Comparing Health and Health Outcomes for CSHCN and Non-CSHCN: Findings from 3 National Surveys

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CAHMI – Child & Adolescent Health Measurement Initiative
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Family Voices
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Agenda

5 mins: Welcome / Introduction

20 mins: CSHCN vs. Non-CSHCN comparison

20 mins: Within CSHCN groups comparison

20 mins: MCHB core outcomes for different grps of CSHCN and Across state variations

20 mins: Resources for accessing NSCH & NS-CSHCN data

Questions/discussion
Once upon a time in a galaxy far, far away ….

There was great need to learn more about children’s health and well-being ………
2001 National Survey of CSHCN

372,174 children, 0 - 17 yrs, in the 196,888 households contacted screened for having CSHCN

CSHCN Screener -- asked for all children in household

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
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
CYSHCN
Children meeting 1 or more of the above qualifying screening criteria
NS-CSHCN interview collects in-depth information for CSHCN group only:

- CSHCN health and functional status
- CSHCN 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 CSHCN and
- Key indicators of CSHCN health & system performance
GOOD START:

**MUCH** was learned in-depth about CSHCN in general

BUT . . .
National Survey of Children’s Health

Child Characteristics

Family Level Influences

Neighborhood and Community Influences

Child Outcomes
Early Childhood questions (Section 6) asked for children ages 0-5

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

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

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

102,353 Children ages 0-17 randomly selected, 1 per HH
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)
NSCH offers first time ever opportunity to:

- **Examine health status & outcomes** for CSHCN and non-CSHCN populations using standardized methods

- **Further characterize** the group of CSHCN identified by the MCHB definition
  - HEALTH CONDITIONS profile
  - HEALTH STATUS profile
  - FAMILY and SCHOOL profile
Health conditions profile

- **Non-CSHCN**
- **CSHCN**

**Current ASTHMA**
- CSHCN: 33.8%
- Non-CSHCN: 3.6%

**ADD/ADHD**
- CSHCN: 26.7% (ever) currently taking meds
- Non-CSHCN: 2.2%

**ADD/ADHD**
- CSHCN: 18.9% (ever)
- Non-CSHCN: 0.3%

NSCH 2003 (n = 102,353)
Health conditions profile

Any physical impairment or develop delay (ever)

14.9% CSHCN

1.0% Non-CSHCN

Frequent HEADACHES

12.4% CSHCN

3.9% Non-CSHCN

BONE, JOINT or MUSCLE problems (ever)

10.8% CSHCN

1.5% Non-CSHCN

NSCH 2003 (n = 102,353)
Health conditions profile

- **Moderate/severe socio-emotional difficulties in 1 or more areas**
  - CSHCN: 31.0%
  - Non-CSHCN: 3.9%

- **Behavior/conduct problems (ever)**
  - CSHCN: 20.7%
  - Non-CSHCN: 1.7%

- **Depression/anxiety problems (ever)**
  - CSHCN: 16.9%
  - Non-CSHCN: 1.2%

NSCH 2003 (n = 102,353)
Health conditions profile

- **LEARNING DISABILITY** (ever) - 27.8%
- **SPEECH problems** (past 12 mos) - 10.9%
- **AUTISM** (ever) - 2.4%

NSCH 2003 (n = 102,353)
6x’s more likely Fair/poor health status

4.5x’s more likely to miss significant amount of school time due to health

NSCH 2003 (n = 102,353)
Health status profile

3+ doctor visits for sick care, past 12 mos.

Twice as likely to get frequent medical care for acute and/or chronic health reasons

- CSHCN: 43.4%
- Non-CSHCN: 19.9%

2 or more ER visits, past 12 mos.

- Over 3x's more likely to visit ER
  - CSHCN: 13.1%
  - Non-CSHCN: 4.1%

NSCH 2003 (n = 102,353)
Home & School profile

Mother’s physical health status rated “fair/poor”
- CSHCN: 15.3%
- Non-CSHCN: 8.8%

Mother’s mental health status rated “fair/poor”
- CSHCN: 11.3%
- Non-CSHCN: 5.5%

Parent often felt aggravated with child during past month*
- CSHCN: 17.4%
- Non-CSHCN: 5.9%

NSCH 2003 (n = 102,353)
* During the past month, how often have you felt:

- . . . (ch’s name) is much harder to care for than most children his/her same age? (S8Q07)

- . . . He/she does things that really bother you a lot? (S8Q08)

- . . . Angry with him/her? (S8Q10)
Home & School profile

- Attends Head Start or Early Head Start (0-5 yrs):
  - CSHCN: 18.2%
  - Non-CSHCN: 8.9%

- Has repeated 1 or more grades (6-17yrs):
  - CSHCN: 17.7%
  - Non-CSHCN: 9.6%

- School has called parent 2+ times about ch’s problems:
  - CSHCN: 37.2%
  - Non-CSHCN: 13.6%

NSCH 2003 (n = 102,353)
Comparing health and health outcomes for different groups of CSHCN
Stratifying groups identified by CSHCN Screener

Makes sense logically & clinically:
- Underlying epidemiology of childhood chronic conditions and disability
- Broader definition of CSHCN as starting point
- Wide variation in number and types of health services needed/used by CSHCN

Options include:

- **Quantitative** – number of qualifying screening criteria
- **Qualitative** – type of qualifying health consequences
- **Other survey information** – alone or in combination w/ screening information
Q1: PRESCRIPTION (RX) MEDS
Q2: ABOVE ROUTINE SERVICE USE
Q3: FUNCTIONAL LIMITATIONS
Q4: SPECIALIZED THERAPIES
Q5: MENTAL HEALTH

**CYSHCN**
Children meeting 1 or more of the above qualifying screening criteria
Number Qualifying CSHCN Screener Criteria

CSHCN ages 0-17 identified by CSHCN Screener across 3 National Surveys

Number Qualifying CSHCN Screener Criteria

- NS_CSHCN 2001 (CSHCN n = 48,690)
- MEPS 2002 (CSHCN n = 2,096)
- NSCH 2003 (CSHCN n = 18,578)
88% Qualified on Functional Limitations (Q3) in addition to 1 or more other criteria

Statewide sample of children ages 0 -12 receiving SSI disability benefits (n=1,493)

CSHCN who qualified on a single screening criterion NS_CSHCN (n= 24,960)
**CYSHCN**
Children meeting 1 or more of the above qualifying screening criteria

**FOUR sub groupings of CYSHCN based on type(s) of qualifying health consequences they experience**

- **Rx Meds ONLY** (Q1 only)
- **Service Use ONLY** (Q2, Q4, and/or Q5)
- **Service Use AND Rx Meds** (Q1 + Q2, Q4, and/or Q5)
- **Functional Limitations** Q3 only or w/ any other Q, Q, Q, Q’s
Type of Health Consequences based on Qualifying CSHCN Screener Criteria

CSHCN ages 0-17 identified by CSHCN Screener across 3 National Surveys

- Managed by RX meds only
  - NS_CSHCN 2001 (CSHCN n = 48,690)
  - MEPS 2002 (CSHCN n = 2,096)
  - NSCH 2003 (CSHCN n = 18,578)

- Elevated use/need of services
  - NS_CSHCN 2001
  - MEPS 2002
  - NSCH 2003

- RX meds & elevated service use/needs
  - NS_CSHCN 2001
  - MEPS 2002
  - NSCH 2003

- Func. limitations + any other
  - NS_CSHCN 2001
  - MEPS 2002
  - NSCH 2003
Number of Qualifying Screener Criteria per Specific Health Consequences Group -- NS_CSHCN 2001 (n = 48, 690)

1. Managed by RX meds only
   - 100%

2. Elevated need/use of services
   - Qualified on 1 criteria: 75%
   - Qualified on 2 criteria: 21%
   - Qualified on 3 criteria: 5%

3. Rx meds AND elevated need/use of services
   - Qualified on 1 criteria
     - Any
     - Managed by RX meds only: 5%
   - Qualified on 2 criteria
     - Func limitations + any other: 33%
   - Qualified on 3 criteria
   - Qualified on 4 criteria
   - Qualified on 5 criteria

4. Func limitations + any other
   - Qualified on 1 criteria
   - Qualified on 2 criteria
   - Qualified on 3 criteria
   - Qualified on 4 criteria
   - Qualified on all 5 criteria: 18%
Non-CSHCN vs. CSHCN Rxmeds only

Overall health status rated FAIR or POOR

- CSHCN -RXMEDS only: 4.5%
- Non-CSHCN: 1.7%

Missed 2 + weeks of school due to illness

- CSHCN -RXMEDS only: 8.1%
- Non-CSHCN: 3.0%

NSCH 2003
3+ doctor visits for sick care, past 12 mos.

- CSHCN - RXMEDS only: 40.8%
- Non-CSHCHN: 19.9%

2 or more ER visits, past 12 mos.

- CSHCN - RXMEDS only: 8.3%
- Non-CSHCHN: 4.1%
% of CSHCN with Depression/Anxiety (ever)

- CSHCN grouped by type of qualifying health consequences:
  - RX meds only: 5%
  - Elevated service use only: 21%
  - RX meds & elevated service use: 29%
  - Functional limitations: 24%

- CSHCN grouped by number of qualifying screener criteria:
  - 1: 18%
  - 2: 31%
  - 3: 31%
  - 4 / 5: 43%
Average total medical expenditures
2001-2002 MEPS

- CSHCN: $2,399
- Non-CSHCN: $717
- RX meds only: $1,416
- Elevated service use only: $1,314
- RX meds & elevated service use: $2,374
- Func limitations + any: $5,064

CSHCN grouped by type of qualifying health consequences
Using Qualitative Groupings to Stratify MCHB Outcomes for CSHCN

**Outcome #5:** Community services organized for ease of use

**Outcome #1:** Families partner in decision making and satisfied w/ services

**Outcome #3:** Adequate public or private insurance to pay for needed services

**Outcome #2:** Coordinated, comprehensive, ongoing care in Medical Home
Outcome #5: SERVICES ORGANIZED FOR EASE OF USE

% CSHCN who DID NOT meet this outcome

CSHCN grouped by type of qualifying health consequences

- RX meds only: 15%
- Elevate service use only: 38%
- RX meds & elevated service use: 23%
- Fund limitations + any: 37%
Outcome #6: FAMILIES PARTNER in DECISIONMAKING and SATISFIED with SERVICES

% CSHCN who DID NOT meet this outcome

CSHCN grouped by type of qualifying health consequences

- RX meds only: 29%
- Elevated service use only: 57%
- RX meds & elevated service use: 43%
- Func limitations + any: 54%
Outcome #3: ADEQUATELY INSURED

% CSHCN who DID NOT meet this outcome

CSHCN grouped by type of qualifying health consequences:

- RX meds only: 32%
- Elevated service use only: 49%
- RX meds & elevated service use: 39%
- Func limitations + any: 49%
% of CSHCN who needed mental health care or counseling during past 12 months (C4Q05_X06)

NS_CSHCN 2001 (n = 38,866)
% CSHCN who needed & DID NOT get all the mental health care/counseling that they needed during past 12 months  (C4Q05_06a)

CSHCN grouped by type of qualifying health consequences

- RX meds only: 28%
- Elevated service use only: 11%
- Func limitations + any: 23%

CSHCN grouped by number of qualifying screener criteria

- 1: 7%
- 2: 16%
- 3: 14%
- 4: 20%
- 5: 23%

NS_CSHCN  2001 (n = 38,866)
Outcome #2: MEDICAL HOME

% CSHCN who DID NOT meet this outcome

- 36% RX meds only
- 59% Elevated service use only
- 46% RX meds & elevated service use
- 59% Func limitations + any

CSHCN grouped by type of qualifying health consequences
% of CSHCN who DO NOT consistently get Family-Centered Care

NS_CSHCN 2001 (n = 38,866)

CSHCN grouped by type of qualifying health consequences

- RX meds only: 23%
- Elevated service use only: 46%
- RX meds & elevated service use: 31%
- Func limitations + any: 43%

CSHCN grouped by number of qualifying screener criteria

- 1: 30%
- 2: 33%
- 3: 38%
- 4: 43%
- 5: 49%
Anchor selection of stratification method to policy or research question, analytic purpose and requirements:

- Do you need an **ordinal vs. categorical** variable?

- Keep **purpose and end users** in mind – How will results be used? By whom? For what purpose(s)?

- Consider the **tradeoffs inherent in each method** in terms of the characteristics of the groups, which CSHCN are likely to be included/excluded, and ability to interpret results.

- Consider **other combinations of screener results** such as CSHCN with emotional, developmental, or behavioral issues (Q5) vs. CSHCN who did not meet these screening criteria (see *MMWR Vol.54:39, October 7, 2005*)
Across States Variation for CSHCN vs. non-CSHCN
Question: **Indicator 5.2: Since starting kindergarten, has (child's name) repeated any grades?** *(S7Q09 -- ages 6-17 only)*

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Indicator 2.7: How many children/youth (ages 2-17) whose parents have ever been told child has ADD/ADHD currently take medication for this condition? (derived)

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<th>ADD/ADHD ever: child currently takes medication</th>
<th>Never told child has ADD/ADHD</th>
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S6Q52: During the past month, did (child's name) regularly attend Head Start or Early Start program? (ages 0-5)

RANGE across states for children ages 0-5: 5.2% - 9.9%

Indicator 3.2: How many children/youth (ages 0-17) had consistent health insurance coverage during the past 12 months? (derived)

RANGE across states for children ages 0-17: 7.0% - 24.8%
% of children ages 0-5 attending Head Start or Early Start program during past month, by Special Health Care Needs

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% children with inconsistent insurance coverage or currently uninsured, by Special Health Care Needs

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<tr>
<td>Montana</td>
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</tbody>
</table>
Resources for using the NSCH and the NS-CSHCN
To go to the NSCH homepage, CLICK here
Begin by selecting one of these three steps - and don't forget to check out the State Profiles option below.

**Start HERE!**

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

**JUST RELEASED!**

The Health and Well-Being of Children in Rural Areas: A Portrait of the Nation 2006

Rural Health Chartbook

**Want to view your state's data profile?**

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

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

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The Health and Well-Being of Children in Rural Areas: A Portrait of the Nation 2006

Rural Health Chartbook
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.
NOTE: Telephones are dialed at random to identify households with one or more children under 18 years old. The interviewer asks to 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.

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

SECTION 1: Initial Demographics
SECTION 2: Child's Health and Functional Status
SECTION 3: Health Insurance Coverage
SECTION 4: Health Care Access and Utilization
SECTION 5: Medical Home
SECTION 6: Early Childhood (0-5 years)
SECTION 7: Middle Childhood and Adolescence (6-17 years)
SECTION 8: Family Functioning
SECTION 9: Parental Health
SECTION 10: Neighborhood Characteristics
SECTION 11: Additional Demographics

SECTION 1: Initial Demographics

1. Child's sex (S1Q01)
2. Respondent's relationship to the child (S1Q02)
2003 National Survey of Children's Health

Survey Section 3: Health Insurance Coverage

**INTRODUCTION:** The next questions are about health insurance.

**S3Q01:** Does [CHILD] have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?

(0) NO [SKIP TO S3Q05]

(1) YES

(6) DON'T KNOW

(7) REFUSED

**HELP SCREEN (S3Q01):** Medicaid refers to a medical assistance program that provides health care coverage to low-income and disabled persons. The Medicaid program is a joint federal-state program that is administered by the states. Private health insurance refers to any type of health insurance, including Health Maintenance Organizations (HMOs), other than public programs. These plans may be provided in part or fully by the person’s employer or union, or purchased directly by the individual.
• DRC indicator datasets available at no cost from CAHMI
  – SAS and SPSS formats
  – All DRC child health Indicator variables included in data set
  – Request data use agreement: cahmi@ohsu.edu

• SAS and SPSS codebooks with programming code used to construct child health indicators

• Download raw datasets and methods reports at: www.cdc.gov/nchs
Upcoming 2005 NS-CSHCN:

- 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 Winter 2007
More information

- [www.childhealthdata.org](http://www.childhealthdata.org)

- [www.cahmi.org](http://www.cahmi.org)