May, 2012

CATALYST
CENTER

IMPROVING FINANCING OF CARE
for Children & Youth
WITH SPECIAL HEALTH CARE NEEDS

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.*

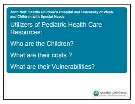
Expert Workgroup Meeting Agenda, September 26, 2011

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:


Welcome
Expert Workgroup Meeting on Risk Adjustment and Other Financial Protections for Children and Youth with Special Healthcare Needs
September 26, 2011

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


John Neff, Seattle Children's Hospital and University of Wash. and Children with Special Needs
Utilizers of Pediatric Health Care Resources:
Who are the Children?
What are their costs ?
What are their Vulnerabilities?
Seattle Children's

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


CAHMI
The Child & Adolescent Health Measurement Initiative
Aligning Financing and Quality Goals and Methods: Considerations, Lessons, Opportunities
Christina Bethell, PhD, MBA, MPH
Oregon Health & Science University
The Child & Adolescent Health Measurement Initiative
Risk Adjustment and Other Financial Protection for CYSHCN
September 26, 2011

Christina Bethell, PhD, MBA, MPH, Child and Adolescent Health Measurement Initiative, Oregon Health and Science University
Aligning Financing and Quality for CYSHCN

Boston University School of Public Health • Health & Disability Working Group
715 Albany Street, Boston, MA 02118 • Tel: 617-638-1930 • Fax: 617-638-1931 • http://www.catalystctr.org

Kickoff Presentation

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Welcome

Expert Workgroup Meeting on Risk Adjustment and Other Financial Protections for Children and Youth with Special Healthcare Needs

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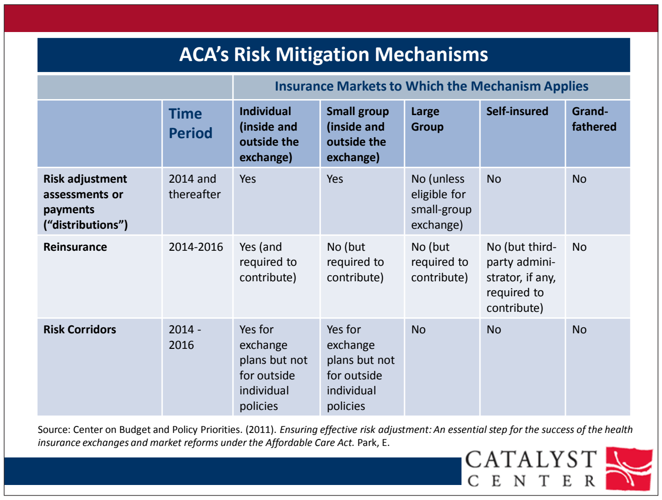
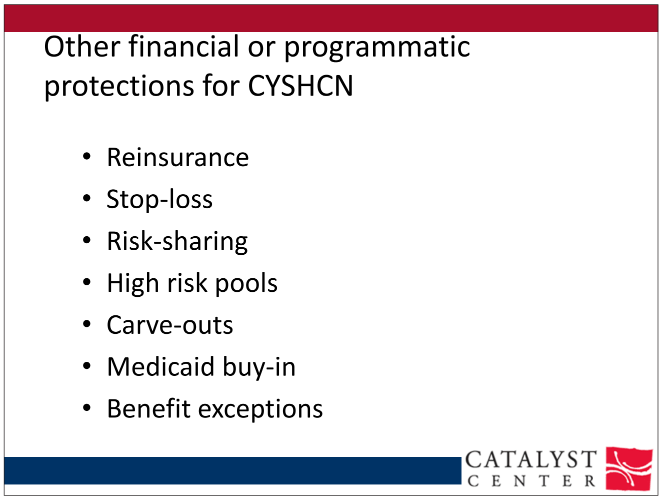


ACA's Risk Mitigation Mechanisms

		Insurance Markets to Which the Mechanism Applies				
	Time Period	Individual (inside and outside the exchange)	Small group (inside and outside the exchange)	Large Group	Self-insured	Grand-fathered
Risk adjustment assessments or payments ("distributions")	2014 and thereafter	Yes	Yes	No (unless eligible for small-group exchange)	No	No
Reinsurance	2014-2016	Yes (and required to contribute)	No (but required to contribute)	No (but required to contribute)	No (but third-party administrator, if any, required to contribute)	No
Risk Corridors	2014 - 2016	Yes for exchange plans but not for outside individual policies	Yes for exchange plans but not for outside individual policies	No	No	No

Source: Center on Budget and Policy Priorities. (2011). *Ensuring effective risk adjustment: An essential step for the success of the health insurance exchanges and market reforms under the Affordable Care Act.* Park, E.



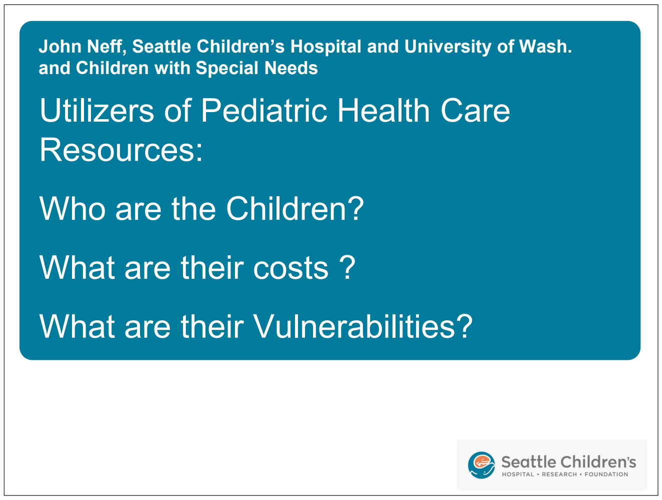
Other financial or programmatic protections for CYSHCN

- 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



John Neff, Seattle Children's Hospital and University of Wash. and Children with Special Needs

Utilizers of Pediatric Health Care Resources:

Who are the Children?

What are their costs ?

What are their Vulnerabilities?

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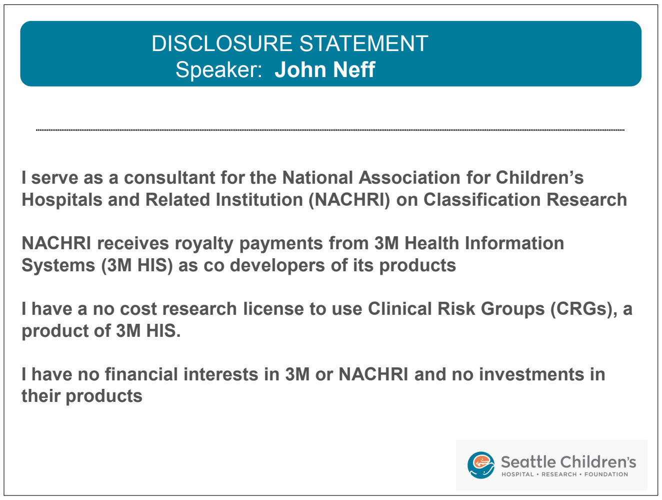

DISCLOSURE STATEMENT
Speaker: **John Neff**

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

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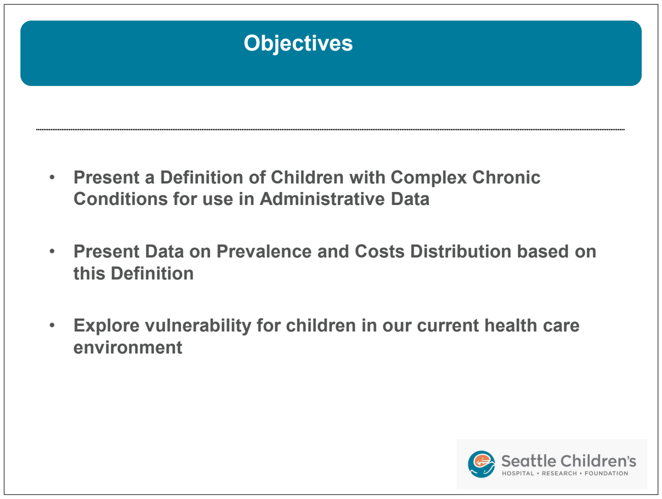

Objectives

- 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

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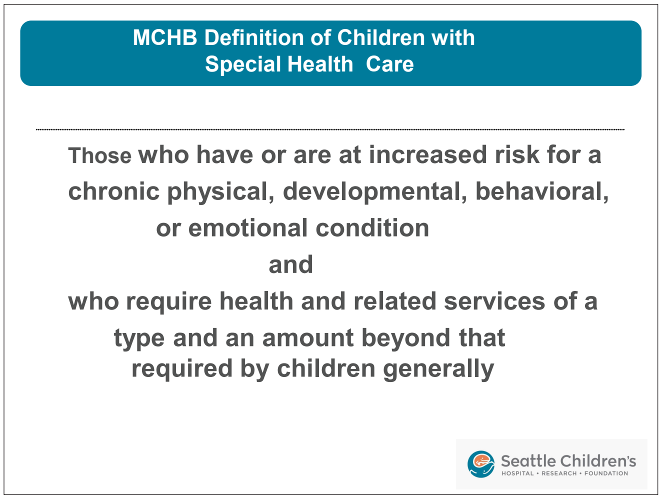

MCHB Definition of Children with Special Health Care

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

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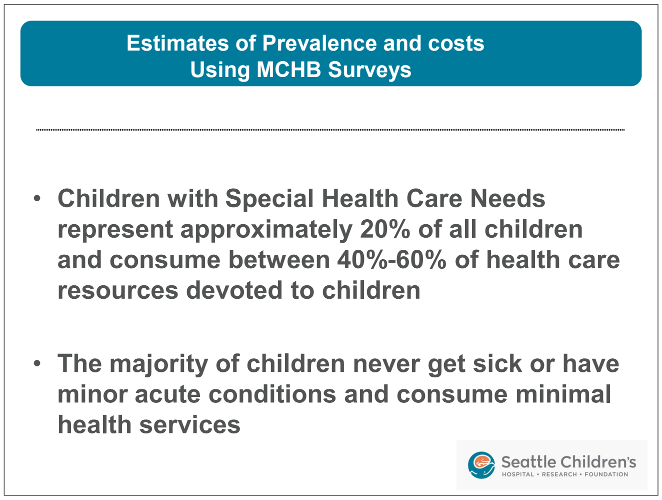

Estimates of Prevalence and costs Using MCHB Surveys

- 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

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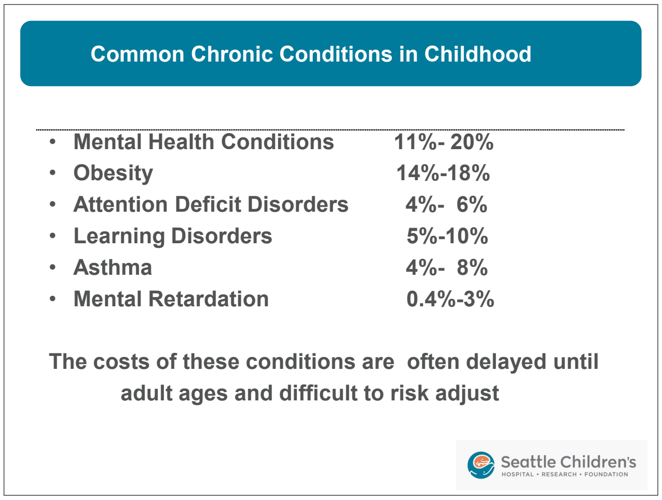

Common Chronic Conditions in Childhood

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

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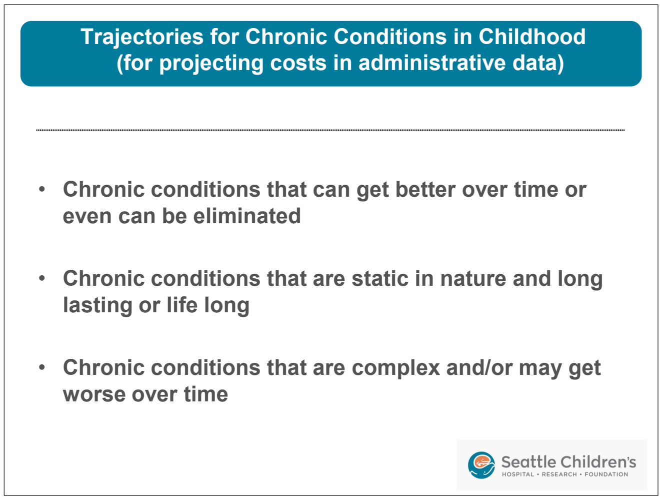
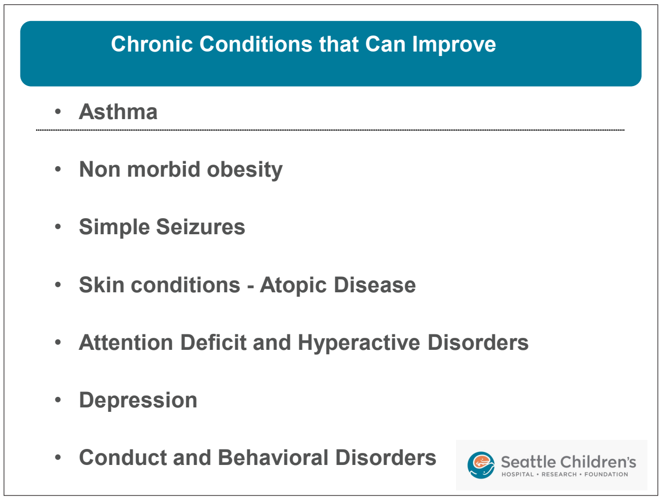
This presentation is available on the Catalyst Center website at http://hdwg.org/sites/default/files/PediatricHealthcareSlides.pdf

Health Care Needs of CYSHCN and Why Financial Protection Is Important (cont.)



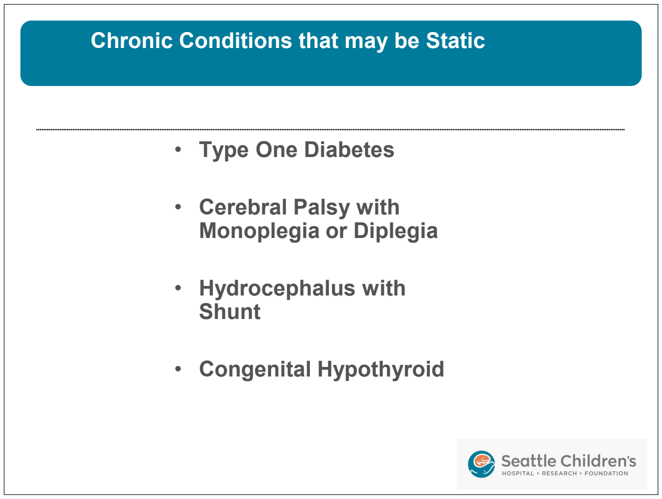
Trajectories for Chronic Conditions in Childhood (for projecting costs in administrative data)

- 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



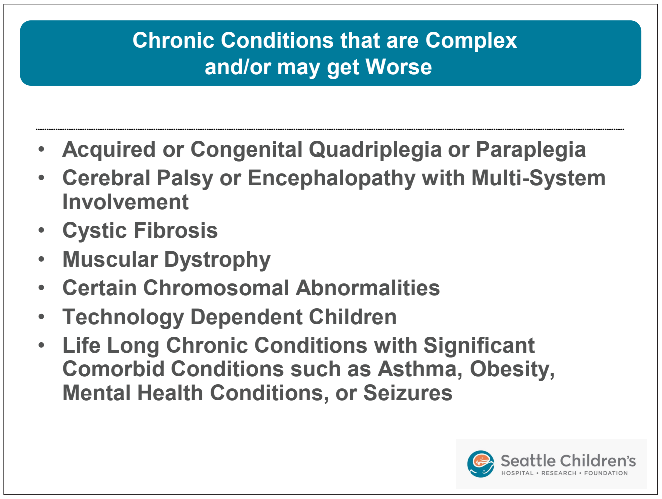
Chronic Conditions that Can Improve

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



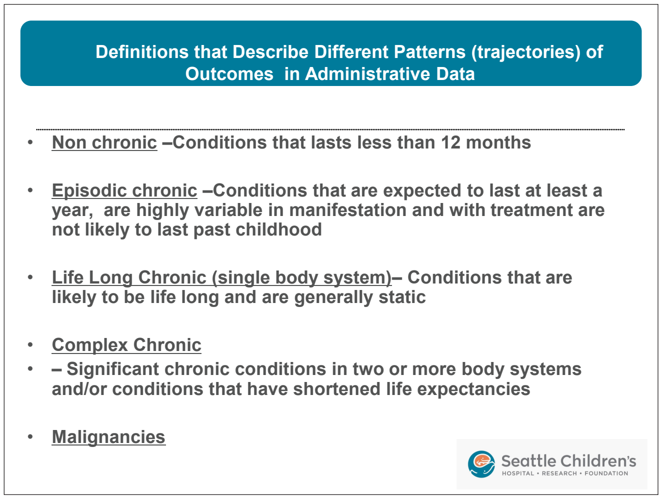
Chronic Conditions that may be Static

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



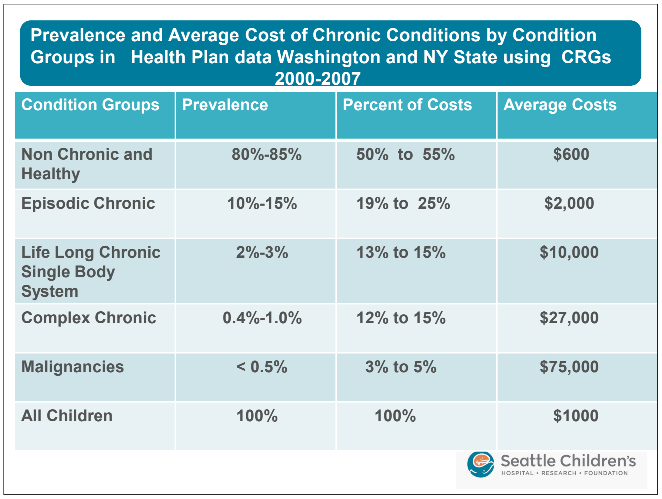
Chronic Conditions that are Complex and/or may get Worse

- 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



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

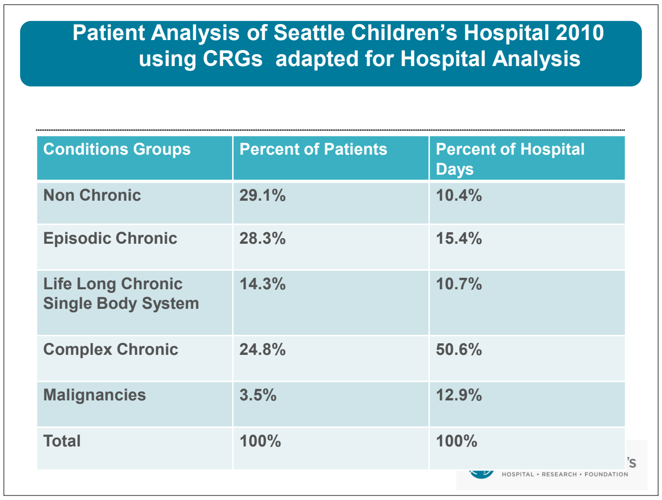


Prevalence and Average Cost of Chronic Conditions by Condition Groups in Health Plan data Washington and NY State using CRGs 2000-2007

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

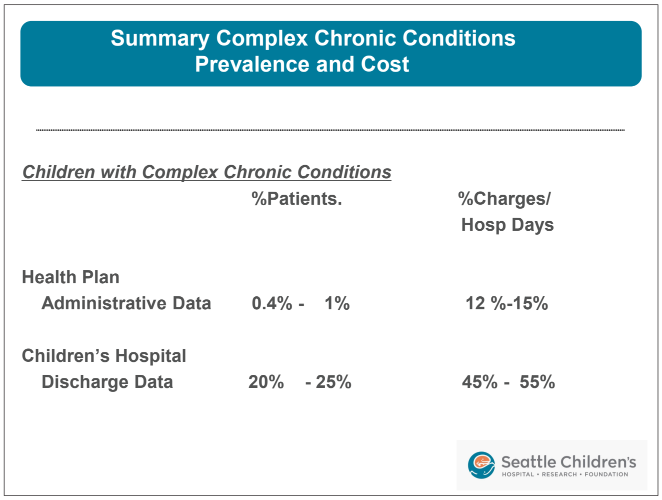
This presentation is available on the Catalyst Center website at
http://hdwg.org/sites/default/files/PediatricHealthcareSlides.pdf

Health Care Needs of CYSHCN and Why Financial Protection Is Important (cont.)



Patient Analysis of Seattle Children's Hospital 2010 using CRGs adapted for Hospital Analysis

Conditions Groups	Percent of Patients	Percent of Hospital Days
Non Chronic	29.1%	10.4%
Episodic Chronic	28.3%	15.4%
Life Long Chronic Single Body System	14.3%	10.7%
Complex Chronic	24.8%	50.6%
Malignancies	3.5%	12.9%
Total	100%	100%



Summary Complex Chronic Conditions Prevalence and Cost

Children with Complex Chronic Conditions

	%Patients.	%Charges/ Hosp Days
Health Plan Administrative Data	0.4% - 1%	12 %-15%
Children's Hospital Discharge Data	20% - 25%	45% - 55%

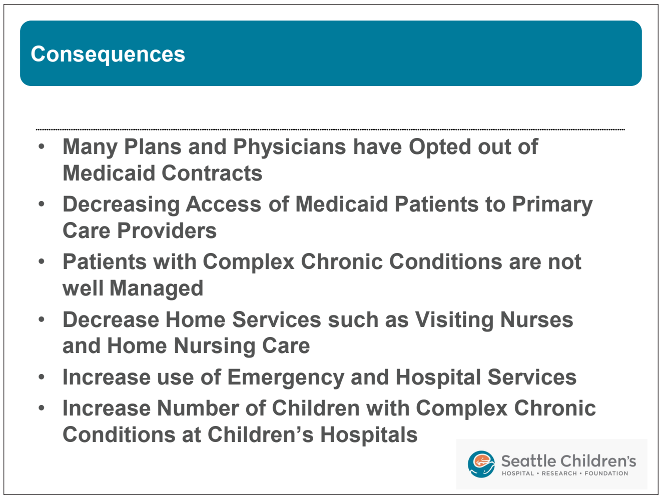
Medicaid Capitated Care 1990 to 2010

- 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

Observation

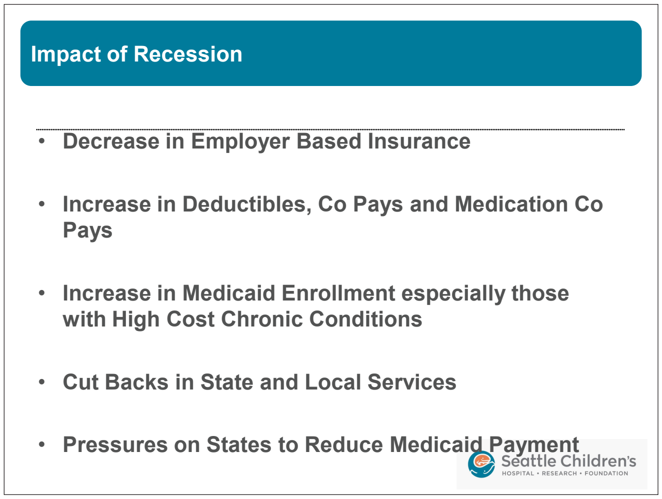
Medicaid Currently Underfunds Health Care Services for Children

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



Consequences

- Many Plans and Physicians have Opted out of Medicaid Contracts
- Decreasing Access of Medicaid Patients to Primary Care Providers
- Patients with Complex Chronic Conditions are not well Managed
- Decrease Home Services such as Visiting Nurses and Home Nursing Care
- Increase use of Emergency and Hospital Services
- Increase Number of Children with Complex Chronic Conditions at Children's Hospitals



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

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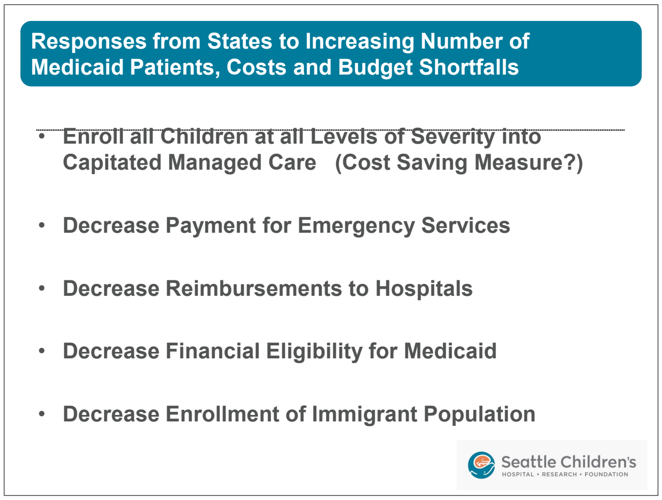
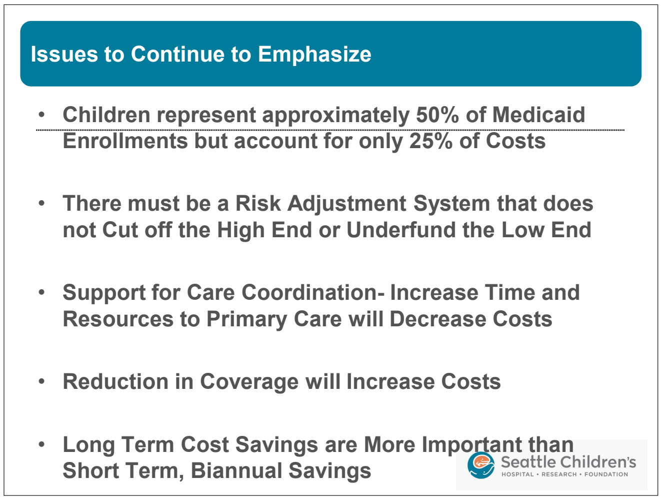


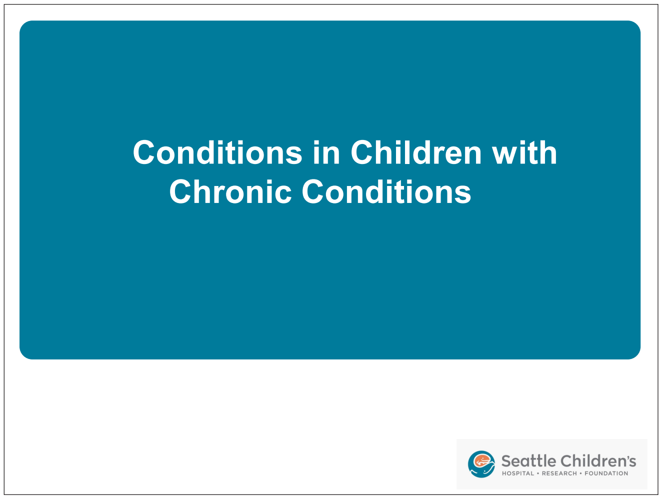
Responses from States to Increasing Number of Medicaid Patients, Costs and Budget Shortfalls

- 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

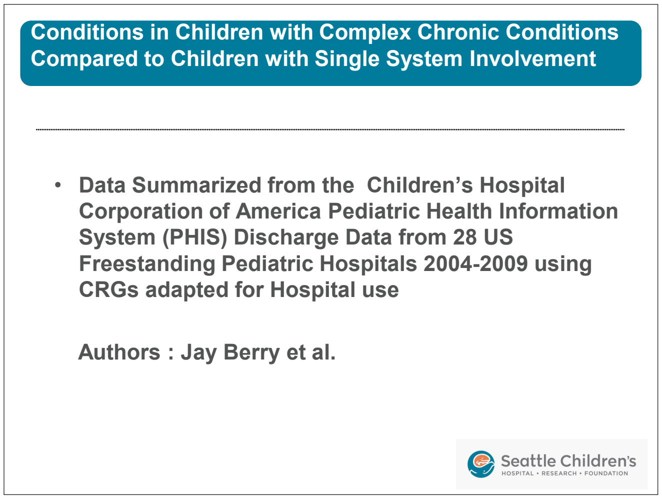


Issues to Continue to Emphasize

- 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



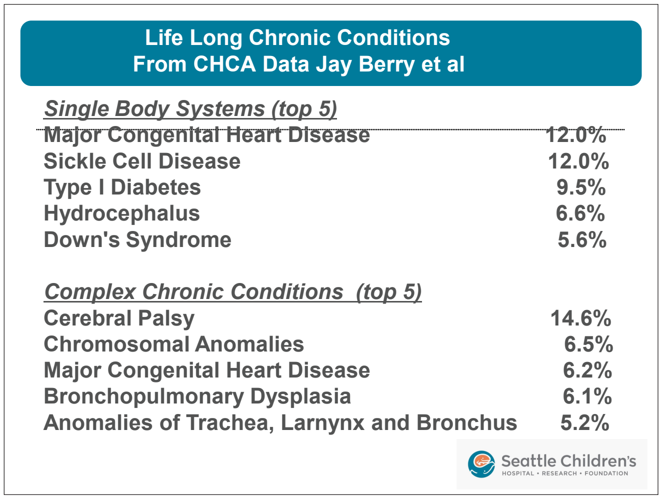
Conditions in Children with Chronic Conditions



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

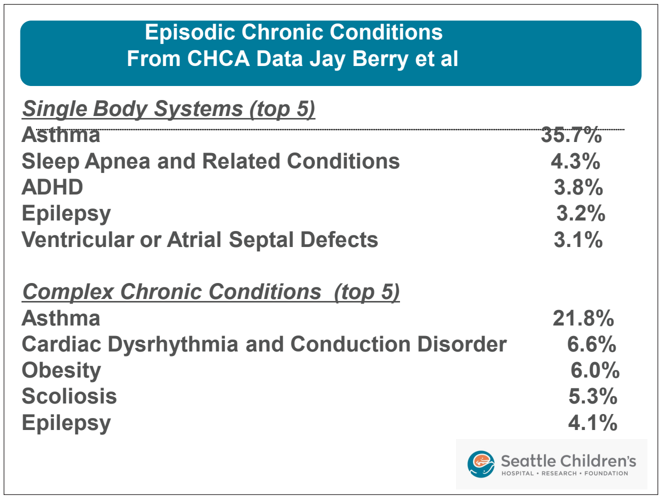
- Data Summarized from the Children's Hospital Corporation of America Pediatric Health Information System (PHIS) Discharge Data from 28 US Freestanding Pediatric Hospitals 2004-2009 using CRGs adapted for Hospital use

Authors : Jay Berry et al.



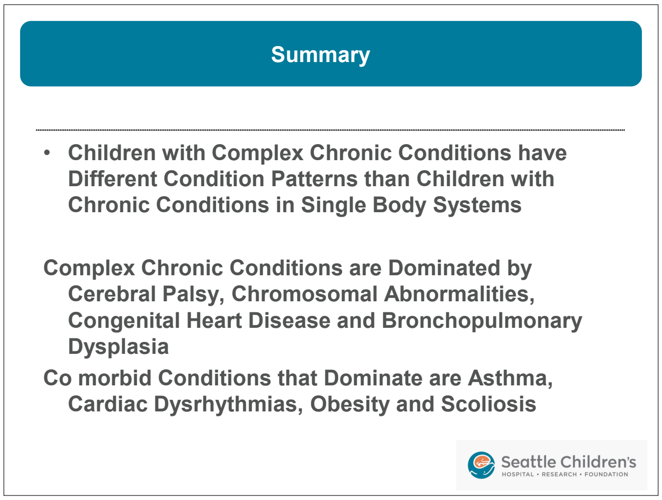
Life Long Chronic Conditions From CHCA Data Jay Berry et al

Single Body Systems (top 5)	
Major Congenital Heart Disease	12.0%
Sickle Cell Disease	12.0%
Type I Diabetes	9.5%
Hydrocephalus	6.6%
Down's Syndrome	5.6%
Complex Chronic Conditions (top 5)	
Cerebral Palsy	14.6%
Chromosomal Anomalies	6.5%
Major Congenital Heart Disease	6.2%
Bronchopulmonary Dysplasia	6.1%
Anomalies of Trachea, Larnynx and Bronchus	5.2%



Episodic Chronic Conditions From CHCA Data Jay Berry et al

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

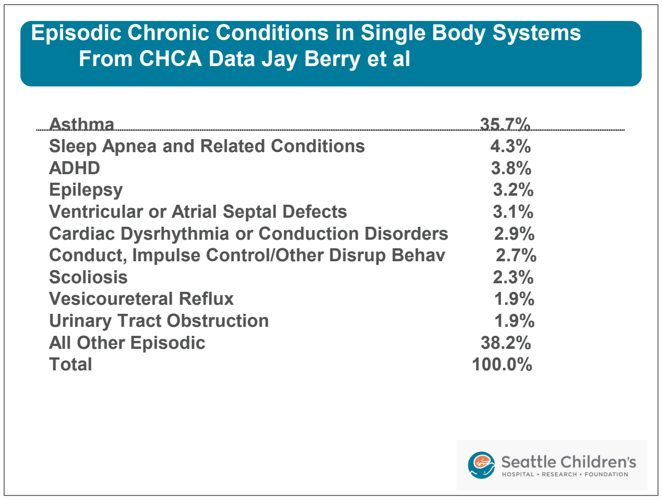


Summary

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

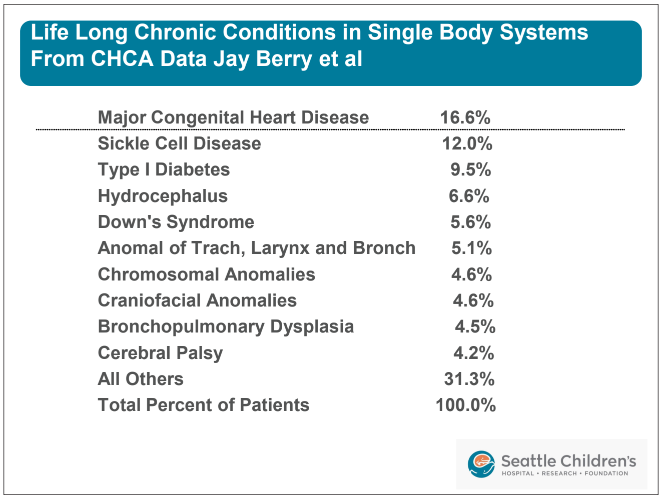
Complex Chronic Conditions are Dominated by Cerebral Palsy, Chromosomal Abnormalities, Congenital Heart Disease and Bronchopulmonary Dysplasia

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



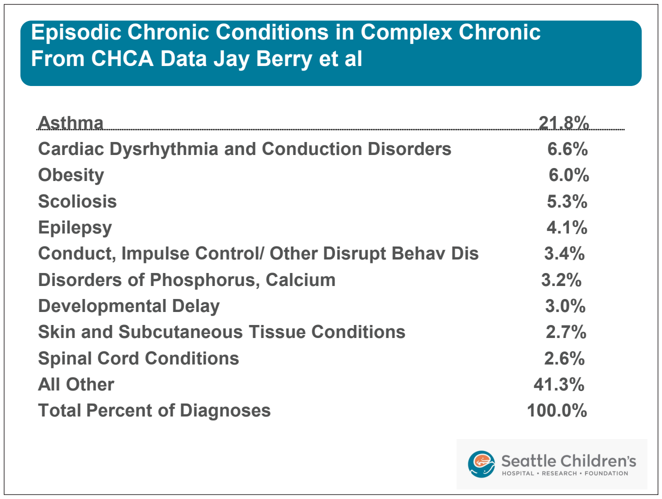
Episodic Chronic Conditions in Single Body Systems From CHCA Data Jay Berry et al

Asthma	35.7%
Sleep Apnea and Related Conditions	4.3%
ADHD	3.8%
Epilepsy	3.2%
Ventricular or Atrial Septal Defects	3.1%
Cardiac Dysrhythmia or Conduction Disorders	2.9%
Conduct, Impulse Control/Other Disrup Behav	2.7%
Scoliosis	2.3%
Vesicoureteral Reflux	1.9%
Urinary Tract Obstruction	1.9%
All Other Episodic	38.2%
Total	100.0%



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

Major Congenital Heart Disease	16.6%
Sickle Cell Disease	12.0%
Type I Diabetes	9.5%
Hydrocephalus	6.6%
Down's Syndrome	5.6%
Anomal of Trach, Larynx and Bronch	5.1%
Chromosomal Anomalies	4.6%
Craniofacial Anomalies	4.6%
Bronchopulmonary Dysplasia	4.5%
Cerebral Palsy	4.2%
All Others	31.3%
Total Percent of Patients	100.0%



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

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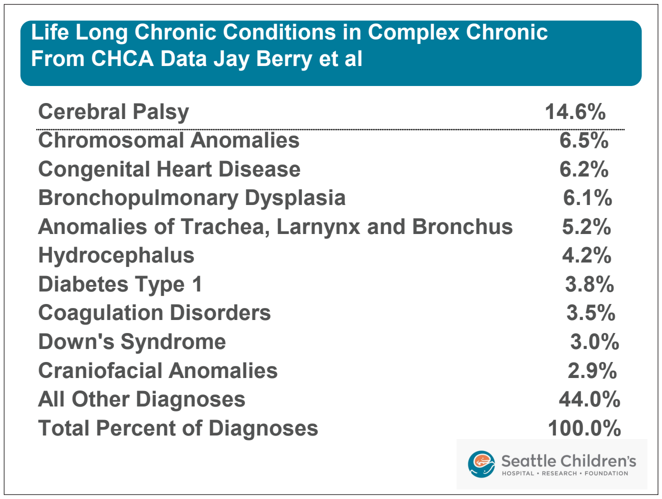
Obesity	6.0%
Scoliosis	5.3%
Epilepsy	4.1%
Conduct, Impulse Control/ Other Disrupt Behav Dis	3.4%
Disorders of Phosphorus, Calcium	3.2%
Developmental Delay	3.0%
Skin and Subcutaneous Tissue Conditions	2.7%
Spinal Cord Conditions	2.6%
All Other	41.3%
Total Percent of Diagnoses	100.0%



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

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

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

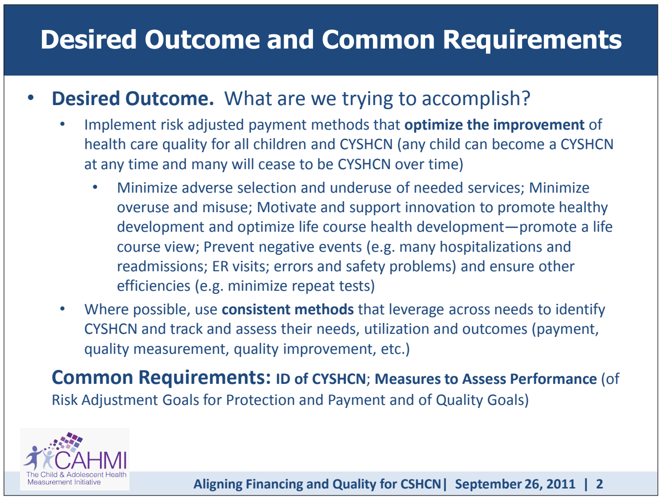
CAHMI The Child & Adolescent Health Measurement Initiative

Aligning Financing and Quality Goals and Methods: Considerations, Lessons, Opportunities

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

Risk Adjustment and Other Financial Protection for CYSHCN

September 26, 2011



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)

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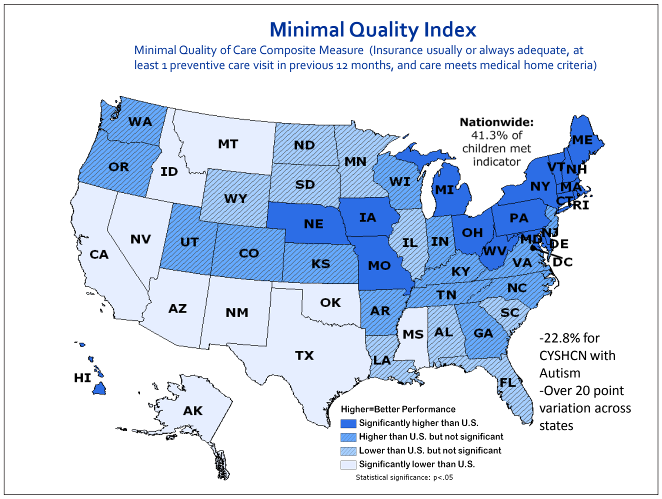
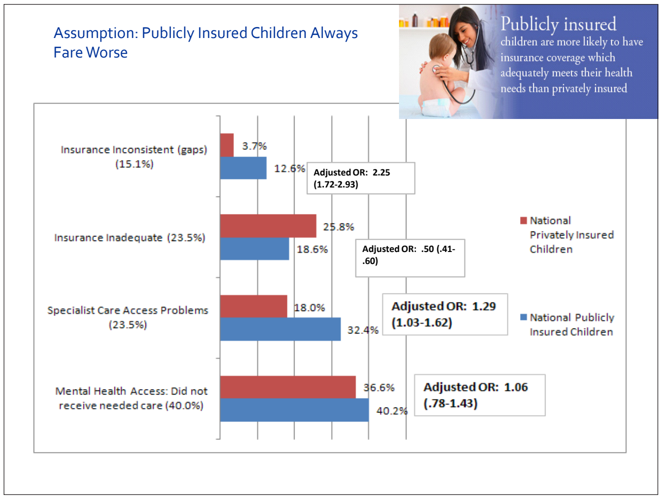


Minimal Quality Index

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)

Nationwide: 41.3% of children met indicator

-22.8% for CYSHCN with Autism
-Over 20 point variation across states



Assumption: Publicly Insured Children Always Fare Worse

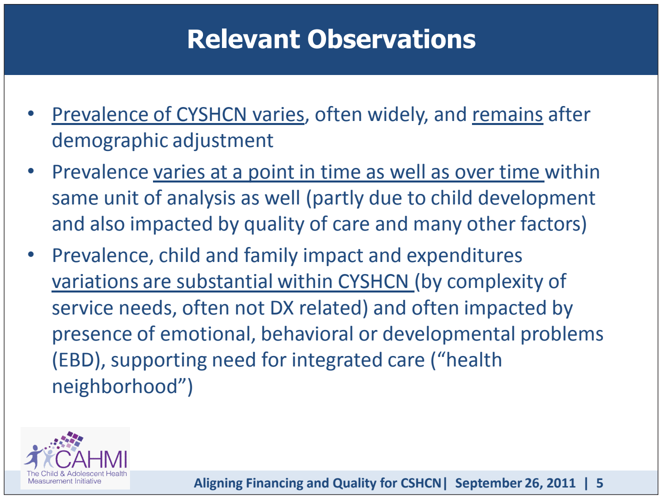
Publicly insured children are more likely to have insurance coverage which adequately meets their health needs than privately insured

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)



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")

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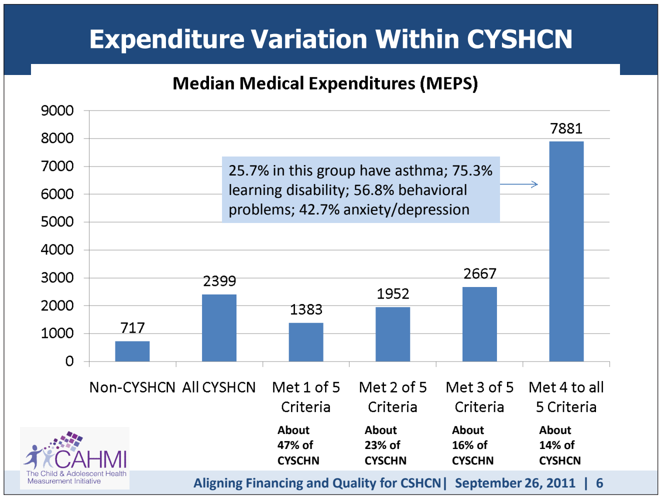

Expenditure Variation Within CYSHCN

Median Medical Expenditures (MEPS)

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

About 47% of CYSCHN

About 23% of CYSCHN

About 16% of CYSCHN

About 14% of CYSCHN

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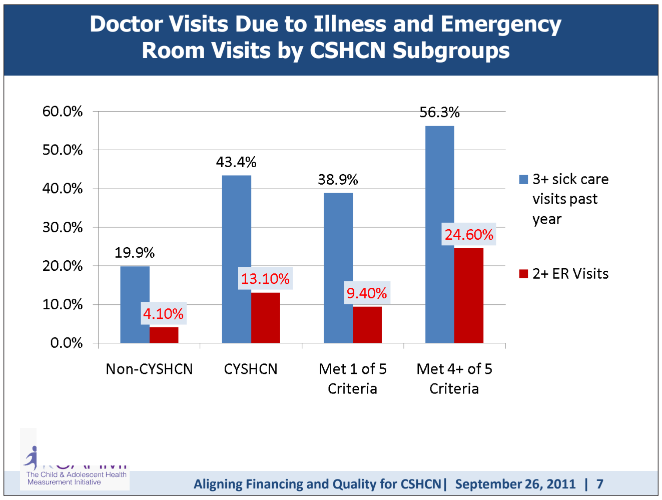
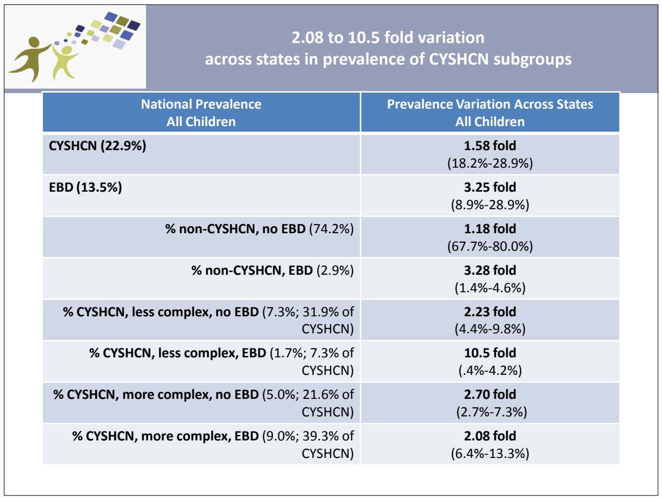
Aligning Financing and Quality for CYSHCN (cont.)

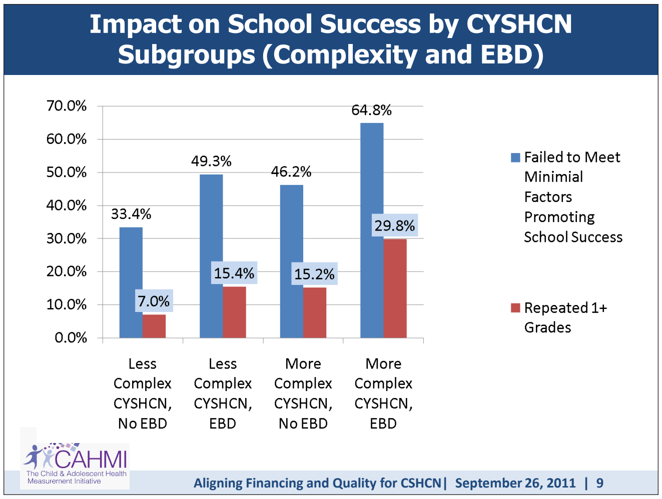


Doctor Visits Due to Illness and Emergency Room Visits by CSHCN Subgroups

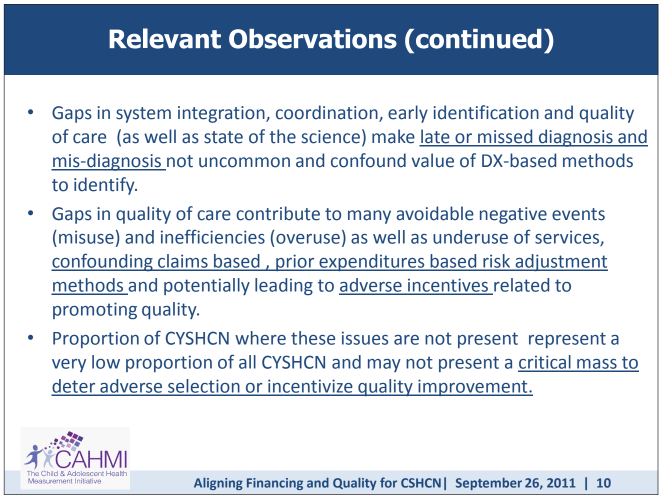


2.08 to 10.5 fold variation across states in prevalence of CYSHCN subgroups

National Prevalence All Children	Prevalence Variation Across States All Children
CYSHCN (22.9%)	**1.58 fold** (18.2%-28.9%)
EBD (13.5%)	**3.25 fold** (8.9%-28.9%)
% non-CYSHCN, no EBD (74.2%)	**1.18 fold** (67.7%-80.0%)
% non-CYSHCN, EBD (2.9%)	**3.28 fold** (1.4%-4.6%)
% CYSHCN, less complex, no EBD (7.3%; 31.9% of CYSHCN)	**2.23 fold** (4.4%-9.8%)
% CYSHCN, less complex, EBD (1.7%; 7.3% of CYSHCN)	**10.5 fold** (.4%-4.2%)
% CYSHCN, more complex, no EBD (5.0%; 21.6% of CYSHCN)	**2.70 fold** (2.7%-7.3%)
% CYSHCN, more complex, EBD (9.0%; 39.3% of CYSHCN)	**2.08 fold** (6.4%-13.3%)

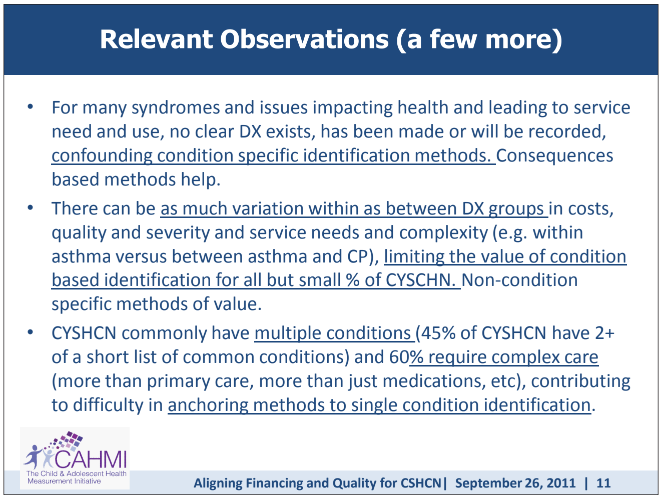


Impact on School Success by CYSHCN Subgroups (Complexity and EBD)



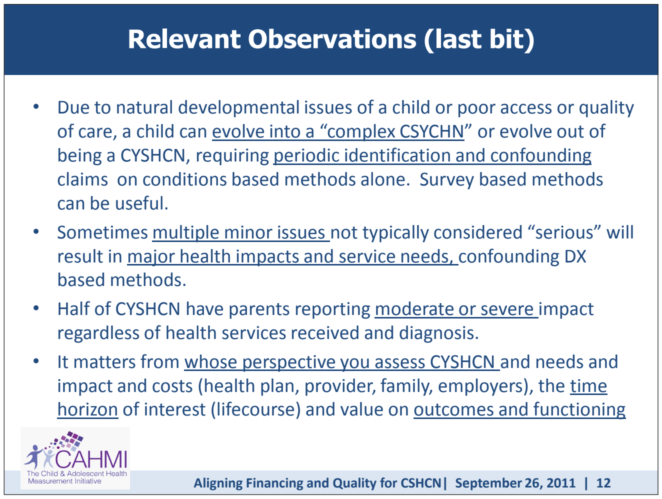
Relevant Observations (continued)

- 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 (a few more)

- For many syndromes and issues impacting health and leading to service need and use, no clear DX exists, has been made or will be recorded, confounding condition specific identification methods. Consequences based methods help.
- There can be as much variation within as between DX groups in costs, quality and severity and service needs and complexity (e.g. within asthma versus between asthma and CP), limiting the value of condition based identification for all but small % of CYSCHN. Non-condition specific methods of value.
- CYSHCN commonly have multiple conditions (45% of CYSHCN have 2+ of a short list of common conditions) and 60% require complex care (more than primary care, more than just medications, etc), contributing to difficulty in anchoring methods to single condition identification.

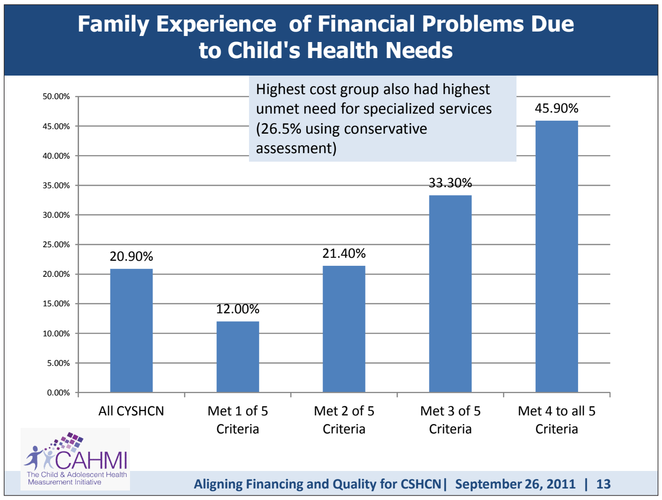


Relevant Observations (last bit)

- Due to natural developmental issues of a child or poor access or quality of care, a child can evolve into a "complex CSYCHN" 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

Aligning Financing and Quality for CYSHCN (cont.)



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)

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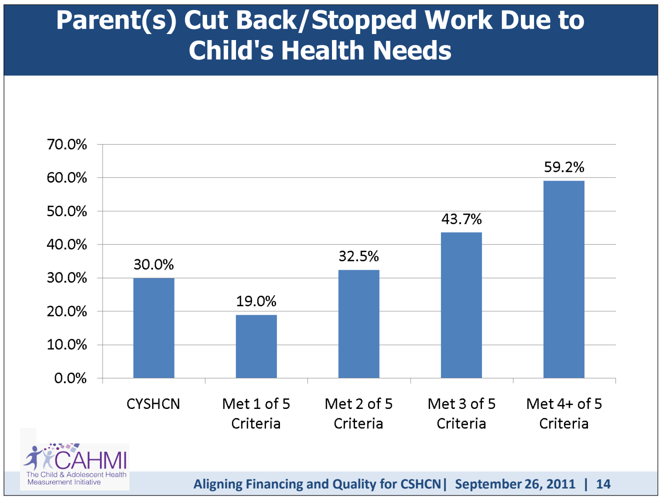

Parent(s) Cut Back/Stopped Work Due to Child's Health Needs

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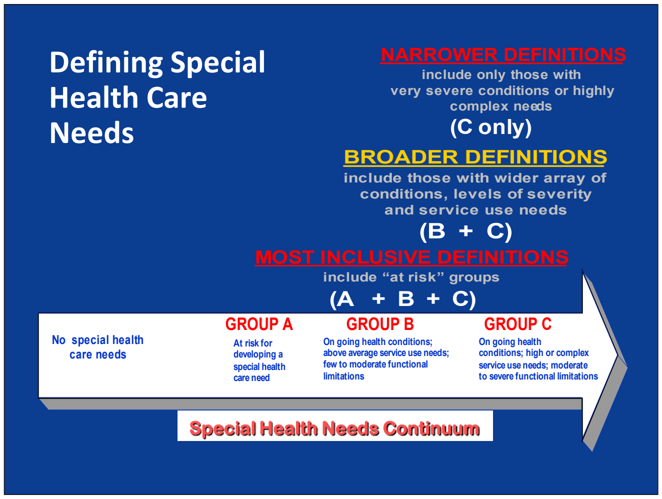


Defining Special Health Care Needs

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)

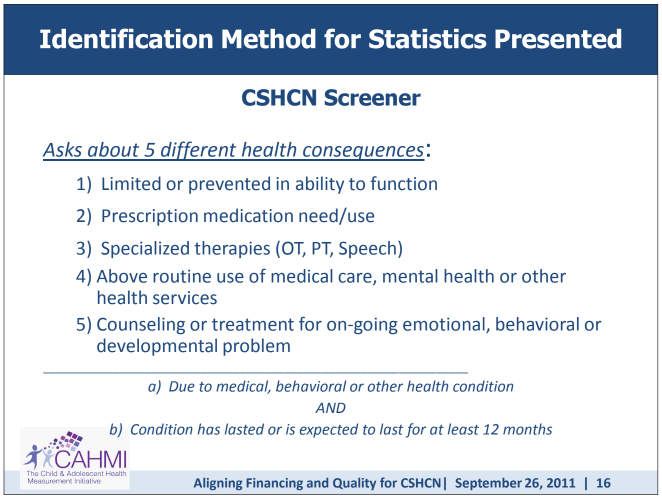
No special health care needs

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



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

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a) Due to medical, behavioral or other health condition

AND

b) Condition has lasted or is expected to last for at least 12 months

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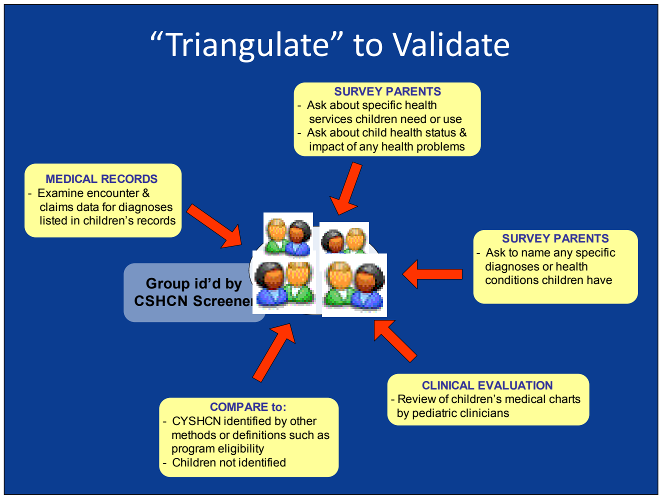


"Triangulate" to Validate

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

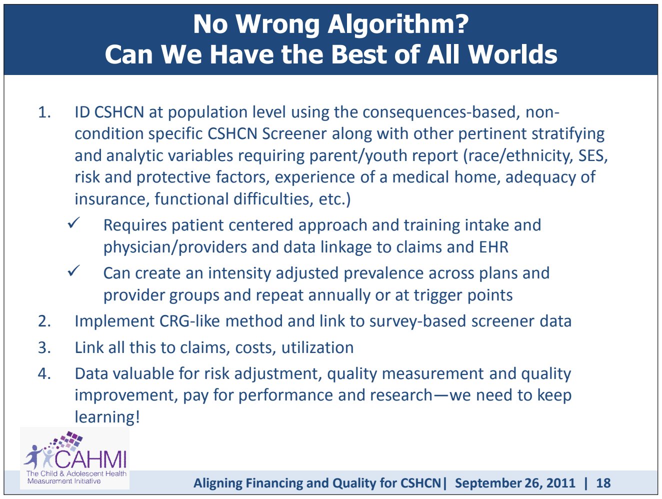
MEDICAL RECORDS
- Examine encounter & claims data for diagnoses listed in children's records

Group id'd by CSHCN Screene

SURVEY PARENTS
- Ask to name any specific diagnoses or health conditions children have

CLINICAL EVALUATION
- Review of children's medical charts by pediatric clinicians

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



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, functional difficulties, etc.)
   - ✓ 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!

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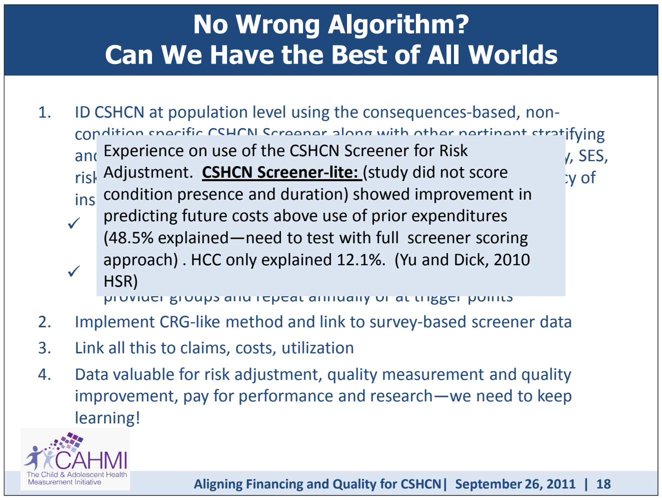
Aligning Financing and Quality for CYSHCN (cont.)



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 … , SES, risk … cy of ins …
   - ✓
   - ✓ … 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!

Experience on use of the CSHCN Screener for Risk Adjustment. **<u>CSHCN Screener-lite:</u>** (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)

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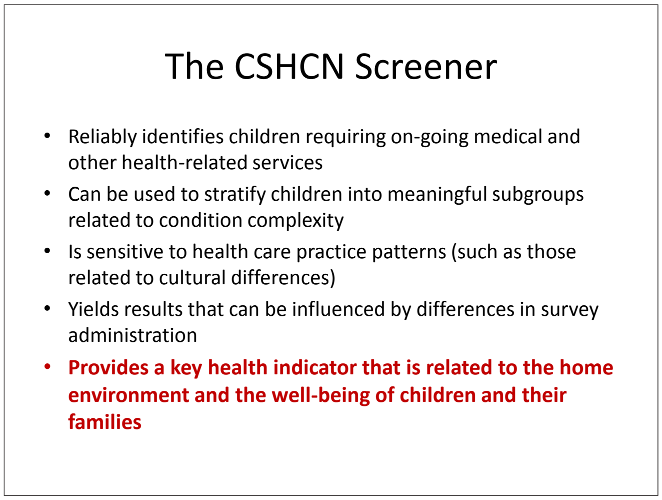
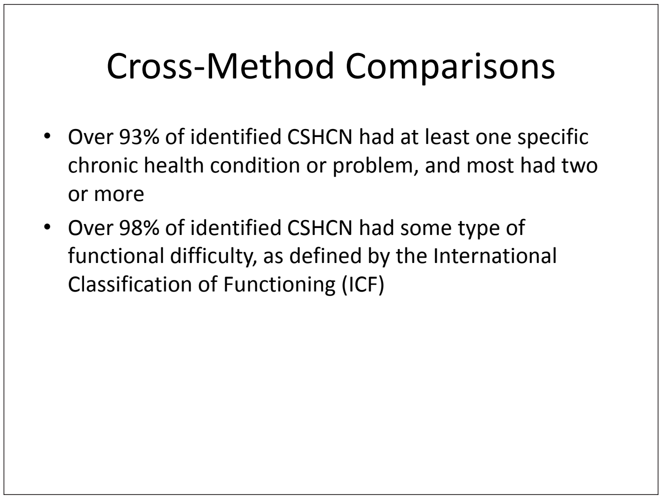


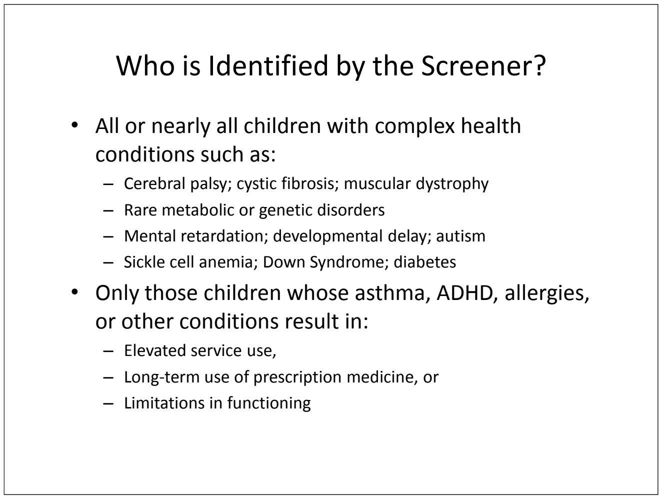
The CSHCN Screener

- 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**



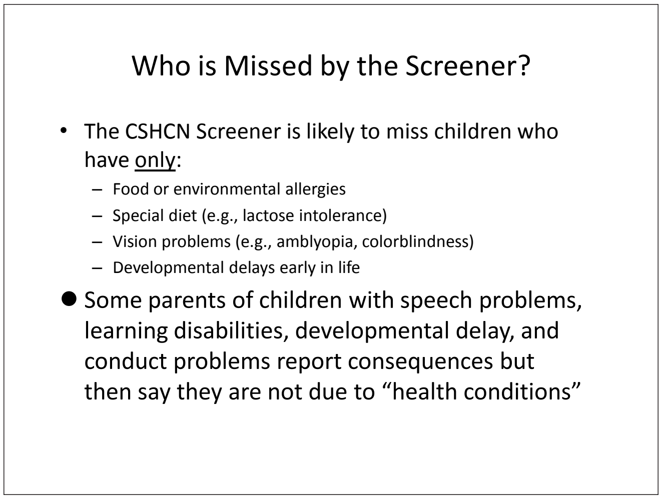
Cross-Method Comparisons

- 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)



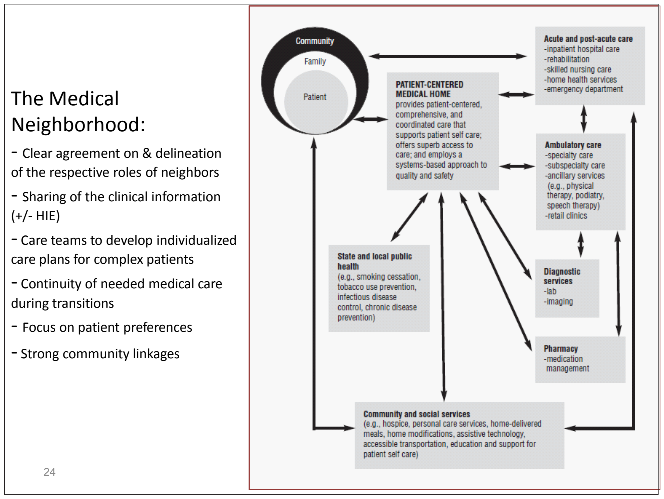
Who is Identified by the Screener?

- 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 <u>only</u>:
  - 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 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

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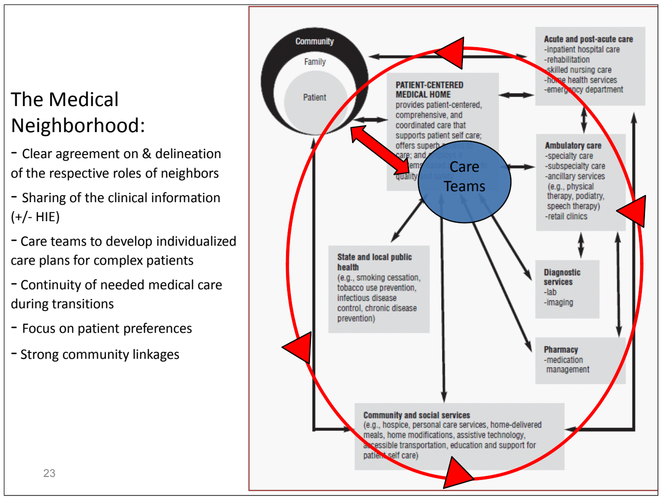
Aligning Financing and Quality for CYSHCN (cont.)



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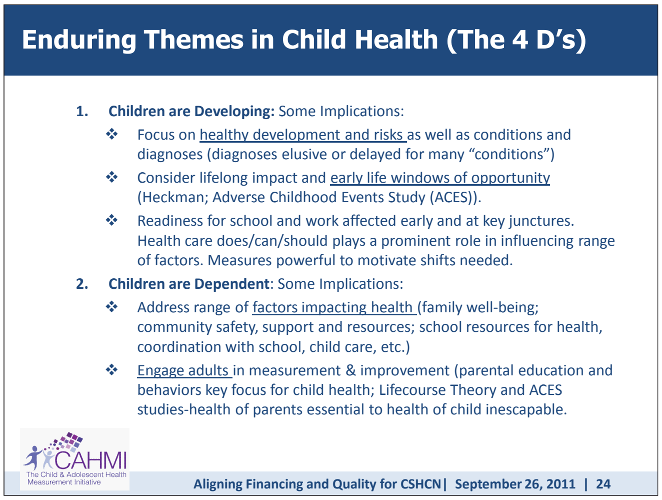

Enduring Themes in Child Health (The 4 D's)

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 plays 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.

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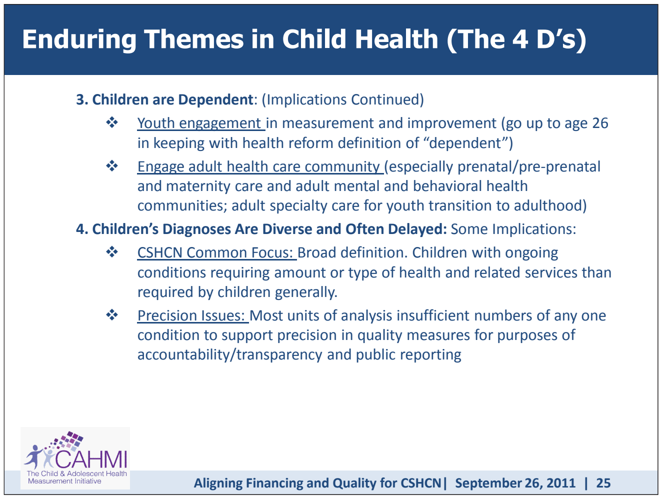

Enduring Themes in Child Health (The 4 D's)

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-prenatal 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

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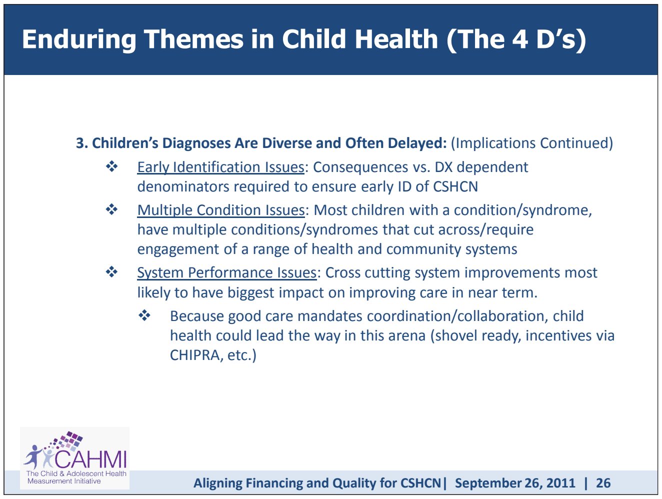

Enduring Themes in Child Health (The 4 D's)

3. Children's Diagnoses Are Diverse and Often Delayed: (Implications Continued)
- 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.)

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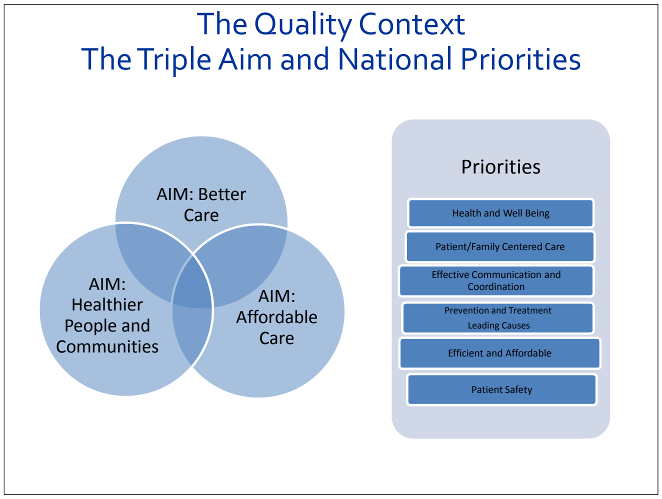
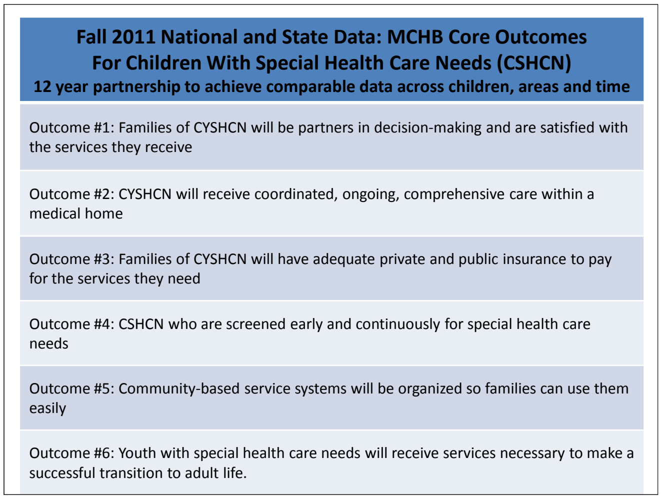


The Quality Context
The Triple Aim and National Priorities

Priorities
- Health and Well Being
- Patient/Family Centered Care
- Effective Communication and Coordination
- Prevention and Treatment Leading Causes
- Efficient and Affordable
- Patient Safety



Fall 2011 National and State Data: MCHB Core Outcomes For Children With Special Health Care Needs (CSHCN)

12 year partnership to achieve comparable data across children, areas and time

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

Outcome #2: CYSHCN will receive coordinated, ongoing, comprehensive care within a medical home

Outcome #3: Families of CYSHCN will have adequate private and public insurance to pay for the services they need

Outcome #4: CSHCN who are screened early and continuously for special health care needs

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

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

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Resources for Risk Adjustment and Other Financial Protections for CYSHCN in Our Evolving Health Care System, a publication of the Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs, May, 2012.

The Initial Core Measures

- Frequency of ongoing prenatal care
- Otitis Media with Effusion - avoidance of inappropriate use of systemic antimicrobials
- Timeliness of prenatal care
- Total EPSDT eligibles who received dental treatment services (EPSDT CMS Form 416 Line 12C)
- % 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)
- 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 (ADHD) medication
- Body Mass Index (BMI) documentation 2 - 18 year olds
- Child and adolescent Major Depressive Disorder
- Rates of screening using standardized screening tools for potential delays in social and emotional development
- Follow up after hospitalization for mental illness
- Chlamydia screening 16-20 females
- Annual hemoglobin A1C testing (all children and adolescents diagnosed with diabetes)
- 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
- Total eligibles receiving preventive dental services
- Annual dental visit
- Pharyngitis - appropriate testing
- Access to primary care practitioners, by age and total

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)

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

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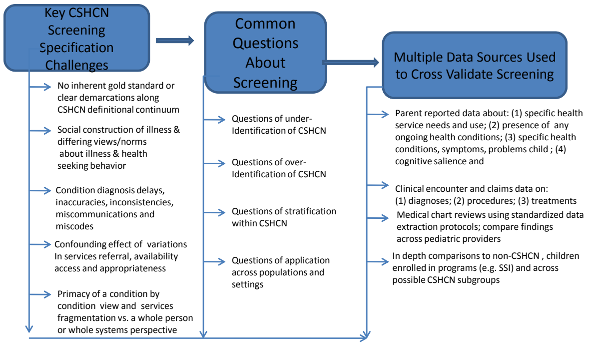
Aligning Financing and Quality for CYSHCN (cont.)



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

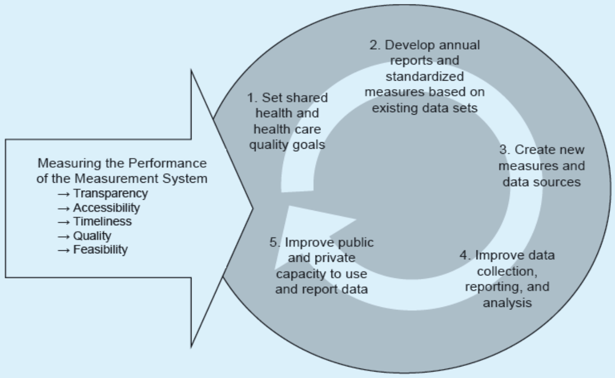
- Questions of under-Identification of CSHCN
- Questions of over-Identification of CSHCN
- Questions of stratification within CSHCN
- Questions of application across populations and settings

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

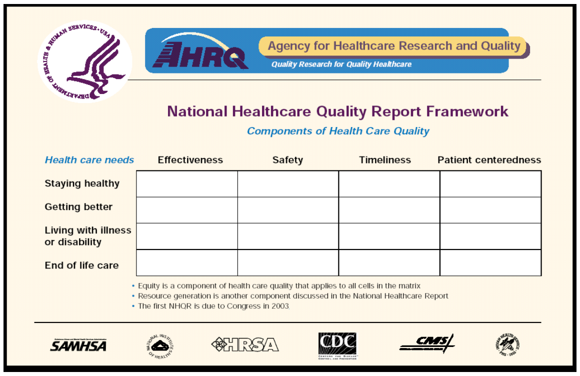
Issue	Quality Improvement	Public Accountability
What to measure	Biggest gap between practice and science	Measures with wide public importance
Requester or Audience	Internal (providers, managers)	External (consumers, purchasers)
Purpose	Identify process to be improved or test results of efforts	Make a purchase decision, provide reassurance to the public, provide incentive for change
Frequency of measure	Very frequent or continuous (feedback daily, weekly, etc.)	Infrequently (e.g. annually)
Comparison	Longitudinal, within one unit, or external for benchmarking)	Cross-sectional (across units)
Sample size	Often relatively small	Large samples with small confidence intervals
Unit of analysis	Smallest relevant unit that can take action to improve	Often aggregate, increasingly disaggregated
Severity adjustment	Often not necessary if processes are changing but input are not	Often critical for fairness
Detection of bias	No audit, measurement internal	External audit
Level of sophistication	Simple, not likely to be challenged	Rigorous and defensible to multiple, often resistant, audiences
Level of detail	Very specific, often miniscule	Summarized, global
Expected response	Behavior change	Decision-making primary, behavior change secondary
Need for confidentialiy	Very high	None

Moving Ahead: Goals and Priorities



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



National Healthcare Quality Report Framework

Components of Health Care Quality

Health care needs	Effectiveness	Safety	Timeliness	Patient centeredness
Staying healthy				
Getting better				
Living with illness or disability				
End of life care				

- 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

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*

Appendix to Risk Adjustment and Other Financial Protections for CYSHCN in Our Evolving Health Care System: Presentation Slides from Sept. 2011 Expert Workgroup Meeting, a publication of the Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs, September, 2011. The Catalyst Center is funded under cooperative agreement #U41MC13618 from 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. Lynda Honberg, MHSA, MCHB/HRSA Project Officer.

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