PARENTS AS PARTNERS
IN QUALITY IMPROVEMENT

ECHO MONTHLY CALL- OCTOBER 11, 2012
Agenda

- Introductions
- Parents as Partners in QI
  - Overview of Patient Centered Care and its role in the Medical Home
  - Parent as Partners in QI – Different Levels of Engagement
  - Spotlight from OCCYSHN: Shelley Barnes
  - Group sharing and reflection
- Heads up and prep for November 10th Learning Session
  - Pre-Meeting Worksheet
  - Practice report out and increased timing

Summary Developed by the Oregon Pediatric Improvement Partnership for the Enhancing Child Health in Oregon Learning Collaborative. This is a project of the Tri-State Children’s Health Improvement Consortium and is supported by the Oregon Health Authority. If these materials are reproduced or referenced, please cite appropriately.
Objectives

- Describe the importance of patient involvement within the medical home
- Describe the different levels of patient involvement and engagement
- Describe practical techniques for recruiting and retaining patients for participation in QI and other clinic processes.
- Share successful strategies for engaging patients across the ECHO practices
Maxims of Patient Centered Care

The needs of the patient come first

Nothing about me without me

Every patient is the only patient

A definition of patient-centered care

The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one’s person, circumstances, and relationships in health care.

Bright Futures: Health & Wellness

- Health promotion / disease prevention is carried out - or not - by families at home every day.
- Families need a broad(er) understanding of health / health care and their roles
- Families need reinforcement, encouragement
- Families need opportunities to share ideas, successes and resources (not only problems and questions)

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Proposed Measure in PCPCH “Version 2.0”

Accountability: Patient and Family Involvement

PCPCH actively and formally involves patient and families in efforts to improve services.

- **Tier 1:** PCPCH involves patients, caregivers, and families as advisors on at least one quality or safety initiative per year.
- **Tier 2:** PCPCH has established a formal mechanism to integrate patient, caregiver, and family advisors as key members of quality, safety, program development and/or educational improvement activities.
- **Tier 3:** Patient, caregiver, and family advisors are integrated into the PCPCH and function in peer support, on hiring committees, or in training roles.
Lessons from the National Center for Medical Home Improvement (CMHI)

- Evaluated practices that improved on their “medical home”ness AND sustained their improvements
- Learnings from these sustained innovators:
  - “If you do nothing else…”
    - Identify your population of CSHCN
    - **Gain family participation/feedback**
    - Develop the capacity for practice-based care coordination and the use of care plans

Adapted from Cooley, W.C. (2012, June). *Care coordination – Assuring a family-centered approach* [PowerPoint Slides].

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Types of Parent Engagement

- Engagement of families input to QI process
  - **Parents on QI teams**
    - Encouraged in your ECHO projects
    - Based on recent learnings, OPIP plans to require this as part of all QI projects in the future
  - Parental input on specific change strategies/tools
    - Examples: Medical home agreements, shared care plans, referral tracking processes
  - Surveys – major and mini
  - Focus groups – episodic
  - Parent advisory groups – on-going
  - **Use of patient/parental engagement tools**
    - Fundamental changes the culture of the office

Adapted from Cooley, W.C. (2012, June). Care coordination – Assuring a family-centered approach [PowerPoint Slides].
Steps For Adding Parent Partners

Adapted from “Parent Partners, Creative Forces on Medical Home Improvement Teams”, Ann Donoghue Dillon, 2003, Center for Medical Home Improvement.
The Team Approach

- **Key improvement partners**
  - Clinic staff
  - Providers
  - Care coordinator
  - Parents

- **Role of the team**
  - Generate ideas for improvement toward the realization of medical home
  - Design and implement small tests of change
  - Redesign how care is provided
Steps For Adding Parents To Your Team

1. Embracing the idea of a parent partner
2. Discussing characteristics, traits, and qualities
3. Successfully selecting a parent partner
4. Inviting and compensating a parent partner
5. Replacing a parent partner (when necessary)
Embracing the Idea

- Discuss the concept in depth
  - Include all stakeholders on current team
  - Be sure to include key thought leaders and decision makers at your practice
  - It is best 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 the value
Discussing Traits and Qualities

See section III (page 9) of the guide for more details

- 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 group dynamic- humor!
  - Experience with local resources and multiple specialists
    - Parents of CYSHN 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 alternate recruiting strategies
  - Signs in waiting room, newsletter, 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

- Be strategic in the presentation of background information and onboarding/orientation information
  - Include information about:
    - Relevant clinic processes (QI Committee process/policies etc)
    - Medical Home concept 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
    - A statement about the value of this effort to your practice
    - A list of characteristics and traits
    - A plan for recruitment
    - A generic/boilerplate contract specifying commitment and compensation
    - Cataloguing of orientation materials
- Consider keeping a list of parents that you identify as potential future participants
Parent Partners in Medical Home

Shelley Barnes
Family Involvement Coordinator, OCCYSHN

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WHY SHOULD WE INCLUDE PARENTS?

• BASIC QI: ASK THE ‘END USER’

• FAMILY PERSPECTIVE

• WORK WITH OTHER PARENTS
WHAT ROLES CAN PARENTS PLAY?

• QUALITY IMPROVEMENT TEAMS

• HELP WITH NON-MEDICAL CARE COORDINATION

• PUBLIC RELATIONS
EXAMPLES OF ROLES (CONT.)

- SATISFACTION SURVEYS
- SCREENERS
- WORK FLOW PLANNING
- REVIEW PUBLICATIONS
- HELP RECRUIT NEW FAMILIES
- CULTURAL ACTIVITIES
- FOLLOW UP WITH PLANS OF CARE
RECRUITING

- FAMILIES THAT VISIT OFTEN
- PARENTS OF KIDS WITH SPECIAL NEEDS
- PARENTS ACTIVE IN THE COMMUNITY
- THINK ABOUT HAVING TWO
WHAT CAN OCCYSHN DO TO HELP!

• GIVE YOU IDEAS ON HOW TO RECRUIT

• WHEN YOU HAVE FOUND A PARENT WE WILL HELP TRAIN THE PARENT

• WE WILL HELP TRAIN THE PROFESSIONALS TO WORK WITH PARENTS
TRAINING THE PARENT:

- HIPPA (CONFIDENTIALITY)
- FAMILY CENTERED CARE
- CULTURAL UNDERSTANDINGS
- COMMUNICATION
- PROFESSIONAL PARTNERSHIPS
- HOW TO WORK WITH YOUR TEAM

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TRAINING THE PROFESSIONAL

- WELCOMING AND INCLUDING A PARENT
- IDENTIFYING A MENTOR
- COMMUNICATION AND LISTENING SKILLS
- ASKING FOR INPUT
- WATCHING THE JARGON
WHAT A PARENT IS NOT

• REPLACEMENT CLERICAL HELP

• EXPECTED TO VOLUNTEER

• YOUR ONLY PUBLIC RELATIONS PERSON
LETS GET PRACTICAL; TIME AND $

• QI TEAMS: 1-2 meetings/month?

• What do you want them to do in your practice?

• What and how do I pay them?

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Discussion
What can you do...

...to actively elicit patient concerns?

...to learn from families about their experiences of care?

...share data with your families/patients and ask them about how we can improve?

...to use family feedback to drive quality improvement in your practice?
**PDSA Ideas**

- **Engage families and/or youth**
  - Enlist two parent partners for QI team
    - Support their time in some manner
    - Try to insure at least one can attend QI team meetings
  - Hold a focus group of 6 to 8 parents
    - Generic or specific (parents of children with ADHD)
    - Consider a youth/young adult focus group
  - Create a Parent Advisory Group
    - Give them a table or bulletin board in the waiting room
    - Ask representative to report regularly to staff meeting
  - Survey some families about their needs/your care
    - Formal survey – CAHPS, etc
    - Mini-surveys on topics of interest – “Do you know about our care coordinator?”

Adapted from Cooley, W.C. (2012, June). Care coordination – Assuring a family-centered approach [PowerPoint Slides].
The Coming Months: Action Periods 2-3

- **October**
  - Site visit and continued contact with practice facilitators
  - Workgroup Call
  - Continued work on PDSA cycles, change implementation
  - Monthly Narrative

- **November**
  - **Pre-Meeting Worksheet**
  - Learning Session #3 (November 10) *Behavioral Health Integration*
  - Site visit and continued contact with practice facilitators
  - Workgroup Call
  - Continue work on PDSA cycles, change implementation
  - Monthly Narrative
Questions?

Thanks from your ECHO Team

Do not hesitate to contact your practice facilitator (or any of us) with any questions or concerns.

PLEASE COMPLETE THE POST CALL SURVEY