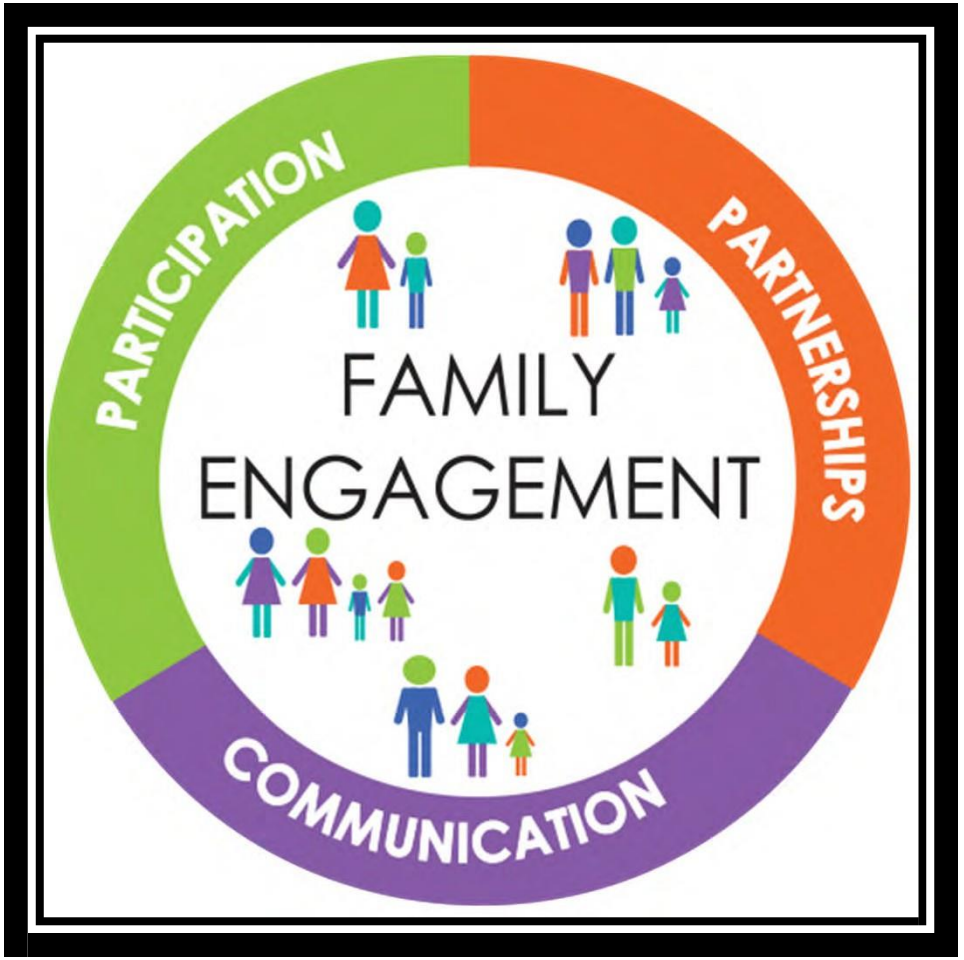
Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

Measuring Family Engagement in MCH: Opportunities and Challenges

Christina Bethell, PhD, MPH, MBA
Professor, Johns Hopkins Bloomberg School of Public Health
Director, Child and Adolescent Health Measurement Initiative

CAHMI
The Child & Adolescent Health Measurement Initiative

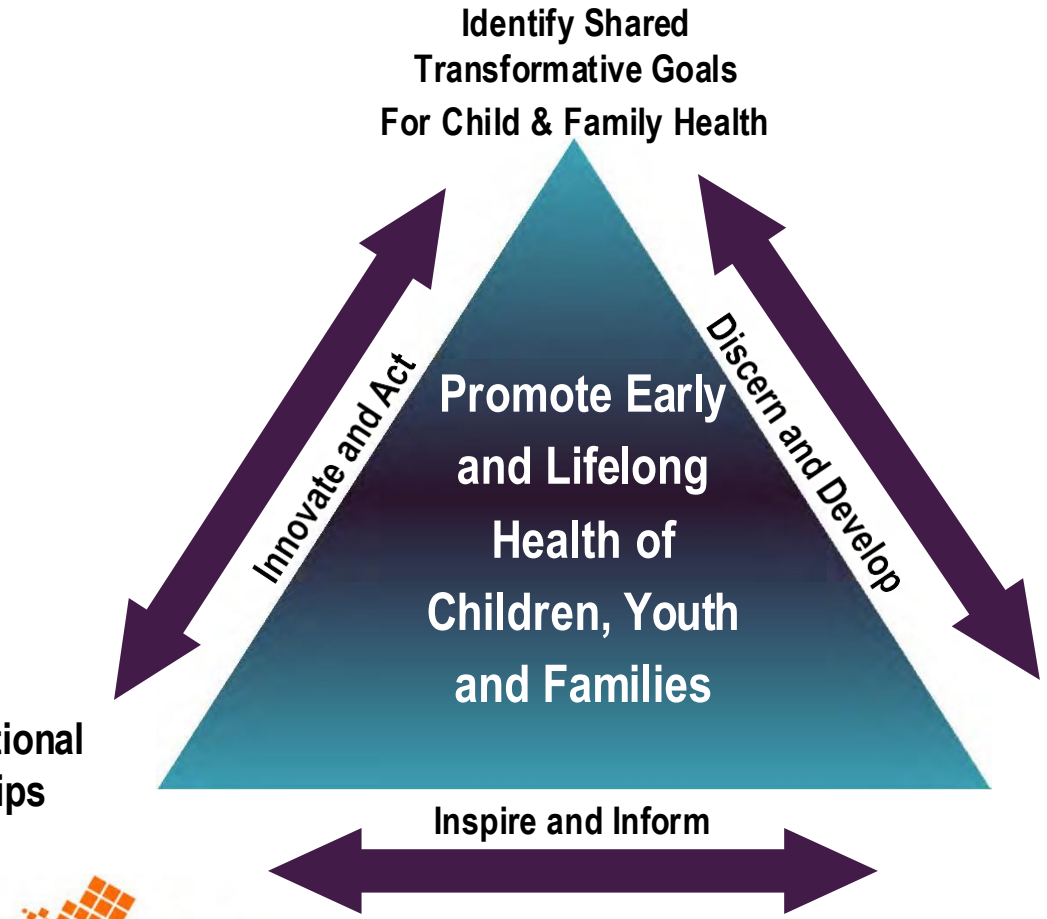
JOHNS HOPKINS
BLOOMBERG SCHOOL of PUBLIC HEALTH



Acknowledgements

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under UA6MC30375 Maternal and Child Health Measurement Research Network. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Measurement and Data In Action Model

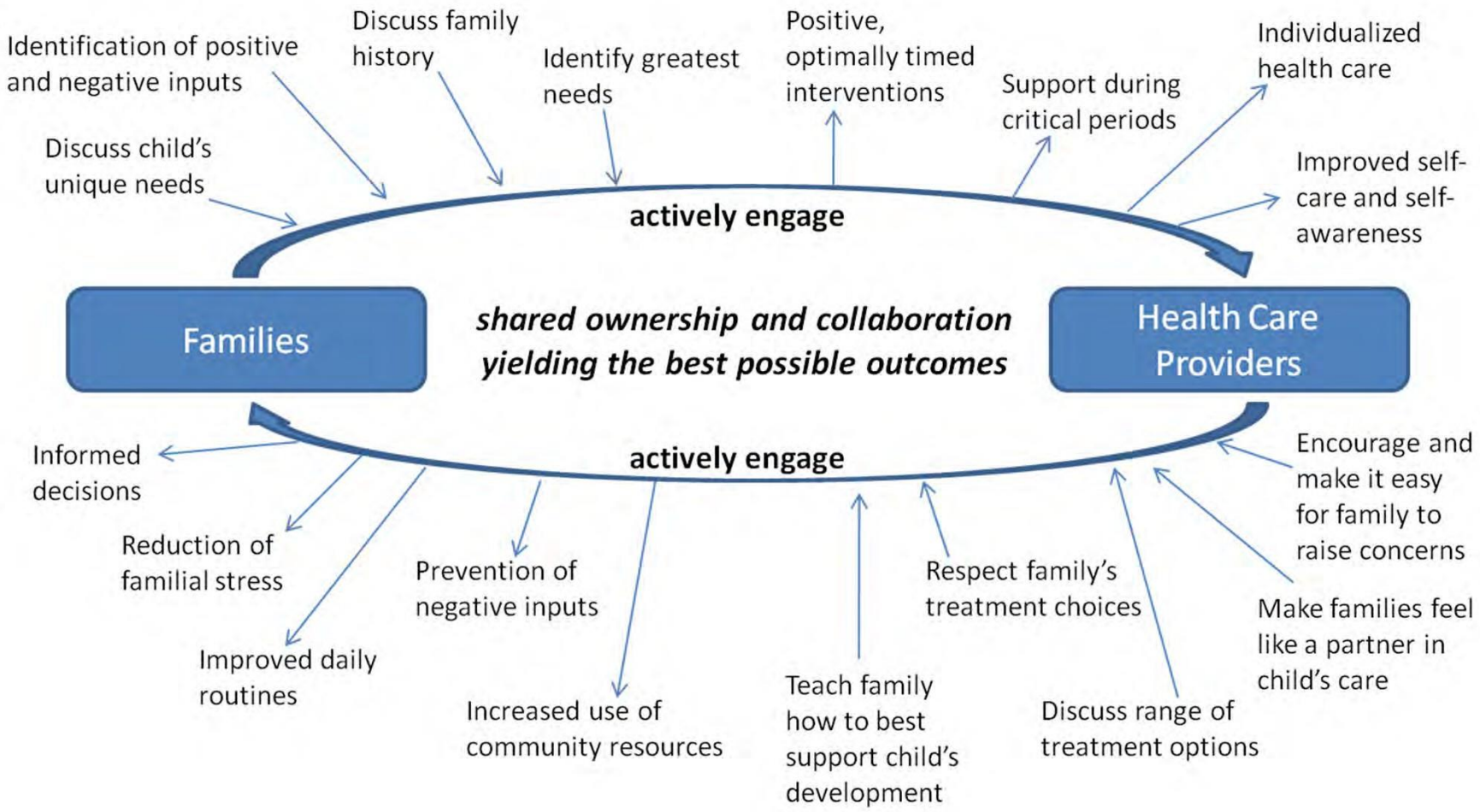


"It's not about being data-driven. It's about being driven by the right data."

~Jeff Andrade-Duncan

CAHMI
The Child & Adolescent Health Measurement Initiative

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

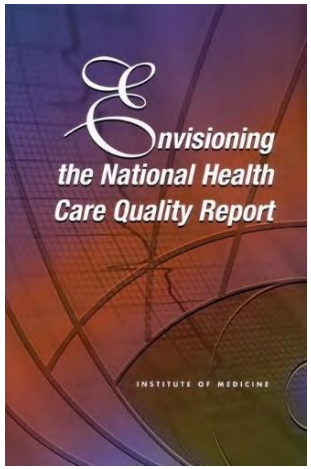

Identification of positive and negative inputs
Discuss family history
Identify greatest needs
Positive, optimally timed interventions
Support during critical periods
Individualized health care
Discuss child's unique needs
Improved self-care and self-awareness
actively engage
Families
shared ownership and collaboration yielding the best possible outcomes
Health Care Providers
actively engage
Informed decisions
Reduction of familial stress
Improved daily routines
Prevention of negative inputs
Increased use of community resources
Teach family how to best support child's development
Respect family's treatment choices
Discuss range of treatment options
Encourage and make it easy for family to raise concerns
Make families feel like a partner in child's care

Early Notions of Family Engagement As Patient- and Family-Centered Care

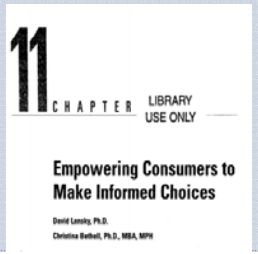
Definitions for the Institute of Medicine's "Envisioning the National Health Care Quality Report" (2001):
Version 2 (expanded): Health care that establishes a working partnership with patients and their families to ensure decisions are made that respect and honor patients' wants, needs, and preferences and to ensure that patients have the education and support they need to act as a central resource in their own health and/or the health of their family.

Patient Centered Care Quality Measure Categories & Specific Measurement Concepts

(Bethell, 2000, "Patient-centered Care Measures for the National Health Care Quality Report")



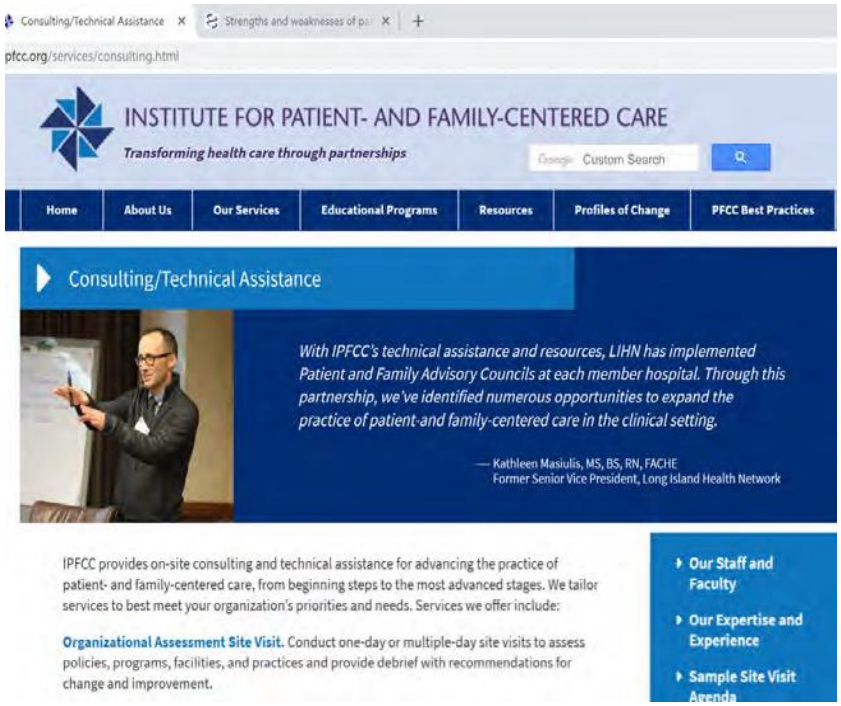
1: Patient Centered Communication and Caring	2: Patient Centered Education and Teamwork	3: Consumer Empowerment	4: Patient Centered Systems of Care
• 1A: Communication with Health Care Providers • 1B: Helpful and Respectful Support Staff	• 2A: Shared Decision Making • 2B: Getting Needed Information • 2C: Self Care Management and Support • 2D: Self Care Efficacy	• 3A: Consumer Activation • 3B: Public Disclosure of Performance Information	•4A: Understanding Population Needs and Preferences •4B: Patient Centered Customer Service, Convenience, and Comfort •4C: Managing for Patient Centered Care •4D: Families as decision making partners in systems programs, policies and all initiatives to engage families



CAHMI The Child & Adolescent Health Measurement Initiative

MCH-MRN Coordinated by CAHMI Maternal & Child Health Measurement Research Network

http://www.ipfcc.org/services/consulting.html

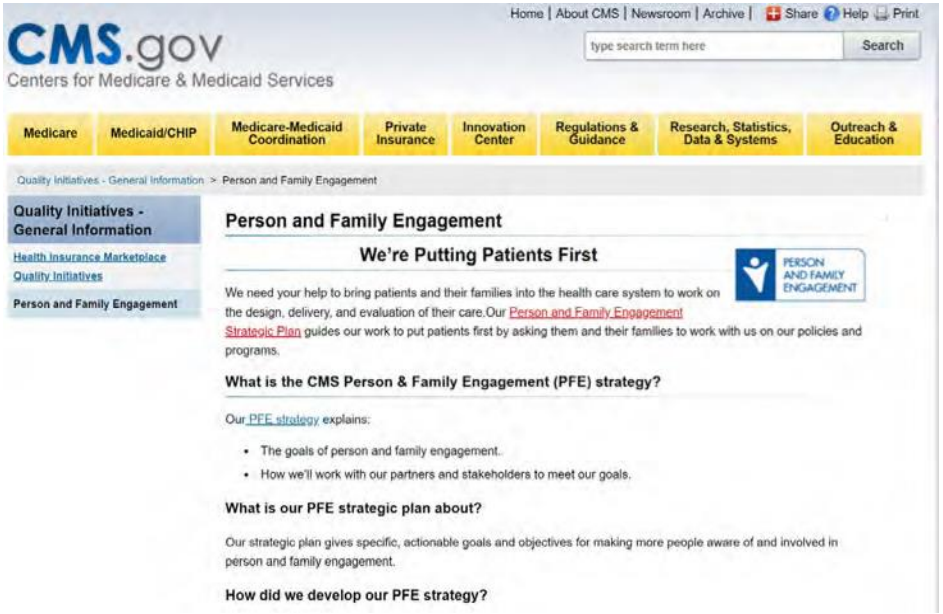


https://www.childwelfare.gov/fei/definition/

CAHMI
The Child & Adolescent Health Measurement Initiative

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Person-and-Family-Engagement.html



https://www.aap.org/en-us/professional-resources/practice-transformation/managing-patients/FPN/Pages/Family-Engagement.aspx

CAHMI
The Child & Adolescent Health Measurement Initiative

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

http://www.amchp.org/programsandtopics/family-engagement/Pages/default.aspx

CAHMI
The Child & Adolescent Health Measurement Initiative

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

Various Definitions of Family Engagement

We define **patient and family engagement** as patients, families, their representatives, and health professionals **working in active partnership at various levels across the health care system**— direct care, organizational design and governance, and policy making—to improve health and health care.

Carman et al., 2013, *Health Affairs*

Family engagement is a **family-centered, strengths-based approach to establishing relationships** with families and sustaining the "work" to be accomplished together with them. On the practice level, this includes setting goals, developing plans, making decisions, and working with families to keep their children safe, provide them with a permanent home, and attend to their well-being. On an organizational or system level, it means including families as key stakeholders and advisors in policy development, service design, and evaluation.

McCarthy, 2012 (Child Welfare Practice Models guide)

Family engagement is the process in which families and youth have a **primary decision-making role** in the youth's treatment. Families are involved in making decisions regarding providers involved in the treatment team, and are encouraged to express preferences, needs, priorities, and disagreements. In addition, families **actively collaborate** in treatment plan development and in identifying desired goals and outcomes. Families are provided with thorough information to guide their decision-making and make joint decisions with their treatment team. Families actively monitor treatment modifications and treatment outcomes.

American Academy of Child & Adolescent Psychiatry, 2009

Family engagement is **an innovative approach** to the planning, delivery, and evaluation of health care that is grounded in **mutually beneficial partnerships** among health care providers, patients, and families.

Johnson et al., 2012, Institute for Patient- and Family-Centered Care

MEDICAL CARE
March 1989, Vol. 27, No. 3, Supplement

Assessing the Effects of Physician-Patient Interactions on the Outcomes of Chronic Disease

SHERRIE H. KAPLAN, PHD, MPH, SHELDON GREENFIELD, MD, AND JOHN E. WARE, JR., PHD

Growing interest in the doctor-patient relationship focuses attention on the specific elements of that relationship that affect patients' health outcomes. Data are presented for four clinical trials conducted in varied practice settings among chronically ill patients differing markedly in sociodemographic characteristics. These trials demonstrated that "better health" measured physiologically (blood pressure or blood sugar), behaviorally (functional status), or more

Published in final edited form as:
J Child Fam Stud. 2010 October 1; 19(5): 629–645. doi:10.1007/s10826-009-9350-2.

Review of Interventions to Improve Family Engagement and Retention in Parent and Child Mental Health Programs

Erin M. Ingoldsby
Prevention Research Center for Family and Child Health, Department of Pediatrics, University of Colorado Denver, Mail Stop #8410, 13121 E. 17th Ave., Room 5303, Aurora, CO 80045, USA

Erin M. Ingoldsby: erin.ingoldsby@ucdenver.edu

Abstract

Engaging and retaining families in mental health prevention and intervention programs is critically important to insure maximum public health impact. We evaluated randomized-controlled trials testing methods to improve family engagement and retention in child mental health programs

AERA Open
July-September 2018, Vol. 4, No. 3, pp. 1–12
DOI: 10.1177/2332858418785904

A New Approach to Defining and Measuring Family Engagement in Early Childhood Education Programs

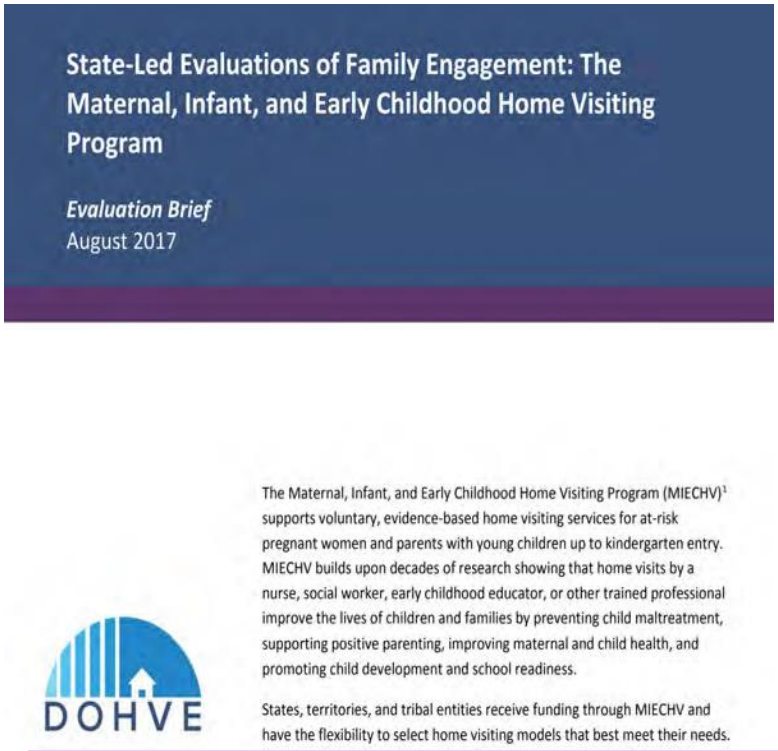
Terri J. Sabol
Teresa Eckrich Sommer
Northwestern University
Amy Sanchez
University of Chicago
Andrea Kinghorn Busby

Almost every state-level Quality Rating and Improvement System (QRIS) in the country includes family engagement as an indicator of early childhood education quality. Yet, most QRIS measure family engagement using a uniform, narrow set of parent involvement activities at the center. We propose an alternative approach that emphasizes a range of direct services for parents, including: (1) parenting classes, (2) family support services, (3) social capital activities, and (4) human capital services. In our proposed rating systems, states would assess how well centers address the highest ranked needs of families and employ evidence-based practices across one or more of the center-selected direct parent service categories. We explore

Family Engagement: Multi-Dimensional, Dynamic, Relationally Dependent Process Foundational to All Positive Health Outcomes

Requires sensitivity to family culture, structures, resources, constraints, socio-cultural and developmental influences underlying the varied pathways to family engagement.

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network



State-Led Evaluations of Family Engagement: The Maternal, Infant, and Early Childhood Home Visiting Program

Evaluation Brief
August 2017

DOHVE

The Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV)[1] supports voluntary, evidence-based home visiting services for at-risk pregnant women and parents with young children up to kindergarten entry. MIECHV builds upon decades of research showing that home visits by a nurse, social worker, early childhood educator, or other trained professional improve the lives of children and families by preventing child maltreatment, supporting positive parenting, improving maternal and child health, and promoting child development and school readiness.

States, territories, and tribal entities receive funding through MIECHV and have the flexibility to select home visiting models that best meet their needs.

"However, engagement is challenging. Up to 40 percent of families invited to enroll in home visiting programs choose not to do so. 17 Research also indicates that families who do enroll may receive less than 80 percent of intended visits, and 25–50 percent may leave the program before completing it.

Family Engagement as an Outcome (vs. as an outcomes of family engagement)

Family engagement in home visiting is the commitment of caregivers and pregnant women to

(1) initially enroll in home visiting services,

(2) engage during home visits, and

(3) complete the intended number of home visits across the intended length of program enrollment.

CAHMI
The Child & Adolescent Health Measurement Initiative

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

Address All Interdependent Aspects of Family Engagement

Common themes:

- Active partnership at all levels levels
- Family-centered approach
- Collaborative decision making
- Building relationships
- Planning, setting goals, delivering, and evaluating health care

Communication between families and providers to build trust

- Open and honest interactions
- Child- and family-centered care
- Building trust and relationships

Family involvement to share decision making and plans of care

- Participation in decision-making
- Joint treatment and goal planning
- Joint input on EMR/patient portal

Active collaboration with organizations and systems for results

- Youth and family advisory boards
- Partner in program design and care delivery
- Participation in policy/program evaluation

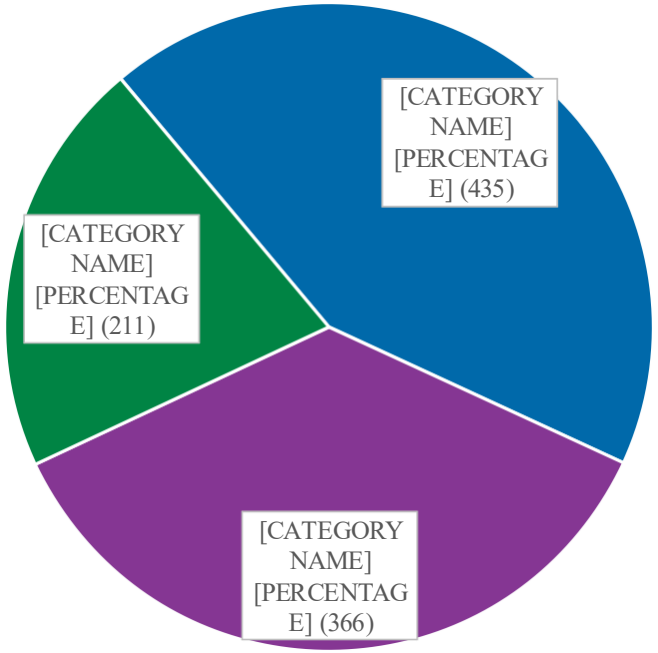
Engage to improve health and well-being

- Proactive health seeking and pursuit of well-being
- Capacity and will to heal, change and learn
- Health promoting behaviors
- Self-management of conditions

Family Engagement in the MCH Measure Compendium

(measures across 11 MCH programs/initiatives)

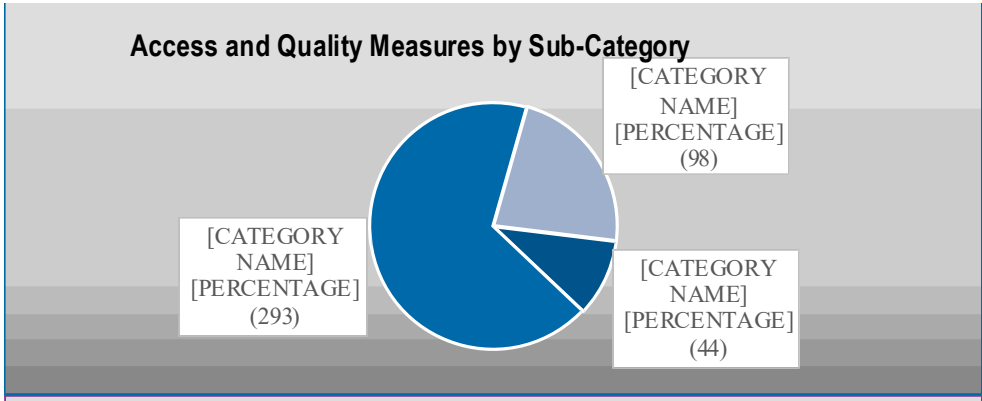
MCH Measure Compendium: Measures by Topic

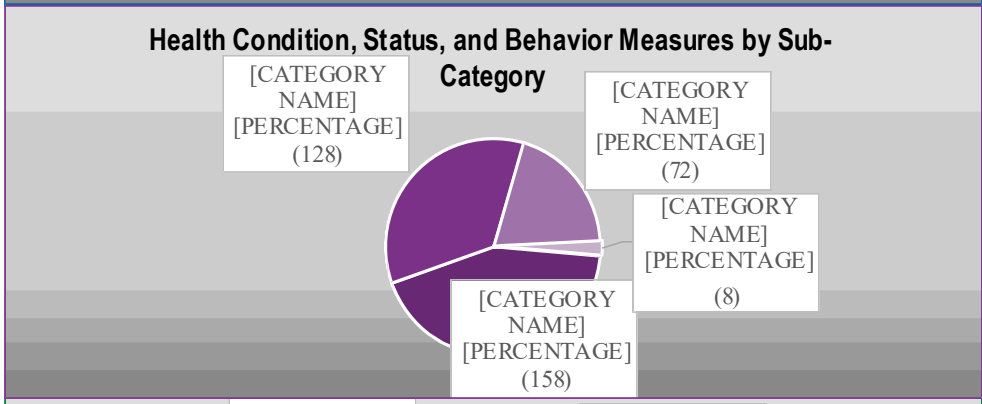


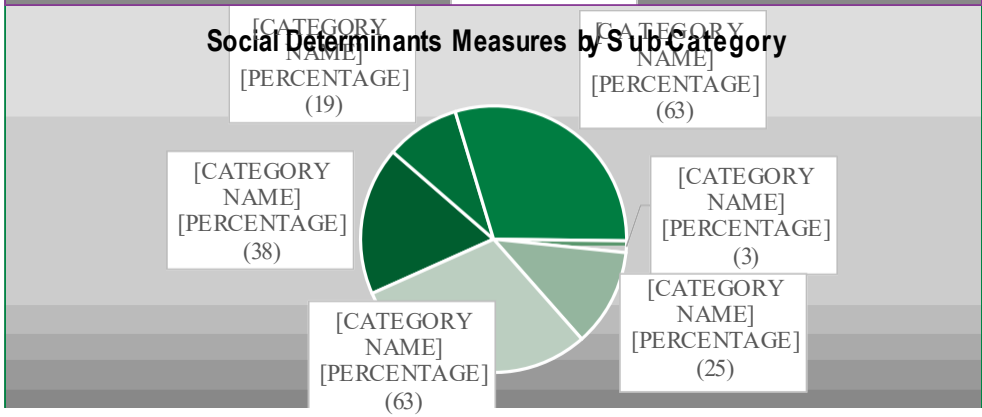
www.mch-measurement.org (CAHMI website)

CAHMI The Child & Adolescent Health Measurement Initiative

MCH-MRN Coordinated by CAHMI Maternal & Child Health Measurement Research Network







Family Engagement in the MCH Measure Compendium

Access to and quality of health care services

Measure Topics (#)	Level of Engagement
Well Visit Utilization	• Engagement in HC • Engagement in own health
CAHPS surveys (6)	• Engagement in HC
Young Adult Health Care Survey (1)	• Engagement in HC • Engagement in own health
Transition to adult health care (5)	• Engagement in HC • Engagement in own health
Shared decision making (1)	• Engagement in HC • Engagement in own health
Anticipatory guidance (6)	• Engagement to promote health
Care coordination (2)	• Engagement facilitator
Family-centered care (1)	• Engagement with provider
Developmental concerns addressed by doctors (1)	• Engagement facilitator • Engagement in HC

Example Measurement gaps

- Engagement with organizations and systems
- Goal setting and shared plans of care
- Building trust and relationships
- Joint EMR input

Potential outcomes of family engagement in health care and health of child and family (etc.)

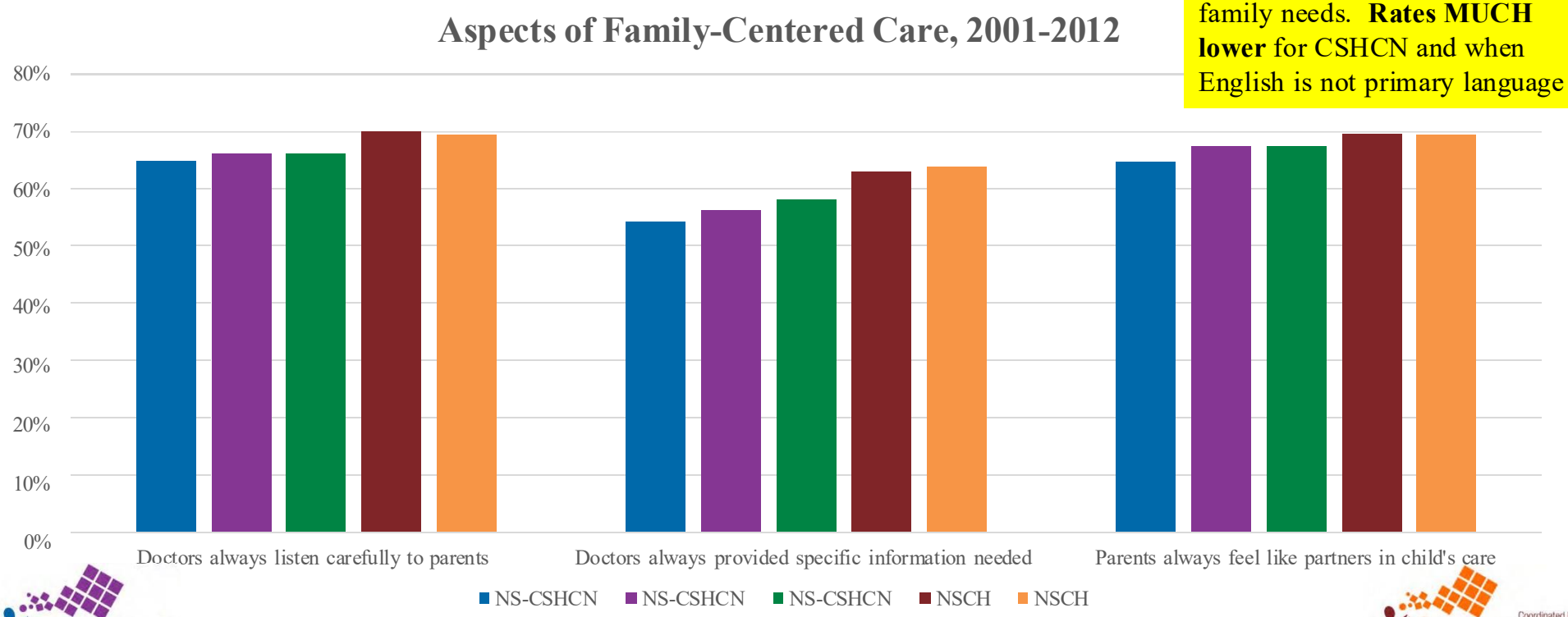
- Reductions in emergency care use
- Healthy and ready to learn
- Healthy family routines and habits
- Family resilience

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

Family Engagement in the NSCH* & NS-CSHCN** (2001 to 2011-12)

*NSCH: National Survey of Children's Health
**NS-CSHCN: National Survey of Children with Special Health Care Needs

LARGE VARIATION: Across states, settings and by child and family needs. **Rates MUCH lower** for CSHCN and when English is not primary language

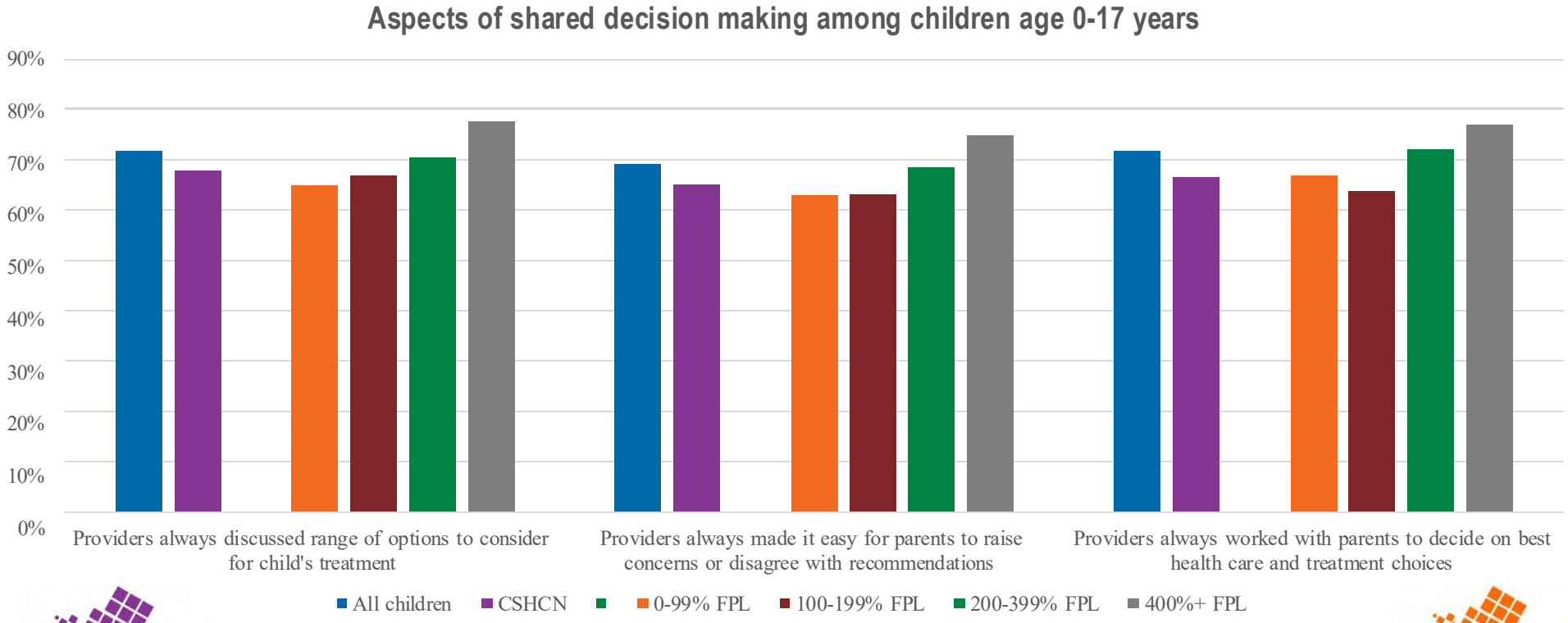


CAHMI The Child & Adolescent Health Measurement Initiative

Coordinated by CAHMI MCH-MRN Maternal & Child Health Measurement Research Network

Family Engagement in the 2016-2017 combined NSCH

LARGE VARIATION: Across states, settings and by child and family needs.
Rates MUCH lower for CSHCN and when English is not primary language

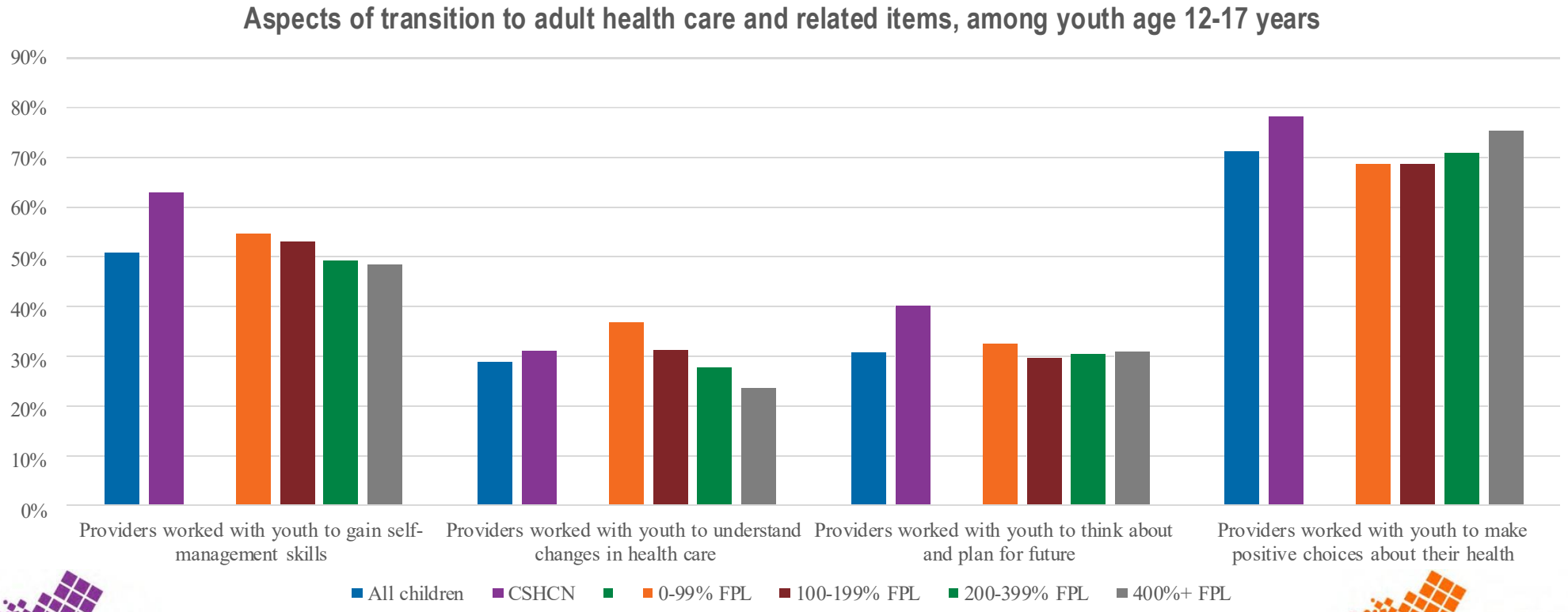


CAHMI
The Child & Adolescent Health Measurement Initiative

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

Family Engagement in the 2016-2017 combined NSCH

LARGE VARIATION: Across states, settings and by child/youth and family needs.



CAHMI
The Child & Adolescent Health Measurement Initiative

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

Family Engagement in the MCH Measure Compendium

Health status, well-being, and health conditions across the life course

Measure Topics (#)	Level of Engagement
Sunscreen use (1)	• Engagement in own health
Smoking cessation (2)	• Engagement in own health
Substance use risk perception (3)	• Engagement in own health
Substance use disapproval (6)	• Engagement in own health
Seat belt use (4)	• Engagement in own health
Vision/hearing protection (3)	• Engagement in own health
Sufficient sleep (1)	• Engagement in own health
Physical activity (7)	• Engagement in own health
Infant safe sleep (3)	• Engagement in own health
Contraceptive use (12)	• Engagement in own health
Meaning/satisfaction in life (2)	• Aspect of positive health

MANY MEASUREMENT GAPS!

Healthy and ready to learn
School engagement
Positive parenting

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

Family Engagement in the MCH Measure Compendium

Social determinants of health

Measure Topics (#)	Level of Engagement
Family, peer, and other adult connections (4)	• Engagement in own health • Aspect of positive health
Early language & literacy activities (2)	• Engagement in own health
Sexual health discussion with parents (8)	• Engagement in own health

Example Measurement gaps

- Family engagement in policy
- Safe, stable housing, food and transportation
- Neighborhood safety and support
- Family resilience
- Relational health and parent-child connection
- Reductions in Adverse Childhood Experiences
- Actions to heal ACEs and build resilience
- Follow through to obtain social support services related to housing, food, transportation, legal support, etc.

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

Family Engagement Measurement Gaps and Opportunities (from the MCH-MRN)

Conceptual
- Measures on a particular topic do not exist

Population-based
- Measures exist, but are not applied across multiple population groups

Use
- Measures exist, but are not well used

Alignment
- Lack of alignment in measurement hinders shared accountability

Application
- Measures are not applied for action

Representative
- Measures are not collected with demographic data, preventing analysis of disparities

Translation
- Measures are being used, but data is not analyzed or presented in a useful way

Specification/ Validity
- Measure concepts exist, but have not been validated or don't have technical specifications

Family Engagement Technical Working Group

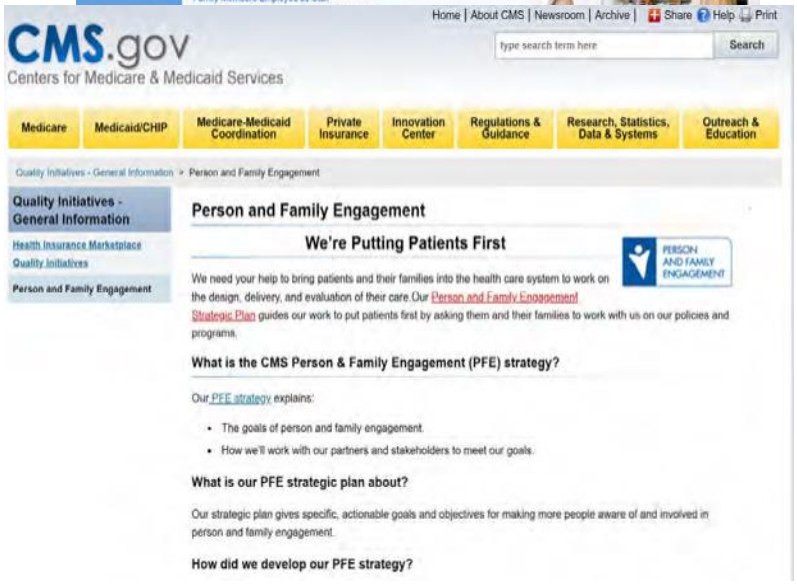
What are the short-term high priority actions and opportunities related to this topic?

1. **Clarify definitions** and meaning of family engagement and family centered care across different systems and context.
2. **Develop and model effective use** of measures, measurement tools, and information collected.
3. **Use available data well** (e.g., National Survey of Children's Health), EHR/EMR, and other sources.
4. **Enhance** measurement of family health and family engagement in **existing data collection platforms** (e.g., NSCH, Title V NOMs/NPMs).
5. **Synthesize existing knowledge** and create a "**launch and learn" evaluation** platform to learn "what works for whom". Consider *Citizen Science* models, not just CoIINs.
6. Ensure **family leadership** in measure development and research on family engagement.

Family Engagement Technical Working Group

What are the potential next steps?

1. **Leverage existing cross-sector commitment** to Family Engagement to "go the distance"
2. **Strategically review, analyze and "make actionable" existing data** and research on family engagement and its measurement in clinical care and system initiatives. Don't reinvent the wheel.
3. Through **Family Voices leadership**, complete development of the family engagement systems tool (FESAT) using best practice measurement development/testing frameworks.
4. **Disseminate completed FESAT tool** and toolkit to state Title V MCH Programs, state Medicaid agencies, hospitals, health systems, and families.
5. Embrace **measurement as intervention** –engaging families in measurement is a good in itself. Example is Well Visit Planner tool to support early childhood development.
6. Develop a **grant application** for research support (e.g., R40 MCH research program).
7. **Publish papers** on family engagement measurement (FESAT) and methods to engage families (WVP/emerging Family Foundation of Care Planner for CSHCN).
8. **Share existing resources** via Internet.



NOW IS THE TIME!

CAHMI
The Child & Adolescent Health Measurement Initiative

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network