

# Best Practices in Family-Centered Care in the Pediatric Medical Home

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# What Is Family-Centered Care (FCC)?

Care where families are full partners

Care is individualized, flexible, and responsive

Care supports and strengthens family functioning



# Principles of Family-Centered Care:

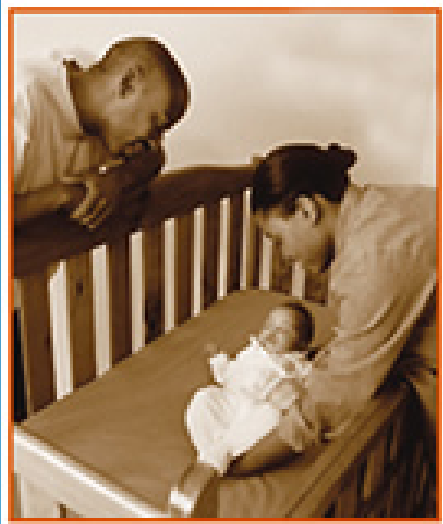
- Acknowledges the family as the constant in a child's life.
- Builds on family strengths.
- Supports the child in learning about and participating in his/her care and decision-making.
- Honors cultural diversity and family traditions.
- Recognizes the importance of community-based services.

# Principles of Family-Centered Care:

- Promotes an individual and developmental approach.
- Encourages family-to-family and peer support.
- Supports youth as they transition to adulthood.
- Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
- Celebrates successes

# Family-Centered Care Associated With:

- Improved health status
- Improved satisfaction
- Improved access to care
- Improved family functioning
- Better communication
- Greater efficiency



Family-centered care is  
essential component of  
medical home;

yet...

Families, particularly families of children with special healthcare needs (CSHCN), report a lack of family-centered care.

According to the 2009-2010 National Survey of Children with Special Health Care Needs, **35.4%** of CSHCN aged 0-17 years did not receive family-centered care\*.

\*Data Resource Center,  
Child and Adolescent Health Measurement Initiative

How to improve adoption of family-centered care?

What are the structures and processes within practices that promote family-centered care?





American Academy of Pediatrics' National Center for Medical Home Implementation, with support from the Maternal and Child Health Bureau, commissioned a review of general pediatric practices that would yield:

- "best practices" in family-centered care
- specific tools or strategies (policies, practices and/or systems) used by pediatric practices to create a family-centered environment

# Developing a Monograph

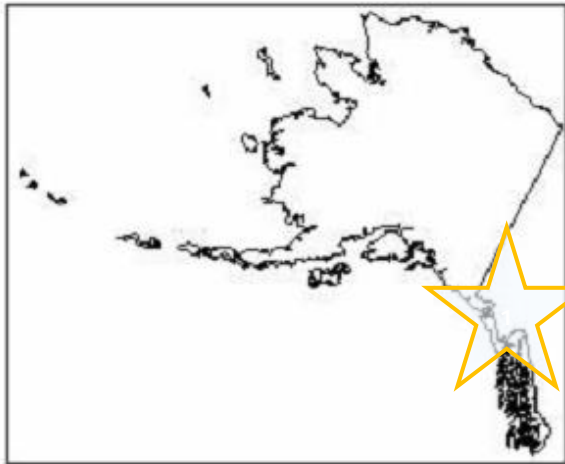
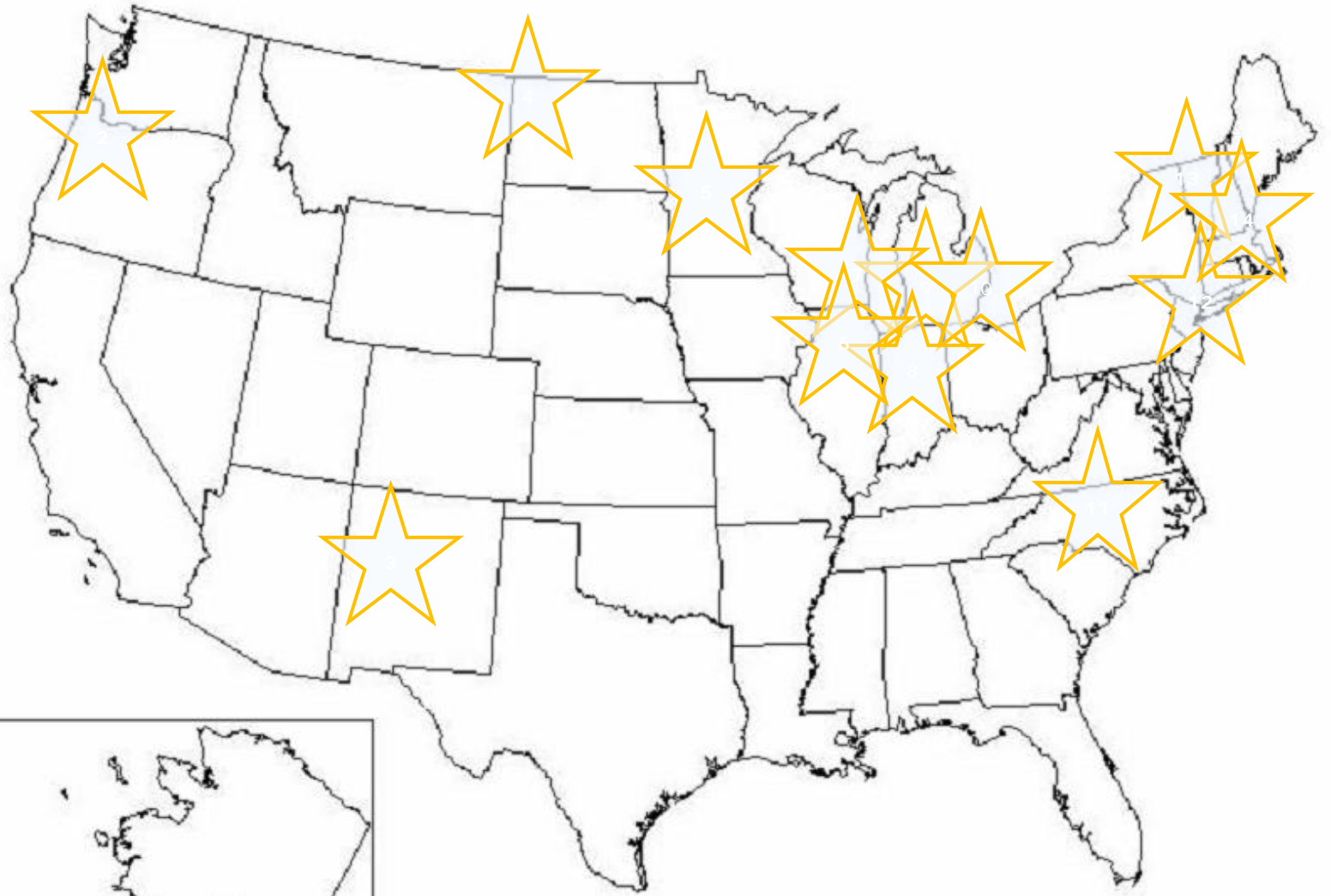
- Consultant and Lead Author
  - **Rebecca Malouin, PhD, MPH**, (Michigan State University)
- Advisory Committee
  - **Michelle Esquivel, MPH** (AAP – National Center for Medical Home Implementation)
  - **Barbara Kahl, JD** (Institute for Patient and Family Centered Care)
  - **Joanna Kaufman, RN, MS** (Institute for Patient and Family Centered Care)
  - **Marie Mann, MD, MPH** (HRSA Maternal and Child Health Bureau)
  - **Lee Partridge** (National Partnership for Women and Children)
  - **Nora Wells, MEd** (Family Voices)

# Methods

- Practice nominations solicited through several national AAP and HRSA/MCHB list-serves
- Nominations reviewed by advisory committee
- Selected practices invited for a 30-60 minute key informant interview by “most knowledgeable” practice representative
- Practices invited to propose a family to participate in 30-60 minute interview

# Results

- Advisory committee reviewed 29 nominations
- Fourteen practices invited for interviews
- Eleven families participated in interviews
- All interviews conducted in 2011



# Findings

- Practices represented a range of geographic locations, practice types, sizes and insurance mix
- The majority reported use of information technology, most commonly electronic health records
- The majority reported some form of formal medical home recognition

# Example of Structures: Care Plans

- Developed jointly with families to reflect their preferences, important information, and patient and family goals
- Provide systematic, disciplined approach to care in the clinical setting and at home with delineation of responsibilities
- Allow for more efficient visits

# A Family's Perspective

*[The care plan] is a whole kind of mini reference letter into all her health issues. So when we go to the emergency [room], I make sure I carry the care plan with me...it kind of helps put a physician and nurses at ease.*





# Example of Structures: Patient Portal

Through a secure electronic system:

- Patients and families view their medical records, request appointments, referrals, or prescription refills, and communicate with the health care team electronically
- Practice share information and resources, administers pre-visit questionnaires

# Example of Processes: Pre-Visit Screening

Knowing in advance what issues the family wants to discuss:

- Allows the scheduler to allocate the right amount of time for the visit
- Directs the clinician's focus to issues most pressing for the family
- Alerts staff to have a translator on hand if one is needed
- Allows the scheduler to maintain balance in an individual provider's schedule
- Minimize wait-times

# A Family's Perspective

*When I call [for an appointment]...  
they know not to put us in  
their tiniest exam room because  
it's harder when you've got  
three kids and one of them is  
in a wheel chair...*



# Dissemination

- Monograph will be published and available Summer 2012
- Manuscripts in preparation for peer-review
- Presentation of findings at various venues including 5<sup>th</sup> International Conference on Patient- and Family-Centered Care

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