Measuring Family Engagement in MCH: Opportunities and Challenges

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Measurement and Data In Action Model

Identify Shared Transformative Goals For Child & Family Health

Promote Early and Lifelong Health of Children, Youth and Families

Innovate and Act Discern and Develop

Transformational Partnerships

Inspire and Inform

Actionable Data & Data-Driven Tools

“It’s not about being data-driven. It’s about being driven by the right data.”

~Jeff Andrade-Duncan
**shared ownership and collaboration yielding the best possible outcomes**

**Families**
- Identification of positive and negative inputs
- Discuss child’s unique needs
- Informed decisions
- Reduction of familial stress
- Improved daily routines
- Increased use of community resources
- Teach family how to best support child’s development

**Health Care Providers**
- Discuss family history
- Identify greatest needs
- Positive, optimally timed interventions
- Support during critical periods
- Individualized health care
- Improved self-care and self-awareness
- Encourage and make it easy for family to raise concerns
- Make families feel like a partner in child’s care
- Discuss range of treatment options
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”)

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<thead>
<tr>
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<tbody>
<tr>
<td>• 1A: Communication with Health Care Providers</td>
<td>• 2A: Shared Decision Making</td>
<td>• 3A: Consumer Activation</td>
<td>• 4A: Understanding Population Needs and Preferences</td>
</tr>
<tr>
<td>• 1B: Helpful and Respectful Support Staff</td>
<td>• 2B: Getting Needed Information</td>
<td>• 3B: Public Disclosure of Performance Information</td>
<td>• 4B: Patient Centered Customer Service, Convenience, and Comfort</td>
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<tr>
<td></td>
<td>• 2C: Self Care Management and Support</td>
<td></td>
<td>• 4C: Managing for Patient Centered Care</td>
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<td></td>
<td>• 2D: Self Care Efficacy</td>
<td></td>
<td>• 4D: Families as decision making partners in systems programs, policies and all initiatives to engage families</td>
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</table>
Consulting/Technical Assistance

With IPFCC’s technical assistance and resources, LHN has implemented Patient and Family Advisory Councils at each member hospital. Through this partnership, we’ve identified numerous opportunities to expand the practice of patient and family-centered care in the clinical setting.

— Kathleen Medulli, MS, BSN, RN, FACHE
Former Senior Vice President, Long Island Health Network

IPFCC provides onsite consulting and technical assistance for enhancing the practice of patient- and family-centered care, from beginning steps to the most advanced stages. We tailor services to meet your organization’s priorities and needs. Services we offer include:

Organizational Assessment Site Visit: Conduct one-day or multiple-day site visits to assess policies, programs, facilities, and practices and provide clarity with recommendations for change and improvement.

- Our Staff and Faculty
- Our Expertise and Experience
- Sample Site Visit Agenda

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

Definitions of Family Engagement

The definition domains include statements, phrases, and/or qualifications that explain the meaning of or provide a description of family engagement for each discipline referenced in the inventory. This section highlights a family engagement definition from research on the designated discipline.

- Child Welfare
- Juvenile Justice

Behavioral Health

Education

CAHMI

MCH-MRN

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

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

Family Engagement & Leadership

Family Engagement in Title V Programs

How states sustain and diversify engagement to improve quality

Families play a critical role in helping to improve maternal and child health services provided through the federal Title V Maternal and Child Health Block Grant. AMCHP set out to measure and describe how programs funded by Title V work to sustain and diversify family and consumer engagement, which the block grant requires them to document.

In 2014 and 2015, AMCHP conducted a survey about family engagement policies and practices in Title V maternal and child health and children and youth with special health care needs programs, with funding from the Lucile Packard Foundation for Children’s Health and the U.S. Maternal and Child Health Bureau. The findings provide a snapshot of strategies to support meaningful family engagement, effective and innovative practices, and areas of need for improvement and technical assistance.

Survey
The survey report — Sustaining and Diversifying Family Engagement in Title V MCH and CYSHCN Programs — is composed of a summary of the results and a series of briefs that detail the results in specific areas.

Family Engagement Executive Summary
Creating a Culture of Family Engagement
Levels of Family Engagement
Roles of Family Staff and Consultants
Family Members Employed as Staff
Sustaining and Diversifying Family Engagement
Evaluating Family Engagement

Case Studies
The case study reports provide examples of engaging families and engaging diverse populations from a total of five states.

http://www.amchp.org/programsandtopics/family-engagement/Pages/default.aspx
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 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 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 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
Assessing the Effects of Physician-Patient Interactions on the Outcomes of Chronic Disease

Sheirin 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.

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

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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.

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

Results of Family Engagement (e.g. Family Resilience; Parenting Routines and Habits, Child Flourishing and School Engagement, etc.)

Family Engagement as an Outcome (participate, seek health care, etc.)

Steps to engage families

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

“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.
Address All Interdependent Aspects of Family Engagement

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

Common themes:
- Active partnership at all levels
- Family-centered approach
- Collaborative decision making
- Building relationships
- Planning, setting goals, delivering, and evaluating health care
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)
## Family Engagement in the MCH Measure Compendium

### Access to and quality of health care services

<table>
<thead>
<tr>
<th>Measure Topics (#)</th>
<th>Level of Engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well Visit Utilization</td>
<td>• Engagement in HC&lt;br&gt;• Engagement in own health</td>
</tr>
<tr>
<td>CAHPS surveys (6)</td>
<td>• Engagement in HC</td>
</tr>
<tr>
<td>Young Adult Health Care Survey (1)</td>
<td>• Engagement in HC&lt;br&gt;• Engagement in own health</td>
</tr>
<tr>
<td>Transition to adult health care (5)</td>
<td>• Engagement in HC&lt;br&gt;• Engagement in own health</td>
</tr>
<tr>
<td>Shared decision making (1)</td>
<td>• Engagement in HC&lt;br&gt;• Engagement in own health</td>
</tr>
<tr>
<td>Anticipatory guidance (6)</td>
<td>• Engagement to promote health</td>
</tr>
<tr>
<td>Care coordination (2)</td>
<td>• Engagement facilitator</td>
</tr>
<tr>
<td>Family-centered care (1)</td>
<td>• Engagement with provider</td>
</tr>
<tr>
<td>Developmental concerns addressed by doctors (1)</td>
<td>• Engagement facilitator&lt;br&gt;• Engagement in HC</td>
</tr>
</tbody>
</table>

### 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
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

Aspects of Family-Centered Care, 2001-2012

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

Aspects of shared decision making among children age 0-17 years.
Family Engagement in the 2016-2017 combined NSCH

Large variation: Across states, settings and by child/youth and family needs.

Aspects of transition to adult health care and related items, among youth age 12-17 years

Providers worked with youth to gain self-management skills
Providers worked with youth to understand changes in health care
Providers worked with youth to think about and plan for future
Providers worked with youth to make positive choices about their health

All children  CSHCN  0-99% FPL  100-199% FPL  200-399% FPL  400%+ FPL
## Family Engagement in the MCH Measure Compendium

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

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

### MANY MEASUREMENT GAPS!

- Healthy and ready to learn
- School engagement
- Positive parenting
Family Engagement in the MCH Measure Compendium

Social determinants of health

<table>
<thead>
<tr>
<th>Measure Topics (#)</th>
<th>Level of Engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family, peer, and other adult connections (4)</td>
<td>• Engagement in own health</td>
</tr>
<tr>
<td></td>
<td>• Aspect of positive health</td>
</tr>
<tr>
<td>Early language &amp; literacy activities (2)</td>
<td>• Engagement in own health</td>
</tr>
<tr>
<td>Sexual health discussion with parents (8)</td>
<td>• Engagement in own health</td>
</tr>
</tbody>
</table>

Example Measurement gaps

- Family engagement in policy
- Equity
- 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.
## Family Engagement Measurement Gaps and Opportunities

(from the MCH-MRN)

<table>
<thead>
<tr>
<th>Conceptual</th>
<th>Measures on a particular topic do not exist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population-based</td>
<td>Measures exist, but are not applied across multiple population groups</td>
</tr>
<tr>
<td>Use</td>
<td>Measures exist, but are not well used</td>
</tr>
<tr>
<td>Alignment</td>
<td>Lack of alignment in measurement hinders shared accountability</td>
</tr>
<tr>
<td>Application</td>
<td>Measures are not applied for action</td>
</tr>
<tr>
<td>Equity</td>
<td>Measures are not collected with demographic data, preventing analysis of disparities</td>
</tr>
<tr>
<td>Translation</td>
<td>Measures are being used, but data is not analyzed or presented in a useful way</td>
</tr>
<tr>
<td>Specification/Validity</td>
<td>Measure concepts exist, but have not been validated or don’t have technical specifications</td>
</tr>
</tbody>
</table>
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 CoINs.
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!