

# Family Engagement Initiatives Update

American Academy of Pediatrics (AAP) – Fall 2019

## Family Engagement Background

While the AAP has a long history of engaging patients and families in its activities, more concerted efforts have taken place over the past several years. Efforts around family engagement have been coordinated by 2 primary groups: (1) the Family Partnerships Network, and (2) a staff Family Engagement Workgroup.

### Family Partnerships Network

The mission of the AAP Family Partnerships Network (FPN) is to represent family and youth perspectives, lead and facilitate youth and family engagement, and support ongoing youth and family involvement at the local, state and national level. Additional information about the FPN can be found at [www.aap.org/fpn](http://www.aap.org/fpn).

### Staff Family Engagement Work Group

The staff Family Engagement Work Group includes staff representatives from nearly every AAP department who meet monthly to advance efforts related to AAP objectives on family engagement and to share information and resources.

## Family Engagement Activities

Family engagement activities taking place at the AAP include the following:

- **National Strategy:** Goal includes increasing family engagement and sharing family perspectives at the national level through involvement in policy, advocacy, mentorship and communication.
  - **Policy:** The FPN has developed a new resource to guide policy authoring groups in considering how best to engage youth and families. Key elements of this document can be found below.
  - **Communication:** A private Facebook group for FPN members will launch in fall 2019. Available communication mechanisms have been suboptimal in engaging family leaders, so this mechanism is being explored and will be evaluated.
  - **Committees and Family Engagement:** The Board of Directors approved the continuation of family liaisons on 4 national committees (Committee on Hospital Care, Committee on Pediatric Emergency Medicine, Committee on Practice and Ambulatory Medicine, and Committee on Psychosocial Aspects of Child and Family Health) for 1 year.
  - **Annual Leadership Forum Resolution:** The FPN partnered with the New Hampshire chapter to submit a 2020 ALF resolution around youth and family engagement.
- **Chapter Strategy:** The primary goal is to promote family engagement at the state/chapter level.
  - During the National Conference & Exhibition, the FPN will sponsor a **Family Reception**, where family leaders and AAP leaders are able to connect and network with one another. The reception will take place on Sunday, October 27 from 4-5:30 pm at the Hilton New Orleans Riverside Hotel, Parish Room. We invite family leaders and other interested individuals to attend.

## AAP FAMILY ENGAGEMENT PRINCIPLES

1. The family is the principal caregiver and the center of strength and support for children.
2. The AAP recognizes that perspectives and information provided by families, children, adolescents, and young adults are essential components of collaborative decision-making in the delivery of high-quality, safe, and compassionate care. Patients and their families are integral partners of the health care team.
3. The AAP recognizes the value of diversity among patients, families, and pediatricians. The delivery of care within the context of appropriate physician knowledge, understanding, and appreciation of cultural and population distinctions take into account families' experiences, beliefs, values actions, customs, and unique health care needs.
4. Recognizing, valuing, and building on the strengths of individual children and families and empowering them to discover and communicate their own strengths, build confidence, and partner in making choices and decisions about their health care is vital to optimal health and development.
5. To promote improved patient, family, and physician experiences and outcomes, the AAP encourages and supports family engagement in its core competencies of education, practice, research, and advocacy.

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- The FPN successfully advocated for changes to the Chapter Annual Report survey to obtain more specific information about youth and family engagement within AAP chapters.
- **Education:** The primary goal is the education of both pediatricians/health care professionals as well as youth/families around family engagement topics.
  - A document entitled, “Top 10 Tips for Successful Child and Family Engagement During All Levels of the Health Care Experience” has been developed and has undergone pediatrician review via several AAP committees. Once finalized, this document will be broadly disseminated. Additionally, the FPN will focus educational activities around these specific tips moving forward.
- **Award:** The primary goal is the exploration of an award/recognition to acknowledge pediatricians or practices that are engaging youth/families well. The FPN has drafted award criteria and will be exploring potential collaboration with AAP groups.
- Members of the Staff Family Engagement Workgroup and FPN, including two youth Executive Committee members, began drafting articles related to AAP family engagement efforts. One article will provide an overview of the long history of family engagement at the AAP and how those partnerships became more formalized. The other article will provide an overview of the FPN and its activities to strengthen partnerships with families.
- A subgroup of the Staff Family Engagement Workgroup began piloting different approaches to elicit feedback from families on AAP patient education materials, including disseminating surveys via a Healthychildren.org parent panel and eliciting feedback from AAP staff.
- A small workgroup met in July to begin planning the development and dissemination of a survey to AAP Managers. The purpose of the survey is to determine if family engagement efforts have increased at the AAP and to see how the Staff Family Engagement Workgroup and the FPN can assist AAP staff with their efforts.

## Family Engagement at the AAP

Currently, at the national level, 8 Committees/Sections/Councils and 12 steering committees, editorial boards, or project advisory committees have an official family liaison. Additional information about some of the AAP family leaders can be found on the [FPN Web page](#).

At the state/chapter level, analysis of the 2018 Chapter Annual Report data revealed that more than 20 chapters are actively engaging family advisors in specific projects; while 7 chapters have family advisors who sit on their Board or Executive Committee.

## What You Can Do

- Encourage youth or family advisors/leaders to join the Family Partnerships Network, particularly if your committee, section, council, or advisory committee has a family liaison. There is no cost to join, and family advisors/leaders can join by completing the online application at: <https://www.surveymonkey.com/r/FPNApp>. Joining the Network will allow family advisors/leaders to receive information about AAP leadership or volunteer opportunities, other relevant child health updates, as well as engage with others who are working on child health-related programs or policy activities.
- Consider how your group or your group’s activities could benefit from youth/family engagement. Review the guide for policy authoring committees below. Reach out to the FPN and/or the staff Family Engagement Workgroup for advice or consultation. For additional information about the FPN or the staff Family Engagement Workgroup, contact Sunnah Kim at [skim@aap.org](mailto:skim@aap.org) or Christina Boothby at [cboothby@aap.org](mailto:cboothby@aap.org).



## Family Engagement in the Development of Statements/Materials Guide for Authors and Staff

AAP Committees/Sections/Councils considering the development of a policy statement or other materials should consider whether youth and family participation or input would be beneficial. The following is intended to serve as a guide.

<p>Involve a Youth or Family Advisor as a Co-Author</p>	<p>If the policy/material relates to a topic where family-professional partnership is critical, consider whether a youth or family advisor should serve as a co-author from the earliest phases. Past statements that have included family co-authors include: Team-based Care, Medical Home, and Family-centered Care. Additionally, all AAP-led Clinical Practice Guidelines include a family advisor on the guideline subcommittee.</p> <p>If the lead authors are not aware of potential youth/family advisors who might be good co-author candidates, they may reach out to the AAP Family Partnerships Network for assistance.</p>
<p>Include Guidance for Families Within the Document</p>	<p>Some AAP documents include a specific section that outlines “Considerations for Families”. Consider whether this type of section might be beneficial to your document, and at minimum, seek youth/family review of this information either informally or formally (as described below). Consider also how families will learn of this material.</p>
<p>Seek Informal Input from Youth/Families During Document Development</p>	<p>Document authors should consider how new recommendations or information might be interpreted and received by youth and families, as well as the general public. Authors could consider soliciting informal feedback from youth/families that they know during the document development process. Ideally, these youth/families would come from diverse backgrounds/lived experiences. Some example questions that you might consider asking Youth/Families are:</p> <ul style="list-style-type: none"> <li>• How would the guidance or recommendations within the document affect you or your family?</li> <li>• From your perspective as a caregiver (or patient), are the recommended treatments(s) or solutions(s) feasible- i.e. would they actually work for your family? Do they resonate with you?</li> <li>• What is missing that you could comment on?</li> <li>• What should be emphasized even more?</li> </ul>
<p>Seek Formal Review from the Family Partnerships Network or Other Related Family Organizations During the Peer Review Phase</p>	<p>Consider whether the document is one that would benefit from youth/family review. Are there new recommendations that impact youth/families? Are youth/families the target audience for the finished product? Might youth/families offer a different perspective that might not be captured otherwise?</p> <p>If the document is lengthy or technical in nature, consider providing family reviewers with specific sections on which to focus their review. It may also be helpful to outline any specific questions that you’d like youth/family reviewers to weigh in on.</p> <p>The AAP Family Partnerships Network has a process to review documents; however, consideration could also be given to whether there is a specific family organization that might offer more specific expertise/input.</p>

**One of the most important things that you can do, is to close the communication loop with the FPN and/or family reviewers. They are very interested in hearing back from the authors about whether their comments were beneficial and whether any revisions were made based on their comments.**