

Incorporating Family Participation Practices Into Your Practice and Project

AAP Medical Home Implementation
CME Series #5

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A Program of the Federal Maternal
and Child Health Bureau in Cooperation
With the American Academy of Pediatrics



**NATIONAL CENTER FOR
MEDICAL HOME
IMPLEMENTATION**

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



**Bright
Futures™**



Presenters

Margaret Ruane, MEd

Parent Partner at Kids First Highpoint

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Bright Futures & Medical Home

Medical home is the standard of primary care for all children in which a pediatrician, in partnership with the family, works with appropriate systems and resources in the community for the optimal health of the child.



Bright Futures & Medical Home

- Bright Futures is the Health Promotion and the Preventive Services Arm of Medical Home.
- The mission of Bright Futures is to promote and improve the health, education, and well-being of infants, children, adolescents, families, and communities.





Family Perspective

Margaret Ruane, MEd
Parent Partner at Kids First
Highpoint



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- I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.



Family Perspective

- Background/Our story
- Why families need support
- How to become involved as a parent partner
- What practices can do to involve parents





Maggie Ruane

- Parent Partner at Kids First Highpoint, Chalfont, PA
- Parent of three sons
- Special education teacher in NJ (previously worked for Parent Training and Information Organization in PA)
- Twins were born prematurely following complications from Twin-to-Twin Transfusion Syndrome



Joseph and Timothy

- Born ten weeks early
- Stayed for two months in the NICU
- Following NICU stay, had subsequent hospitalizations and surgeries
- Had significant reflux, asthma, eating difficulties, and growth problems
- Visited numerous specialists
- Received early intervention services

Joey and Timmy Today

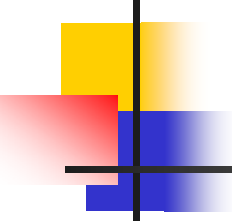
- Both boys are in 4th grade
- Both boys enjoy sports and other activities
- Timmy is eating more, but continues to receive nutritional support





Why Families Need Support

- Limited time to coordinate care
- Juggling medical care, insurance coverage issues, therapy schedules, and education issues
- Often isolated from others or experience personal stress
- One parent is often required to leave his/her job to coordinate the care of the child

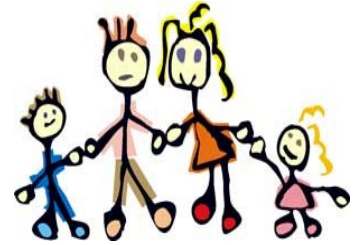


How I became involved as a Parent Partner:

- Tried to be proactive in my children's care
- Felt empathetic toward other parents experiencing similar issues
- Eager to "pay it forward"
- Approached by staff to join the Parent Partner team
- Looking for opportunities to network with other families
- Recognized the advantages for both parents and pediatric staff



How to Involve Families



- Invite families to meetings that involve idea sharing and resource sharing
- Invite families to support other parents through phone calls or support groups
- Share news of what is happening at the practice and around the community
- Ask families to forward news and events happening at local groups or organizations

How to Involve Families



- Ask families to spread the word about Medical Homes to other families and organizations
- Ask families to participate in panel discussions with healthcare and service providers to help everyone understand family needs
- Have families be present at resource fairs to offer support to attendees
- Invite families to Medical Home conferences that develop the skills of families to become leaders

How to Keep Families Involved

- Continue to recognize the expertise of parents and caregivers
- Meet at times convenient for working families and, if possible, offer child care
- Demonstrate your appreciation for family involvement



Pennsylvania Medical Home Initiative

Educating Practices in Community Integrated Care

Renee Turchi, MD, MPH, Director



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Overview

- What is family centered care in a medical home
- Engaging parents and caregivers
- Maintaining and sustaining family participation
- Parent Partners as Leaders

Family Centered Care in a Medical Home



What is Patient/Family Centered Care?

- Dignity & Respect
- Information Sharing
- Participation
- Collaboration

Institute for Family Centered Care, 2008



Family Centered Care

- Core element of Medical home
- “..assures health and well being of children and their families through respectful family professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to the table”

Bishop, Wall, Arango, 2002-04



Mission Statement:

PA Medical Home Program

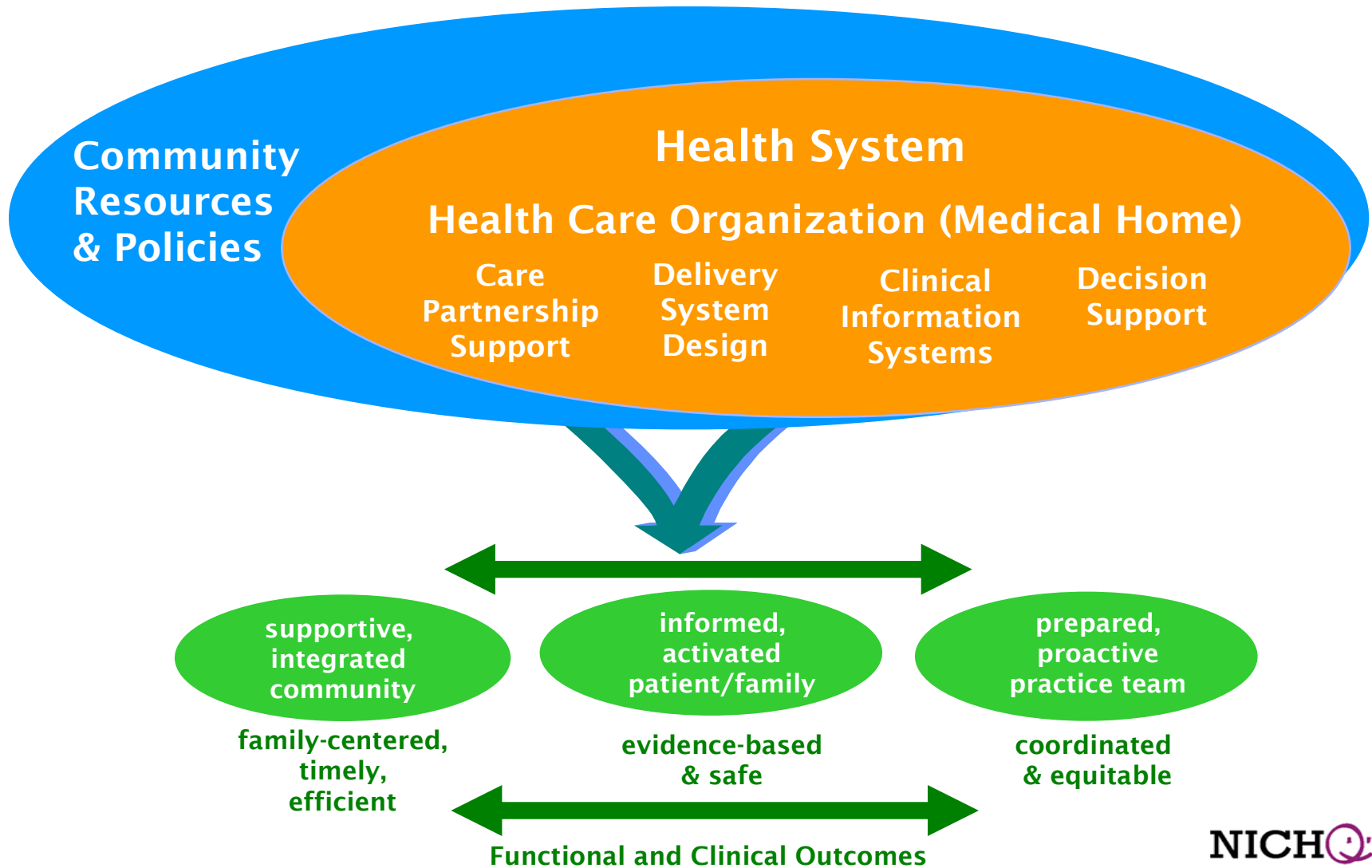
To enhance the quality of life for CYSHCN through recognition and support of families as the central caregiver for their children, effective community-based coordination, enhanced communication and improved primary health care.



What is the PA Medical Home Program?

- Quality improvement initiative - 2001
- Work with pediatric practices to implement Medical Home and practice redesign
- Data Collection and Management
- Site visits/Technical Assistance

Care Model for Child Health in a Medical Home





Different Priorities

Parents	Physicians	Rank of Service
9	1	Respite Care
21	2	Day Care
3	3	Parent Support Groups
10	4	Help with Behavior Problems
2	5	Financial information or help
20	6	After-school child care
15	7	Assistance with physical household changes
6	8	Vcational counseling
5	9	Psychological services
22	10	Homemaker services
4	13	Recreational opportunities
1	14	Information about community resources

-Liptak et al. *Pediatrics*, 1989.

Engaging and Maintaining Parent Partners





Why Parent Partners?

- Fosters understanding and cooperation
- Promotes respectful, effective, partnerships
- Results in efficient planning to ensure services meet family needs
- Provides effective mechanism for receiving consumer input

Most importantly.....

- Parents are experts in their child's care

How to Choose a Parent Partner



- Parents who have:
 - experienced various systems of care
 - a desire to help other parents navigate systems of care
 - a child without a recent diagnosis
 - good communication skills – especially listening
 - a sense of cultural and linguistic competence
 - team building attributes



Engaging Parent Partners

Focus Groups

- Invite 10-12 parents
- Provide food, parking, child care reimbursement
- Medical home concept and role of FCC
- Expectations
- Discuss positive aspects of practice and areas for growth
- Examples include scheduling, referral processing, telephone call backs, on-call protocols, office visits



Maintaining and Sustaining Parent Involvement

- Avoid tokenism
- At least 2-3 parents per practice
- Varying age and diagnosis of CYSHCN
- Contract
- Invite to staff meetings
- Family Faculty
- Family Advisory Council

Challenges for Practices

- Fear of practice in receiving feedback
- “Can we fix things?”
- Time commitment for parents
- Changing needs
- Family obligations and needs of child
- Transition



Examples of Impact of Parent Partners





Positive Feedback

- Referral process
- Care plan components
- Bulletin boards
- Parent catalyst for quality improvement



Models that have worked...

- Resource Nights
- Suggestion boxes
- Practice visits and resource highlight
- Patient care conference
- Positive feedback
- Newsletters
- Parent to Parent Resource
- Information



Parents as Leaders

- Work with other parents
- Valued team member
- Reimbursement
- Presentations and conferences
- “Nothing about us, without us”
- Family to Family Health Information Systems, Parent to Parent, other Advocacy Groups
- Leadership training

www.pamedicalhome.org

Pennsylvania
Medical Home Initiative



EPIC IC

Educating Practices in
Community-Integrated Care



Parents & Caregivers
START HERE



Medical Practices
START HERE

A Medical Home is not a building,
a house, or a hospital...

...it is an approach to health care
that emphasizes the partnership between
pediatric clinicians and families,
providing care for children and
youth with special health care needs
(CYSHCN) that is:

- accessible
- continuous
- comprehensive
- family-centered
- coordinated
- compassionate, and
- culturally-effective

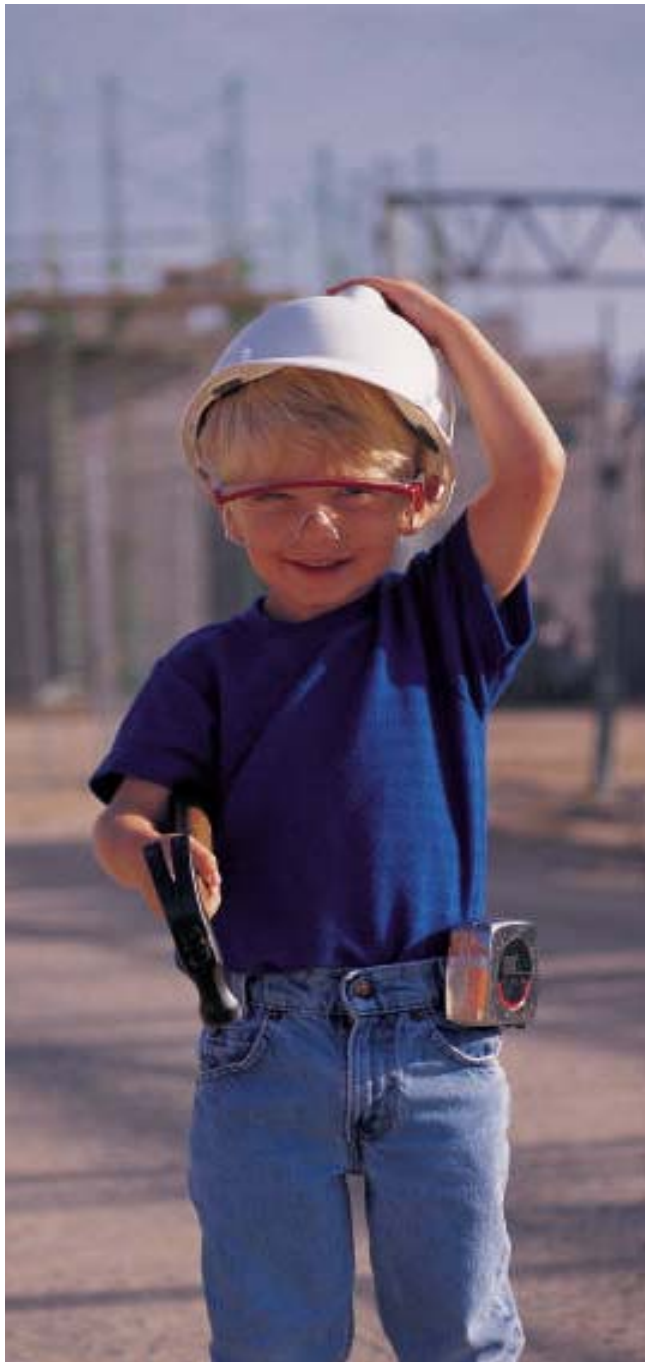


Especially for Parents

- “Especially for Parents” is a Web 2.0 application, designed to increase in value as the size of the community and activity level increases.
- Launched in September 2008.
- The website operates under the premise that parents are experts and have valuable insights and information to share knowledge and offer support.
- Members are able to start a discussion, share tips, tricks and shortcuts, offer support to others, write a blog, create a group for parents with similar interests or situations, create a virtual meeting spot for a local community group, promote events and invite friends to join the web community.



- Anyone can use the social networking site, including parents outside of Pennsylvania!
- Visit us by going to www.pamedicalhome.org and clicking on the parents button.



Pennsylvania Medical Home Initiative



A statewide quality improvement initiative for children and youth with special health care needs

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Program Planning & Implementation

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™

Pennsylvania Chapter

DEPARTMENT OF
HEALTH

U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration
Maternal and Child Health Bureau

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Thank you

- Grant support
 - Maternal Child Health Bureau (MCHB):H02MC04133
 - PA Department of Health SAP # 4100023019
- PA Chapter, American Academy of Pediatrics
- Pediatric practices in EPIC IC
- Children and families



TeenScreen Program for Fond du Lac Youth

Marian Sheridan, Project Director



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School-community partnership

- Parent and adolescent centered program
- Addressed a gap in our schools and community
- TeenScreen provides an emotional health screening designed to find risk factors and mental health concerns



Mental Illness and U.S. Teens

- 11% of U.S. children and adolescents suffer from a serious mental disorder that causes significant functional impairment at home, in school and with peers.¹
- 80% of mentally ill youth are not identified and do not receive mental health services.
- Half of all mood, anxiety, impulse-control and substance-use disorders start by age 14.²

¹ Mental Health: A Report of the Surgeon General (1999).

² Kessler et al., 2005.



Why Screen for Mental Illness and Suicide Risk?

- Suicide is the third leading cause of death for 11-18 year-olds.¹
- Up to 20% of youth experience mental, emotional or behavioral disorders at any given time.
- Mental illness is treatable.
- There is ample time to intervene before a teen dies by suicide.
- No one else is asking teens these questions.
- They will give us the answers IF we ask the questions.



How TeenScreen Works

- Targets 9th grade students
- Uses active parental consent – student and parents must both give permission
- 10 Minute - Computerized interview – Diagnostic Predictive Scales (DPS)
- All students/patients are debriefed after taking screen
- Students that score positive on the DPS receive a clinical interview with mental health specialist
- Referrals for further evaluation may result



Screening – Referrals – Follow-up

- Active permission (in school & primary setting)
 - Buy in from the beginning
 - More receptive to referrals
- Nurse case-managers
 - Releases signed and matching services with insurance
 - Follow-up for 3 visits
 - Provide support services for parents
- Parent Survey



Parent Survey

- Primary problems and services received
- Medications
- Appointments/hospitalization
- Was participation pos/neg/neutral experience for your family
- Comments/willing to share/involved



2007-2008 Parent Survey Results (of students referred for services)

- 80 parents participated in the survey
- 18% of parents were not aware that their child was experiencing difficulties before TeenScreen
- Students:
 - 51% referred for depression
 - 29% referred for anxiety
 - 15% referred for suicide ideation
- 74% scheduled & kept 1st appointment



Parent Participation

- Parent serving on advisory board
- “A mother’s story”
- School newsletters
- Letter from Primary Care Site
- Presentations at schools
- Media and marketing plans



Parent Involvement – Impact to Program

- Outreach
- Increase participation
- Improves the “message”
- Program improvement
- Parent to parent communication



Resources

Bright Futures: Promoting Family Support:

http://brightfutures.aap.org/bright_futures_power_point_presentations.html

Family Voices: The Family-Centered Care Self-Assessment Tools (includes Provider Tool and Family Tool): www.familyvoices.org/catalog.php

Family Voices & Bright Futures: Partnership with Families:

http://brightfutures.aap.org/Family_Resources.html

PA Medical Home: Parent & Caregiver social networking site:

www.pamedicalhome.org

The TeenScreen National Center for Mental Health Checkups:

www.teenscreen.org (email: MentalHealthCheckups@childpsych.columbia.edu)

National Center for Medical Home Initiatives for Children With Special Needs: Tools for Families: www.medicalhomeinfo.org/tools/familyindex.html

AAP Community Pediatrics: Family Participation Resources:

www.aap.org/commpeds/resources/family_participation.htm



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QUESTIONS???

Please type your questions into
the question pane