

Issues in Defining and Identifying Children with Special Health Care Needs



Presented by:

Christina Bethell, PhD

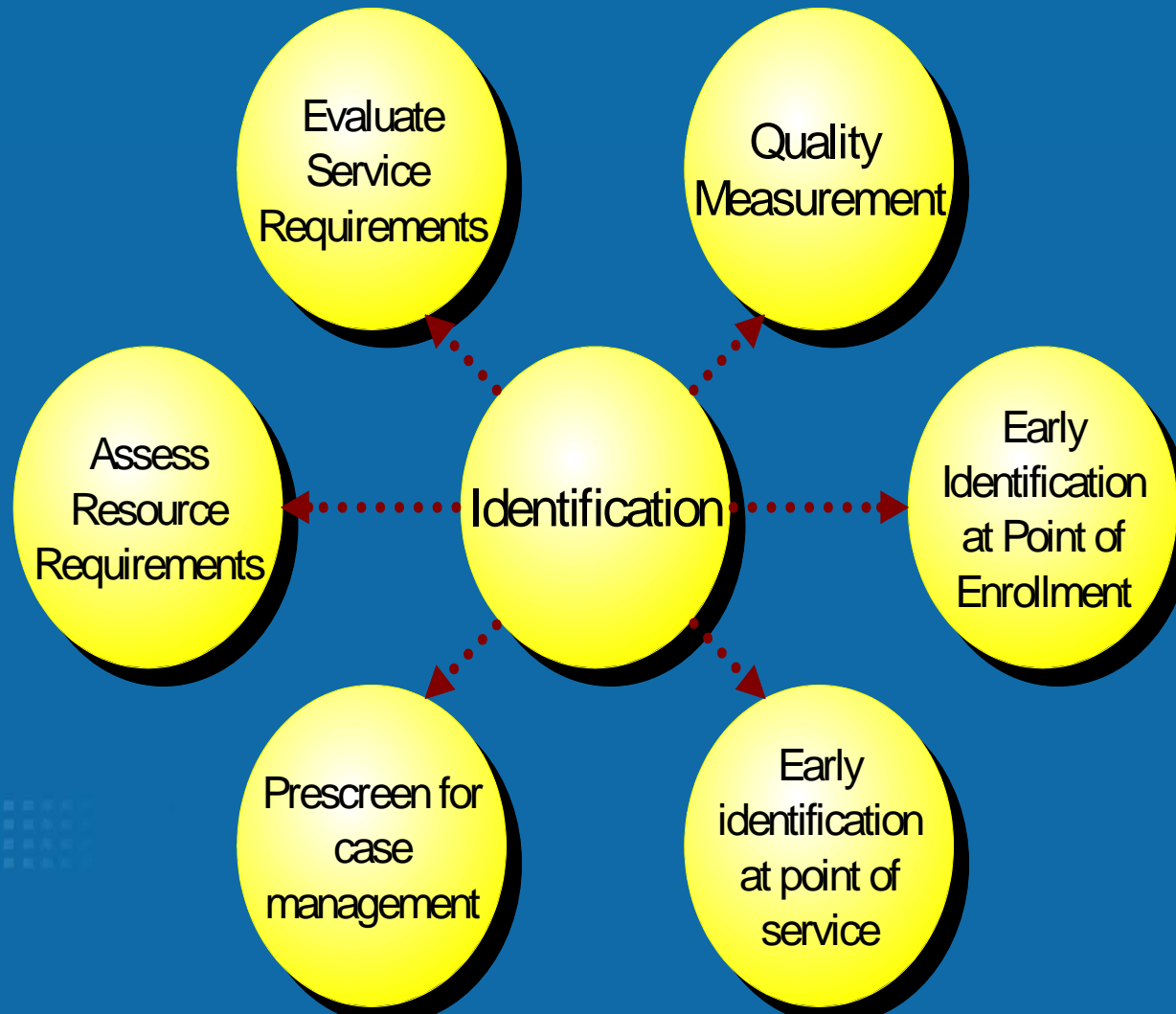
Debra Read, MPH

CAHMI-Child and Adolescent Health
Measurement Initiative

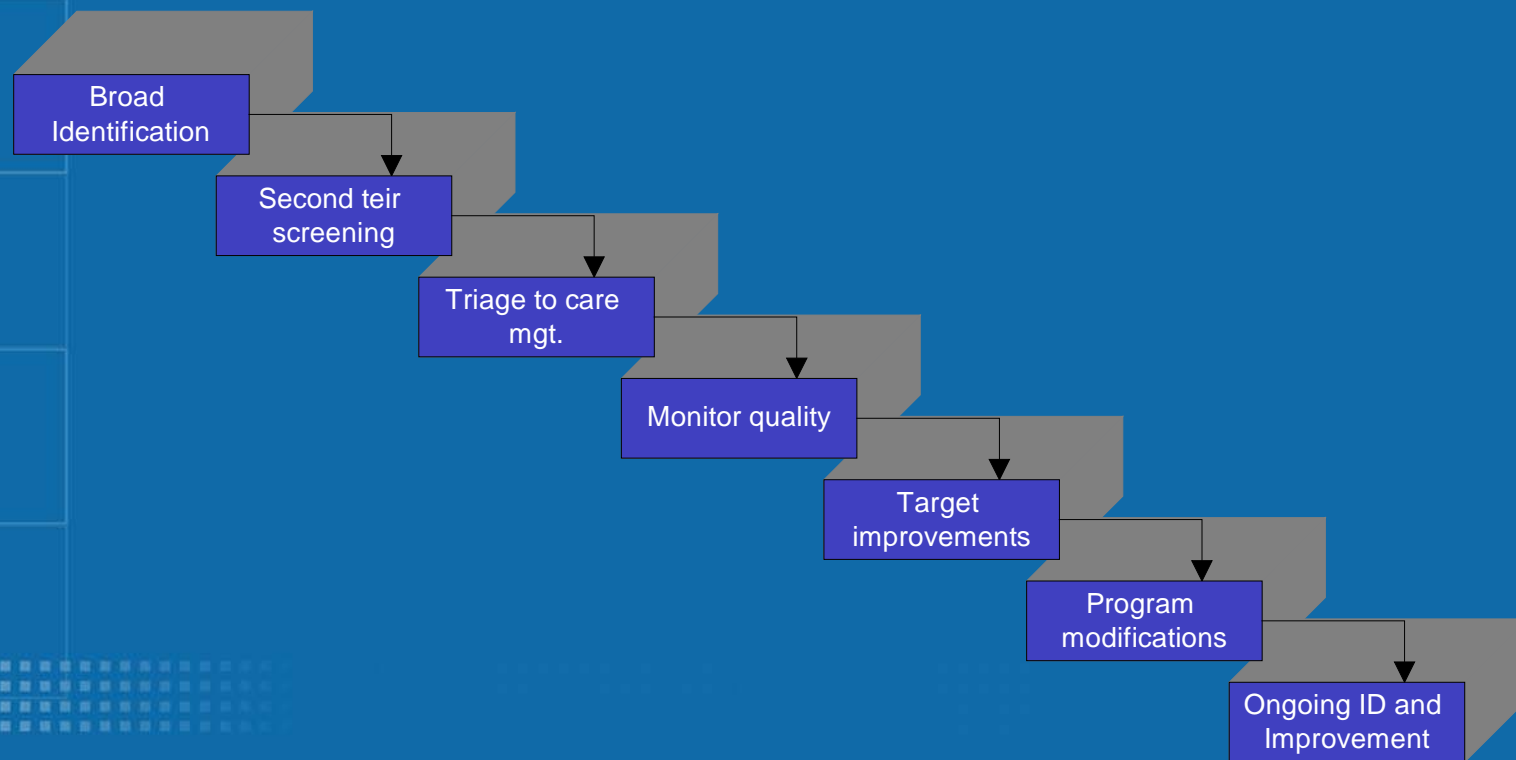
Motivation for Identification of Special Health Care Need Populations

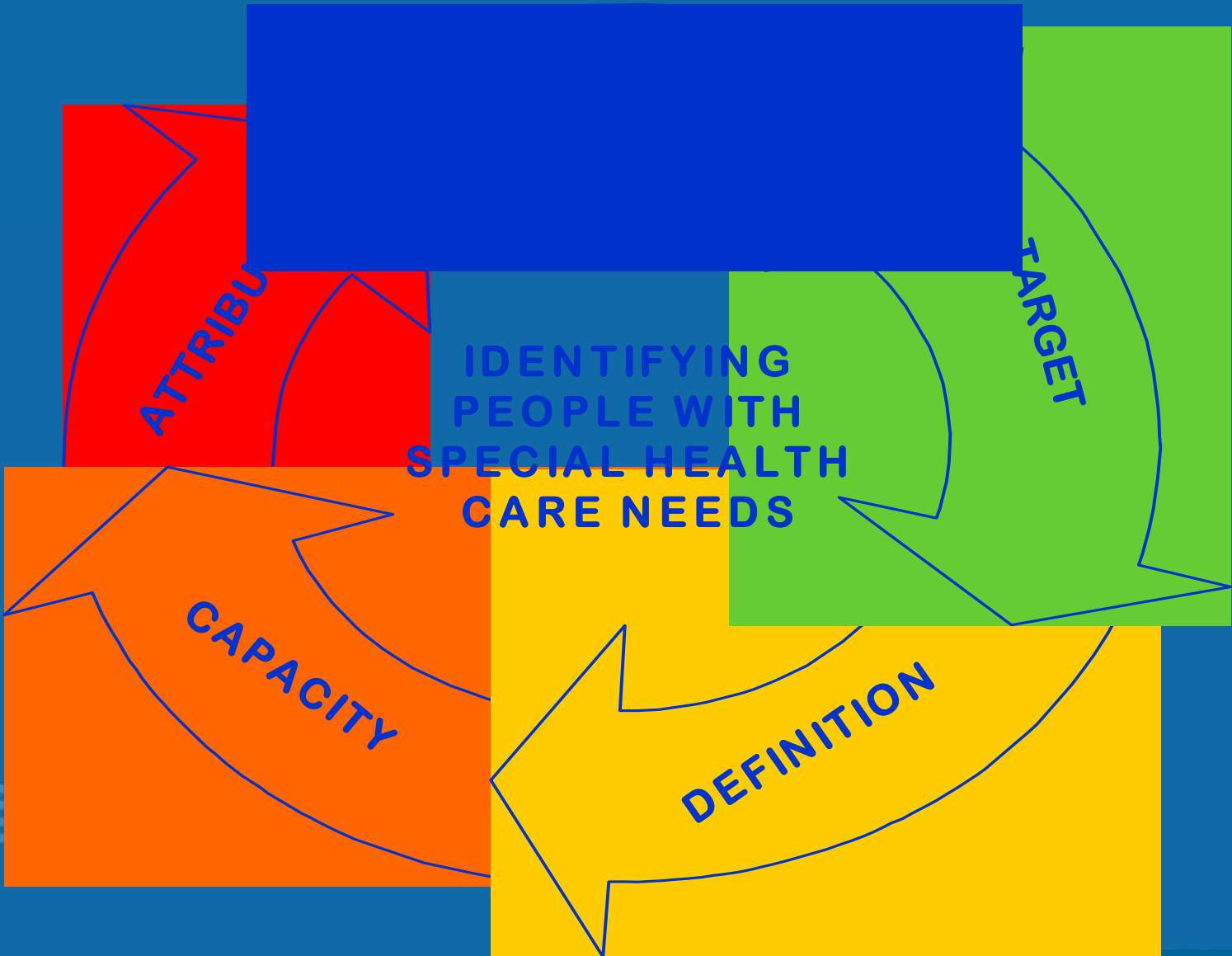
- **Health Care Needs**: Distinct in terms of the type, scope, duration and complexity of health care needs
- **Quality Assessment**: Given increased exposure, experiences of people with special health care needs more sensitive indicator of quality
- **Costs**: People with special health care needs account 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



From Identification to Improved Care





ATTRIBU

IDENTIFYING
PEOPLE WITH
SPECIAL HEALTH
CARE NEEDS

TARGET

CAPACITY

DEFINITION

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

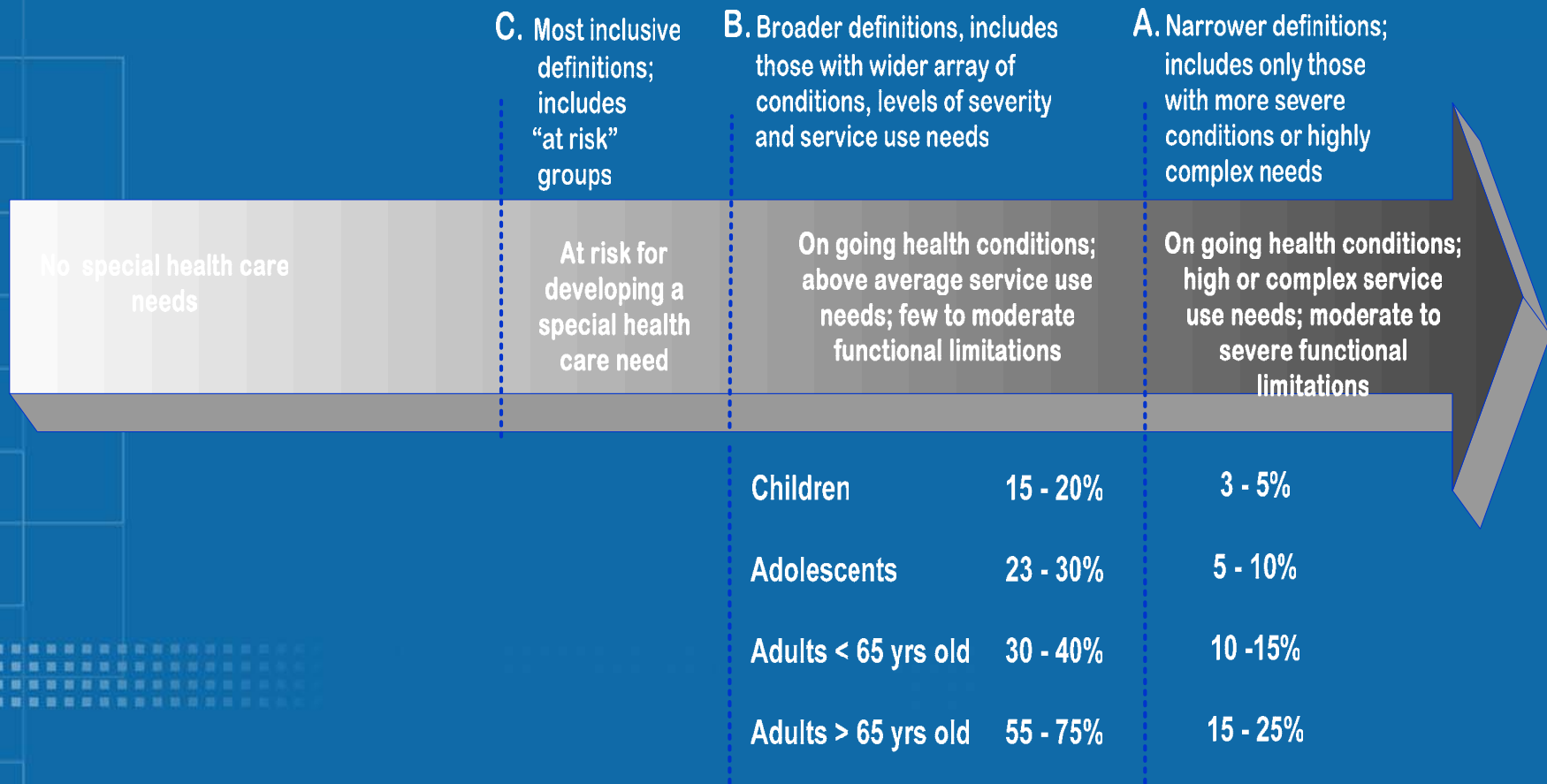
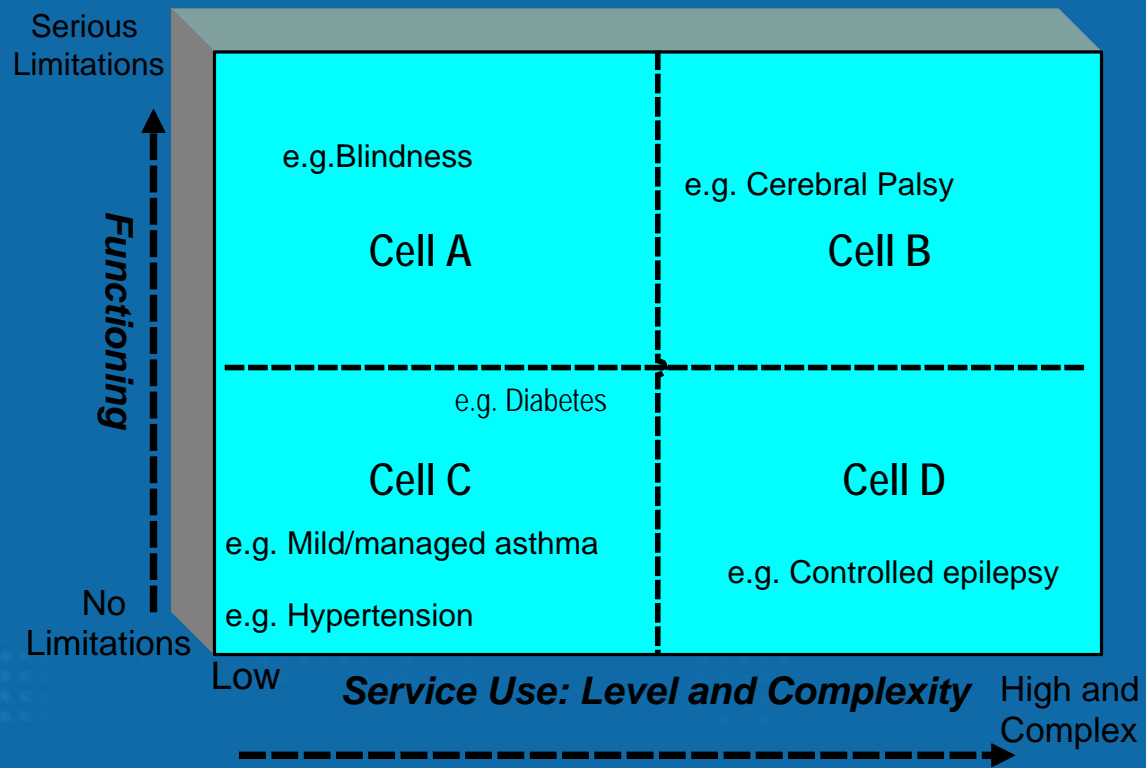


Figure 2: Special Health Care Needs Identification Continuum



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

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Why not just ask parents “does your child have a special health care need?”

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

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 enrollement) 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

	<u>% CSHCN</u>
– 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 QulCCC

NOT identified ICD-9 code list

- 20% identified by CSHCN Screener
- 24% identified by QulCCC

Comparison of Administrative & Survey-based Methods

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

	<u><i>% overall agreement btw methods</i></u>
<hr/> – CRG's & QuICCC-R:	85%
– ICD-9 list & QuICCC:	66%
– CRG's & CSHCN Scr:	89%

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

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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

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

Source: Bethell, Read, Neff, Blumberg, Stein, Sharp, Newacheck, 2002

Comparing the QuICCC-R & the CSHCN Screener

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

Source: Bethell, Read, Neff, Blumberg, Stein, Sharp, Newacheck, 2001 (in review JAP)

Percentage Identified by Survey-based methods

	<u>CSHCN Scr</u>	<u>QuICCC-R</u>
<i>SLAITS Pilot</i>	16.6%	24.2%
<i>CAHMI / MCO Trials</i> (13 samples):		
Population	16 - 22%	25%
SSI	94%	
CRG level 3 or 4	98%	

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**