Fact Sheet

Five Top Tips for Engaging Families in Advisory Roles: Advice from a Family Leader

Teresa Jurado, the mother of a 27-year-old son with cerebral palsy, currently is a parent mentor at Lucile Packard Children’s Hospital Stanford. She previously chaired a family advisory committee for the Health Plan of San Mateo in California. Her wealth of experience navigating the myriad systems essential to her son’s health and well-being, combined with her professional background as a parent health liaison and a parent mentor, led to her role as chair of the committee. She takes pride in having facilitated and maintained a lively, engaged group whose feedback to the Health Plan resulted in service delivery improvements. Ms. Jurado offers her five top tips for meaningfully engaging a group of family advisors.

1. Organization Values Families’ Time and Input

- Provide compensation. Offer stipends, food, and free parking. Families want to give input, but they do not want to be the only ones at the table paying out of pocket to be there.
- Ensure that family members hear directly from health plan leadership that parent input is needed to make improvements to health care delivery.
- Give family members the opportunity to request and make suggestions on agenda items.
- Structure meetings to be interactive and choose content that is intended for parent input.
- Require decision makers to attend meetings.
- Follow up with family members on their input. What was important about the information they provided? What was the response or impact? If the organization is unable to act on parent feedback, explain why. Close the communication loop. When family members see the change or impact, they want to come back.
- Listen.

2. Organization Offers Ongoing Training and Support to Family Members

- As part of the recruitment process, hold an informational session for identified candidates. Define roles and expectations of FAC members. “This is what the advisory group is. This is what the advisory group isn’t.” Training starts before the family member joins the committee.
- Train new family members on policies and practices of the advisory committee. Outline the “dos and don’ts” of serving on the FAC.
- Provide mentorship to family members. FAC chair should be available to debrief after meetings or to connect by phone in between meetings for support and meeting preparation.
Build in “mini trainings” for family members at each meeting. Provide information, resources, and tools related to the agency, organization, or related community-based services to help them be more successful in their advisory roles.

3. Organization Provides Support to Committee Chair

Assign a mentor or point person at the organization to support the committee chair. This person may be a staff liaison to the committee or sit on the committee as a representative of the organization. Ensure buy-in from the organization. Support for the committee and committee chair should come from plan administration / leadership.

4. Chair Models Appropriate Facilitation and Behavior

Manage the time. Set a time limit for every agenda item, including public comment. Adhere to the time limits. Be prepared to move the meeting along when the time limit is up. Ask members if the agenda item should be included on the next meeting agenda to continue the discussion.

Manage the meeting topic. Adhere to the set agenda items. Gently remind the committee about staying on topic when a member veers away from an agenda item. Be prepared to refer family members to the appropriate resource for support or complaints when personal issues arise.

Have a contingency plan for responding to time, topic, or behavior issues. Examples:

- If a family member is angered by an agenda item, give a reminder that the committee is not a place to air grievances or show disrespect.
- If a family member is emotionally triggered by an agenda item, be prepared for the vice-chair to offer emotional support outside of the meeting.
- Be prepared to back up silence. If the chair asks a question and no one answers, it may be necessary to provide an example to initiate the discussion.

5. Chair Builds Community, Cohesion, and Trust

Require chair or co-chair position be filled by family member. Family members are more comfortable with other family members. A family member chair is empathetic and therefore more approachable by other parents. A family member chair encourages buy-in from parents.

Provide a meal before the meeting. (Covered by the organization.) All FAC members, both family members and organization staff, should attend, providing a chance for members to mingle. Family members feel less intimidated in a meeting setting when given the opportunity to socialize with staff beforehand.

Create a safe space. Balance the ratio of parents and organization staff at each meeting to help parents feel more comfortable. Rotate in on the agenda staff who are seeking input from the committee.

Practice transparency between family members and organization staff. Encouraging open communication helps develop trust and build relationships.

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