

Developing and Sustaining Patient and Family Involvement in Safety

MICHIGAN HEALTH AND HOSPITAL ASSOCIATION
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PATIENT- AND FAMILY-CENTERED CARE

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care.

Patient- and family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support are integral components of health care. They promote the health and well-being of individuals and families and restore dignity and control to them.

Patient- and family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction.

Core Concepts

- ❖ Respect
- ❖ Strengths
- ❖ Choice
- ❖ Information
- ❖ Support
- ❖ Flexibility
- ❖ Collaboration
- ❖ Empowerment

In patient- and family-centered care:

- ❖ People are treated with dignity and respect.
- ❖ Health care providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.
- ❖ Individuals and families build on their strengths by participating in experiences that enhance control and independence.
- ❖ Collaboration among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.



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Trustees, Administrators, and Medical and Nursing Leaders: Key Questions to Ask

Leadership

- ▼ Do the hospital's or health system's vision, mission, and philosophy of care statements reflect the principles of patient- and family-centered care?
- ▼ Are the vision, mission, and philosophy communicated clearly throughout the hospital, to patients and families, and others in the community?
- ▼ Do hospital leaders model collaboration with patients and families?

Patients and Families as Advisors

- ▼ Do patients and families serve as advisors to the hospital or health system?
- ▼ Do patients and families serve on committees and work groups involved in:
 - Strategic planning?
 - Facility design?
 - Quality improvement?
 - Patient safety initiatives?
 - Staff orientation and education?
 - Ethics?

Architecture and Design

- ▼ Does the hospital's architecture and design:
 - Create positive and welcoming impressions throughout the facility for patients and families?
 - Reflect the diversity of patients and families served and address their unique needs?
 - Provide for the privacy and comfort of patients and families?
 - Support the presence and participation of families?
 - Enhance patient and family access to information?
 - Support the collaboration of staff across disciplines and with patients and families?

Patient and Family Participation in Care

- ▼ Are patients and families encouraged and supported to participate in care and decision-making?
- ▼ Are hospital policies, programs, and staff practices consistent with the view that families are allies and important to patient health and well-being?

Patient and Family Access to Information

- ▼ Are there systems in place to ensure that patients and families have access to complete, unbiased, and useful information?

Human Resources

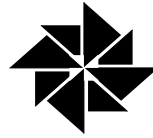
- ▼ Does the hospital's human resources system support and encourage the practice of patient- and family-centered care?
- ▼ Are there systems in place to ensure that:
 - Individuals with patient- and family-centered skills and attitudes are hired?
 - There are explicit expectations that all employees respect and collaborate with patients, families, and staff across disciplines and departments?

Education of Students and Trainees

- ▼ In academic medical centers, do the education programs prepare students and trainees for patient- and family-centered practice?
- ▼ Are patients and families involved in teaching students and trainees?

Research

- ▼ In research programs, do patients and families participate in:
 - Shaping the agenda?
 - Conducting the research?
 - Analysis?
 - Dissemination?



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PARTNERS IN CARING

- Families want to be consistently and respectfully involved in decisions about their children's health care.
As physicians and staff, we can . . .

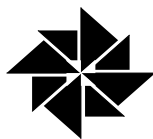
- Families want physicians and other hospital staff to listen to their observations and incorporate their preferences about their children's treatment into the hospital plan of care.
As physicians and staff, we can . . .

- Families want and need useful and understandable information from physicians and other hospital staff.
As physicians and staff, we can . . .

- Families want a personal connection, a relationship with their physicians and other hospital staff. They need to be able to trust the people caring for their children.
As physicians and staff, we can . . .

- Children's comfort and the control of their pain is important to their perceptions of the hospital experience, and to their families' perceptions, as well.
As physicians and staff, we can . . .

- Families want information and support for handling transitions in health care.
As physicians and staff, we can . . .



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PATIENTS & FAMILIES AS ADVISORS: BROADENING OUR VISION

There are countless ways that patients and families can serve as advisors to policy makers, program planners, and care providers. Some are formal and ongoing, others are time limited and informal. At other times, it may be important to seek patients' and families' input on one specific issue. All are necessary to ensure that the system of care is truly responsive to consumer needs, priorities, goals, and values. Below is a list of some of the ways that patients and families can serve as advisors.

- ▼ Create an advisory council with patients and families served by the program.
- ▼ Invite patients or families to present at staff orientation and inservice programs.
- ▼ Hold a monthly family/staff coffee hour.
- ▼ Ask patients or families to host a dinner for a professional-in-training.
- ▼ Include consumers on site visit teams to other programs.
- ▼ Hold brainstorming sessions with patients and families before developing educational materials.
- ▼ Develop, with patients and families, a consumer satisfaction survey and involve them in developing the responses to issues and problems identified.
- ▼ Keep a suggestion book in waiting rooms, so families can record their ideas.
- ▼ Create peer mentor or family liaison positions.
- ▼ Appoint patients and families to task forces and work groups related to hospital renovations, admitting procedures, discharge planning, patient safety, pain management, and other continuous quality improvement endeavors.
- ▼ Ask patients and families to assist in translating patient information materials.
- ▼ Create regular opportunities for consumers to talk with department heads or the senior management team.
- ▼ Ask consumers to accompany staff when they meet with funders and other community groups.
- ▼ Convene focus groups of patients and families as specific issues arise.
- ▼ Solicit patient and family input in community and program needs assessments.
- ▼ Conduct follow-up phone calls with patients and families after hospital discharge.
- ▼ Set up "exit interviews" with administrators when patients and families are leaving the hospital or program.

Adapted from Jeppson, E. & Thomas, J. (1994). *Essential Allies: Families as Advisors*. Institute for Family-Centered Care, Bethesda, MD.

Additional guidance resources available through the Institute for Family-Centered Care: Webster, P. D., & Johnson, B. H. (2000). *Developing and Sustaining a Patient and Family Advisory Council*; Blaylock, B. L., Ahmann, E., & Johnson, B. H. (2002). *Creating Patient and Family Faculty Programs*.



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Patient Safety: Key Questions to Ask

- ▼ Is patient safety a regular agenda item for the hospital or clinic's Patient and Family Advisory Council?

- ▼ Do patients and families serve as members of the hospital's or clinic's Patient Safety Committee?

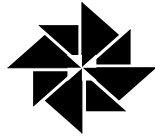
- ▼ Do patients and families participate in the teaching of medical students, residents, fellows, other physicians, and nurses about medical errors and how to disclose a medical error with a patient and family?

- ▼ Are patient and family advisors involved in developing the ways that other patients and families are informed about their role in patient safety? About ways they can promote safety and prevent errors?

- ▼ Are patients and families involved in developing systems of support for patients or families who have experienced a medical error?

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Tips for Group Leaders and Facilitators on Involving Patients and Families on Committees and Task Forces

Selecting Patients and Families to Serve as Advisors

- Look for people who are:
 - interested in serving as advisors;
 - comfortable in speaking in a group with candor;
 - able to use their personal experience constructively;
 - able to see beyond their own experience;
 - concerned about more than one issue or agenda;
 - able to listen and hear differing opinions;
 - representative of patients and families served by the hospital.
- Having just one patient or family member on a committee is not usually successful. Strive for patients and family members to be one third to one half of the committee's membership.
- Remember that serving as a patient or family advisor is a new role for many people. Some patients and family members will need more support than others. Recognize that individuals can grow and develop in this role.

Preparation for Meetings

- Consider the convenience and schedules of patients and families as well as staff in planning the times and locations for meetings.
- Send agenda and minutes ahead of time to all committee members, remembering to allow time for material to reach patients and families (they may not have faxes, email etc.).
- Provide a list of committee members with a brief description of who each person is.
- Offer a mentor, an experienced patient or family advisor or another committee member, to serve as support for a new advisor.
- Offer to have someone come to the first meetings with a new member and debrief afterwards.
- Remember that this type of collaboration is new for many people so preparation and orientation is important for staff as well as patients and family members.
- Plan for compensation of time, expertise, and expenses for patients and families.
- Designate one staff member to be responsible for reimbursement and other practical or logistical issues for patient and family advisors.

During Meetings

- Spend extra time on introductions at the beginning of a meeting, especially for a new committee or when there are new members.
- Consider beginning some meetings with a brief story that captures patients' and families' experiences and perceptions of care.
- As the leader or chair, discuss the concept of collaborating with patients and families explicitly, recognizing that it is a process with everyone learning together how to work in new ways. Convey that it will be important for the group to discuss how the process is working from time to time.
- Acknowledge that there will be tensions and differing opinions and perceptions.
- Provide clear information about the purpose of the committee or task force and the roles of individual members.
- Avoid using jargon. Explain technical terms when used.
- Ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as committee members.
- To avoid becoming stuck in the power of a negative situation, acknowledge the negative experience and ask if there was anything supportive, helpful, or positive for the group to learn from the situation. Ask for ideas and suggestions to prevent or improve the situation.
- If a personal story becomes very prolonged, acknowledge the power and importance of the story, suggest that some policy implications can be learned from the story and that there may be other more appropriate forums where this story should be shared.
- When there are extreme differences in opinions or perceptions, consider:
 - appointing a task force for further study of the issue;
 - asking the opinion of other groups (e.g., another hospital committee or patient/family advisory group); or
 - delaying a decision and considering it at a future meeting.

Anticipate Illness Demands

- Patients and their family members may not be able to attend every meeting. There are other demands on their time and stamina.
- Acknowledge to patients and families themselves and to the committee as a whole that their presence was missed and their participation is valued when they are able to participate. Mailing the minutes and future agendas helps reinforce that their participation is valued.
- Having shared memberships on the committee may help.
- Consider having a "patient and family leave policy" so that consumers can choose an inactive role but maintain their membership should there be circumstances that require some time off.
- Creating a variety of ways for patients and families to participate in the consideration of issues may be useful (e.g., conference calls, written review of materials).

For additional guidance resources available through the Institute for Family-Centered Care: Webster, P. D., & Johnson, B. H. (2000). *Developing and Sustaining a Patient and Family Advisory Council*; Blaylock, B. L., Ahmann, E., & Johnson, B. H. (2002). *Creating Patient and Family Faculty Programs*; Blaylock, B. L., & Johnson, B. H. (2002). *Advancing the practice of patient- and family-centered geriatric care*; Jeppson, E. S., & Thomas, J. (1995). *Essential Allies: Families as Advisors*; and Thomas, J., & Jeppson, E. S. (1997). *Words of Advice: A Guidebook for Families Serving As Advisors*.



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www.familycenteredcare.org . . . Special Topics . . . Environment and Design . . . Professional Education . . . Patient and Family Resource Centers . . . Parental Illness and its Impact on Families

NOTE:

Special supplement to *Clinics in Perinatology* focused on NICU Design and Environment edited by Robert White, MD scheduled for publication September, 2004.

An article by Richard Van Enk, MD, the infection control officer for Bronson Medical Center in Kalamazoo, Michigan *should appear in the near future in the Journal for Infection Control and Hospital Epidemiology*.

Articles by Leonard Berry on the business case for supportive design are scheduled for publication in *Healthcare Financial Management* and *Frontiers of Health Service Management* in the fall of 2004.

A paper on single room care by Roger Ulrich is scheduled for publication in the fall of 2004.