


UAB Pediatric Pulmonary Center Parent Consultant Overview

Expectations and Responsibilities

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**“Tell me and I forget;
show me and I remember;
involve me and I understand.”
- unknown**

Goals of Parent Consultants Meeting

- Broad range of diverse input is received from new and veteran families
- Policy and program recommendations reflect the needs of real families
- Meaningful relationships are created between families and professionals
- Parents and Professionals work from common ground
- Services are designed in a family centered, culturally appropriate manner

Family Advisory Councils

- Members should be paid a stipend or honorarium for their time and reimbursed for expenses
- Ensure that membership is diverse as possible.
- Ownership
 - Vote on a chairperson to run the meetings
 - Allow the membership to set the agenda
- Provide a safe, trusting environment to share ideas.
 - Families have the most to gain, but they also have the most to lose by participating
- Limit staff participation to one or two key people to allow for open discussions

Rules of the Road

- Use common language – avoid acronyms and specialized words
- Respect other committee members and their points' of view
- Don't interrupt when someone is speaking
- Be sure everyone who wishes to has time to give input
- Stay on topic
- Should not be used only to complain about problems but to provide suggestions and solutions

Parents: Questions to ask

- What is the time commitment?
 - Meetings
 - Other activities
- Why was I asked to be a parent consultant?
 - Represent others “like you” – cultural, ethnic, racial, geographic, diagnosis, age of child, experience, etc.
 - The value of your family story
- What is my role as a parent consultant?
 - Provide perspective as parent of a child who is a patient of the Pediatric Pulmonary Center

Parents: Questions to ask

- What are my responsibilities?
 - Attend meetings
 - Be prepared
 - Read through materials sent prior to meetings – agenda, minutes, program descriptions, etc.
 - Provide honest and thoughtful suggestions and recommendations
 - Participate in activities such as program evaluation, training fellows and clinicians, program or service planning
 - Recruit other parents for projects, etc when needed.

Parents: Questions to ask

- What are my responsibilities?
 - Know...
 - the history of the Pediatric Pulmonary Center
 - how the Center is funded
 - the types of programs offered by the Center
 - about future directions, long-range plans, etc.
 - other parent consultants and staff
 - current challenges

Parent Expectations

- Parents should expect that the Center staff will...
 - value their time, stories, experience and diversity
 - provide information and training materials
 - in a format and language that can be understood by a general audience (a board manual can be helpful)
 - provide information on roles and responsibilities of staff
 - ensure introductions at each meeting
 - ensure adequate time for questions and answers

Pediatric Pulmonary Center Staff Responsibilities

- Validate parents' experience by listening and incorporating ideas and suggestions
- Involve families from the beginning of a project if at all possible
- Select meeting times that will work for all participants
- Compensate parents for their time and expertise as you would any other consultant

Pediatric Pulmonary Center Staff Responsibilities

- Present parents with the big picture of project goals and partners
- Provide orientation and training for fellows, new professionals to work effectively with parent consultants
- If working on projects outside scheduled meetings parent consultants should know what their specific responsibilities, tasks and deadlines are

Pediatric Pulmonary Center Staff Responsibilities

- Develop agendas that include protected time for sharing family stories and building family-professional partnerships
- Create opportunities for families to network and learn from one another
- Make sure to recruit a diverse group of families

Role of meeting facilitator or chairperson

- Introductions
- Team approach
- Be aware of full participation
- Be conscious of the use of language that would confuse new consultants
- Keep discussion on topic
- Encourage listening by everyone (discourage side discussions)
- Be mindful of time constraints

Anticipating and Resolving Problems

- A dominating personality
 - Talk with individuals and ask them to give other members a chance to speak and voice opinions
- Conflict between members
 - When it comes to the health care of family members, especially children, parents are very passionate and may unintentionally offend other council members
 - Have a plan in place or possibly a specific staff member who can help resolve these conflicts

Anticipating and Resolving Problems

- Conflict between members and staff
 - It is often difficult to hear criticism or complaints from families; some staff may become defensive or resentful
 - Be aware that this can negatively impact the provision of health care
 - Talk with staff ahead of time to discuss how they might respond and work through criticism

Responding to Criticism and Complaints

- Staff do not have to address the issue at that meeting
 - Take time to get over the emotional response
 - Look into the criticism or complaint to understand all sides of the issue
 - Determine how the issue will be resolved and measures that will be put in place to prevent a reoccurrence
- Don't forget about it or dismiss it
 - Families will lose their confidence and trust

Final thoughts

- Parent consultants should not be receptacles for information in the form of reports but should be active involved partners in the success of the health care program.
- A Family Advisory Council can help you to elevate the quality of care at your facility and build successful partnerships with all families.
- Councils will help you to “walk a mile in our shoes.”