.0
6.9	100.0
6.6	100.0
6.3	100.0
5.9	100.0
57	100.0

0.4	100.0
0.2	100.0
0.1	100.0
9.7	100.0
9.3	100.0
8.4	100.0

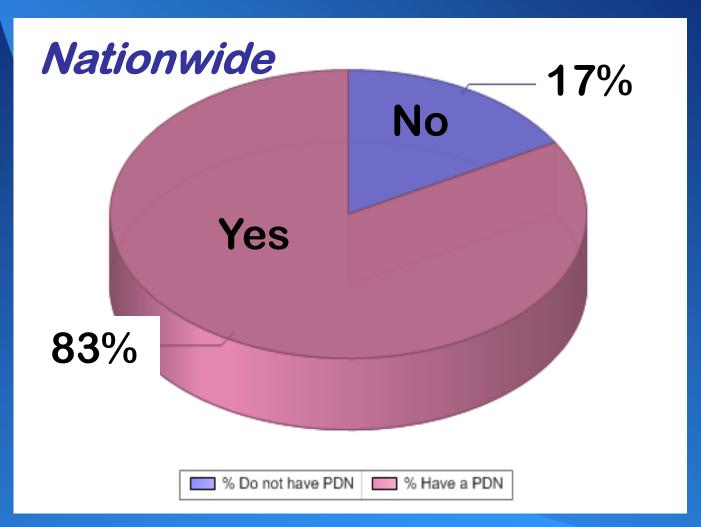
Examples	s of available	
•	rmation	Select
i unucical and liontal Moairn	needed preventive dental care	0
	ly using medicatio or ADHD/ADD	n 0
Health Insurance Coverage		0
Health Care Access and Quality		0
Community and School Activities		C
Family Health and Activities		0
Neighborhood Safety and Support		0

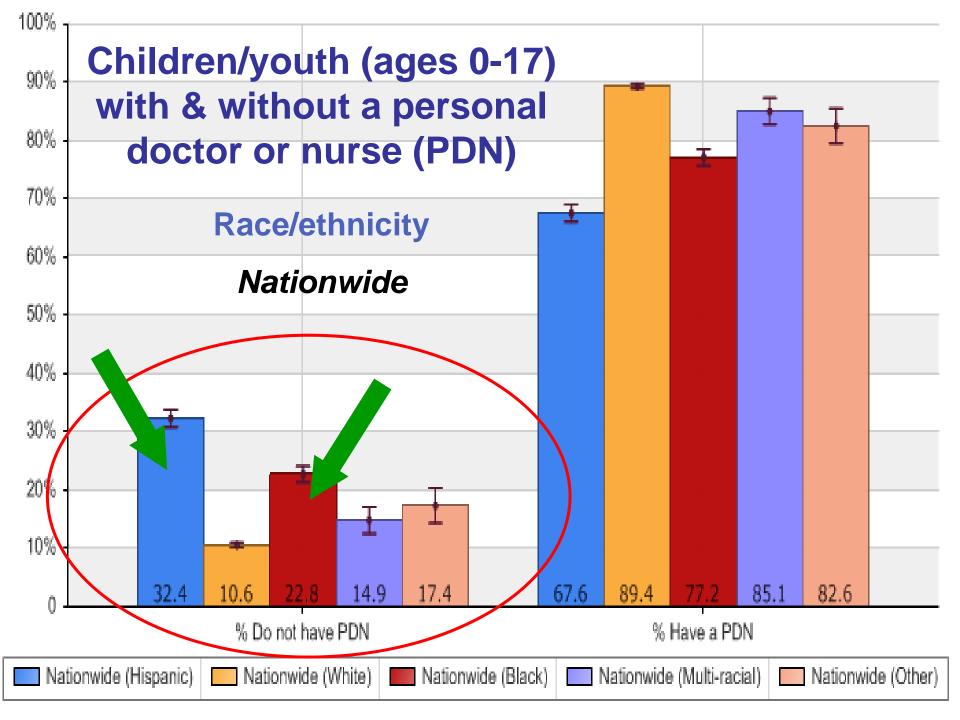




Examples of available	
2. Select a Topic information	Select
Physical and Dental Health Getting needed preven dental Care	tive o
Emotional and Mental Health Currently using medica	tion ⁰
for ADHD/ADD Health Insurance Coverage	0
Health Care Access and Quality Child has a personal nurse (primary care primary car	v.
Community and School Activities	0
Family Health and Activities	C
Neighborhood Safety and Support	C

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)





Race/ethnicity data

1. Hispanic

- 2. White, non-Hispanic
- **3.** Black, non-Hispanic
- 4. Multi race, non-Hispanic
- 5. Other:
 - Asian
 - Native American; Native Alaskan
 - Native Hawaiian

Race/ethnicity data

National Center for Health Statistics <u>only</u> releases data when minority grp makes up least 5% of child population State:

Asian

- 5 states (CA, NJ, NY, WA, HI)
- Native American; Native Alaskan
 - 7 states (AK, AZ, MT, NM, ND, OK, SD)
- Native Hawaiian; Pacific Islander
 - 1 state (HI)

National Survey of Children's Health

Data Resource Center — Your Data... Your story



- FAST FACTS about the National Survey of Children's Health (PDF) Who sponsors the survey? What areas of child health and well-being are addressed? How many surveys were collected? Quick answers to these and other questions.
- Sampling and Administration Process (PDF)
 One-page diagram summarizing the sampling and administration steps or the National Survey of Children's Health.

Guide to Topics and Questions Asked (PDF)
 Summary of the provisions asked in each section of the National Survey of Children's Health – very helpful for
 navigating the provision of the survey instrument.

- National Survey of Children's Health Full Length Instrument (PDF) Download the 65-page Computer Assisted Telephone Interview (CATI) version of the Conal Survey of Children's Health.
- Design and Operation of the National Survey of Children's Health, 2003 (PDF) Technical report authored by CDC staff describes the methodological details of the survey's sampling and data collection procedures.
- National Center for Health Statistics (NCHS)

NCHS conducted the National Survey of Children's Health. This link takes users to the NCHS website for additional information about the survey, including downloadable SAS input files of the survey data.



National Survey of Children's Health

Questions?

Examples of use?

How do the surveys differ?

- Population: CSHCN versus all children 0-17
- How subject of the interview is identified: Randomly selected a CSHCN after screening all children in household versus randomly selected one child in each household and then asked CSHCN screening questions

How do the surveys differ?

 Topic areas: CSHCN-specific versus inclusion of family, neighborhood, and wellness information

 <u>CSHCN sample size</u>: 750 per state for NS-CSHCN vs. about 300 per state for NSCH

How do the surveys differ?

<u>NS-CSHCN:</u>

All <u>CSHCN ages 0-17</u> in a state are the **GROUP** the question results pertain to

<u>NSCH:</u>

All children ages 0-17 in a state are the GROUP the question results pertain to

 SELECT "<u>SPECIAL HEALTH CARE NEEDS</u> <u>STATUS</u>" from the COMPARE SUBGROUPS menu to view results for CSHCN.

Other key considerations:

- 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 . . .
- To calculate prevalence, use correct weighting variable – esp. important detail for NS-CSHCN because there are the 3 different denominators each have their own weighting variable

Other key considerations:

- In order to make statistical comparisons, analysis software that adjusts variances for complex survey design must be used (e.g. SUDAAN, STATA, SPSS complex samples)
- Each state's data can be analyzed separately but do not subset data within a state or nationally unless using SUB POP options that account for complex survey design
- The approaches to dealing with "unknown responses" (DON'T KNOW or REFUSE) vary ---- be sure to consider this issue when reporting estimates that involve population counts (% point estimates are generally not affected)

REMEMBER:

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

Kristin Grimm, Spitfire Strategies



To Get Help or More Information:

Go to "Ask a Question" at www.childhealthdata.org, www.cshcndata.org or www.nschdata.org

Download raw datasets and methods reports at: <u>www.cdc.gov/nchs</u>

