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?
The Data Resource Center (DRC) on Child and Adolescent Health website puts national, state and regional survey findings right at your fingertips!

**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.
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** web-based 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
Two Surveys – what do they have in common?

• Sponsored by the Maternal and Child Health Bureau

• Use SLAITS (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 non-institutionalized child population ages 0-17 in each state, and nationally
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.
“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:

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 CSHCN

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

- **Denominator #1**
  - Households w/ children

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

## California

Children age 0-17 years old

### Prevalence Statistics

<table>
<thead>
<tr>
<th>Child-Level Prevalence:</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of Children &amp; Youth with Special Health Care Needs, 0 - 17 yrs old</td>
<td>10.3</td>
<td>12.8</td>
</tr>
</tbody>
</table>

**Household-Level Prevalence:**

<table>
<thead>
<tr>
<th>Household-Level Prevalence:</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of Households with Children that have one or more CYSHCN, 0 - 17 yrs old</td>
<td>17.0</td>
<td>20.0</td>
</tr>
</tbody>
</table>

**Prevalence by Age:**

<table>
<thead>
<tr>
<th>Prevalence by Age:</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children 0-5 years of age</td>
<td>5.7</td>
<td>7.8</td>
</tr>
<tr>
<td>Children 6-11 years of age</td>
<td>11.2</td>
<td>14.6</td>
</tr>
<tr>
<td>Children 12-17 years of age</td>
<td>14.0</td>
<td>15.8</td>
</tr>
</tbody>
</table>

**Prevalence by Sex:**

<table>
<thead>
<tr>
<th>Prevalence by Sex:</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>8.3</td>
<td>10.5</td>
</tr>
<tr>
<td>Male</td>
<td>12.3</td>
<td>15.0</td>
</tr>
</tbody>
</table>

**Prevalence by Poverty Level:**

<table>
<thead>
<tr>
<th>Prevalence by Poverty Level:</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>0% - 99% FPL</td>
<td>7.5</td>
<td>13.6</td>
</tr>
<tr>
<td>100% - 199% FPL</td>
<td>9.7</td>
<td>13.6</td>
</tr>
<tr>
<td>200% - 399% FPL</td>
<td>11.0</td>
<td>12.8</td>
</tr>
<tr>
<td>400% FPL or greater</td>
<td>13.8</td>
<td>13.6</td>
</tr>
</tbody>
</table>

**Prevalence by Race/Ethnicity:**

<table>
<thead>
<tr>
<th>Prevalence by Race/Ethnicity:</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic</td>
<td>7.6</td>
<td>8.5</td>
</tr>
</tbody>
</table>

### Indicators

**Child Health:**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) % of CYSHCN whose health conditions consistently and often greatly affect their daily activities.</td>
<td>24.0</td>
<td>23.2</td>
</tr>
<tr>
<td>2) % of CYSHCN with 11 or more days of school absences due to illness.</td>
<td>16.2</td>
<td>15.8</td>
</tr>
</tbody>
</table>

**Health Insurance Coverage:**

<table>
<thead>
<tr>
<th>Health Insurance Coverage:</th>
<th>State %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>3) % of CYSHCN without insurance at some point during the past year.</td>
<td>9.9</td>
<td>11.6</td>
</tr>
<tr>
<td>4) % of CYSHCN currently uninsured.</td>
<td>4.3</td>
<td>5.2</td>
</tr>
<tr>
<td>5) % of currently insured CYSHCN with coverage that is not adequate.</td>
<td>36.5</td>
<td>33.8</td>
</tr>
</tbody>
</table>

**Access to Care:**

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

9) % of CYSHCN without a usual source of care (or who rely on the emergency room).  
   9.5  9.3

10) % of CYSHCN without a personal doctor or nurse.  
    13.2  11.0

**Family-Centered Care:**

11) % of CYSHCN without family-centered care.  
    43.7  33.2

**Impact on Family:**

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

13) % of CYSHCN whose families  
    19.2  20.9
INDICATOR #11: CYSHCN without family-centered care

California vs. Nationwide
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
Survey Sections 1 – 5 and 8 – 11 are asked for children of all ages.

Denominator #1: Children, ages 0-17

102,353 Children ages 0-17 randomly selected, 1 per HH

Denominator #2: Children, ages 0-5 asked for children ages 0-5

Denominator #3: Children/youth, ages 6-17
NSCH Survey Domains

- Child Characteristics
- Family Level Influences
- Neighborhood and Community Influences
- Child Outcomes
Survey yields over 100 indicators of child health & well-being in the following areas:

- Child’s **health status**: physical, emotional, dental
- Child’s **health care** – including medical home
- Child’s **school & activities**
- Child’s **family & neighborhood** -- including maternal health status
- **Early childhood** (ages 0-5)
- **School-age** (ages 6-17)
STEP 2: Start data query — Search the data

- **Child Health Measures**
  Over 60 indicators of child health and well-being derived from the survey

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

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

- **Survey Sections**
  Search and compare results for the questions asked in each section of the survey
## Topics to search under NSCH Child Health Measures

<table>
<thead>
<tr>
<th>Topic</th>
<th>Select</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical and Dental Health</td>
<td></td>
</tr>
<tr>
<td>Emotional and Mental Health</td>
<td></td>
</tr>
<tr>
<td>Health Insurance Coverage</td>
<td></td>
</tr>
<tr>
<td>Health Care Access and Quality</td>
<td></td>
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<tr>
<td>Community and School Activities</td>
<td></td>
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<tr>
<td>Family Health and Activities</td>
<td></td>
</tr>
<tr>
<td>Neighborhood Safety and Support</td>
<td></td>
</tr>
</tbody>
</table>
Examples of available information

<table>
<thead>
<tr>
<th>2. Select a Topic</th>
<th>Select</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical and Dental Health</td>
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</table>

Getting needed preventive dental care
### Indicator 4.2: Getting needed preventive dental care

<table>
<thead>
<tr>
<th>Survey Item(s):</th>
<th>Derived from: S4Q10 and S4Q13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denominator:</td>
<td>Children ages 1-17 years whose parents report that child needed routine preventive dental care during past 12 months (S4Q09 = Yes) OR (S4Q1C = Yes)</td>
</tr>
<tr>
<td>Numerator(s):</td>
<td>Children ages 1-17 whose parents report that child needed routine preventive dental care AND did not get all care that was needed (S4Q10 = Yes) OR (S4Q13 = No)</td>
</tr>
</tbody>
</table>

**ADDITIONAL NOTES:**
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.
<table>
<thead>
<tr>
<th>2. Select a Topic</th>
<th>Select</th>
</tr>
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<tbody>
<tr>
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</tr>
<tr>
<td>Neighborhood Safety and Support</td>
<td></td>
</tr>
</tbody>
</table>

**Examples of available information**

- Getting needed preventive dental care
- Currently using medication for ADHD/ADD
Use of medication for ADD or ADHD -- children/youth ages 2-17

Nationwide
Use of medication for ADD or ADHD -- children/youth ages 2-17

Nationwide vs. California
### Examples of available information

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<td></td>
</tr>
<tr>
<td>Getting needed preventive dental care</td>
<td></td>
</tr>
<tr>
<td>Currently using medication for ADHD/ADD</td>
<td></td>
</tr>
<tr>
<td>Child has a personal doctor or nurse (primary care provider)</td>
<td></td>
</tr>
</tbody>
</table>
**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)
Children/youth (ages 0-17) with & without a personal doctor or nurse (PDN)

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>% Do not have PDN</th>
<th>% Have a PDN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide (Hispanic)</td>
<td>32.4</td>
<td>67.6</td>
</tr>
<tr>
<td>Nationwide (White)</td>
<td>10.6</td>
<td>89.4</td>
</tr>
<tr>
<td>Nationwide (Black)</td>
<td>22.8</td>
<td>77.2</td>
</tr>
<tr>
<td>Nationwide (Multi-racial)</td>
<td>14.9</td>
<td>85.1</td>
</tr>
<tr>
<td>Nationwide (Other)</td>
<td>17.4</td>
<td>82.6</td>
</tr>
</tbody>
</table>
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 only 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)
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 for the National Survey of Children’s Health.

Guide to Topics and Questions Asked (PDF)
Summary of the questions asked in each section of the National Survey of Children’s Health – very helpful for navigating the full-length survey instrument.

National Survey of Children’s Health – Full Length Instrument (PDF)
Download the 65-page Computer Assisted Telephone Interview (CATI) version of the National 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.
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

- **CSHCN sample size**: 750 per state for NS-CSHCN vs. about 300 per state for NSCH
How do the surveys differ?

**NS-CSHCN:**
All **CSHCN ages 0-17** in a state are the **GROUP** the question results pertain to …..

**NSCH:**
All **children ages 0-17** in a state are the **GROUP** the question results pertain to …..

- SELECT “**SPECIAL HEALTH CARE NEEDS STATUS**” from the COMPARE SUBGROUPS menu to view results for CSHCN.
Other key considerations:

- The **denominator** for ALL results in both surveys is **always CHILDREN** -- never parents!
  - **Correct** -- % 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).
“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: www.cdc.gov/nchs