Resources for Risk Adjustment and Other Financial Protections for Children and Youth with Special Health Care Needs in Our Evolving Health Care System

This document contains the presentations from the September 2011 Expert Workgroup Meeting convened to discuss risk adjustment for children and youth with special health care needs (CYSHCN). It accompanies the report Risk Adjustment and Other Financial Protections for CYSHCN in Our Evolving Health Care System.

Expert Workgroup Meeting Agenda, September 26, 2011

Moderator/facilitator: Sara Bachman

9:30 - 9:45 a.m. Welcome and Introductions – Lynda Honberg, Carol Tobias

9:45 - 10:30 a.m. Health care needs of CYSHCN and why financial protection is important - John Neff

10:30 - 11:15 a.m. An overview of risk adjustment strategies - Dave Knutson

11:15 AM - 12:00 p.m. Provider and plan experiences with risk adjustment for CYSHCN - Chris Born

12:30 - 1:30 p.m. Risk adjustment through the exchanges under health reform - Sara Bachman

1:30 - 2:30 p.m. Other financial protections for CYSHCN (stop-loss, reinsurance, high risk pools, benefit exceptions) - Carol Tobias and Cindy Ehnes

2:45 - 3:30 p.m. Aligning Financing and Quality for CYSHCN - Christina Bethell

3:30 - 4:30 p.m. Where do we go from here? Practical application of this knowledge - Sara Bachman

The following were presented at the meeting:

Carol Tobias, MMHS, Catalyst Center, Health & Disability Working Group, Boston University School of Public Health

Kickoff Presentation

John Neff, MD, Center for Children with Special Needs, Seattle Children’s Hospital and Regional Medical Center

Health Care Needs of CYSHCN and Why Financial Protection Is Important

Christina Bethell, PhD, MBA, MPH, Child and Adolescent Health Measurement Initiative, Oregon Health and Science University

Aligning Financing and Quality for CYSHCN
Welcome
Expert Workgroup Meeting on Risk Adjustment and Other Financial Protections for Children and Youth with Special Healthcare Needs

September 26, 2011

ACA’s Risk Mitigation Mechanisms

<table>
<thead>
<tr>
<th>Insurance Markets to Which the Mechanism Applies</th>
<th>Time Period</th>
<th>Individual (inside and outside the exchange)</th>
<th>Small group (inside and outside the exchange)</th>
<th>Large Group</th>
<th>Self-Insured</th>
<th>Grandfathered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk adjustment assessments or payments (“Distributions”)</td>
<td>2014 and thereafter</td>
<td>Yes</td>
<td>Yes</td>
<td>No (unless eligible for small-group exchange)</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Reinsurance</td>
<td>2014-2016</td>
<td>Yes (and required to contribute)</td>
<td>No (but required to contribute)</td>
<td>No (but third-party administrator, if any, required to contribute)</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Risk Corridors</td>
<td>2014 - 2016</td>
<td>Yes for exchange plans but not for outside individual policies</td>
<td>Yes for exchange plans but not for outside individual policies</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>


Other financial or programmatic protections for CYSHCN

- Reinsurance
- Stop-loss
- Risk-sharing
- High risk pools
- Carve-outs
- Medicaid buy-in
- Benefit exceptions

This presentation is available on the Catalyst Center website at http://hdwg.org/sites/default/files/ExpertWorkgroupMeetingWelcome.pdf

Health Care Needs of CYSHCN and Why Financial Protection Is Important
John Neff, MD, Center for Children with Special Needs, Seattle Children’s Hospital and Regional Medical Center

Utilizers of Pediatric Health Care Resources:
Who are the Children?
What are their costs?
What are their Vulnerabilities?

DISCLOSURE STATEMENT
Speaker: John Neff

I serve as a consultant for the National Association for Children’s Hospitals and Related Institution (NACHRI) on Classification Research.
NACHRI receives royalty payments from 3M Health Information Systems (3M HIS) as co developers of its products.
I have a no cost research license to use Clinical Risk Groups (CRGs), a product of 3M HIS.
I have no financial interests in 3M or NACHRI and no investments in their products.

Objectives

• Present a Definition of Children with Complex Chronic Conditions for use in Administrative Data
• Present Data on Prevalence and Costs Distribution based on this Definition
• Explore vulnerability for children in our current health care environment

MCHB Definition of Children with Special Health Care

Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require health and related services of a type and an amount beyond that required by children generally

Estimates of Prevalence and costs Using MCHB Surveys

• Children with Special Health Care Needs represent approximately 20% of all children and consume between 40%-60% of health care resources devoted to children
• The majority of children never get sick or have minor acute conditions and consume minimal health services

Common Chronic Conditions in Childhood

• Mental Health Conditions 11%-20%
• Obesity 14%-18%
• Attention Deficit Disorders 4%-6%
• Learning Disorders 5%-10%
• Asthma 4%-8%
• Mental Retardation 0.4%-3%

The costs of these conditions are often delayed until adult ages and difficult to risk adjust

This presentation is available on the Catalyst Center website at http://hdwg.org/sites/default/files/PediatricHealthcareSlides.pdf

Trajectories for Chronic Conditions in Childhood (for projecting costs in administrative data)

- Chronic conditions that can get better over time or even can be eliminated
- Chronic conditions that are static in nature and long lasting or life long
- Chronic conditions that are complex and/or may get worse over time

Chronic Conditions that Can Improve

- Asthma
- Non morbid obesity
- Simple Seizures
- Skin conditions - Atopic Disease
- Attention Deficit and Hyperactive Disorders
- Depression
- Conduct and Behavioral Disorders

Chronic Conditions that may be Static

- Type One Diabetes
- Cerebral Palsy with Monoplegia or Diplegia
- Hydrocephalus with Shunt
- Congenital Hypothyroid

Chronic Conditions that are Complex and/or may get Worse

- Acquired or Congenital Quadriplegia or Paraplegia
- Cerebral Palsy or Encephalopathy with Multi-System Involvement
- Cystic Fibrosis
- Muscular Dystrophy
- Certain Chromosomal Abnormalities
- Technology Dependent Children
- Life Long Chronic Conditions with Significant Comorbid Conditions such as Asthma, Obesity, Mental Health Conditions, or Seizures

Prevalence and Average Cost of Chronic Conditions by Condition Groups in Health Plan data Washington and NY State using CRGs 2000-2007

<table>
<thead>
<tr>
<th>Condition Groups</th>
<th>Prevalence</th>
<th>Percent of Costs</th>
<th>Average Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non Chronic and Healthy</td>
<td>80%-85%</td>
<td>50% to 55%</td>
<td>$600</td>
</tr>
<tr>
<td>Episodic Chronic</td>
<td>10%-15%</td>
<td>19% to 25%</td>
<td>$2,000</td>
</tr>
<tr>
<td>Life Long Chronic Single Body System</td>
<td>2%-3%</td>
<td>13% to 15%</td>
<td>$10,000</td>
</tr>
<tr>
<td>Complex Chronic</td>
<td>0.4%-1.0%</td>
<td>12% to 15%</td>
<td>$27,000</td>
</tr>
<tr>
<td>Malignancies</td>
<td>&lt; 0.5%</td>
<td>3% to 5%</td>
<td>$75,000</td>
</tr>
<tr>
<td>All Children</td>
<td>100%</td>
<td>100%</td>
<td>$1000</td>
</tr>
</tbody>
</table>

Definitions that Describe Different Patterns (trajectories) of Outcomes in Administrative Data

- Non chronic –Conditions that lasts less than 12 months
- Episodic chronic –Conditions that are expected to last at least a year, are highly variable in manifestation and with treatment are not likely to last past childhood
- Life Long Chronic (single body system)– Conditions that are likely to be life long and are generally static
- Complex Chronic
- – Significant chronic conditions in two or more body systems and/or conditions that have shortened life expectancies
- Malignancies

This presentation is available on the Catalyst Center website at
http://hdwg.org/sites/default/files/PediatricHealthcareSlides.pdf
Patient Analysis of Seattle Children’s Hospital 2010 using CRGs adapted for Hospital Analysis

<table>
<thead>
<tr>
<th>Conditions Groups</th>
<th>Percent of Patients</th>
<th>Percent of Hospital Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non Chronic</td>
<td>29.1%</td>
<td>10.4%</td>
</tr>
<tr>
<td>Episodic Chronic</td>
<td>28.3%</td>
<td>15.4%</td>
</tr>
<tr>
<td>Life Long Chronic Single Body System</td>
<td>14.3%</td>
<td>10.7%</td>
</tr>
<tr>
<td>Complex Chronic</td>
<td>24.8%</td>
<td>50.6%</td>
</tr>
<tr>
<td>Malignancies</td>
<td>3.5%</td>
<td>12.9%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Summary Complex Chronic Conditions Prevalence and Cost

<table>
<thead>
<tr>
<th>Conditions Groups</th>
<th>%Patients.</th>
<th>%Charges/Hosp Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Plan Administrative Data</td>
<td>0.4% - 1%</td>
<td>12% - 15%</td>
</tr>
<tr>
<td>Children’s Hospital Discharge Data</td>
<td>20% - 25%</td>
<td>45% - 55%</td>
</tr>
</tbody>
</table>

Medicaid Capitated Care 1990 to 2010

- Unevenly Applied
- Savings not Returned to Providers
- Generally Exempted High Cost Patients
- Underfunded Care Coordination, Provider Fees, Time for Care of Complex Children, Transition to Adult Services, Specialty Services
- Hospitals have been able to Cross Subsidize Medicaid Shortfalls with Commercial Insurance

Medicaid Currently Underfunds Health Care Services for Children
- Primary Provider
- Health Education
- Practitioner Face Time with Family
- Care Coordination
- Specialty Services
- Support for Home Care
- Special Diets
- Medication Costs

Impact of Recession

- Decrease in Employer Based Insurance
- Increase in Deductibles, Co Pays and Medication Co Pays
- Increase in Medicaid Enrollment especially those with High Cost Chronic Conditions
- Cut Backs in State and Local Services
- Pressures on States to Reduce Medicaid Payment

This presentation is available on the Catalyst Center website at http://hdwg.org/sites/default/files/PediatricHealthcareSlides.pdf
Responses from States to Increasing Number of Medicaid Patients, Costs and Budget Shortfalls

- Enroll all Children at all Levels of Severity into Capitated Managed Care (Cost Saving Measure?)
- Decrease Payment for Emergency Services
- Decrease Reimbursements to Hospitals
- Decrease Financial Eligibility for Medicaid
- Decrease Enrollment of Immigrant Population

Issues to Continue to Emphasize

- Children represent approximately 50% of Medicaid Enrollments but account for only 25% of Costs
- There must be a Risk Adjustment System that does not Cut off the High End or Underfund the Low End
- Support for Care Coordination- Increase Time and Resources to Primary Care will Decrease Costs
- Reduction in Coverage will Increase Costs
- Long Term Cost Savings are More Important than Short Term, Biannual Savings

Conditions in Children with Complex Chronic Conditions Compared to Children with Single System Involvement

- Data Summarized from the Children’s Hospital Corporation of America Pediatric Health Information System (PHIS) Discharge Data from 28 US Freestanding Pediatric Hospitals 2004-2009 using CRGs adapted for Hospital use

Authors: Jay Berry et al.

Life Long Chronic Conditions From CHCA Data Jay Berry et al

<table>
<thead>
<tr>
<th>Single Body Systems (top 5)</th>
<th>12.0%</th>
<th>12.0%</th>
<th>9.5%</th>
<th>6.6%</th>
<th>5.6%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major Congenital Heart Disease</td>
<td>12.0%</td>
<td>Sickle Cell Disease</td>
<td>Type I Diabetes</td>
<td>Hydrocephalus</td>
<td>Down's Syndrome</td>
</tr>
<tr>
<td>Complex Chronic Conditions (top 5)</td>
<td>14.6%</td>
<td>Chromosomal Anomalies</td>
<td>Major Congenital Heart Disease</td>
<td>Bronchopulmonary Dysplasia</td>
<td>Anomalies of Trachea, Larnynx and Bronchus</td>
</tr>
</tbody>
</table>

Episodic Chronic Conditions From CHCA Data Jay Berry et al

<table>
<thead>
<tr>
<th>Single Body Systems (top 5)</th>
<th>35.7%</th>
<th>4.3%</th>
<th>3.8%</th>
<th>3.2%</th>
<th>3.1%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>Sleep Apnea and Related Conditions</td>
<td>ADHD</td>
<td>Epilepsy</td>
<td>Ventricular or Atrial Septal Defects</td>
<td></td>
</tr>
<tr>
<td>Complex Chronic Conditions (top 5)</td>
<td>21.8%</td>
<td>6.6%</td>
<td>6.0%</td>
<td>5.3%</td>
<td>4.1%</td>
</tr>
<tr>
<td>Asthma</td>
<td>Cardiac Dysrhythmia and Conduction Disorder</td>
<td>Obesity</td>
<td>Scoliosis</td>
<td>Epilepsy</td>
<td></td>
</tr>
</tbody>
</table>

This presentation is available on the Catalyst Center website at http://hdwg.org/sites/default/files/PediatricHealthcareSlides.pdf
Summary

- Children with Complex Chronic Conditions have Different Condition Patterns than Children with Chronic Conditions in Single Body Systems

Complex Chronic Conditions are Dominated by Cerebral Palsy, Chromosomal Abnormalities, Congenital Heart Disease and Bronchopulmonary Dysplasia

Co morbid Conditions that Dominate are Asthma, Cardiac Dysrhythmias, Obesity and Scoliosis

Episodic Chronic Conditions in Single Body Systems From CHCA Data Jay Berry et al

<table>
<thead>
<tr>
<th>Condition</th>
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<tbody>
<tr>
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<td>Epilepsy</td>
<td>3.2%</td>
</tr>
<tr>
<td>Ventricular or Atrial Septal Defects</td>
<td>3.1%</td>
</tr>
<tr>
<td>Cardiac Dysrhythmia or Conduction Disorders</td>
<td>2.9%</td>
</tr>
<tr>
<td>Conduct, Impulse Control/Other Disrup Behav</td>
<td>2.7%</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>2.3%</td>
</tr>
<tr>
<td>Vesicoureteral Refux</td>
<td>1.9%</td>
</tr>
<tr>
<td>Urinary Tract Obstruction</td>
<td>1.9%</td>
</tr>
<tr>
<td>All Other Episodic</td>
<td>38.2%</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Life Long Chronic Conditions in Single Body Systems From CHCA Data Jay Berry et al

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<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
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<tr>
<td>Major Congenital Heart Disease</td>
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<tr>
<td>Sickle Cell Disease</td>
<td>12.0%</td>
</tr>
<tr>
<td>Type I Diabetes</td>
<td>9.5%</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>6.6%</td>
</tr>
<tr>
<td>Down's Syndrome</td>
<td>5.6%</td>
</tr>
<tr>
<td>Anomal of Trach, Larynx and Bronch</td>
<td>5.1%</td>
</tr>
<tr>
<td>Chromosomal Anomalies</td>
<td>4.6%</td>
</tr>
<tr>
<td>Craniofacial Anomalies</td>
<td>4.6%</td>
</tr>
<tr>
<td>Bronchopulmonary Dysplasia</td>
<td>4.5%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>4.2%</td>
</tr>
<tr>
<td>All Others</td>
<td>31.3%</td>
</tr>
<tr>
<td>Total Percent of Patients</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Episodic Chronic Conditions in Complex Chronic From CHCA Data Jay Berry et al

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>21.8%</td>
</tr>
<tr>
<td>Cardiac Dysrhythmia and Conduction Disorders</td>
<td>6.6%</td>
</tr>
<tr>
<td>Obesity</td>
<td>6.0%</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>5.3%</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>4.1%</td>
</tr>
<tr>
<td>Conduct, Impulse Control/Other Disrup Behav</td>
<td>3.4%</td>
</tr>
<tr>
<td>Disorders of Phosphorus, Calcium</td>
<td>3.2%</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>3.0%</td>
</tr>
<tr>
<td>Skin and Subcutaneous Tissue Conditions</td>
<td>2.7%</td>
</tr>
<tr>
<td>Spinal Cord Conditions</td>
<td>2.6%</td>
</tr>
<tr>
<td>All Other</td>
<td>41.3%</td>
</tr>
<tr>
<td>Total Percent of Diagnoses</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Life Long Chronic Conditions in Complex Chronic From CHCA Data Jay Berry et al

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebral Palsy</td>
<td>14.6%</td>
</tr>
<tr>
<td>Chromosomal Anomalies</td>
<td>6.5%</td>
</tr>
<tr>
<td>Congenital Heart Disease</td>
<td>6.2%</td>
</tr>
<tr>
<td>Bronchopulmonary Dysplasia</td>
<td>6.1%</td>
</tr>
<tr>
<td>Anomalies of Trachea, Larnynx and Bronchus</td>
<td>5.2%</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>4.2%</td>
</tr>
<tr>
<td>Diabetes Type 1</td>
<td>3.8%</td>
</tr>
<tr>
<td>Coagulation Disorders</td>
<td>3.5%</td>
</tr>
<tr>
<td>Down's Syndrome</td>
<td>3.0%</td>
</tr>
<tr>
<td>Craniofacial Anomalies</td>
<td>2.9%</td>
</tr>
<tr>
<td>All Other Diagnoses</td>
<td>44.0%</td>
</tr>
<tr>
<td>Total Percent of Diagnoses</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

This presentation is available on the Catalyst Center website at http://hdwg.org/sites/default/files/PediatricHealthcareSlides.pdf

Aligning Financing and Quality for CYSHCN
Christina (Christy) Bethell, PhD, MBA, MPH, CAMHI, Oregon Health and Science University

Desired Outcome and Common Requirements

- **Desired Outcome.** What are we trying to accomplish?
  - Implement risk adjusted payment methods that optimize the improvement of health care quality for all children and CYSHCN (any child can become a CYSHCN at any time and many will cease to be CYSHCN over time)
  - 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 to identify CYSHCN and track and assess their needs, utilization and outcomes (payment, quality measurement, quality improvement, etc.)

- **Common Requirements:**
  - ID of CYSHCN
  - Measures to Assess Performance (of Risk Adjustment Goals for Protection and Payment and of Quality Goals)

### Minimal Quality Index

Minimal Quality of Care Composite Measure (Insurance usually or always adequate, at least 1 preventive care visit in previous 12 months, and care meets medical home criteria)

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

### 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”)

### Expenditure Variation Within CYSHCN

Median Medical Expenditures (MEPS)

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

This presentation is available on the Catalyst Center website at [http://hdwg.org/sites/default/files/RiskAdjustmentPowerpoint.pdf](http://hdwg.org/sites/default/files/RiskAdjustmentPowerpoint.pdf)
Doctor Visits Due to Illness and Emergency Room Visits by CSHCN Subgroups

<table>
<thead>
<tr>
<th>Subgroup</th>
<th>Prevalence</th>
<th>Visits per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-CYSHCN, No EBD</td>
<td>43.1%</td>
<td>1.10/1.06</td>
</tr>
<tr>
<td>CYSHCN, No EBD</td>
<td>19.9%</td>
<td>2.08/2.05</td>
</tr>
<tr>
<td>Met 1 of 5 Criteria</td>
<td>38.9%</td>
<td>2.40/2.40</td>
</tr>
<tr>
<td>Met 4+ of 5 Criteria</td>
<td>56.3%</td>
<td>2.10/2.10</td>
</tr>
</tbody>
</table>

Impact on School Success by CYSHCN Subgroups (Complexity and EBD)

<table>
<thead>
<tr>
<th>Complexity</th>
<th>EBD</th>
<th>Grades</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less</td>
<td>Less EBD</td>
<td>49.3%</td>
</tr>
<tr>
<td>More</td>
<td>More EBD</td>
<td>64.8%</td>
</tr>
</tbody>
</table>

Relevant Observations (continued)

- Gaps in system integration, coordination, early identification and quality of care (as well as state of the science) make late or missed diagnosis and mis-diagnosis not uncommon and confound value of DX-based methods to identify.
- Gaps in quality of care contribute to many avoidable negative events (misuse) and inefficiencies (overuse) as well as underuse of services, confounding claims based, prior expenditures based risk adjustment methods and potentially leading to adverse incentives related to promoting quality.
- Proportion of CYSHCN where these issues are not present represent a very low proportion of all CYSHCN and may not present a critical mass to deter adverse selection or incentivize quality improvement.

Relevant Observations (last bit)

- Due to natural developmental issues of a child or poor access or quality of care, a child can evolve into a “complex CYSHCN” or evolve out of being a CYSHCN, requiring periodic identification and confounding claims on conditions based methods alone. Survey based methods can be useful.
- Sometimes multiple minor issues not typically considered “serious” will result in major health impacts and service needs, confounding DX based methods.
- Half of CYSHCN have parents reporting moderate or severe impact regardless of health services received and diagnosis.
- It matters from whose perspective you assess CYSHCN and needs and impact and costs (health plan, provider, family, employers), the time horizon of interest (lifecourse) and value on outcomes and functioning.

This presentation is available on the Catalyst Center website at http://hdwg.org/sites/default/files/RiskAdjustmentPowerpoint.pdf

Family Experience of Financial Problems Due to Child's Health Needs

Parent(s) Cut Back/Stopped Work Due to Child’s Health Needs

Defining Special Health Care Needs

Identification Method for Statistics Presented

No Wrong Algorithm? Can We Have the Best of All Worlds

This presentation is available on the Catalyst Center website at http://hdwg.org/sites/default/files/RiskAdjustmentPowerpoint.pdf
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 risk adjustment. CSHCN Screener-lite (study did not score condition presence and duration) showed improvement in predicting future costs above use of prior expenditures (48.5% explained—need to test with full screener scoring approach). HCC only explained 12.1%. (Yu and Dick, 2010 HSR)

- Requires patient centered approach and training intake and physician/providers and data linkage to claims and EHR
- Can create an intensity adjusted prevalence across plans and provider groups and 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!

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”

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
Enduring Themes in Child Health (The 4 D’s)

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 play a prominent role in influencing range of factors. Measures powerful to motivate shifts needed.

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.

Enduring Themes in Child Health (The 4 D’s)

3. Children are Dependent: (Implications Continued)
   - 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-natal and maternity care and adult mental and behavioral health communities; adult specialty care for youth transition to adulthood)

4. Children’s Diagnoses Are Diverse and Often Delayed: Some Implications:
   - CSHCN Common Focus: Broad definition. Children with ongoing conditions requiring amount or type of health and related services than required by children generally.
   - 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
   - Early Identification Issues: 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.
   - Because good care mandates coordination/collaboration, child health could lead the way in this arena (shovel ready, incentives via CHIPRA, etc.)

The Quality Context

The Triple Aim and National Priorities

Priorities
- Health and Well-being
- Patient/ Family Centered Care
- Effective Communication and Coordination
- Safe, Reliable Quality and Safety
- Efficient and Affordable
- Patient Safety

Objective #1: Families of CYSCHN will be partners in decision-making and are satisfied with the services they receive.

Objective #2: CYSCHN will receive coordinated, ongoing, comprehensive care within a medical home.

Objective #3: Families of CYSCHN will have adequate private and public insurance to pay for the services they need.

Objective #4: CYSCHN who are screened early and continuously for special health care needs.

Objective #5: Community-based service systems will be organized so families can use them easily.

Objective #6: Youth with special health care needs will receive services necessary to make a successful transition to adult life.

This presentation is available on the Catalyst Center website at http://hdwg.org/sites/default/files/RiskAdjustmentPowerpoint.pdf
The Initial Core Measures

Frequency of ongoing prenatal care
- Otoscopic Mitis with Effusion - avoidance of inappropriate use of systemic antibiotics
- Tonniness of prenatal care
- Total EPST eligibles who received dental treatment services (EPST CMS Form 416 Line 12)
- % of live births weighing less than 2,500 grams
- Emergency Department Utilization - Average number of emergency room visits per member per reporting period
- Conduct Rate for Low-risk First Birth Women
- Pediatric, reactive associated blood-stream infection rates (ICU and high risk nursery patients)
- Immunizations for 2-year-olds
- Annual number of asthma patients (> 1 year-old) with > 1 asthma related ER visit
- Adolescent immunization
- Follow-up care for children prescribed attention-deficit/hyperactivity disorder medication

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) (6)
- 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)

Example Health and Well Being Measures Concepts
- 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

Aligning Financing and Quality for CYSHCN (cont.)

Moving Ahead: Goals and Priorities

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 provider capacity for new and rapid data

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

Tabular data:

<table>
<thead>
<tr>
<th>Issue</th>
<th>Quality Improvement</th>
<th>Public Accountability</th>
</tr>
</thead>
<tbody>
<tr>
<td>What to measure</td>
<td>Support 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 measurement 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</td>
<td>Often aggregate, increasingly disaggregated</td>
</tr>
<tr>
<td>Severity adjustment</td>
<td>Often not necessary if processes are changing but inputs 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 minutiae</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>

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Key CSHCN Screening Specification Challenges

About the Catalyst Center

The Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs is a national center funded by the Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services, and is located at the Boston University School of Public Health. The Catalyst Center provides support to the efforts of stakeholders at the federal, state, and local levels in assuring adequate health insurance coverage and financing to meet the diverse needs of children and youth with special health care needs and their families.

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This resource accompanies the technical brief Risk Adjustment and Other Financial Protections for CYSHCN in Our Evolving Health Care System, available on the Catalyst Center website at http://hdwg.org/catalyst/risk