Healthy Kids Steering Committee
Assessing and promoting access to quality health care

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Director, The Child & Adolescent Health Measurement Initiative

January 5, 2012
• **Desired Outcome.** What are we trying to accomplish?
  – Implement quality measurement methods that **optimize both efficiency, safety and the improvement** of health and health care quality for all children and CYSHCN (NOTE: any child can become a CYSHCN at any time and many will cease to be CYSHCN over time—children are developing!)
  – **Minimize** adverse selection and underuse of needed services; Minimize overuse and misuse;
  – Motivate and **support innovation** to promote healthy development and optimize life course health development—promote a life course view;
  – **Prevent** negative events (e.g. many hospitalizations and readmissions; ER visits; errors and safety problems) and ensure other efficiencies (e.g. minimize repeat tests)
  – Where possible, use **consistent methods** that leverage across needs for quality measurement data (payment, quality measurement, quality improvement, etc.)

• **Baseline Requirements:**
  – CHIPRA core measures
  – Identification/Stratification by CYSHCN, Race/Ethnicity, SES
Baseline Quality Requirements in States

**BBA – Section 438: Managed Care**

**Subpart D – Quality Assessment & Performance Improvement**
($§438.200 – 438.242$)
Final Rule June 14, 2002

**Subpart E – External Quality Review**
($§438.310 – 438.364$)
Final Rule Jan 24, 2003

- **Mandatory activities** – EQRO must use information from:
  1. Validation of performance improvement projects required by State – annually
  2. Validation of MCO performance measures reported as required by State or calculated by State – annually
  3. Review conducted within previous 3 yr period to determine MOC compliance w/ standards set forth in Subpart D; except with respect to those related to quality improvement projects

- EQRO may provide tech assistance to MCOs re:
  - assist in conducting activities re: to mandatory and optional activities

- EQRO results shall include at least:
  - detailed tech report
  - assessment of each MCO’s strengths/weaknesses: re: quality, timeliness, access
  - recommendations re: how to improve quality of services / care

- States determine, methodologically appropriate comparative info about all MCOs
- assessment of the degree to which MCOs addressed QI recs by EQRO from last EQR

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**Prepared by CAHMI – The Child & Adolescent Health Measurement Initiative**

**July 2004**
Why Do State Programs Need a Strategy and Framework to Measure Access and Quality of Care?

1. **Gaps and variations in quality** at every level; major opportunities for health promotion across the life span

2. **Quality measurement is essential** to each key role states play:
   - What is measured is what is focused on
   - States lead the way in regulations related to quality measurement and improvement focused on children

3. **Integrating measurement strategies** across each of these roles can enhance value and ensure efforts are actionable and sustainable over time.

4. **Current endorsed/commonly used measures** do not provide a comprehensive, child-centered picture of quality
   - The existing minimum core measurement set is essential but not sufficient to establish a profile of performance, inform consumers or support improvements in quality.

5. **Existing incentives and resources** are inadequate to meet goals for quality measurement

6. **There are opportunities** (and examples!!) for Medicaid/CHIP to leverage existing required activities to advance broader health outcomes, efficiency, and quality of care goals
   - States using innovative approaches are achieving innovative gains
1. **Children are Developing**: Some Implications:
   - Focus on *healthy development and risks* as well as conditions and diagnoses (diagnoses elusive or delayed for many “conditions”)
   - Consider lifelong impact and *early life windows of opportunity* (Heckman; Adverse Childhood Events Study (ACES)).
   - Readiness for school and work affected early and at key junctures. Health care does/can/should plays a prominent role in influencing range of factors. Measures powerful to motivate shifts needed.
Special Mandate for Medicaid/CHIP
Rate of Return to Investment in Human Capital

High Gains

Low Gains

Age

0

JJ Heckman, 2000
2. **Children are Dependent**: Some Implications:

- **Address range of factors impacting health** (family well-being; community safety, support and resources; school resources for health, coordination with school, child care, etc.)

- **Engage adults in measurement & improvement** (parental education and behaviors key focus for child health; Lifecourse Theory and ACES studies-health of parents essential to health of child inescapable.

- **Youth engagement in measurement and improvement** (go up to age 26 in keeping with health reform definition of “dependent”)

- **Engage adult health care community** (especially prenatal/pre-prenatal and maternity care and adult mental and behavioral health communities; adult specialty care for youth transition to adulthood)
The Challenge and Opportunity
Protective Home Environment Summary Measure

Home Environment Summary Index for CSHCN (2007 NSCH)

(Share 4+ Meals Week; Read/Sing to Child (<5); No Smoking in the Home; Ever Breastfed (<5), No TV in Bedroom & < 2 Hours/Day; Parent Met Most Friends (6-17); Usually Does Required Homework)
Enduring Themes in Child Health (The 4 D’s)

3. Children’s Diagnoses Are Diverse and Often Delayed: Some Implications:
   - **Precision Issues**: Most units of analysis insufficient numbers of any one condition to support precision in quality measures for purposes of accountability/transparency and public reporting.
   - **CSHCN Common Focus**: Broad definition. Children with ongoing conditions requiring amount or type of health and related services than required by children generally.
   - **Early Identification Issues**: Risk and Consequences vs. DX dependent denominators required to ensure early ID of CSHCN.
   - **Multiple Condition Issues**: Most children with a condition/syndrome, have multiple conditions/syndromes that cut across/require engagement of a range of health and community systems.
   - **System Performance Issues**: Cross cutting system improvements most likely to have biggest impact on improving care in near term.

4. **Children are disproportionately disadvantaged and diverse**
   Higher proportion of children are low income and minority.
State Disparities in CYSHCN Disparities for Factors Promoting School Success

Figure 1. Ratio between Non-CSHCN without EBD and CSCHN with EBD and More Complex Service Needs Meeting All 3 Promoting School Measures (Children age 6-17 years)

Legend of State Markers
- Largest Ratio between Groups: 75-100th Percentile
- Medium-Large Ratio between Groups: 50-74th Percentile
- Medium-Small Ratio between Groups: 25-49th Percentile
- Smallest Ratio between Groups: 0-25th Percentile

National Average of Non-CSHCN without EBD Meeting Promoting Measures (63.6%)
National Average of CSHCN with EBD, More Complex Services Needs Meeting Promoting Measures (36.0%)
<table>
<thead>
<tr>
<th>MCHB Core Outcomes</th>
<th>For Children With Special Health Care Needs (CSHCN)</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 year partnership to achieve comparable data across children, areas and time</td>
<td></td>
</tr>
<tr>
<td>Outcome #1: Families of CYSHCN will be partners in decision-making and are satisfied with the services they receive</td>
<td></td>
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<tr>
<td>Outcome #2: CYSHCN will receive coordinated, ongoing, comprehensive care within a medical home</td>
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<tr>
<td>Outcome #3: Families of CYSHCN will have adequate private and public insurance to pay for the services they need</td>
<td></td>
</tr>
<tr>
<td>Outcome #4: CSHCN who are screened early and continuously for special health care needs</td>
<td></td>
</tr>
<tr>
<td>Outcome #5: Community-based service systems will be organized so families can use them easily</td>
<td></td>
</tr>
<tr>
<td>Outcome #6: Youth with special health care needs will receive services necessary to make a successful transition to adult life.</td>
<td></td>
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</tbody>
</table>
### Whole System, Whole Child View

<table>
<thead>
<tr>
<th>Age 0-11 years:</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>12.7%</td>
<td>15.3%</td>
<td>16.1%</td>
<td>20.2%</td>
<td>25.3%</td>
</tr>
<tr>
<td></td>
<td>CSHCN with one or more EBD* issues</td>
<td>CSHCN with more complex needs</td>
<td>Publicly insured CSHCN</td>
<td>All CSHCN age 0-11</td>
<td>Privately insured CSHCN</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age 12-17 years:</th>
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<th></th>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>6.2%</td>
<td>6.4%</td>
<td>8.9%</td>
<td>13.6%</td>
<td>19.2%</td>
</tr>
<tr>
<td></td>
<td>Publicly insured CSHCN</td>
<td>CSHCN with one or more EBD* issues</td>
<td>CSHCN with more complex needs</td>
<td>All CSHCN age 12-17</td>
<td>Privately insured CSHCN</td>
</tr>
</tbody>
</table>
## OREGON 2009/10
### Whole System, Whole Child View

<table>
<thead>
<tr>
<th>Age Category</th>
<th>Met all CSHCN Measure criteria</th>
<th>Met 2 or fewer criteria</th>
<th>Met 5+ (12-17 only)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age 0-11 (5 criteria)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>16.1%</td>
<td>38.1%</td>
<td>NA</td>
</tr>
<tr>
<td>Private</td>
<td>22.9%</td>
<td>24.1%</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Age 12-17 (6 criteria)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>14.3%</td>
<td>51.6%</td>
<td>18.8%</td>
</tr>
<tr>
<td>Private</td>
<td>2.6%</td>
<td>23.5%</td>
<td>14.3%</td>
</tr>
</tbody>
</table>
CHIPRA: The Initial Core Measures

QUALITY OF CARE: Access
- Total EPSDT eligibles who received dental treatment services (EPSDT CMS Form 416 Line 12C)
- Annual dental visit
- Total eligibles receiving preventive dental services
- Well-child Visits 1) WCVs in the First 15 months of life; 2) WCVs in the third, fourth, fifth and sixth years of life; 3) Adolescent WCV
- HEDIS CAHPS 4.0 including supplements for children with chronic conditions and Medicaid Plans
- Access to primary care providers

QUALITY OF CARE: Health Promotion/Prevention
- Immunizations for 2 year-olds
- Adolescent immunization
- Body Mass Index (BMI) documentation 2 - 18 yrs
- Chlamydia screening 16-20 females
- Rates of screening using standardized screening tools for potential delays in social and emotional development
- Frequency of ongoing prenatal care
- Timeliness of prenatal care

QUALITY OF CARE: Care Management Indicators
- Follow-up care for children prescribed attention-deficit/hyperactivity disorder (ADHD) medication
- Follow up after hospitalization for mental illness
- Annual hemoglobin A1C testing (all children and adolescents diagnosed with diabetes)
- Pharyngitis - appropriate testing
- Child and adolescent Major Depressive Disorder
- HEDIS CAHPS 4.0 including supplements for children with chronic conditions and Medicaid Plans

QUALITY OF CARE: Negative Event Indicators
- % of live births weighing less than 2,500 grams
- Emergency Department Utilization - Average number of emergency room visits per member per reporting period
- Cesarean Rate for Low-risk First Birth Women
- Pediatric catheter associated blood stream infection rates (ICU and high risk nursery patients)
- Annual number of asthma patients (> 1 year-old) with > 1 asthma related ER visit
- Otitis Media with Effusion - avoidance of inappropriate use of systemic antimicrobials
ARTICLES—STATE PROFILES, DURATION OF COVERAGE, AVAILABILITY OF SERVICES, QUALITY MEASURES, MEASURING FAMILY EXPERIENCES OF CARE, STATE QUALITY MEASURE NEEDS, REPORTING QUALITY

A National and State Profile of Leading Health Problems and Health Care Quality for US Children: Key Insurance Disparities and Across-State Variations

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ABSTRACT

BACKGROUND: Parent/child-reported data is valuable and necessary for population-based monitoring of many key child health and health care quality measures relevant to both the Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009 and the Patient Protection and Affordable Care Act of 2010 (ACA).

OBJECTIVES: The aim of this study was to evaluate national and state prevalence of health problems and special health care needs in US children; to estimate health care quality related to adequacy and consistency of insurance coverage, access to specialist, mental health and preventive medical and dental care, developmental screening, and whether children meet criteria for having a medical home, including care coordination and family centeredness; and to assess differences in health and health care quality for children by insurance type, special health care needs status, race/ethnicity, and/or state of residence.

METHODS: National and state level estimates were derived from the 2007 National Survey of Children's Health (N = 94,642; children aged 0–17 years). Variations between children with public versus private sector health insurance, special health care needs, specific conditions, race/ethnicity, and across states were evaluated using multivariate logistic regression and/or standardized statistical tests.

RESULTS: An estimated 43% of US children (32 million) currently have at least 1 of 20 chronic health conditions assessed, increasing to 54.1% when overweight, obesity, or being at risk for developmental delays are included; 19.2% (14.2 million) have conditions resulting in a special health care need, a 1.6% point increase since 2003. Compared with privately insured children, the prevalence, complexity, and severity of health problems were systematically greater for the 29.1% of all children who are publicly insured children after adjusting for variations in demographic and socioeconomic factors. Every five percent of all children in the United States scored positively on a minimal health composite measure: 1) adequate insurance, 2) preventive care visit, and 3) medical home. A 2.2 point difference existed across states and there were wide variations by health condition (diabetes, 22.3%; asthma, 39.3%). After adjustment for demographic and health status differences, quality of care varied between children with public versus private health insurance on all but the following 3 measures: not receiving needed mental health services, access to mental health services, and performance on the minimal health composite. A 4.6 fold (p < 0.01) difference in dental care visits between children who were uninsured and those who had health insurance.

CONCLUSIONS: Findings emphasize the importance of health care insurance, access to care, and health care quality on population health. Differences in health care quality between children with public and private health insurance speak to the pervasive nature of availability, coverage, and access issues for mental health services in the United States, as well as the system-wide problem of care coordination and access issues for pediatric care for all children. Variations across states in key areas amenable to state policy and program management support cross-state learning and improvement efforts.

Keywords: children's health insurance, children's health care, chronic conditions, childhood asthma, mental health, quality of care

AERSCI PEDIATRICS 2011;11:522–533
## Available National and State Data

### Indicators by CHI PRA Core Measure Domain

<table>
<thead>
<tr>
<th>Prevention &amp; Health Promotion</th>
<th>Availability</th>
<th>Management of Acute Conditions</th>
<th>Management of Chronic Conditions</th>
<th>Family Experiences of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well Visits</td>
<td>Adequacy of Health Insurance</td>
<td>N/A</td>
<td>6 CSHCN Core Outcomes (e.g. Medical Home...)</td>
<td>Family-Centered Care</td>
</tr>
<tr>
<td>Dental Visits</td>
<td>Consistency of Health Insurance</td>
<td></td>
<td></td>
<td>Shared Decision Making</td>
</tr>
<tr>
<td>Developmental Surveillance</td>
<td>Mental health Care Access</td>
<td></td>
<td></td>
<td>Ease of accessing special services</td>
</tr>
<tr>
<td>Developmental Screening</td>
<td>Specialist Access</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

- All measures stratified by CSHCN, SES and Race/Ethnicity
Defining and Measuring Access to and Quality of Care

- Insurance Coverage
  - Insurance Status & Consistency
  - Insurance Adequacy

### Consistency of Insurance in Oregon

- Publicly Insured: 11.0
- Privately Insured: 4.9

### Adequacy of Health Insurance in Oregon

- Publicly Insured: 24.8
- Privately Insured: 18.1
Defining and Measuring Access to and Quality of Care

Access to Quality Care

- Receipt of preventive care
  - Child had 1+ preventive visit in past year (All Children) difference aged
  - Child had 1+ preventive visit within past year (All Children) point difference aged
  - Standardized developmental (age 10-71 months; All Children) 36.3 point difference aged

Preventive Services in Oregon

- Preventive Medical Visit:
  - Publicly Insured: 84.8%
  - Privately Insured: 81.8%

- Preventive Dental Visit:
  - Publicly Insured: 75.0%
  - Privately Insured: 80.9%
Access to Quality Care

- Problems getting needed services (All Children: 23.8%)
- Difference across age groups

Did not receive needed services (All Children: 44.4%)

Access to Specialist Services in Oregon

- Specialist Care
  - Publicly Insured: 32.3%
  - Privately Insured: 15.7%

- Mental Health Care
  - Publicly Insured: 64.7%
  - Privately Insured: 34.3%

*Sample size not sufficient to compare developmental screening rates within Oregon.
Defining and Measuring Access to and Quality of Care

Experience of Quality Care

Receipt of family centered care & Medical Home

Coordinated Systems of Care in Oregon

<table>
<thead>
<tr>
<th></th>
<th>Publicly Insured</th>
<th>Privately Insured</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family-Centered Care</td>
<td>59.9</td>
<td>80.9</td>
</tr>
<tr>
<td>Medical Home</td>
<td>48.5</td>
<td>73.4</td>
</tr>
</tbody>
</table>

Child received family centered care (All Children difference: 57.5%; 23.9 point difference)

Met Medical Home Care

75.2% Adj OR: 0.84 (0.72-0.98)
66.5% Adj OR: 0.75 (0.64-0.84)
Defining and Measuring Access to and Quality of Care

- Quality of Care Index
  - Adequate Insurance
  - Preventive Medical Visit in past 12 months
  - Medical Home

Quality of Care Index

Publicly insured children are more likely to have insurance coverage which adequately meets their health needs than privately insured.
Stratification and Aggregation Allow Action-Shaping Assumptions to Be Checked: Do Publicly Insured Children Always Fare Worse?

- Adjusted OR: 2.25 (1.72-2.93)
- Adjusted OR: .50 (.41-.60)
- Adjusted OR: 1.29 (1.03-1.62)
- Adjusted OR: 1.06 (.78-1.43)
Stratification and Aggregation Allow Action-Shaping Assumptions to Be Checked: Very few children have special health care needs?

OREGON: More children meet high threshold CSHCN criteria than entire population of Salem (155.5K); equals 2816 school buses filled with CSHCN—24 miles of school buses lined up back to back; could fill 7.3 Rose Garden stadiums!

CYSHCN + Overweight or Obesity (+85% BMI) = 41% (10-17 Year Olds)

31.6% of children age 10-17 are overweight or obese, with states ranging from 23.1%-44.4%.

Over half of children age 6-17 years have a TV in their bedroom.
<table>
<thead>
<tr>
<th>Condition Description</th>
<th>Publicly Insured Children (N=19,748) % (State Range)</th>
<th>Privately Insured Children (N=64,165) % (State Range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple conditions: has ≥2 of 20 conditions assessed (among children with at least 1 condition)</td>
<td>52.7 (40.9-72.3)</td>
<td>42.1 (35.5-48.4)</td>
</tr>
<tr>
<td>Moderate or severe: parent-rated condition as greater than mild (among child with a least 1 condition)</td>
<td>57.5 (45.6-66.8)</td>
<td>45.6 (40.1-52.1)</td>
</tr>
<tr>
<td>Service need complexity: CSHCN with ≥1 of 20 conditions assessed who require multiple types of special services, beyond primarily prescription medication management</td>
<td>73.4 (58.1-91.5)</td>
<td>52.2 (41.6-67.7)</td>
</tr>
</tbody>
</table>
Data Must Allow Action-Shaping Assumptions to Be Checked

State with the lowest overall rate had the highest insurance disparity
Why a Framework for Measurement?
Why a Framework for Measurement?

A roadmap to ensure measures are strategically selected to provide comprehensive coverage of the dimensions of children’s health care quality in the most actionable and efficient manner possible!
**Core Functions of Any Framework**

- **Understand your population**
- **Assess system performance**
- **Examine improvement opportunities**
- **Select priorities**
- **Set targets**
  - Identify promising improvement models
- **Monitor progress**

Measuring the Performance of the Measurement System
→ Transparency
→ Accessibility
→ Timeliness
→ Quality
→ Feasibility

1. Set shared health and health care quality goals
2. Develop annual reports and standardized measures based on existing data sets
3. Create new measures and data sources
4. Improve data collection, reporting, and analysis
5. Improve public and private capacity to use and report data
Building on Earlier Work

A look back at the Consumer Information Framework

- Initially developed by FACCT for CMS (then HCFA) – June 1997 (CAHMI)
- Adopted by IOM, AHRQ, NCQA, FEHB
- Tested with 700+ consumers:
  - Medicare
  - Commercial
  - Chronic disease
  - Parents of sick children
  - Medicaid

![AHRQ National Healthcare Quality Report Framework](image-url)
Consumer Information Framework - 4 M’s

Key Components to Inform Current Approaches

• **Model:** to organize quality information for decision-making

• **Messages:** to inform and empower key stakeholders to take action (consumers, purchasers, providers, policymakers)

• **Measures:** relevant, understandable evaluations of health care performance maximizing and integrating all sources of data; iterative consideration of set and measure criteria

• **Methods:** Integrated case finding, sampling, data collection, scoring, grading and reporting methods
CAHMI’s Consumer Information Framework*

- **Focus of Measurement:** Collect data on key aims for quality across each patient-centered outcomes of care category
  - Key Domains
    - Results of Good Care (effectiveness, equity, safe)
    - Steps to Good Care (effectiveness, efficiency)
    - Experience of Care (patient centered, timely, equity)
  - Consumer Relevant Outcomes
    - Healthy Development/Staying Healthy
    - Getting Better
    - Living With Illness

- **Data Collection Strategy:** Collect data in ways that create a profile of performance at the child level

- **Scoring and Reporting:** Report data in ways that tell a story to engage partners to act on information provided

*Used in national quality reports and by NCQA and IOM. Developed by FACCT and by the same staff as currently lead the CAHMI*
Identifying Measures Using a Framework

CAHMI Framework for Selection & Application of Pediatric Measures

USER FILTER: Who and for what purpose
- Consumers: selection, education & empowerment
- Purchasers: value-based purchasing
- Program Managers: program evaluation
- Providers: quality improvement

UNIT OF ANALYSIS FILTER:
Setting(s) for measurement activities
- PCPs or Medical Groups
- Community Wide
- Agencies/Orgs
- Public Health

RELEVANT CATEGORIES FILTER:
Performance areas of interest
- The Basics
- Staying health
- Living w/ illness
- Getting Better
- Changing Needs

Core Set of Pediatric Quality Measures

Health Kids Steering Committee Presentation (Christina Bethell) | January 5, 2012
Implementing a Framework
CAHMI’s Sustainable and Integrated Quality Model

Step 1: Identify and convene stakeholders of healthcare measurement activities

Step 2: Identify common goals and needs for information; identify future quality measurement activities; identify technical and financial resources include data sources

Quality Measurement Strategies Designed:
-- High value consumer - centered measures used
-- Access AND quality of care measures used
-- Sampling conducted in way that allows for multiple stakeholders to receive feedback
-- Measures are linked with multiple data sources
Swamp the System (in a good way!)

Consider Measures that can be used at Multiple Levels

- Used to collect data across geographic areas and system and service settings
- Yield data comparable across units of analysis and key subgroups
- Have benchmarks available
- Currently collected and have potential to be adapted through sampling strategies, etc. to yield more robust data for relevant subgroups
### Consumer Information Framework

**Measurement Model - What the CHIPRA Legislation Says**

- **Topics (Goals of Care-Outcomes?)**
  - Clinical quality
  - Health Care Safety
  - Family Experience with Care
  - Health Care in the Most Integrated Setting
  - Elimination of Disparities

- **Types of measure (process, outcome, experience of care)**
  - Structure of the Clinical Care System
  - Process of Care
  - Outcome of Care
  - Patient Experiences of Care

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"clinical quality, health care safety, family experience with health care, health care in the most integrated setting, and elimination of racial, ethnic, and socioeconomic disparities in health and health care."

-- CHIPRA § 401, 123 Stat. 73

"the term ‘pediatric quality measure’ means a measurement of clinical care... including the structure of the clinical care system, the process of care, the outcome of care, or patient experiences of care."

-- CHIPRA § 401, 123 Stat. 75
Consumer Information Framework

Messages - What the CHI PRA Legislation Says

**Messages:** to inform and empower key stakeholders to to take action (establish interest, gain credibility, guide action)

Messages for a broad range of audiences

- Purchasers
- Families
- Health Care Providers

**Audiences Suggested by the CHIPRA legislation**

“Allow purchasers, families, and health care providers to understand the quality of care in relation to the preventive needs of children, treatments aimed at managing and resolving acute conditions, and diagnostic and treatment services whose purpose is to correct or ameliorate physical, mental, or developmental conditions that could, if untreated or poorly treated, become chronic.” -- CHIPRA § 401, 123 Stat. 73
Consumer Information Framework

Methods & Measures - What the CHIPRA Legislation Says

**Methods:** Scoring, grading and presenting performance scores—alone and across domains!

**Measures:** relevant, understandable evaluations of health care performance—allow stratification; maximize value across sources of data and over time

Stratification to Examine Disparities

- Children with special health care needs
- Race/ethnicity
- Socioeconomic status

“The types of measures that, taken together, can be used to estimate the overall national quality of health care for children, including children with special needs, and to perform comparative analyses of pediatric health care quality and racial, ethnic, and socioeconomic disparities in child health and healthcare for children -- CHIPRA § 401, 123 Stat. 72
A few observations across a decade

- Diagnosis not sufficient
  - variation within vs. between conditions;
  - common co-morbidity;
  - mis/missed DX;
- Utilization not sufficient
  - have to wait for over/under/mis-use to identify;
  - Time 1 utilization is a poor predictor for time 2 utilization—HCC predicted 12%
- Non-Condition specific; consequences-based CSHCN identification powerful complement to DX and Utilization data
Defining Special Health Care Needs

**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
Stratifying Within CSHCN Stratification Expenditure Variation Within CSHCN

Median Medical Expenditures (MEPS)

- 25.7% in this group have asthma; 75.3% learning disability; 56.8% behavioral problems; 42.7% anxiety/depression

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Non-CYSHCN</th>
<th>All CYSHCN</th>
<th>Met 1 of 5 Criteria</th>
<th>Met 2 of 5 Criteria</th>
<th>Met 3 of 5 Criteria</th>
<th>Met 4 to all 5 Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>About 47% of CYSHCN</td>
<td>717</td>
<td>2399</td>
<td>1383</td>
<td>1952</td>
<td>2667</td>
<td>7881</td>
</tr>
<tr>
<td>About 23% of CYSHCN</td>
<td></td>
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<tr>
<td>About 16% of CYSHCN</td>
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<tr>
<td>About 14% of CYSHCN</td>
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</tr>
</tbody>
</table>
Family Experience of Financial Problems Due to Child's Health Needs

Highest cost group also had highest unmet need for specialized services (26.5% using conservative assessment)

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>All CYSHCN</td>
<td>20.90%</td>
</tr>
<tr>
<td>Met 1 of 5 Criteria</td>
<td>12.00%</td>
</tr>
<tr>
<td>Met 2 of 5 Criteria</td>
<td>21.40%</td>
</tr>
<tr>
<td>Met 3 of 5 Criteria</td>
<td>33.30%</td>
</tr>
<tr>
<td>Met 4 to all 5 Criteria</td>
<td>45.90%</td>
</tr>
</tbody>
</table>
Parent(s) Cut Back/Stopped Work Due to Child's Health Needs

- CYSHCN: 30.0%
- Met 1 of 5 Criteria: 19.0%
- Met 2 of 5 Criteria: 32.5%
- Met 3 of 5 Criteria: 43.7%
- Met 4+ of 5 Criteria: 59.2%
Doctor Visits Due to Illness and Emergency Room Visits by CSHCN Subgroups

- Non-CYSHCN: 19.9%
- CYSHCN: 43.4%
- Met 1 of 5 Criteria: 38.9%
- Met 4+ of 5 Criteria: 56.3%
- 2+ ER Visits: 4.10%, 13.10%, 9.40%, 24.60%

CAHMI
The Child & Adolescent Health Measurement Initiative

Health Kids Steering Committee Presentation (Christina Bethell) | January 5, 2012
System Performance By CSHCN Subgroups

Percentage of CSHCN Meeting all Age-Relevant Core Outcomes by Number of Screener Criterion Met

*National and state-level prevalence of all outcomes by demographics & subgroups are available.

CAHMI

Health Kids Steering Committee Presentation (Christina Bethell) | January 5, 2012
Impact on School Success by CYSHCN Subgroups (Complexity and EBD)

- Less Complex CYSHCN, No EBD: 33.4%
- Less Complex CYSHCN, EBD: 49.3%
- More Complex CYSHCN, No EBD: 46.2%
- More Complex CYSHCN, EBD: 64.8%
- Failed to Meet Minimal Factors Promoting School Success
- Repeated 1+ Grades

Health Kids Steering Committee Presentation (Christina Bethell) | January 5, 2012
No Wrong Algorithm?  
Can We Have the Best of All Worlds

1. ID CSHCN at population level using the consequences-based, non-condition specific CSHCN Screener along with other pertinent stratifying and analytic variables requiring parent/youth report (race/ethnicity, SES, risk and protective factors, experience of a medical home, adequacy of insurance)  
   - **Experience on use of the CSHCN Screener for Risk**  
     - Adjustment showed improvement in predicting future costs above use of prior expenditures. HCC only explained 12.1%.  
     - (Yu and Dick, 2010 HSR)

   - Repeat annually or at trigger points

2. Implement CRG-like method and link to survey-based screener data

3. Link all this to claims, costs, utilization

4. Data valuable for risk adjustment, quality measurement and quality improvement, pay for performance and research—we need to keep learning!
# National Healthcare Quality Report Framework

**Components of Health Care Quality**

<table>
<thead>
<tr>
<th>Health care needs</th>
<th>Effectiveness</th>
<th>Safety</th>
<th>Timeliness</th>
<th>Patient centeredness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staying healthy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting better</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with illness or disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>End of life care</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

- Equity is a component of health care quality that applies to all cells in the matrix
- Resource generation is another component discussed in the National Healthcare Report
- The first NHQR is due to Congress in 2003
Domain 1: Patient and Family Engagement
• Shared decision-making (11)
• Bridge gap between expert and public knowledge (10)
• Patient/family centered systems of care (8)
• Communication, respect and cultural sensitivity (7)
• Health literacy (6)
• Consumer empowerment, including transparency (3)
• Patient experience with care (3)
• Patient/family activation (2)

Domain 2: Care Coordination including Transitions
• Having a Medical or “Health Home” (14)
• Access to referrals and appropriate follow-up (11)
• Success/failure rates in handoffs (11)
• Help coordinating care (4)
• Effective transition to adult services (2)
Domain 3: Population Health including Primary and Secondary Prevention & Communities

- Population health outcomes (15)
- Early and continuous screening and appropriate, timely follow-up (12)
- Community and neighborhood resources, support and safety (8)
- Population health oriented systems of care (needs assessment, shared accountability, etc) (4)
- Health Promotion (2)

Domain 4: Clinical Effectiveness in Acute and Chronic Care Management

- Appropriate tests and follow-up (15)
- Medications (appropriateness, management, adherence) (12)
- Self care management and support (12)
- Effective care plans (10)
- Burden of Illness, Symptoms & Functional Status (6)
Domain 5: Safety
- Adverse events (13)
- Patient communication and knowledge regarding consent & safety (2)
- Medication and sedation safety (1)

Domain 6: Overuse
- Overuse of procedures and surgery (11)
- Medication overuse (10)
- Avoidable ED and hospital readmission (7)
- Duplicate testing (2)

Domain 7: Palliative Care
- Caregiver/family burden (2)
- Advance preparations defined and honored (1)
- Pain management and symptom relief (0)
- Access to supportive services (0)
- Access to spiritual, cultural and psychological needs (0)
Leverage the Current Context to Innovate A System Trying to Transform!

AIM: Better Care

AIM: Healthier People and Communities

AIM: Affordable Care

Priorities

- Health and Well Being
- Patient/Family Centered Care
- Effective Communication and Coordination
- Prevention and Treatment Leading Causes
- Efficient and Affordable
- Patient Safety
Example Health and Wellness Measures
National Priority Partnerships (NPP)

• Adequate social supports
• Emergency department visits for injuries
• Healthy behavior index
• Binge drinking
• Obesity
• Depression
• Dental caries and untreated dental decay
• Use of the oral health systems
Example Patient and Family Centered Care Measures Concepts

- Patient and family experience of quality, safety and access (not satisfaction!)
- Patient involvement in decisions and health care
- Joint development of treatment goals and plans of care
- Confidence in managing chronic conditions
- Easy to understand instruction to manage conditions
1. Ensure child health care leaders (YOU!) **speak with one voice** to advance a common foundation statewide to:
   - Identify and use performance measures for all populations
   - Ensure approaches for financing, data collection, aggregation, auditing and reporting are child centered and actionable

2. **Quality Strategy** (Required activity)
   -- Define a measurement framework (Innovative example: MA)
   -- Create a culture of quality (Innovative example: RI)

3. **Leverage** contracts with MCO, PCCM Providers
   - **Required performance measures**
     a. Require actionable, child centered quality measures
     b. Consider cycling measures (Innovative Example: NY)
     c. Consider survey-based measurements that are beyond satisfaction and experience of care—content of care; ease of sampling and stratification
   - **Required performance improvement projects**
     a. Require concentrated efforts on specific topic areas
     b. Encourage, and give incentives, for collaborative efforts
     c. Consider models of consumer involvement and patient engagement (with teeth)
     d. Consider enhancing these efforts by Medicaid sponsored QI
   - **Pay for Performance (P4P)**
     a. Consider P4P efforts, Consider measures beyond access to care/PCMH-like
4. **Invest** in a “system” to coordinate and invest in the ongoing use and improvement of quality measures
   *Focus needed on:*
   -- Developing the data collection infrastructure & reporting systems required to efficiently and effectively collect and use the quality information

5. Establish **infrastructure** to support ongoing learning networks and fully leverage national resources to help states identify tools and models to measure and improve quality
   - related to core measures
   - related to other measures of health care quality for children
   -- To create profiles of performance in each of the key aims for and key outcomes for care

6. Develop **demonstrations** that identify effective models for **engaging consumers** in using quality information and becoming **active partners** in their health care
   - make value based decisions in health care
   - to partner in defining and using quality information drive improvements in care with providers they have already chosen

Some recommendations to consider
Customer Satisfaction and Content of Care
Specific but not sensitive!

MOV/Art of Medicine and PHDS
Office Level: MOV Q03 by Selected PHDS Item

Survey Item
Mean Score Rank Groups: 0=Lowest 2; 1=Middle 6; 2=Highest 2
Customer Satisfaction and Content of Care
Specific but not sensitive!
Seeing improvement in access and quality of care measures: The mandate for patient engagement and activation

**Shared ownership and collaboration yielding the best possible outcomes**

- Families
  - Identification of positive and negative inputs
  - Discuss family history
  - Discuss child’s unique needs
  - Informed decisions
  - Reduction of familial stress
  - Improved daily routines
  - Increased use of community resources

- Health Care Providers
  - Positive, optimally timed interventions
  - Support during critical periods
  - Individualized health care
  - Improved self-care and self-awareness
  - Encourage and make it easy for family to raise concerns
  - Make families feel like a partner in child’s care
  - Respect family’s treatment choices
  - Teach family how to best support child’s development
  - Discuss range of treatment options
PARENTS— We Need You

Well-child care is about much more than your child getting weighed or immunized.

We aim to PARTNER WITH YOU to CUSTOMIZE YOUR CHILD’S CARE and GIVE THE BEST CARE possible.

The Children’s Clinic is changing well-child visits for young children!

Here is What Parents Of Children Under 4 Can Expect:

1. After Your Child’s Well Visit: Give Us Feedback
   by completing an online, confidential questionnaire at home about the health care your child received.
   
   When: July-December 2009
   The Children’s Clinic will give eligible children’s parents a postcard with information about this survey.

2. Using Your Feedback: The Children’s Clinic Will Understand Where We Can Do Better

   When: December 2009
   Our partners in this project, the Child and Adolescent Health Measurement Initiative (CAHMI), will share summarized, confidential questionnaire results with us.

3. Before Your Child’s Well Visit: Learn About & Identify Your Priorities
   by completing an online tool at home. You and your child’s doctor can use this information to customize the well-visit to your child and family needs.
   
   Coming Soon!
   When: Early 2010
   We will be asking you to do this online tool before your well-visits beginning in early 2010.

THANK YOU IN ADVANCE FOR PARTNERING WITH US
Some recommendations to consider

6. Innovate in **identification and measurement for CSHCN** and socio-economic subgroups

- Diagnosis not sufficient (variation within vs. between conditions; common co-morbidity; mis/missed DX;
- Utilization not sufficient (have to wait for over/under/mis-use to identify; present utilization spotty predictor for future utilization—overall and at child level—about 12% predicted)
- Non-Condition specific; consequences-based CSHCN identification powerful complement to DX and Utilization data
Why does it matter?

Driver system change through measurement and reporting on performance

Knowledge and evidence on what is needed and what is effective

Adoption of best practices focused on achieving outcomes

Drive system change through implementation of best practice improvement innovations

Health Outcomes for Children and Adolescents
Why does it matter?

- Policies that seek to remedy deficits incurred in early years are much more costly than early investments wisely made, and do not restore lost capacities even when large costs are incurred. The later in life we attempt to repair early deficits, the costlier the remediation becomes.

James J. Heckman, PhD
Nobel Laureate in Economics, 2000
Extra Slides
Christina Bethell
January 5, 2012
The Data Menu

The H’Ordeurves
- Characteristics of population
- Counts of services
- Basic satisfaction with services

The Appetizer
- Processes of Care-got needed services
- Intermediate outcomes
- Changes in behavior, knowledge, attitudes, etc.

The First Course
- Attribution and associations between processes, intermediate outcomes and
- Services organization, delivery, coverage, population characteristics, etc.
The Main Course!

- Health Outcomes
- Attributed to Programs and Services
- In a Valid Way
Healthy Consumption of Data

• Plan Ahead—be intentional
• Don’t fill up on H’Ordeurves
• Don’t get caught by “fast food” data
• Use a recipe
• Don’t order more than you can eat
• Know when you are full. There is a point where more is not better!
• Save room for the main course!
Measure Mantra – Part 2

*What turns data into a measure*

- A denominator
- A numerator
- A clearly specified, standardized strategy for **collecting** the data
- Clearly specified **scoring methodology**
- Mechanisms for **reporting and interpreting** results
Differences between Populations: Public versus Private Insurance

Table 2. Prevalence of Special Health Care Needs, Chronic Health Problems, and Key Health Risks for All Children Aged 0 to 17 Years, by Type of Health Insurance Coverage

<table>
<thead>
<tr>
<th>Condition Description</th>
<th>All Children Aged 0–17 Years (N = 91,642) % (Quartiles)</th>
<th>Publicly Insured Children (n = 19,748) % (Quartiles)</th>
<th>Privately Insured Children (n = 64,165) % (Quartiles)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN‡: has ongoing health conditions resulting in above routine and/or special health care need (CSHCN)</td>
<td>19.2 (14.5; 17.9; 22.7; 24.4)</td>
<td>23.6 (12.5; 22.9; 30.5; 37.1)</td>
<td>18.1 (13.2; 16.6; 19.8; 23.0)</td>
</tr>
<tr>
<td>Chronic condition: currently has ≥1 of 20 chronic conditions (see Appendix B for list of conditions; 90.2% of CSHCN had ≥1 from list)</td>
<td>43.0 (33.5; 41.2; 47.0; 53.3)</td>
<td>47.4 (28.4; 47.4; 55.8; 61.7)</td>
<td>42.3 (33.8; 39.6; 45.1; 49.5)</td>
</tr>
<tr>
<td>Multiple conditions: has ≥2 of 20 conditions assessed (among children with at least 1 condition) (See Appendix B for condition-specific results)</td>
<td>45.0 (37.1; 43.2; 48.7; 51.1)</td>
<td>52.7 (40.9; 49.7; 59.3; 72.3)</td>
<td>42.1 (35.5; 39.8; 44.1; 48.4)</td>
</tr>
<tr>
<td>Moderate or severe: parent-rated condition as greater than mild</td>
<td>49.9 (44.0; 47.8; 52.1; 55.3)</td>
<td>57.5 (45.6; 55.4; 62.3; 66.8)</td>
<td>45.6 (40.1; 43.6; 48.3; 52.1)</td>
</tr>
<tr>
<td>Service need complexity: CSHCN with ≥1 of 20 conditions assessed who require multiple types of special services, beyond primarily prescription medication management</td>
<td>60.3 (52.0; 57.9; 65.0; 77.2)</td>
<td>73.4 (58.1; 67.5; 80.1; 91.5)</td>
<td>52.2 (41.6; 49.2; 56.8; 67.7)</td>
</tr>
<tr>
<td>Health risks/BMI§: meets criteria for being overweight or obese (aged 10–17 years only)</td>
<td>31.6 (23.1; 29.4; 33.9; 44.4)</td>
<td>43.2 (27.2; 37.2; 45.3; 52.5)</td>
<td>27.3 (18.4; 23.9; 26.8; 37.8)</td>
</tr>
<tr>
<td>Health risks/development: meets criteria for being at risk for developmental, social or behavioral delays (aged &lt;6 years)</td>
<td>26.4 (18.6; 22.7; 27.7; 35.2)</td>
<td>32.7 (16.8; 26.6; 36.7; 44.2)</td>
<td>22.1 (14.7; 19.5; 24.2; 26.3)</td>
</tr>
</tbody>
</table>

*State-specific findings can be found in Appendices C1, C2, and C3. Statistical analysis showed no significant outliers in the distribution across states (Grubbs test). State distributions in parentheses (0% lowest across states, 25%, 75%, and 100% highest across states).
†Adjusted for child’s age, sex, race/ethnicity, and household income using logistic regression analysis. OR = odds ratio; CI = confidence interval.
‡CSHCN = children with special health care needs.
§BMI = body mass index.

Publicly insured children are more likely to have special health care needs, have more complex service needs and more likely to be overweight/obese.
The Medical Neighborhood:
- Clear agreement on & delineation of the respective roles of neighbors
- Sharing of the clinical information (+/- HIE)
- Care teams to develop individualized care plans for complex patients
- Continuity of needed medical care during transitions
- Focus on patient preferences
- Strong community linkages
Innovative Delivery Systems

• Team based care: greater utilization of non-MD providers

• Intensive management
  – 24X7 access via clinic visit, home visit, email and social media

• Care coordination
  – Care coordinator for each family
  – Care plans
  – Co-management agreements
  – Hospital at home

• Enhanced family involvement
  – Individualized patient goals
  – Use of lay navigators
  – System navigation education for families
  – Family participation in planning and operations
Innovative Delivery Systems

• Information systems
  – HER
  – PHR
  – Home telemetry
• Enhanced home care programs
  – Regular home visits
  – Hospital at home program
• Mental and behavioral health
  – Mental health professional part of the team
  – All families receive mental health assessment
• Transitions program
  – Transition to school/adolescence
  – Transition to adulthood
Innovative Payment Systems

PROMISING PAYMENT REFORM: RISK-SHARING WITH ACCOUNTABLE CARE ORGANIZATIONS
Suzanne F. Delbanco: Catalyst for Payment Reform
Innovative Payment Systems

• Movement away from Fee for Service (FFS)
  – FFS with full reimbursement of Care Coordination CPT codes and Nurse Coordinator codes
  – Bundled payments
  – Partial/full capitation
  – Episode or case based reimbursement
  – Global payments of population health

• Shared savings if cost/quality goals exceeded

• Shared risk
  – Bonus at risk
  – Market share risk (patients incentivized to go to low cost providers)
  – Risk of baseline revenue loss if you do not meet cost/quality goals
  – Financial risk for health of population

None of these risk based incentive systems have been rigorously evaluated and shown to be effective
Why Wait? Working with what we have available.

Using the National Survey Indicators

• National Survey of Children’s Health (NSCH)
• National Survey of Children with Special Health Care Needs (NS-CSHCN)
• Both surveys are conducted using State and Local Area Integrated Telephone Survey (SLAITS)
  – Surveys are administered using Computer-Assisted Telephone Interviewing (CATI) Instruments
National Survey Data

Applying the Results at Multiple Levels

• Sampling weights permit national and state-specific estimates of health and well-being
  – Sub-state data for Rural/Urban areas is available on DRC website
  – Local – County estimates not available in the survey, however, synthetic estimates are possible!

• Weights are adjusted to match American Community Survey population totals for various demographic groups
We all know availability of data does not equal access or effective use of data

Meaningful Data Available

Simple and Usable Quick Access Mechanisms

Application and Interpretation Assistance
Welcome to the Data Resource Center for Child & Adolescent Health!

Welcome to the newly redesigned DRC website. Take a tour of the site and give us your feedback.

The mission of the Data Resource Center (DRC) is to take the voices of parents, gathered through the National Survey of Children’s Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN), and share the results through this online resource so they can be used by researchers, policymakers, family advocates and consumers to promote a higher quality health care system for children, youth and families. Learn more about the DRC.

DRC Highlights

- Child Obesity State Report Cards
- New NS-CSHCN Data Trends
- New chartbook comparing CSHCN with children who do not have special health care needs

Most Popular Topics

What you can do on the DRC website?

- Learn about the National Survey of Children’s Health and the National Survey of Children with Special Health Care Needs
- Browse national and state findings on hundreds of child health indicators
- Search data based on numerous important topics and subgroups of children
- Download and print snapshot profiles on key

Data at a Glance

At your fingertips—easy-to-read data snapshots for each state

State/Region

Narrow

Browse Data Snapshots

childhealthdata National study finds that providing insurance to the poor helps them maintain both health and financial stability: http://t.co/y0XSHib
4 days ago • reply • retweet • favorite

childhealthdata 1 in 5 high school students meets the medical criteria for addiction, according to a Columbia study. Read an article at http://t.co/a30x4H2
6 days ago • reply • retweet • favorite
What Data are Available on the DRC Website

• Data Snapshots
  – View Multiple Indicators from each survey
  – Compare Multiple Indicators Across Years
  – View Topic Specific Snapshots

• Individual Indicators
  – Available by state, region, and nationwide
  – Can be stratified by subgroups
  – Compare all states on individual indicators

• State Ranking Maps
Medical Home Data Portal
www.medicalhomedata.org

This website presents state-by-state summaries and across-state comparisons on children’s medical home using standardized data. The collection of these data was initiated and sponsored by the federal Maternal and Child Health Bureau, conducted by the National Center for Health Statistics, and based upon the American Academy of Pediatrics (AAP) definition of medical home.

What is a Medical Home?
The AAP developed the medical home as a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective to every child and adolescent. A medical home addresses preventive, acute, and chronic care from birth through transition to adulthood. A medical home facilitates an integrated health system with an interdisciplinary team of patients and families, primary care physicians, specialists and subspecialists, hospitals and healthcare facilities, public health, and the community.

What Data is Available?
AAP Guidelines and across-state comparisons for all children and children with special health care needs. Findings are presented by subgroups of children. The medical home measure includes an assessment of whether children and youth:
- Have a personal doctor or nurse
- Have a usual source of care
- Receive care that is family-centered
- Receive care that is culturally sensitive
- Obtain needed specialty care referrals
- Receive needed help coordinating care across multiple providers and types of services

Access Data For Your State
- Get one-page at-a-glance profiles on how many children in your state meet overall criteria for having a medical home and topic-by-topic specific findings for:
  - All children in your state - using data from the 2007 National Survey of Children’s Health (NSCH)
  - All children with special health care needs in your state - using data from the 2005/06 National Survey of Children with Special Health Care Needs (NS-CSHCN)
- Interactively search and compare measures by important subgroups of children, such as age, sex, race/ethnicity, insurance type, and household income

Compare Your State
- Compare your state to other states and the nation on the percentage of children who receive ongoing, comprehensive, and coordinated care within a medical home
- Download maps comparing medical home measures across all states in the US
- View state rankings on each topic included in the medical home measure for all children and CSHCN

Additional Resources
- Learn about the history and development of the medical home concept
- Learn about the patient-centered measurement of Medical Home
- Get tools and resources for implementing medical home in pediatric practices
- Find resources for families
- Link to important articles and websites

The Medical Home Data website is developed by the Child & Adolescent Health Measurement Initiative in collaboration with the American Academy of Pediatrics. The Medical Home Data website is supported by the Maternal & Child Health Bureau, Health Resources & Services Administration through Cooperative Agreement with the CHHI AAP.
# How the Data Resource Center Can Support Improvement Partnerships

<table>
<thead>
<tr>
<th><strong>Understand your population</strong></th>
<th>User generated tables, bar and pie charts, and customizable reports supply prevalence estimates and population counts to help define your population of CSCHN and their health needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assess system performance</strong></td>
<td>Immediate access to over 100 state-specific indicators of child health and well-being and system performance for children overall and children with special health care needs (CSHCN).</td>
</tr>
<tr>
<td><strong>Examine improvement opportunities</strong></td>
<td>“Point and click” menu allows users to explore disparities and gaps in access and services for different population subgroups of children and CSHCN.</td>
</tr>
<tr>
<td><strong>Select priorities</strong></td>
<td>User generated tables, bar and pie charts, and customizable reports supply prevalence estimates and population counts to help guide selection of priority needs.</td>
</tr>
<tr>
<td><strong>Set targets</strong></td>
<td>“All States” ranking maps and tables provide benchmark data to assist in identifying state-negotiated performance measure targets.</td>
</tr>
<tr>
<td><strong>Identify promising improvement models</strong></td>
<td>Information on national, within and across States variation using standardized indicators helps identify where quality is better and can help in cross-state learning for purposes of identifying promising models for improvement as well as identify key collaborators for improvement.</td>
</tr>
<tr>
<td><strong>Monitor progress</strong></td>
<td>Centralized resource for standardized, population-based survey questions to use in collecting child health and health care quality data locally</td>
</tr>
</tbody>
</table>
CSHCN Identification: Relevant Observations

• Prevalence of CYSHCN varies, often widely, and remains after demographic adjustment
• Prevalence varies at a point in time as well as over time within same unit of analysis as well (partly due to child development and also impacted by quality of care and many other factors)
• Prevalence, child and family impact and expenditures variations are substantial within CYSHCN (by complexity of service needs, often not DX related) and often impacted by presence of emotional, behavioral or developmental problems (EBD), supporting need for integrated care (“health neighborhood”)
2.08 to 10.5 fold variation across states in prevalence of CYSHCN subgroups

<table>
<thead>
<tr>
<th>National Prevalence All Children</th>
<th>Prevalence Variation Across States All Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>CYSHCN (22.9%)</td>
<td>1.58 fold (18.2%-28.9%)</td>
</tr>
<tr>
<td>EBD (13.5%)</td>
<td>3.25 fold (8.9%-28.9%)</td>
</tr>
<tr>
<td>% non-CYSHCN, no EBD (74.2%)</td>
<td>1.18 fold (67.7%-80.0%)</td>
</tr>
<tr>
<td>% non-CYSHCN, EBD (2.9%)</td>
<td>3.28 fold (1.4%-4.6%)</td>
</tr>
<tr>
<td>% CYSHCN, less complex, no EBD (7.3%; 31.9% of CYSHCN)</td>
<td>2.23 fold (4.4%-9.8%)</td>
</tr>
<tr>
<td>% CYSHCN, less complex, EBD (1.7%; 7.3% of CYSHCN)</td>
<td>10.5 fold (.4%-4.2%)</td>
</tr>
<tr>
<td>% CYSHCN, more complex, no EBD (5.0%; 21.6% of CYSHCN)</td>
<td>2.70 fold (2.7%-7.3%)</td>
</tr>
<tr>
<td>% CYSHCN, more complex, EBD (9.0%; 39.3% of CYSHCN)</td>
<td>2.08 fold (6.4%-13.3%)</td>
</tr>
</tbody>
</table>
Identification Method for Statistics Presented

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
The CSHCN Screener

• Reliably identifies children requiring on-going medical and other health-related services
• Can be used to stratify children into meaningful subgroups related to condition complexity
• Is sensitive to health care practice patterns (such as those related to cultural differences)
• Yields results that can be influenced by differences in survey administration

• Provides a key health indicator that is related to the home environment and the well-being of children and their families
Cross-Method Comparisons

• Over 93% of identified CSHCN had at least one specific chronic health condition or problem, and most had two or more
• Over 98% of identified CSHCN had some type of functional difficulty, as defined by the International Classification of Functioning (ICF)
Who is Identified by the Screener?

• All or nearly all children with complex health conditions such as:
  – Cerebral palsy; cystic fibrosis; muscular dystrophy
  – Rare metabolic or genetic disorders
  – Mental retardation; developmental delay; autism
  – Sickle cell anemia; Down Syndrome; diabetes

• Only those children whose asthma, ADHD, allergies, or other conditions result in:
  – Elevated service use,
  – Long-term use of prescription medicine, or
  – Limitations in functioning
Who is Missed by the Screener?

• The CSHCN Screener is likely to miss children who have only:
  – Food or environmental allergies
  – Special diet (e.g., lactose intolerance)
  – Vision problems (e.g., amblyopia, colorblindness)
  – Developmental delays early in life

● Some parents of children with speech problems, learning disabilities, developmental delay, and conduct problems report consequences but then say they are not due to “health conditions”
Key CSHCN Screening Specification Challenges

- No inherent gold standard or clear demarcations along CSHCN definitional continuum
- Social construction of illness & differing views/norms about illness & health seeking behavior
- Condition diagnosis delays, inaccuracies, inconsistencies, miscommunications and miscodes
- Confounding effect of variations in services referral, availability access and appropriateness
- Primacy of a condition by condition view and services fragmentation vs. a whole person or whole systems perspective

Common Questions About Screening

- Questions of under-identification of CSHCN
- Questions of over-identification of CSHCN
- Questions of stratification within CSHCN
- Questions of application across populations and settings

Multiple Data Sources Used to Cross Validate Screening

- Parent reported data about: (1) specific health service needs and use; (2) presence of any ongoing health conditions; (3) specific health conditions, symptoms, problems child; (4) cognitive salience and
- Clinical encounter and claims data on: (1) diagnoses; (2) procedures; (3) treatments
- Medical chart reviews using standardized data extraction protocols; compare findings across pediatric providers
- In depth comparisons to non-CSHCN, children enrolled in programs (e.g. SSI) and across possible CSHCN subgroups
<table>
<thead>
<tr>
<th>Issue</th>
<th>Quality Improvement</th>
<th>Public Accountability</th>
</tr>
</thead>
<tbody>
<tr>
<td>What to measure</td>
<td>Biggest gap between practice and science</td>
<td>Measures with wide public importance</td>
</tr>
<tr>
<td>Requester or Audience</td>
<td>Internal (providers, managers)</td>
<td>External (consumers, purchasers)</td>
</tr>
<tr>
<td>Purpose</td>
<td>Identify process to be improved or test results of efforts</td>
<td>Make a purchase decision, provide reassurance to the public, provide incentive for change</td>
</tr>
<tr>
<td>Frequency of measure</td>
<td>Very frequent or continuous (feedback daily, weekly, etc.)</td>
<td>Infrequently (e.g. annually)</td>
</tr>
<tr>
<td>Comparison</td>
<td>Longitudinal, within one unit, or external for benchmarking</td>
<td>Cross-sectional (across units)</td>
</tr>
<tr>
<td>Sample size</td>
<td>Often relatively small</td>
<td>Large samples with small confidence intervals</td>
</tr>
<tr>
<td>Unit of analysis</td>
<td>Smallest relevant unit that can take action to improve</td>
<td>Often aggregate, increasingly disaggregated</td>
</tr>
<tr>
<td>Severity adjustment</td>
<td>Often not necessary if processes are changing but input are not</td>
<td>Often critical for fairness</td>
</tr>
<tr>
<td>Detection of bias</td>
<td>No audit, measurement internal</td>
<td>External audit</td>
</tr>
<tr>
<td>Level of sophistication</td>
<td>Simple, not likely to be challenged</td>
<td>Rigorous and defensible to multiple, often resistant, audiences</td>
</tr>
<tr>
<td>Level of detail</td>
<td>Very specific, often miniscule</td>
<td>Summarized, global</td>
</tr>
<tr>
<td>Expected response</td>
<td>Behavior change</td>
<td>Decision-making primary, behavior change secondary</td>
</tr>
<tr>
<td>Need for confidentiality</td>
<td>Very high</td>
<td>None</td>
</tr>
</tbody>
</table>
National prevalence of DS-PC among children 10-71 months was 19.5%, ranging from 10.7% in Pennsylvania to 47.0% in North Carolina.
Figure 3: Proportion of children age 12-71 months with an early intervention plan: by developmental risk status and parent completion of a standardized developmental screening instrument (DS_PC)

- Proportion with an Early Intervention Plan Among Children Whose Doctor or Health Care Provider Had the Parent Complete a Standardized Developmental Screening Instrument In Past 12 Months
  - All Children (12-71 months): 8.6% (P=.001)
  - Among children categorized as high risk (PEDS): 34.7% (P<.001)
- Proportion with an Early Intervention Plan Among Children Whose Doctor or Other Health Care Provider Did NOT have the Parent Complete a Standardized Developmental Screening Instrument In Past 12 Months
  - All Children (12-71 months): 3.6%

Data: 2007 National Survey of Children's Health
Results
Disparities in the Rate of DS-PC Across States
By Type of Health Insurance

Legend of State Markers
- Smallest Ratio 0-25th Percentile: 0.239-1.022
- Medium-Small Ratio 25-49th Percentile: 1.025-1.342
- Medium-Large Ratio 50-74th Percentile: 1.343-1.613
- Largest Ratio 75-100th Percentile: 1.634-3.445

National Average of Privately Insured Children (17.8%)
National Average of Publicly Insured Children (23.6%)
<table>
<thead>
<tr>
<th></th>
<th>Non-CSHCN</th>
<th>All CSHCN</th>
<th>CSHCN Meeting RX Use Criteria Only</th>
<th>CSHCN meeting Functional Limitations Criteria (98.3% met other criteria as well)</th>
<th>CSHCN With Only Asthma and/or Allergies as Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of all CSHCN</td>
<td>N/A</td>
<td>100%</td>
<td>43.7%</td>
<td>21.5%</td>
<td>34.7%</td>
</tr>
<tr>
<td>Mean # doctor visits</td>
<td>2.3</td>
<td>5.1</td>
<td>4.1</td>
<td>6.6</td>
<td>4.5</td>
</tr>
<tr>
<td>Percentage with two or more ER visits</td>
<td>4.8%</td>
<td>19.3%</td>
<td>13.9%</td>
<td>29.7%</td>
<td>16.2%</td>
</tr>
<tr>
<td>Mean # current conditions reported</td>
<td>0.3</td>
<td>1.9</td>
<td>1.5</td>
<td>2.7</td>
<td>1.5</td>
</tr>
<tr>
<td>Two or more conditions reported</td>
<td>4.3%</td>
<td>57.2%</td>
<td>54.3%</td>
<td>76.0%</td>
<td>N/A</td>
</tr>
<tr>
<td>Mean # of functional difficulties reported</td>
<td>0.3</td>
<td>2.5</td>
<td>1.2</td>
<td>4.5</td>
<td>1.2</td>
</tr>
<tr>
<td>Two or more functional difficulties</td>
<td>6.7%</td>
<td>54.2%</td>
<td>26.2%</td>
<td>85.8%</td>
<td>22.2%</td>
</tr>
</tbody>
</table>
Community-based services are organized for ease of use.

Children are screened early and continuously for special health care needs.

Youth with special health care needs receive services necessary for a successful transition to adult life.

Families of CSHCN have adequate insurance to pay for the services they need.

Families of CSHCN are partners in decision making at all levels.
1. Children screened prenatally and through transition to adulthood, especially during critical periods and transitions. 
2. Screening performed by health care providers, families, teachers and any other adults in working with child.

- Identification of diverse kinds of emerging needs as early as possible.
- Identification of family’s strengths.
- Identification of family or environmental stressors (poverty, mental health issues, difficult family dynamics, etc)

- Appropriate and timely treatment and care.
- Maximization and encouragement of family’s strengths.
- Family linked to resources in the community that can help relieve stressor(s).

- Minimized short and long-term consequences.
- Improved child well-being and resilience.
- Improved daily inputs and routine for child.