Identifying Children & Youth with Special Health Care Needs for the National Survey of CSHCN

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AMCHP 2004 Annual Conference
Feb 28 – Mar 3
Washington, DC
Part 1:

Identifying Children & Youth with Special Health Care Needs for the National Survey of CSHCN
KEY questions:

• How are special health care needs defined?

• What method is used to identify children who meet this definition?

• Who is identified by the screening method used?
The “Challenges”

• **CYSHCN vary widely:**
  – Types & level of functional limitations
  – Type, intensity & scope of service use needs
  – Types of diagnoses (physical, emotional, developmental, behavioral, etc.)

• **No perfect method** for identifying CYSHCN
  – Diagnostic check lists, parent-report & administrative data records all have inherent limitations

• **No “gold standard”** for determining what constitutes a special health care need
Implications

• **CYSHCN vary widely**
  – Have to be very specific about whom you want to identify and WHY……

• **No perfect method**
  – All methods miss some children and mis-identify others (false negatives vs. false positives)
  – Always tradeoffs! (finding a robust group vs. not missing anyone)

• **No “gold standard”**
  – ‘Gray area’ group will always be a factor
KEY questions:

- How are special health care needs defined?
Defining Special Health Needs – WHO do we want to identify?

NARROWER DEFINITIONS
include only those with very severe conditions or highly complex needs
(C only)

BROADER DEFINITIONS
include those with wider array of conditions, levels of severity and service use needs
(B + C)

MOST INCLUSIVE DEFINITIONS
include “at risk” groups
(A + B + C)

GROUP A
At risk for developing a special health care need

GROUP B
On going health conditions; above average service use needs; few to moderate functional limitations

GROUP C
On going health conditions; high or complex service use needs; moderate to severe functional limitations

Special Health Needs Continuum
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
KEY questions:

- What **method is used to identify** children/youth who meet the MCHB definition?
Finding children/youth who meet the MCHB definition – HOW?

• Ask parents if child has “special health care needs”?
  - Not as simple or reliable as it sounds!
  - Misses or mis-identifies many children b/c too vague
  - Parents reluctant to “label” their children

• Ask parents to name children’s diagnoses / conditions?
  - Not as simple or reliable as it sounds!
  - Diagnostic checklists are too limited to cover vast numbers & types of childhood chronic conditions
  - Misses children are not yet diagnosed or whose parents do not know or recall specific dx’s
Finding children/youth who meet the MCH definition – HOW?

CSHCN Screener

• A set of well-tested, standardized questions used in the National Survey of CSHCN to identify children who meet the MCH definition

• Non-categorical approach --- uses health consequences currently experienced by child to identify special needs; not specific diagnoses or disabilities

• Focuses on the health consequences research shows are MOST likely to indicate special health care needs
CSHCN Screener

• 5 multi-part questions, each asking about a different health consequence

• All parts of at least one question must be answered “YES” for a child to qualify as having a special health care needs

• Parents/caregivers can answer by paper/pencil or telephone interview

• Takes about 1 minute to complete
Sample question:

Q3) Is (child’s name) limited or prevented in any way in his/her ability to the things that most children of the same age can do?

IF YES:

Q3a) Is (child’s name) limitation in abilities because of ANY medical, behavioral or other health condition?

IF YES:

Q3b) Is this a condition that has lasted or is expected to last for at least 12 months?

All three parts of question 3 must be answered YES for a child to qualify on the functional limitations consequences criteria.
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
CSHCN Screener

- Developed through a national process involving state leaders, families, experts, and policymakers

- Over 36,000 children / youth screened during development & testing phases

- Several versions tested, leading to final screener
KEY questions:

• Who is identified by the CSHCN Screener ..... (how do we know we found the group we want to identify?)
NO GOLD STANDARD?  
“Triangulate” to Validate

SURVEY PARENTS
- Ask about specific health services children need or use
- Ask about child health status & impact of any health problems

MEDICAL RECORDS
- Examine encounter & claims data for diagnoses listed in children’s records

GROUP id’d by CSHCN Screener

COMPARE to:
- CYSHCN identified by other methods or definitions such as program eligibility
- Children not identified

CLINICAL EVALUATION
- Review of children’s medical charts by pediatric clinicians
Agreement with Other Definitions & Methods

Parent survey of children 0-12 yrs old receiving SSI benefits (n = 1583)

95% identified by CSHCN Screener*

Other non-categorical or consequences-based methods:

Agree with CSHCN Screener 9 out of 10 times */**

* WA State Medicaid Pilot Study, CAHMI 2000  ** Nat.Sur.CSHCN / Pretest I  2000
Comparison with Group NOT Identified by CSHCN Screener – Parent Survey

Parents’-rating of their children’s overall health

- Excellent / very good: 87%
- Fair / poor: 10% (Children identified by CSHCN Screener)
- Fair / poor: 2% (Children who did not meet screening criteria)

WA State Medicaid Pilot Study, CAHMI 2000
Comparison with Group NOT Identified by CSHCN Screener – Parent Survey

Number of times children went to doctor’s office or clinic during past 6 months

- No visits: 10% (identified), 27% (not identified)
- 1-2 visits: 45% (identified), 41% (not identified)
- 3-4 visits: 28% (identified), 20% (not identified)
- 5 or more visits: 21% (identified), 8% (not identified)

WA State Medicaid Pilot Study, CAHMI 2000
Comparison with Group NOT Identified by CSHCN Screener – Parent Survey

Parent-report of health services needed or used by children during past 6 months

WA State Medicaid Pilot Study, CAHMI 2000
Parent-named conditions for group identified by CSHCN Screener

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other chronic conditions</td>
<td>28%</td>
</tr>
<tr>
<td>Asthma</td>
<td>23%</td>
</tr>
<tr>
<td>ADHD/ADD</td>
<td>18%</td>
</tr>
<tr>
<td>Conditions of uncertain severity/duration</td>
<td>16%</td>
</tr>
<tr>
<td>No condition named</td>
<td>13%</td>
</tr>
<tr>
<td>Acute conditions</td>
<td>1%</td>
</tr>
</tbody>
</table>

Parent-named conditions for group identified by CSHCN Screener

- **Other chronic conditions**: 28%
- **Asthma**: 23%
- **ADHD/ADD**: 18%
- **Conditions of uncertain severity/duration**: 16%
- **No condition named**: 13%
- **Acute conditions**: 1%

Nat.Sur. / Pretest I 2000
Examples of Health Conditions Named by Parents

“Other chronic conditions”
- Spina bifida, autism, depression, seizure disorders, Down syndrome, limited hearing, eating disorder, PTSD, cerebral palsy, leukemia, diabetes, muscular dystrophy …..

“Conditions of uncertain severity/duration”
- Migraines, mental health issues, dyslexia, anger/behavioral problems, acne, allergies, “lazy eye”, ear infections, emotional problems, “unable to spell or pronounce problem” ….
SUMMARY

Based on parent survey data, children/youth identified by the CSHCN Screener are DIFFERENT in important ways from those not identified:

– **Poorer** overall health status

– **Much more likely to both** have gone to a doctor and to have visited more frequently

– Need/use **dramatically more** health-related services and/or prescription medicines

– Parents name **one or more childhood conditions** of the type, complexity and duration likely to produce the health consequences used as non-categorical screening criteria
“Wait a MINUTE”! question

- Remember the special needs continuum -- CYSHCN are a varied group

- Can the CSHCN Screener results be used to identify subgroups of CYSHCN’s whose needs are more complex or extensive?
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

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

Rx Meds ONLY (Q1)
Service Use ONLY (Q2, Q4, or Q5)
Rx Meds AND Service Use (Q1 and Q2, Q4, or Q5)
Functional Limitations (Q3 only or w/ any other Q Q Q Q’s)
Four groupings of CYSHCN, 0 – 12 yrs old, based on type of health consequences they experience as a result of ongoing health conditions.
CYSHCN Subgroups – Parent Survey

- 10 or more dr office/clinic visits, past 12 mos.: 17%
- Health condition affects ch. all, some or most of the time: 39%
- Child's health condition rated "severe/very severe" by parent: 91%

Nat. Survey / Pretest II, 2001
Four groupings of CYSHCN, 0 – 17 yrs old, based on type of health consequences they experience as a result of ongoing health conditions.

- Managed by Rx meds: 37%
- Above Routine Use/Need of Services Only: 18%
- Rx meds AND Service Use: 24%
- Functional Limitations: 21%

Nat.Sur. of CSHCN, 2001 (Screener file)
Part 2: Describing CYSHCN identified by the CSHCN Screener Using Clinical Data
Data Available for Clinical Review

- Pharmacy claims for CY 1999
- Chart Reviews on child’s PCP clinic charts for 391 children, conducted in 2000
- All available data for 897 sampled children merged into an Access database for easy review by physicians
### Physician Evaluation-1

<table>
<thead>
<tr>
<th>Summary Category:</th>
<th>2</th>
<th>Attention Deficit Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child also on an inhaler for asthma and has eczema</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Specific conditions identified:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Chronic?</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADD, ADHD</td>
<td>✓</td>
</tr>
<tr>
<td>Asthma &amp; related</td>
<td>✓</td>
</tr>
<tr>
<td>Other</td>
<td>✓</td>
</tr>
</tbody>
</table>

**Note:** The table includes specific conditions identified during the evaluation. Conditions such as ADD, ADHD, Asthma & related, and Other are listed with corresponding chronic status.
# Physician Evaluation-2

<table>
<thead>
<tr>
<th>MCHB Definition Evaluation:</th>
<th>present</th>
<th>at risk?</th>
<th>last 12+ months</th>
<th>requires services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dimension</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical:</td>
<td>✔️</td>
<td></td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Developmental:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral:</td>
<td>✔️</td>
<td></td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Emotional:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Does child meet MCHB definition, including "at risk"? ✔️
Resultant Clinical Evaluations

- **MCHB Definition**
  - Definitely/Possibly CYSHCN vs. At Risk vs. Not CYSHCN
  - Physical &/or Developmental &/or Behavioral/Emotional [combined]

- **Condition-specific**
  - Have only included PRIMARY condition identified
Clinical Evaluation vs. CSHCN Screener by MCHB Definition

N = 897 convenience sample
Clinical CYSHCN Identification

- No special need identified 468
- Identified as “At Risk” by either or both doctors 42
- One doctor identified as “special need” [Possibly CYSHCN] 105
- Both doctors identified as “special need” [Definitely CYSHCN] 282
Principal Diagnoses of CYSHCN, Physician Definition

- Substance Abuse & Dependency
- Mental Retardation, Dev't Delay
- Minor Chronic Illnesses
- Neonatal & Premature Infants
- Diabetes
- Communication Disorders
- Asthma
- Mental Health Conditions
- Major Chronic Illnesses
- ADD/ADHD

Number of Children

- Definitely CYSHCN
- Possibly CYSHCN
CSHCN Screener vs. Clinical Evaluations, by Screener Subgroup

- NOT CSHCN
- "At Risk" Only
- Possibly CSHCN
- Definitely CSHCN

Bar graph showing the distribution of CSHCN status across different categories:
- Rx Meds Only
- Service Use Only
- Meds + Service Use
- Any Functional Limitation

 Impressions:
- The Screener subgroups are categorized based on their CSHCN status.
- The graph visually represents the percentage distribution of each subgroup across the categories.

(38)
Clinically-Defined Conditions by CSHCN Screener Subgroup

• Rx Meds Only:
  – 41% Asthma
  – 16% ADHD
  – 16% Major Chronic
  – 9% Mental Health

• Service Use Only
  – 30% Major Chronic
  – 19% Commun. Dx
  – 19% Mental Health
  – 14% ADHD

• Rx Meds + Service Use
  – 45% ADHD
  – 15% Major Chronic
  – 12% Mental Health
  – 11% Asthma

• Any Functional Limitation
  – 29% Major Chronic
  – 18% ADHD
  – 18% Mental Health
  – 14% Asthma
CYSHCN Identified by Doctors but not by Parents (n=111)

- 28% Mental Health Conditions
- 15% Communication Disorders
- 14% Major Chronic Illness
  - 6 of 15 = Congenital Heart Disease
- 12% Asthma
- 9 of 11 Neonatal/Premature Infants
Conclusions....

• There is clearly no one “right” way to identify CYSHCN
• The CSHCN Screener identifies virtually all of the “sickest” kids, i.e. those using health services
• Stratifying the CSHCN Screener into the suggested Subgroups is clinically meaningful & provides an appropriate grouping related to condition complexity
More information

- www.facct.org/cahmi.html
- debra.read@kpchr.org
- www.cshcndata.org