



INSTITUTE FOR FAMILY-CENTERED CARE

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PATIENTS & FAMILIES AS ADVISORS IN PRIMARY CARE: BROADENING OUR VISION

There are countless ways that patients with chronic conditions and families can serve as advisors to health care providers, program planners, and administrators. Some are formal and ongoing, others are time limited and informal. All are necessary to ensure that the system of care is centered on patient and family needs, strengths, priorities, goals, and values. Below is a list of some of the ways that patients and families can serve as advisors in ambulatory care.

Patients and families can participate as advisors for:

Councils, Task Forces, and Work Groups:

- Create an advisory council of patients and families who receive care at the ambulatory practice.
- Appoint patients and families to task forces and work groups related to facility design, waiting room activities, registration procedures, clinic flow, documentation systems, patient safety, and other quality improvement endeavors.
- Include patients and families on site visit teams to other programs.

Clinic Programs and Services:

- Hold brainstorming sessions with patients and families before developing educational materials and involve them throughout the development process.
- Ask patients and families to assist in adapting patient information materials to meet the literacy and language needs of patients served by the practice.
- Include patients and families on teams to plan, conduct, and evaluate group visits.
- Offer opportunities for patients and families to lead or co-lead educational and support programs.
- Create volunteer or staff positions for patients and families such as clinic greeter, peer mentor/coach, or peer liaison.
- Solicit patient and family involvement in building relationships with community programs and resources.
- Ask patients and families to join staff when they meet with funders and community groups.

Physician and Staff Education:

- Invite patients or families to present at staff orientation and inservice programs.
- Ask patients or families to offer a professional-in-training the opportunity to spend a day with them to observe how patients manage their care in their daily life.

Evaluation of Clinic or Program:

- Conduct follow-up phone calls with patients and/or families after clinic visits to gather their perspectives on how they experience care.
- Hold quarterly or semi-annual coffee hours with patients, families, and staff to explore ideas for improving care.
- Invite patients and families to assist in creating or revising a patient/family satisfaction survey and involve them in developing strategies to respond to concerns and problems reported.
- Convene focus groups of patients and families as specific issues arise. Ask a patient or family advisor to co-facilitate the group.

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*.

For additional information about patients and families serving as advisors and leaders in improvement in primary health care, visit the following websites:

Center for Medical Home Improvement at <http://www.medicalhomeimprovement.org>.

Institute for Family-Centered Care: Advancing the Practice: Patients as Advisors and Leaders at <http://www.familycenteredcare.org/advance/pafam.html>.

New Health Partnerships at <http://www.newhealthpartnerships.org>.