

Creating a Patient and Family Advisory Council: A Toolkit for Pediatric Practices



Contents

- **Introduction and FAQ**
- **Step One:** Assess Practice Readiness
- **Step Two:** Recruit Members
- **Step Three:** Engage and Involve
- **Step Four:** Sustain, Evaluate and Improve
- **Index of Resources**
- **Annotated Bibliography**

Do you have feedback on the toolkit or suggestions to make it better? Let us know! Email us at communications@nichq.org.

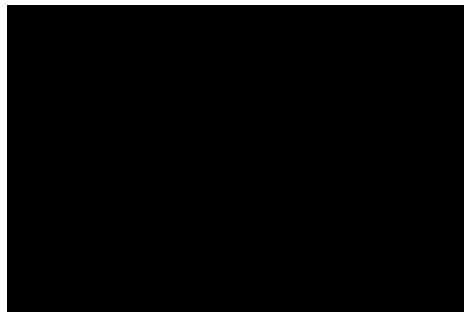
Introduction

Forward-thinking pediatric practices all over the country are forming patient and family advisory councils. As the “customers” of the practice, patients and families bring experience and expertise that can help enhance service delivery and improve overall quality. Practices that encourage, value and utilize family perspectives and experiences in planning for high quality medical care can accelerate their path toward becoming truly patient- and family-centered.

This toolkit is designed to help your pediatric practice build a system for listening to this feedback – by creating your own **Patient and Family Advisory Council (PFAC)**. The kit provides step-by-step guidance on how to effectively engage family perspectives in the design of services and to improve overall quality in the delivery of those services. These resources will help medical practices ensure that meaningful dialogue is established and maintained and that services for families are responsive to their needs.

This toolkit is a product of the Family-to-Family Health Information Center at the Federation for Children with Special Needs, Mass Family Voices and NICHQ. Together, we have tapped into the extensive experiences of family members who are regularly supporting other families. In this regard, this toolkit is the result of peer-to-peer efforts to inform medical professionals and staff of practical ways to ensure the services families receive are high quality and on target.

Funding for this toolkit was provided by a Physicians Foundation grant to Massachusetts Health Quality Partners (MHQP).



VIDEO: Cristin Lind, a Program Associate and Family Leader for Massachusetts Family Voices, introduces NICHQ's online PFAC toolkit. Ms. Lind serves as a family faculty member for NICHQ's Massachusetts Medical Home Initiative and is a member of NICHQ's Board of Directors. <https://vimeo.com/56029160>

Background

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 merely the expertise and tools to make this happen. The toolkit seeks to fill some of that gap.

Commitment to family involvement begins with top leadership who provide the guidance, flexibility and resources to ensure that family involvement is encouraged and proactively sought. It is not enough to simply invite family members to participate in a meeting. More context must be provided and deeper relationships created.

Meaningful family involvement is an ongoing process where interested and affected family representatives are consulted and included in the decision making of the organization. To be truly effective, family involvement in the PFAC should include:

- A thoughtful process in which diverse family representatives in the midst of a sensitive environment are invited to express their satisfaction and concerns based on their personal experiences with the organization.
- Assurances that everyone involved has adequate information and the necessary support to understand the materials being presented and make a meaningful contribution to the discussion.
- Clarity on the roles and responsibilities of all council participants.
- Clear processes for collecting information and supports to encourage full participation.
- A plan to ensure that recommendations from the PFAC are considered and that regular feedback is relayed to those who participated.

We welcome you to explore the ideas and resources contained in this toolkit and wish you good luck in creating your own Patient and Family Advisory Council.

Frequently Asked Questions (FAQ)

What are some specific things PFAC do?

In addition to providing feedback about their general experience as patients and families, PFACs can also complete hands-on work, act as a liaison between the practice in the community, and much, much more.

Our hospital or community health center already has an advisory council. How will our practice PFAC be different?

Practice and hospital PFACs are similar in their purpose - they are both used as a way to gather information from patients and families. Practice PFACs however can provide feedback to practice leadership on a more specific level. Practice PFACs can sometimes function more like on-going focus group and allow a practice to drill down into consumer experiences in a way that hospital PFACs cannot. Practice leadership may also be able to provide feedback to their own practice PFAC members in a way that they cannot to hospital PFAC members.

Hospital and practice PFACs also often differ in their available personnel and financial resources. For that reason, practice PFACs may not require or be able to maintain the same formality of structure such as bylaws, officers, application processes and term limits.



VIDEO: Representatives from Holyoke Pediatric Associates and South County Pediatrics, two practices participating in NICHQ's CHIPRA Massachusetts Medical Home Initiative, discuss their experiences in creating a Patient and Family Advisory Council (PFAC). <https://www.youtube.com/watch?v=3L-bXQ0VCXk>

What are some other ways we can get patient and family feedback about their experience in our practice?

PFACs are but one in a spectrum of structured activities designed to capture the voice of the consumer. Other ways include:

- Patient experience surveys and market surveys
- Focus groups and in-depth interviews
- Information forwarded by customer contact associates
- Individual patient and family communications captured through emails, letters and contact centers
- Suggestion boxes
- Customer-generated and social media
- Patient/family leadership involvement on quality improvement teams
- Patient/family faculty or training in professional development
- Discovery Shopping or shadowing patients on visits ([watch the video below](#) about the "Footsteps of Patient" exercise)

Developing a strategy that systematically captures patient and family feedback in a variety of ways will help your practice be responsive, provide family-centered care, and be more targeted in your improvement initiatives.



"Walking in the Patient's Footsteps" is an innovative program that Dr. Soma Stout started at the Revere Family Health Center in MA that allows a medical student to shadow a patient through their primary care visit to get a true sense of what the patient experience is. <http://www.youtube.com/watch?v=u5vhYBVpZ4w>

What are some things we should encourage patients/families to think about when deciding whether to join our practice's PFAC?

Joining a PFAC can be an opportunity for patients and families to use their personal experiences to improve your practice for themselves as well as others. Depending on your practice's PFAC structure, participating in a PFAC may require a commitment of a patient's or family's time and energy. Here are some questions that can help patients and/or families decide if joining your practice's PFAC is right for them:

National Institute for Children's Health Quality

1. Am I pleased at the prospect of providing information to the practice about how their policies affect my family?
2. Do I believe I can suggest some variations on how they do things that will be helpful to others?
3. Am I able to separate out my views about my own child/ren from overall issues and themes?
4. Do I want to be a good role model to help other parents express themselves in a comfortable way?
5. Can I commit the required time?
6. Do my viewpoints reflect my experiences as a family member of a child or youth with special health care needs and/or a family member of typical children?

Step One: Assess Practice Readiness

Overview

A Patient and Family Advisory Council (PFAC) can provide a critical feedback loop that enables practices to enhance service and improve quality. Best practices in patient and family involvement show that engaging patients and their families in meaningful ways improves services, makes service delivery more responsive to the needs of families, and ultimately saves resources. Strong family involvement can lead to better service delivery and improved health outcomes.

A thriving PFAC requires some planning and effort to get it off the ground, even before a single member is recruited. Every high-functioning, engaged PFAC needs to receive support and resources from practice leadership and staff early to ensure its success.

Is Your Practice Ready for a PFAC?

Your practice may be considering creating a PFAC for a number of reasons. You may feel that a PFAC is an effective way to listen to your patients and families talk about their experience with your practice. You may also be in the process of transforming your practice into a medical home using guidelines or tools like [NCQA Medical Home Standards](#) or the Center for Medical Home Improvement's [Medical Home Index](#). Both require or encourage that practices demonstrate continuous quality improvement initiatives and patients and families are part of this process.

Regardless of why your practice is considering a PFAC, creating one requires the commitment of resources from your practice, leadership and staff. You will benefit from assessing your readiness in order to determine what resources your practice possesses and what it lacks.

We welcome you to explore the ideas and resources contained in this toolkit and wish you good luck in creating your own PFAC.

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 experience. Setting aside time at a staff meeting to discuss a possible PFAC early in the process is critical to future engagement.

Some staff resistance may be due to a lack of information about what PFACs do. [This video](#) from MaineGeneral's PFAC may be helpful to show staff to give them a general vision of how patients and families are getting involved at other organizations.

Ultimately, acknowledging and assuaging concerns is critical to meaningful family-professional partnership. This [self-assessment](#) contains some questions that can facilitate an open, honest conversation.



VIDEO: This video, from MaineGeneral's PFAC, may be helpful to show staff to give them a general vision of how patients and families are getting involved in PFAC's at other organizations. http://www.youtube.com/watch?v=luxHx4Va_EE

Creating a PFAC Launch Team

Once your practice has determined that it is ready to support a PFAC, a team can be convened to manage the launch. One practical way to do this is to create a small PFAC launch team which includes practice members who have the authority to commit resources and the time available to do the necessary work to get the PFAC off the ground. This often means including someone in a leadership role as well as someone with administrative expertise.

Authentic patient and family engagement means including them not only in the evaluation of your practice, but also in the planning and implementation of the PFAC launch itself. The earlier the patient and family voice is included in the process, the more authentic your PFAC will be.

Creating a PFAC launch team that includes leadership, staff and a family member is one way you can ensure that both adequate resources and a genuine patient and family perspective are present right from the start.

Here are some possible roles and responsibilities for a PFAC launch team.

PFAC Champion

A leader of the practice who values family-professional partnerships.

- Confirms practice readiness and supports the work of the PFAC liaison (see below) by securing financial and personnel resources and negotiating the removal of barriers with other leaders in the practice.
- Defines the purpose of the PFAC and ensures its alignment with other leadership activities.
- Determines the general structure of the PFAC.
- Advocates for the PFAC with staff and leadership and keeps leadership informed about PFAC activities and accomplishments.
- Helps to recruit patients and families. Provides PFAC launch team with data on practice demographics to support the recruitment of PFAC members who reflect the culture and experience of all patients and families.
- Ensures that recommendations of the PFAC are implemented in practice policy and works with PFAC leadership to communicate improvements back to PFAC members.
- May attend PFAC meetings.

PFAC Liaison

A staff member of the practice who values family-professional partnerships.

- Acts as an active link between the PFAC and the practice.
- Works closely with the PFAC champion to launch and sustain the PFAC.
- Coordinates the launch of the PFAC: creates recruitment materials and plans, recruits and selects interested members.
- Prepares and distributes pre-meeting materials.
- Books meeting space and coordinates logistics, such as parking and catering needs.
- Supports the PFAC chair or co-chairs in the planning and facilitation of PFAC meetings.
- Works with PFAC chair or co-chairs to identify training needs and materials for members and staff.
- Creates a budget for PFAC activities.

PFAC Launch Partner(s)

One or more patients or family members who have some family leadership or advocacy experience and value family-professional partnerships.

- Assists the PFAC champion and liaison in launching the council and represents the patient/family perspective until a chair/co-chair is selected by the PFAC.
- Reviews or co-creates the recruitment material, recruitment plan, selection process and first meeting agenda “through the eyes of the patient/family,” to ensure that they are patient- and family-centered.
- Functions as the family voice in facilitating early meetings until a chair/co-chair are identified. May transition into role of chair/co-chair officially after the PFAC launch.

Clarifying the Structure of Your PFAC

There is no single model for a successful PFAC. They vary in the formality of their structure and size, as well as in their frequency of meetings. Some PFACs are highly structured, with bylaws, officers, term limits, applications and a formal interview process. Others are much less structured, functioning more as a series of stand-alone focus groups open to any patient and family member who wants to attend. However, a focus group, while helpful, is not a substitute for the establishment of a PFAC. It is possible to start with a less formal group and let it organically evolve. Our goal with this toolkit is to urge practices to move toward full patient and family engagement and quality improvement strategies.

As your practice assesses which PFAC structure is right for you, here are a few considerations:

Informal, Focus Group-Style PFAC Structure

Advantages

- Requires less work to get it off the ground
- Easier to become more structured over time than vice versa
- Can engage more patients and families
- Open to any patient/family member; no need to turn anyone away
- Ensures a wide range of perspectives if promoted and facilitated effectively

Disadvantages

- Lower level of engagement from members
- Difficult to sustain a conversation with same members over time
- Some time spent on orientation/introductions at every meeting
- Informal nature makes it easy to put off as a practice priority
- Easy to skip important steps

Traditional, Formal PFAC Structure

Advantages

- Creates deeper, longer term relationships with and among members
- Allows members to increase their skills and knowledge of your practice
- Clear guidelines and term limits
- Opportunity to screen for particular skills and traits
- Accountability to bylaws ensures that meetings happen regularly
- Opportunity for thoughtful planning

Disadvantages

- Requires more work to launch
- Engages fewer patients and families

Transitional Informal-to-Formal PFAC Structure

Advantages

- By launching informally and becoming more structured over time, as capacity and leadership are identified, this structure shares the advantages of both models

Disadvantages

- May require more active leadership to facilitate the ongoing transition

Clarifying the Purpose of Your PFAC

The PFAC purpose and structure that is right for your practice will be based on your practice's resources and needs as well as the needs of your patients and families. The PFAC champion is likely in the best position to ensure that the PFAC aligns with the practice's goals and vision. He/she may also be able to best assess the practice capacity and guide the process for determining your PFAC structure. Other members of the PFAC launch team and the practice can also be asked for feedback and ideas.

This worksheet contains some questions to help you identify your PFAC's purpose and determine the right PFAC for your practice. Let the answers to these questions be your primary guide when creating a purpose statement for you PFAC. A few examples from established PFACs are available below for reference.

Purpose Statement: *The Massachusetts General Hospital for Children's Family Advisory Council (MCHC PFAC)*

The Massachusetts General Hospital for Children's Family Advisory Council is dedicated to fostering the partnership of parents, children and professionals working together to ensure a climate of responsiveness to the needs of children and their families in all areas of care delivery within Massachusetts General Hospital. The council's goals are to align with the broader Mass General/MGHC goal of enhancing patient-physician communication by fostering family-centered communication and promoting the principles of patient- and family-centered care:

- *Dignity and Respect:* Honoring patient and family perspectives, choices, knowledge, values, beliefs and cultural backgrounds.
- *Information Sharing:* Communicating and sharing complete, unbiased, accurate and timely information with patients and families so they can effectively participate in care and decision-making.
- *Participation:* Encouraging and supporting patient and family participation in care and decision-making at the level they choose.
- *Collaboration:* Partnering with patients and families in the delivery of care; policy and program development and evaluation; healthcare facility design; and, professional education.

Purpose Statement: *BJC HealthCare Patient and Family Advisory Council*

To serve as a formal mechanism for involving patients, family and staff as partners for policy and program decision making in healthcare settings.

Purpose Statement: *The Missouri Baptist Medical Center Patient and Family Advisory Council*

The Missouri Baptist Medical Center Patient and Family Advisory Council will be a partner with the Missouri Baptist Cancer Center team, involved in decision making and committed to creating an environment of safety, dignity, respect and honesty to assure the very best for patients and families.



- For practices that have decided to launch a less formal PFAC, skip ahead to Step 2 of the PFAC Toolkit.
- For practices that have decided to launch their PFACs through a more formal structure — including bylaws and an application process — please continue to the end of Step 1.



Creating PFAC Bylaws

Most PFACs working at the hospital level require bylaws as a way of establishing transparent guidelines, procedures and expectations. On the practice level, it can be useful to create bylaws as a way of clarifying and communicating expectations to patients and families who are thinking about becoming members. If your PFAC is essentially organized as a series of open-invitation focus groups, you may not need them at first, or at all.

If you do decide to create bylaws, review these [helpful guidelines](#).

IDEA TO TRY

Devote an all-staff meeting to discussing development of a Patient and Family Advisory Council using the resources and tools mentioned above.

Possible Agenda:

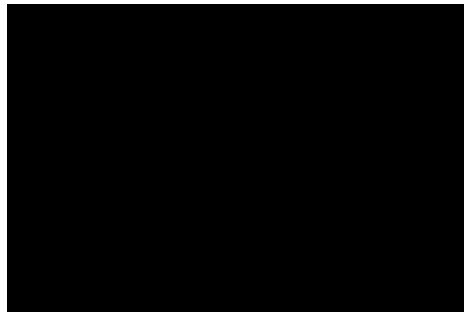
1. Explain the benefits. What can a PFAC help us achieve that we can't do without them?
2. Share [this video](#) from MaineGeneral's PFAC and/or show web reports of other organizations to help staff understand what a PFAC does (*see Introduction*).
3. Encourage an open, honest conversation on concerns using the Staff Readiness Assessment.
4. Discuss the PFAC's purpose and structure using the worksheets in *Clarifying the Purpose of Your PFAC*. Acknowledge that concerns may not have been entirely addressed, but ask staff to answer these questions above as if they were.
5. Circle back to unresolved concerns. Now that you have some clarity on the purpose and structure of your PFAC, have some of these concerns been resolved?
6. Solicit or introduce PFAC launch team members and describe what they will do.

Step Two: Recruit Diverse Patient and Family Representatives as Council Members

Overview

Now that your practice has spent time laying the groundwork for a PFAC, your PFAC launch team is ready to reach out to patients and families. Your next steps depend on what PFAC model your practice has decided is right for you:

- If your practice has decided on a **less formal, focus group-style PFAC** (see *Step One*) as a way to get started, you can focus your efforts recruiting patients and families for your first meeting.
- If your practice has decided on a **formally structured PFAC** (see *Step One*), you will want to set aside time to recruit, interview, select and prepare PFAC members before convening your first meeting.



VIDEO: Representatives from Holyoke Pediatric Associates and South County Pediatrics, two practices participating in NICHQ's CHIPRA Massachusetts Medical Home Initiative, share some tips and suggestions for creating a Patient and Family Advisory Council (PFAC). Source: <http://www.youtube.com/watch?v=DCoFXIiy1Rg>

Recruitment Fundamentals: Creating a PFAC that Represents the Voices of Your Entire Practice

Regardless of your PFAC structure, several fundamental principles apply when it comes to recruitment of PFAC members. Since the essential function of the PFAC is to provide feedback, it's critical that you make every effort to include patients and family members who represent your entire practice.

Fundamental 1: Eligibility

Who can be a member of your PFAC? It sounds like a simple question, but it's more complicated than it seems.

Parents are likely to join. But what about guardians, like grandparents and foster parents? How about caregivers who may not be legal guardians but who are allies of your patients? They might have insights to share, too. Letting families define themselves ensures that all perspectives are included. Former patients and families who

have aged out of your practice can also provide valuable feedback.

What about your young adult and youth patients? Will you engage them? You could set aside one PFAC meeting to focus on teen perspectives. Some practices create special Teen PFACs to ensure that their voices are heard. Giving younger patients opportunities to give feedback through youth-friendly feedback surveys, like a simple postcard, is a wonderful way to encourage engagement from a young age and raise your future PFAC members!

Staff who are also patients/families have a unique vantage point and can be invited to join PFACs. However, it can be difficult for them to share negative feedback about the practice in front of patients and families. Special consideration should be given to their participation.

Too many staff members present in general can also affect the dynamic of the PFAC. Try to maintain a ratio of no more than one staff person to every two to three patients/family members. If staff people want to attend the meetings and there is a risk that staff will outnumber patients/family members, it may make sense to limit staff attendance to the portions of the meeting most relevant to their role. Many PFACs require that more than 50 percent of the membership be held by non-staff patients and families.

Fundamental 2: Ensuring Diversity

Recruiting a PFAC membership that reflects the diversity of your entire practices takes effort. There are many types of diversity, including gender, race, culture/heritage, age (of patients and of family members), language, socio-economic background, disease or disability, family structure and sexual orientation.

Here are some ideas for encouraging diversity as you recruit PFAC members:

- Ask staff for ideas on recruiting for diversity.
- Remove as many barriers to participating as possible. Offer childcare, food, parking vouchers and even stipends in the form of cash or a gift certificate to a local grocery store as recognition of members' contribution of time.
- Ask patients and families what accommodations would allow them to attend.
- Have the invitation and recruiting materials translated and make arrangements for interpreters at your meeting.
- Use simple and welcoming language and make sure it is easy to read.
- In recruiting materials, using the term "family" instead of "parents" and allowing families to define themselves helps to include a wide range of voices.
- Make a special effort to reach out to both parents. Providing child care, for example, makes it easier for both parents to attend. For some families, both parents may not think to attend — so ask!
- Seek help from others in your organization who have expertise in multi-cultural affairs or who have close community connections.
- If possible, connect with community organizations that may have recommendations or referrals for your patients.
- Create a recruitment plan so that you have enough time to publicize.

Clarifying PFAC Membership Expectations

Understand your expectations of commitment before you start asking. Clearly communicating expectations can help avoid unnecessary conflict and confusion. For example, a document similar to a job description outlining the following points can help both your practice and the applicants.

Membership Expectations Overview

Use this list to clarify what you're asking of members. The document outlining membership expectations should contain the following:

- *General Summary:* A few sentences about your practice and the PFAC purpose.
- *Duties and Responsibilities:* Describe what PFAC members will do, how often they will meet, term appointment, etc. If a minimum number of meetings are mandatory, be upfront about that.
- *Skills and Abilities:* List the useful or preferred qualities. See below for more information.
- *Application Process:* Explain how to apply.
- *Special Requirements:* Describe any special requirements that PFAC members will be required to complete, such as completing a CORI check or drug screen, or providing a social security number.

Qualities and Skills of Patient and Family Advisors

There are a number of leadership and collaboration skills that have been identified as crucial to success on advisory councils. Here are a few qualities and skills of patient and family advisors identified by the Institute for Patient and Family-Centered Care [See Bibliography]:

Seek individuals and families who are able to ...

- Share insights and information about their experiences in ways that others can learn from them
- See beyond their personal experiences
- Show concern for more than one issue or agenda
- Listen well
- Respect the perspectives of others
- Speak comfortably in a group with candor
- Interact well with many different kinds of people
- Work in partnership with others

Recruitment Planning

Whether you're trying to recruit patients and families to apply for formal PFAC membership or to simply attend an open PFAC meeting, you need to get the word out.

As a team, brainstorm on all the possible ways you can invite patients and families to join in on PFAC activities. Using multiple outreach techniques will ensure that your message reaches a wider audience.

Recruitment Materials, Samples and Templates

Here are some recruitment materials, samples and templates that your practice may want to use.

- [Flyer for First PFAC Meeting](#)
- [Recruitment Plan Worksheet](#)

Conducting Informational Meetings with Interested PFAC Members

In-person meetings are an effective way to get to know the patients and families interested in joining your PFAC. It's a chance to explore the values, needs and skills of both you and the interested patients and families. Every meeting is a chance to build relationships with patients and to have a conversation about what matters to them and how you can partner to make a difference. Use these meetings to confirm that patient/family members are a good match for your PFAC, to learn more about what might prevent them from 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 your 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. Consider holding the meeting at a location like a coffee shop that is convenient to the patient/family member. 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.)
- **Challenges:** What keeps you from action? What do you fear? What would you want to learn? What might prevent you from fully engaging? (Discover barriers to participation.)
- **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.)

If your practice has decided on a formally structured PFAC, you will want to set aside time to recruit, interview, select and bring on board PFAC members before convening your first meeting.

For practices launching a more informal PFAC, you'll need to finalize certain details regarding your first meeting so that you can include the information on your invitation. The [invitation checklist](#) below is a list of things to consider when planning your first meeting.

- **What?** Describe the meeting and the focus of the meeting. If you're only going to be asking questions about a specific aspect of your practice, it's important to let people know ahead of time. See **Step 3** of the PFAC Toolkit for more details on how to create a framing question.

- **When?** Pick a date and time that is convenient for the greatest number of families. Weeknights are usually best.
- **Where?** Let people know where you'll be meeting. If the practice has different security/parking procedures during the time you're meeting, let everyone know.
- **How?** Include details on what you'll be offering, such as child care, interpreter services, food, parking vouchers, stipends for time and transportation.
- **Why?** Explain what your practice will do with the feedback.
- **Other Information:** Include contact details if people have questions or to RSVP. Encourage them to bring a friend who is also a patient or family member of the practice if that is appropriate. Invite people to be in touch if they're interested in participating in the future but can't make this meeting.

PFAC Member Selection and Orientation

Some PFACs will benefit from formal and specific membership, and others may wish to be less formal and more open. There are advantages and disadvantages to each style.

Limited vs. Open Membership

Having a set team can foster relationship and commitment, but interviewing and selecting patients can feel uncomfortable if you're worried that turning people away will jeopardize the relationship between the patient/family and the care team. If your PFAC will only contain a limited number of members, let applicants know you will be choosing a cross section of families (age, disability, care team) at this time and that future opportunities will also be available.

You may realize through the informational meeting process that a particular person isn't the right person for the role. If candidates are not selected to serve on your PFAC, take the time to tell them and think about ways to engage them now or in the future. If the interview process helped you learn enough about the patients so that you can identify other ways that they can participate and contribute, share that with them. For example, you could put them in touch with a hospital or community committee or council or ask them to give feedback on a specific issue that they seem knowledgeable about. There may be a smaller project that they could work on that you would both feel good about, like [Discovery Shopping](#) or shadowing other patients during their visits to discover more about patients' experiences. (See this [Walking in the Patient's Footsteps](#) video for more information.)



*"Walking in the Patient's Footsteps" is an innovative program that Dr. Soma Stout started at the Revere Family Health Center in MA that allows a medical student to shadow a patient through their primary care visit to get a true sense of what the patient experience is. **Source:***

<http://www.youtube.com/watch?v=u5vhYBVpZ4w>

Confirming Membership

Regardless of how members are selected, confirming membership in writing is an opportunity to ensure the PFAC member's understanding of what he or she will be doing. Be sure to use simple, straightforward language. It can include:

- Details about membership
- Instructions on next steps, like paperwork procedures or orientation dates
- The name of a person to contact with any questions

Here is a [sample membership agreement letter](#).

Orientation for New PFAC Members

Your organization may have paperwork requirements for new volunteers and staff. Check with your human resources department, volunteer department or hospital PFAC liaison (if you have one) regarding these requirements. Those departments may also be able to help you in creating an orientation for new board members.

If you need to design an orientation yourself, consider including the following orientation components from the Institute for Patient and Family-Centered Care [See Bibliography]:

- Introductions and the sharing of personal and family stories
- The vision and goals of the organization
- The purpose statement of the PFAC
- The role of the council, how it fits within the organization's structure, and
- how it can assist the organization in achieving its vision and goals
- The roles and responsibilities of members
- The roles and responsibilities of officers

National Institute for Children's Health Quality

- HIPAA and expectations for honoring privacy and confidentiality
- Meeting attendance expectations of members
- The roles and responsibilities of staff on the council
- How to be an effective council member
- How to present issues effectively
- How to be most effective in collaborating with hospital/clinic staff and faculty

In addition, you could also give new members a tour of the practice and introduce key staff. Most importantly, use orientation as an opportunity to show your gratitude for new member participation by creating a welcoming experience and creating a warm, hospitable environment.

Step Three: Support the Process of Authentic Family Engagement and Involvement

Overview

Supporting family advisors to become effective and authentic contributors to your PFAC and to quality improvement in your practice is an intentional process. It requires logistical support for the participants to remove barriers to participation and assist everyone — advisors and staff — to develop the skills to participate with success. Ignoring critical issues can undermine your PFAC and create a sense of frustration and/or failure to achieve your desired outcomes of patient- and family-centered practice improvement.

Some advisory councils report such things as:

- "Our meetings sometimes last for hours, without results."
- "One person dominates our meetings; I wish everybody would speak up."
- "We can't seem to sort out our priorities; we head off in all directions at once."
- "We make decisions, but then revisit them again and again."

As a practice leader who designs, leads, facilitates or manages the work of your PFAC, you have the opportunity to prevent or solve issues like these.

Consider these two key principles:

1. Meaningful family involvement is something to be valued and supported by the practice.
2. Family advisors, like any of the professionals involved in a practice and PFAC, function best with consistent support, clear expectations, understanding of the skills needed and a simple orientation to the tasks they are being asked to do.

Practical Supports to Enhance Effective Involvement

If your practice has come this far in creating a PFAC, you already recognize and appreciate the value that family advisors bring. If you want your patients and families to fully participate — and participate more than once — it's critical to remove the barriers that prevent real engagement. Ensure reasonable accommodations for meeting participants by considering the following.

Meeting Logistics

Give consideration to meeting time, accessible locations, transportation concerns and child care needs. Family advisors have limits on their time and resources which inhibit their ability to participate. For example, family advisors may not have gainful employment outside of their homes or may need to take unpaid time away from their jobs to participate. These types of circumstances need to be anticipated and policies, such as modest stipends, can prevent those obstacles from becoming limiting factors. Practices which chose not to address these issues often find that PFAC members do not represent the diversity of their entire practice or that they cannot sustain engagement over time.

Preparing Meeting Materials to Enhance Family Participation

Depending upon the Family Advisors' level of experience, pre- and post-meeting support may be needed. If a family advisor is unfamiliar with the processes of the practice or the PFAC itself, it may be helpful to hold a pre-

meeting orientation session to review key concepts and procedures.

Also remember to consider health literacy and the reading level of all PFAC participants. You should assume jargon isn't understood by all members. Consider providing a list of commonly used acronyms and a reference sheet for important medical words and terms to be discussed.

Finally, become familiar with [Universal Design for Learning \(UDL\)](#) and how it relates to auditory and visual presentation of materials. Incorporating some basic principles of UDL can make it easier for all PFAC members to enhance access to your information and materials.

Adopting a Meeting Structure that Facilitates Engagement

Be sure to create a welcoming space. Have staff present to welcome everyone, then let a family advisor facilitate the meeting. Use an agenda and walk attendees through it at the beginning, then stay on task.

Before opening up the discussion, ask the group to create some guidelines for the meeting. Capture these guidelines on a large poster and display and confirm them at each meeting. Examples of guidelines might include:

- Confidentiality: What happens here, stays here.
- Don't feel you need to share if you don't want to or aren't ready.
- Keep the tone collaborative by avoiding "us and them" language.
- Keep meetings jargon-free.
- Let everyone have a chance to share.
- Avoid using individual names when something didn't go well.
- Think about how your experience connects with the bigger picture.
- Recognize that this is not a forum to resolve issues for a specific individual.

When new material is distributed, allow time for review if content is directly relevant to the discussion. You should also take care to structure activities so that everyone has a chance to share their view. For example, when asking a question of the group, give participants paper and pens to write down their ideas, then review them one-by-one as a group.

Finally, end on time and have staff say "thank you!"



• If your meeting is being conducted like a focus group, see Step Three: Focus Groups below.

• If you are conducting a more formalized meeting, skip down to Step Three: Understanding Family Leadership Development.



Focus Groups

If your practice has decided to conduct a focus group as a way to launch your PFAC, here are some ideas and resources to help.

- [Tips for Using a Focus Group Format in a PFAC Meeting](#)
- [Helpful Phrases for Facilitating Focus Groups](#) (Bright Futures for Families)

Understanding Family Leadership Development

Family advisors provide a valuable service by contributing their perspectives as consumers of services to the practice. Family advisors deserve respect and appreciation for their willingness to share their personal thoughts. They have an important role to fulfill as leaders in your efforts to improve your practice. Remaining open to the insights of PFAC members will benefit the discussion.

Family Voices and other family groups, through many years of experience working with PFACs, have learned that when respected and listened to as leaders, family advisors can make a profound difference in the quality of services.

“The practice of leadership requires, perhaps first and foremost, a sense of purpose — the capacity to find the values that make risk-taking meaningful.”

Ron Heifetz, *Leadership Without Easy Answers*

Survey of Parent Leaders

A simple survey of expectations of parent leaders provides insight into simple yet profound learning. Parent leaders were asked by Massachusetts' Federation for Children with Special Needs to respond to four questions:

1. What kinds of information do you need as a leader?
2. What would you most like to accomplish during the activities?
3. What would you consider doing to encourage other parents to become parent leaders over the next year or two?
4. What do you hope your advisory council will accomplish working together?

Replies fell into two essential issues:

Family advisors want to understand their role as a leader.

- To determine if I can be of value as a leader. I want to give back to my community.
- I would like to gain knowledge and confidence to help other parents.
- I hope to become a more effective leader.
- Develop some skills in moving important issues forward within our community without looking like a group of disgruntled parents.
- Gain leadership and negotiation skills.
- Be able to advocate for my son and others who do not have a voice but need help to fit into society.

Family advisors want to understand what their involvement will lead to — they want to make a difference. Here are some sample comments from some family advisors. When asked, “Why did you become involved in a family advisory role?” responses included:

- I wanted to knit together my son’s services as a cohesive system of supports.
- To be more connected to our community.
- To get more parents to come out and get involved, and to collaborate more.
- To learn what does and doesn’t work in other communities.
- To learn how we can best support our families, work with school administration, medical community and recreation.
- To build a consensus, team approach to problem solving with the service providers in my community, schools, medical and social services.

This list shows how many themes are on the minds of parents and family leaders as they come together. They focus on their own children, but also have a wider view of the needs of the community. They also are looking for self-development as leaders who will value training and leadership opportunities as they expand into other realms of participation.

Family Advisors Work Best When Viewed as Part of a Team

This section addresses how to measure the readiness of a group for working together. First we need to define leadership and what roles are particular to parents when engaging in activities as parent leaders. [This document](#) includes a list of some of the most important characteristics of effective family advisors.

Essential Skills Development for Family Advisors and Practice Staff

In addition to the meeting details and logistics, PFAC facilitators will want to provide opportunities for family advisors and practice staff to develop and practice essential skills, which ensure the highest possible levels of engagement.

Below are some essential skills along with activities you can use within your own PFAC meetings to support both families and staff. The learning modules/resources will help PFAC 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.

Skill 1: Storytelling

Family advisors are first and foremost story tellers of their own experiences. PFAC advisors are called upon to reflect and report on their personal experiences with access to healthcare and of the quality of services. Learning to tell a personal story in such 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 story as well as the many ways the listeners might hear it.

Skill 2: Self Awareness and Identification

Self awareness greatly enhances leadership in many settings. 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.

Skill 3: Deep Listening and Respectful Conversations

Improving communication skills around deep listening and respectful conversations allows diverse, and perhaps controversial, perspectives of team members to all 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 PFAC members.

Exercises

Here are a number of short exercises you can use with your PFAC to cultivate skills for deep listening and respectful conversations. These exercises can all be found in the [Additional Resources](#) PDF.

Deep Listening

Understanding Difficult Conversations

The Feelings Conversation

The "What I Really Want" Conversation Method

The ORID Conversation Technique

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.

Skill 4: Conflict Resolution and Cultural Competency (Intercultural Collaboration)

At its core, the function of the PFAC is to bring together a variety of experiences to generate new ideas which improve patient care. An effective PFAC will bring together a variety of perspectives, voices and essentially 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 development of the PFAC in this regard involves helping members to develop skills which 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 own attitudes and behavior. It also necessitates that one acquires 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.

Exercises

The following learning modules will help PFAC members develop some necessary skills for intercultural collaboration.

[Early Memories](#)

The purpose of this exercise is to understand the role of reciprocal relationships to help PFAC members empathize and support people from other cultures and backgrounds. Early memories reflect our experiences that have shaped our views of differences.

[The Brick Wall and the Gateway](#)

This exercise is intended to help individuals reflect on the experience of respectful conversations and identify best practices. It may also result in a set of meeting guidelines.

Resource: [National Center for Cultural Competence](#)

Step Four: Sustain and Evaluate Your PFAC

Overview

Creating a vibrant, active PFAC takes more than simply bringing people together. Financial and administrative resources as well as a practice's willingness to engage in the partnership process are required to engage patients and families so that they don't just come once, but keep coming back to contribute their ideas and opinions.

Like all teams and organizations, PFACs need continuous evaluation to identify ways to improve and to identify the ways in which your PFAC has been successful. If they are to be sustainable, they also need an ongoing commitment from the entire practice.

Sustaining Your PFAC

One effective method of sustaining commitment to your PFAC is to continuously share their accomplishments with your practice. The PFAC champion and PFAC liaison can act as promoters for the PFAC, seeking out as many ways as possible to spread the word about how the PFAC has changed your practice.

You can use this [PFAC Sustainability Worksheet](#) to help you think of ways to promote the work of your PFAC. If your organization has a marketing and communication team, they may be able to help you with this step.

Evaluating Your PFAC

PFAC members will keep coming back if they feel that they are valued and that they are making a difference — in essence, if they feel there is an authentic family-professional partnership. By involving PFAC members in your evaluation activities, you can incorporate their feedback into the work that you do, which can in turn foster engaging and rewarding partnerships. Evaluation allows you to judge the success of activities that you undertake to develop your PFAC, thus acknowledging what is working well, and also 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 to identify areas for improvement in addition to identifying areas that are going well, and track overall progress towards the aim of your PFAC. Such evaluation can then inform the strategies that you utilize for strengthening the partnership. Evaluation can demonstrate areas of success as well as areas that are not working well, which can provide valuable information on how to continually improve your PFAC. There are a number of measures that evaluate this partnership from a practice's and patient and family member's perspective.

Below are excerpts or adaptations from a number of different assessment tools that measure patient-professional partnerships broadly and PFACs specifically. Select one tool that most closely measures what is important to your

practice and commit to using it on a regular basis, such as every six months. Keep track of your data in a simple spreadsheet, such an excel spreadsheet, to monitor changes in your data over time.

- **Consumer Involvement Scale**
- **Medical Home Index**
- **Family-Centered Care Self-Assessment Tool**
- **Medical Home Family Index and Survey**
- **Checklist for Involving Families as Advisors and Consultants [Adapted]**

We suggest that your 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 next time you collect data.

Consumer Involvement Scale

As part of their Consumer Involvement Toolkit, Consumer Quality Initiatives, Inc. developed the following scale to describe a progression of consumer involvement. Applying this scale to both PFAC governance and the influence of PFAC activities on practice policy can be a helpful measure in assessing authentic partnership.

Level	Description
6	Consumers have control, with guidance from organization
5	Consumers agree to make certain decisions about the project, or are delegated to make such decisions
4	Consumers plan/work jointly with staff to make decisions
3	Consumers advise staff
2	Consumers are consulted intermittently
1	Consumers receive information
0	None

Table developed by Jonathan Delman, JD, MPH, PhD and Consumer Quality Initiatives, Inc.

Let's start by using the scale to determine the level of patient/family involvement in PFAC governance (i.e. who creates and runs it). Starting at the lowest level, patients receive and contribute no information about the possible creation of the PFAC.

- At Level 1, they receive information but are not consulted.
- At Level 2, they give intermittent feedback, perhaps helping the practice to determine the best way to launch.
- At Level 3 and 4, there is an increasing involvement of consumers, similar to the inclusion of a PFAC patient partner on the PFAC launch team; PFAC members may select new members and co-create the bylaws.
- At Levels 5 and 6, PFAC governance is handled by the PFAC membership itself.

Using the scale to assess the impact that patients and families have on practice procedures and policies can also be useful. At the lowest levels, patients and families feedback is not sought. Patients and families might be informed of practice policies but not asked for feedback. Levels 2 and 3 might best represent the involvement level resulting from focus groups and surveys, or PFACs that are asked to give feedback on practice-generated questions. Levels 4, 5 and 6 represent escalating levels of authenticity in the partnership. It may not seem appropriate that patients and families would ever reach level 6, with control of your practice, but challenge yourself to look for opportunities to include their perspective and experience in as many decisions as possible. Implementing the recommendations and feedback of the PFAC is one method of joint decision making.

If you chose to use this scale, you can use it as a self-assessment and you can also ask your PFAC members or member leaders to complete it. Your answers may differ and can provide the basis for a conversation which generates ideas for next steps regarding improving partnerships in your practice.

Medical Home Index

The Center for Medical Home Improvement's [Medical Home Index](#) is a self-assessment tool for practices to measure their progress toward medical home transformation. One section of the index specifically rates family feedback (Domain 1, Theme #1.5) according to a progressive scale of increasing engagement. You may want to consider adding target/goal values for each of the scales (e.g. by X months, goal is to improve by 1 level/or - by x date, goal is to achieve level 3)

- Level 1: Family feedback to the practice occurs through external mechanisms such as satisfaction surveys issued by a health plan; this information is not always shared with practice staff.
- Level 2: Feedback from families of CSHCN is elicited sporadically by individual practice providers or by a suggestion box; this feedback is shared informally with other providers and staff.
- Level 3: Feedback from families of CSHCN regarding their perception of care is gathered through systematic methods (e.g., surveys, focus groups or interviews); there is a process for staff to review this feedback and to begin problem solving.
- Level 4: In addition to level 3, an advisory process is in place with families of CSHCN which helps to identify needs and implement creative solutions; there are tangible supports to enable families to participate in these activities (e.g., childcare or parent stipends).

The optimal level is level 4. You can use the text description in each of these levels to inform the next steps that you can work towards. For example, if you are currently at level 2, you know that you should be working towards what is described in level 3 (i.e. gathering feedback from families through systematic methods).

Medical Home Family Index and Survey

Patients and families can also be asked about their perception of whether the practice is seeking feedback from consumers. The Center for Medical Home Improvement's [Medical Home Family Index and Survey](#) includes two indices.

- I know the practice has conducted surveys, focus groups, or discussions with families (in the last two years) to determine if they are satisfied with their children's care. [Yes] [No]
- I have seen changes made at the office as a result of my suggestions or those made by other families. [Yes] [No]

You may also consider adding an opportunity for open text comments following these two questions to collect more information from respondents on ways in which feedback opportunities could be improved.

Using Quality Improvement Techniques to Improve Your PFAC

The Model for Improvement, developed by [Associates in Process Improvement](#), is a robust and powerful approach for accelerating improvement. Its philosophy of setting an aim, thinking about how to measure progress toward the aim and small tests of change underlie all of NICHQ's improvement work. Around the world, hundreds of health care organizations use The Model for Improvement to improve many different health care processes and outcomes. The Model can be useful in helping you improve your PFAC.

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) cycle** to test and implement changes in real work settings. The PDSA cycle guides the test of a change to determine if the change is an improvement.

The Plan-Do-Study-Act (PDSA) learning and improvement cycle allows you to test a change in the real work setting — by planning it, trying it, observing the results, and acting on what is learned. This is the scientific method used for action-oriented learning and may be a method that you will find useful in thinking about how to improve your PFAC.

See below for an example of how you could use The Model for Improvement to improve your Patient and Family Advisory Council.

Example: Quality Improvement in Action

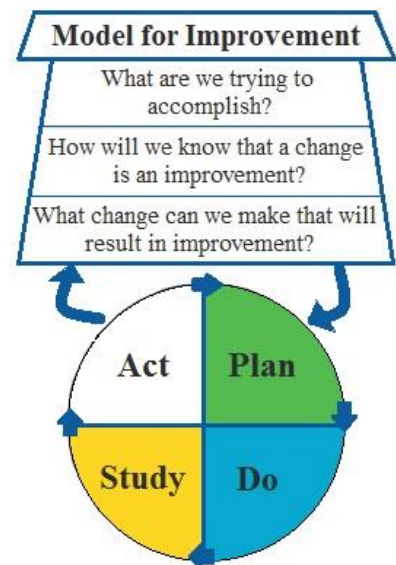
Your clinic or organization has formed its patient and advisory council and just noticed that you lack youth membership as well as representatives from the largest cultural community groups you serve. You could apply the Model for Improvement in the following way:

Set Aims: *What are we trying to accomplish?*

We aim to have a Patient and Family Advisory Council that represents our patient and family constituents. In the next 6 months, we will recruit and orient 2 youth members, and 2 members for the two largest cultural groups in our practice – Hispanic people and new immigrants from Somalia. We want to engage the council in shaping our medical home and seek their advice to improve family and patient partnership.

Establish Measures: *How will we know a change is an improvement?*

We will track attendance at our monthly meetings as a surrogate measure of PFAC engagement. In addition, we will survey our members quarterly to learn whether and how they rate their contribution to the clinic and how easy it is for them to make suggestions that get acted upon. This data will be displayed on run charts and we will supplement the quantitative with illustrative quotes from our PFAC members.



Select Changes to Test: *What changes can we make to bring about improvement?*

We will test different recruitment strategies to see what works.

PDSA Cycle

PLAN

If we ask providers, PFAC members and other care team members to nominate people they know who attend our clinic, will we get enough names to get started with invitations? Will we find a time when we can meet if we include youth and representatives from different cultural groups?

At the next meeting we will ask PFAC members to make a list of potential PFAC members; between now and then we will ask our care team members to do the same. Dr. Hilda will ask the care team members and Camilla will ask the PFAC members. The list will be reviewed the day after the PFAC meeting.

Next, Dr. Walter will send a letter inviting the potential members to come to the clinic for a supper and feedback session on what would make a better clinic visit. This will enable us to see how the candidates interact in a group session (a try-out, so to speak). In addition, Maria will do a phone follow up 3 days before the meeting to make a personal connection and confirm. Rita will order the food.

We predict we will have 7 people who come to the meeting and from those there will be 5 we can invite to participate on the council.

DO

We got a list of 4 people from the PFAC and 12 from our staff. We invited them to a supper meeting and 8 came. We got some great suggestions from them on what we could do to improve things around here.

STUDY

We realize that we will need at least one translator for the youth and patient representing the Somali community and that we will need a time to meet that is not during school hours if we want the youth to attend.

ACT

Our next step is to formally extend invitations and plan for an orientation for 6 of those who attended the session. We imagine not all will be able to participate. If this is successful then we will begin to track attendance and prepare a survey to learn more about the members experience with the PFAC.

Annotated Bibliography

Listed Alphabetically by Title

***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 practice's to gauge staff perspective and readiness in shifting towards increased patient-family partnerships. Of note, Part V provides important guidance, with specific suggestions, for identifying and developing patient- family leadership.

View: <http://www.ipfcc.org/pdf/GettingStarted-AmbulatoryCare.pdf>

***Consumer Involvement Toolkit: A Resource for State Agencies.* Community First Systems Transformation Grant, in Collaboration with the University of Massachusetts Medical School Office of Long-Term Support Studies. Boston, Massachusetts: June 2010.**

The Commonwealth of Massachusetts was awarded a five-year Systems Transformation grant from the Centers for Medicare and Medicaid Services (CMS). The grantee's mission was to transform the state's long-term support system for elders and people with disabilities served by the Executive Office of Health and Human Services (EOHHS) /Office of Disability Policies and Programs and the Executive Office of Elder Affairs (Elder Affairs). Stakeholders contributed to the publication's identification of key development areas for meaningful engagement. Emerging patient and family advisory councils can benefit from this structured approach to consumer involvement.

View: http://www.medicaid.gov/mltss/docs/consumer_involvement_toolkit.pdf

***Creating Patient and Family Advisory Councils.* Institute for Patient- and Family-Centered Care. Bethesda, Maryland: October 2010.**

This brief provides an overview on developing a PFAC with clear identification of the basic structure of the council. Review of sections on orientation for new members and sustaining the council could be quite helpful to PFAC facilitators.

View: http://www.ipfcc.org/advance/Advisory_Councils.pdf

***Webster, P. D., & Johnson, B. H. Developing and Sustaining a Patient and Family Advisory Council.* Bethesda, MD: Institute for Patient- and Family-Centered Care, 2000.**

This resource profiles consumer advisory councils, their structures, and activities. Guidance on establishing a new council and sustaining the momentum of an existing council is included. Descriptions include council responsibilities and the potential impact a council can have on an organization.

View/Order: http://resources.ipfcc.org/product_p/32085.htm

***Jeppson, E. S., & Thomas, J. Essential Allies: Families as Advisors.* Bethesda, MD: Institute for Patient- and Family-Centered Care, 1995.**

This is a how-to manual on involving families as consultants and advisors in policy and program development. Included are examples and descriptions of how hospitals, state agencies, community programs, and universities foster collaboration and partnership between providers and families. This resource emphasizes approaches to involve families traditionally underrepresented in policy-making activities.

View/Order: http://resources.ipfcc.org/product_p/32060.htm

***Fostering Consumer Engagement in Practice Transformation: A Toolkit for Practices on the Journey to Patient-Centered Medical Homes.* Massachusetts Patient-Centered Medical Home Initiative, 2011.**

This publication focuses on engaging consumers in health care practices with an emphasis on quality improvement. Suggestions for developing advisory councils and using focus groups as well.

View: <http://medicalhome.nichq.org/~media/files/resources/pfac%20toolkit/ma-pcmhi-toolkit.ashx>

Brown, L., and West, M. *Patient and Family Advisory Council: Getting started Toolkit.* BJC Health Care (Barnes Jewish St. Peters Hospital).

This is a step-by-step guide for creating a Family Advisory Council that addresses all elements of beginning a PFAC including a helpful pre-planning checklist and descriptions of the various roles within the council.

View: http://www.theberylinsitute.org/resource/resmgr/webinar_pdf/pfac_toolkit_shared_version.pdf

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 Healthcare 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.

View: <http://www.nichq.org/how%20we%20improve/resources/powerful%20partnerships>

Thomas, J., & Jeppson, E. S. *Words of Advice: A Guidebook for Families Serving As Advisors.* Bethesda, MD: Institute for Patient- and Family-Centered Care, 1997.

This publication is a practical step-by-step guide for conducting training sessions for families and providers to increase the involvement of families serving in advisory roles.

View/Order: http://resources.ipfcc.org/product_p/32061.htm