





Methodology and Design
of the National Survey of Children with
Special Health Care Needs, 2005-06

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Centers for Disease Control and Prevention
National Center for Health Statistics
SAFER • HEALTHIER • PEOPLE™

February 14, 2008
MCHCOM.COM Webcast

Locating and Identifying CSHCN

- Random digit dial telephone survey using independent random samples for all 50 states plus D.C.
- Screened households for children under 18 years of age
- Screened all children to identify children with special health care needs




Interview Process

- Asked detailed questionnaire for children with special health care needs
- One CSHCN randomly selected from households with multiple CSHCN
- Target was 750 CSHCN per state
- Calling and screening of households continued until we met the target in all states
- Data were collected from April 5, 2005 until February 5, 2007




Interview Process

- Respondent was a parent or guardian knowledgeable about the health of the child
 - 78% mother, 16% father, 4% grandparent
- Interview lasted about 28 minutes (mean)
- Interviews conducted in English, Spanish, Mandarin, Cantonese, Vietnamese, and Korean



Sample Size

- 364,841 children screened for special health care needs
 - Minimum: 5,605 in Delaware
 - Maximum: 11,275 in California
 - More than 7,000 in each of 25 states
- 40,840 completed interviews for CSHCN
 - Minimum: 741 in Alaska
 - Maximum: 939 in California
 - More than 800 in each of 22 states



Response Rates

- Overall response rate: 56.1%
 - Resolution rate = 82.7%
 - Age screener completion rate = 88.4%
 - Screener completion rate = 79.7%
 - Interview completion rate = 96.2%
- 21 states were above 60%
 - Minimum: 49.3% in New Jersey
 - Maximum: 68.3% in North Dakota



CSHCN Questionnaire

- Health and functional status
- Access to care, utilization, unmet need
- Medical home
- Satisfaction with care
- Health insurance and adequacy
- Impact on the family



Improved Content for 2005-06

- Functional status and common health conditions
- Receipt of and unmet need for care coordination
- Reasons why families had trouble using community based services
- Unmet need for anticipatory guidance about making transitions to adult health care



Performance Measure #5: Service Systems Organized for Ease of Use

- 2001
 - “Are those services organized in a way that makes them easy to use?”
 - 74.3% reported usually or always
- 2005 ~~2006~~
 - “Have you had any difficulties trying to use these services during the past 12 months?”
 - 89.1% reported “no”



Component of Performance Measure #3: Coordination and Communication

- 2001
 - "How well do you think that the child's doctors and other health care providers communicate with each other about child's care?"
 - 54.4% reported "excellent" or "very good"
- 2005 2006
 - "Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among child's doctors and other health care providers? "
 - 63.8% reported "very satisfied"



Component of Performance Measure #3: Personal Doctor or Nurse

- 2001
 - "Do you have one person you think of as child's personal doctor or nurse?"
 - 89.0% reported "yes"
- 2005 2006
 - "Do you have one or more persons you think of as child's personal doctor or nurse?"
 - 93.5% reported "yes"



Performance Measures with Little or No Change

- Families partner in decision making (#2)
- Usual place for sick care (component of #3)
- Family centered care (component of #3)
- Adequate health insurance (#4)



For more information...

- AMCHP Skills Building Session
 - C6 - MCHB/Division of State and Community Health Block Grant Training: Providing Data to Tell the MCH Story
 - Sunday, March 2, 1:00 PM - 4:30 PM
- Summary Tables from NS CSHCN
 - http://www.cdc.gov/nchs/data/slaits/Summary_tables_NSCSHCN_0506.pdf
 - <http://tinyurl.com/2BR9XQ>
- E mail: sblumberg@cdc.gov



National Survey of Children with Special Health Care Needs, 2005-2006

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 Health Resources and Services Administration (HRSA)
 Department of Health and Human Services

November 28, 2007



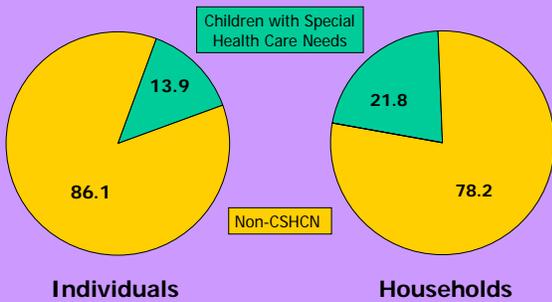
Purpose of the NS-CSHCN

- Measures and Tracks Prevalence of CSHCN
 - Nationally
 - By State
- Describes Demographic Characteristics
- Other Measures Include
 - Functional Limitations
 - Health Care Access
 - Needs and Satisfaction with Care
 - Burden and Impact on Family

Uses of the NS-CSHCN Data

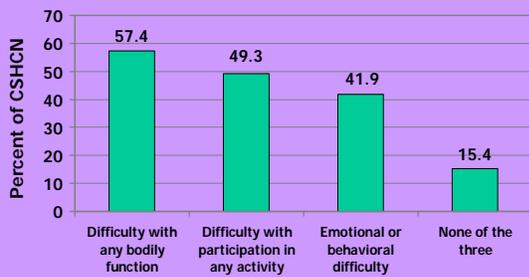
- Title V performance measures
- Measuring Healthy People 2010 objectives
- Planning and program development at the State level
- Compare changes since 2001 NS CSHCN
- Inform organizations that work directly with CSHCN
- Scientific research

Prevalence of CSHCN



Functional Difficulties

Types of Functional Difficulties Among CSHCN



Specific Health Care Needs

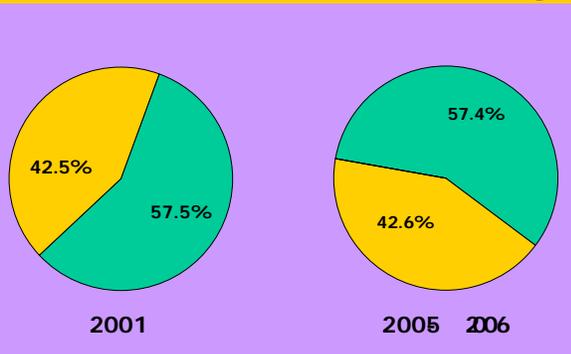
Percentage of CSHCN Needing Specific Health Services



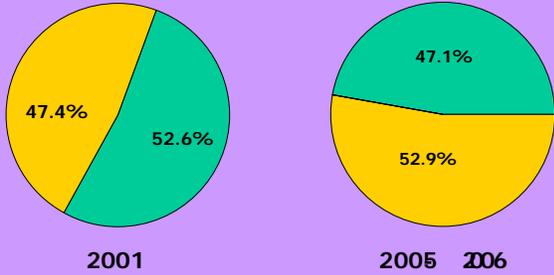
Comparability between Performance Measures in 2001 and 2005-2006

- PM 2: Partner in Decision-Making ■ Comparable
- PM 3: Medical Home ■ NOT comparable
- PM 4: Adequate Health Insurance ■ Comparable
- PM 5: Ease of Service Use ■ NOT comparable
- PM 6: Transition Planning ■ NOT comparable

Performance Measure 2: CSHCN'S Families Partner in Decision-Making

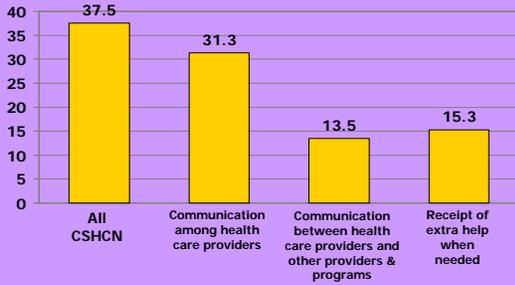


Performance Measure 3: CSHCN who have a Medical Home



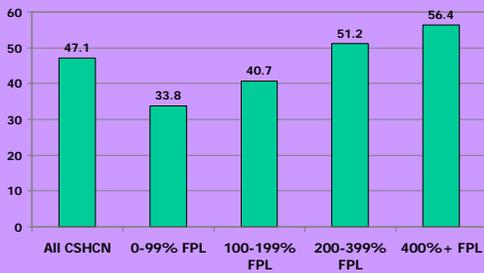
Care Coordination

Percentage of CSHCN Lacking One or More Elements of Care Coordination

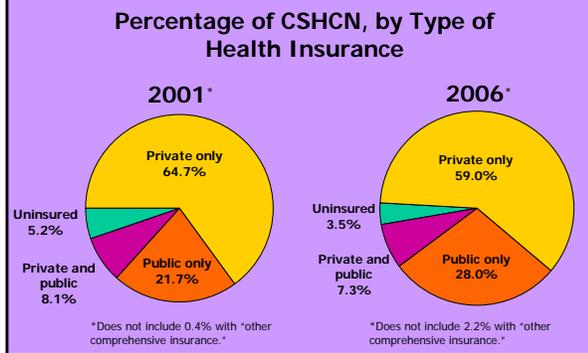


CSHCN in a Medical Home

Percentage of CSHCN Receiving Care Through a Medical Home, by Family Income



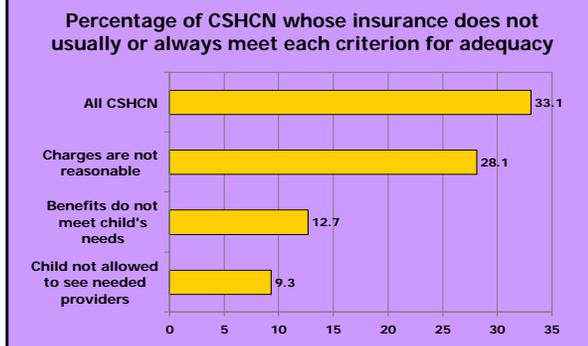
Health Insurance Coverage



Performance Measure 4: CSHCN with Adequate Health Insurance



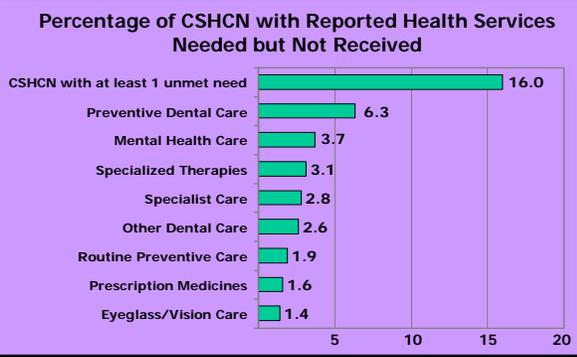
Adequacy of Health Insurance



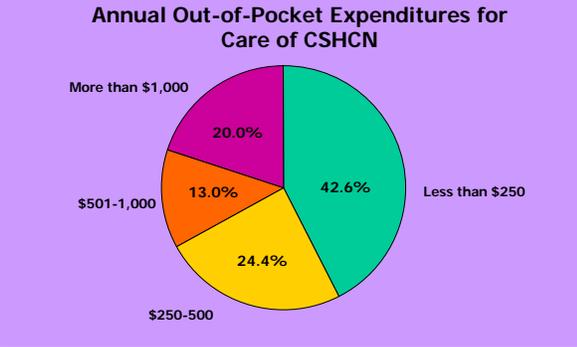
Performance Measure 5: Service Systems Organized for Ease of Use



Access to Care

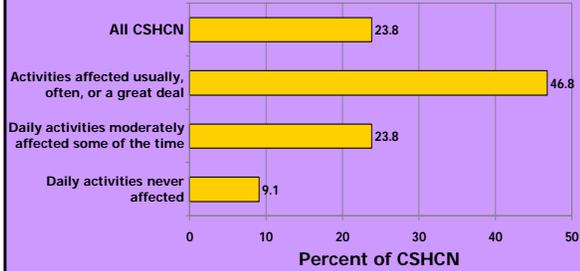


Financial Impact on the Family



Impact on Parent's Employment

CSHCN Whose Parents Cut Back on Work or Stopped Working to Care for the Child



NS-CSHCN Chartbook





The Data Resource Center for Child and Adolescent Health

www.childhealthdata.org

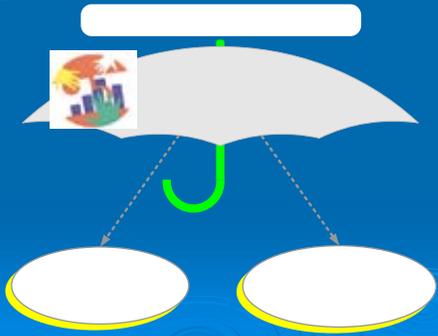
Christina Bethell, PhD, MPH, MBA
The Child and Adolescent Health Measurement Initiative (www.cahmi.org)



 **What are the Data Resource Center 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.

 **Available Datasets on the DRC**





What features are available?

- Learn about the surveys
- Search and compare national, state, and regional survey results 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



What other features are available?

- Download cleaned, labeled state-specific national survey datasets with pre-constructed indicators and additional variables (SAS & SPSS)
- Sign up for regular e-updates and “e-facts”
- Find out about and access the latest publications, reports & abstracts using the national survey data

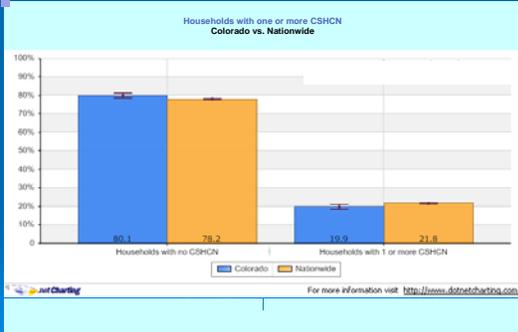


Three Types of User Generated Data Reports

- 1) State Profile Tables
- 2) Interactive “All States” Comparison/Ranking Tables
- 3) Interactive Graphs and Tables for Every Indicator



Example Data Findings





Data Findings To Look For

Outcome #1: Families partner in decision making and are satisfied with services

- **Variations Across States**
 - State Range: 46.6% (CA) to 65.7% (NE)
- **Variations Across Population Subgroups**
 - In Nebraska, Outcome #1 ranges from 46.2% for children < 100% of FPL to 72.6% for children > 400% of FPL.
- **Variations Across Years**
 - The < 100% to > 400% FPL disparity in Outcome #1 increased from 20.3% in 2001 to 26.4% in 2005/06
 - MS ranked last in Outcome #1 in 2001, but ranked 26 in 2005/06



Thinking about ways data could be used

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

Visit soon!

- www.childhealthdata.org
National Survey of Children with Special Health Care Needs
- www.cshcndata.org
- www.nschdata.org
National Survey of Children's Health

Questions & Answers

Thank you for attending this event.

Please complete the evaluation directly following the webcast.

Archives of the event are located at <http://www.mchcom.com>
