Issues in Defining and Identifying Children with Special Health Care Needs

Presented by:
Christina Bethell, PhD
Debra Read, MPH
CAHMI-Child and Adolescent Health Measurement Initiative
Motivation for Identification of Special Health Care Need Populations

- **Health Care Needs**: Distinct in terms of the type, scope, duration and complexity of health care needs

- **Quality Assessment**: Given increased exposure, experiences of people with special health care needs more sensitive indicator of quality

- **Costs**: People with special health care needs account for majority of health care costs and represent group for which greatest savings may occur

- **Improvement Opportunities**: Information about quality shows tremendous need and opportunity for improvement
Identification Purposes

- Evaluate Service Requirements
- Quality Measurement
- Early Identification at Point of Enrollment
- Early identification at point of service
- Prescreen for case management
- Assess Resource Requirements
From Identification to Improved Care

- Broad Identification
- Second tier screening
- Triage to care mgt.
- Monitor quality
- Target improvements
- Program modifications
- Ongoing ID and Improvement

Ongoing ID and Improvement Program modifications

From Identification to Improved Care

- Broad Identification
- Second tier screening
- Triage to care mgt.
- Monitor quality
- Target improvements
- Program modifications
- Ongoing ID and Improvement
Purpose

- Estimate prevalence
- Evaluate care quality
- Early identification for purposes of follow-up/more in-depth needs assessment
Target Population

- Categorical groups (SSI, Title V, Foster Care…)
- Children and adolescents age 0-18
- Children enrolled in Medi-Cal Managed Care Health Plans
Definition

• Definitional Approach
  – Program-based
  – Diagnosis-based
  – Consequences-based

• Specific Criteria
  – Level and types of functional limitations
  – Level, frequency and types of services needed
  – Types of conditions
  – Diagnostic status
  – Duration of condition status
No Gold Standard

• Gray area exists between children at-risk and those with more clearly established special health care need
• Inherent limitations exist in both self report and administrative data reports of conditions
Continuum for Defining Children and Adults with SHCN

A. Narrower definitions; includes only those with more severe conditions or highly complex needs

B. Broader definitions, includes those with wider array of conditions, levels of severity and service use needs

C. Most inclusive definitions; includes “at risk” groups

No special health care needs
At risk for developing a special health care need
On going health conditions; above average service use needs; few to moderate functional limitations
On going health conditions; high or complex service use needs; moderate to severe functional limitations

<table>
<thead>
<tr>
<th>Group</th>
<th>C</th>
<th>B</th>
<th>A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adolescents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults &lt; 65 yrs old</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults &gt; 65 yrs old</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 - 20%</td>
<td>15 - 20%</td>
<td>3 - 5%</td>
<td></td>
</tr>
<tr>
<td>23 - 30%</td>
<td>23 - 30%</td>
<td>5 - 10%</td>
<td></td>
</tr>
<tr>
<td>30 - 40%</td>
<td>30 - 40%</td>
<td>10 - 15%</td>
<td></td>
</tr>
<tr>
<td>55 - 75%</td>
<td>55 - 75%</td>
<td>15 - 25%</td>
<td></td>
</tr>
</tbody>
</table>
Figure 2: Special Health Care Needs Identification Continuum

- **Serious Limitations**:
  - Cell A: e.g. Blindness
  - Cell B: e.g. Cerebral Palsy
  - Cell C: e.g. Diabetes
  - Cell D: e.g. Controlled epilepsy

- **No Limitations**:
  - e.g. Mild/managed asthma
  - e.g. Hypertension
Program-Based Approaches

Considerations:

- Accuracy and availability of program records
- Consistent application of eligibility rules
- Narrow definition of CSHCN
Diagnostic-Based Approaches

Considerations:
• Availability and accuracy of encounter records
• Availability of data for new enrollees
• Selection of qualifying diagnoses
• Selection of “scoring” algorithm (e.g. level of dx, number of times indicated, setting of care, etc.)
• Accounting for missed DX and mis-DX,
• Time lag between encounters and records of encounters
• Validity issues for condition checklists
Consequence-Based Approaches

Considerations:
- What consequences to include?
- Require a DX in addition to consequences?
- Requires use of surveys of families
- Does not require families to name a DX or specific condition
- Length of enrollment is not a factor
- Includes those not able to access care and for whom encounter records do not exist
Capacity

• Availability and quality of enrollee contact information
• Availability and quality of encounter data
• Technical expertise and analytic capacity
Attributes of Available Identification Tools

- Development, testing and use history
- Direct and indirect costs
- Availability of tool and technical support
- Use with existing client data collection
- Scalability
- Cultural sensitivity
Suggested Criteria for Selection of Methods

• Readily available & documented
• Strong development, testing & use history
• Potential for standardization
Tools to be reviewed at next meeting:

- **Survey-based methods**
  - QuICCC and QuICCC-R
  - CSHCN Screener
  - Other?

- **Administrative data-based tools**
  - Clinical risk groups method (CRGs)
  - Chronic disability payment system method (CDPS)
Developing an Identification Strategy for CSHCN

Christina Bethell, PhD
Debra Read, MPH
CAHMI-Child and Adolescent Health Measurement Initiative
Why not just ask parents “does your child have a special health care need?”

<table>
<thead>
<tr>
<th></th>
<th>“Does your child have any medical conditions that have lasted at least 3 months” (n = 1392, Medicaid)</th>
<th>“In the last 12 months, did your child have any medical, behavioral or other health conditions” (n = 613, Commercial)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% “yes” overall</td>
<td>15.7%</td>
<td>26.9%</td>
</tr>
<tr>
<td>% who met the CSHCN Screener in the study</td>
<td>18%</td>
<td>15.5%</td>
</tr>
<tr>
<td>% “yes” who did not meet CSHCN Screener</td>
<td>36.3%</td>
<td>63.2%</td>
</tr>
<tr>
<td>% who met the CSHCN Screener who said “no”</td>
<td>44.8%</td>
<td>36.4%</td>
</tr>
</tbody>
</table>

Source: Bethell and Read, FACCT—The Foundation for Accountability, 2000
Why not just see if they have a DX code?

- Used a comprehensive list of childhood chronic condition ICD-9 codes
- Reviewed administrative data & included all children with one or more hospitalizations or one/two or more outpatient visits with the ICD-9 code listed
- 40% of CAHPS eligible children (6 mos continuous enrollment) had no encounter records found
- 52.5% of those meeting DX criteria met the CSHCN Screener (N = 4,040)
- 82.3% meeting CSHCN Screener had a DX code
- 19% with no encounter records met the CSHCN Screener
- Other, more sophisticated, administrative data based methods give different results (e.g CRGs)
Identification Toolkit

Focus on tools for:
- flagging individuals for more in-depth assessment
- identifying a cohort for quality assessment and improvement

Not focusing on tools for:
- make a diagnosis
- confirm a specific diagnosis
- identify at-risk children
- determining expected utilization and risk adjusted payment rates
- determining qualification for case management
Inclusion Criteria

• Tool is aligned with the MCHB definition of CSHCN
• Tool is readily available and documented
• Tool has known development, use and testing history
• Tool has potential for standardization
Identification Tools

Meeting Criteria

- The Questionnaire to Identify Children with Chronic Conditions (QuICCC)
- 3M/CRG Administrative Data Algorithm
- CSHCN Screener
Characterizing Tools

• Definitional Approaches
  – Program-based - *none*
  – Diagnosis-based - *none*
  – Consequences-based - *QuICCC-R, CSHCN Screener*
  – DX + Consequences - *CRG’s*
Attributes of Available Identification Tools

- Development, testing and use history
- Direct and indirect costs
- Availability of tool and technical support
- Use with existing client data collection
- Scalability
- Cultural sensitivity
Useful Comparisons

- Administrative vs. Survey Based
- Alternative Survey Based Methods
  - Checklists
  - QuICCC-R
  - CSHCN Screener
Administrative-based Methods

*Important things to keep in mind:*

- People have to have data records in order to be identified
- Accuracy & availability of records varies within & across settings
- Time lag btw. actual encounters & data record availability
- Most methods require at least 6 mos. of data
- Available methods vary in complexity of scoring algorithm used, qualifying criteria and, as a result, % identified
- Available methods differ in capacity to identify individuals vs. diagnostic cohorts
What Administrative & Survey-based Methods Can We Compare?

Comparison data exists for:

• **3M/CRG’s**
  – Combines DX & consequences-based approaches
  – Uses ICD-9 and procedure codes to classify cases; requires 2 or more encounters with same DX code
  – Requires at least 6 months of data
  – Type & # of DX’s; recency/reoccurrence; # of acute incidences; costs & type, combination & frequency of services all taken into account in scoring.
  – Able to identify both individuals and population cohorts; also assigns severity rating
  – Individuals assigned to mutually exclusive groups (healthy, acute, chronic).
What Administrative & Survey-based Methods Can We Compare?

Comparison data exists for:

- **Comprehensive ICD-9 code list of chronic childhood conditions**
  - Uses diagnostic-based approach; expert consensus on codes to include
  - All children with one or more inpatient and/or outpatient encounter records w/ one or more of the ICD-9 codes on list are included
  - **Exception**: 2 or more outpatient encounters are required for asthma, ADHD, failure to thrive, conduct disorder/emotional disturbance
  - Does not identify individuals; only non-mutually exclusive diagnostic cohorts; no severity rating
  - Studies reviewed up to 24 months of records
What Administrative & Survey-based Methods Can We Compare?

Comparison data exists for:

- **QuICCC & QuICCC-R**
  - Uses consequences-based approach
  - Does not require formally recorded or named DX
  - Relies on parent-report
  - Interviewer administered *only* (phone or in person)
    - QuICCC: 41 question sequences
    - QuICCC-R: 16 question sequences
  - 3 part structure: consequences, presence of a condition, duration of condition
  - Positive responses to all three parts of 1 or more question sequences in order to qualify
  - Designed to identify population cohort; can identify individuals, as well
What Administrative & Survey-based Methods Can We Compare?

Comparison data exists for:

- **CSHNC Screener**
  - Uses consequences-based approach
  - Does not require formally recorded or named DX
  - Relies on parent-report
  - Self or interviewer administered (*mail or phone*)
    - 5 question sequences
  - 3 part structure: consequences, presence of a condition, duration of condition
  - Positive responses to all three parts of 1 or more question sequences in order to qualify
  - Designed to identify population cohort; can identify individuals, as well
Comparison of Administrative & Survey-based Methods

• **Methods vary in % identified**

  - **CRG’s:** 10% - 18%
  - **ICD-9 list:** 14% - 44%
  - **QuICCC/QuICCC-R:** 19% - 36%
  - **CSHCN:** 16% - 22%
Comparison of Administrative & Survey-based Methods

- Methods vary in agreement with each other

**Identified by consequences-based surveys (QuICCC-R & CSHCN Screener)**
- 86.2% met CRG criteria for chronic condition
- 66.4% of CRG Positive met survey criteria

**NOT identified by consequences-based surveys (QuICCC-R & CSHCN Screener)**
- 18.5% met CRG criteria for chronic condition
- 23.2% of CRG Positive met survey criteria
Comparison of Administrative & Survey-based Methods

• **Methods vary in agreement with each other**

**Identified by ICD-9 code list**
- 52% met CSHCN Screener
- 53% met QuICCC

**NOT identified ICD-9 code list**
- 20% identified by CSHCN Screener
- 24% identified by QuICCC
Comparison of Administrative & Survey-based Methods

• Survey-based & administrative-based methods are not simple substitutes for each other

<table>
<thead>
<tr>
<th>Method Combination</th>
<th>% Overall Agreement btw Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>CRG’s &amp; QuICCC-R</td>
<td>85%</td>
</tr>
<tr>
<td>ICD-9 list &amp; QuICCC</td>
<td>66%</td>
</tr>
<tr>
<td>CRG’s &amp; CSHCN Scr</td>
<td>89%</td>
</tr>
</tbody>
</table>
Comparison of Administrative & Survey-based Methods

Why so much variation?

- Coding errors / omissions
  - mis-DX; “missed” DX
  - rule-out DX’s; non-reimbursed services/DX’s
- Measurement error
- Survey report error
- Different criteria used in working definition
- Intentional differences in design
  - Designed to be more or less sensitive or specific on purpose
  - Greater or lesser tolerance for “false positives” or “false negatives”
Comparison of Administrative & Survey-based Methods

What do we know about WHO might be missed?

CSHCN identified by consequences-based survey and NOT administrative data are highly likely to:

- Have developmental or emotional disorders that are not coded in encounter records
- Use services not reimbursed under the benefit structure
- Have multiple health issues that include a range of educational, developmental and mental health service need consequences
- Be in transition btw health plans and/or primary care providers
Comparing Survey-based Methods for Identifying CSHCN

Christina Bethell, PhD
Debra Read, MPH
CAHMI-Child and Adolescent Health Measurement Initiative
Survey-based Methods

- **QuICCC** -- Questionnaire for Identifying Children with Chronic Conditions (41 question sequences)

- **QuiCCC-R** -- Questionnaire for Identifying Children with Chronic Conditions -- revised (16 question sequences)

- **CSHCN Screener** -- Children with Special Health Care Needs Screener (5 question sequences)

- **Condition “check lists”** such as the NHIS checklist of childhood health conditions
Survey-based Methods

• The QuICCC & the CSHCN Screener use similar criteria:

1. **Consequences**
   - Functional limitations
   - Dependency
   - Need for services (medicines, therapies, counseling, equipment)

2. **Presence** of a condition (medical, behavioral, mental, learning)

3. **Duration** (lasting or expected to last 12 months)
Comparing the QuICCC-R & the CSHCN Screener

- **Definition:** same (functioning, dependency, use)
- **Number of components:** 14 vs. 41
- **Structure:** similar three part structure -- consequences, presence of condition, duration
- **Scoring:** similar
- **Item wording:** similar
- **Administration:** QuICCC_R--- interviewer only
  
  (phone or in person)

  CSHCN Screener-- self or interviewer

  (mail or phone)
Comparing the QuICCC-R & the CSHCN Screener

<table>
<thead>
<tr>
<th></th>
<th>National CSHCN Survey 1st Pretest (n = 2,420)</th>
<th>Health Plan Study (n = 496)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CSHCN and QUICCC-R</td>
<td>CSHCN and QUICCC-R</td>
</tr>
<tr>
<td>1) % BOTH methods classify child as having a special health need</td>
<td>14.9%</td>
<td>15.5%</td>
</tr>
<tr>
<td>2) % BOTH methods classify child as NOT having a special health need</td>
<td>75.3%</td>
<td>73.6%</td>
</tr>
<tr>
<td>3) % Overall agreement between methods</td>
<td>90.2%</td>
<td>89.1%</td>
</tr>
</tbody>
</table>

Source: Bethell, Read, Neff, Blumberg, Stein, Sharp, Newacheck, 2002
Comparing the QuICCC-R & the CSHCN Screener

<table>
<thead>
<tr>
<th>Mode</th>
<th>National CSHCN Survey 1st Pretest</th>
<th>Health Plan Population Sample</th>
<th>State-wide Medicaid Managed Care Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response rate</td>
<td>Tel: 49.2%</td>
<td>Tel: 80.0%</td>
<td>Mail/telephone: 57.7%*</td>
</tr>
<tr>
<td>Number of cases</td>
<td>n = 2,420</td>
<td>n = 497</td>
<td>n = 3,894*</td>
</tr>
<tr>
<td>Age range</td>
<td>0 – 17yrs old</td>
<td>0 – 14yrs old</td>
<td>0 – 13yrs old</td>
</tr>
<tr>
<td>Mean age</td>
<td>n/a</td>
<td>7.3 yrs</td>
<td>6.9 yrs</td>
</tr>
<tr>
<td>% Male</td>
<td>n/a</td>
<td>53.2</td>
<td>51.2</td>
</tr>
<tr>
<td>% identified by CSHCN Screener</td>
<td>16.0</td>
<td>16.7</td>
<td>20.7</td>
</tr>
<tr>
<td>% identified by QuICCC-R</td>
<td>23.6</td>
<td>25.2</td>
<td>n/a</td>
</tr>
</tbody>
</table>

Source: Bethell, Read, Neff, Blumberg, Stein, Sharp, Newacheck, 2001 (in review JAP)
## Percent age Identified by Survey-based methods

<table>
<thead>
<tr>
<th></th>
<th>CSHCN Scr</th>
<th>QuICCC-R</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SLAITS Pilot</strong></td>
<td>16.6%</td>
<td>24.2%</td>
</tr>
<tr>
<td><strong>CAHMI / MCO Trials</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(13 samples):</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Population</strong></td>
<td>16 - 22%</td>
<td>25%</td>
</tr>
<tr>
<td><strong>SSI</strong></td>
<td>94%</td>
<td></td>
</tr>
<tr>
<td><strong>CRG level 3 or 4</strong></td>
<td>98%</td>
<td></td>
</tr>
</tbody>
</table>
Percent age Identified by Survey-based methods

• QuICCC versus the NHIS checklist of childhood health conditions
  – Checklist method identified more children
    • QUICCC:  19% CSHCN
    • NHIS checklist:  35% CSHCN
  – One half of conditions named by parents in the QuICCC + group were NOT on the checklist
Why consider a self-reported consequences-based approach?

- Self-report most amenable to uniform data collection across settings (vs. adm. or medical chart data)
- Establishes similar set of consequences for children across conditions in terms of functioning, service and quality of care needs
- Poor discrimination and inherent gaps in condition check-lists (NHIS check list yields 40%; still, many cases missing due to missed DX and poor recall)
Why consider a self-reported consequences-based approach?

• Poor discrimination, uniformity and validity of administrative diagnostic data

• Increases probability of identifying children with consequences who are not diagnosed or whose parents are not able/willing to name condition or who don’t have a formal DX

• Decreased probability of identifying children without consequences
Other “Inevitabilities”

- **Gray area** between children at-risk and those with clearly established special health care needs
- **Inherent limitations** in both parent reports and administrative/clinical data
- All methods will lead to some **false negatives**
- The most comprehensive methods will have the most **false positives**
- All methods require **follow up assessment** to be useful for individual children
Other “Inevitabilities”

- Not all children with a DX will be identified
- Not all children identified will have a DX
- Not all children with a special health care need
  - are diagnosed
  - have their diagnosis recorded in records
  - have their diagnosis understood (or accepted) by parents