Back to Basics: Meaningfully and Effectively Engaging Families in Pediatric Practices and Systems

A webinar series brought to you by the National Center for Medical Home Implementation, the National Center for Family Professional Partnerships, and the Bright Futures National Center

Moving Beyond Cooperation: Engaging Families in Health Care Organizations and Practices
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11 – Noon Central

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Moving Beyond Cooperation: Engaging Families in Health Care Organizations and Practices

brought to you by the National Center for Medical Home Implementation, the National Center for Family Professional Partnerships, and the Bright Futures National Center

Moderator:
Janet DesGeorges
Executive Director
Hands & Voices, Inc.
About the Sponsors

• **Funded by:** Maternal and Child Health Bureau and Health Resources and Services Administration

• **Goal statements**
  • National Center for Medical Home Implementation
    • Ensure all children and youth—particularly those with special health care needs—have access to a medical home
  • National Center for Family Professional Partnerships
    • Reduce health care disparities of families of children and youth with special health care needs
  • Bright Futures National Center
    • Support primary care practices (medical homes) in providing well-child and adolescent care
Disclosures

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Objectives

- Define and describe the characteristics of family engagement at the health care organization level
- Identify practical strategies and tools to encourage and measure family engagement at the practice and health care organization level
- Describe evidence-based and evidence-informed practices for family engagement among pediatric practices and health care organizations
Partnership Continuum

• Where are you and/or your organization on this continuum?
• How can you move to the next level on the continuum?

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Faculty:
RJ Gillespie, MD, MHPE, FAAP
Pediatrician
The Children’s Clinic
Medical Director, Oregon Pediatric Improvement Partnership
Maxims of Patient-Centered Care

• The needs of the patient come first
• Every patient is the only patient
• Nothing about me without me

Lessons from the Center for Medical Home Improvement (CMHI) Learning Collaborative

• Evaluated practices that improved on their “medical home-ness” AND were able to sustain improvements after learning collaborative ended

• Those who sustained innovations:
  • Identified the population of children and youth with special health care needs
  • Gained family participation and feedback
  • Developed the capacity for practice-based care coordination and the use of care plans

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Family-Professional Partnerships: Beyond “Engagement”

- Adding parents (or adolescents) to quality improvement (QI) Teams
- Surveying families for their experiences
  - Major and mini-surveys
- Focus groups, parent advisory groups
- Peer navigators and peer support specialists
Steps for Adding Parents to Your Team

- Embracing the idea of a parent partner
- Discussing characteristics, traits and qualities
- Successfully selecting a parent partner
- Inviting and compensating a parent partner
- Replacing a parent partner (when necessary)

Adapted from “Parent Partners, Creative Forces on Medical Home Improvement Teams”, Ann Donoghue Dillon, 2003, Center for Medical Home Improvement.
Embracing the Idea

- Discuss the concept in depth
  - Include all stakeholders on current team
  - Include key thought leaders and decision-makers at your practice
  - Do not to debate the concept AFTER bringing a parent into the mix
• Start this journey committed to the concept
  • There may be barriers experienced and refinements needed
  • Committing to work through this experience is key to achieving success and realizing their value
Discussing Traits & Qualities

• Determine what collection of characteristics meets your needs

• Key traits include:
  • Has the time to commit (access to childcare, etc.)
  • Confident and able to speak up in group settings
  • Fit with the group dynamic – humor!
Discussing Traits & Qualities Cont’d

- Key traits include:
  - Experience with local resources and multiple specialists
    - Parents of children and youth with special health care needs have an extremely valuable perspective when it comes to medical homes for children
  - Multiple partners with different experiences provide for an even more rich parent perspective
Selecting a Parent Partner

• Ask clinicians and staff in your practice to suggest parents that fit your list of traits
• Consider alternative recruiting strategies
  • Signs in waiting room, newsletter, website, Facebook, etc.
• Conduct meetings and interviews to explore interest and fit
Inviting and Compensating

• Be detailed in laying out the time commitment and stipend
  • Parents as consultants typically receive $12-25 per hour for their time and effort
Inviting and Compensating Cont’d

• Be strategic in the presentation of background information and onboarding / orientation information
  • Include information about:
    • Relevant clinic processes (quality improvement committee process / policies, etc.)
    • Medical home concepts in general
    • Specific projects in which they will be participating
  • Consider connecting to parent partners in other practices, or other parent-to-parent resources
Replacing Parent Partners (As Needed)

- It would be to your benefit to plan for turnover from the outset
  - Document the results of completing the steps the first time
    - Statement about the value of this effort to your practice
    - List of characteristics and traits
    - Recruitment plan
Replacing Parent Partners (As Needed) Cont’d

- Document the results of completing the steps the first time continued
  - Generic / boilerplate contract specifying commitment and compensation
  - Catalogue of orientation materials
- Consider keeping a list of parents that you identify as potential future participants
Surveys – Major and Mini

- Patient experience of care surveys
  - Consumer Assessment of Health Care Providers and Systems
  - Press-Ganey
- Practice-driven surveys
  - Topic-specific, brief survey designed to get input on a specific subject
  - Designed by the practice rather than a standardized survey
  - Example
    - Urgent Care Survey
Focus Groups & Advisory Councils

- **Focus groups:** Short-term/temporary mechanisms for gaining family input on specific subjects
- **Advisory councils:** More permanent structures, provide input and support into clinic operations
  - Drive their own agenda about recommendations for practice
  - Address specific subjects or problems
  - Some practices engage adolescents in advisory councils
Peer Navigators / Peer Support Specialists

- Permanent employees of the practice
- Parents are often more willing to “get real” about their needs and challenges with a peer compared to a clinician
Peer Navigators/ Peer Support Specialists Cont’d

• Function in conjunction with care coordinators, serving many of the same functions
  • Care coordinators: Focus on medical coordination
  • Peer support specialist: Focus on community-based resources, helping parents advocate within school systems
• Some states offer training to allow billing for services
Measuring your Family Participation

- **Medical Home Standards:** Include standards around family participation and engagement
  - Standards about patient surveys
  - Standards around participation in QI or other practice operations
- Measurement tools for assessing degree of family participation
  - **Medical Home Index:** Revised short form
Patient Centered Primary Care Home (PCPCH) Example

• Standard 2.C – Patient and Family Involvement in Quality Improvement

• Measures:
  • 2.C.1 - PCPCH involves patients, caregivers, and patient-defined families as advisors on at least one quality or safety initiative per year. (5 points)
  • 2.C.2 - PCPCH has established a formal mechanism to integrate patient, caregiver, and patient-defined family advisors as key members of quality, safety, program development and/or educational improvement activities. (10 points)
  • 2.C.3 - Patient, caregiver, and patient-defined family advisors are integrated into the PCPCH and function in peer support or in training roles. (15 points)
## Family Engagement Example

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<tr>
<th>STANDARD</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
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<tbody>
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<td><strong>1.5 Family Feedback</strong></td>
<td>Family feedback to the <em>practice</em> occurs through external mechanisms such as satisfaction surveys issued by a health plan; this information is not always shared with <em>practice</em> staff.</td>
<td>Feedback from families of <em>children with special health care needs (CSHCN)</em> is elicited sporadically by individual <em>practice</em> providers or by a suggestion box; this feedback is shared informally with other providers and staff.</td>
<td>Feedback from families of <em>CSHCN</em> regarding their perception of care is gathered through systematic methods (e.g. surveys, focus groups, or interviews); there is a process for staff to review this feedback and to begin problem solving.</td>
<td>In addition to Level 3, an advisory process is in place with families of <em>CSHCN</em> which helps to identify needs and implement creative solutions; there are tangible supports to enable families to participate in these activities (e.g. childcare or parent stipends).</td>
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Moving Beyond Cooperation:
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Faculty:
Kathy Ostler, MD
Pediatrician
Wasatch Pediatrics, Summit Office
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Faculty:
Dustina Frisby
Care Coordinator
Wasatch Pediatrics, Summit Office
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Faculty:
Elizabeth Wall
Parent Partner
Wasatch Pediatrics, Summit Office
In the beginning...

- Medical Home Integrated Services Project – 2006-2009
  - Required a team of four – doctor, front office, medical assistant, and parent partner
  - Immediate changes
  - Support from Utah Family Voices and rest of project participants
  - Job description
  - Limitations
The Culture of Quality Improvement

- Preventing, Recognizing and Treating Obesity 2008-2009
- Early Autism Detection and Referral 2009-2010
- The move from “Networking” to “Cooperation” was complete!
Parent Partner 2.0

CHIC Medical Home Demonstration Project
2011-2014

Liz moved into paid position

Paid care coordinator

Mental Health Problems in Children
2011-2013

“Collaboration” has been achieved!
Striving for “Partnership”

- Liz participates in URLEND 2014
- Formal training in Montana 2015
- Field trip to Boston Children’s and Dartmouth-Hitchcock 2014
- Family Engagement Quality Improvement Project 2016-2017
A Day in the Life

- 25 hours per week in clinic
- Inclusion from the beginning
- Pre-appointment phone calls
- Home and hospital visits
- Individual Educational Planning meetings (advice and advocacy)
A Day in the Life Cont’d

• Instructing on how to navigate systems (i.e. school, Supplemental Security Income, Division of Services for People with Disabilities, etc.)
• Peer to peer support
• Help doctors understand the parent perspective
Family Council

- Why a family council and a parent partner?
- Choosing families to serve on council
- Resources used to guide our family council model
  - What our model looks like
- Resources:
  - [Creating a Patient and Family Advisory Council: A Toolkit for Pediatric Practices](#)
Family Council Cont’d

• What did we learn from our first year?
  • Some families are looking for meaningful ways to be involved
  • Patients don’t know what they don’t know
  • Services offered should be well advertised
  • Staff benefitted from getting to know more about the families
Three Important Questions

• Why employ a parent partner do this work instead of a “regular” staff member?
• How does this improve care for the patient?
• Is there a conflict of interest?
Resources

• National Center for Medical Home Implementation
  • Resources for practices
  • Resources for families
  • “How-to” videos: family advisory groups, care partnership support
  • Visit www.medicalhomeinfo.org for more information

• Have a question about medical home? Contact us!
  • www.medicalhomeinfo.org
  • Medical_home@aap.org
  • Subscribe to our Listserv!
  • 800/433-9016 ext 7605
Resources

• **National Center for Family Professional Partnerships**
  o Partnering with your Provider and Partnering with your Health Plan tip sheets
  o Family Centered Care

• **Family Voices**
  o Family Centered Care Assessment tool

• **Kids as Self-Advocates**
  o Health focused articles written by youth and young adults

• **IMPACT on Health and Wellness**
  o The Well Visit Planner Media Toolkit, with materials in English and Spanish, created with family leader input, to help disseminate information about the Child and Adolescent Health Measurement Initiative’s Well Visit Planner.
Resources

• Bright Futures National Center
  • About Bright Futures Video
  • Resources for Families
  • Resources for Children and Teens
  • Bright Futures Activity Book
  • Bright Futures VisitPlanner App
  • Eliciting Parental Strengths and Needs Tip Sheet
  • Community Resources Tip Sheet
  • Bright Futures Presentations
  • Visit brightfutures.aap.org for more information
Questions
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Medical_home@aap.org
Subscribe to our Listserv!

800/433-9016 ext 7605
Achieving True Partnership:
Integrating Family Engagement in Systems of Care
June 20, 2017
1 to 2pm Central
For more information and registration visit the NCMHI Web site.