CAHMI

The Child & Adolescent Health
Measurement Initiative

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

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Desired Outcome and Baseline Requirements

- **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)
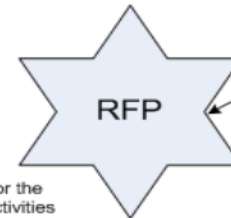
Final Rule June 14, 2002

RFP

Procedures used for the mandatory EQO activities must be consistent with (not identical) w/ the specified 3 protocols

This is the outline of specific components that must be included in the State's MCO contracts re: quality assessment & performance measurement

A) Each State must have written quality strategy

B) The elements of State quality strategies must include at a minimum:

- MCO/PIHP contract provisions that incorporate the standards specified in this subpart.

- Procedures that:
  1. Assess quality & appropriateness of care for all Medicaid enrollees AND individuals with SHCN

  2. Identify race, ethnicity, primary language of each enrollee (State must provide to MCO)

  3. Regularly monitor/evaluate MCO compliance with standards:
     - annual EQR of services covered in MCO contract

     - info system that supports review of State's quality strategy

     - standards as least as stringent as described in rest of subpart for:

Access to care
Operations & structure
Quality meas/improvement

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: to 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/ weakness re: quality, timeliness, access
- recommendations re: how to improve quality of services / care
- as State determines, methodologically appropriate comparative info about all MCOs
- assessment of the degree to which MCOs addressed QI recs by EQRO from last EQR

ACCESS TO CARE STANDARDS
- availability of services
- assurance of adequate capacity/services
- coordination & continuity of care
  id SHCN (State must id to MCO)
  assess SHCN (MCO must do for id grp)
  id mechanisms must be specified in
  State quality improvement strategy
- coverage & authorization of services

STRUCTURE & OPERATIONS STANDARDS
- provider selection
- enrollee information
- confidentiality
- enrollment/disenrollment
- grievance systems
- subcontractual relationships

QUALITY MEASUREMENT & IMPROVEMENT STANDARDS
- practice guidelines
- MCO have quality assessment & performance improvement program
- health information systems

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
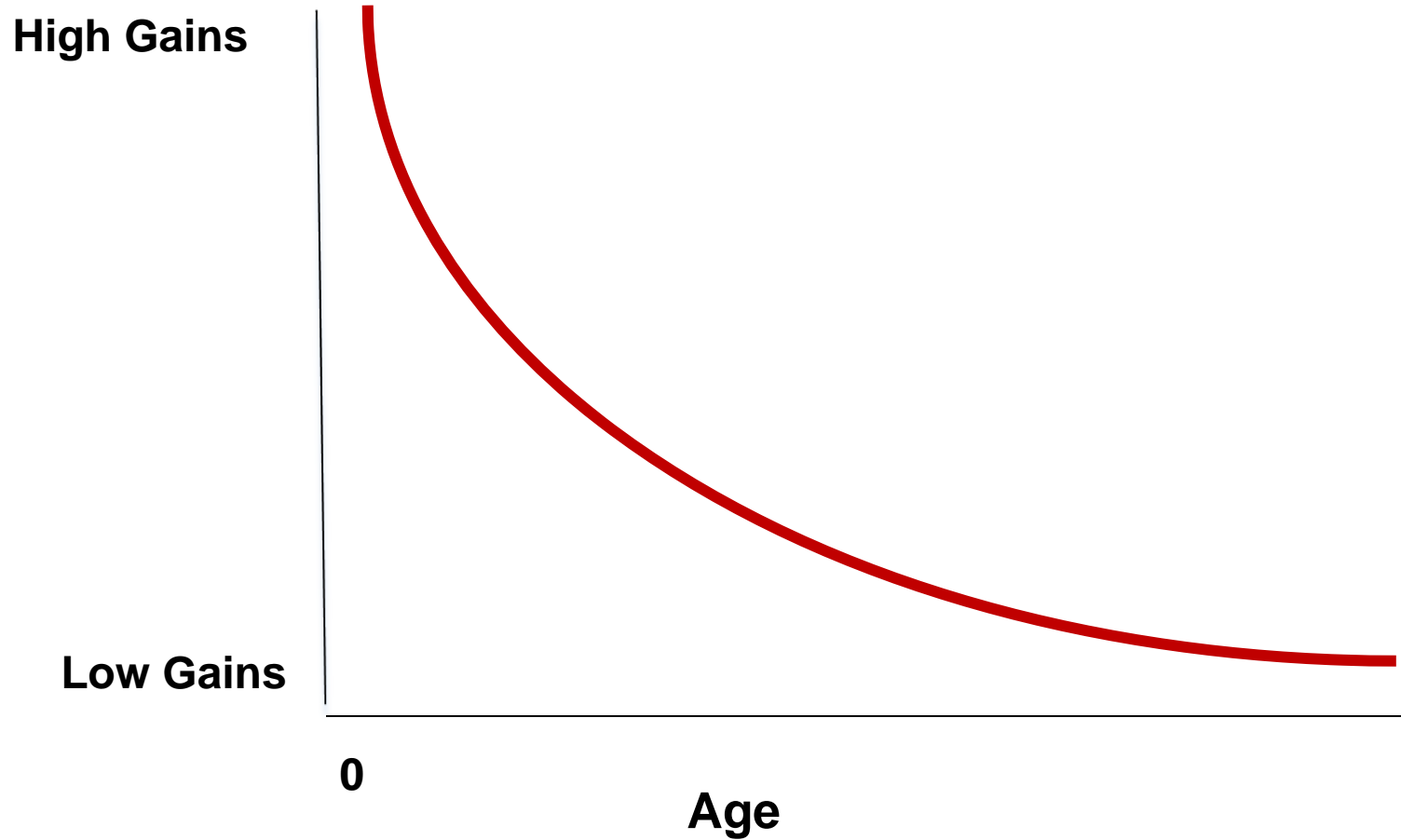   - States using innovative approaches are achieving innovative gains

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

1. **Children are Developing:** Some Implications:

   ❖ Focus on <u>healthy development and risks</u> as well as conditions and diagnoses (diagnoses elusive or delayed for many "conditions")

   ❖ Consider lifelong impact and <u>early life windows of opportunity</u> (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.

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Special Mandate for Medicaid/CHIP
Rate of Return to Investment in Human Capital

High Gains

Low Gains

0

Age

JJ Heckman, 2000

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

2. Children are Dependent: Some Implications:

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

❖ <u>Engage adults</u> 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.

❖ <u>Youth engagement</u> in measurement and improvement (go up to age 26 in keeping with health reform definition of "dependent")

❖ <u>Engage adult health care community</u> (especially prenatal/pre-prenatal and maternity care and adult mental and behavioral health communities; adult specialty care for youth transition to adulthood)

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The Challenge and Opportunity
Protective Home Environment Summary Measure

Home Environment Summary Index for CSHCN
(2007 NSCH)
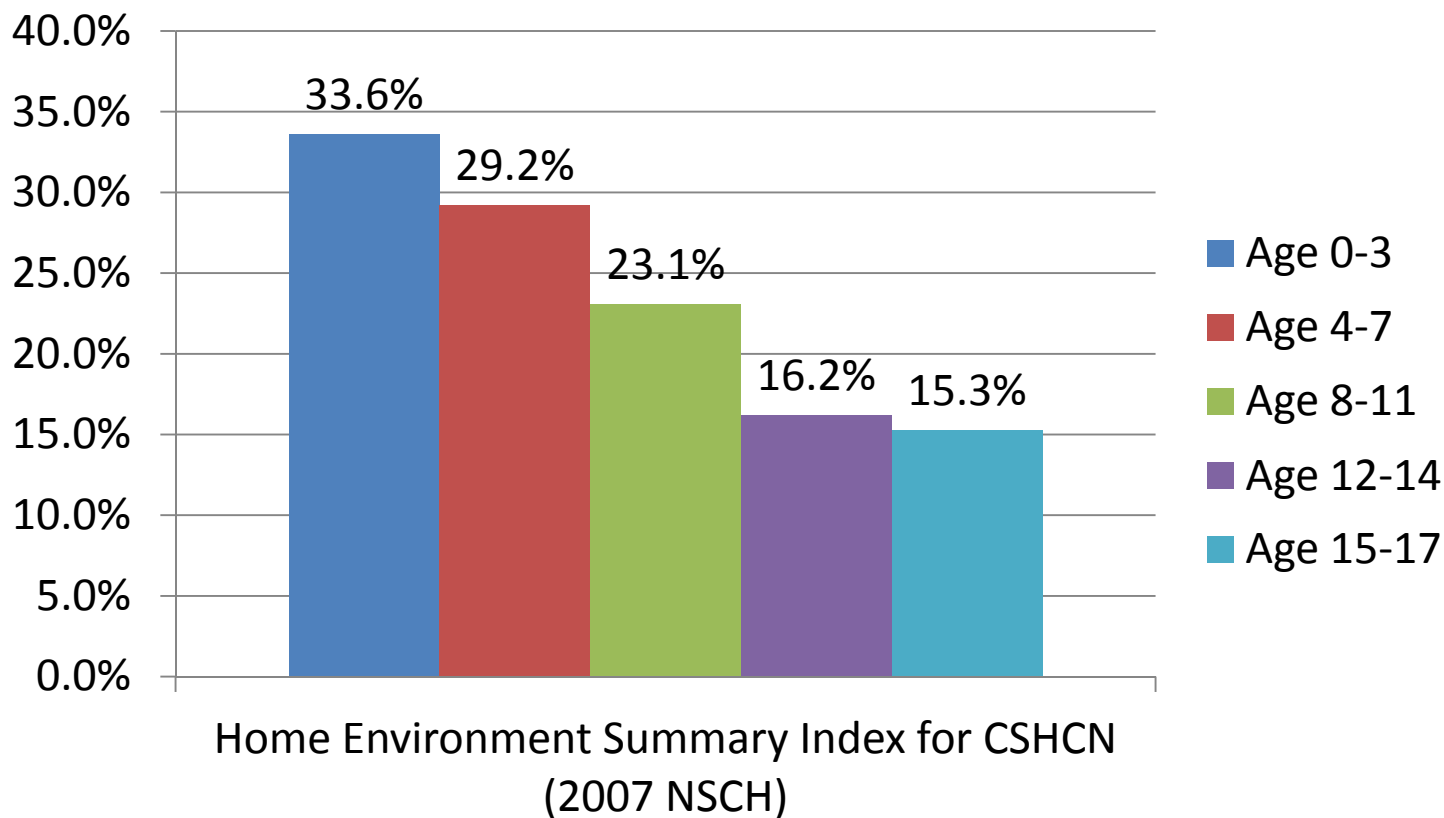
(Share 4+ Meals Week; Read/Sing to Child (<5); No Smoking in the Home; Ever Breastfed (<5), No TV in Bedroom & < 2 Hours/Day; Parent Met Most Friends (6-17); Usually Does Required Homework)

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

3. Children's Diagnoses Are Diverse and Often Delayed: Some Implications:

❖ <u>Precision Issues:</u> Most units of analysis insufficient numbers of any one condition to support precision in quality measures for purposes of accountability/transparency and public reporting

❖ <u>CSHCN Common Focus:</u> Broad definition. Children with ongoing conditions requiring amount or type of health and related services than required by children generally.

❖ <u>Early Identification Issues</u>: Risk and Consequences vs. DX dependent denominators required to ensure early ID of CSHCN

❖ <u>Multiple Condition Issues</u>: Most children with a condition/syndrome, have multiple conditions/syndromes that cut across/require engagement of a range of health and community systems

❖ <u>System Performance Issues</u>: Cross cutting system improvements most likely to have biggest impact on improving care in near term.
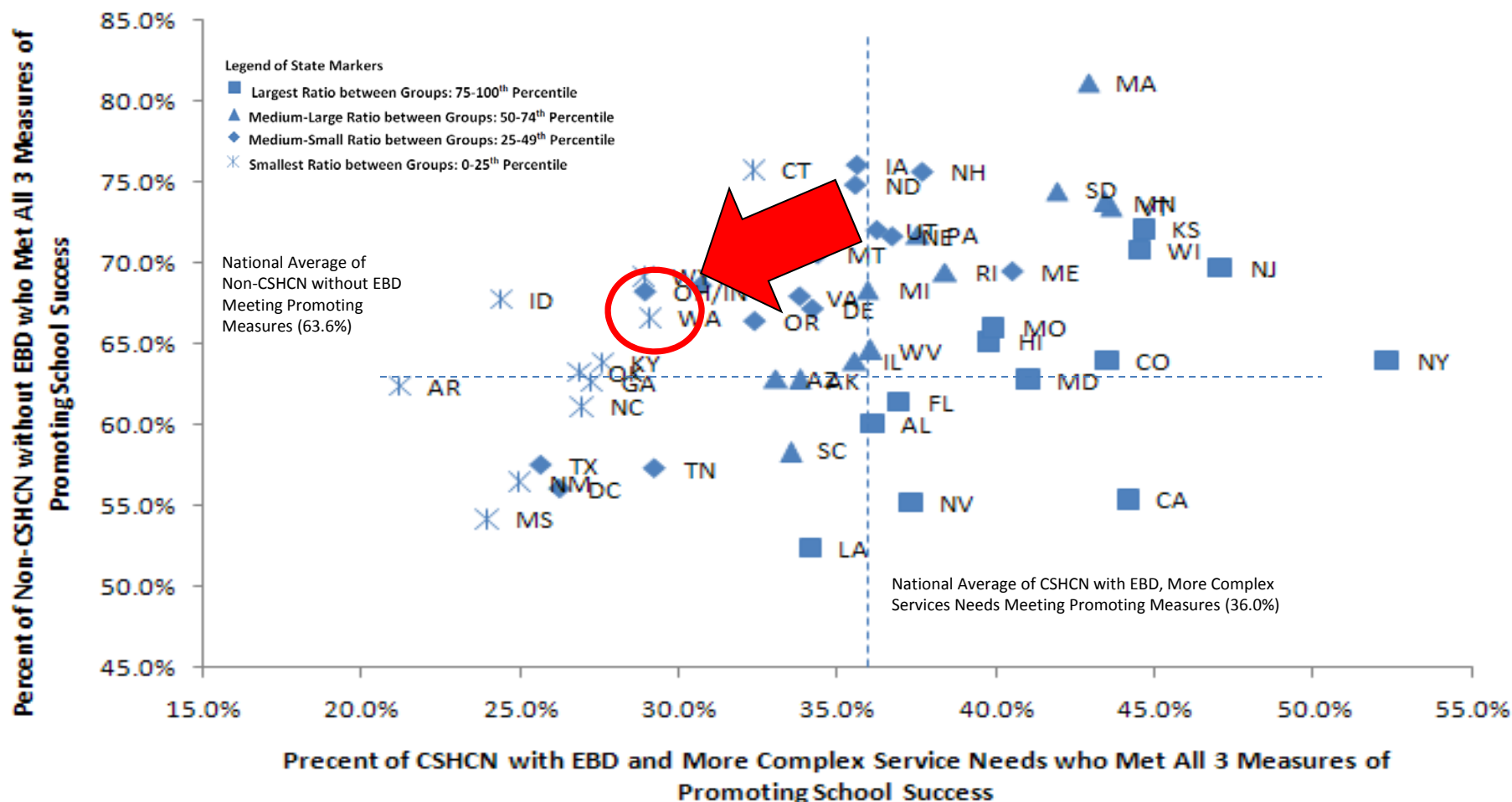
4. Children are disproportionately disadvantaged and diverse

Higher proportion of children are low income and minority

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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)

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.

Whole System, Whole Child View

DRC
A project of CAHMI

Age 0-11 years:

12.7%	**15.3%**	**16.1%**	**20.2%**	**25.3%**
CSHCN with one or more EBD* issues	CSHCN with more complex needs	Publicly insured CSHCN	All CSHCN age 0-11	Privately insured CSHCN

Age 12-17 years:

6.2%	**6.4%**	**8.9%**	**13.6%**	**19.2%**
Publicly insured CSHCN	CSHCN with one or more EBD* issues	CSHCN with more complex needs	All CSHCN age 12-17	Privately insured CSHCN

OREGON 2009/10
Whole System, Whole Child View

	Met all CSHCN Measure criteria	Met 2 or fewer criteria	Met 5+ (12-17 only)
Age 0-11 (5 criteria)	17.7%	33.3%	NA
Public	16.1%	38.1%	NA
Private	22.9%	24.1%	NA
Age 12-17 (6 criteria)	10.0%	33.6%	17.4%
Public	14.3%	51.6%	18.8%
Private	2.6%	23.5%	14.3%

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

09/18/10

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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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The views expressed in this report are those of the authors and do not necessarily represent those of the Department of Health and Human Services, the Agency for Healthcare Research and Quality, or the Centers for Medicare & Medicaid Services.
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ABSTRACT

BACKGROUND: Parent/consumer–reported data is valuable and necessary for population-based assessment 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 = 91 642; 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. Forty-five percent of all children in the United States scored positively on a minimal quality composite measure: 1) adequate insurance, 2) preventive care visit, and 3) medical home. A 22.2 point difference existed across states and there were wide variations by health condition (autism, 22.8, to asthma, 39.4). 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, care coordination, and performance on the minimal quality composite. A 4.60 fold (gaps in insurance) to 1.27 fold (preventive dental and medical care visits) difference in quality scores was observed across states. Notable disparities were observed among publicly insured children according to race/ethnicity and across all children by special needs status and household income.

CONCLUSIONS: Findings emphasize the importance of health care insurance duration and adequacy, health care access, chronic condition management, and other quality of care goals reflected in the 2009 CHIPRA legislation and the ACA. Despite disparities, similarities for public and privately insured children 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 accessing specialist 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 services; chronic conditions in childhood; CSHCN medical home; national survey of children's health (NSCH); quality of care

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Available National and State Data

Indicators by CHIPRA Core Measure Domain

Prevention & Health Promotion	Availability	Management of Acute Conditions	Management of Chronic Conditions	Family Experiences of Care
• Well Visits • Dental Visits • Developmental Surveillance • Developmental Screening	• Adequacy of Health Insurance • Consistency of Health Insurance • Mental health Care Access • Specialist Access	N/A	• 6 CSHCN Core Outcomes (e.g. Medical Home…) • All measures stratified by CSHCN, SES and Race/Ethnicity	• Family-Centered Care • Shared Decision Making • Ease of accessing special services

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➢ **Insurance Coverage**

   ➢ **Insurance Status & Consistency**

   ➢ **Insurance Adequacy**
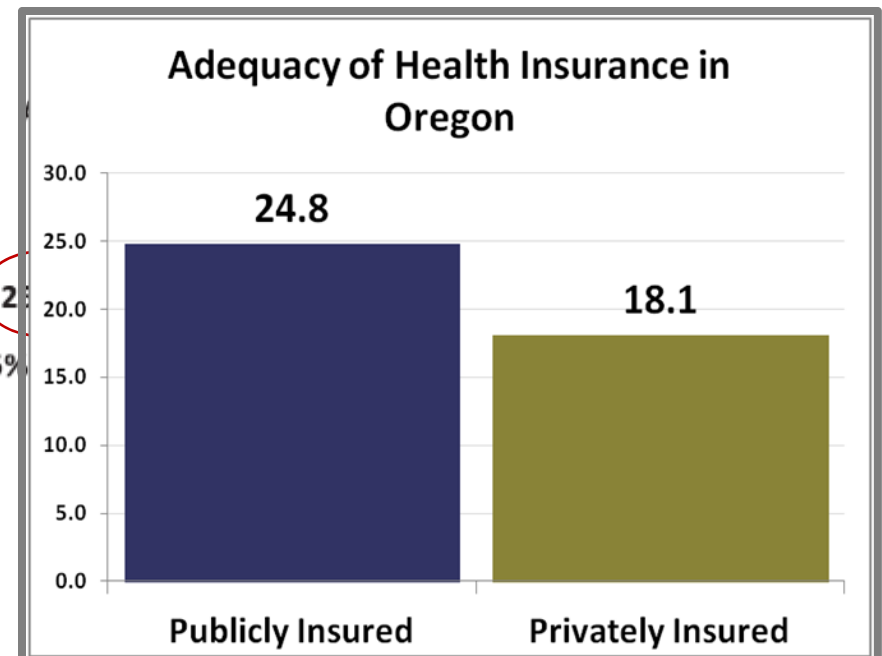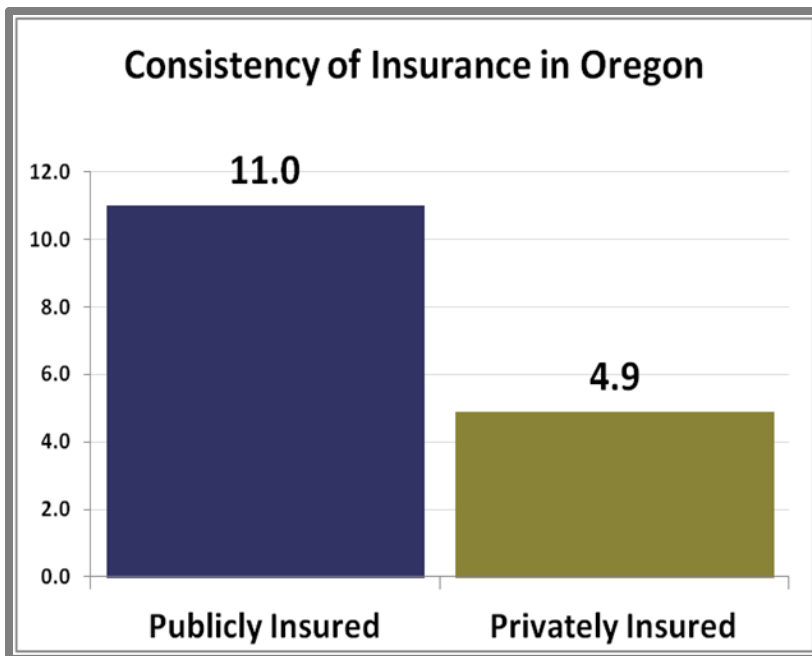
Defining and Measuring
Access to and Quality of Care

➢ **Access to Quality Care**

    ➢ **Re:**

Child had 1+ preventi
past year (All Childre
difference ac

Child had 1+ preventiv
within past year (All Chi
point difference

Standardized develo
(age 10-71 months; A
36.3 point differenc

■ National Privately Insured Children

■ National Publicly Insured Children

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

■ Publicly Insured ■ Privately Insured

89.5%

91.4%   Adj OR: 1.36 (1.11-1.65)

%   Adj OR: 1.37 (1.13-1.66)

➢ Access to Quality Care

   ➢ Receipt of specialized services
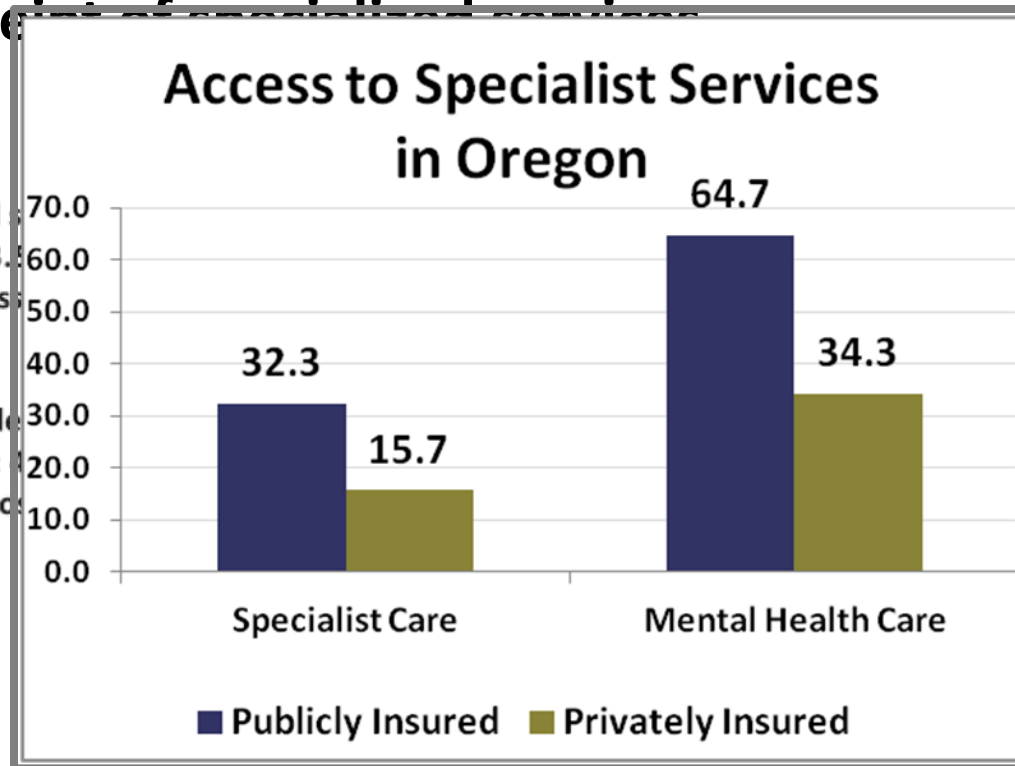
Problem getting needed s____
child (All Children: 23.___
difference acros___

Did not receive neede___
services (All Children: ___
difference acro___

Access to Specialist Services in Oregon

- National Privately Insured Children
- National Publicly Insured Children

	Specialist Care	Mental Health Care
Publicly Insured	32.3	64.7
Privately Insured	15.7	34.3

(__-1.48)

*Sample size not sufficient to compare developmental screening rates within Oregon

A project of CAHMI

➢ **Experience of Quality Care**

   ➢ **Receipt of family centered care & Medical Home**

Child received family centered care (All Children difference)

Met Medical Home 57.5%; 23.9 point diff

Coordinated Systems of Care in Oregon

Family-Centered Care: 59.9 (Publicly Insured), 80.9 (Privately Insured)

Medical Home: 48.5 (Publicly Insured), 73.4 (Privately Insured)

■ Publicly Insured   ■ Privately Insured

75.2% Adj OR: 0.84 (0.72-0.98)

66.5% Adj OR: 0.75 (0.64-0.84)

■ National Privately Insured Children

■ National Publicly Insured Children

A project of CAHMI
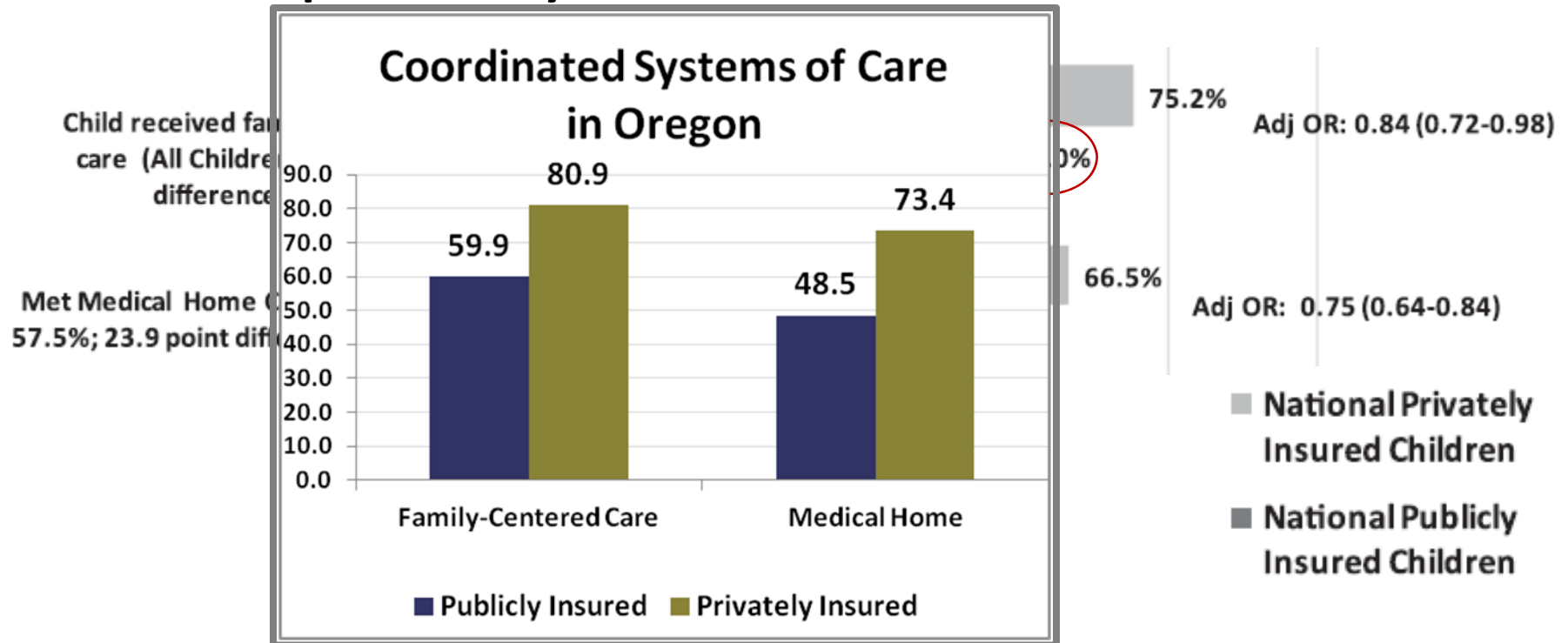
➢ **Quality of Care Index**

    ➢ **Adequate Insurance**

    ➢ **Preventive Medical Visit in**

past 12 months

    ➢ **Medical Home**

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

State Ranking

Higher=Better Performance

Significantly higher than U.S.
Higher than U.S. but not significant
Lower than U.S. but not significant
Significantly lower than U.S.

Statistical significance: p <.05

Oregon — 49.3 / 41.9
Nationwide — 49.0 / 37.5

■ **Privately Insured**   ■ **Publicly Insured**
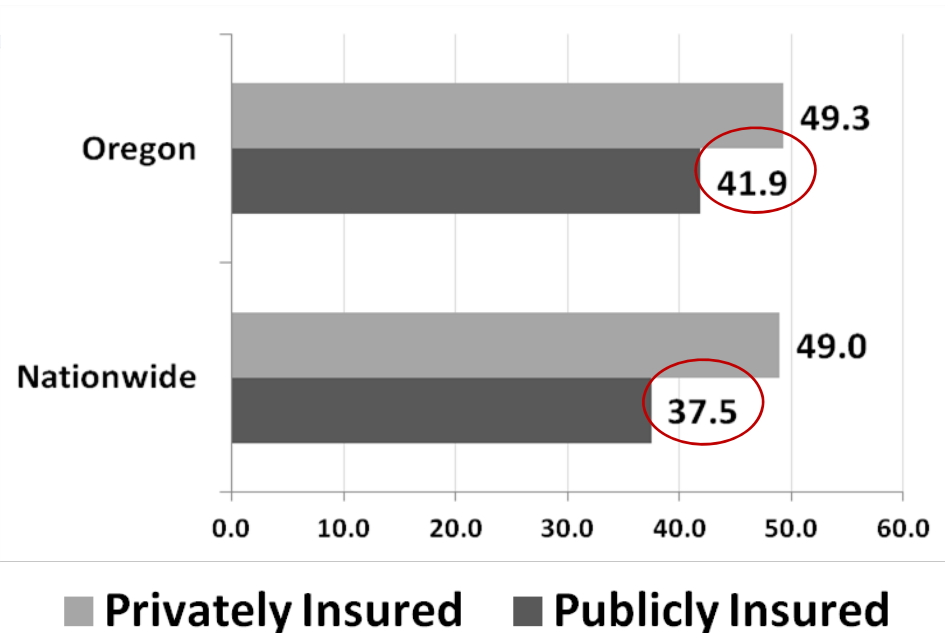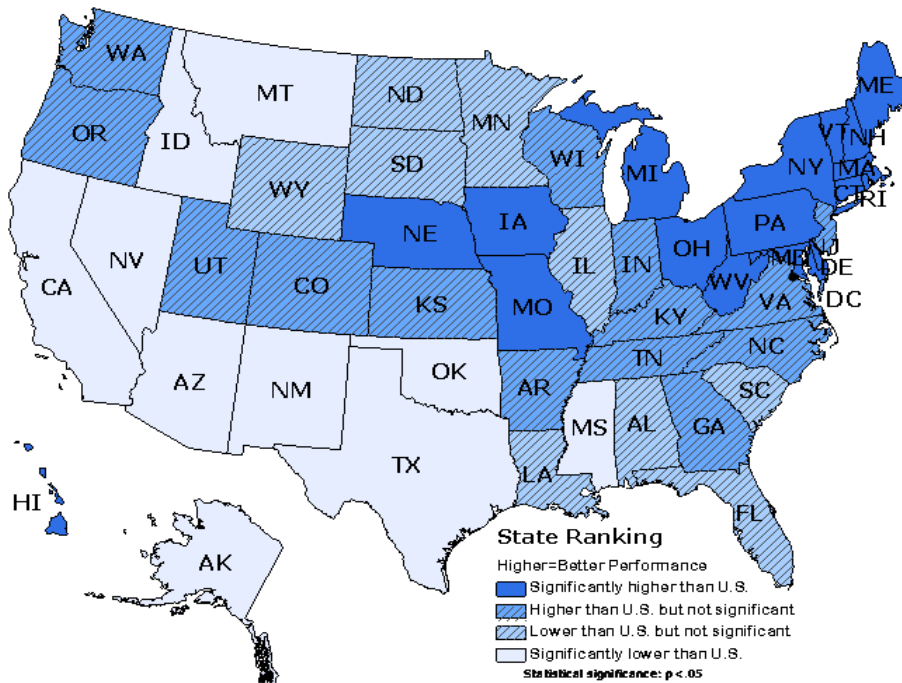
Stratification and Aggregation Allow Action-Shaping Assumptions to Be Checked: Do Publicly Insured Children Always Fare Worse?
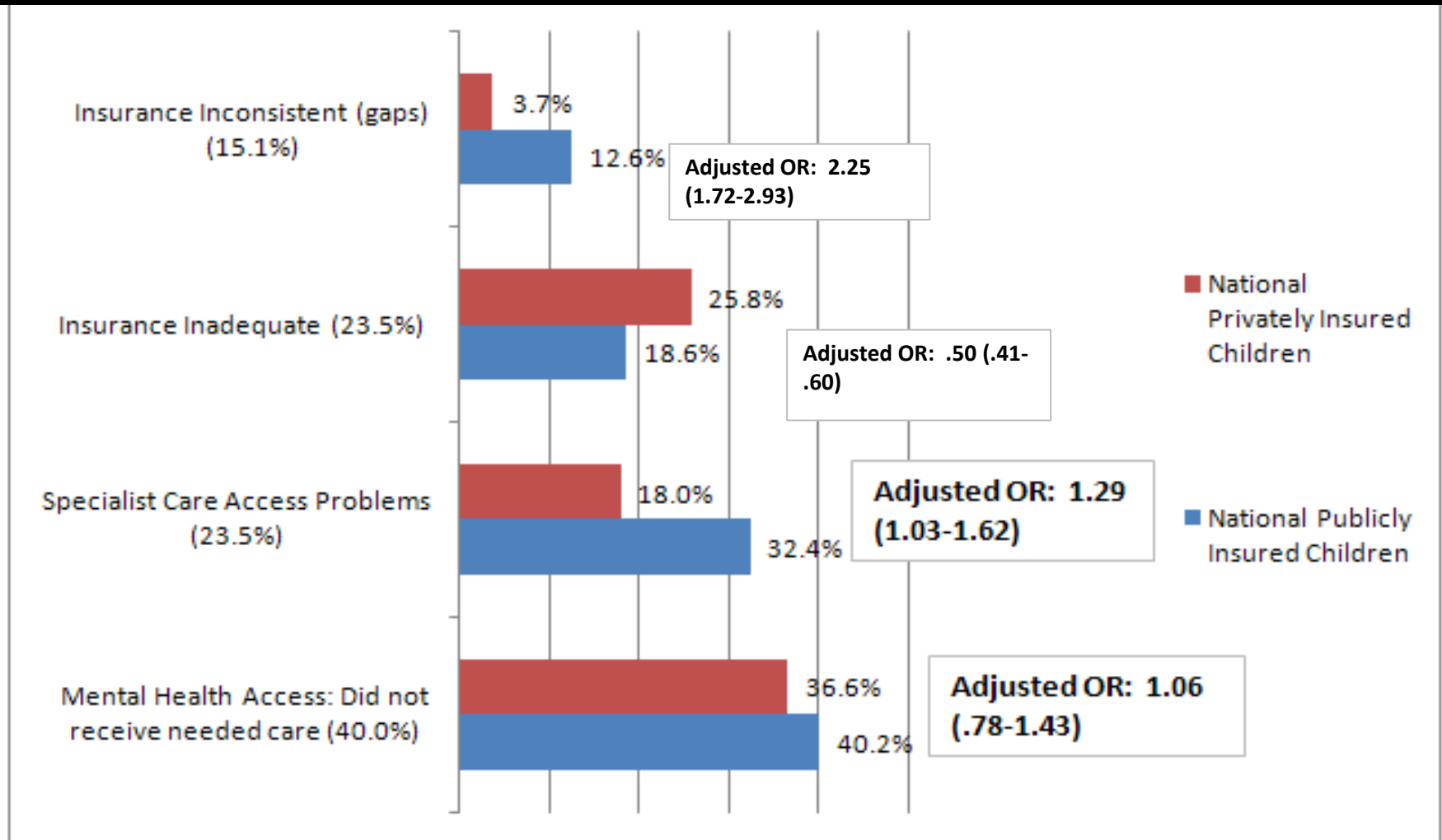
Stratification and Aggregation Allow Action-Shaping Assumptions to Be Checked: Very few children have special health care needs?

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
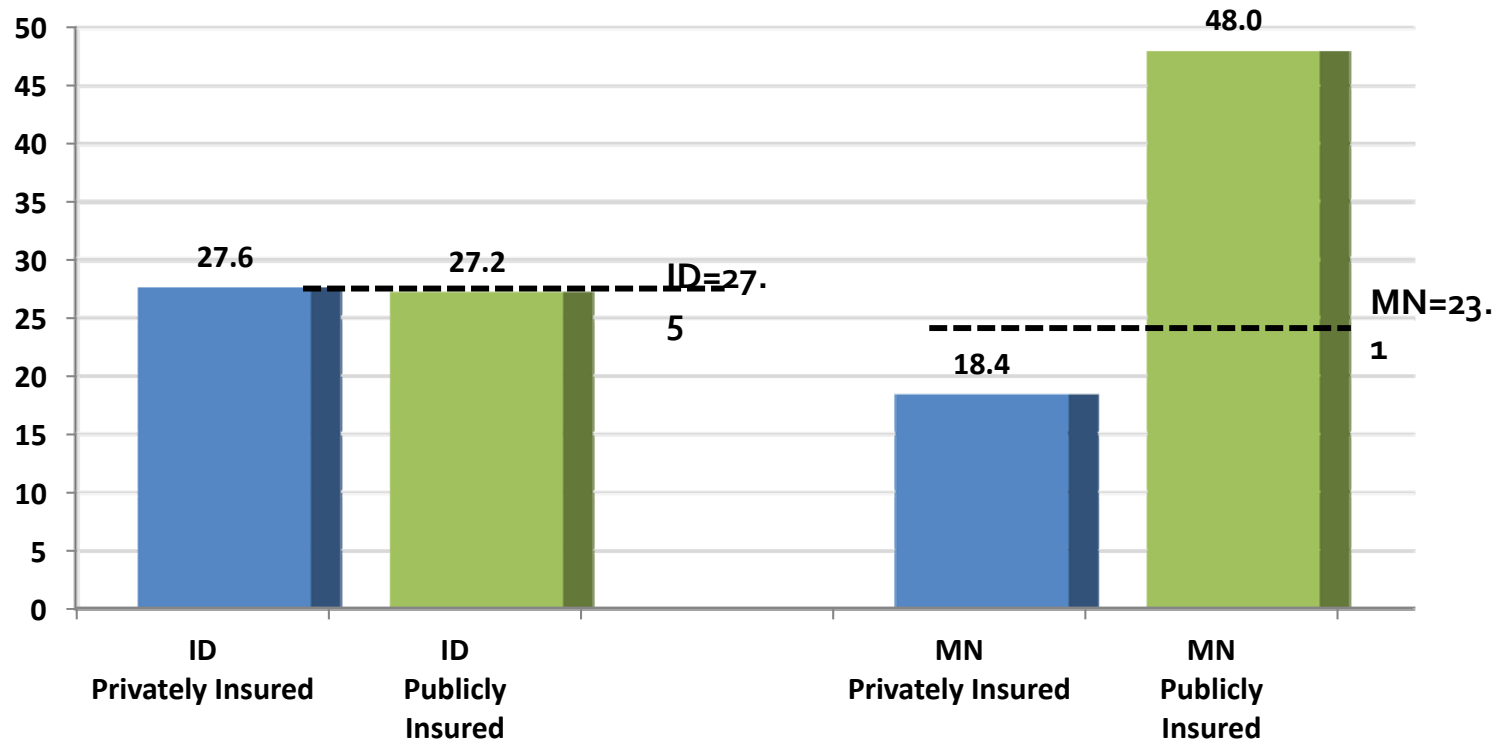
Stratification and Aggregation Allow Action-Shaping Assumptions to Be Checked:
Most CYSHCN have 1 major condition and have non-complex needs?

	Publicly Insured Children (N=19,748) % (State Range)	Privately Insured Children (N=64,165) % (State Range)
Multiple conditions: has ≥2 of 20 conditions assessed (among children with at least 1 condition)	52.7 (40.9-72.3)	42.1 (35.5-48.4)
Moderate or severe: parent-rated condition as greater than mild (among child with a least 1 condition)	57.5 (45.6-66.8)	45.6 (40.1-52.1)
Service need complexity: CSHCN with ≥1 of 20 conditions assessed who require multiple types of special services, beyond primarily prescription medication management	73.4 (58.1-91.5)	52.2 (41.6-67.7)

Data Must Allow Action-Shaping Assumptions to Be Checked

State with the lowest overall rate had the highest insurance disparity

Chart showing insurance rates:
- ID Privately Insured: 27.6
- ID Publicly Insured: 27.2
- MN Privately Insured: 18.4
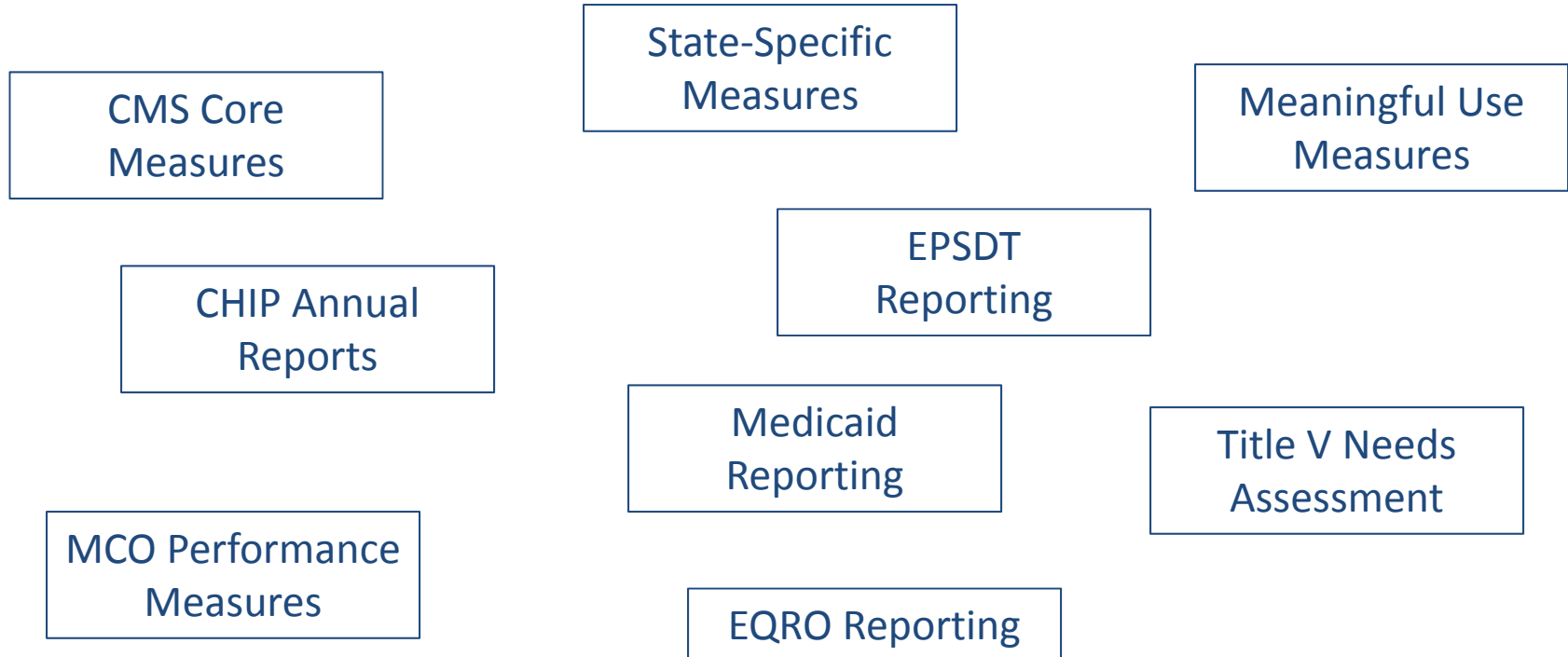- MN Publicly Insured: 48.0

ID=27.5
MN=23.1

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 <u>children's health care quality in the most actionable and efficient manner possible!</u>

State-Specific Measures

CMS Core Measures

Meaningful Use Measures

EPSDT Reporting

CHIP Annual Reports

Medicaid Reporting

Title V Needs Assessment

MCO Performance Measures

EQRO Reporting

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Core Functions of Any Framework

Understand your population

Assess system performance

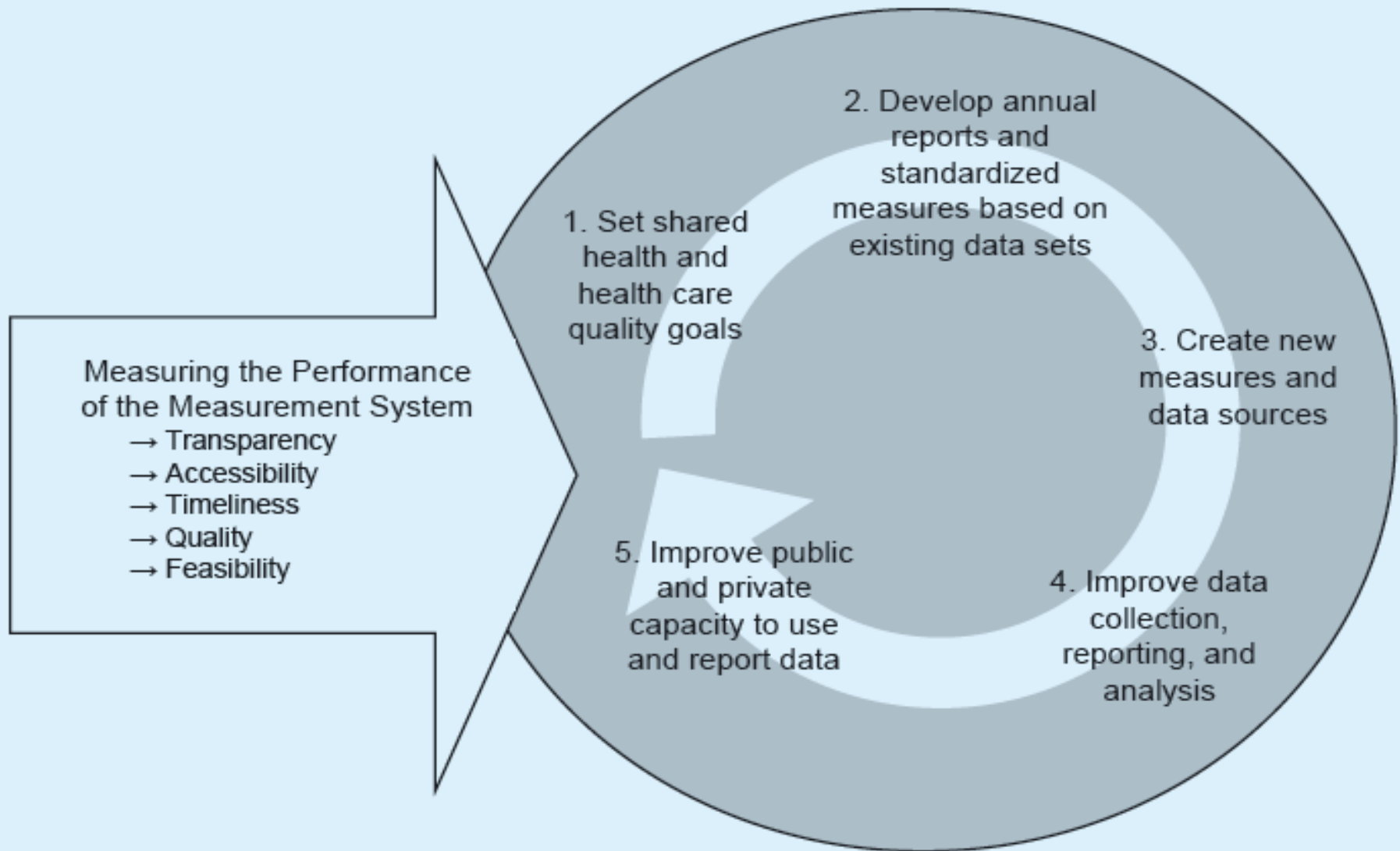**Examine improvement opportunities**

Select priorities

Set targets

Identify promising improvement models

Monitor progress

Meta-Framework for Measurement Institute of Measurement (2011)

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

Agency for Healthcare Research and Quality
Quality Research for Quality Healthcare

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

SAMHSA   HRSA   CDC   CMS/

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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

RELEVANT CATEGORIES FILTER:

Performance areas of interest

- The Basics
- Staying health
- Living w/ illness
- Getting Better
- Changing Needs

UNIT OF ANALYSIS FILTER:

Setting(s) for measurement activities

- PCPs or Medical Groups
- Community Wide
- Health Plans
- Agencies/ Orgs Public Health

Core Set of Pediatric Quality Measures

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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
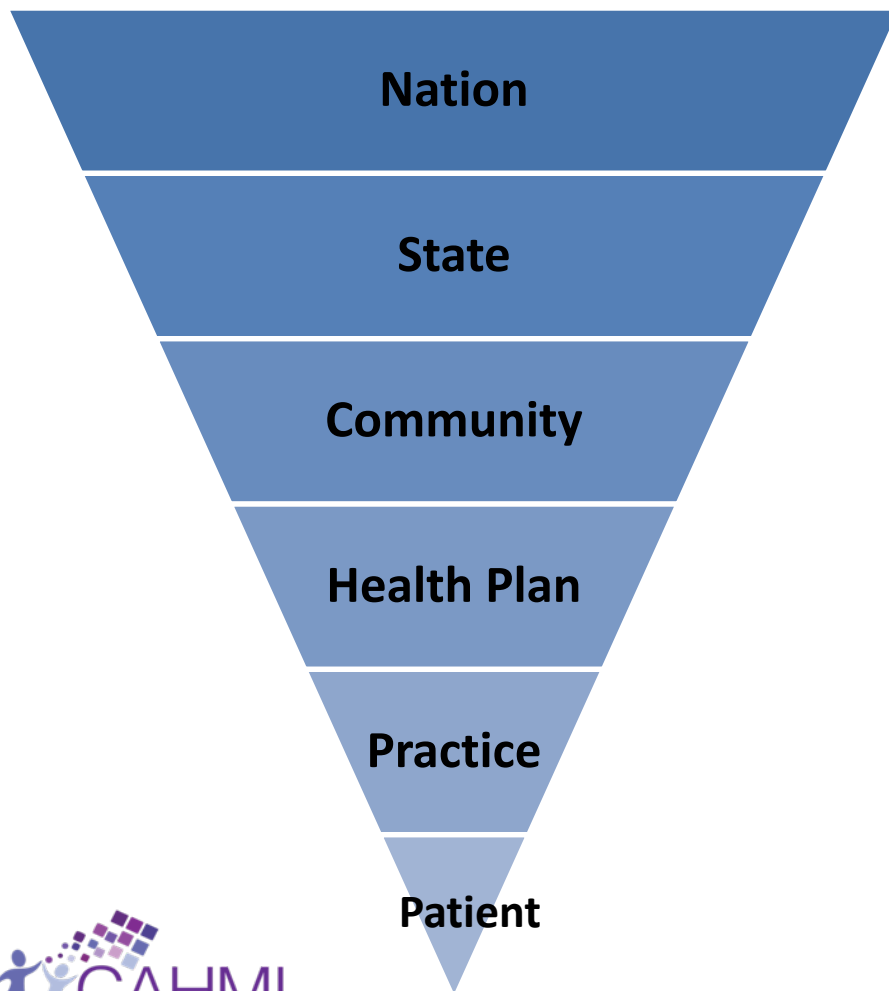
Quality Measurement Strategies Designed:

-- 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

Federal & State Reporting

Quality Improv.

Purchasing- Contracting

Consumer Information
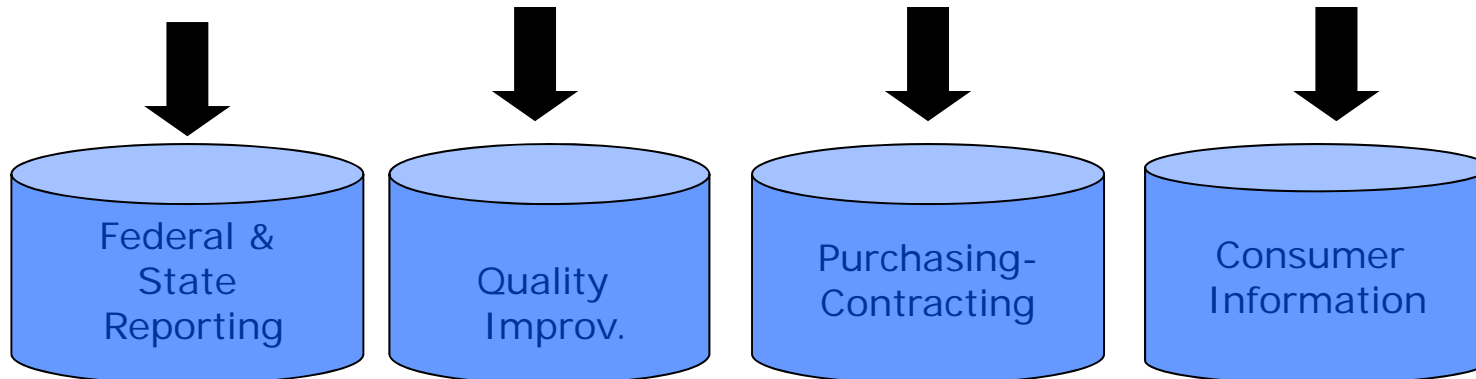
Swamp the System (in a good way!)

Consider Measures that can be used at Multiple Levels

Nation

State

Community

Health Plan

Practice

Patient

- 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

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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

> "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**

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

> "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**

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Messages – What the CHIPRA 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**

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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**

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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)

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
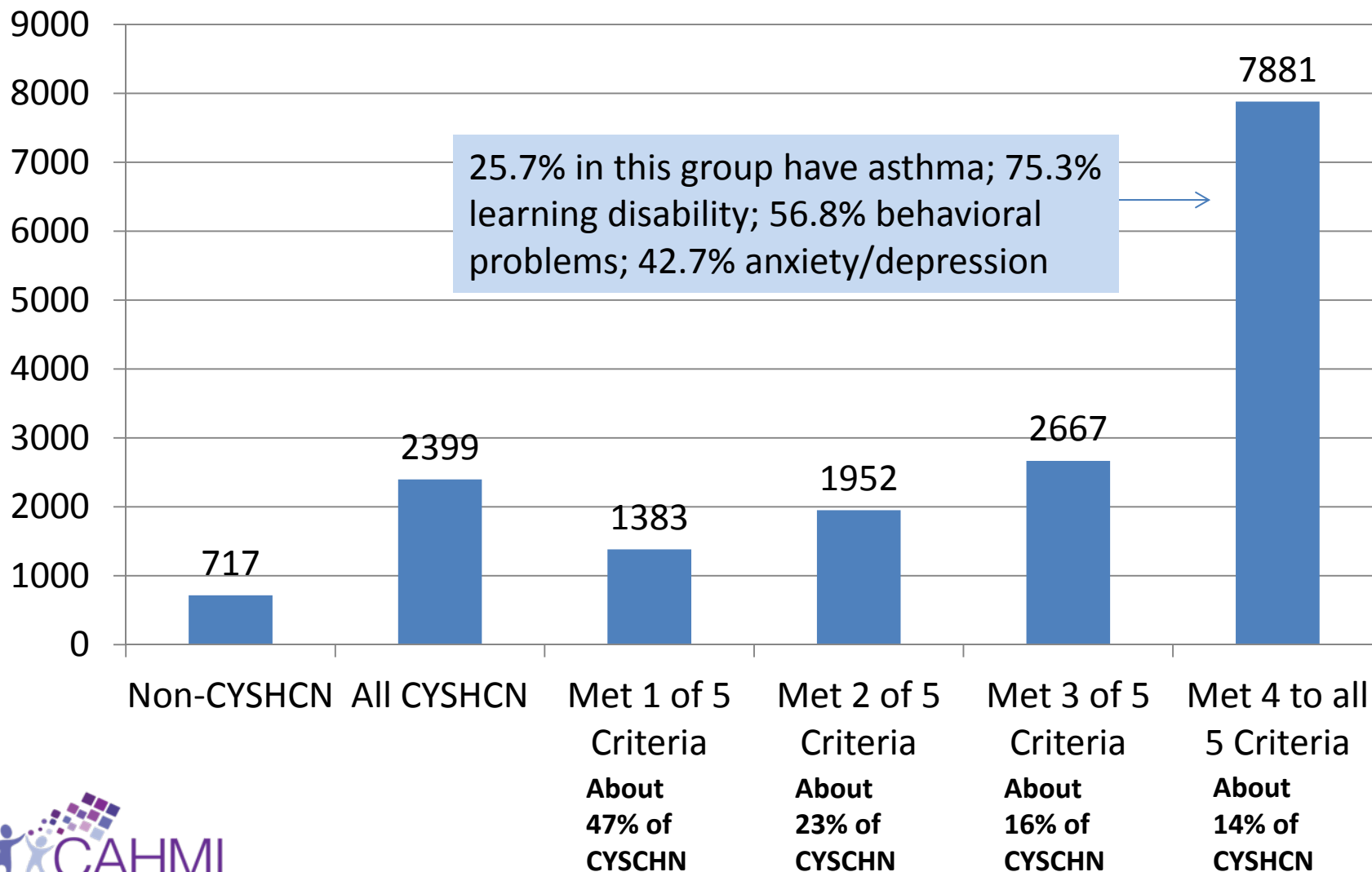
GROUP C
On going health conditions; high or complex service use needs; moderate to severe functional limitations

Special Health Needs Continuum

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

Category	Value
Non-CYSHCN	717
All CYSHCN	2399
Met 1 of 5 Criteria (About 47% of CYSCHN)	1383
Met 2 of 5 Criteria (About 23% of CYSCHN)	1952
Met 3 of 5 Criteria (About 16% of CYSCHN)	2667
Met 4 to all 5 Criteria (About 14% of CYSCHN)	7881

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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)

Category	Percentage
All CYSHCN	20.90%
Met 1 of 5 Criteria	12.00%
Met 2 of 5 Criteria	21.40%
Met 3 of 5 Criteria	33.30%
Met 4 to all 5 Criteria	45.90%

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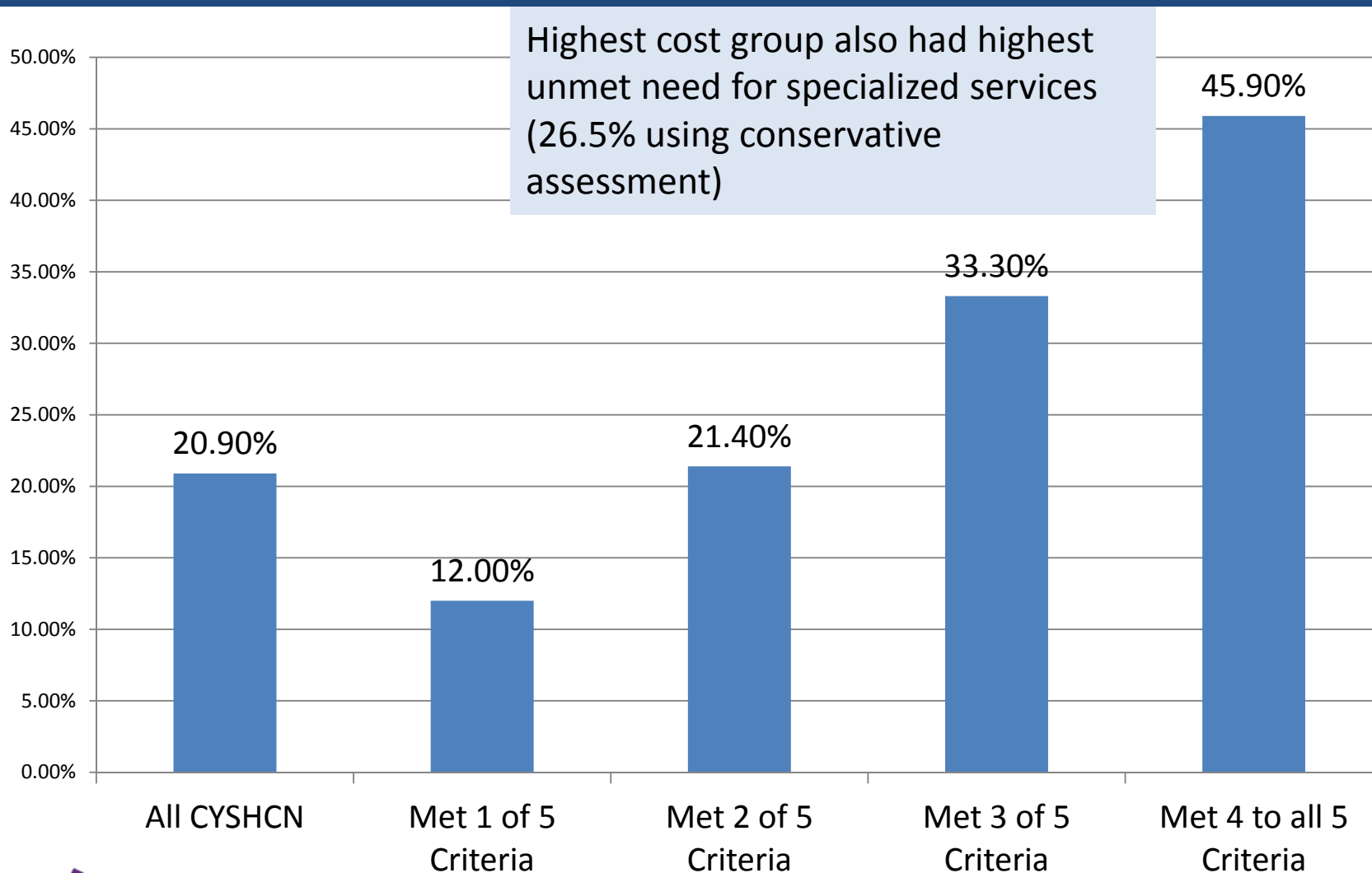
Parent(s) Cut Back/Stopped Work Due to Child's Health Needs
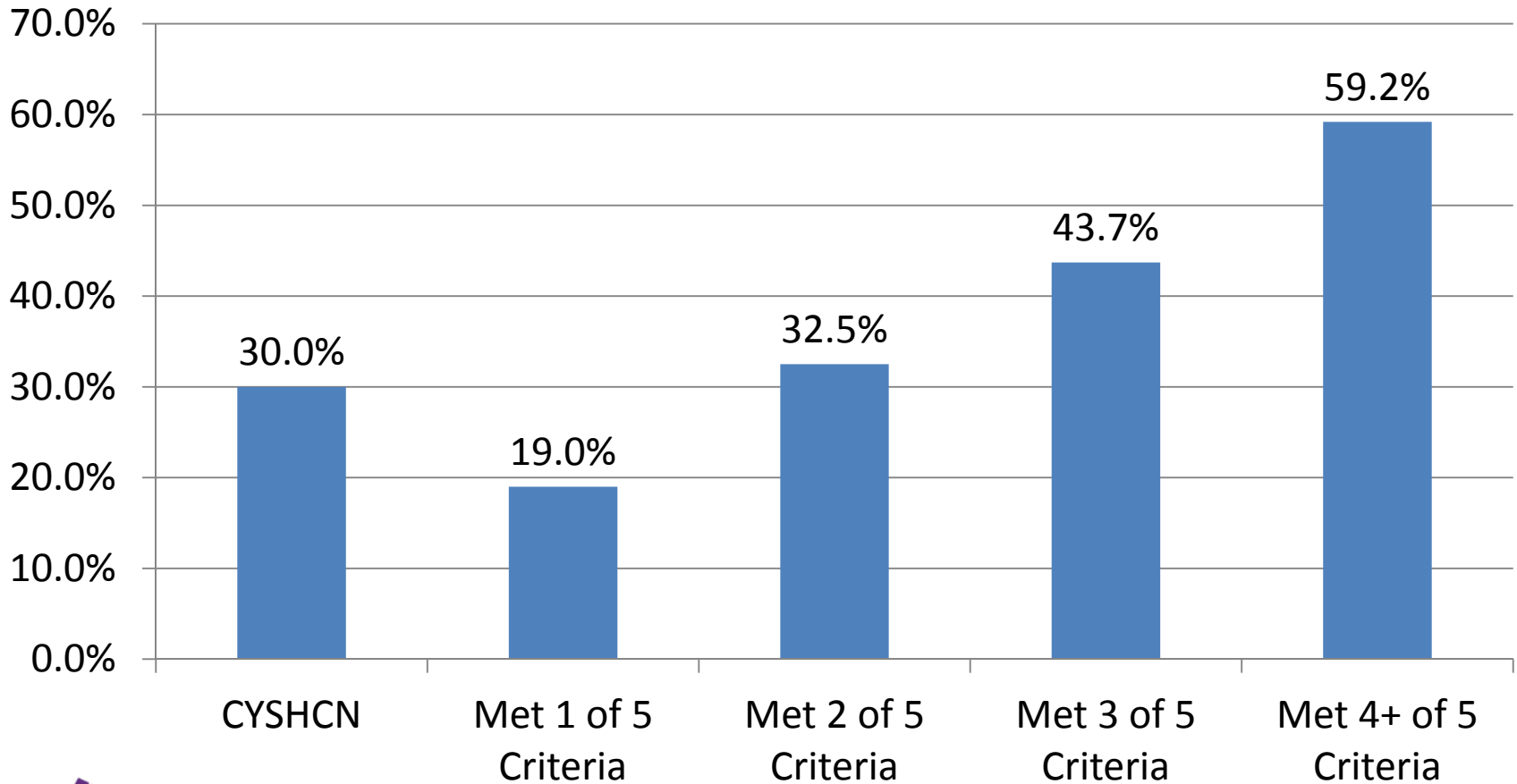
Doctor Visits Due to Illness and Emergency Room Visits by CSHCN Subgroups

Legend:
- 3+ sick care visits past year
- 2+ ER Visits

Non-CYSHCN: 19.9%, 4.10%
CYSHCN: 43.4%, 13.10%
Met 1 of 5 Criteria: 38.9%, 9.40%
Met 4+ of 5 Criteria: 56.3%, 24.60%
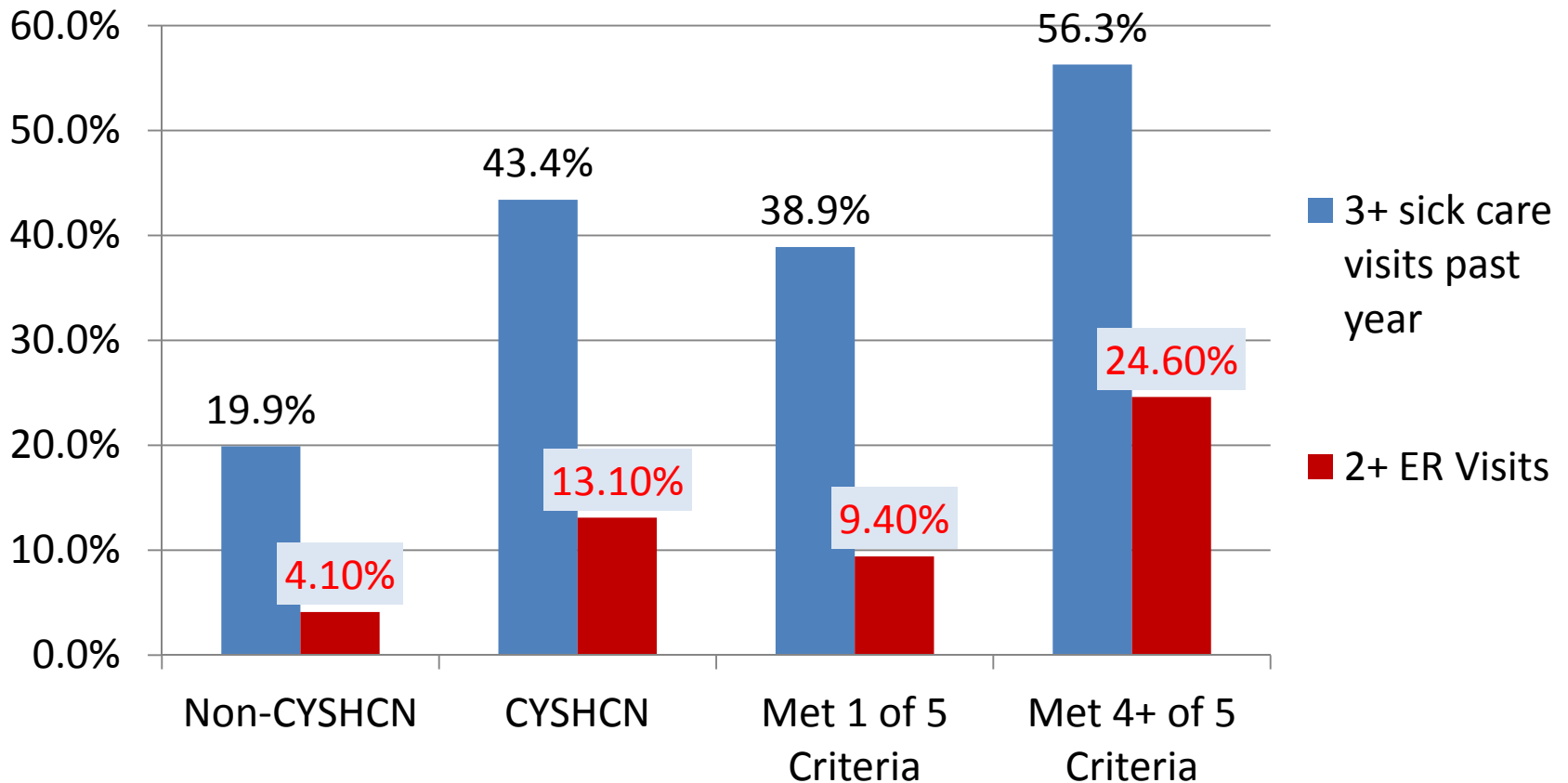
System Performance By CSHCN Subgroups

Percentage of CSHCN Meeting all Age-Relevant Core Outcomes by Number of Screener Criterion Met
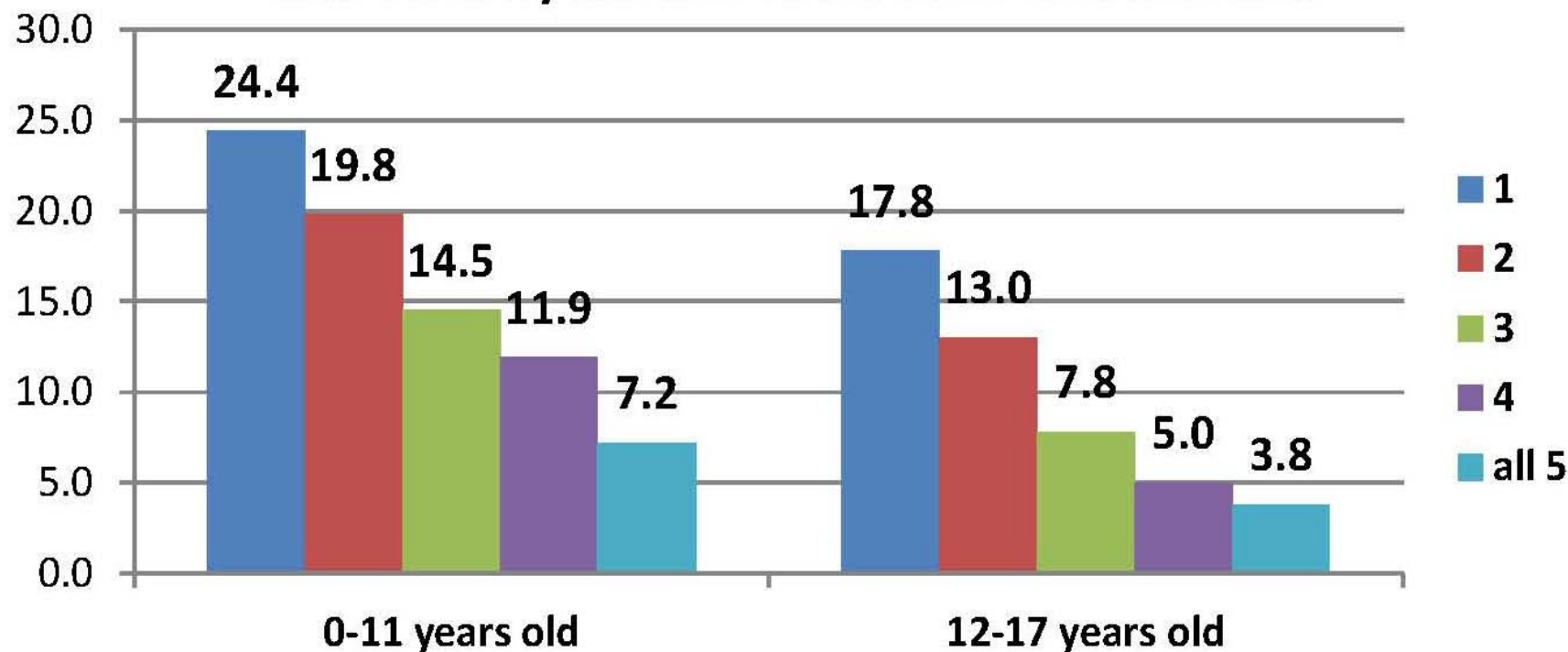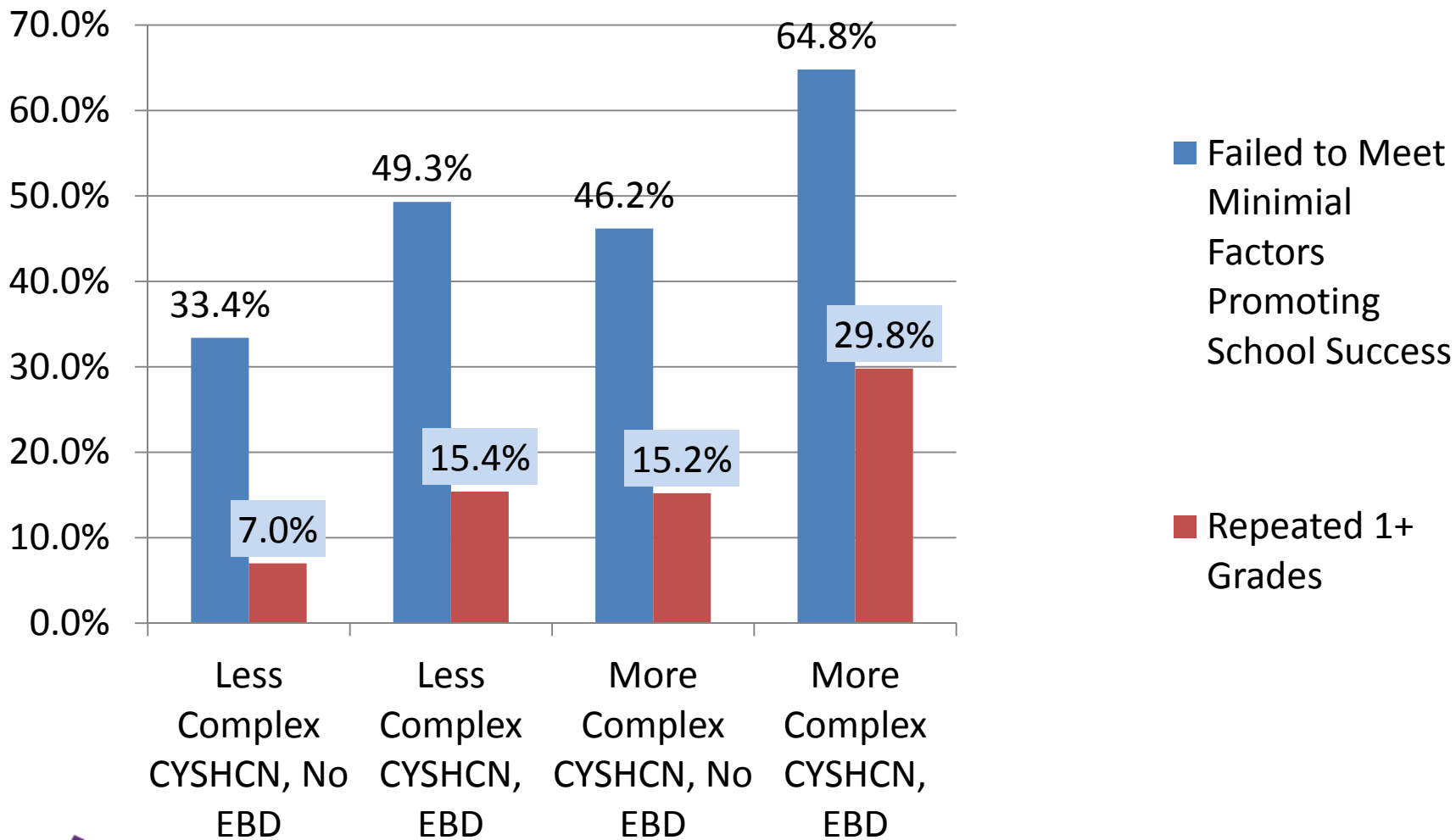
*National and state-level prevalence of all outcomes by demographics & subgroups are av

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

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 ins...

   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)

   ✓

   ✓

   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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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.

Agency for Healthcare Research and Quality
Quality Research for Quality Healthcare

AHRQ

SAMHSA   NATIONAL INSTITUTES OF HEALTH   HRSA   CDC   CMS   INDIAN HEALTH SERVICE

OHSU
OREGON HEALTH & SCIENCE UNIVERSITY

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National Quality Forum Child Health Stream Measurement Domains and Sub-Domains Set Forth for Prioritization

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)

National Quality Forum Child Health Stream Measurement Domains and Sub-Domains Set Forth for Prioritization

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)

National Quality Forum Child Health Stream Measurement Domains and Sub-Domains Set Forth for Prioritization

Domain 5: Safety

- Adverse events (13)
- Patient communication and knowledge regarding consent & safety (2)
- Medication and sedation safety (1)

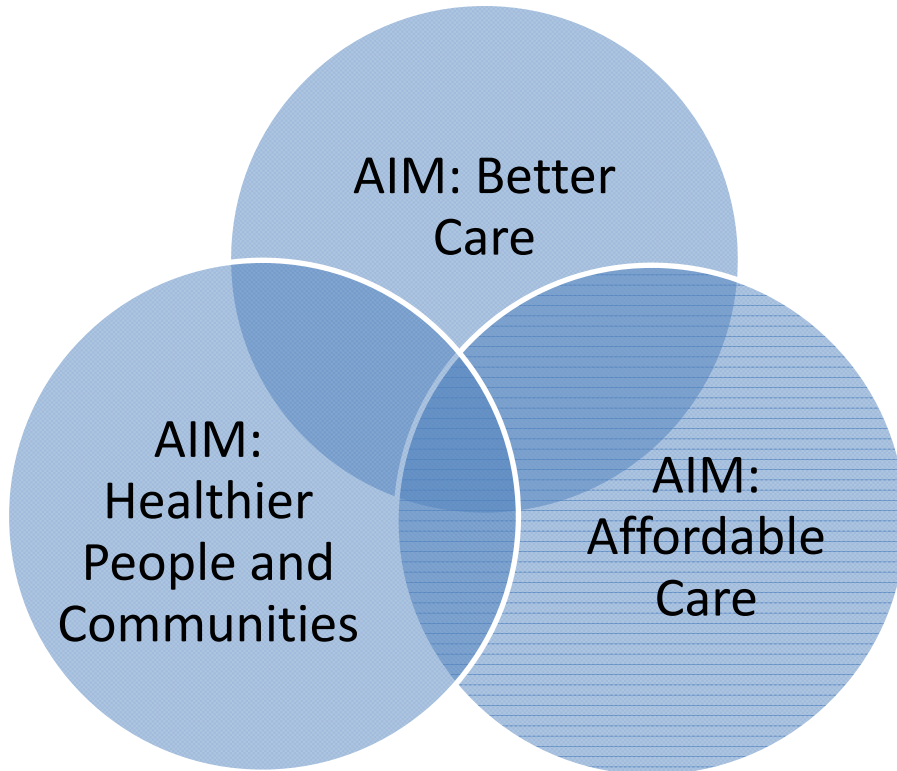**Domain 6: Overuse**

- 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

Some Recommendation To Consider

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)
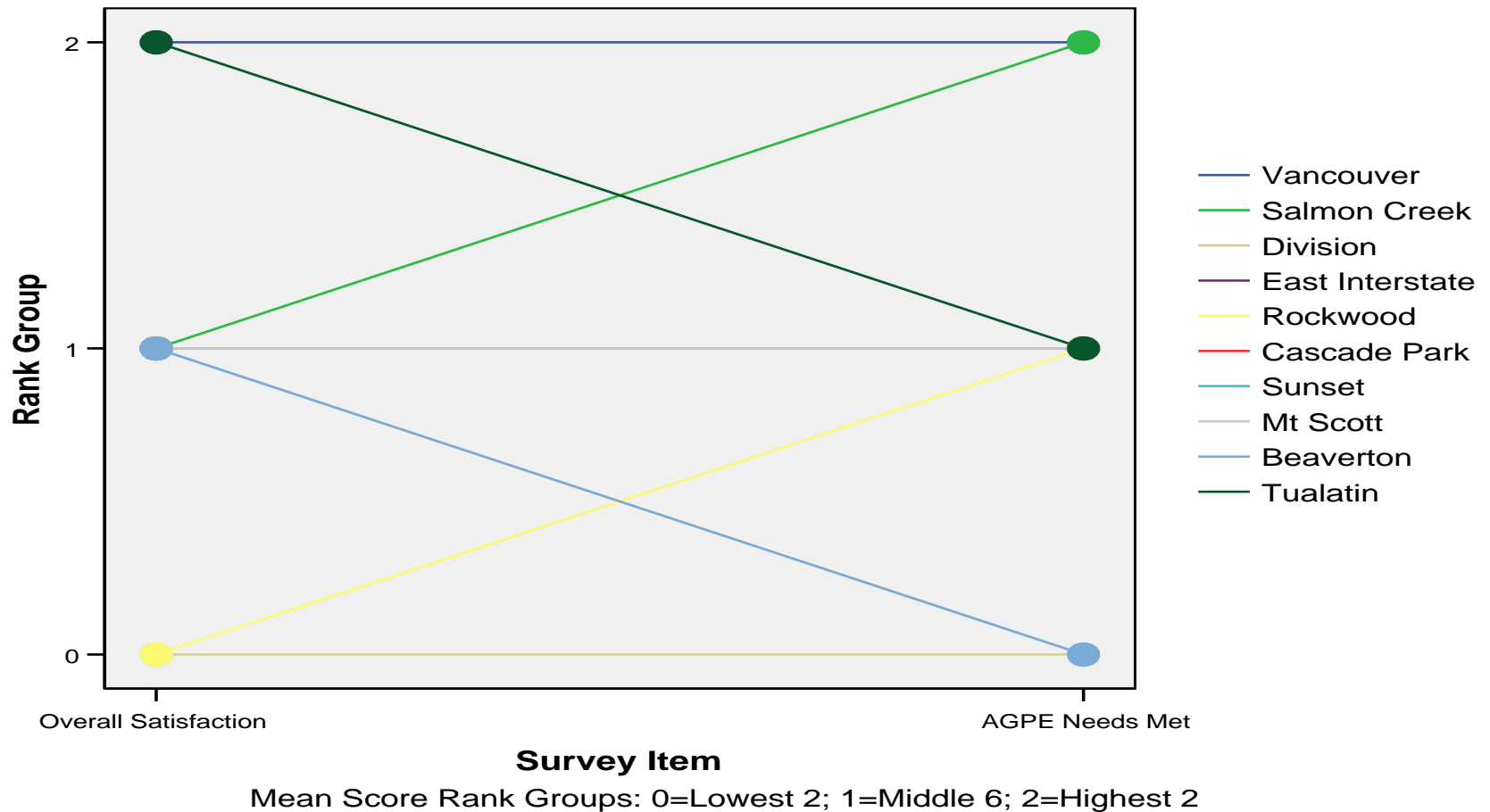   -- Create a culture of quality (Innovative example: RI)

3. **Leverage** contracts with MCO, PCCM Providers
   - <u>Required performance measures</u>
     a. Require <u>actionable</u>, child centered quality measures
     b. Consider cycling measures (Innovative Example: NY)
     c. Consider survey-based measurements that are <u>beyond</u> satisfaction and experience of care—content of care; ease of sampling and stratification
   - <u>Required performance improvement projects</u>
     a. Require <u>concentrated efforts on specific topic areas</u>
     b. Encourage, and give incentives, <u>for collaborative</u> efforts
     c. Consider models of consumer involvement and patient engagement (with teeth)
     d. Consider enhancing these efforts by Medicaid sponsored QI
   - <u>Pay for Performance (P4P)</u>
     a. Consider P4P efforts, <u>Consider measures beyond access to care/PCMH-like</u>

Some recommendations to consider

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

Customer Satisfaction and Content of Care
Specific but not sensitive!

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

Mean Score Rank Groups: 0=Lowest 2; 1=Middle 6; 2=Highest 2

Customer Satisfaction and Content of Care
Specific but not sensitive!

MOV/Art of Medicine and PHDS
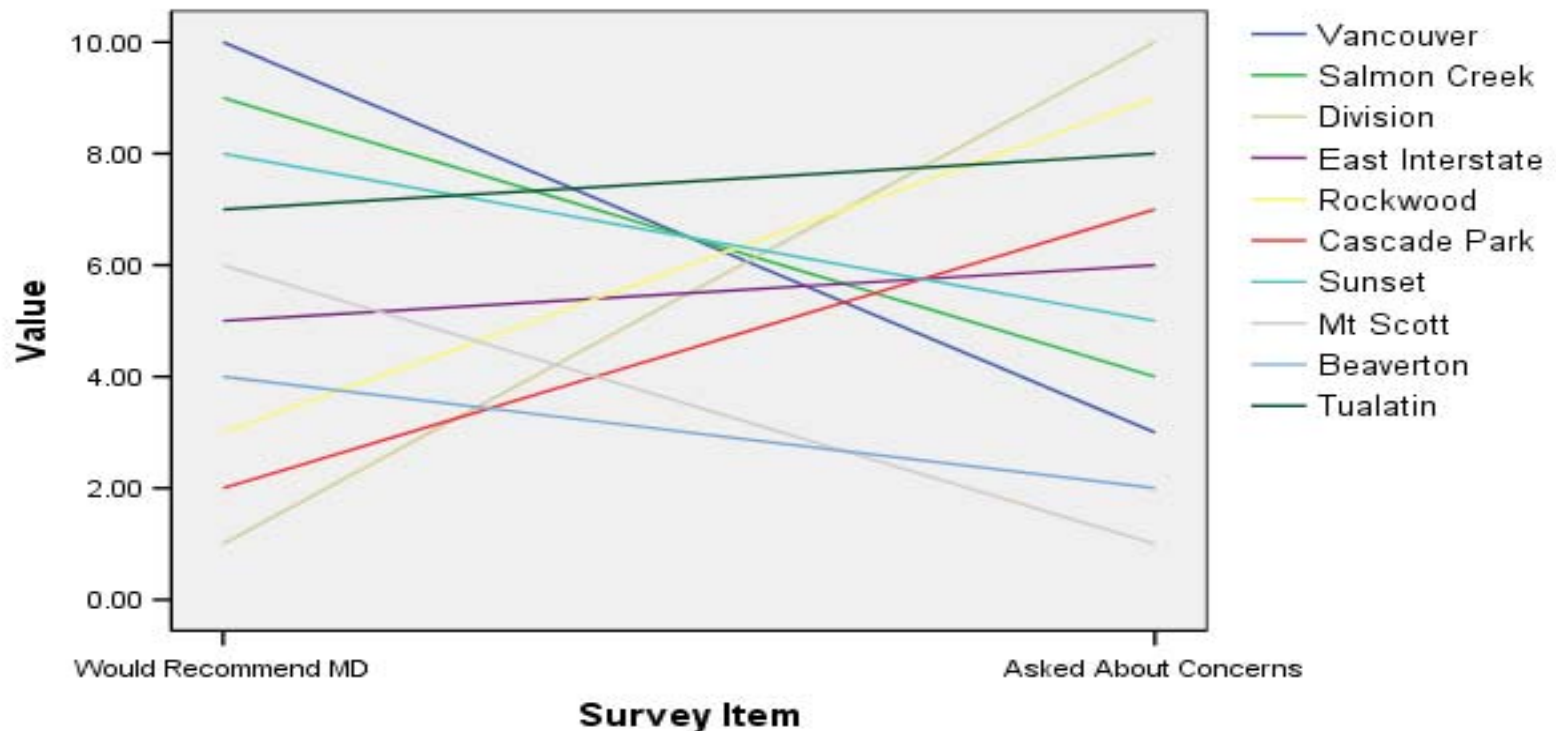
Seeing improvement in access and quality of care measures: The mandate for patient engagement and activation

59

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 utilzation spotty predictor for future utilzation—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?
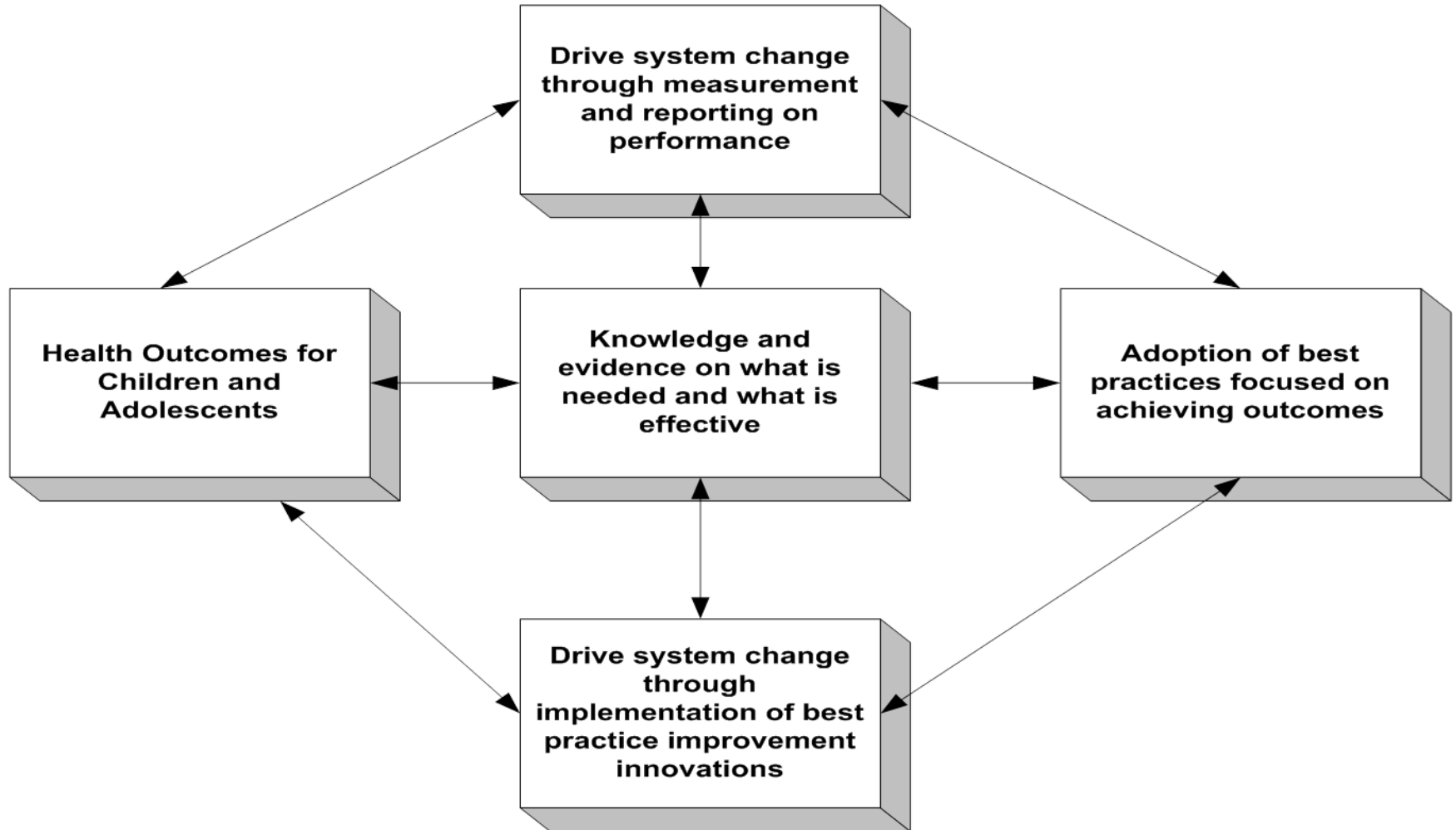
Why does it matter?

- 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

Measures Mantra-Part 1

Standardize
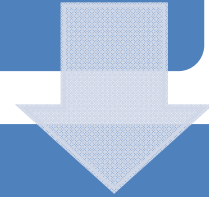
Compare
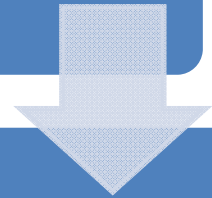
Learn

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 <u>denominator</u>

- A <u>numerator</u>

- A clearly <u>specified, standardized strategy</u> for **collecting** the data

- Clearly specified <u>scoring methodology</u>

- Mechanisms for **<u>reporting and interpreting</u>** results

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*

	All Children Aged 0–17 Years (N = 91 642) % (Quartiles)	Publicly Insured Children (n = 19 748) % (Quartiles)	Privately Insured Children (n = 64 165) % (Quartiles)
CSHCN‡: has ongoing health conditions resulting in above routine and/or special health care need (CSHCN)	19.2 (14.5; 17.9; 22.7; 24.4)	23.6 (12.5; 22.9; 30.5; 37.1)	18.1 (13.2; 16.6; 19.8; 23.0)
Chronic condition: currently has ≥1 of 20 chronic conditions (see Appendix B for list of conditions; 90.2% of CSHCN had ≥1 from list)	43.0 (33.5; 41.2; 47.0; 53.3)	47.4 (28.4; 47.4; 55.8; 61.7)	42.3 (33.8; 39.6; 45.1; 49.5)
Multiple conditions: has ≥2 of 20 conditions assessed (among children with at least 1 condition) (See Appendix B for condition-specific results)	45.0 (37.1; 43.2; 48.7; 51.1)	52.7 (40.9; 49.7; 59.3; 72.3)	42.1 (35.5; 39.8; 44.1; 48.4)
Moderate or severe: parent-rated condition as greater than mild	49.9 (44.0; 47.8; 52.1; 55.3)	57.5 (45.6; 55.4; 62.3; 66.8)	45.6 (40.1; 43.6; 48.3; 52.1)
Service need complexity: CSHCN with ≥1 of 20 conditions assessed who require multiple types of special services, beyond primarily prescription medication management	60.3 (52.0; 57.9; 65.0; 77.2)	73.4 (58.1; 67.5; 80.1; 91.5)	52.2 (41.6; 49.2; 56.8; 67.7)
Health risks/BMI§: meets criteria for being overweight or obese (aged 10–17 years only)	31.6 (23.1; 28.4; 33.9; 44.4)	43.2 (27.2; 37.2; 45.3; 52.5)	27.3 (18.4; 23.9; 29.8; 37.8)
Health risks/development: meets criteria for being at risk for developmental, social or behavioral delays (aged <6 years)	26.4 (18.6; 22.7; 27.7; 35.2)	32.7 (16.8; 26.6; 36.7; 44.2)	22.1 (14.7; 19.5; 24.2; 26.3)

*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|distribu 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

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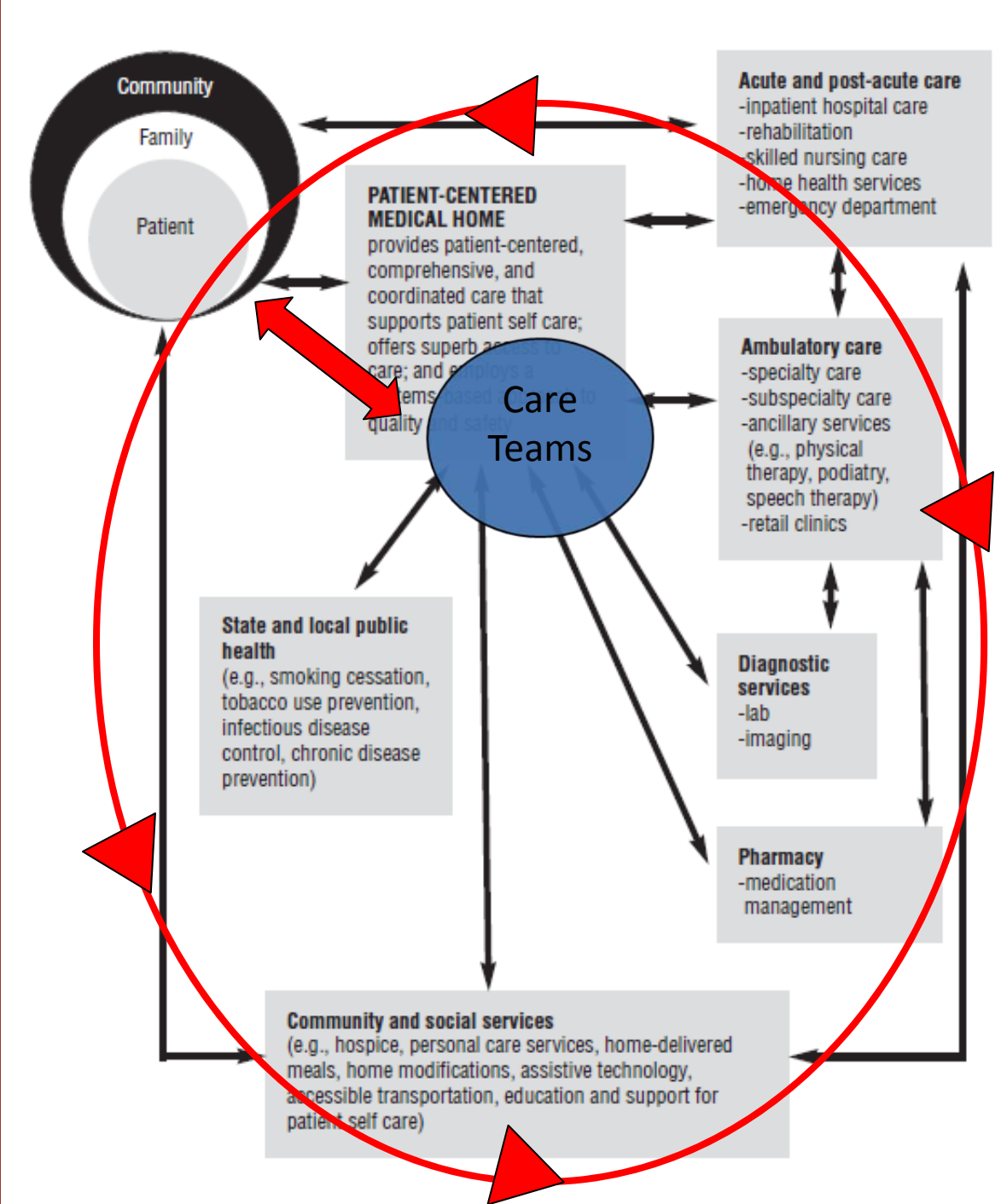
Innovative Delivery Systems

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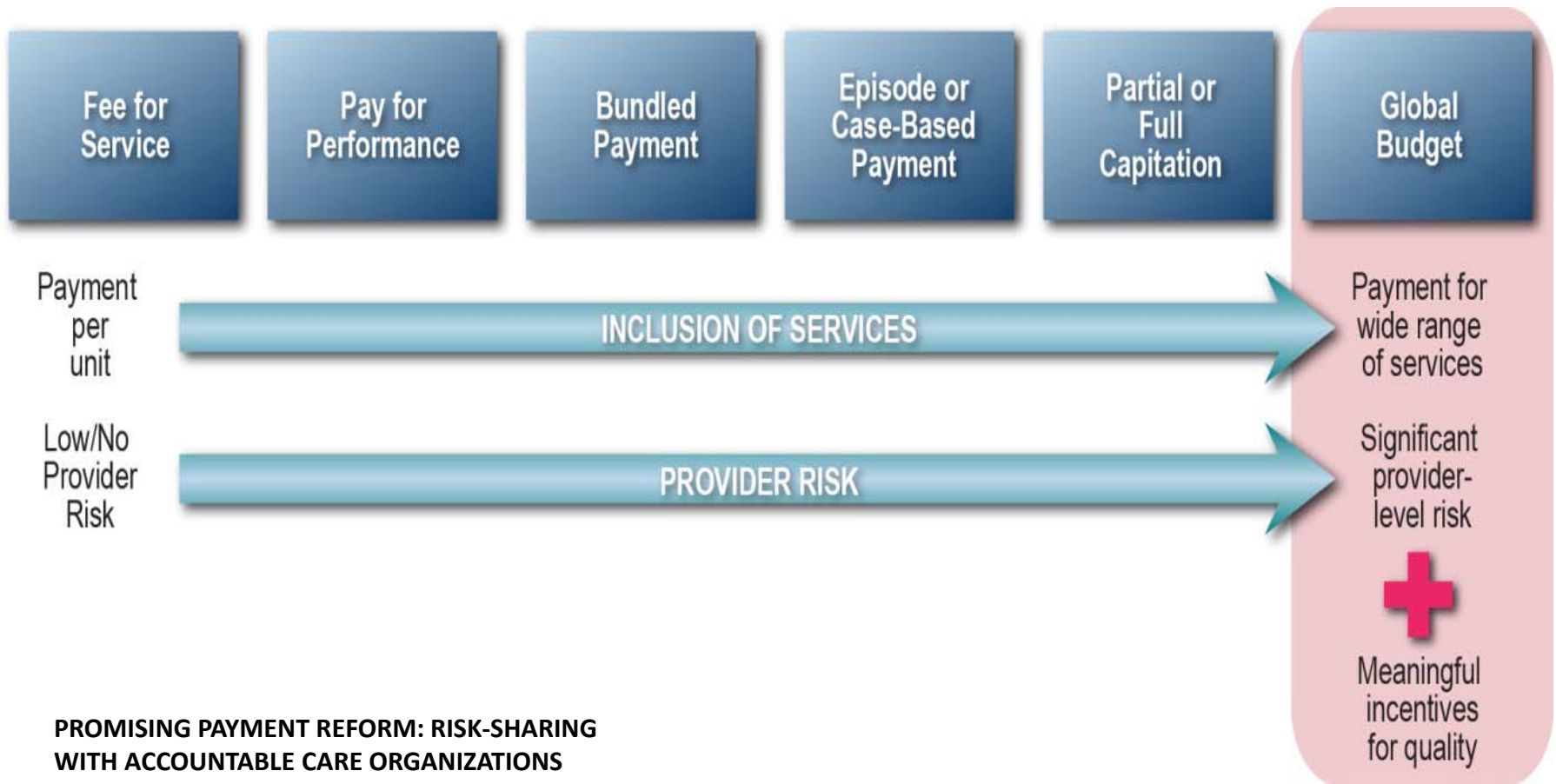
PROMISING PAYMENT REFORM: RISK-SHARING
WITH ACCOUNTABLE CARE ORGANIZATIONS
Suzanne F. Delbanco: Catalyst for Payment Reform

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

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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

Ask us a question | Request a dataset

▸ Open your data briefcase

Your Data ...Your Story

Data Resource Center for Child & Adolescent Health

A project of the Child and Adolescent Health Measurement Initiative

| About the Data Resource Center | Learn About the Surveys | Browse the Data | Put Data into Action | Get Help |

Publicly insured

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

▸▸ Survey Fast Facts

▸▸ Quick Data Search

▸▸ Browse by State

▸▸ How to Use This ___

Keyword Search

Data at a Glance

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

State/Region Nationwide

Browse Data Snapshots

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 careeeee 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

___ct with the DR___

gn up for

email address   **Submit**

childhealthdata National study finds that providing insurance to the poor helps them maintain both health and financial stability: http://t.co/y0X8Hlb
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/a3ox4H2
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. 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?

At-A-Glance state data profiles 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

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 federal Maternal & Child Health Bureau, Health Resources & Services Administration through Cooperative Agreement activities with the CAHMI & AAP.

www.medicalhomedata.org

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

How the Data Resource Center Can Support Improvement Partnerships

Understand your population	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
Assess system performance	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).
Examine improvement opportunities	"Point and click" menu allows users to explore disparities and gaps in access and services for different population subgroups of children and CSHCN.
Select priorities	User generated tables, bar and pie charts, and customizable reports supply prevalence estimates and population counts to help guide selection of priority needs.
Set targets	"All States" ranking maps and tables provide benchmark data to assist in identifying state-negotiated performance measure targets.
Identify promising improvement models	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.
Monitor progress	Centralized resource for standardized, population-based survey questions to use in collecting child health and health care quality data locally.

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")

CAHMI
The Child & Adolescent Health
Measurement Initiative

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%)

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

"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 Screener

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

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"

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

Results

- 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

State	Percent
Alabama	12.1%
Alaska	20.7%
Arizona	17.3%
Arkansas	15.9%
California	14.0%
Colorado	25.9%
Connecticut	16.6%
Delaware	10.9%
District of Columbia	14.3%
Florida	17.1%
Georgia	22.7%
Hawaii	27.2%
Idaho	18.1%
Illinois	21.1%
Indiana	19.4%
Iowa	18.7%
Kansas	24.7%
Kentucky	15.5%
Louisiana	28.7%
Maine	21.5%
Maryland	22.3%
Massachusetts	16.4%
Michigan	18.2%
Minnesota	41.6%
Mississippi	20.0%
Missouri	19.0%
Montana	16.7%
Nebraska	18.8%
Nevada	18.6%
New Hampshire	18.1%
New Jersey	12.7%
New Mexico	29.6%
New York	11.7%
North Carolina	47.0%
North Dakota	17.6%
Ohio	20.8%
Oklahoma	20.8%
Oregon	13.5%
Pennsylvania	10.7%
Rhode Island	14.5%
South Carolina	19.1%
South Dakota	18.8%
Tennessee	29.0%
Texas	19.2%
Utah	20.6%
Vermont	17.9%
Virginia	18.2%
Washington	25.6%
West Virginia	31.9%
Wisconsin	25.9%
Wyoming	20.2%

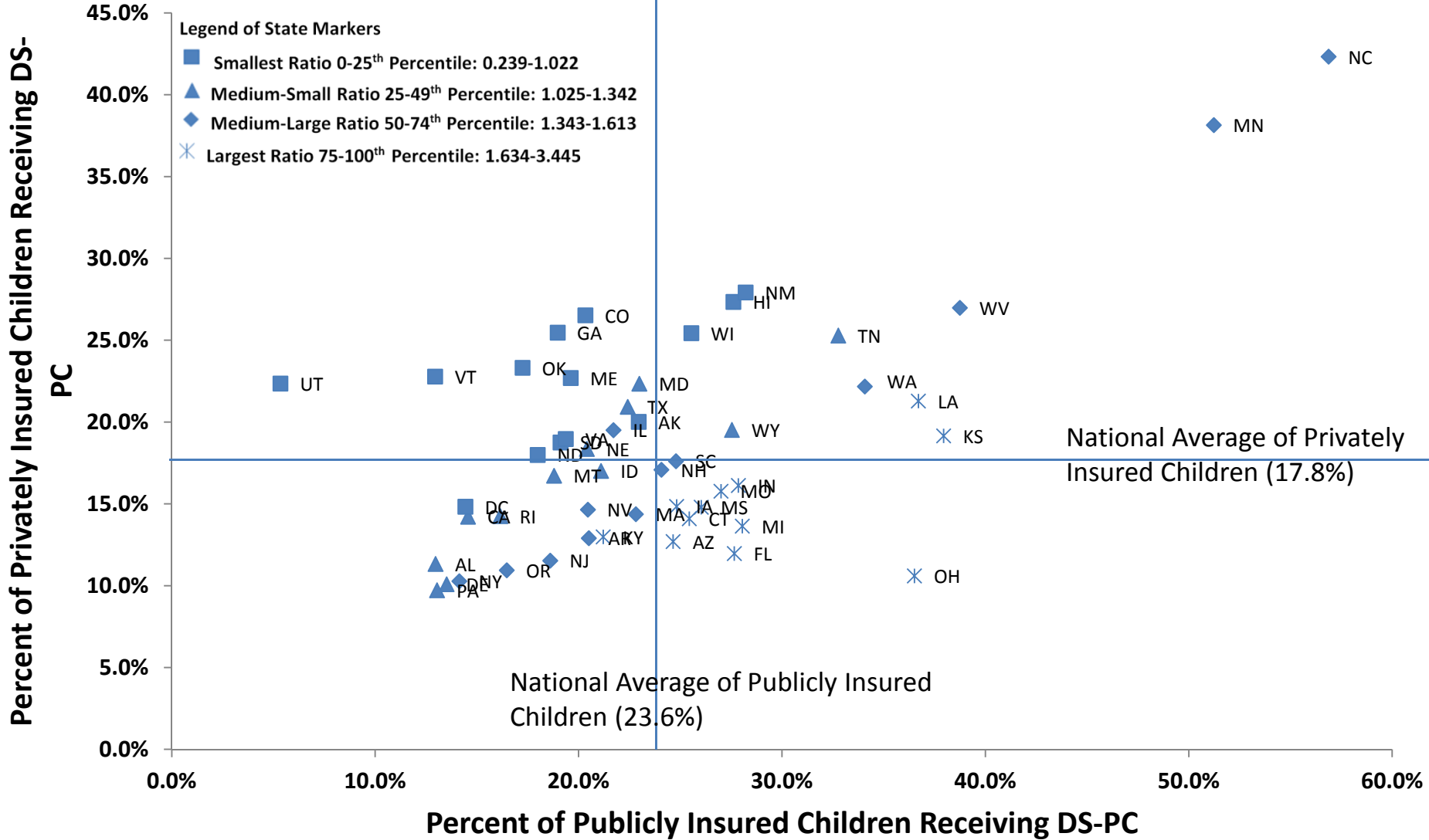Percent of children receiving developmental screening

Results

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)
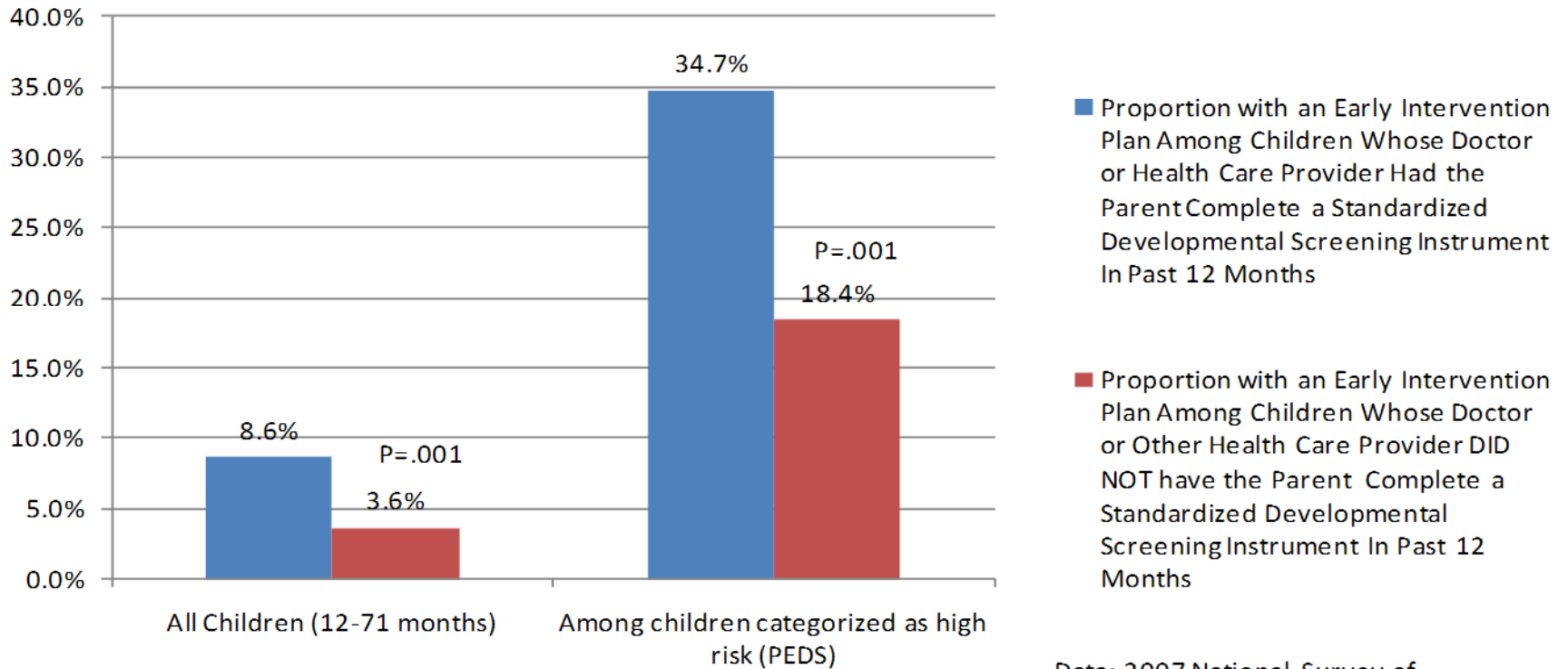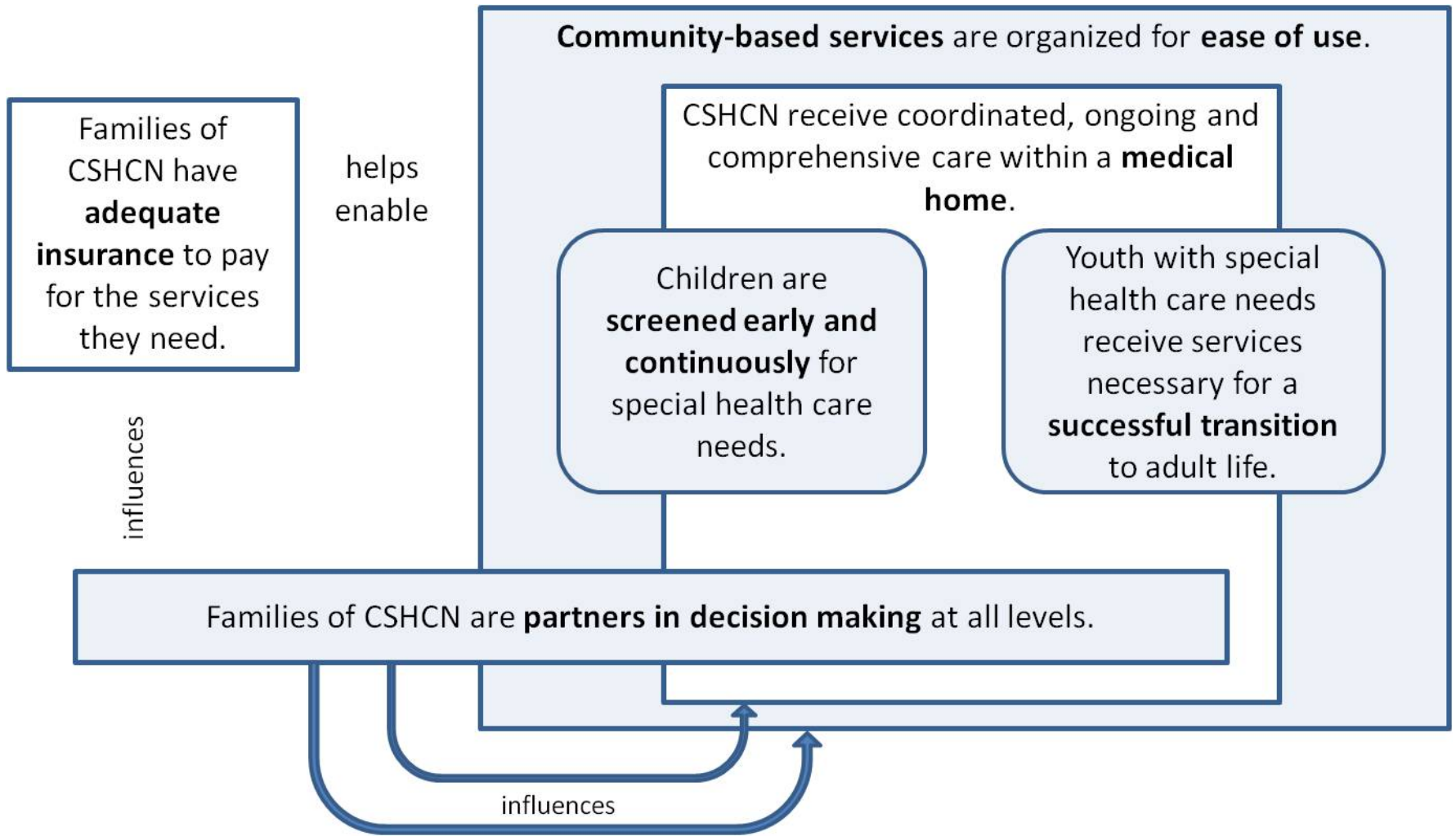
Results
Disparities in the Rate of DS-PC Across States
By Type of Health Insurance

	Non-CSHCN	All CSHCN	CSHCN Meeting RX Use Criteria Only	CSHCN meeting Functional Limitations Criteria (98.3% met other criteria as well)	CSHCN With Only Asthma and/or Allergies as Conditions
Percentage of all CSHCN	N/A	100%	43.7%	21.5%	34.7%
Mean # doctor visits	2.3	5.1	4.1	6.6	4.5
Percentage with two or more ER visits	4.8%	19.3%	13.9%	29.7%	16.2%
Mean # current conditions reported	0.3	1.9	1.5	2.7	1.5
Two or more conditions reported	4.3%	57.2%	54.3%	76.0%	N/A
Mean # of functional difficulties reported	0.3	2.5	1.2	4.5	1.2
Two or more functional difficulties	6.7%	54.2%	26.2%	85.8%	22.2%

Community-based services are organized for **ease of use**.

CSHCN receive coordinated, ongoing and comprehensive care within a **medical home**.

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

helps enable

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.

influences

Families of CSHCN are **partners in decision making** at all levels.

influences

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.