

# 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

Thursday, May 25, 2017  
11 – Noon Central



**NATIONAL CENTER FOR  
MEDICAL HOME  
IMPLEMENTATION**

A cooperative agreement between the Maternal and Child Health Bureau/HRSA and the American Academy of Pediatrics

**National Center for  
Family  Professional Partnerships**

a project of  
Family Voices, Inc



**Bright Futures™**

prevention and health promotion for infants,  
children, adolescents, and their families™

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

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**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



- We have no relevant financial relationships with the manufacturers(s) of any commercial products(s) and/or provider of commercial services discussed in this activity.
- We do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.

# Objectives

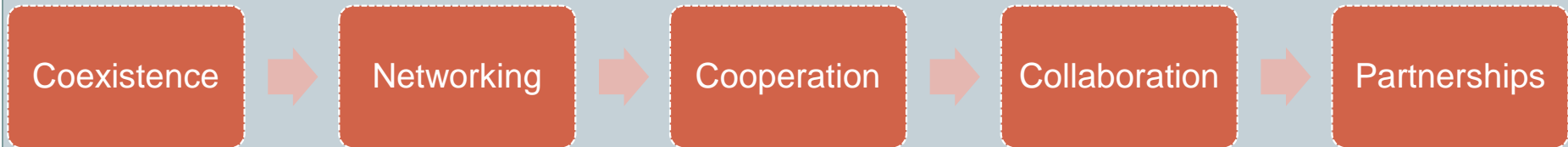


- Define and describe the characteristics of family engagement at the health care organization level
- Identify practical strategies and tools to encourage and measure family engagement at the practice and health care organization level
- Describe evidence-based and evidence-informed practices for family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

*From: D. Berwick. What 'Patient-Centered' Should Mean: Confessions of an Extremist.  
Health Affairs, 28, no.4 (2009): w555-565.*



# 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

Cooley, C. (2012). Medical transformation in pediatric primary care. [Powerpoint slides]. Retrieved from [http://www.ohsu.edu/edcomm/flash/flash\\_player.php?params=4`/hosp/peds/gr-062812.flv`vod`s&width=640&height=480&sec=true&title=PEDS%20GR%206-28-12](http://www.ohsu.edu/edcomm/flash/flash_player.php?params=4`/hosp/peds/gr-062812.flv`vod`s&width=640&height=480&sec=true&title=PEDS%20GR%206-28-12)

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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

# Embracing the Idea Cont'd



- 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



STANDARD	Level 1	Level 2	Level 3	Level 4
<b>1.5 Family Feedback</b>	Family feedback to the <i>practice</i> occurs through external mechanisms such as satisfaction surveys issued by a health plan; this information is not always shared with <i>practice</i> staff.	Feedback from families of <i>children with special health care needs (CSHCN)</i> is elicited sporadically by individual <i>practice</i> providers or by a suggestion box; this feedback is shared informally with other providers and staff.	Feedback from families of <i>CSHCN</i> 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.	In addition to Level 3, an advisory process is in place with families of <i>CSHCN</i> 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).
___ PARTIAL ___ COMPLETE	___ PARTIAL ___ COMPLETE	___ PARTIAL ___ COMPLETE	___ PARTIAL ___ COMPLETE	___ PARTIAL ___ COMPLETE

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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

2014  
Field trip to  
Boston  
Children's and  
Dartmouth-  
Hitchcock

2016-2017  
Family  
Engagement  
Quality  
Improvement  
Project

# 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](http://www.medicalhomeinfo.org) for more information
- Have a question about medical home? Contact us!
  - [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)
  - [Medical\\_home@aap.org](mailto:Medical_home@aap.org)
  - [Subscribe to our Listserv!](#)
  - 800/433-9016 ext 7605

# Resources



- [National Center for Family Professional Partnerships](#)
  - [Partnering with your Provider and Partnering with your Health Plan tip sheets](#)
  - [Family Centered Care](#)
- [Family Voices](#)
  - [Family Centered Care Assessment tool](#)
- [Kids as Self-Advocates](#)
  - [Health focused articles written by youth and young adults](#)
- [IMPACT on Health and Wellness](#)
  - [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](http://brightfutures.aap.org) for more information



# Questions



# We're Here to Help You!



Have a question about medical home?  
Contact us!

[www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)

[Medical\\_home@aap.org](mailto:Medical_home@aap.org)

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800/433-9016 ext 7605

**Stay Tuned!**



**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.](#)