



The Child & Adolescent Health Measurement Initiative

Promoting early and lifelong health using family-centered data and tools

(Putting children, youth and families at the center of quality measurement and improvement)

The Child and Adolescent Health Measurement Initiative

Background and Overview of CAHMI and the CAHMI Measurement Framework

Background

The CAHMI is a national initiative established to put children, youth and families at the center of quality measurement and improvement in order to advance a high-quality consumer-centered health care system. The CAHMI was initiated in May 1996 by FACCT—The Foundation for Accountability and NCQA—The National Committee on Quality Assurance, with funding leadership from the Agency for Healthcare Research and Quality and the David and Lucile Packard Foundation. During 1996-2002 the CAHMI was funded through grants from The David and Lucile Packard Foundation, The Commonwealth Fund, The Robert Wood Johnson Foundation. NCQA's role was funded by the federal Agency for Healthcare Research and Quality. From 2003-2013 primary funders of the CAHMI were the federal Maternal and Child Health Bureau, The Commonwealth Fund and the Lucile Packard Foundation for Children's Health with additional support from other state and federal health agencies and private foundations. Funding partners between 2014-2022 remained stable, with the federal Maternal and Child Health Bureau, the Robert Wood Johnson Foundation and the Lucile Packard Foundation for Children's health providing primary support for the work of the CAHMI.

Mission

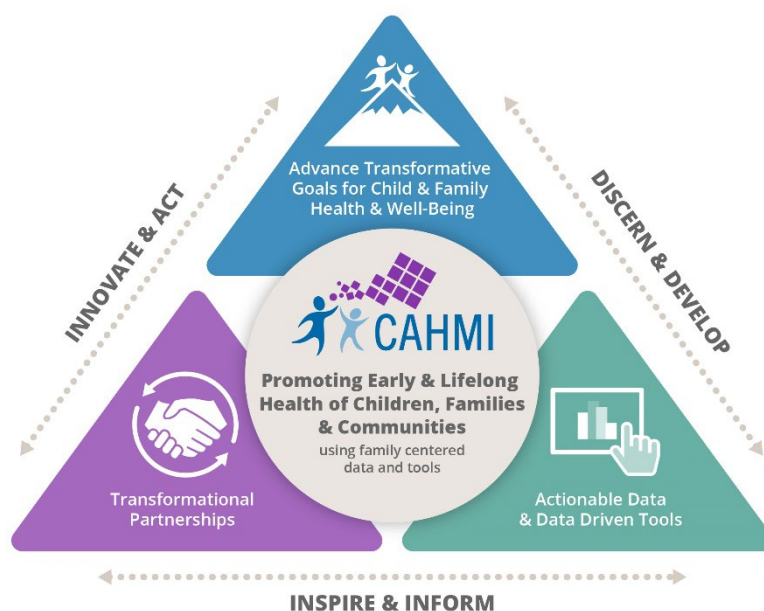
The mission of the Child and Adolescent Health Measurement Initiative is advance patient-centered innovations and improvements in children's health and health care quality. Taglines:

1. Promoting early and lifelong health using family-centered data and tools
2. Putting children, youth and families at the center of quality measurement and improvement

Theory of Action

The CAHMI has consistently followed an intentional theory and pathway of action to spark positive change that begins with (1) articulating a family-centered and stakeholder engaged shared vision and goals for child health and moving to (2) collaborative measurement design, validation, endorsement and use to (3) data dissemination and research to inspire and inform transformational partnerships that advance child health goals, build evidence and generate sustainable momentum for positive change.

Figure 1: CAHMI's Theory of Action



Phases of Work

The CAHMI has moved through four distinct phases of work, each anchored to a consistent vision, set of aims, values and objectives, methodologic approaches and strategies. These phases and key milestones each focused on establishing or using data based on family centered health, health care quality and systems performance measures. From the start, CAHMI’s work was informed by ecological models of child health and research on the role of early life experiences to healthy development and lifelong health, including the impact of home, community and school environments and resources to mitigate and optimize healthy development for all children and the functioning and well-being for children and youth with special health care needs.

CAHMI’s first phase 1 of work (1996-2002) focused on the specification of a measurement framework and the grounding of this framework and numerous new quality measures in national measurement systems. Expert tasks forces were convened to specify measure and testing protocols for each domain using the CAHMI’s six stage “Start Where You Want to End Up” measurement development, testing and endorsement process (see Figure 2).

Figure 2: CAHMI’s MultiPhase Measurement-In-Action Development Process

5 Level Framework for Conceptualizing Measures	6 Stage Measurement Development Process	7 Criteria for Measurement Review and Endorsement	6 M’s for Implementation and Improvement
<p>LEVEL I. USE Audience (e.g., policy makers, payers, providers, families, consumers) and purpose (e.g., use for surveillance, accountability, improvement, engagement, etc.).</p> <p>LEVEL II. AIMS Broad and specific outcomes seeking to influence (e.g., healthy development, staying healthy, getting better when sick, living well with illness, managing transitions)</p> <p>LEVEL III. TARGET POPULATION (e.g., age, developmental status, risk, geographic populations)</p> <p>LEVEL IV. ACTION FACTORS / THEORY OF CHANGE (e.g., protective and risk factors, process and policy requirements, program aims)</p> <p>LEVEL V. UNIT OF ANALYSIS & INFLUENCE: (e.g., geographic area, program, clinic)</p>	<p>STAGE 1: Engage professional experts, families/consumers, and other stakeholders to establish measure and set relevance, evidence, framework and approach.</p> <p>STAGE 2: Starting point measurement proposal for stakeholder, cost, and feasibility review.</p> <p>STAGE 3: Specify methods options, issues, design field test.</p> <p>STAGE 4: Conduct field test, including reporting and communication models.</p> <p>STAGE 5: Refine measure(s) specifications for each application and reporting criteria.</p> <p>STAGE 6: Document scientific and technical methods, implementation, dissemination, and maintenance requirements.</p>	<p>CRITERIA 1: Relevant and meaningful.</p> <p>CRITERIA 2: Based on best available evidence.</p> <p>CRITERIA 3: Demonstrated validity and reliability based on appropriate methods.</p> <p>CRITERIA 4: Actionable policy, program, and/or intervention strategies available or advanced with measurement.</p> <p>CRITERIA 5: Feasible data collection and reporting strategies.</p> <p>CRITERIA 6: Parsimony and added value.</p> <p>CRITERIA 7: Clear requirements for sustaining measure use, maintenance, and improvement over time.</p>	<p>MODEL: Use-case specific measure matrix and conceptual logic model and change model.</p> <p>MEASURES: Detailed specifications for each use case (design based).</p> <p>METHODS: Detailed methods for implementing measurement specification for each population and setting/use case.</p> <p>MESSAGES: Data scoring, grading, reporting format, and messages (specific to user/audience and purpose).</p> <p>MEANING: Confirm meaning made from measures and adapt methods and messages as required.</p> <p>MAINTENANCE: Establish credible and sustainable resources and processes for routine review and to support consideration of measures by researchers, endorsing bodies, and new and exiting users. Learn, publish, and build field capacity to ensure progress.</p>
<p>FOUNDATIONS: Stakeholder and expert derived Design-based and outcomes-based goals, premises, and principles Review processes, parameters, and periodicity</p> <p style="text-align: right;">Start where you want to end up!</p>			

CAHMI’s second phase of work (2003-2008) sought to activate and spread use of the new

family centered measures and data through state learning networks, national chartbooks, continued testing and new measurement development (e.g., Developmental Screening, updated Medical Home metrics) as well as through the design and development of the National Data Resource Center for Child and Adolescent Health to support digital access to data findings, technical assistance and data sets and codebooks to dramatically expand the use of now available family reported data at the national and across state level for numerous subgroups of children and youth (e.g., National Survey of Children’s Health).

Phase 3 of the CAHMI (2009-2014) expanded the data and resources available through the DRC and advanced the development and dissemination of data and research based on new measures focused on social determinants and positive and relational health, like Adverse Childhood Experiences, Child Flourishing, Family Resilience and School Readiness. This “Liberation and Disruption” phase of work was informed by now available evidence of continued poor quality of care for children with special health care needs and in preventive services for young children and youth as well as continued lack of use of available data to authentically engage families and communities as partners in monitoring, improving and shaping health care and systems to meet their needs and priorities. During this time CAHMI again assembled a national partnership to create and test disruptive family-facing IT based technologies to operationalize Bright Futures Guidelines by engaging families in previsit planning and quality measurement and improvement through the CAHMI’s Cycle of Engagement Well Visit Planner approach to well child care.

The most recent phase of the CAHMI (2015-2022) focused on leveraging accumulated data from measures created to build national, state and local awareness and policy, program and policy actions to address ACEs and translate the science of healthy development in children’s health, education and social programs. Sparked by new integrated national and across state data on ACEs, social determinants, child flourishing and protective factors, CAHMI partnered with AcademyHealth to create the “Prioritizing Possibilities” national agenda in collaboration with over 500 representatives across ten sectors (e.g., families, pediatricians, hospitals, child welfare, Medicaid, state and federal agencies, health systems, juvenile justice). As part of this effort, in 2017 a special issue of Academic Pediatrics was published that curated publications on emerging models, frameworks, evidence and implementation and policy approaches essential to preventing and mitigating impacts of ACEs and related social determinants to promote positive health, flourishing and school readiness and engagement for children and youth. During this time the CAHMI led the Maternal and Child Health Measurement Research Network which took stock of all MCH measures used across MCH programs and quality and performance measurement systems. This results in the creation of an online, searchable MCH Measurement Compendium to inform an updated measurement framework and strategic measurement agenda. A key goal was to identify measurement assets and gaps and to drive shared performance measures across MCH programs to foster collaborative action in achieving MCH outcomes.

CAHMI's Measurement In Action Vision

The CAHMI envisions a future where children and families experience a health care system tailored to maximize the healthy development and well-being of children. Measurement should help consumer, purchasers, providers and policymakers play their role in ensuring high quality health care and positive health outcomes for children, youth, families and communities. Specifically, the CAHMI envisions a future where:

- **Consumers, Families and Youth**
 1. understand and seek information about the quality of health care (broadly defined)
 2. provide direction to the health system about what's important
 3. participate as partners in their health and health care to define, assess and ensure high quality and optimal outcomes
 4. select health care providers in consideration of their performance and outcomes

- **Purchasers**
 1. create health-focused partnerships with employees, beneficiaries, providers and the community to measure and improve health
 2. care quality and outcome
 3. contract with health care providers so as to support and provide incentives for improving children's health care quality and outcomes
 4. give consumers real health care choices
 5. provide information and support for quality-based decision making
 6. providers, health plans and medical and public health systems of care measure, monitor, improve and reward performance in the areas that matter most to the health of children and youth
 7. partner with consumers and communities in measuring and improving care
 8. compete on quality as well as price

- **Policymakers and program leaders**
 1. distinguish child from adult health care in all aspects of policymaking
 2. set policies that compel and provide infrastructure support for
 3. quality measurement and improvement in children's health care
 4. sponsor the routine collection and dissemination of standardized national and state data on children's health and health care quality
 5. fund research and innovative demonstrations to advance child health and health care quality

Points of Leverage and Role

A number of environmental factors impact the CAHMI are considered in the development of specific strategies, objectives and activities. These factors include:

1. Child health needs and gaps in child health and health care quality
 2. Trends in public health and the health care system market
 - Purchaser requirements and behavior
 - Financing – public and private sector
 - Organization of care
 3. State and Federal initiatives and child health and health care related legislation and regulation
 4. Technology development and trends in clinical care and population health improvement
 5. Consumer demands and behavior
 6. Prevalence and type of other national, state and local quality related initiatives and players.
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Based on an assessment of the environment and an extensive review of the current demand for and supply of quality information about the following are the primary points of leverage for consideration:

- 1) National efforts will continue to shape and drive state and local child, youth and family health and health care quality and outcomes measurement and systems change efforts. The CAHMI currently is well-placed in the renewed drive for evidence-based and patient infused healthcare. To leverage this core knowledge effectively, the CAHMI will need infrastructure to be continually agile in its ability to align with and demonstrate continued relevance to these efforts.
- 2) State governments and consumer demand are likely to be the [key drivers](#) for deployment and evaluation of the child and adolescent data and tools CAHMI focuses on. The CAHMI has had ongoing relationships and working arrangements family organizations and state health agencies. We require infrastructure and support to strengthen existing relationships and utilize them as the bases for expanding work with state efforts and family and child advocacy organizations.
- 3) Substantial gaps still exist in developing and using family-centered quality measures and tools related to engagement, activation, unmet needs and care coordination. Under the current political environment, the CAHMI's core knowledge and skills are well-placed to engage in much of this needed work. Infrastructure support is needed to bolster CAHMI's ability to take advantage of this unique opportunity.

The three primary roles for the CAHMI include:

- 1) A national “**leadership partner**” that articulates the case for actionable data, consumer empowerment and health improvement through consumer- centered quality measurement and data-driven policy and practice.
- 2) An “**agent of innovation**” in consumer-centered quality measurement and improvement and the research and development of frameworks, strategies, tools and measurement technologies to advance consumer-centered and data-driven policy and practice.
- 3) A “**strategic and technical consultant**” to translate consumer-centered, data-driven health care quality strategies into policy and practice.

Strategic Objectives

CAHMI’s strategic objectives have been routinely reviewed and yet have remained largely unchanged since 1997. The key objectives outlined below serve as the guiding force behind all the work undertaken by the CAHMI.

- **Objective #1: Keep the Focus: Communicate and Coordinate**

Keep the focus on consumer and family–centered child and adolescent health and health care quality measurement and improvement in national, state and local contexts.

Objective 1A: Provide leadership and technical assistance in the specification and implementation of family, child and adolescent-centered strategies to measure and stimulate improvements in child and adolescent health and health care systems and services quality

Objective 1B: Assist in the coordination of cross sector stakeholders to advance research, action and policies for child and adolescent health and health care quality measurement and improvement

- **Objective #2: Build the Supply: Develop and Disseminate**

Build the supply of consumer and family-centered child and adolescent health and health care quality data, tools and strategies that are effective in shaping and driving improvements in outcomes, services, systems, programs and policies.

Objective 2A: Facilitate standardization and the sustainable and actionable use of family- and consumer-centered health and quality measures across priority units of analysis and applications.

Objective 2B: Fill priority gaps in child and adolescent health and health care quality measurement and data dissemination and communication methods

- **Objective #3: Build the Demand: Translate and Demonstrate**

Build the demand for the use of consumer and family–centered child and adolescent health and health care quality measurement and improvement tools and strategies in national, state

and local context.

Objective 3A: Specify, test and demonstrate the impact of family-and consumer- centered tools and strategies to inform and activate families as child and adolescent health and health care quality improvement partners

Objective 3B: Assist and partner with leaders to build will and capacity to define and advance national, state and local strategies to put “patients/families/children in the center”

Specific Aims

Data In Action: Maintain and further evolve the National Data Resource Center for Child and Adolescent Health (www.childhealthdata.org) and related data resources (Possibilities Data Query)

Measurement In Action: Leverage existing capacity to support access to, use and research on existing and emerging CAHMI measures, including the MCH Measurement Compendium as possible.

Engagement In Action: Further establish CAHMI’s family-driven quality measurement and improvement Cycle of Engagement (COE) model and tools (e.g., www.wellvisitplanner.org; www.carepathforkids.org; www.cycleofengagement.org) and drive translation into practice and policy.

Flourishing In Action: Contribute to shifting the narrative toward a positive approach to health and health care and partner to translate the science of flourishing and healing into practice, policy and culture. (www.cahmi.org/flourishing_in_action)

Guiding Values

Four key values guide the CAHMI’s specification of and implementation of measures for action

- **Family and consumer empowerment**

Families and consumers have a need and right to know about the quality of health care provided to children and adolescents and to be fully engaged in assessing and improving the quality of health care for their children and adolescents.

- **Family and consumer involvement**

Families and consumers will be involved at every level of identifying, specifying, deploying and communicating information about child and adolescent health care quality.

- **Scientific credibility**

In order to ensure the scientific credibility of the quality measurement and communications tools and strategies developed through the CAHMI, the CAHMI will use an explicitly defined

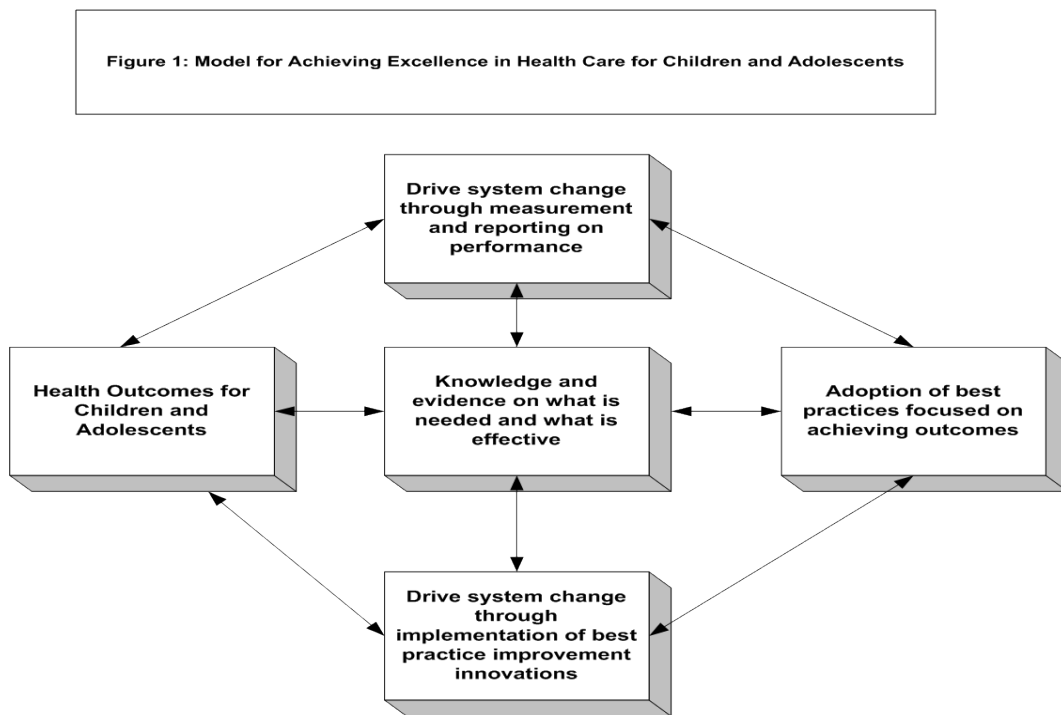
and open development and testing process (six-stage process) that incorporates ongoing involvement of expert and stakeholder reviewers. The CAHMI will seek to make available the results of testing and applying quality measure in the professional literature and in other venues.

Collaboration

The CAHMI will initiate and be responsive to collaboration with other efforts in the area of child and adolescent quality measurement, reporting and improvement to ensure that the CAHMI compliments and adds value to these other efforts. Collaboration is also essential to effectively navigate the political and strategic challenges inherent in quality measurement and reporting for children and adolescents.

CAHMI Measurement Framework and Assumptions Guiding Quality Measurement Efforts

The overarching theoretical model used in the CAHMI is adapted from a model set forward by Don Berwick, MD of the Institute for Healthcare Improvement. This model acknowledges that improvements occur when external policy, financial incentives and stimulus for change are combined with the adoption of innovations for achieving outcomes among the program leaders, service providers and others who directly impact the achievement of desired outcomes at the community level. Child and adolescent health and health care quality measurement is essential to each step in this process. This model is illustrated in the Figure 1 below.



The health care quality measurement framework adopted by the CAHMI Advisory Committee in 1997 built on the *Consumer Information Framework* developed by principal investigators of the CAHMI through the work of the Foundation for Accountability to develop a framework for use in Medicare, Medicaid and by private payers of health care to inform and engage patients and consumers to drive high quality, affordable health care. The CAHMI measurement framework included the following components (see Figure 2):

1. **Users** of quality measures – consumers, purchasers, program managers, providers
2. Quality **measurement categories** – desired outcomes to which quality measures are related (e.g. access to needed care, staying healthy, getting better, living as well as possible with an ongoing illness)
3. The **population** of children and adolescents for which quality measures should be developed
4. Health care **setting or system** for which quality should be evaluated and measures developed (health plans or systems, medical groups, communities)

The CAHMI define a “measure” as a quantifiable construct that clearly specifies the following:

1. The **unit of analysis** (e.g., health plan, provider, hospital, geographic area, program)
2. A **standardized sampling/case finding** protocol and **data collection process** to support measurement, scoring and reporting parameters for the measure
3. A **numerator** (care met criteria for “shared decision making”)
4. A **denominator** (children with special health care needs that required treatment)
5. A **scoring model**, including composite scoring, weighting or risk adjustment methods
6. A **reporting and communications model** for sharing results with appropriate audiences to achieve goals for the measure (e.g. families to choose a provider, payers to hold health plans accountable, government agency to monitor performance, etc.)

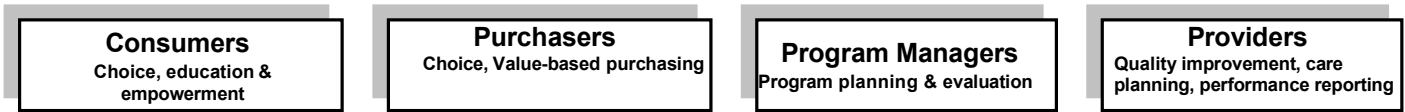
Key issues recognized as inherent in any measurement development process include:

- balancing comprehensiveness with parsimony and selecting among correlated concepts
- breadth vs. depth within and across definitional components (e.g. definition of “medical home”)
- relative importance of definitional components to child health
- anchoring individual child data to relevant programs, providers and systems of care (key for stratification and making meaning of the resulting data for program development and assessment)
- gaps in available data
- relevance of specific concepts to all children versus subgroups and sample size realities.

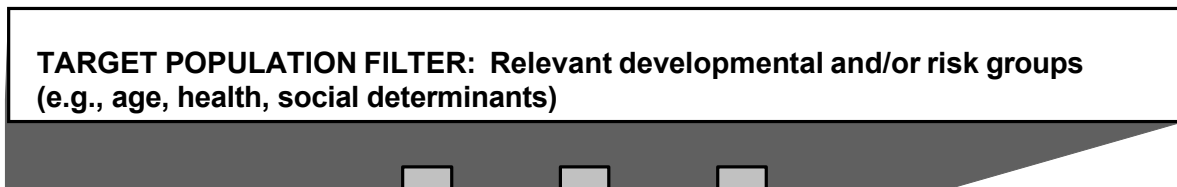
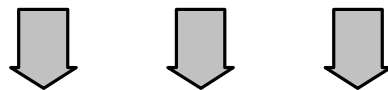
Figure 2 below is an example of considerations for developing measures of mental and behavioral health for children and youth.

Figure 2: Child and Adolescent Health Measurement Initiative Framework for Selection and Application of Pediatric Quality Measures (1997)

USER FILTER: Who and for what purpose



RELEVANT CATEGORIES FILTER: Performance areas of interest



UNIT OF ANALYSIS FILTER: Setting(s) for measurement activities

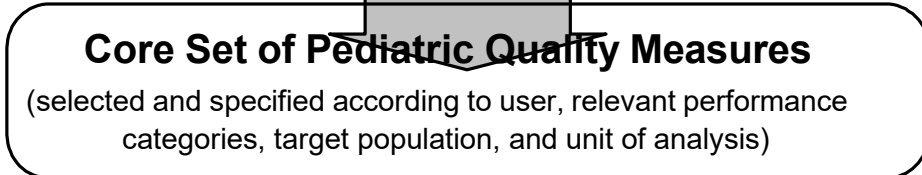
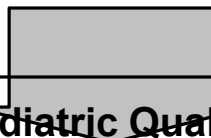
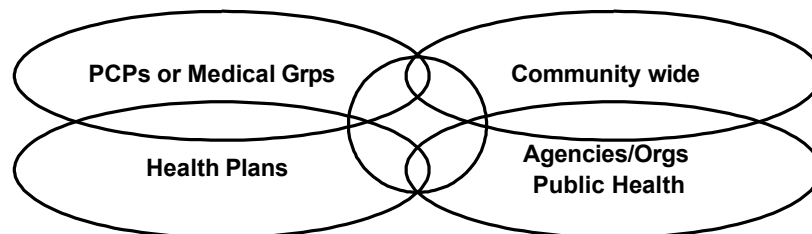
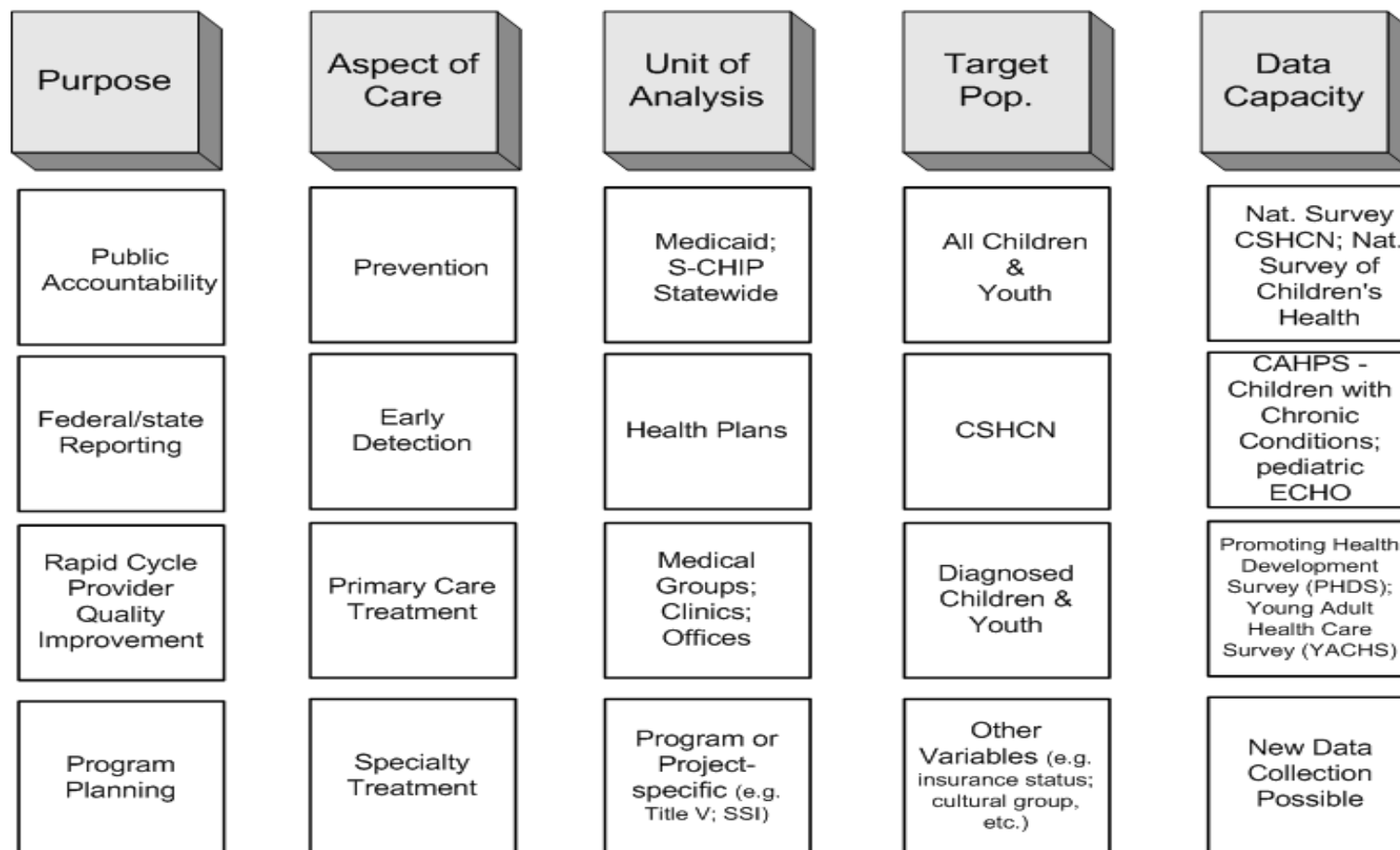


Figure 3:

FACTORS SHAPING THE DEVELOPMENT OF MEASURES OF MENTAL/BEHAVIORAL HEALTH CARE QUALITY



CAHMI Measurement Development Criteria and Process

Criteria used for the identification of e quality measures and methods include:

- (1) **relevance** to consumers, providers, purchasers and policymakers
- (2) empirical **evidence** linking the measurement topic to valued outcomes
- (3) psychometrically **valid and reliable** measurement tools
- (4) improvement models or **strategies available**
- (5) **feasible** data collection and reporting strategies available
- (6) **parsimony** with respect to the full set of available quality measures

In addition, all measures developed under the rubric of the CAHMI use the standard six stage CAHMI process for developing and testing quality measures summarized in Figure 3 below.

Figure 4: CAHMI Six Stage Measurement Development Process

Stage 1: Conceptual Framework and Relevance: Develop conceptual framework for measurement within topical area, obtain consumer input, review available literature, measurement methods and tools, establish and obtain input from an expert advisory group.
Key focus: Consumer and Professional Relevance, Face Validity and Usefulness

Stage 2: Develop starting point measurement proposal and conduct phase I feasibility and stakeholder review.

Key Focus: General Feasibility and Content Validity

Stage 3: Specify viable measurement methods and tools and convene advisory group to select options for further development and design field test.

Key Focus: Applied Feasibility and Empirical Soundness of Measures

Stage 4: Conduct field testing (minimum 3 sites), conduct data analysis and engage advisory group in review and interpretation of findings.

Key Focus: Feasibility and Soundness of Measures

Stage 5: Revise and refine quality measure specifications for each application (e.g. health plan comparison) addressing each criteria. Obtain additional consumer input and specify scoring and reporting guidelines.

Key Focus: Relevance, Feasibility, Soundness and Interpretability

Stage 6: Develop scientific and technical documentation and begin larger scale implementation and dissemination.

Key Focus: Application, Generalizability and Usefulness

Key Assumptions Underlying CAHMI Quality Measurement

Engaging partners in defining and measuring health care quality requires clarity of assumptions about answers to common questions. Below is a summary of the key topics and questions for which clear assumptions and answers were articulated to facilitate effective stakeholder-based design, testing, endorsement and use of quality measures developed through the CAHMI.

1. What is quality?

- The degree to which services result in and/or increase desired health outcomes.
- The degree to which services that are consistent with current professional knowledge are provided including:
 - Tests
 - Procedures
 - Medications
 - Patient education
 - Family-centered, coordinated, culturally competent care.
- Information about the cost of care is not quality information.
- Data on rates of service utilization rarely provides information about whether specific services were provided to the people who needed them and whether services were provided in a high quality manner. For example, rates of well-visits for children do not indicate whether necessary preventive and developmental services were provided.

2. What is a quality measure?

- A measure of quality provides information about quality of care compared to specific criteria. Quality measures are used to answer the question “how is care compared to what it should or could be?”
- Quality performance measures are most often reported only as comparisons between providers or plans, as opposed to indications of actual performance. In this way, they are “descriptions of distributions” and not “pictures of performance”. Most quality reports do not answer the question “how is care compared to what it should or could be”. Rather, they answer, “How does plan A compare to plan B?” Meaningful quality reports should answer both questions.
- A concept is not a measure – there are many intricate and unexpected details as well as many political issues involved in constructing a quantitative assessment of quality. Measures appropriate for use in standardized comparisons of quality across providers normally take 2-4 years to develop, validate and implement widely.

3. Why should we measure health care quality?

- Measuring and reporting quality information is necessary to:
 - Help consumers make informed choices and to increase their participation as partners in their health care. Parents need to know what to expect from their children’s health care, how to verify that they are getting good care and what their role is in improvement. Without this knowledge, commitments to family- centered care and “informed and activated patients” are simply rhetoric.
 - Help physicians and managers improve clinical care. Physicians and managers need to rely on data not assumptions about health care quality. Assumptions about the services provided, patients’ experiences and health outcomes are usually very different than what actually occurs.
 - Help purchasers evaluate performance and provide incentives and support for improvement.
 - Help policymakers monitor health system performance.

- When anecdotal information is all that is available, providers, consumers, purchasers and policymakers act on assumptions alone. At a minimum, information on quality should be collected to verify the assumptions that are used to inform the design and payment structure for health care services for children and adolescents.
 - Quality measurement and reporting is essential to informing, shaping and stimulating improvement. Care is below optimal levels, in one or more areas, for nearly all children. In other words, almost no children receive all of a core set of preventive care services or, if illness is present, recommended care for that illness. Children and adolescents who have specific health conditions (e.g. asthma, depression) receive care that is approximately 40 to 60 percent of optimal. Preventive and developmental care is approximately 20 to 60 percent of optimal depending on the aspect of care measured. Most parents report one or more problems accessing routine and/or specialized services for their child and/or receiving family-centered care. Coordination of care is especially poor.
4. Can child health care quality be measured in a valid and feasible manner?
- While quality measurement is a relatively young field, numerous tested measures are available for use at the state, community, health plan and provider levels.
 - Provider-level measures have not been extensively developed or tested especially for purposes of transparency and public reporting.
 - Available measures focus on the basics of good care (e.g. access, customer service and family-provider communication), preventive services, basic aspects of care for children with special health care needs, some condition specific clinical measures and some aspects of acute care quality.
 - The largest gaps in measures are in the areas of hospital and ER based care, care for specific clinical conditions, health outcomes, cultural competency and preventive care for children ages 5-11.
 - Potentially important hospital-based measures are collected by JCAHO, but they are not publicly reported. Patients, providers, purchasers and policymakers cannot access the data for analysis or reporting. As a result, JCAHO hospital quality data is of limited value.
 - The scientific evidence base is much weaker for child and adolescent health care than for adult health care. This has a large impact on our ability to develop valid measures that will gain the support of a broad group of stakeholders – especially for use in comparing performance across providers, systems of care, states, programs or other units of analysis. As such, there are many fewer measures for child health care than adult health care.
 - New models of measurement are needed to accommodate the unique issues for children. National health care quality measurement, reporting and improvement efforts focus on specific clinical conditions. Reports on quality problems (e.g. “Crossing the Quality Chasm”) do not adequately address specific child and adolescent health issues. For example, few children have any one condition which makes robust measurement for any one diagnosis difficult, especially at the individual provider or clinic level. New models for quality measurement are required for children and adolescents.
5. Is transparency and disclosure of health care quality information to patients and consumers essential to improving quality?
- Decades of provider- driven efforts have failed to produce needed information or improvements. Transparency and disclosure are essential to providing the incentives and comparative information providers and consumers need to push for change and innovation.

6. What are the major barriers to making information about quality readily available?
- Lack of training and role models: Training for medical professionals and system managers rarely address quality measurement and reporting.
 - Lack of demand for information: Media and public reports on health care focus on the cost and access and rarely report on the widespread problems with quality. While, health industry insiders knew about patient safety risks and errors for over a decade before the Institute of Medicine reported them in “To Err is Human” in 2000, the public did not learn of these issues until the media highlighted findings from this report. Upon disclosure of this information, public awareness and concern was raised and the demand for information about safety and errors rose markedly. In turn, public and private sector resources for measuring, reporting and reducing medical errors also rose dramatically.
 - Poor data infrastructure: The information infrastructure needed to track health needs, target improvements in care and learn about what drives outcomes for children do not exist at the provider, plan or system level. Very few health care providers and health plans keep the patient registries needed to identify and track quality and outcomes for individuals who experience certain health conditions and require specific health services. Information across systems of care (e.g. mental health carve-outs and health plans; Title V and Medicaid) is rarely integrated hampering any efforts to perform child-centered quality measurement that examines all care needed and used by children. Medical records at doctors’ offices around the country do not conform to any standards and are only available as paper-based charts making it difficult to share information with other providers and patients themselves.
 - Lack of evidence: Quality measurement and reporting is rare. When it does occur, the methods used are generally not well tested and its impact on cost, outcomes and care processes is not well documented. Health care innovators need to create a knowledge base on the value (e.g. “the business case”) of quality measurement and improvement in order to stimulate broader adoption of these types of efforts and ensure that the most effective methods are employed.
 - Financing and incentives: Few health care purchasers require or offer incentives for quality measurement and disclosure among contracted health care providers.
 - Fragmentation of health services: Health care quality is generally measured on a setting or clinical service specific level, yet health outcomes for children *are generated through the application of services and skills across many settings and systems of care*. Providers often believe that they can not control the variables driving quality nor are they compensated to collaborate across systems. These factors work against a comprehensive child-centered system of quality measurement and improvement.
7. Are standardized measurement methods critical to using quality information to shape and stimulate system improvements?
- Common measures used across health plans, provider groups, demographic groups and communities are essential to establishing a common language for assessing and understanding system performance, gaps in care and opportunities for improvement. Even small differences in quality measurement, scoring, grading and reporting methods can drastically reduce, or even eliminate, opportunities to use information to compare performance and improve care.
 - Standardization can be challenging and fraught with political and technical challenges. For example, some health plans maintain data that others do not. Implementing a standard method may require plans to invest in new data systems. Some providers are willing to

assume responsibility for certain aspects of care (e.g. coordination of care) while others do not see this as their role. Any standard method will have strengths and weaknesses and will be met with resistance by some stakeholders.

8. Are current quality measurement efforts effective?
 - Current efforts to measure and report on health care quality rarely succeed in shaping a collective understanding of the problems within the health system and identify goals and methods for improving care.
 - Quality information is rarely collected or scored and reported so that people can understand and use the information to select among health care providers and/or to act on the information in ways that can stimulate improvements in care with their current providers.
9. Who should ensure the collection and communication of quality information?
 - The government is ultimately responsible for ensuring that resources used on behalf of the public are used in a way that provides the greatest benefit. As such, unless widespread voluntary efforts are forthcoming, Medicaid agencies should ensure quality is measured and improved using regulatory, program design and/or contractual methods.
 - While the government must play a critical role, effective quality measurement and improvement are not possible without cross-agency, cross-health system and cross-sector collaboration.
10. What is the role of the person (parent, child or adolescent) in defining and participating in quality measurement and improvement?
 - People - parents, children and adolescents - need to be involved at every level of defining quality, determining how to measure, report and interpret quality information, and in prioritizing aims and strategies for improvement.
 - Informed and activated parents, children and adolescents are essential in efforts to achieve system improvements. Methods for motivating people are just being developed and empirical evidence on the impact of informing and activating people is not extensive.
 - Parent and patient reported information should be integrated into all comprehensive quality strategies. Quality cannot be evaluated properly without person-reported information. Most parent reported information focuses on clinical processes of care, outcomes of care and critical components of the experience of care (e.g. care coordination; getting needed information; shared decision making). Parents and/or children and adolescents are the most reliable reporters of most of this type of information not medical records or administrative and encounter data.
 - Information technology employed in other industries is vastly underused as a way to routinely measure quality and engage people in their health care. For example, people should have the opportunity to own and have access to their own medical records and be empowered to add information to these records. Personal health records (PHRs) are essential to informing and activating patients, because they offer an integrated and comprehensive view of health information, including information people generate themselves (symptoms and medication use and information from providers, pharmacies and insurance companies). PHRs may encourage integration, help organize health care needs and drive quality improvement. PHR's may also catch potential medical errors by providing a mechanism for real time communication of issues and concerns.