Families as Partners – From Idea to Reality

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Learning Objectives

By the end of this session, participants will be able to:

• Describe a methodology for enhancing family engagement in pediatric primary care.
• Identify tools and resources Title V programs and others can utilize to enhance family engagement in pediatric practice.
• Discuss one test of change for improving family engagement.
Agenda

• Overview and History
• Project Methodology
• Results and Lessons Learned
• Tools and Resources
• Interactive Participant Time
National Center for Medical Home Implementation (NCMHI)

- Works to ensure that all children and youth have a medical home
- Collaborates with federal, state, and other agencies/stakeholders
- Adapts and responds to new and emerging issues in health care, public policy, and technology
Family Engagement

An innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.
Why Family Engagement?

• 2001 Institute of Medicine report presents evidence to support family engagement in clinical practice

• Only 67% of families indicated that their child received family-centered care (2011/2012)

• 54% of families indicated that their child received care within a coordinated, comprehensive medical home (2011/2012)
Overview and History

Family-Centered Care Pilot Project → Family-Centered Care QI Project, Phase 1 → Family Engagement QI Project, Phase 2
Project Methodology

- Utilized the Institute for Healthcare Improvement Learning Collaborative and Web&ACTION Models
- Each team tested small changes within their practice
- Multidisciplinary core improvement team with parent/caregiver partner
Project Aim

Over a 6 month Action Period, 10 pediatric primary care practice teams will work individually and collaboratively to test, implement, disseminate, and plan to sustain strategies that lead to improved family engagement in clinical practice through enhanced shared decision-making and connection of families to appropriate supports and services.
Project Measures

• 6 Medical Record Review Measures
• 6 Family Survey Measures
• Focus on:
  • Shared decision-making
  • Care planning
  • Family strengths
  • Communication
  • Trust, dignity, and respect
Post Visit Family Survey

1. Did you feel like you could be honest with your child’s doctors and nurses about the choices you make for your child?

2. Did our doctors and nurses explain things about your child’s health in a way that was easy to understand?

3. Did our doctors and nurses listen to what you and your family had to say?
4. Did our doctors and nurses give thoughtful responses to your questions and concerns?
5. Did our receptionists and other clinic staff treat you and your family with respect?
6. Did our doctors and nurses involve you and your family in decisions about your child's health?
Interventions

- 2 in-person learning sessions
- Change package
- Monthly webinars
- Quality improvement coaching calls
- Peer support initiative
- Parent/Caregiver partner calls
- Monthly mailers
Parent/Caregiver Partners

• Members of the core improvement team
• Supported by:
  • job description
  • monthly webinars
  • quality improvement coaching calls
  • facilitated discussions with a family leader (expert group member)
  • parent/caregiver panel discussion
Data Collection and Evaluation

- Pre/post implementation survey
- Family Surveys
- Medical Record Reviews
- Monthly Progress Reports
- Qualitative Telephone Interviews
## Results: Medical Record Reviews

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Action Period 6</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elicit patient/family concerns</td>
<td>83.6</td>
<td>83.9</td>
<td>+0.6</td>
</tr>
<tr>
<td>Address patient/family concerns</td>
<td>94.2</td>
<td>92.5</td>
<td>-1.7</td>
</tr>
<tr>
<td>Identify and discuss family strengths</td>
<td>37.6</td>
<td>57.0</td>
<td>+19.4</td>
</tr>
<tr>
<td>Medical summary or care plan created</td>
<td>96.4</td>
<td>90.3</td>
<td>-6.1</td>
</tr>
<tr>
<td>Medical summary or care plan reviewed and offered to patient/family</td>
<td>54.1</td>
<td>74.7</td>
<td>+20.6</td>
</tr>
<tr>
<td>Communication of age-appropriate screening results with families</td>
<td>63.0</td>
<td>88.2</td>
<td>+25.2</td>
</tr>
</tbody>
</table>
## Results: Family Surveys

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Action Period 6</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Families can be honest with the child’s clinicians about choices they make for their child</td>
<td>98.2</td>
<td>100</td>
<td>+1.8</td>
</tr>
<tr>
<td>Provider/clinician listens to what the family has to say</td>
<td>98.2</td>
<td>100</td>
<td>+1.8</td>
</tr>
<tr>
<td>Clinic staff treat family with dignity and respect</td>
<td>99.1</td>
<td>97.8</td>
<td>-1.3</td>
</tr>
<tr>
<td>Provider/clinician explained things about the child’s health that was easy for the family to understand</td>
<td>97.3</td>
<td>98.9</td>
<td>+1.6</td>
</tr>
<tr>
<td>Provider/clinician gave thoughtful responses to family concerns</td>
<td>97.3</td>
<td>100</td>
<td>+2.7</td>
</tr>
<tr>
<td>Provider/clinician involved family in decision about child’s health</td>
<td>96.5</td>
<td>97.7</td>
<td>+1.2</td>
</tr>
</tbody>
</table>
Successes: 
Focus on Innovative Partnerships

- Parent/caregiver partners
- Multidisciplinary teams
- Lunch and learns
- “Open house”
- Community connections
- Social determinants of health
- Family advisory councils
From the teams...

“I had no idea how many areas of the practice, and how much we did, could benefit from the family engagement process.”

“Engaging families equals better outcomes and more education for everyone involved. As patients become invested we have noticed less ‘no show’ or late cancel/late patient instances which in turn improves quality of care.”
Challenges

• Understanding quality improvement
• Scale-up and spread
• “Survey burnout”
• Parent/caregiver partners
• Care planning
• Family strengths
• Documentation
• Lack of time
Lessons Learned

- Family engagement is a continuum
- Practices are beyond the “What” and “Why,” want to focus on “How”
- Parent/caregiver partners are important, but clear roles and responsibilities crucial to success
- Small changes are key to success
- Quality improvement methodology takes time to learn and implement
- Innovative strategies to meet as a team
Strategies for Title V

- Acknowledge that family engagement is a continuum
- Raise awareness about Title V; many practices unaware of potential partnerships
- Parent/caregiver partners crucial; recognize challenges, provide job descriptions and expectations
- Family feedback crucial; surveys may not be the best strategy, what are some alternatives?
- Encourage small tests of change
- Incentives are important for practices and families
Next Steps

• Qualitative interviews
• Encourage sustainability; connect practices to Title V, AAP chapters, F2F HIC
• Family Engagement QI Project Tool box
• Webinar series
• Manuscript development
• How else can we help Title V programs?
Tools and Resources

- Change package
- Sample Plan-Do-Study-Act cycles
- Project aims and measures
- Parent/caregiver partner “Job Description”
- Family engagement continuum
Table Top Exercise

• Break into small groups
• Designate someone as a note-taker and someone to report out
• Which of the family engagement strategies ("Tests of change") discussed during this presentation would you be interested in testing within your own organization?
• How can state Title V agencies support practices in implementing these strategies?
• Report out to the full group
Questions?

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