FAMILY ENGAGEMENT GUIDE

The Role of Family Health Partners in Quality Improvement Within a Pediatric Medical Home

NICHQ
National Institute for Children's Health Quality

CONTENTS

INTRODUCTION

In this chapter:

This Family Engagement Guide provides direction on how to effectively engage family perspectives in a pediatric practice. We've designed this guide to help your practice work with families as improvement partners. It is our intention that this guide will be responsive to both the needs of the practice and the needs of patients and families. We welcome you to explore these ideas and resources and we wish you success in increasing family engagement within your medical home.

What is a medical home?

A **medical home** is not a physical building or care provided in a patient's home, but rather a way to provide comprehensive primary healthcare. It's a model of care that is patient- and family-centered, **culturally effective** and includes coordination of care across healthcare and community settings, **continuity of care** and patient education.

A pediatric medical home is a primary healthcare practice that provides continuous care from childhood through adolescence while facilitating a smooth transition to adult services for all children and youth, including those with special healthcare needs.

These patient- and family-centered medical homes (also known as PFCMHs) encourage a cooperative partnership between doctors, nurses, other medical staff and the patients' families to provide the best care possible for children. This healthcare team, which includes the patient and family, develops a trusting relationship and makes decisions about the child's healthcare together, working toward meeting the needs of the child and family.

Along with providing direct medical care for the child, the healthcare team partners with the patient and family to access and coordinate specialty healthcare, educational services, out-of-home care, family supports and other community resources and programs that are important to the overall health of the child and family.

INTRODUCTION

FOR MORE GUIDANCE ON MEDICAL HOME ACTIVITIES, VISIT STEP 3 OF THIS GUIDE.

In summary, primary health practices committed to transforming into a medical home:

- Support quality improvement throughout the practice
- Provide patient- and family-centered care
- Include families as improvement partners working within the healthcare practice
- Offer team-based healthcare that includes doctors and medical staff along with patients and families
- Improve care coordination

Role of Family Health Partners in a medical home

One way to demonstrate family-centered care and authentic partnership in a pediatric medical home is to invite families as experts and consumers to assist with evaluating, planning and improving your practice. Family Health Partners can play an integral role in a pediatric healthcare practice's transformation into a medical home and in its continuous quality improvement. Informed by their experience as caregivers and consumers, Family Health Partners provide valuable family perspective to pediatric providers and the healthcare team.

Effective Family Health Partners provide honest feedback, regularly participate in practice improvement activities, generalize their personal experience to benefit all practice patients, are open to new perspectives and respect differing points of view.

The title Family Health Partner may be new to you, but the work they do may already be familiar. Family involvement in healthcare has been known by many names: Parent Resource Specialist, Family Advisor, Parent Representative, Family Partner, etc. We elected Family Health Partners to acknowledge the collaborative role of caregivers in a medical care setting.

Further exploration of how Family Health Partners contribute to medical home quality improvement continues in this guide in Step 1: Examine the role and benefits of Family Health Partners.

INTRODUCTION

CHIPRA Massachusetts Medical Home Learning Collaborative

The National Institute for Children's Health Quality (NICHQ) has successfully worked with 13 pediatric practice teams, each of which included Family Health Partners, focused on improving child health at the practice, larger organization and system levels. Visit **NICHQ**, a project partner in the Massachusetts Children's Health Insurance Program Reauthorization Act (MA CHIPRA) Quality Demonstration Grant, to learn about best practices from this medical home learning collaborative.

How to use this guide

This guide was created as an in-depth exploration of family involvement in quality improvement within pediatric medical home practices. Some guide users may choose to approach it sequentially, as a step-by-step process to increase their understanding and knowledge of building family engagement within their pediatric practice. Others may only need specific elements or certain steps to advance their practice's partnership with families. We invite all users to approach the guide in the way that best meets their practice's individual needs.

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This guide is a product of Mass Family Voices, a project at the Federation for Children with Special Needs and the National Institute for Children's Health Quality (NICHQ). Together, we leveraged the extensive experiences of family members who regularly support other families and pediatric medical home improvement teams that worked hard to successfully engage families. This guide is the result of peer-to-peer efforts to inform interested families, medical professionals and practice staff of practical ways to ensure that medical services are high quality and family-driven.

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STEP ONE

EXAMINE THE ROLE AND BENEFITS OF FAMILY HEALTH PARTNERS

In this chapter:

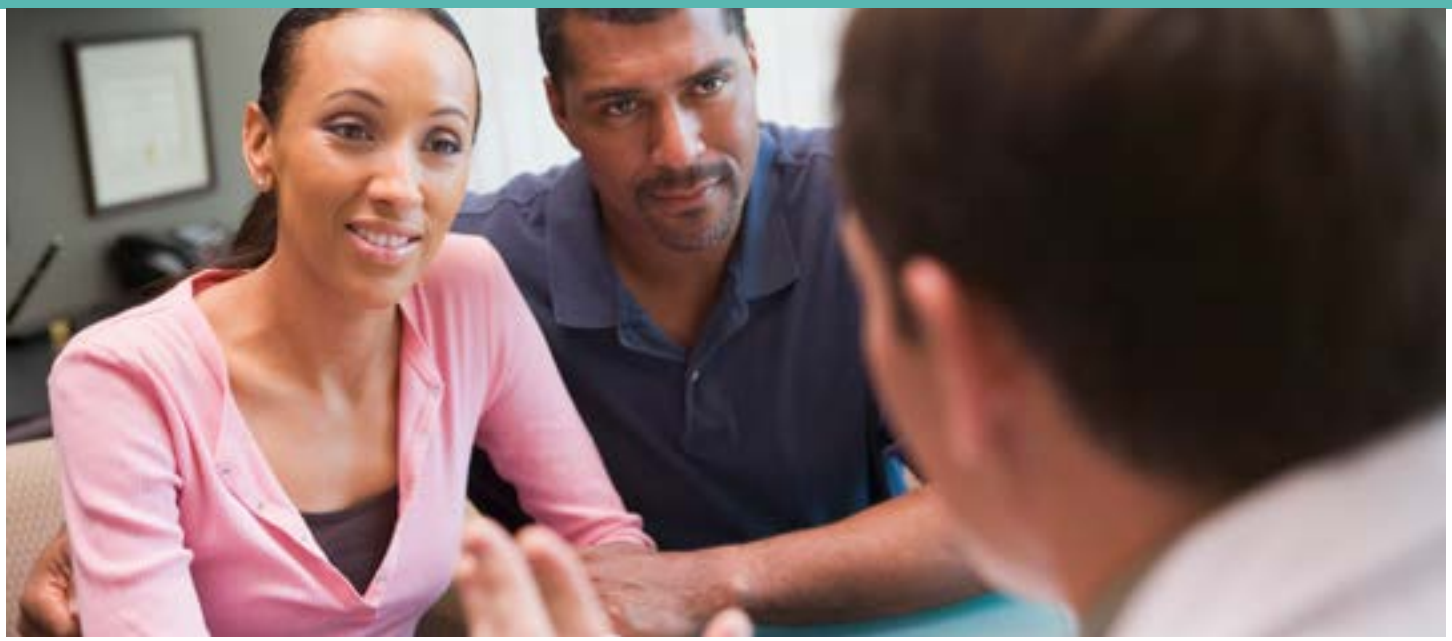
As pediatric practices begin or deepen their commitment to patient- and family-centered medical homes, they foster transformation by creating a quality improvement team of doctors and other practice staff.

This team will identify areas of the practice in need of change or innovation, select a method for testing change and work toward applying proven strategies.

Including Family Health Partners in a practice quality improvement team requires thoughtful consideration of how they will be utilized by the medical home within the quality improvement process. It can be beneficial to recognize what motivates and rewards families who participate in medical homes and improvement activities. Equally important are the benefits that practice providers and staff experience when working collaboratively with families.

Along with a willingness to participate, families also bring their own skills and strengths that contribute to the effectiveness of quality improvement teams. Later in this section, we've identified what attributes are helpful and the activities that Family Health Partners can perform within a patient- and family-centered medical home.

STEP ONE EXAMINE THE ROLE AND BENEFITS OF FAMILY HEALTH PARTNERS



How families benefit from partnering in the medical home

When families meaningfully participate in their medical home, they develop an appreciation for the larger impact their input has not only for their family, but also for all the children and families in the practice. Many Family Health Partners report it feels good to "give back" to care providers who have supported their families, and they are proud to contribute to improvements that can lead to better health outcomes for all children.

Families participating in quality improvement within the pediatric medical home report feeling rewarded by these additional benefits:

- Having opportunities to bring about meaningful changes to the practice
- Having opportunities to network with and share information with other parents
- Learning that their "lived experience" is an important perspective when designing delivery of care
- Developing collaborative relationships with providers
- Learning new skills and expanding knowledge of medical care
- Developing relationships with other Family Health Partners
- Being acknowledged as a valuable contributor in improvement team discussions

STEP ONE EXAMINE THE ROLE AND BENEFITS OF FAMILY HEALTH PARTNERS

"Having parents there while we're brainstorming, they'll bring up different scenarios they've encountered, and that certainly helps our clinical team change the way we think about something. It's a benefit to have a parent in the room while we're in a meeting, speaking with us directly about what we're focused on."

Maria Mignone, RN, Pediatric Associates of Greater Salem

How healthcare professionals benefit from partnering with families

As part of a patient- and family-centered medical home team, families provide ongoing feedback on their experience to the practice providers and staff. They are strong allies in advocating for improvements in care delivery and can assist parents and caregivers in linking to community-based services and programs.

Working in partnership with parents benefits healthcare professionals and practice staff in the following ways:

- Informs the planning process so that changes in care are feasible for staff and relevant to families' needs
- Improves communication between medical home staff and families
- Brings fresh perspective to problems
- Increases provider understanding of families' daily experiences and challenges
- Brings about better patient and family satisfaction

Integration of Family Health Partners into improvement efforts ensures that improving patient care remains the central focus of the improvement efforts, allowing improvement teams to envision and strive for better care.

STEP ONE EXAMINE THE ROLE AND BENEFITS OF FAMILY HEALTH PARTNERS

Why become a Family Health Partner?

Some families knew the moment they were asked that they wanted to become more deeply engaged in their pediatric practice and give back to their practice. Others report they wanted to be a part of supporting changes and improvements to the practice. For some it was a chance to learn, to educate and to be a voice for families. Whatever the motivation, contributing to medical home transformation can be an opportunity for families to build their confidence and problem-solving capacity while discovering the value of caregiver expertise in partnering for quality improvement within their child's pediatric practice.

Below, Family Health Partners from the CHIPRA Massachusetts Medical Home Learning Collaborative share their personal stories and why partnering in their medical home matters to them.

WHY I PARTICIPATE, BY PARENT PARTNER ZIVA MANN, DECEMBER 14, 2013

Family partners can play a key role in providing guidance for how to make change work for practices transforming into medical homes. Ziva Mann is one of these family partners, working with a team from Cambridge Pediatrics in Massachusetts. An advocate and mother of a child with hemophilia, she shares her story on the importance of a medical home and how partnering with healthcare professionals helped a practice achieve improvements.

WHY I PARTICIPATE, BY PARENT PARTNER OLGA CAPPAS, AUGUST 15, 2013

In NICHQ's work on improving medical homes, healthcare professionals work closely with parents to make improvements to pediatric systems. Olga Cappas shares her story of raising a son with cerebral palsy and why the streamlined care offered in a medical home is so important.

Families interested in learning more about becoming Family Health Partners are encouraged to read the article **"Who You Gonna Call?"** as it contains helpful background information on family engagement and important questions for reflection at the end.

Essential attributes of Family Health Partners

Family Health Partners offer a unique assortment of lived experience, personal attributes and communication styles. Despite that variety, there are universal traits identified as important to medical homes and their quality improvement teams. Effective Family Health Partners increase their creditability as collaborators when they look beyond personal interest and represent the broader needs of children in the practice, are willing to express their opinions candidly, have good listening skills and have the ability to work with others of differing opinions.

Family Health Partners working in medical homes have highlighted these additional attributes and skills as helpful in their work. Family Health Partners should be:

- Comfortable sharing ideas, concerns and their personal story in a meaningful and confident way
- A reliable work partner that follows through on commitments
- Open to learning new ideas and different perspectives
- Honest, candid and comfortable asking questions when needed
- Compassionate and non-judgmental
- Able to respect confidentiality and honor the privacy of families, providers and staff
- Patient and cognizant that sustainable change takes time
- Good at time management and possessing strong organizational skills

STEP ONE EXAMINE THE ROLE AND BENEFITS OF FAMILY HEALTH PARTNERS

Activities and the role of Family Health Partners

Along with contributing to system-level changes as part of a quality improvement team, Family Health Partners provide vital support to families that enhances the patient and family experience.

Family Health Partners assist the medical home in supporting families by:

- Hosting information workshops and resource fairs
- Developing resource materials and bulletin boards promoting community services and programs
- Building community connections for families, including making referrals to community resources
- Gathering practice-wide input from families by creating surveys or hosting focus groups
- Informing families in the practice of quality improvement activities
- Creating and facilitating a practice patient and family advisory council (PFAC)

TO LEARN MORE ABOUT CREATING A PFAC FOR YOUR MEDICAL PRACTICE, DOWNLOAD THE PFAC TOOLKIT.

Activities and the role of Family Health Partners

As a systems-level partner, a Family Health Partner successfully contributes to all levels of practice improvement by:

- Supporting clinical partners and care teams in refining the delivery of health services at the practice
- Evaluating how the practice responds to families and identifying areas for improvement (see Step 3 Discovery Shopping)
- Regularly attending practice staff meetings to reinforce the voice of families in improvement efforts
- Providing instructive suggestions for family-centered process flow and operational improvements
- Initiating testing for small cycles of change (see Step 3 Plan/Do/Study/Act-PDSA) to assist the practice in meeting quality improvement goals
- Promoting spread of quality improvement gains within the practice, any affiliated health organizations (if applicable) and to broader external systems of care
- Contributing to the design of patient portals and other interfaces between families and the care team
- Advising on family education materials relevant to family needs
- Helping to design office space that meets the needs of patients and families

STEP TWO

BUILDING PRACTICE READINESS FOR FAMILY HEALTH PARTNERS AS TEAM MEMBERS

In this chapter:

Family experiences in pediatric practices vary considerably, and the success of family engagement can vary as well. Most practices seek to be responsive, but may lack the resources or the expertise to make this happen. Meaningful family involvement is an ongoing process where interested and affected families are consulted and included in the decision making of the practice. When considering adding Family Health Partners to your practice, you will need meaningful commitment from your practice leaders, providers and staff. It's wise to assess your practice's readiness to determine existing resources and identify areas in need of further development. The practice assessment below should be completed by practice leaders and members of your staff.

Assessing readiness

Practice readiness assessment

Use this leadership self-assessment as the basis for a conversation among practice providers and senior leaders to determine your practice's level of readiness for including Family Health Partners in your medical home transformation. Consider to what degree the statements on the assessment are true for your practice.

PRACTICE LEADERSHIP assessment for family engagement readiness	1 Strongly Agree	2 Somewhat Agree	3 Neutral	4 Somewhat Disagree	5 Strongly Disagree
At all levels of staff in our practice, we believe that our patients' and families' perspectives are as important as our own when it comes to how our practice is run.					
We believe that engaging families in quality improvement activities allows us to access patients' and families' perspectives in novel ways that no other feedback process can.					
We have staff within the practice excited about family leadership and willing to contribute effort.					
We can commit sufficient and realistic financial and personnel resources to this project.					
We have families who want to provide us with feedback and ideas, and we believe this is a useful forum for doing so.					
We are open to having interested patients with a variety of view-points participate, including those of varying cultural backgrounds.					

Staff readiness assessment

Most staff and providers are both excited and nervous about the idea of asking patients and families for direct feedback about their experiences. Setting aside time at a staff meeting to discuss including Family Health Partners into your medical home early in the process is critical to successful engagement.

Some staff resistance may be due to a lack of information about what Family Health Partners do. Ultimately, acknowledging and assuaging concerns is critical to meaningful family-professional partnership. The following self-assessment contains some questions that can facilitate an open, honest conversation with practice staff.

Assessing readiness

STAFF assessment for family engagement readiness	1 Strongly Agree	2 Somewhat Agree	3 Neutral	4 Somewhat Disagree	5 Strongly Disagree
I believe that parents bring unique expertise to our relationship.					
I believe in the importance of family participation in decision making at the program and policy level.					
I believe that parents' perspectives and opinions are as important as those of professionals.					
I believe that families bring a critical element to the team that no one else can provide.					
I consistently let others know that I value the insights of families.					
I work to create an environment in which families feel supported and comfortable enough to speak freely.					
I listen respectfully to the opinions of family members.					
I believe that family members can look beyond their own child's and family's experiences.					
I can clearly state what is required and expected of families in their advisory roles.					
I can help parents set clear goals for their role.					
I understand that a child's illness or other family demands may require parents to take time off from advisory responsibilities.					
I feel comfortable delegating responsibility to families.					
I am willing to test ideas that families contribute to improve the medical home.					

Staff Assessment for family engagement readiness adapted from "Essential Allies: Families as Advisors" and the Institute for Patient- and Family-Centered Care.

Assessing readiness

Practice readiness assessments

These assessment results offer your practice valuable insight on whether your patient- and family-centered medical home is ready to move forward in engaging families and building authentic partnerships. If practice leadership or staff needs more time, a potential next step would be to create opportunities for family engagement with limited commitment.

The following suggestions can help your practice progress in its development of embracing families as improvement partners:

- Invite a successful team of medical home provider-family partners to speak at a practice staff meeting (identify partners through an affiliated health organization or professional network)
- Experiment with discovery shopping, using a family within the practice to walk through the patient experience and present their perspective at a practice staff meeting (See Step 3 Discovery Shopping)
- Highlight assessment results in need of improvement and correlate them to quality measures used in your practice such as the Patient Experience survey or Medical Home Index

Practices transforming to a patient- and family-centered medical home need to honor that change takes time and staff may need to see a demonstration that families can be useful and effective as quality improvement partners.

Creating a Family Health Partners launch team

When your practice has determined that it is ready for Family Health Partners as a part of the quality improvement process, begin by considering the recruitment process. For practices with existing quality improvement efforts, recruitment could be integrated into the work of the improvement team. Other practices will want to create a launch team to approach recruitment in a structured manner. This assures that practice leadership and staff are involved and invested in family engagement early on and that family perspective is a part of planning for Family Health Partners in your medical home.

Whatever method of recruitment you choose, we offer you an overview of the steps necessary to successfully identify, create a role for and recruit Family Health Partners that represent the needs of your patients and families and help your practice achieve its quality improvement goals.

What is a launch team's role?

The launch team should be accountable for:

- Defining the purpose of the Family Health Partners' role within the practice and ensuring that it aligns with other quality improvement and practice initiatives
- Identifying the role and responsibilities of the Family Health Partners within the practice and creating the job description
- Creating an outreach plan with vital attention to the recruitment of families who reflect the culture and experience within the practice
- Creating a training and orientation checklist and assigning staff resources to support implementation
- Promoting Family Health Partners within the practice by introducing them to staff as team members and including them in all staff activities

If using a launch team, practices should include a practice provider champion and a clinical or administrative leader involved in quality improvement initiatives who can act as the Family Health Partners' liaison. Some patient- and family-centered medical homes have found a provider champion is the best liaison for the family; reflection on the assessments results above can help determine what would work best for your practice. Another critical representative of the launch team is a family member

Creating a Family Health Partners launch team

What is a launch team's role?

who can ensure that a genuine patient and family perspective is present right from the start.

These practice allies should have time available to champion the family's value as a contributing team member, facilitate the training and orientation and provide support as needed throughout the family partner's participation.

Family engagement means including families in the evaluation of your practice and in the planning and implementation of quality improvement activities, including the Family Health Partners role. The earlier the patient and family voice is included in the process, the more authentic family participation in the practice will be.

Provider champion

Family Health Partners will need support and guidance from multiple allies within your practice. Select a leader from the practice who values family-professional partnerships, has a genuine willingness to promote the partnership at all levels of the practice and who has the authority to allocate necessary resources to support meaningful family engagement.

This provider champion should be accountable for:

- Identifying and recruiting suitable family partners
- Promoting authentic family partnerships within the practice with all levels of staff and providers
- Securing financial and personnel resources to support family engagement
- Negotiating the removal of barriers with other leaders and staff in the practice
- Confirming practice readiness
- Supporting the work of the Family Health Partners liaison (see below)
- Inviting the Family Health Partners to participate in medical home improvement activities
- Contributing to the activities of the Family Health Partners launch team
- Keeping practice leadership informed about Family Health Partners activities and contributions

Creating a Family Health Partners launch team

Family Health Partners liaison

Family Health Partners will work best with a staff member of the practice who values family-professional partnerships. The liaison should coordinate the launch team and ensure that Family Health Partners receive the training and support needed to be effective in their role as team members.

The Family Health Partners liaison should be accountable for:

- Working closely with the provider champion to promote authentic partnership and engagement of the Family Health Partners at all levels of the practice
- Coordinating the Family Health Partners launch team
- Working with the provider champion to identify and recruit a family representative for the launch team
- Ensuring that Family Health Partners receive an initial orientation to the practice and improvement team along with ongoing training as needed
- Including Family Health Partners in scheduled all-staff meetings and quality improvement team activities
- Supporting the Family Health Partners, providing guidance and direction as needed
- Working collaboratively with the Family Health Partners to evaluate and sustain family involvement within the practice

Family representation for launch team

ONCE THE FAMILY HEALTH PARTNERS HAVE BEEN SELECTED AND ACCEPTED, THE FAMILY REPRESENTATIVE'S MISSION IS ACCOMPLISHED.

Incorporating Family Health Partners into the practice requires some degree of family advisement at the onset of planning. The family representative's role on the launch team is temporary and serves to provide family perspective in the development and recruitment of a Family Health Partner. If possible, find someone within the practice, either a staff member or the parent of a patient, who has family leadership or advocacy experience and who values family-professional partnerships. This person should function as the family voice in launch team activities and will review or co-create the Family Health Partners' role and responsibilities, recruitment material, recruitment plan and selection process "through the eyes of the family" to ensure that family perspective is considered throughout development.

Family Health Partners role and expectations

Job description

Including Family Health Partners in a practice improvement team requires thoughtful consideration of how they will be incorporated into the medical home transformation process. In the beginning, the practice launch team can establish the scope of work and determine how best the family partner can assist your patient- and family-centered medical home. Utilizing the unique expertise of families requires collaborative planning so that Family Health Partners can co-create their role within the practice.

Documenting the roles and responsibilities in a written job description provides guidance and direction to the Family Health Partners' work on the improvement team. As medical home transformation progresses and the family professional-partnership deepens, the Family Health Partners role may evolve and be revisited. At a minimum, the role should be discussed between the Family Health Partners and the practice liaison every six months.

The job description should include:

- **General Summary:** A few sentences about your practice and the role of Family Health Partners
- **Duties and Responsibilities:** Describe what Family Health Partners will do in your medical home (See Step 1 for more Activities and roles for Family Health Partners). If applicable, include their role in:
  - The quality improvement team
  - Building connections and linkages to community resources
  - Your practice's Parent and Family Advisory Council (PFAC)
  - Attending practice staff meetings, trainings and new staff orientation
- **Skills and Abilities:** List the useful or preferred qualities or attributes required of the Family Health Partners
- **Application Process:** Define how and who will be interviewing interested families
- **Special Requirements:** Describe any special paperwork that Family Health Partners will be required to complete or provide such as a Criminal Offender Record Information (CORI) check, drug screen, privacy and confidentiality form or a social security number.

Family Health Partners role and expectations

Time Commitment

The time Family Health Partners spend involved in quality improvement work will vary based on their role and responsibilities within the medical home and their availability. When a medical practice engages Family Health Partners, it must recognize the realities of family commitments and the time constraints many Family Health Partners face.

Ensuring that diversity within the medical home practice is represented requires improvement teams to schedule meetings with Family Health Partners' work and family schedules in mind. Improvement teams that embrace partnerships will need to find meeting times that accommodate everyone's schedule, which can be a challenge.

Family Health Partners should identify their available time and commit to improvement work responsibly. The credibility of the parent professional partnership is elevated when time commitments are met and Family Health Partners follow through on improvement work obligations.

Compensation

Families engaged as active partners in medical home improvement are committing both their time and effort. Family professionals' contributions are valuable, and they should receive compensation for their expertise whenever possible. Creating paid positions for family leaders facilitates the development of professional partnerships. When family partners are paid, it validates the time and attention they devote to their work in the medical home and holds them accountable.

The decision of how to compensate Family Health Partners can vary based on their role and practice budgets. Some Family Health Partners are paid to participate because their position requires delivery of work on a consistent basis. Other Family Health Partners may be paid a stipend or are paid through an alternate funding source (e.g., grants, state agency, etc.). Some Family Health Partners may prefer to engage on a voluntary basis to maintain their autonomy and flexibility. The Family Health Partner liaison and each Family Health Partner should discuss what the practice can offer and if it meets the needs of that Family Health Partner. This is especially important if the Family Health Partners responsibilities increase over time. Family Health Partners should receive compensation commensurate with their abilities and accomplishments.

Recruitment

Ensuring practice diversity is represented

Patient- and family-centered medical home practices should ideally recruit two Family Health Partners for improvement team activities. It's beneficial to have more than one engaged family member, so that they can cover for each other when one is unavailable to attend improvement team meetings. Having two Family Health Partners will also discourage tokenism, and provide necessary peer support and mentoring.

Family Health Partners should reflect the diversity of the populations served by your practice, and this takes effort. There are many types of diversity, including gender, race, culture/heritage, age (of patients and of family members), language, socioeconomic background, disease or disability, family structure and sexual orientation.

Here are some ideas for encouraging diversity as you recruit:

- Ask staff for ideas on recruiting for diversity with your practice
- If necessary, ensure that materials are translated into Family Health Partners' native languages and that interpreters are available for meetings and other important discussions
- Remove barriers to participation; offer flexible work scheduling and participation in meetings by phone
- Avoid using acronyms, jargon and complex medical terms; use simple, plain language when providing explanations or descriptions
- Written materials should use the term "family" instead of "parents;" include a wide range of voices by allowing families to define themselves
- Seek help from others within or outside of your organization who have expertise in multicultural affairs or who have close community connections with families in your practice
- Ask families what accommodations would enable them to attend
- If possible, connect with community organizations that work with patients in your practice; they may have recommendations or referrals of families with whom they've engaged
- Create a recruitment plan to track feedback from the families who've been approached; record barriers to participation, as trending issues may require creative solutions

Recruitment

Ensuring practice diversity is represented

DEMOGRAPHIC FACTORS

- AGE
- GENDER
- RACE AND ETHNICITY
- FAMILY CULTURE
- LANGUAGE SPOKEN
- SOCIOECONOMIC STATUS

NON-DEMOGRAPHIC FACTORS

- MEDICAL CONDITION AND/OR DISABILITY TYPE
- SERVICES USED
- GEOGRAPHIC LOCATION
- PRIMARY CARE SITE

In addition to cultural representation, the practice should consider including other groups. If there is a large percentage of children with chronic conditions such as asthma or ADHD, consider inviting a family whose child has that condition. Also consider representing different ages: issues for families with a three-year-old can look quite different from those with a 16-year-old. Strive to get family representation for the age ranges with the most representation in your medical home.

The consumer organization **Community Catalyst** offers guidance for ensuring greater diversity. We have provided an adapted version that reflects the specific needs of pediatric practices. We offer these suggestions to emphasize the importance of engaging Family Health Partners who can relate to the broad needs of the families within your practice.

Outreach to families can take many forms. The best approach is often a direct one, especially when a provider or other trusted member of the care team is the one who asks families. Some families welcome the chance to build a deeper relationship with their pediatric practice and are eager to help in quality improvement. If your practice already has a Patient and Family Advisory Council (PFAC), ask the council leadership to recommend family members involved in the group.

Another idea is to conduct a focus group, asking for input on improvement needs within the practice. This exercise can serve the dual purpose of providing the practice with feedback and identifying families with an interest in participating in practice improvements.

Conducting informational meetings with interested Family Health Partners

An in-person meeting can be an effective way to understand a family's interest in contributing to your practice's quality improvement. It's a chance to explore your practice's values, needs and skills—as well as those of the interested families. Every meeting is a chance to build relationships and have a conversation about what matters to families and how you can partner to make a difference within your pediatric medical home. Use these meetings to confirm that a family

Recruitment

Conducting informational meetings with interested Family Health Partners

member is a good match for your practice, to learn more about what might prevent them from fully engaging and to identify what kind of training and support you will need to provide.

Organizing for Health's ***Recruitment Guide*** offers a rich framework for engaging in an exploratory dialogue with patient/family leaders around partnering in healthcare transformation. They recommend in-person meetings as the most effective way of getting to know potential partners. They advise opening the meeting by sharing something meaningful about yourself, like what brings you to this work, as a way to invite an open conversation.

Here are some adapted questions that can guide your meeting:

STORY: What's your family story? What in your life brought you here today? (Discover ability to connect personal story to larger context.)

HOPE: What motivates you to act to improve our practice? What's your vision of how things could be different if we worked together? (Discover shared values.)

LEADERSHIP RESOURCES: What skills do you have? How do you lead others already in your life? What would you be willing to bring to this work? (Discover leadership and collaborative skills.)

CHALLENGES: What challenges do you foresee that may prevent you from meaningfully contributing to improvement work in our medical home? (Discover barriers to participation.)

Securing commitment

When your practice has chosen family members that you want to partner with on quality improvement in your medical home, create a written offer that clearly states the details they'll need to get started. Include the Family Health Partner's job description, the time commitment required, important dates such as their start, orientation and training dates, their compensation, any required paperwork and the name of the person to contact with any questions.

STEP THREE

ENGAGE AND INVOLVE FAMILY HEALTH PARTNERS: FAMILY TRAINING AND PARTNER ORIENTATION

In this chapter:

Although the Family Health Partners may already be involved in your medical home practice as patients or parents/caregivers, they may not understand all aspects of how the practice operates. Providing an overview of practice administration and office procedures offers new Family Health Partners the organizational structure and context that will better inform their perspective as members of the practice improvement team.

Family Health Partners are a part of the practice staff and should receive orientation similar to that of a new employee. Introductions to Provider Partners, the medical team staff and professional providers orient the Family Health Partners to the care team. Depending on your practice, this may include physician assistants, nursing staff, lab personnel, care coordinators, mental health providers and other service providers.

Orientation to the practice

Office policies and procedures

To ensure that Family Health Partners are informed advisors within the quality improvement team, they should understand all care delivery and operational aspects of the medical home practice that affect patients and families.

Family Health Partners should also become familiar with the following practice tools, policies and procedures:

- Care team structure, including responsibilities of each member
- Electronic health record system
- Population registries
- Standing orders
- Care coordination
- Referral tracking
- Systems to link families to community resources and community resources lists
- Transition planning
- Mechanisms for families to provide feedback to the practice – complaints, suggestions, etc.

Practice administration and support staff are vital to the day-to-day operation of a medical home and are the stewards of patient-centered service. Family Health Partners should meet these staff members and understand how the administrative medical home functions.

The following office policies and procedures are an important part of the patient experience and should be included in the Family Health Partners' training:

- New patients and required paperwork
- Scheduling appointments; routine vs. urgent care
- Appointment reminders
- Visit registration
- Billing
- HIPAA (the Health Insurance Portability and Accountability Act of 1996) and policy for honoring privacy and confidentiality
- Other practice paperwork that families receive

Orientation to the practice

Discovery shopping

To understand the patient experience and identify areas for improvement, Family Health Partners can engage in **discovery shopping**, which is conducted by a practice staff member, a child's parent/Family Health Partner (acting as parent or self) and the child or adolescent acting as the patient.

The designated discovery shoppers should begin at the first point of contact: making an appointment and entering the office as patients. The shopping experience continues through all phases of an office visit. It's important to record the experience and what it was like: Where are the delays, bottlenecks or long waits? What makes sense and what doesn't? Consider using photography to document these observations, as long as you have consent from patients and family members.

Discovery shopping should be conducted with full sensory awareness; what you see, hear and smell matters. By noting areas in need of improvement, a medical home can begin to set goals and benchmarks for improving patient experiences and practice systems.

Affiliated healthcare organizations

Quality improvement initiatives undertaken by your medical home may have an impact on or be influenced by the broader healthcare arena in which your medical practice operates. Family Health Partners should be aware of this larger health system. Is the practice independently owned and operated or is it a part of a group of practices? At which hospital(s) do the doctors have admitting privileges? Is there a preferred network of providers they refer to for specialty care? Consider the healthcare arena that your medical home operates within and provide the Family Health Partners with a context for understanding how this influences the quality improvement team's activities and decisions.

STEP THREE FAMILY TRAINING AND PARTNER ORIENTATION

Orientation to the medical home

Family Health Partners should be knowledgeable about the medical home concept. A medical home is not a place but a process of care that emphasizes "home" as a headquarters for care where patients and families feel recognized, welcomed and supported. The American Academy of Pediatrics (AAP) developed the medical home model for delivering primary healthcare that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective to all.

Patient- and family-centered care

Patient- and family-centered care is about patients, families, doctors, nurses and other professionals working together. Medical home practice that embraces the patient- and family-centered values described below can achieve high-quality care.

- Honoring racial, ethnic, cultural and socioeconomic diversity and its effect on the family's experience and understanding of care
- Encouraging each child and family to discover their own strengths, build confidence and make choices and decisions about the child's care even in difficult and challenging situations
- Ensuring flexibility within the practices so services can be created to meet the unique needs, beliefs and cultural values of each child and family
- Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming
- Providing connections to community supports for the child and family during all stages of childhood including adolescence and young adulthood

FOR RESOURCES ABOUT MEDICAL HOME TO SHARE WITH FAMILIES, VISIT

http://www.nichq.org/sitecore/content/medical-home/medical-home

"When patient- and family-centered care is practiced it shapes health care policies, programs, facility design, evaluation of health care and day-to-day interactions among patients, families, physicians, and other health care professionals."

"Patient- and Family-Centered Care and the Pediatrician's Role," American Academy of Pediatrics policy statement

Orientation to the medical home

Culturally responsive care

In an effective patient- and family-centered medical home, a family's cultural background, including beliefs, rituals and customs, is recognized, valued, respected and incorporated into the care plan. All efforts are made to ensure that the child and family understand the results of the medical visit and the care plan. When needed, **translators or interpreters** should be offered.

Culturally and linguistically appropriate services are defined as "care and services that are respectful of and responsive to the cultural and linguistic needs of all individuals and are increasingly recognized as effective in improving the quality of care and services."[1]

Keep in mind that family members of a similar ethnic or language group are not all the same, even though within one group or across groups, people might face similar challenges. Ask families about their cultural beliefs, how these relate to their child's plan of care and how they make decisions about care. When providers ask families to define themselves in their own words, authentic partnering is reinforced.

Cultural humility encourages providers to constantly self-assess their own views of cultural norms and acknowledge the power imbalance between patients and providers. By exercising cultural humility, providers can more effectively establish partnerships with their patients to let their needs and beliefs inform care decisions.

Medical home care team

Patient-centered care teams in medical homes deliver care that is guided by patients and families. Care teams might include a primary care physician or nurse practitioner, other nursing staff and a medical assistant. Family Health Partners may also be included along with other professional staff (such as a behavioral health provider, care coordinator, dietician, etc.), depending on the patient's or family's needs. Team roles and responsibilities may vary by practice, so distribute tasks among care team members to reflect their skills, abilities and training.

NICHQ has created a medical home care team builder tool that assists practices in developing care teams within their medical home.

[1] Beach et al., 2004; Goode, Dunne, & Bronheim, 2006

Orientation to the medical home

Care plans

A **care plan** compiles the patient's information—current and past medical history, list of medications, list of doctors and specialists, community resources or services accessed by the family—along with personal preferences of the patient and family regarding a child's health-care, all together in one place. Also known as a portable medical summary, the plan may include medical and social aspects of a child's and family's needs, and any medical equipment the patient uses.

Patients and families can use this summary to convey medical information to other medical providers not familiar with their care history. It can be especially helpful for families in the case of a medical emergency when care providers do not have access to their child's medical record.

A **care notebook** is a tool that patients and families use to keep important medical information organized. Bringing the notebook to appointments and meetings allows families to easily share information with doctors, therapists and school or childcare staff.

A care notebook can help patients and families:

- Prepare for appointments
- Store information about health history
- Keep track of current medications, including allergies
- Organize contact information (address and phone numbers) for health-care providers and community organizations supporting the families

Orientation to the medical home

Care coordination

Pediatric care coordination is driven by identifying the needs of a child and his or her family and connecting them to medical services and community services to meet those needs. In a medical home, the provider and practice staff may help patients and families make contact with other health providers, specialty care doctors, family support organizations or other services that assist families. Care coordination may be a specific role within a practice or it may be a function of the medical home practice.

Patient- and family-centered medical homes aim to deliver care coordination that:

- Is family-centered and community-based
- Is proactive, planned and comprehensive
- Promotes self-care and management skills for children, youth and families
- Helps patients and families connect with other healthcare providers

Care coordination functions within a medical home by completing **needs assessments** with patient and families, developing a plan of care and tracking referrals to providers and other supports. How care coordination is handled within medical homes varies, but they all share a similar goal of helping children achieve good health and wellness.

Linkage to community resources

Medical home care teams can assist and guide families in need of more than just medical services. Medical home practices must discover the programs and services in their patients' communities that provide positive assistance to families. Established organizations with experience supporting patients and families can be productive partners in medical home practices looking to improve outcomes.

During visits, care teams can discuss a patient's and family's concerns and any challenges they are facing. Also, consider conducting a survey of all patients and families in the practice; ask them what needs they have that aren't being met and what they think would help. Consider asking what community resources have been useful to families. What better way to learn about beneficial programs and services than through the families who are using them?

Orientation to the medical home

Linkage to community resources

Here are additional ways to identify community assets and start linking families to necessary resources:

- Network with other medical professionals
- Connect with early childhood programs (e.g., Head Start, Early Intervention, etc.)
- Establish contacts in school districts (elementary and secondary school level)
- Learn of resources available through faith-based organizations
- Check community education, town recreation, YMCA and Boys & Girls clubs
- Look for family support organizations
- Check local and state Department of Public Health
- Review services of State Maternal and Child Health Title V programs

Have reliable information for patients and families catalogued and readily available.

A HELPFUL RESOURCE: MATERNAL AND CHILD HEALTH LIBRARY'S COMMUNITY SERVICES LOCATOR

Established medical homes build community resource knowledge within their medical homes by:

- Creating a practice resource book
- Using waiting room and common area bulletin boards to broadcast information
- Inviting community partners to staff meetings to learn about programs and services they offer
- Hosting resource fairs
- Including community groups' contact information on the practice's website or in the patient portal
- Devoting time during staff meetings for success stories of community linkages

Orientation to the medical home

Linkage to community resources

Family support organizations

Peer support (also known as parent-to-parent support) can provide valuable opportunities for families to learn about the systems and services needed to help their children thrive. By sharing a common experience, families often develop a trust that can lead to deeper identification of needs. These relationships allow families to develop community connections while gaining practical knowledge.

Other community resources of value to families:

- **Family to Family Health Information Centers**; assistance with health insurance questions
- State-funded family relief programs (e.g., food, housing, electricity, transportation, equipment)
- Educational rights and resources, including workshops and trainings
- **Parent 2 Parent USA**
- Employment rights and resources, including resources for those affected by unemployment
- Condition/diagnosis-specific patient education materials/classes
- Adapted recreation
- Patient self-management tools/guidance
- **National Federation of Families for Children's Mental Health**
- Language-appropriate services and resources
- Parent support groups
- External care management assistance
- Home care/respite help
- Title V, schools, **American Academy of Pediatrics (AAP)**, American Academy of Family Physicians (AAFP), **Family Voices**

Quality improvement
Practice transformation

Many pediatric healthcare practices in the process of transforming into a patient- and family-centered medical home use guidelines or tools like the National Committee for Quality Assurance's (NCQA) **Medical Home Standards** or the Center for Medical Home Improvement's (CMHI) **Medical Home Index**. Both require or encourage that practices demonstrate continuous quality improvement initiatives and that patients and families are part of this process.

As a result of their experience in seeking and receiving medical care for their children, families bring unique skills to a patient- and family-centered medical home partnership. Families can help doctors create improvement plans that increase the quality of care for all children. Practices that encourage, value and include family perspectives and experiences in developing high-quality medical care can speed up their progress toward becoming a truly patient- and family-centered medical home.

"The insight and knowledge parents bring to the table is beyond what we could ever imagine." Jacqueline Johnson, Chief Operating Officer, Caring Health Center

According to NCQA, by transforming primary care practices into patient-centered medical homes (PCMHs), patients and families can get what they want: a focus on patients and their healthcare needs. To achieve these aims, medical home transformation requires continuous development, ongoing quality improvement, family partnership skills, an attitude of teamwork and strong care coordination.

Quality improvement

Practice improvement teams

Medical home transformation and continuous quality improvement activities require the dedication of a unified team. The **Center for Medical Home Improvement (CMHI)** identifies high-functioning teams as those made up of "front lines of care," that are engaging family partners, have the capacity to test changes quickly and possess the resilience to deal with the complexities of primary care.

Including Family Health Partners in the practice improvement team enhances the delivery of family-centered care within that practice. Their contribution to medical home transformation helps a practice identify quality improvement priorities by identifying existing barriers and collaborating on new quality improvement initiatives.

Teams require the benefit of support from practice providers and administrative leaders. Supported teams can gain practicewide buy-in for their improvement innovations and other procedural changes, which ensures success. Teamwork is fundamental to effective medical home improvement.

Quality improvement

Plan Do Study Act (PDSA) cycles and the Model for Improvement

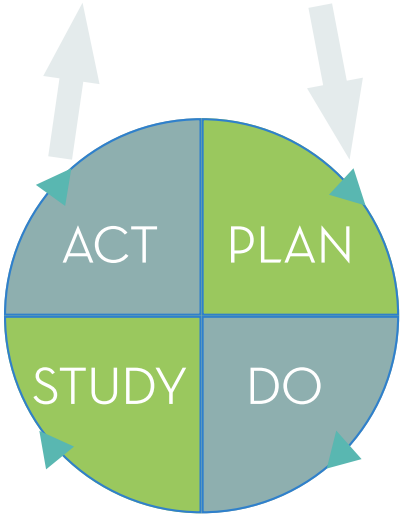
The Model for Improvement, developed by **Associates in Process Improvement**, is a robust and powerful approach for executing and accelerating improvement. The Model for Improvement philosophy involves setting an aim, determining how to measure progress toward the aim and making changes that brings about improvement. Around the world, healthcare organizations use Plan Do Study Act (PDSA) cycles and the Model for Improvement to change many different healthcare processes and outcomes. The model can also be used to incorporate and maximize engagement of Family Health Partners in your practice's medical home.

MODEL FOR IMPROVEMENT

What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?



OVERVIEW OF THE MODEL FOR IMPROVEMENT

The Model for Improvement has two parts:

1. Three fundamental questions, which can be addressed in any order:

- What are we trying to accomplish? (Setting aims)
- How will we know if a change is an improvement? (Establishing measures)
- What changes can we make that will result in improvement? (Selecting changes to test)

2. W. Edwards Deming's Plan-Do-Study-Act (PDSA) learning and improvement cycle allows you to test a change in the real work setting—by planning it, predicting what will happen, trying it, observing the results and acting on what is learned. This is the scientific method used for action-oriented learning and may be useful to your medical home improvement team.

STEP FOUR

TEAM DEVELOPMENT: BUILDING COMMUNICATION AND LEADERSHIP SKILLS

In this chapter:

A strong family and professional partnership is built on trust, understanding and mutual respect. Although these relationships may grow organically, your quality improvement team will benefit from exploring the essential skills needed to form effective partnerships.

Below are activities you can use within your practice to support families and staff. The learning modules/resources will help participants expand on fundamental skill development in four crucial areas: storytelling, self-awareness and identification, deep listening and respectful conversations and conflict resolution and cultural collaboration.

STORYTELLING:

Family Health Partners are called upon to reflect and report on their personal experiences with access to healthcare and the quality of services. Practice providers and staff working with families have stories to share as well. Learning to tell a personal story in a manner that creates change without embarrassment or over-exposure is a critical skill.

EXERCISE: Storytelling to make a difference

This learning exercise brings to awareness the potential power of a family's story and many ways that listeners might hear it.

SELF-AWARENESS AND IDENTIFICATION:

Understanding and appreciating who we are and how we differ from others makes it easier to work collaboratively without sacrificing one's own unique vantage point.

RESOURCE: **True Colors**

True Colors is a highly regarded, commercially developed tool that is an adaptation of a Myers-Briggs inventory. Users complete a self-inventory tool to identify to which of four color types they belong.

Essential skill development

Self-awareness and identification

Identifying with our personality and the personalities of others provides insights into different motivations, actions and communication approaches. The mutual understanding of our core values and needs offers a solid base to communicate, motivate and achieve common goals with utmost dignity, efficacy and mutual respect. You may want all your team members to learn and share what their true color is. It can help team members work together in ways that take into consideration the diversity of everyone's preferences and styles.

True Colors has been used successfully with many family-professional partnership teams to help them work collaboratively. It offers a universal language that accelerates problem solving, increases trust and reduces conflict.

DEEP LISTENING AND RESPECTFUL CONVERSATIONS:

Improving communication skills around deep listening and respectful conversations allows all perspectives—including diverse and perhaps controversial ones—to be given consideration. Discussions, regardless of the topic sensitivity, should occur respectfully, leading to better working relationships and greater understanding of the perspective of all.

"Seek first to understand, then to be understood."

Steven R. Covey, *The Seven Habits of Highly Effective People*

Deep listening and respectful conversations

EXERCISES:

Deep listening:

This exercise helps to lower fear and discomfort levels by establishing a sense of safety and trust. It is an explicit practice of bypassing stereotypes and bias by focusing on listening to another person without responding or judging.

Essential skill development

Deep listening and respectful conversations

Understanding difficult conversations:

Situations leading to difficult conversations happen daily. Parents and professionals have strong feelings about many topics, and opinions will differ in large and small ways. This exercise explores the book ***Crucial Conversations*** and the three ingredients of challenging or difficult conversations.

The feelings conversation:

When expressing themselves, many people tend to use words that are related to feelings but aren't really feelings. Learn how we always have a choice in how and when we express our feelings.

The "What I really want" conversation method:

Reflecting on these simple questions helps to re-focus energies on a productive approach to conversation.

The focused conversation (ORID) technique:

The ORID (Objective, Reflective, Interpretive and Decisional) technique is a form of structured conversation led by a facilitator. The method was developed by the Institute for Cultural Affairs as a means to analyze facts and feelings, to ask about implications and to make decisions intelligently.

RESOURCE: **Technology of Participation (ToP)®**

Technology of Participation (ToP)® is a framework offered by the Institute for Cultural Affairs in the USA, which teaches team members how to collaborate on projects and teaches group facilitators how to effectively lead their teams.

Essential skill development

Conflict resolution

A practice's commitment to quality improvement requires a variety of experiences to generate new ideas that improve patient care. An effective practice will bring together a variety of perspectives, voices and cultures. From this variety, conflict will likely occur.

Conflict can be both positive and negative. Conflict can be positive when it helps open up the discussion of an issue, results in problems being solved or new ideas being generated and releases emotions that have been stored up. It can be negative when it diverts people from dealing with the really important issues, creates feelings of dissatisfaction among the people involved or leads to individuals and groups becoming insular and uncooperative.

Supporting the quality improvement team involves helping members develop skills that will allow them to leverage the beneficial aspects of conflict while still treating each other with mutual respect.

At an individual level, this requires an understanding of one's own worldview (culture) and how it is reflected in one's attitudes and behavior. It requires that people acquire values, principles, areas of knowledge, attributes and skills in order to work in cross-cultural situations in a sensitive and effective manner. These skills are sometimes referred to as cultural competence or intercultural collaboration.

Bringing together a variety of perspectives, voices and cultures leads to differences of opinions and possible conflict. Teams must reflect on their worldviews and develop skills to participate in respectful conversations when opinions differ.

EXERCISES:

Early memories: Reflect on the experiences that have shaped your views of differences. Work to understand the roles of reciprocal relationships to help quality improvement team members empathize with and support people from other cultures and backgrounds.

The brick wall and the gateway: This exercise helps individuals reflect on the experience of respectful conversations and identify best practices. It may also result in a set of meeting guidelines.

STEP FIVE

EVALUATE, SUSTAIN AND IMPROVE FAMILY ENGAGEMENT AND THE FAMILY HEALTH PARTNER ROLE

In this chapter:

Families will meaningfully engage in your practice's quality improvement if they feel that they are valued and making a difference. Involving Family Health Partners in the assessment of family participation in your practice will further develop a meaningful, authentic partnership and a more patient- and family-centered medical home. These evaluation activities allow you to collectively review the success of family engagement within your quality improvement activities. They also provide an opportunity to acknowledge what is working well and what needs to be improved.

With time and attention, even the most informal feedback interactions between patients and families and practices can evolve into an authentic partnership. Evaluating this partnership using the same measures over time can help track overall progress toward the quality improvement aims of your medical home. Such evaluation can then inform the strategies that you use for strengthening the partnership. There are a number of measures that evaluate this partnership from a practice's and from the patient and family perspective.

Assessing family engagement

Checklist for involving families as advisors and partners in a medical home

Below are excerpts or adaptations from a number of different assessment tools that can be used to measure patient-professional partnerships. Select the tool that most closely measures what is important to your practice and commit to using it on a regular basis, such as every 3-6 months. Keep track of your data in a simple spreadsheet to monitor changes in your data over time.

- Checklist for involving families as advisors and partners in medical home [adapted]
- Patient- and family-centered care organizational self-assessment tool
- Patient Experience Surveys

We suggest that you review the data collected from your selected tool and identify action steps to address and improve upon areas that were rated poorly. By tracking this measure over time, you can assess whether the actions you took resulted in improvements.

The following checklist is a tool to help practices think about ways that families are participating in quality improvement and in the transformation to a patient- and family-centered medical home. Rate each item and then cite specific examples that illustrate to what degree the practice is involving families. Use this tool to initiate new opportunities to partner with families or to expand on current activities. For example, you could identify all items that were indicated as not being done well, and develop an action plan to improve on one or two of them by the next time you collect data on this measure.

CHECKLIST FOR INVOLVING FAMILIES as Advisors and Partners in Medical Home	We are not doing well	We are doing ok	We are doing very well	Examples
We recognize that patients and family members bring unique perspectives and expertise to medical home transformation and quality improvement activities.				
We seek to involve families who reflect the racial, ethnic, cultural and socioeconomic diversity of families currently served by our practice.				
We use a variety of strategies to identify and recruit families to partner in our practice's medical home transformation and quality improvement.				
We have developed a range of ways for families to advise on patient- and family-centered care and services in our medical home by: • Offering activities that engage other families, such as patient family advisory councils and/or focus groups				
• Having families conduct trainings in staff orientation and in-service programs				
We offer our Family Health Partners the following: • Clear expectations about their role and responsibilities in the practice				
• Thorough practice orientation				
• Training on medical home and quality improvement				
• Compensation commensurate with their contribution to quality improvement				
We provide training to staff and families on working collaboratively on quality improvement.				
We offer Family Health Partners these meaningful ways to participate in QI activities: • Identifying needs of family in practice and areas of gaps in service				
• Designing policies to address needs and gaps				
• Implementing new policies				
• Assessing and evaluating new policies that meet the needs of families and address gaps				
We demonstrate appreciation for the contributions that families make to our medical home transformation and in our quality improvement activities.				
We recognize family commitments may impact Family Health Partners' participation at times and offer alternatives to continue engagement.				
Our Family Health Partners are supported by the practice liaison and provider champion.				

This checklist was adapted from the following resources: *Essential Allies: Families as Advisors and Developing* and *Sustaining a Patient and Family Advisory Council,* both published by the Institute for Patient- and Family-Centered Care.

Assessing family engagement

Patient- and family-centered care organizational self-assessment tool

This self-assessment tool can help your practice evaluate how your medical home is performing in relation to specific components of patient- and family-centered care, or serve as a basis for conversations about patient-centeredness. This tool allows organizations to understand the range and breadth of elements of patient- and family-centered care and to assess where they are compared to the leading edge of practice.

Patient- and Family-Centered Care Organizational Self-Assessment Tool

This tool was a collaborative effort of the National Institute for Children's Health Quality (NICHQ), the Institute for Healthcare Improvement (IHI) and the Institute for Patient- and Family-Centered Care.

Patient Experience Survey

Engaging Family Health Partners deepens your practice's commitment to patient- and family-centered care. A major benefit of having family perspective in quality improvement work is gaining insight into what families want and need from their medical home. Testing and implementing changes that meet those needs can lead to greater family satisfaction and improved health outcomes for children.

A patient experience survey is an important quality testing tool that can help your practice measure patient satisfaction. This quality measurement tool asks patients and families about their encounters with care providers and office staff. The survey results provide direct insight into patient and family experiences with services and care in the medical home. Quality improvement teams can use this information to identify areas in need of change, measure progress on quality improvement over time and increase patient and family satisfaction.

The following patient experience surveys are recommended for pediatric medical homes:

- **Child 12-Month Survey with Patient-Centered Medical Home (PCMH) Items**
- **Supplemental Items for the Child Surveys**

Examining barriers

When Family Health Partners join a patient- and family-centered medical home to engage in transformation and quality improvement, they are likely entering a realm of work otherwise unfamiliar to themselves and quite possibly the medical home practice as well. This is an opportunity for learning and discovery on many fronts and, with this new growth, challenges may emerge. You may identify barriers unique to your practice and the families engaged in it. Some challenges may occur as a result of unforeseen difficulties, communication breakdowns or lack of support. Compiled below are some commonly reported barriers experienced by practices and families working within medical homes.

Some obstacles may be beyond the practice's control. For example, family availability and capacity can be dependent on multiple variables that don't resolve readily. However, in most instances, these barriers present a chance to re-examine the readiness or the training/orientation of the practice and family. A medical home practice facing challenges in recruiting and retaining Family Health Partners may require some creative problem solving. A medical home that has been successful at family engagement may be a great resource for ideas and suggestions on how to move beyond the difficulties your practice faces.

Sustaining, supporting and advancing family engagement

A successful measure of your partnership with families is continued interest from both the practice and the Family Health Partners to carry on the relationship. If the work within your medical home improvement team is ongoing, there may be ample opportunity to continue to engage families within the practice. Ongoing support should reinforce essential elements of their initiation into your practice and their role as family leaders.

If there is capacity and interest, consider broadening the Family Health Partners' role in representing your practice in the community or larger health arena. Family leaders are emerging as an integral part of quality improvement at all levels of the healthcare system. Using your Family Health Partners as champions of your practice's quality improvement is an authentic demonstration that your practice is patient- and family-centered.

Sustaining, supporting and advancing family engagement

The suggestions below offer guidance on how to support and sustain your Family Health Partners.

Help Family Health Partners be well prepared and effective at their work

- Develop realistic expectations for Family Health Partners and provide clear role descriptions
- Designate a staff liaison to recruit patient and family advisors, coordinate training and practice orientation, provide mentorship and assure that opportunities for meaningful participation are continuous
- Ensure that Family Health Partners have access to a work space with a computer and internet access so they can complete work assignments with professional tools

Support Family Health Partners in their leadership development

- Offer opportunities for Family Health Partners to lead meetings or trainings with staff or other patients in the practice
- Encourage Family Health Partners to take an active role in creating or facilitating a Patient and Family Advisory Council
- Seek opportunities for Family Health Partners and practice providers or staff to co-present on quality improvement work they've partnered on
- Have a designated staff person in the practice to whom the Family Health Partners report; this staff person can also be there as a resource and support
- Make the Family Health Partners feel they are part of the team

Connect families to peers and mentors

- Connect Family Health Partners to family organizations that offer family leadership training, mentoring and inspiration through peer support programs
- Prepare less experienced Family Health Partners for participation in meetings and educational sessions, linking them with an experienced patient or family member whenever possible
- If your practice is part of a larger health system, connect Family Health Partners to other family leaders within other medical home practices or your affiliated hospital's Patient and Family Advisory Council (which some states require in every hospital)

Sustaining, supporting and advancing family engagement

When celebrating successes, highlight the role of the Family Health Partners

- The practice provider champion and Family Health Partners liaison can promote the Family Health Partners' work and seek out ways to share their contributions (e.g., practice newsletters, bulletin boards and practice website)

Promote family engagement within your medical home and beyond

- Consistently assert the importance of partnering with families in improving healthcare within your practice, medical neighborhood and your community
- Consider how to expand the Family Health Partners' role beyond quality improvement in your practice. Other medical homes have been successful in linking families to community services, coordinating care and facilitating Patient and Family Advisory Councils.
- Suggest family participation in other areas of the healthcare system such as policymaking, administration, clinical care, patient safety, education and patient-centered research

Family Health Partners turnover

There are times when Family Health Partners will need to move away from their quality improvement work. They may experience competing life demands that require more of their time and attention. It's important to recognize their accomplishments and express appreciation for their contributions while assuring them that their family will always be welcome as patients at the practice.

As part of a Family Health Partner's departure activities, conduct an exit interview. Their feedback can be useful in refining future quality improvement activities and recruitment of new Family Health Partners. When possible, identify other opportunities for future engagement; the person may welcome the chance to contribute to your medical home in another way.

Aquino, E., Bristol, T.E., Crowe, V., DesGeorges, J., & Heinrich, P., Gordon, A. (ed). ***Powerful Partnerships: A Handbook for Families and Providers Working Together to Improve Care***. Boston, MA: National Initiative for Children's Health Quality. This guide is intended to help both family members and healthcare professionals who are working together to improve care for children with special healthcare needs. Joining together in multi-disciplinary teams, family members and providers are increasingly working as equal partners to improve care. Collaborating as equals may be new for family members and providers. This guide includes information and guidance on how to get the most out of this potentially powerful partnership. http://www.nichq.org/how-we-improve/resources/powerful-partnerships

Advancing the Practice of Patient- and Family-Centered Care in Primary Care and other Ambulatory Settings: How to Get Started. Bethesda, MD: Institute for Family-Centered Care. Offers a philosophical overview of patient- and family-centered care along with assessments and surveys for practices to gauge staff perspective and readiness in shifting towards increased patient-family partnerships. Of note, Part V provides important guidance and specific suggestions for identifying and developing patient-family leadership. http://www.ipfcc.org/pdf/GettingStarted-AmbulatoryCare.pdf

Blue-Banning, M., Summers, J., Frankland, H. C., Nelson, L., & Beegle, **G**. ***Dimensions of family and professional partnerships: Constructive guidelines for collaboration.*** Arlington, VA: Exceptional Children. Winter 2004, volume 70, number 2, pp. 167-184. This study identifies important themes in the development of collaborative partnerships between professionals and families. With input from multiple focus groups, the interpersonal domains of communication, commitment equality, skills, trust and respect are explored more closely. https://www2.bc.edu/~peck/BluBanning.pdf

Carman, K.L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. ***Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies***. Bethesda, MD: Health Affairs, February 2013, volume 32 number 2, pp. 223-231. This framework looks at the continuum of patient and family engagement and the levels of the health system in which they can engage. Moving across the continuum from consultation to shared decision-making through partnering, this framework illustrates the ways that further engagement can develop. http://content.healthaffairs.org/content/32/2/223.full

Dillon, A.D., McAllister, J.W. (ed.), LaValley, J. (ed.), & Cooley, W.C. (ed.). ***Parent Partners: Creative Forces on Medical Home Improvement Teams. A Guide for Parent and Practice "Partners" Working to Build Medical Homes for Children with Special Heath Care Needs.*** Elk Grove Village, IL: Center for Medical Home Improvement (CMHI). This guide defines and describes the role of parents as partners on the medical home improvement team. It offers insight into how practices can engage families in their efforts to build strong medical homes. http://www.medicalhomeimprovement.org/pdf/CMHI-Parent-Partner-Guide.pdf

Johnson B, Abraham M, Conway J, Simmons L, Edgman-Levitan S, Sodomka P, et al. ***Partnering with patients and families to design a patient- and family-centered health care system: recommendations and promising practices***. Bethesda, MD: Institute for Patient and Family-Centered Care, Institute for Healthcare Improvement with support from the California HealthCare Foundation; April 2008. This report highlights conference discussions including hospitals, ambulatory programs, medical and nursing schools, funders of health care, patient- and family-led organizations, and other health care entities. Examples of best practices in supporting and engaging patients and families are shared. http://www.ipfcc.org/pdf/PartneringwithPatientsandFamilies.pdf

Malouin, R.A. ***Positioning the Family and Patient at the Center: A Guide to Family and Patient Partnership in the Medical Home.*** Elk Grove Village, IL: American Academy of Pediatrics and Center for Medical Home Implementation, 2013. This monograph focuses on case studies of 17 pediatric practices nominated by their peers or patients as exemplary patient- and family-centered medical homes. http://www.medicalhomeinfo.org/downloads/pdfs/Positioning_FINAL_May24.pdf

McAllister, J.W., Cooley, W.C., Van Cleave, J., Boudreau, A.A., & Kuhlthau, K. ***Medical home transformation in pediatric primary care–what drives change?*** Leawood, KS: Annals of Family Medicine. May-June 2013; volume 11, supplement 1:S90-8. This study analyzed and identified common elements in medical practices that were highly effective in transforming to successful medical homes. http://www.annfammed.org/content/11/Suppl_1/S90.long

National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care. Rockville, MD: United States Office of Health and Human Services, Office of Minority Health. This guidance is intended to advance health equity, improve quality and help eliminate healthcare disparities by providing a blueprint for individuals and health and healthcare organizations to implement culturally and linguistically appropriate services. http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=53

Patient- and Family-Centered Care and the Pediatrician's Role. Elk Grove, IL: Pediatrics. February 1, 2012, volume 129, number 2, pp. 394 -404. The American Academy of Pediatrics offers a policy statement that outlines the core principles of patient- and family-centered care, summarizes some of the recent literature linking patient- and family-centered care to improved health outcomes and lists various other benefits of engaging in patient- and family-centered pediatric practice. The statement concludes with specific recommendations for how pediatricians can integrate patient- and family-centered care in hospitals, clinics, community settings and in broader systems of care. http://pediatrics.aappublications.org/content/129/2/394.full

Schaefer, J., Van Borkulo, N., Morales, L., Coleman, K., Brownlee, B., Phillips, K.E., & Weir, V., eds. ***Patient-Centered Interactions: Engaging Patients in Health and Healthcare. Safety Net Medical Home Initiative Implementation Guide,*** second edition. Seattle, WA: Qualis Health and the MacColl Center for Health Care Innovation at the Group Health Research Institute, 2013. This guide provides an overview of medical home transformation, specifically addressing the components of patient- and family-centered care. http://www.safetynetmedicalhome.org/sites/default/files/Implementation-Guide-Patient-Centered-Interactions.pdf

Scholle, S.H., Torda, P., Peikes, D., Han, E., & Genevro, J. ***Engaging Patients and Families in the Medical Home.*** Rockville, MD: Agency for Healthcare Research and Quality. June 2010. This document looks at patient and family engagement through the lens of active participation in care decision, in practice improvement and policy development. Through systematic analysis, this material reviews the rationale, provides examples and identifies the issues encountered in partnering, offering reasonable solutions leading to more meaningful engagement. http://pcmh.ahrq.gov/sites/default/files/attachments/Engaging%20Patients%20and%20Families%20in%20the%20Medical%20Home.pdf

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