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

A webinars 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

Achieving True Partnership: Integrating Family Engagement in Systems of Care
Tuesday, June 20, 2017
1-2pm Central

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Achieving True Partnership: Integrating Family Engagement in Systems of Care

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Moderator:
Deborah Garneau, MA
Co-Director, Health Equity Institute
Title V Director
Rhode Island Department of Health
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
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• 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 systems level.
- Identify practical strategies and tools that encourage and measure family engagement at the systems level, including partnerships between Title V programs, state AAP Chapters, and Family-to-Family Health Information Centers.
- Describe evidence-based and evidence-informed practices for family engagement at the systems level.
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:
Cornelia Deagle, PhD, MSPH
Director, Division of Child and Family Health
MCH/ Title V Director, Virginia Department of Health
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Faculty:
Barbara Kahler, MD, FAAP
General Pediatrician
Bon Secours Kilmarnock Pediatrics
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Faculty:
Dana Yarbrough
Parent Partner
Center for Family Involvement
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Faculty:
Marcus C Allen, MPH
Children and Youth with Special Health Care Needs Program
Virginia Department of Health
Welcome to Virginia
Barb’s Perspective
• Clinical focus
• Previous attempts to incorporate Bright Futures
• AAP Chapter interest
  • Key goal in AAP Presidency

Cornelia’s Perspective
• Public health focus
• Title V transformation goals
• Strong clinical support in public health
  • Foundation already existed

***Shared goals, but working on parallel tracks***
## Why We Applied

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<th>Why We Applied</th>
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<td>• Multidisciplinary and diverse team approach (clinical and non-clinical)</td>
<td>• Monetary stipend (and technical assistance) to kick start reconnection among partners</td>
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<td>• Family representative on leadership team was valued and integral</td>
<td>• Reinforced value of data collection and improving the system(s)</td>
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<td>• Designed with clear and practical goals and objectives</td>
<td>• Plan, do, study, act cycles gave practices opportunity to fine tune improvements</td>
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<td>• Provided framework to build and strengthen – Practice team &amp; Chapter leadership team</td>
<td>• Opportunity to broaden perspectives and have community partners work directly with AAP Chapter</td>
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<td>• Added more bricks to foundation of the medical neighborhood</td>
<td>• Opportunity to identify gaps in the system at all levels (clinical, public health, state, family)</td>
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Medical neighborhood

- Maternal and Child Health Workforce Development Center project
- Background/support (technical assistance, etc.)
- Embraced and highlighted the importance of family participation/family representation
  - Family rep came up with term “medical neighborhood”
Alignment and synergy

- Bright Futures Preventive Services Improvement State Spread Project (PreSIPS2) & medical neighborhood initiatives naturally fit together
- PreSIPS2 goals align strongly with the Title V MCH transformation goals
- Both projects reconfirmed they are stronger together
Lessons Learned

• Shared project can rebuild connections
• Family representative is integral
  • Noticed gaps we were blind to see
• Importance of financial support
  • Look for in-kind support to minimize expenses
• Plan, do, study, act cycles allow small improvements/successes – manageable
• Data agreement can be a tough barrier
Foundation: Families are important subject matter experts

- Experience is often the “best” teacher
- Recognize *wisdom* versus *knowledge*
- All voices are important – the best scenario is inclusive
  - Families and health professionals
  - Specialists and generalists
  - Multi-disciplines represented
- It takes time... be patient with each other
Partner shared philosophies for engaging families

- Importance of enhancing connections in an effort to increase positive outcomes for children with special health care needs
  - Within families
  - Between families and their communities
  - Between families and the systems that serve them
Partner shared philosophies for engaging families

• This takes
  • Engaging in dialogue with families
  • Committing resources
  • Connecting parents with other parents
  • Training parents for leadership
  • Facilitating connection and collaboration across the child’s various service systems
Partner shared philosophies for engaging families

- Use conversations with families as an opportunity to hear and listen rather than to tell and report
Partner shared philosophies for engaging families

Family involvement is a process, not just a set of activities

- Induction
- Integration
- Investment
Brought partners to the table to plan

- American Academy of Pediatrics, Virginia Chapter
- Family to Family Health Information Center
- Title V, Virginia Department of Health
Honed our vision based on family input
Solidified family role on team
Committed to understanding how families enter into relationships with clinicians

We need to appreciate

- How each parent takes in information
- What and who their trusted resources are
- What factors most impact their decision-making
Acknowledged things we cannot change

- Parent socio-economic status
- Number of children with disabilities
- Cultural beliefs
And the things we can change

- Knowledge
- Behaviors
- Beliefs
As well as things we can change between parents and clinicians

- Collaboration
- Communication
- Partnering
AAP involvement with Medical Neighborhood
  - Prioritizes family perspectives
  - Goal: make broad population health based changes involving communities/families
Currently focused on promoting importance of medical home and transition
  - Alignment with PreSIIPS2
Interconnectivity of programs
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

Family Voices, National Center for Family Professional Partnerships

• Family Leadership and Building Partnership Training Opportunities

• Family Professional Partnerships: What is FPP and how do families partner to improve care for CYSHCN?

• Partnering with Title V: Link to webinars and tip sheets on partnering opportunities

• Family to Family Health Information Centers Data Report: Learn about the roles of F2F HIC’s in every state and DC

• National Center for Family Professional Partnerships: Use the map on the home page to locate the F2F HIC in your state
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
  - Bright Futures Webinars

Visit brightfutures.aap.org for more information
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