



PARENTS AS PARTNERS IN QUALITY IMPROVEMENT: NIPN All Sites Call – December 20, 2012

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Maxims of Patient Centered Care

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

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

Parents as Partners: Within OPIP

1. IP/Organization Level
2. Project-Level
3. Practice-Level
 - ▣ Practices we work with on QI Projects

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Parents as Partners: At the OPIP Organization Level

1. Mission statement
2. Executive Committee/Steering Committee



Parents as Partners: At the OPIP Organization Level

OPIP Mission:

The Oregon Pediatric Improvement Partnership is a public/private partnership dedicated to building health and improving outcomes for children and youth by:

1. Collaborating in quality measurement and improvement activities across the state,
2. Supporting evidence-guided quality activities in clinical practices,
3. **Incorporating the patient and family voice into quality efforts, and**
4. Informing policies that support optimal health and development for all children and youth.

Parents as Partners: At the OPIP Organization Level

Executive Committee/Steering Committee

- At the beginning:
 - Recruited family advocacy group: Family Voices
 - Oregon Center for Children and Youth with Special Health Care Needs (OCCYSHN) Director. (Title V)
- As we evolve:
 - Hired a parent to consult/advise us overall and on specific projects
 - She will be joining our steering committee Partnership
 - Considering adding a parent who has gone through the OCCYSHN Lend Training
 - LEND =Leadership Education in Neurodevelopmental and Related Disabilities (LEND); Funded by the Maternal and Child Health Bureau
 - Sits within our local Title V

Parents as Partners: At the Project-Level

1. Membership on Project Team
2. Faculty to the Learning Curriculum
3. Part of community engagement about needs

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Parents as Partners: At the Project-Level

- Added a PAID Parent Partner to the Medical Home Project Team
 - Contracted for up to 15 hours per month
 - Attends the project team meetings, group meetings with the practices and in-person learning sessions
 - Reviews and provides feedback on QI tools practices are using
 - Shared care plans
 - Patient information about medical home
- Partnership with our Title V/Family Voices was essential
 - Helped with structuring and reviewing contract
 - Example: Compensation- consider situational context
 - Parents with special needs children may need specialized childcare to participate in meetings etc. They should feel like they are still a paid member of the team, not just that they break-even with costs
 - Helped with advising us on on-boarding and orientation process
 - Had previously worked with/trained parent we ended up hiring

Parents as Partners: At the Project-Level

- Faculty to Learning Curriculum
 - Input on the curriculum overall and topics of high-value to families
 - Learning Sessions
 - Parents serve as our key note for each of the learning sessions
 - Presentations anchored to goals/objectives of the meeting
 - Prepare parents beforehand about the audience, goals for the meeting
 - Presentations highlight their personal stories AND suggestions for solutions that are feasible
 - Monthly conference calls with the sites
 - Focused a whole call with practices on how they can/should engage parents. (Happy to share presentation with other IPs)

Parents as Partners: At the Project-Level

Part of community engagement about needs:

- Convened parents in “community cafes” to give us ideas to help shape the improvement project
- As the project formulated, went back to the parents to get their insight and input

Parents as Partners: At the Practice-Level

- Strongly encouraging parent engagement and participation at the practice-level
- Practices we work with on QI Projects

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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 – Patients are a member of the team**
 - 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].

Types of Parent Engagement Practices Can Use

- Engagement of families input to QI process
 - **Parents on QI teams**
 - Encouraged in 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

Parents As Partners in Practice-Level QI

- Quality improvement team members
 - ▣ satisfaction surveys
 - ▣ screeners
 - ▣ work flow changes/planning
 - ▣ review publications
 - ▣ help recruit new families
 - ▣ cultural activities
 - ▣ follow up with plans of care
- Help with non-medical care coordination
- Public relations

Adapted from Barnes, S. (2012, October). *Parents as Partners in Medical Homes* [PowerPoint Slides].

What Parents Are NOT

- ❑ Replacement clerical help
- ❑ Expected to volunteer
- ❑ Your only public relations person



Adapted from Barnes, S. (2012, October). *Parents as Partners in Medical Homes* [PowerPoint Slides].

Parents as Partners in QI at the Practice-Level: Oregon Medical Home Practices Engagement of Families

A start.....

- Woodburn Pediatrics
 - ▣ Focus group of families to inform medical home efforts
 - ▣ Recruited Hispanic/Latino families
- Family input: Reviewed and gave input on:
 - ▣ Medical home brochure
 - ▣ Shared Care Plans

Parents as Partners in QI at the Practice-Level: Some Preliminary Learnings from OPIP

- Important of framing expectations
 - ▣ In the contracts we encouraged parent partners, but we didn't require it
 - ▣ In the future, we plan on requiring it as part of the work of the project
- Culture Shift to Involve Parents/Youth that requires time
 - ▣ Amongst all the other things, feels like the practices feel like this is a lot of work
 - ▣ Great resource!!!!!!!!!!!!!!: "Parent Partners, Creative Forces on Medical Home Improvement Teams", Ann Donoghue Dillon, 2003, Center for Medical Home Improvement.
 - ▣ <http://www.medicalhomeimprovement.org/pdf/CMHI-Parent-Partner-Guide.pdf>
- That said, when parents/youth are engaged, incredibly valuable

Questions?

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