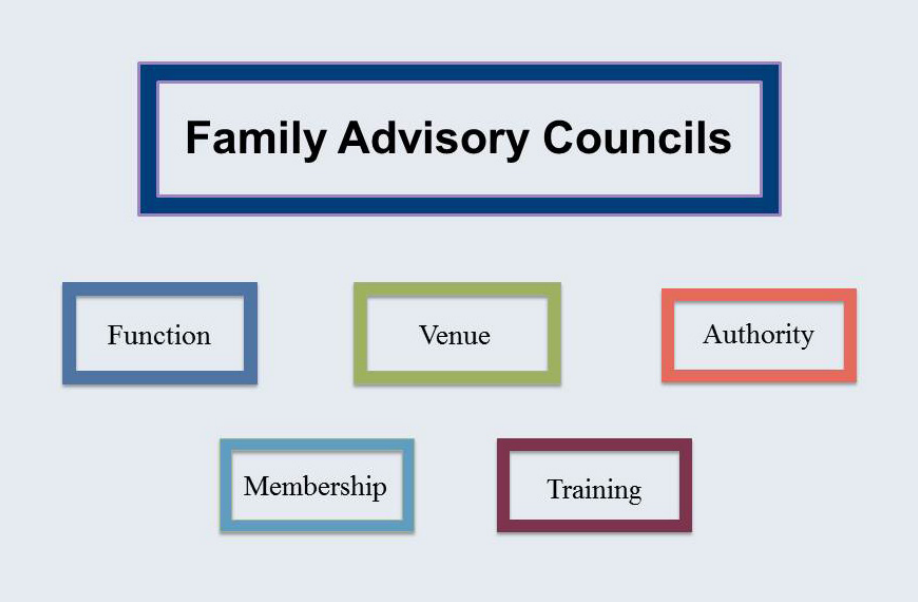
Lucile Packard Foundation *for* Children's Health

Report

Creating and Sustaining Effective Hospital Family Advisory Councils

Findings from the California Patient and Family Centered Care Network of Pediatric Hospitals



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ABOUT STANFORD CHILDREN'S HEALTH AND LUCILE PACKARD CHILDREN'S HOSPITAL: Lucile Packard Children's Hospital Stanford is an internationally recognized 311-bed hospital, research center, and regional medical network providing the full complement of services for the health of children and expectant mothers, in partnership with Stanford Children's Health and Stanford University School of Medicine.

Lucile Packard Foundation for Children's Health

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ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children's Health is a public charity, founded in 1997. Its mission is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. The Foundation works in alignment with Lucile Packard Children's Hospital Stanford and the child health programs of Stanford University School of Medicine.

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Abstract

Establishing effective Family Advisory Councils (FACs) in health care organizations is one means of ensuring that families have a strong voice regarding the care delivered to their children. To encourage the establishment of Councils, the Lucile Packard Foundation for Children's Health provided grant funding for the formation of the California Patient & Family Centered Care Network, a statewide collaborative composed of parents and providers representing 15 pediatric hospitals and clinics. The primary goal of the Network is to support the formation of FACs in pediatric settings. A secondary goal is to establish agreed-upon recommendations aimed at sustaining Network FACs.

Executive Summary

In 1987, U.S. Surgeon General C. Everett Koop first called for the nation's health care system to transition from system-centered to family-centered care. The concept of family-centered care has achieved significant gains since then, and now is considered a core element of quality health care. Family Advisory Councils (FACs) represent one strategy to build and promote family-centered care within a health care organization. FACs are intended to give administrators and clinicians a better understanding of the patient and family perspective, and typically represent the first step in transitioning an organization from system-centered to family-centered. However, current structure, operation, and support for FACs is idiosyncratic and signifies a need for agreed-upon best practices to initiate and sustain the work of Councils over time.

To support the development of effective FACs in pediatric settings, the Lucile Packard Foundation for Children's Health provided grant funding in 2012 to create the California Patient & Family Centered Care Network (CA-PFCC). Network membership includes parents and providers from 15 hospitals and clinics throughout the state. The primary goal of the Network is to share ideas and resources to facilitate the formation of sustainable Family Advisory Councils in health care settings.

To achieve this goal, Network members participated in a range of activities (webinars, ideation sessions, and work groups) to gather information about the current state of FACs in California. Analysis of the data resulted in identification of foundational elements of FACs: function, venue, authority, and membership configuration. Network members also identified challenges related to initiating and sustaining FACs. Collectively, this work resulted in a checklist of key activities intended to guide the creation of new FACs and to enhance and expand the work of existing Councils.

Introduction

Defining Family-Centered Care

The concept of family-centered care has achieved significant gains since 1987 when US Surgeon General C. Everett Koop called for US health care to transition from system-centered to family-centered[1]. Family-centered care is an approach to health care that shapes policies, programs, facility design, and day-to-day clinical interactions among patients and their families, physicians, nurses, and other health care providers. More specifically, family-centered care recognizes and respects the unique role of patients and families and is based on four core elements[2]:

- **Dignity and Respect**. Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing**. Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- **Participation**. Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- **Collaboration**. Patients, families, health care practitioners, and leaders collaborate in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

In 2001, the Institute of Medicine's Committee on Quality in Health Care in America outlined a framework for a patient- and family-centered health care system[3]. More recently, quality oversight agencies and governmental regulatory bodies have asked health care systems to focus on partnerships that engage and empower patients and families in their own health care decisions. This appeal grows from the expanding Patient Rights Movement[4] as well as related literature suggesting that patient satisfaction, patient safety, and clinical outcomes improve when patients and families become partners in their own care. One way to speed the transformation of hospitals and clinics from system-centered to family-centered is to implement Patient and Family Advisory Councils[5,6].

Family Advisory Councils

Family Advisory Councils are part of a set of strategies to build and promote family-centered care. In general, FACs are groups of family members who meet on a periodic basis to give input into the work of a hospital or other clinical setting. FACs are intended to give administrators and clinicians a better understanding of the patient and family perspective and typically represent the first step in transitioning an organization from system-centered to family-centered[7].

FACs offer the opportunity for providers and families to work in partnership to generate or redefine policies, programs, and clinical care in the best interest of the patient and family. Ultimately, the goal is to fully integrate the family perspective into hospital operations by including parents on strategic committees, patient safety efforts, and change initiatives[8].

California Patient & Family Centered Care Network

While numerous oversight committees and regulatory agencies continue to call for family-centered care, there is limited guidance and no agreed-upon standards for creating productive and sustainable Family Advisory Councils. Nonetheless, individual hospitals and clinics have launched successful FACs that affect health care policies and practices in their respective settings.

To support the development of effective FACs, the Lucile Packard Foundation for Children's Health funded the creation of the California Patient & Family Centered Care Network (CA-PFCC). Formed in 2012, the CA-PFCC Network is a group of parents and providers representing 15 hospitals and clinics throughout the state (See Appendix A). Participants represent a cross-section of child health care providers: California Children's Services (California's Title V public health program for children with special health care needs), academic hospitals, stand-alone children's hospitals, pediatric units within adult hospitals, and managed care organizations. The purpose of the CA-PFCC Network is to share ideas and resources to facilitate the formation of sustainable FACs in health care settings throughout California.

Current State of FACs

Over a two-year period, the CA-PFCC hosted three two-day Network member meetings as well as numerous webinars, conference calls, and document exchanges to build a compendium of information related to Family Advisory Councils. These various interchanges provided an opportunity to capitalize on the breadth and depth of knowledge and experience of CA-PFCC Network members.

As a first step, Network members engaged in five ideation sessions to determine the current state of FACs in California using an organizing framework that included: value of FAC, scope of activities, expected outcomes, challenges, and different models or approaches.

These sessions generated a range of concepts, methods and ideas that highlighted commonalities as well as differences in Network FACs. Key points from each session are summarized below, followed by a "Family Advisory Council Operational Checklist" that emerged from analysis of the ideation data.

Value of FACs

To engage families, providers, and administrators it is essential to convey the value that will be achieved from the establishment of a FAC. Value is defined as the worth or usefulness of a FAC to an institution. Overall, Network members indicated that value of FACs was broad-reaching and included:

- qaualitative real-time feedback from the patient and family;
- incorporation of the family experience into all aspects of health care operations;
- provision of perspectives that differ from internal staff perspectives;
- creation of a "safe place" to test and learn about the value of parent-provider partnerships;
- creation of a venue to "walk the talk" of mission statements (i.e., "patients and families at the center of care);
- aid in the development of effective patient safety and quality initiatives; and
- creation of efficiencies in which FAC input identified "right-fit" policies and practices for patients and families.

Scope of FAC Activities

FACs potentially can focus on a broad array of activities that promote partnerships with internal and external stakeholders. Scope was defined as the audiences, projects, initiatives, departments or agencies potentially influenced by input from a FAC. Traditionally, FACs form partnerships with administrators and patient safety and clinical staff to improve care or to design new facilities[5,6,7,9]. But Network members identified a broader range of audiences who could benefit from FAC input. (See Table 1.)

No single institution engaged all of the entities listed but all members agreed that it is useful to work with a cross-section of audiences. Network members pointed out that expanding the work of

Family Advisory Councils to diverse internal audiences promotes rapid diffusion of family-centered practices and principles enterprise-wide, while working with external audiences advances family-centered policies and programs beyond the scope of the hospital or clinic. Each FAC must establish its priorities for both activities and partnerships.

Table 1. Stakeholders Who May Benefit from FAC Input

Internal	External
• Residents	• Community family advocacy groups
• Pharmacy	• Local pediatricians
• Security	• Government agencies
• Housekeeping	• Medical school instructors
• Board members	• State agencies
• Billing	• Local community agencies
• Admitting	• Regulatory groups
• Social work	• National collaboratives
• Rehabilitative services	• Foundations
• Finance	• CCS clinics
• Marketing	• Legislators
• Patient education	• Legal advocacy groups
• Lean Initiative for improved care delivery	• Local care coordination collaboratives
• Research initiatives	• Staff training
• Government relations	

Expected Outcomes

Network members agreed that a significant limitation for family-centered care in general, and FACs in particular, is the lack of measurement methodologies and agreed-upon outcomes to guide Council work. The group concurred that a FAC toolkit identifying goals, potential measures, evaluation methodologies, simple analytics, and messaging formats is an important next step in the evolution of FACs. As a start, Network members identified priority areas to determine the value of FAC engagement:

- patient safety initiatives;
- parent/provider decision-making;
- staff engagement;

- parent/provider communication; and
- Lean Initiatives.

A Network workgroup has been formed to develop a FAC "toolkit" that will provide information on measurement goals and approaches and will be available in a subsequent report.

Key Challenges

Network members identified two key challenges related to FACs: 1) launching FACs and 2) sustaining FACs. Challenges to launching a FAC included recruitment of parents, achieving diverse parent representation, working with staff uncomfortable with parent perspectives, staff concerns that parents might "lose confidence" in the hospital, and staff expectations about the function and authority of a FAC. FAC developers must do preparatory work to make a strong case for a FAC's value, scope of activities, and desired local actions before attempting launch.

Once launch is achieved, Network members agreed that sustaining a FAC includes some of the following challenges:

- aligning parent and administration expectations regarding function, scope, and authority;
- sustaining parent and provider interest in the work;
- balancing staff and parent input;
- assuring equal voice among parent participants;
- assuring FAC engagement in meaningful work;
- accommodating to the slow process of change in health care settings;
- marketing the FAC within the enterprise; and
- the lack of evidence related to the impact of FAC work.

A key strategy to mitigate these challenges is to engage Council members in frequent debriefings and analysis of the work and quickly address issues as they arise.

Network FAC Models

The 15 Network members represented 15 different FAC models. The models differed among five characteristics: function, venue, authority, membership, and member training (See Table 2).

FAC Function

Function was defined as the general approach or work of the Council. Each Network FAC assumed one of three different types of function and concomitant responsibilities:

- **Advising**—Council members advise on projects, policies, and change initiatives presented by hospital staff.
- **Implementing**—Council members identify and implement agreed-upon projects.
- **Hybrid: Advising/Implementing**—Council members advise on projects, policies, and change initiatives and implement Council-based projects.

FAC Venue

In general, FACs focused their work on either a unit within the hospital, a clinic, or the entire hospital. Clinic- and unit-based FACs typically adopted the Hybrid: Advising/Implementing approach while hospital-wide FACs tended towards Advising-Only approaches. However, one hospital-wide FAC utilized an Implementing-Only approach.

FAC Authority

Authority was defined as the degree to which input from FAC parent members determined actions on the part of hospital staff. Network participants identified four types of Council authority:

- parent members advise with multiple perspectives—input not binding;
- parent members vote on best approach—vote constitutes recommendation;
- parent members vote on best approach or project—input binding; and
- staff and parent members vote together on best approach or project—input binding.

In most FACs authority was not well established or clear. In some cases, members within a Council differed in their view of the Council authority. In other hospitals, Council members had articulated their level of authority but were not aligned with staff perceptions. These misalignments resulted in frustration on the part of parent members and confusion on the part of hospital staff. On the other hand, FACs were highly productive when FAC members and hospital staff agreed on Council authority. Network members reported that alignment among FAC members and hospital staff was the result of various strategies: frequent messaging of function and authority to FAC members and hospital staff; monthly debriefings for FAC members; and FACs led by a parent-provider partnership.

FAC Membership

FAC membership varied in requirements for parent participants as well as staff-to-parent ratios. Some hospitals required that a Council participant's child be a current patient while others did not. Membership requirements also varied in terms of the child's health status, type of medical service(s) received, and staff recommendations. Generally, Council membership requirements were driven by the culture of the hospital and local circumstances. In terms of staff-to-parent ratios, most FACs included both staff and parents. One hospital had only one staff member (with rotation of hospital staff for discussions at each meeting) and another had parent members only. All other hospitals had a one-fourth to one-third staff-to-parent ratio. Network members agreed that the ideal council size was approximately 15 to 20 members.

FAC Training

Training of FAC members differed substantially among Network participants and included a mix of various preparations: hospital orientation; one-time FAC orientation; monthly trainings; and/or multiple tiered trainings (advisor to leadership). All Network FACs required a hospital orientation and most FACs conducted a one-time orientation to the Council's operation. Two hospitals offered a monthly training in the form of a post-FAC meeting debrief as well as a tiered training to develop FAC leadership. Hospitals with more varied and frequent training opportunities tended to have

expanded roles for FAC parents that included participation on committees, staff trainings, and other change initiatives.

Table 2: Characteristics of Family Advisory Councils

Function	Advising	Implementing	Hybrid: Advising/implementing	
Venue	Hospital-Wide	Unit-Based		
Authority	Parents Advise Multiple Perspectives	Parents Vote Recommendation	Members Vote Input Binding	Staff/Parents Vote Input Binding
Membership	Parent of a Current Patient	Parent of a Chronically Ill Child	Advisors Only	Advisors and Staff Members
Training	Hospital Orientation	One Time FAC Orientation	Monthly Training FAC Debrief	Tiered Advisory/ Leadership Training

Recommendations for Creating a Successful FAC

The FACs of the 15 Network members all continue to mature and evolve, and additional hospitals are interested in establishing Councils of their own. Table 3 provides guidance, in the form of a checklist, for creating new FACs and for strengthening existing ones.

Table 3: Family Advisory Council Operational Checklist

Family Advisory Council Operational Checklist	
1. FAC Function	
☐	Determine function of Council (advise; implement; hybrid)
☐	Identify resource needs to proceed with identified function (Advising—do you have diverse representation? Implementing—do you have capacity to plan and implement?)
☐	Set clear expectations regarding function with Council members
☐	Clarify function with hospital administration and staff
☐	Incorporate FAC function into member orientation
☐	Intervene when Council work veers from stated function
2. FAC Authority	
☐	Develop co-agreement of Council authority (advice; recommendation; binding recommendation) with hospital administration
☐	Set clear expectations with Council members
☐	Maintain parent as leader or co-leader to model expected "authority level"
☐	Incorporate FAC authority definition into member orientation
☐	Create feedback loops from initiatives, projects, and policies to determine effectiveness of FAC input
☐	If staff members are part of Council membership, clarify their role in giving input
☐	Make sure hospital staff understands FAC authority prior to work with Council

3. Scope	
☐	Brainstorm potential internal and external projects and individuals who would benefit from FAC input
☐	Prioritize projects and individuals for highest impact
4. Member Management	
☐	Create a recruitment process that includes: • a set of member characteristics that are aligned with Council goals • an interview process to determine goodness-of-fit • opportunities for potential parent participants to observe FAC prior to committing
☐	Screening: List of member characteristics identified by Network—a beginning list • good communication skills • able to speak in broad terms as well as specific terms about health care experience • child not in active disease process (not hospitalized or in diagnostic phase) • interested in change
☐	Training: • should be ongoing (more than a one-time orientation) • a brief debriefing should occur after each Council meeting • facilitate respect for varying opinions • provide strategies to tell an effective story • identify strategies for providing “solutions” to issues
☐	Feedback: Facilitate Council members agreement on approach to give feedback that promotes partnership and respects differing opinions
☐	Feedback: FAC facilitator develop set of communication strategies to enhance parent feedback; some suggestions: • “That’s a powerful story—what would have improved your experience?” • “What would you like to see changed based on your story?” • “Let’s pull out the key elements of your story and think of recommendations for change.”
☐	Feedback: Assure that all Council members are provided the opportunity to give input at every meeting. • Suggestion: Provide written notification (table card) asking, “Has everyone been heard?” as a reminder to let everyone have input

Meeting Management (Sustaining FACs)	
☐	Mix up type of Council work • short-term focus group • ongoing project input • environmental "walk-abouts" • meet and greets • policy input • document review • special Council project • variety of topics (customer service; patient safety; new construction)
☐	Tap into member interests and passion (arrange for feedback in an area of member interest).
☐	To help plan (or expand) the FAC agenda—reflect on the following: • Does FAC work reflect the institution's strategic goals? • Does the agenda include presentations from both ongoing staff champions as well as staff unfamiliar with the FAC? • Which hospital-based change initiatives would benefit from parent input?
☐	Pre-meeting protocol with provider-presenter • interview health care provider prior to presentation to clarify function and authority of FAC • get "homework" or pre-materials to prepare Council members to give input
☐	Post-meeting protocol with provider-presenter • send thank-you to provider • check in with provider to determine if additional input is needed • determine next steps or date of return • periodically check in with provider to determine additional input needs

☐	Post-meeting debrief with Council members • discussion generates thoughts-feelings-concerns? • what was the quality of Council input? • was everyone heard? • need for more training? • describe how issues/questions/input fit into hospital operations
6. Accountability/Messaging	
☐	Periodic newsletters to list accomplishments of FAC
☐	Presentations to hospital leadership to describe Council function and accomplishments
☐	Ongoing list of FAC agenda items
☐	Content analysis of FAC input to trend type and frequency of work

Conclusion

Family Advisory Councils offer a vehicle for increasing family-centered care in hospitals. In California, Councils vary widely in form and function, yet each has had success introducing the voice of families into patient care and administrative services. Challenges remain in growing the influence of Councils and ensuring their continuing operation, but the experience of FACs in California offers both guidance and optimism for the future. Building and sustaining effective Councils to ensure that the voices of families are heard remains a challenge. The CA-PFCC Network is continuing to work on sharing, evaluating and conveying their experience and developing new models and tools that can advance family-centered care.

Appendix A—CA-PFCC Network Participants

Rady Children's Hospital, San Diego

Children's Hospital Los Angeles

Mattel Children's Hospital UCLA

Kaiser Permanente, Santa Clara

Sutter, Alameda Health System

University of California at San Francisco, Benioff

Oakland Children's, Benioff

Lucile Packard Children's Hospital Stanford

Dominican Hospital

Kaiser Permanente, Redwood City

Palo Alto Medical Foundation

Veteran's Administration of Palo Alto

California Pacific Medical Center

California Children's Services of San Mateo

Children's Hospital of Orange County

References

1. Koop, CE. 1987. US Surgeon General's report: children with special health care needs: campaign '87. Rockville, MD: US Department of Health and Human Services.
2. Institute for Family-Centered Care, 2015. Patient- and Family-Centered Care. http://www.ipfcc.org/pdf/CoreConcepts.pdf.
3. Institute of Medicine (IOM). 2001. Crossing the quality chasm. A new health system for the 21st century. Washington, DC: National Academies Press.
4. Cohen, J., & Ezer, T. 2013. Human rights in patient care: A theoretical and practical framework. *Health and Human Rights*. 15(2), 7-19.
5. Haycock, C., & Wahl, C. 2013. Achieving patient and family engagement through the implementation and evolution of advisory councils across a large health care system. *Nursing Administration Quarterly*, 37(3), 242-6.
6. Halm, M.A., Sabo, J., & Rudiger, M. 2006. The patient-family advisory council: Keeping a pulse on our customers. *Critical Care Nurse*; 26:58-67.
7. Britto, M.T., et al. 2006. Cincinnati Children's Hospital Medical Center: Transforming care for children and families. *Joint Commission Journal on Quality and Patient Safety*. 32(10): 541-8.
8. Taloney, L., & Flores, G. Building blocks for successful patient and family advisory boards: Collaboration, communication, and commitment. *Nursing Administration Quarterly*. 37(3): 247-53.
9. Friesen, M.A., Herbst, A., Turner, J.W., Speroni, K.G., & Robinson, J. 2013. Developing a patient-centered ISHAPED handoff with patient/family and parent advisory councils. *Journal of Nursing Care Quality*; 28(3):208-16.