



## Starting and Supporting Family Advisory Groups

### Part of the 3-part “How-To” Webinar Series, Fostering Partnerships and Teamwork in the Pediatric Medical Home

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#### Questions and Answers

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**Moderator:**

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This document includes questions presented by participants that were not answered during the live webinar due to time constraints:

Questions	Answers
How is your experience with parent blogs, emails, and websites, particularly for Latino parents? Are these resources well received? Do the parents have access to these resources?	<b>Dr Pelaez:</b> Currently, we do not have any blogs here at USF due to liability issues, but I refer my patients to <a href="http://healthychildren.org">healthychildren.org</a> (in English and Spanish) to get information from the American Academy of Pediatrics.

	<p><b>Tim Lane:</b> While I know that doesn't cover everyone, email should absolutely be the primary communication vehicle.</p>
<p>Regarding materials and information for parents: are flyers effective? Do you take into account the family literacy levels?</p>	<p><b>Dr Pelaez:</b> Yes, I use them all the time. I use very clear, short, and easy to read messages.</p> <p><b>Susan Sommer:</b> In general, we limit the amount of paper we give families with whom we do home visits and we write everything at a fifth grade level. In terms of the advisory board, at one point we made each parent a binder in which they could keep their meeting minutes and other materials that we handed out or they picked up at the meetings. Parents really liked these binders and would keep them up-to-date.</p> <p><b>Tim Lane:</b> Flyers and leave-behind pieces would likely be the next effective step. The best plan there is not only to post them, but have them as a hand-out sometime during an office visit. Definitely need to be bi-lingual.</p>
<p>How do we have the parents or patients heard at the meetings by providers? There seems to be such fear in having the public in the meetings.</p>	<p><b>Dr Pelaez:</b> We did not hear any negative feedback from parents regarding speaking at public meetings. Parents are usually very polite and we tell them that we want them to be honest. We encourage parents to provide negative and positive information so that our practice can improve.</p> <p><b>Susan Sommer:</b> Some parents were shy, but many others were comfortable speaking up and expressing their view points. As Chanese mentioned, parents really supported each other and we tried to ensure that everyone's voice was valued and heard. Since we were not based in the medical home however, we did not have the children's providers at the table, but several of our initiative's staff, including nurses, the MD program director, and a representative from Community Benefits were present.</p> <p><b>Dr Lail:</b></p>

	<p>I have found that the pervasive concept of respect for families and regard for their input in shared decision making and care planning is a good first step to empower families to contribute in meetings. Creating a safe environment for all idea-sharing is important for staff members as well as families.</p> <p><b>Tim Lane:</b> You need to recruit your best speakers, and help them script and prepare for an effective presentation. Parent presenters cannot be expected to “wing things.”</p>
<p>Can you provide some practical tips on recruiting parent advisors? Who was the person responsible for doing so in your practices?</p>	<p><b>Dr Pelaez:</b> Our recruitment was provider driven and by word of mouth. We also put a board up in the waiting room to promote participation.</p> <p><b>Susan Sommer:</b> Recruitment and retention is definitely challenging and ongoing. We did have a very steady core group of about 6-8 parents with some turnover yearly and some new additions. Our Community Health Workers and nurses, who were in the home, would make suggestions to the team and would ask the families. We did try to have a mix of race and ethnicity. We had a couple of fathers. A fair number of parents, who agreed and who we thought would be great additions, never showed-up, presumably because they had too many competing demands. Incentives do help to a point. We also polled prospective parents for best day, time, and location. We also did evenings (6-6:30 pm for dinner and conversation, meeting from 6:30 – 8 pm).</p> <p><b>Dr Lail:</b> At Cincinnati Children’s, we have employed parents who lead the Family Advisory work for the institution and for the Quality Improvement initiatives. They, in turn, recruit volunteer families to consult on specific topics and sometimes, for specific conditions. As well at CCHMC, there is an effort to have families on the Board, on Board Committees, and other high level leadership groups, such as the Outcomes Steering Committee.</p>
<p>Do you include transition to adult care in the work that family advisory groups do?</p>	<p><b>Dr Pelaez:</b> Yes we do, this is very important.</p> <p><b>Susan Sommer:</b> This was not a focus of our particular group.</p>

<p>In either of the practice examples, was any leadership training provided for the parents?</p>	<p><b>Dr Pelaez:</b> No, but this is a great idea.</p> <p><b>Susan Sommer:</b> We didn't do general leadership training, though I think that's a great idea. Someone from our Government Relations office did do some formal political advocacy training, starting with how policies and laws get made, the value of communicating with city council, legislative representatives, etc.</p>
<p>What is a HIPAA business agreement compared to HIPAA disclosure required by parents/patients?</p>	<p><b>Dr Pelaez:</b> We did not deal with HIPAA issues because we were discussing the system of care and patient protected information.</p> <p><b>Susan Sommer:</b> We did not have any board members sign any disclosures.</p> <p><b>AAP Medical Liability Staff:</b> Since pediatricians are considered covered entities under HIPAA, they are required to comply with the requirements including those for privacy and security. Many of these requirements changed September 23, 2013 necessitating pediatricians and their practices to revise their HIPAA compliance manuals. These manuals include the Business Associates Agreement and the Notice of Privacy Practices.</p> <p><i>About the Notice of Privacy Practices</i></p> <ul style="list-style-type: none"> <li>• A Notice of Privacy Practices is a document that health care providers must develop to inform patients about their rights concerning their protected health information.</li> <li>• Medical practices and other covered entities must provide patients with the Notice of Privacy Practices for private health information <b>and</b> use best efforts to obtain the patient's or legal representative's written acknowledgment of receipt of the Notice.</li> <li>• If written acknowledgement of the receipt of the Notice of Privacy Practices is not obtained, then <ul style="list-style-type: none"> <li>○ The practice must document its efforts to do so.</li> <li>○ The practice may not deny medical treatment for failure to sign an acknowledgment of receipt of the Notice of Privacy Practices.</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ The practice may use and disclose the patient’s protected health information in accordance with HIPAA’s Privacy Rule and state law regardless of the patient’s refusal to sign an acknowledgment.</li> </ul> <p><i>Business Associates Agreements</i></p> <p>Covered entities, such as pediatricians, have many business associates. HIPAA has a specific algorithm for determining whether or not an entity satisfies the criteria of a business associate under the regulations, but for many clinics and practices the following are examples of business associates: data storage providers, billing service/agency, collection agency, accountant/consultant who needs access to protected health information, answering service, lockbox service, transcription service, practice management software vendor, electronic medical records software vendor, and data shredding services.</p> <p>HIPAA requires every covered entity to have a business associate’s agreement with each and every entity that has access to its patients’ protected health information. Changes in the HIPAA regulations that went into effect on September 23, 2013 required all covered entities including pediatricians to redo all their business associates agreements.</p>
<p>How is the optimum number of parents determined for a parent advisory board?</p>	<p><b>Dr Pelaez:</b> We recruited 18 families, but only received 8.</p> <p><b>Susan Sommer:</b> For us, we had to invite about 15 parents to consistently get 10 to come to meetings. 10-12 parents seemed to be a good number, in terms of people having enough time to express themselves, as well as get a good conversation going.</p>
<p>For a multi-site group, do you find it better to have a separate PAC for each practice (given different practice cultures and demographics) or one for the group as a whole? Any pros/cons of each approach?</p>	<p><b>Dr Pelaez:</b> We are a large academic practice with four sites, and we recruited from all four sites to have representation from all over the clinics. I would not recommend having one family advisory group for each separate clinic because this is very time consuming and difficult to sustain. Unless you have a dedicated staff and a great lead physicians. What you could do is have a parent partner at each site.</p>

<p>How do you secure funding to support incentives for family members?</p>	<p><b>Dr Pelaez:</b> We received funding from the department of pediatrics. Lobby the leadership in your institution, you can use the videos from the National Center for Medical Home Implementation to assist you, and I would be happy to talk to anyone if this is needed.</p> <p><b>Susan Sommer:</b> We are largely grant-funded, in addition to some funding that comes through the hospital's Community Benefits office. Fortunately, we had a mix of private and government funding, so that we could use private funding for meals and incentives. We also have been very lucky to have Healthy Tomorrows Partnership for Children Program (HTPCP) funds over much of the life of our advisory board. These grants are community-focused and help support family advisory boards, which are a requirement for the grant. The CDC REACH US grant also was focused on Community-Based Participatory approaches and helped fund the board.</p>
<p>What is the approximate cost to run a family advisory council?</p>	<p><b>Dr Pelaez:</b> This will be determined by the number of parents and food. We did \$40 per family. We use facilities that are free of charge and conference call/webinars which are also free, so in general for us it was not very expensive.</p> <p><b>Susan Sommer:</b> For each meeting of the board:</p> <ul style="list-style-type: none"> <li>- Food \$350 (we always ended up with way too much food, but we would tell the caterer how many people we expected; often fewer people came, plus we would get some kid-friendly choices)</li> <li>- Gift cards: 10x\$20 dollars each, \$200</li> <li>- Personnel (10 hours): \$271.71</li> <li>- Meeting venue: in kind</li> <li>- Total: \$821.71/meeting</li> </ul> <p>For 4 meetings: \$3286.84</p>
<p>How do organizations pay for a staff point person to a Family Advisory Group? Do they write it into the budget – use grant money? If this can be done through grants, do you have any information about an organization that would give grants for a Family Advisory Group?</p>	<p><b>Dr Pelaez:</b> I am very sure that a grant will be ideal to sustain a family advisory group, including salary for a dedicated staff member to follow up and set up meetings. Our staff members did not get paid, our advisory group was part of a medical home initiative.</p> <p><b>Susan Sommer:</b></p>

	<p>The responsibility for the advisory board is shared by a few staff members. The administrative assistant, who coordinates the meetings, including sending invitations/reminders to parents, ordering food, arranging child care, setting up before the meeting, etc. says it takes about 4 hours per meeting to do these tasks. Other staff members are in communication to varying degrees with board members, depending on any additional work or activities that might be taking place between the general meetings, which are 3-4 times per year. Yes, HTPCP, as part of their community-based initiatives.</p>
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