

# PARTNERING WITH PATIENTS AND FAMILIES TO DESIGN A PATIENT- AND FAMILY-CENTERED HEALTH CARE SYSTEM

## Recommendations and Promising Practices

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The California HealthCare Foundation is committed to supporting innovative efforts to redesign the health care system to enhance access to quality health care. We are extremely grateful for the Foundation's investment in the development and dissemination of this report. Veenu Aulakh, a Senior Program Officer at the Foundation, participated in the June 2006 *Expert Panel Meeting on Partnerships with Patients and Families* and has helped us identify and connect with some of the exemplary programs described in this report.

The Robert Wood Johnson Foundation supported the planning and convening of the June 2006 *Expert Panel Meeting on Partnerships with Patients and Families*. Rosemary Gibson, Senior Program Officer at the Foundation, brought her commitment to partnerships as an essential component of transformational change in the health care system to the design of a meeting that brought leaders in health care from many different organizations together with patient and family leaders.

The development of this report has been a team effort in many ways. Our team of authors—Marie Abraham, Jim Conway, Laurel Simmons, Susan Edgman-Levitan, Pat Sodomka, Juliette Schlucter, and Dan Ford—brought tremendous insight, expertise, and experience to this project. The writers' work was greatly facilitated by the expert assistance of Julie Moretz, Director of Special Projects at IFCC, who managed the planning of the *International Conference on Patient- and Family-Centered Care*. Joanna Kaufman and Barbara Kahl, Information Specialists for Patient- and Family-Centered Care at IFCC, generously helped in literature searches and writing of some of the promising practices. We had a terrific team of editors, Elizabeth Ahmann and Linda Harteker, who helped bring organization and clarity to recommendations and examples described in the report. We also acknowledge the excellent work done by our design and production team, which was led by Ilana Gordon of Word Wizards. Our proofreading team, Sharon Love and Sandy McDougall, likewise provided invaluable assistance.

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Finally, we are grateful to our own families, who supported us through the preparation of this report and who enriched our understanding of health care and how it needs to change.

After a period of review and comment of the draft report, we finalized the report and disseminated it through the websites of the Institute for Family-Centered Care, the Institute for Healthcare Improvement, and the California HealthCare Foundation.

With gratitude to all,



Beverley H. Johnson  
President/CEO  
Institute for Family-Centered Care

## INTRODUCTION

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The U.S. health care system faces serious challenges. Health care financing is an overriding issue; others include overcoming disparities in access to care, improving health literacy, meeting the needs of a burgeoning population of older Americans and of the increasing numbers of people living with chronic conditions, improving patient safety, overcoming workforce shortages, and ensuring the appropriate use of technology. There is growing awareness that to achieve the best outcomes, patients and families must be more actively engaged in decisions about their health care and must have enhanced access to information and support.

These issues are not amenable to quick fixes. Moreover, they are interrelated. Tackling one challenge will necessitate confronting others. As a result, most experts now agree, the health care system must be fully redesigned. Because of the extent and complexity of the challenges, this endeavor will require the collaborative efforts of many stakeholders. Partnerships at many levels—involving patients and their families, health care professionals, health care administrators, planners and policymakers, third-party payers, and government agencies will be essential.

The collaborative efforts must begin by establishing a shared understanding of the problem. The next steps are to develop a vision for the future and an action plan that clearly sets forth, in measurable terms, how that vision can be realized. Next, all those involved must make a long-term commitment to work collaboratively to realize the vision. Patients and families, too often neglected in policy and program deliberations, are key to every step of the process.

To set this collaborative process in motion, a one-day invitational meeting was convened by the Institute for Family-Centered Care (IFCC) in collaboration with the Institute for Healthcare Improvement (IHI). The meeting was held on June 2, 2006, in Cambridge, MA. The Robert Wood Johnson Foundation provided funding for the meeting. Leadership from The John D. Stoeckle Center for Primary Care Innovation also participated in meeting planning. As stated in the letter of invitation, the goal of the meeting was to “explore how to enhance efforts to collaborate with patients and families in the redesign of health care and to realize the enormous potential of patient and family partnerships.”

This meeting brought together 26 patient and family advisors and 59 administrative and clinical leaders from hospitals and other health care organizations. Leaders from three foundations also attended the meeting, as did 19 individuals from IHI. Appendix A lists all meeting attendees.

This report is based on the deliberations that took place at that meeting and on the recommendations that emerged from it. Its purpose is to provide guidance to key constituents in health care—patients and families, providers, administrators, educators, researchers, advocates, and funders—for advancing patient- and family-centered care, and specifically for creating partnerships with patients and families in quality improvement and health care redesign. Many of the report’s recommendations are illustrated by examples drawn from health facilities and other organizations that are making exemplary progress in partnering with patients and families.

## Developing a Shared Understanding of Patient- and Family-Centered Care

In preparation for the meeting, each participant received a copy of a background paper titled, *Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future. A Work in Progress* (available at <http://www.familycenteredcare.org/tools/downloads.html>). The paper set out a patient- and family-centered framework for creating a shared vision and for developing recommendations for change. The paper offered historical background and examples to give meeting participants a common understanding of the state of the field of patient- and family-centered care. To assure shared terminology, the paper defined patient- and family-centered care as “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.”

The paper also defined the following four core concepts of patient- and family-centered care:

- ◆ **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 hospital 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.

The following excerpt from the paper, which further explains the concept of patient- and family-centered care, was also essential to deliberations at the June meeting:

Patient- and family-centered care redefines relationships in health care. It places an emphasis on collaborating with patients and families of all ages, at all levels of care, and in all health care settings. Further, it acknowledges that families, however they are defined, are essential to patients’ health and well-being and are crucial allies for quality and safety within the health care system. A patient- and family-centered approach recognizes that the very young, the very old, and those with chronic conditions—the individuals who are most dependent on hospital care and the broader health care system— are also those who are most dependent on families.

## Meeting Purpose and Goals

The purpose of the June 2 meeting was as follows:

To elicit suggestions and recommendations for a plan to ensure that meaningful, sustained partnerships with patients and families are put in place in hospitals and health systems; in community clinics and other ambulatory settings; in schools educating the next generation of health care professionals; in national associations; in federal, state, and community agencies; in foundations and advocacy organizations; and among payers.

Meeting goals were:

- ◆ To develop a shared vision and action plan for improving health care by advancing the practice of patient- and family-centered care and by creating partnerships with patients and families both in all health care settings and within the organizations and agencies having an impact on health care.
- ◆ To build commitment and synergy among participants and their organizations to advance the practice of patient- and family-centered care.
- ◆ To ensure that meaningful and sustained partnerships are an essential component of quality improvement and the redesign of health care in the future.
- ◆ To outline specific action steps and develop recommendations for:
  - ▼ How to engage and support patients, families, health care professionals, and administrative leaders in working together on quality improvement and the redesign of health care;
  - ▼ How to overcome the barriers to creating and sustaining these partnerships; and
  - ▼ How to build the evidence base, resources, structures, processes, and culture to support and sustain this work.

## Visioning the Ideal Health Care System

At the meeting, participants were arranged in small groups. Patient and family advisors and various professionals were part of each group. A facilitator assisted each group by raising questions and recording discussions.

As a first step, participants were asked to share their visions for the health care system by responding to the following prompts:

1. What do you really care about?
2. What are your hopes?
3. What if ... ?
4. What matters most?

Major themes from the visioning discussion are summarized in Appendix B.

## Developing Recommendations for Realizing a Shared Vision

Next, participants were asked to discuss 13 questions that built on the four topics discussed during the visioning exercise. The questions apply to the full range of health care settings, organizations, agencies, and institutions involved in health planning, delivery, and evaluation, as well as reimbursement.

Participants were asked to draw on their backgrounds, training, and experiences in health care, as well as on ideas sparked by the background paper and the visioning exercise, to develop recommendations in response to each question. The questions may be found in Appendix C.

## How to Use This Report

This report synthesizes the results of the discussions that took place at the June 2 meeting and presents them in the form of 11 sets of recommendations. Chapter 1, the broadest, deals with the overall topic of building effective partnerships with patients and families. The following two chapters focus on partnership building in specific settings, namely, hospitals (Chapter 2) and ambulatory facilities (Chapter 3). Chapters 4 and 5 present recommendations for a redesigned educational system for health care professionals and executive leaders, respectively. Chapter 6 relates to evaluation and research. Next, the focus moves to the organizational level; Chapter 7 deals with health care finance, accreditation, and licensing, while Chapter 8 suggests new roles for professional associations; and Chapter 9 deals with partnerships with quality improvement and patient safety organizations. Chapter 10 provides suggestions for supporting patient and family advisors. The report ends with a chapter on the role of funders in the newly envisioned health care system.

The recommendations presented, although ambitious, are not unrealistic. As evidence, the authors of this report have drawn on their own experience and that of others to present scores of examples that illustrate how forward-thinking organizations nationwide have already successfully implemented many of the recommendations. Each chapter concludes with a list of print resources and websites. An alphabetized list of organizations and projects mentioned in the report may be found in Appendix D.

## Moving Forward

We hope that readers will use this report to inform and support their organizations' efforts to advance the practice of patient- and family-centered care and to create partnerships with patients and families to enhance the quality and safety of health care. Readers can also use the report as a resource for connecting with others committed to making patient- and family-centered care an organizational priority.

We also hope that readers will share with us examples of work they are doing within their own organizations to advance partnerships with patients and families. You may send them to us at [Institute@iffcc.org](mailto:Institute@iffcc.org). With your permission, we will then post these stories about emerging best practices on the Institute for Family-Centered Care website (<http://www.familycenteredcare.org>).

Through building sustained partnerships with patients and families at all levels of care, we can, together, address the serious challenges that face us and successfully transform the U.S. health care system.



# MAKING PARTNERSHIPS WITH PATIENTS AND FAMILIES AN ESSENTIAL ASPECT OF HEALTH CARE REDESIGN AND QUALITY IMPROVEMENT

### Key recommendations at a glance...

1. Inform and convince policymakers, administrators, health care providers, educators, and patients and family members of the importance and value of partnerships with patients and families.
2. Offer opportunities for health care administrators, educators, and providers to learn practical strategies for implementing and sustaining patient- and family-centered care.
3. Employ patient and family leaders in meaningful positions in the health care system.
4. Work with community groups to educate consumers to expect partnerships in their own health care and meaningful roles in health care institutions and the health care system.
5. Enlist accrediting bodies in developing standards related to partnerships with patients and families and patient- and family-centered care.
6. Enlist purchasers and payers in expanding their definition of quality to include outcomes that reflect patient- and family-centered practices and to utilize such criteria in payment.

Patients and families have experience, expertise, insights, and perspectives that can be invaluable to bringing about transformational change in health care and enhancing quality and safety. A variety of clearly defined roles for patients and families to participate as partners in quality improvement and in the redesign of health care needs to be in place in all types of health care organizations. These include hospitals, ambulatory practices, community-

based organizations, agencies, and the educational programs preparing the next generation of health care professionals and administrative leaders. Similar partnerships need to be in place for payers, accrediting organizations, and foundations.

Strategies to encourage, develop, and sustain these partnership roles, as described here, are essential to change and improvement in health care.



## 1. Inform and convince policymakers, administrators, health care providers, and patients and family members of the importance and value of partnerships with patients and families.

Raise awareness of meaningful roles for patients and family members in health care institutions and the health care system. These roles include:

- ◆ Caregivers, advocates, and collaborators in planning and providing individual patient care.
- ◆ Co-leaders and leaders of patient and family education and support groups.
- ◆ Leaders of advocacy groups.
- ◆ Members of patient and family advisory councils.
- ◆ Members of key institutional committees, such as safety, quality improvement, facility planning, information technology, ethics, and others.
- ◆ Patient and family faculty for educational programs for health care professionals and administrative leaders.
- ◆ Members of national health care advisory boards.
- ◆ Paid positions in institutions, agencies, and organizations.

Tailor messages about patient- and family-centered care and partnerships to the needs and concerns of the specific audience (e.g., CEOs, administrators, managers, front-line staff, administrative staff, and patient and family advisors and leaders).

Use television, radio, print, and other media to publicize meaningful roles for patients and family members in the health care system.

*Remaking American Medicine*, a four-part national PBS series that aired in the fall of 2006, highlighted leaders in ambulatory and hospital programs who have developed effective partnerships with patients and families.

This series also profiled the experiences of patients and families in community hospitals, academic medical centers, and community-based ambulatory settings, showing the promise of how health care can be improved through partnerships, more inclusive communication, care coordination, and the practice of patient- and family-centered care.

A public awareness campaign, supported by a website and the statewide Quality Improvement Organizations, encouraged dialogue and activities in local communities and provided tools and resources in conjunction with this PBS series.

Recent articles in mainstream print media highlight partnerships with patients and families that are changing and improving health care and the design of health care facilities, and describe research that is shaping these changes.

- ◆ “Hospitals’ Focus Now All About Patients,” *Chicago Daily Herald*, September 3, 2007.
- ◆ “Hospitals Boost Patients’ Power as Advisers,” *Wall Street Journal*, August 8, 2007.
- ◆ “ICUs’ New Message: Welcome, Families,” *Wall Street Journal*, July 12, 2007.
- ◆ “Patients, Families Take Up the Cause of Hospital Safety,” *Wall Street Journal*, May 30, 2007.
- ◆ “For the Tiniest Babies, the Closest Thing to a Cocoon,” *New York Times*, May 29, 2007.
- ◆ “Tufts Doctor’s Specialty is Empathy,” *Boston Globe*, January 22, 2007.

Create an initiative, similar to the Institute for Healthcare Improvement’s 100,000 Lives and the 5 Million Lives Campaigns, to encourage hospitals and other health care organizations to publicly report measurable indicators for patient- and family-centered practice and related partnerships, providing national and regional accountability and visibility.

Collect and disseminate data regarding the impact of partnerships with patients and families in order to increase the evidence base for change.

**Blanchfield Army Community Hospital** (BACH) at Fort Campbell in Kentucky has been a leader among Military Treatment Facilities (MTFs) in creating partnerships with patient and family advisors. A Patient- and Family-Centered Care Council was established in 2005 at BACH. Over the last two years, over 25 patient and family advisors have been involved in various quality improvement initiatives.

Radiologists and hospital staff worked with patient and family advisors in redesigning the mammography experience. Women can now self-refer and the experience is one of information-sharing and support for women—enhancing patient and staff/physician satisfaction and meeting health promotion/disease prevention targets. Blanchfield is the first MTF to meet the HEDIS\* performance measures for mammography screening.

\*The Health Plan Employer Data and Information Set (HEDIS) is a set of standardized performance measures designed to ensure that purchasers and consumers have the information they need to reliably compare the performance of managed health care plans.

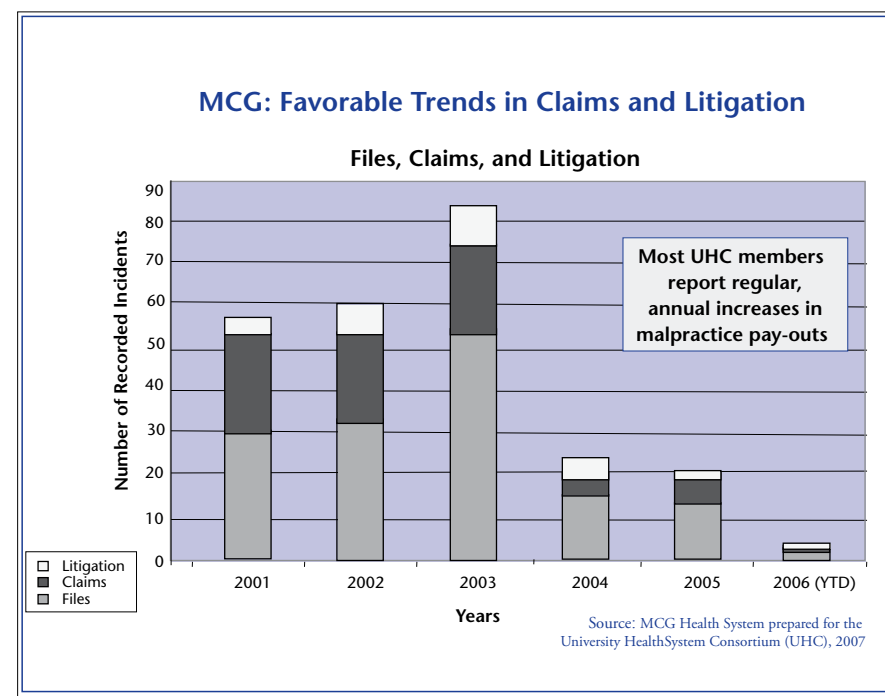
**The Health Foundation** in the U.K. has set up a five-year multi-million dollar research initiative called the *Quest for Quality and Improved Performance*. The purpose is to systematically collect, analyze, and disseminate data based on the **Institute of Medicine's**, *Crossing the Quality Chasm* report. Patient-centered care and patient engagement have been selected as topics for analyses.

#### Develop the business case for partnerships with patients and families.

Incorporating patient and family advisors at all levels of an institution can contribute to efficiency, quality, safety, satisfaction, and even market share.

The **MCG Health System** in Augusta, Georgia, is nationally recognized for its commitment to patient- and family-centered care and partnerships with patients and families at all levels of care. The process for change began in 1993. Today, 155 patient and family advisors serve on seven councils and 45 hospital committees and task forces, including the Patient Safety and Medicine Reconciliation Committees.

Patient- and family-centered care has become the business model for the organization as it impacts positively each of MCG's business metrics (finances, quality, safety, satisfaction, and market share). This academic medical center is the most cost-efficient hospital in the **University HealthSystem Consortium** (UHC) database. From 2001–2006, MCG reports a decrease in malpractice claims and litigation while many other academic medical centers, as measured by the University HealthSystem Consortium, report annual increases in these expenditures. Patient- and family-centered care is central to the values, strategic plan, and personnel policies and practices. Partnerships with patients and families are embedded at all levels of the organization.



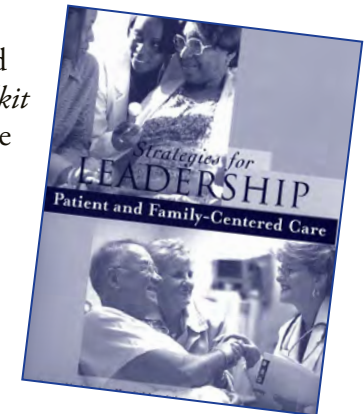
Patient and family advisors guided the development of the **Neuroscience Center for Excellence**. The following represents three years of quality improvement data:

- ◆ Patient Satisfaction—10th to 95th percentile.
- ◆ Length of stay decreased 50% in Neurosurgery.
- ◆ Reduction in medical error by 62%.
- ◆ Discharges (volume) increased 15.5%.
- ◆ Staff vacancy rate went from 7.5% to 0%; now have a waiting list of five RNs.
- ◆ Positive change in perception of the unit by doctors, staff, and house staff.

Patient and family advisors participated in the redesign of the mammography program. The view of this program has shifted from primarily the provision of technical procedures to an experience for a woman where she is getting health information and doing something beneficial for herself. Satisfaction scores have risen from percentiles in the 40s to the high 90s.

#### Encourage key leaders who support partnerships with patients and families to share their commitment and experiences.

The **American Hospital Association**, in partnership with the Institute for Family-Centered Care, created and disseminated the *Patient- and Family-Centered Care Toolkit* as part of its *Strategies for Leadership* series. The videotape and written materials capture senior health care leaders' views about the benefits of partnering with patients and families.



The publications developed by the **Joint Commission Resources** and the **Advisory Board Company** (see pages 94–95) also capture the views and recommendations of leaders for developing and maintaining partnerships with patients and families.

## 2. Offer opportunities for health care administrators, educators, and providers to learn practical strategies for implementing and sustaining patient- and family-centered care (see Chapters 4 and 5).

Provide opportunities for professionals to experience partnership at all levels of health care.

The **Memorial Healthcare System** in Hollywood, Florida, holds an annual conference on patient- and family-centered care to celebrate and further the development of partnerships with patients and families. Patient and family advisors are an integral part of planning, presenting, and evaluating these conferences. This organization is investing in building leaders who have an understanding of, and commitment to, patient- and family-centered care.

The **National Initiative for Children's Healthcare Quality (NICHQ)**, with funding from the **Maternal and Child Health Bureau**, worked together with the **Epilepsy Foundation** and eight states on a quality improvement initiative focused on improving care for children with epilepsy. Parents of children with epilepsy participated in the planning phase of the project and on the improvement teams. A parent served as a project/faculty co-chair. She participated in faculty calls, led calls with parents, and reviewed and contributed to presentations and project documents. A video, *Partnering with Parents for Improvement*, was produced to highlight lessons learned and the benefits of parent involvement in this initiative.

Develop support communities for administrators, clinicians, and patients and families implementing patient- and family-centered approaches.

**New Health Partnerships**, an initiative to improve chronic illness care sponsored by the **Institute for Healthcare Improvement**, has a new online community providing information and support for providers, individuals, and families interested in improving care for people with chronic conditions by advancing the practice of patient- and family-centered, collaborative self-management support ([www.newhealthpartnerships.org](http://www.newhealthpartnerships.org)). The website facilitates dialogue among ambulatory clinicians, administrative leaders, patients, and families (see page 34 for further information about *New Health Partnerships*).



The **International Alliance of Patients Organizations (IAPO)** located in London, England, is a membership organization focused on building global efforts to advance “patient-centred health care” through capacity building for partnerships within and across patient organizations; facilitating the patient voice in international advocacy; and working collaboratively with organizations and individuals across disciplines who share a commitment to partnership and patient-centred care. IAPO convenes the Global Patients Congress and training workshops, disseminates a policy statement on patient involvement, and has a variety of other resources, briefing papers, tools, and toolkits on its website. The site also includes a listserv called the Patients’ Exchange for members to share ideas and resources, discuss challenges and practical solutions, and build solidarity.

Provide inservice and other training and support for administrators and staff members transitioning to a more collaborative approach to care, allow them to voice and work through concerns, and then hold them accountable for change.

Every employee at **Griffin Hospital** in Derby, Connecticut, a **Planetree** hospital, attends a week-long orientation prior to beginning work at the hospital. During the orientation, new employees participate in a two-day retreat focusing on the Planetree philosophy of care, facilitated by Griffin’s Vice President of Patient Care Services. Through team building and personal exercises, role playing, story telling, and information sharing, new employees are supported in developing an understanding of, and commitment for, this organization’s culture that embraces patient- and family-centered concepts.

The **Institute for Family-Centered Care** sponsors two types of educational meetings—in-depth seminars and international conferences. At each of these educational venues, patient and family advisors and leaders, as well as clinicians and administrators, are faculty members and presenters, thus creating an experiential learning environment for partnerships for participants. There is also planned opportunity for dialogue to explore new ways of working together and strategies for changing organizational culture.

Additionally, the Institute designs and facilitates on-site retreats and planning meetings with patient and family advisors and health care leaders. These on-site retreats and meetings can be used to advance the practice of patient- and family-centered care within hospitals, ambulatory programs, and agencies.

See pages 53–55 and 71–73 for further information about inservice training sessions offered by specific hospitals.

Develop, expand, and disseminate guidance and tools for creating and sustaining partnerships.

Three recent publications highlight the work of leaders who have made partnerships an essential aspect of the way they work to create high-quality, safe, and cost-efficient health care organizations:



- ◆ *Patients as Partners: Toolkit for Implementing National Patient Safety Goal 13*, published by **Joint Commission Resources**.
- ◆ *Patients as Partners: How to Involve Patients and Families in Their Own Care*, published by **Joint Commission Resources**.
- ◆ *The Family as Patient Care Partner: Leveraging Family Involvement to Improve Quality, Safety, and Satisfaction*, published by the **Advisory Board Company**.

The **Institute for Family-Centered Care** develops and publishes the Pinwheel Series, and resource materials on how to create and sustain partnerships with patients and families. Many examples of partnerships in ambulatory, hospital, long-term care, and educational settings are described.

Use patient and family stories as a teaching tool for administrators, providers, and consumers.

A group of health care professionals created the nonprofit organization **Professionals with Personal Experience in Chronic Care (PPECC)** to advocate for improved systems of care after personal and family experiences with chronic illness and long-term care. Health care professionals are encouraged to share their experiences with the health care system in order to promote change. PPECC intends to use these stories and personal experiences to develop policy initiatives.

**Doctors Nova Scotia**, formerly the Medical Society of Nova Scotia, is providing first-year medical students at the **Dalhousie University Faculty of Medicine** in Halifax, with copies of the book, *Privileged Presence: Personal Stories of Connections in Health Care*. This book is a collection of personal stories—both patient and family stories and narratives from physicians, nurses, and other health care professionals. Tools for creating partnerships are included in the book. This medical school at Dalhousie University offers a Medical Humanities Program. Through music, art, literature, film, and facilitated discussions, medical students are offered the opportunity to explore issues related to communication, compassion, and truly connecting with patients and families.

Additional examples of patient and family panels and patient and family faculty programs are described in Chapter 4.

### 3. Employ patient and family leaders in meaningful positions in the health care system.

Hospitals, clinical units, ambulatory programs, and public health agencies are creating paid positions for patient and family leaders to advance the practice of patient- and family-centered care and facilitate the development of partnerships with patients and families. Hospitals and health systems that employ patient

and family leaders include **Children's Hospital & Regional Medical Center** in Seattle, **University of Washington Medical Center**, the **Children's Hospitals and Clinics of Minnesota**, **MCG Health System** in Augusta, Georgia, the **Memorial Health System** in Hollywood, Florida, **Cincinnati Children's Hospital Medical Center**, **The Children's Hospital of Philadelphia**, and the **C.S. Mott Children's Hospital** in Ann Arbor, Michigan. Public health agencies that have created positions for patient and family leaders include the **HIV/AIDS Bureau of the Massachusetts Department of Public Health**, the **Wisconsin Department of Health and Family Services**, and the **Pennsylvania Department of Health**.

### 4. Work with community groups to educate consumers to expect partnerships in their own health care and meaningful roles in health care institutions and the health care system.

The purpose of **Consumers Advancing Patient Safety (CAPS)** is to foster partnerships with consumers in patient safety improvements.

CAPS partnered with the **Health Learning Center of Northwestern Memorial Hospital**, **Zipperer Project Management**, and the **Chicago Metropolitan Library System** to raise awareness and educate consumers on patient safety issues in Illinois. Activities for the Partnering for Patient Empowerment through Community Awareness (PPECA) project include holding information sessions in public libraries to raise consumer awareness regarding patient safety issues. To further develop the PPECA train-the-trainer program model, CAPS is partnering with the **Hardin Library for the Health Sciences** at the University of Iowa.

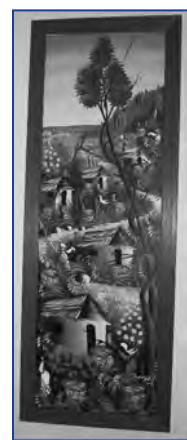
The Hardin Library will collaborate with the University of Iowa College of Public Health and its Institute for Quality Healthcare, the University of Iowa Hospitals and Clinics (UIHC), and Zipperer Project Management to train public health educators and program planners on the use of a community-focused, patient safety consumer awareness program. Five rural Iowa communities will be targeted for the project, as well as a kick-off program at the UIHC. The program will provide a train-the-trainers workshop for librarians, consumer advocates, health care educators, and hospital and public health employees.

Ensure availability of advocacy support and training for individuals and organizations desiring assistance with their participation in partnerships.

**The Center for Patient Partnerships** is an interdisciplinary educational center of the Schools of Law, Medicine and Public Health, and Nursing at the University of Wisconsin-Madison. Several advocacy projects demonstrate its commitment to partnership. The Center's Clinical Education Program trains graduate and professional students from law, medicine, social work, pharmacy, psychology, public health, and public policy in patient advocacy. These trained advocates

then assist clients with serious chronic or life-threatening illness and their families as they make more informed medical decisions, form effective partnerships with providers, and develop self-advocacy skills. Advocates support clients and families dealing with medical, legal and/or financial uncertainty, and clients' values and priorities serve to guide advocacy efforts. Through funding from the Madison Affiliate Chapter of the Susan G. Komen Foundation, the Center for Patient Partnerships recently launched another project, the Komen Advocates Training Program, which trains breast cancer survivors to advocate for others with breast cancer. The Center is also developing and testing a curriculum to inform Wisconsin employers about how to help employees and their families navigate the health care system.

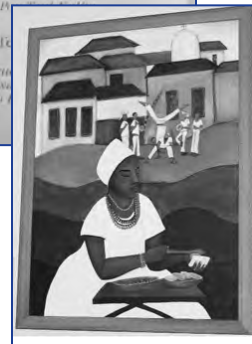
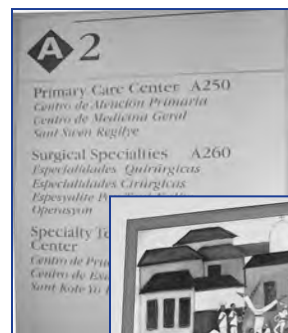
### Use community advisors to assist in addressing linguistic and multicultural issues.



The **Cambridge Health Alliance** in Cambridge, Massachusetts, serves the culturally diverse communities of Cambridge and Somerville, as well as other “immigrant gateway” communities near Boston. It is a unique model that incorporates public health, clinical care, academic programs, and research. Over 300 volunteer health advisors from these culturally diverse communities have been trained and provided with continuing education by the Alliance’s Community Affairs Department since 2001. These advisors collectively speak 16 different languages and represent the local Haitian,

Brazilian, Latino, South Asian, African-American, and African communities. Currently program staff and over 120 advisors work collaboratively with churches and community organizations to organize health fairs, educational events, and health screenings; provide basic health education in disease prevention and wellness; and educate community members about services.

The Somerville Hospital has a patient and family advisory council helping staff develop a deeper understanding of the needs and perceptions of the diverse community it serves. The Cambridge Health Alliance also has a patient and family advisory group specific to the Haitian population. Hospital and clinic signs are all in four languages, and artwork in corridors and public spaces reflects the diversity of the cultures served. Patient and family informational materials and community educational programs are offered in many languages.



### Assure that all communications in the health care encounter—conversations, materials, and educational and support meetings—are offered in the appropriate language and at the level of individual patient and family understanding.

A common problem faced by hospitals and other health care facilities is the gap between what needs to be communicated in medical encounters and the health literacy skills of patients and families. The **University of Washington Medical Center** and **Children’s Hospital & Regional Medical Center** in Seattle have staff trained on the use of specific graphic standards and offer the services of a health education editor to help clinicians develop reader-friendly educational materials for patients and families. Both hospitals have also developed patient and family review processes, which support engaging patients and families in the development, review, and evaluation of education and information materials.

In addition, to support medical staff at the University of Washington Medical Center, a health literacy booklet, a training module, and a health literacy website were developed. At Children’s, staff training was offered by a national plain English expert and an online toolkit of materials was developed for staff use.

### Encourage knowledgeable health care providers and consumers to reach out to community groups to spread the word on patient- and family-centered care.

Believing that a partnership among the patient, family, surgeon, and other members of an interdisciplinary team will result in the best outcomes, the **American Academy of Orthopaedic Surgeons** launched the “Getting Better Together” multimedia public service education campaign in 2006. These activities mark the beginning of a major Academy effort to increase the public’s awareness about orthopaedic conditions, their impact on society, and the importance of partnerships to safe medical practice.

The Academy distributed a series of public service announcements (PSAs) on patient- and family-centered care to more than 3,500 news outlets—radio stations, major television networks and cable systems, and 7,000 magazines and newspapers nationwide. Posters were placed in 200 airports throughout the United States.

Key aims of the campaign are to help patients and the public learn about, and participate in, a more collaborative approach to health care. The PSAs and posters provide helpful, concise communication tips for “Getting Better Together” such as:



- ◆ Got questions for your doctor? Write them down!
- ◆ Talk much with your doctor? Communication between doctors and patients is powerful medicine.
- ◆ Get the most out of a visit with your doctor. Plan ahead.

Develop training programs for health care consumers in patient- and family-centered care (see Chapter 10).

5. **Enlist accrediting bodies in developing standards related to partnerships with patients and families and patient- and family-centered care (see Chapter 7).**
6. **Enlist purchasers and payers in expanding their definition of quality to include outcomes that reflect patient- and family-centered practices and to utilize such criteria in payment (see Chapter 7).**

### Summary

Building partnerships with patients and families in health care, as this chapter has pointed out, must be a well-planned, inclusive process that reaches out to planners and policymakers, members of the business community, accrediting bodies and foundations, and third-party payers, as well as to health care administrators, clinicians, educators and members of the community at large. Partnership-building efforts must be grounded in the recognition that patients and families are essential to effecting transformational change in health care and to enhancing its safety and quality. Building on this shared premise, it is then necessary to create meaningful roles for patients and families in all aspects of health care planning, delivery, education, and evaluation, and to prepare all participants to successfully assume their roles in the collaborative process. Education and guidance materials are essential, both to create partnerships and to maintain their ongoing effectiveness. It is not an easy process, but, as the many examples in this chapter demonstrate, it is one that is bringing enormous benefits to health systems, providers, and patients and families nationwide.

### FOR FURTHER INFORMATION . . .

- For the most recent references on this topic, please see the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>
- Information about *Remaking American Medicine*, the PBS series, is available through its national outreach campaign at <http://www.ramcampaign.org>. DVD's, tools, information on their public awareness campaign, and other resources are also available here.
- Six articles that may be of special interest:
  - ◆ Hitzeman, H. (September 3, 2007). "Hospitals' focus now all about patients." *Chicago Daily Herald*, p. 4.
  - ◆ "Hospitals Boost Patients' Power as Advisers," *Wall Street Journal*, August 8, 2007 at <http://online.wsj.com/public/article/SB118652860268491024.html>.
  - ◆ "ICUs' New Message: Welcome, Families," *Wall Street Journal*, July 12, 2007 at <http://online.wsj.com/article/SB118419577614963880.html?mod=article-outset-box>.
  - ◆ "Patients, Families Take Up the Cause of Hospital Safety," *Wall Street Journal*, May 30, 2007 at [http://online.wsj.com/article/SB118048050393817811.html?mod=todays\\_us\\_personal\\_journal](http://online.wsj.com/article/SB118048050393817811.html?mod=todays_us_personal_journal).
  - ◆ "For the Tiniest Babies, the Closest Thing to a Cocoon," *New York Times*, May 29, 2007 at <http://www.nytimes.com/2007/05/29/health/29baby.html?em&ex=1180670400&en=9c217435403bcf2c&ei=5087%0A>.
  - ◆ "Tufts doctor's specialty is empathy." *Boston Globe*, January 22, 2007 at [http://www.boston.com/news/globe/health\\_science/articles/2007/01/22/tufts\\_doctors\\_specialty\\_is\\_empathy](http://www.boston.com/news/globe/health_science/articles/2007/01/22/tufts_doctors_specialty_is_empathy).
- A profile on the MCG Health System in Augusta, GA, is featured at <http://www.familycenteredcare.org/profiles/prof-mcg.html>. The health system's website provides additional information about its patient- and family-centered initiatives at [http://www.mcghealth.org/Patient\\_Visitor\\_Info/patient-family\\_center-care/Alice\\_Reese.html](http://www.mcghealth.org/Patient_Visitor_Info/patient-family_center-care/Alice_Reese.html).
- The resources in the Patient- and Family-Centered Care Toolkit—Strategies for Leadership, produced by the American Hospital Association and the Institute for Family-Centered Care, can be downloaded from <http://www.aha.org/aha/issues/Quality-and-Patient-Safety/strategies-patientcentered.html>.
- To learn more about NICHQ's Awareness and Access to Care for Children and Youth with Epilepsy initiative and to download a four-minute clip from the DVD, *Partnering with Parents for Improvement*, go to <http://www.nichq.org/NICHQ/Programs/CollaborativeLearning/Epilepsy2005.htm>. To obtain a copy of the entire DVD, contact NICHQ at [info@nichq.org](mailto:info@nichq.org).



- The website for New Health Partnerships is <http://www.newhealthpartnerships.org>.
- Resources from the International Alliance of Patients Organizations (IAPO) can be found at <http://www.patientsorganizations.org>.
- Information about the Planetree organization and its philosophy, educational programs, and resources is available at <http://www.planetree.org>. The publication, *Putting Patients First: Designing and Practicing Patient-Centered Care*, is available for purchase on the site.
- Several sources of information on patients as partners:
  - ◆ Pillow, M. (Ed.). (2007). *Patients as partners: Toolkit for implementing National Patient Safety Goal 13*. Oakbrook Terrace, IL: Joint Commission Resources.
  - ◆ McGreevey, M. (Ed.). (2006). *Patients as partners: How to involve patients and families in their own care*. Oakbrook Terrace, IL: Joint Commission Resources.
  - ◆ Hirschoff, A. (Ed.). (2006). *The family as patient care partner: Leveraging family involvement to improve quality, safety, and satisfaction*. Washington, DC: The Advisory Board Company.
- Educational programs, guidance publications and videos, tools for change, and profiles on partnerships with patients and families from the Institute for Family-Centered Care are available at [www.familycenteredcare.org](http://www.familycenteredcare.org).
- Resources and activities of Professionals with Personal Experience in Chronic Care are described at <http://www.ppecc.org>. The book, *It Shouldn't Be This Way: The Failure of Long-Term Care*, describing the personal story that inspired the creation of this organization, is available through the website.
- *Privileged Presence: Personal Stories of Connections in Health Care* is available from the Bull Publishing Company ([http://www.bullpub.com/privileged\\_presence.html](http://www.bullpub.com/privileged_presence.html)).
- The Consumers Advancing Public Safety organization is described at <http://www.patientsafety.org>.
- To learn more about The Center for Patient Partnerships, see: <http://law.wisc.edu/patientadvocacy>.
- PSAs and information about the American Academy of Orthopaedic Surgeons' public awareness campaign are available at <http://www6.aaos.org/About/Pemr/PSA/psa.cfm>.



# CREATING PARTNERSHIPS IN HOSPITAL SETTINGS

### Key recommendations at a glance...

1. Provide incentives and rewards for hospitals and affiliated long-term care facilities implementing patient- and family-centered care to encourage its development and to assure that it is a recognized value in the marketplace.
2. Develop Federal and other payer regulations and accreditation requirements (e.g., the Centers for Medicare & Medicaid Services and The Joint Commission) calling for patient- and family-centered care.
3. Assure involvement of patients and families at all levels in the health care system.
4. Ensure that patient and family perspectives, including their experience of care, are key drivers in improving care processes and structures.
5. Integrate a patient- and family-centered care philosophy into the mission, vision, values, definition of quality, strategic plan, and personnel practices in health care settings, for both acute and long-term care.
6. Provide information and training for health care providers, staff, administrators, trustees, patients, and families for creating and sustaining effective partnerships.
7. In academic medical centers, involve patient and family faculty in the education of the next generation of practitioners and administrators.

*“Watch out for the ‘myth’ of engagement of patients and families.”*

A Participant at the Expert Panel Meeting on Patient and Family Partnerships, June 2006  
*It is all too easy to welcome patient or family participation on a committee or two and then call a hospital “patient- and family-centered.” True change occurs only when patients and families are equal collaborators in the wide range of decisions that are made in health care settings, from establishing vision for the organization and design of the facilities to hiring, policy development, quality improvement efforts, and bedside care.*

**A**cross the health care system, hospitals were first to begin to implement patient- and family-centered care. Many pediatric hospitals have implemented aspects of patient- and family-centered care, others have not. More recently, hospitals providing care to adult patients are recognizing that patient- and family-centered care is better care and better

business. Yet, hospital culture is slow to change and there is much still to be done.

It remains an important task to ensure that every hospital has structures and processes in place to develop and sustain effective partnerships with patients and families to enhance quality, safety, and the experience of care. Following are recommendations to encourage and support that process.

**1. Provide incentives and rewards for hospitals and affiliated long-term care facilities implementing patient- and family-centered care to encourage its development and to assure that it is a recognized value in the marketplace.**

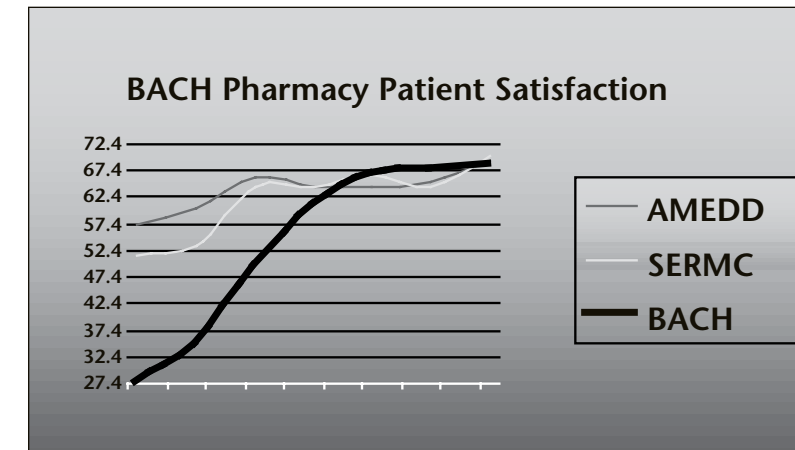
The **American Hospital Association’s McKesson Quest for Quality Prize** acknowledges the vision for healthcare that is described in the Institute of Medicine’s *Crossing the Quality Chasm* report.

This prestigious \$75,000 award recognizes hospitals that have demonstrated commitment and exceptional ability to align institutional efforts in quality, safety, and partnerships with patients and families and through these efforts focus on all six aims of the *Crossing the Quality Chasm* report (safety, patient-centeredness, effectiveness, efficiency, timeliness, and equity).

The AHA McKesson Prize criteria include the following patient- and family-centered concepts:

- ◆ Hospital leadership engages patients and their families in defining quality and determining quality goals and ensures that there is a system for patients and families to easily report safety and risk concerns.
- ◆ There are opportunities for patients and families to serve on hospital advisory and management committees including environmental design, to assist in the design and development of organizational policies and procedures, and to participate in staff orientation and continuing education.
- ◆ Staff leadership establishes clear behavioral expectations for teamwork and partnership with patients and families.
- ◆ Care providers systematically engage patients and their families, to the extent they desire, in health care discussions and decisions.
- ◆ Hospital policy and practice assures the patient’s easy and continuous access to the medical record.
- ◆ There is ongoing performance monitoring regarding communication; shared decision-making; timeliness, coordination, and continuity of care; emotional and physical comfort; and involvement of family as desired by the patient.
- ◆ Human resource management includes orientation of all staff to patient- and family-centered care and provisions for ongoing training in collaboration and partnerships.
- ◆ The hospital’s physical environment is designed to create welcoming first impressions, enhance access to information, and support family presence and participation.

See page 23 for information about the 2006 recipient of the AHA McKesson Quest for Quality Prize—Cincinnati Children’s Hospital Medical Center.



The **Military Health System (MHS)** has implemented the **Healthcare Innovations Program (HIP)** as a way to share new ideas, methods or devices to improve quality and access to care, increase satisfaction of patients and staff, and decrease health care delivery costs. Each year the top innovators are featured at the Annual TRICARE Conference.

In 2007, the Healthcare Innovations Program added a new category, Effective Patient Partnerships, with the following criteria:

Promoting an active voice from the patient’s perspective in hospital/clinic policies and philosophy of care by:

- ◆ Facilitating techniques for patient involvement in informed decision-making;
- ◆ Initiatives that promote progressive self-care management; and
- ◆ Improved satisfaction of physical and emotional needs.

The Department of Pharmacy at **Blanchfield Army Community Hospital (BACH)** in Fort Campbell, Kentucky, received the first “Effective Patient Partnerships” recognition award.

BACH’s Department of Pharmacy revolutionized the way they delivered services to the 70,000+ beneficiaries in the Fort Campbell community. Partnering with the hospital’s Patient and Family Centered Care Committee, they developed a PFCC Pharmacy Advisory Committee to improve services to beneficiaries. Hearing directly from patient and family advisors helped the team make improvements that mattered the most from the customer’s point of view.

The pharmacy extended their weekday Outpatient Hours, and added Saturday Outpatient Pharmacy hours, increased efficiency, decreased waiting time, and made other improvements that led to record high patient satisfaction. They made “one-stop shopping” available for patients with diabetes so they could pick up supplies along with medications. They worked with the facilities staff to make “facelifts” for the waiting areas and the refill pharmacy, and added a “Kids’ Zone.” The pharmacy now publishes a quarterly patient newsletter. The pharmacy website has been redesigned for patients and healthcare providers and includes the current formulary and a formulary search tool. All of these improvements and more were instituted without adding staff.

Create a designation process and award (similar to Magnet status for nursing) for patient- and family-centered practice.

The **Patient-Centered Hospital Designation Program** is a voluntary program created by **Planetree** to recognize individual hospitals' achievements in implementing and sustaining patient-centered care. The Program evaluates hospitals' implementation of more than 40 patient-centered care practices in 11 areas, including organizational structures, human interactions, patient education and access to information, involvement of family and friends, integrative therapies, and healing environment. In order to achieve designation, a hospital must undergo a rigorous, yet collaborative, process to verify that it has successfully implemented programs that meet the designation criteria. A designation committee of national healthcare experts, including a patient, oversees the program. The Patient-Centered Designation Program is recognized by **The Joint Commission**, who will include the award in each designated hospital's profile on the Joint Commission Quality Check website.

The **Picker Institute**, a leader in measurement and improvement of the patient experience and patient-centered care, has selected the **Pioneer Network** as the winner of the annual organizational Picker Awards for Excellence® in the Advancement of Patient-Centered Care. The Pioneer Network is at the forefront of changing the culture of aging and long-term care of elders. The Pioneer Network is made up of individuals and organizations across America who are committed to creating a culture of change. In accepting the 2007 award, Dr. Bonnie Kantor, Executive Director, states, "Person-centered care is a fundamental component in Pioneer Network's dedication to bringing deep system change to the culture of aging and long-term care. Person-centered care promotes living environments where elders and direct-care workers are able to express choice in meaningful ways. Our message is that person-centered living environments are a win-win. Research shows we can improve health outcomes without a detrimental effect on cost."

**Blue Cross Blue Shield of Massachusetts** (BCBSMA) has created an annual \$100,000 Health Care Excellence Award. In presenting the 2008 award to **Dana-Farber Cancer Institute**, the Chairman and Chief Executive Officer of BCBSMA said, "One of the ways to improve our health care system is to recognize and support organizations that can guide us to exceptional achievement in creating and implementing innovative programs and partnerships . . . Dana-Farber has transformed the delivery of care through their entire organization with their model of patient- and family-centered care, which encourages collaboration, communication, and engagement – activities that are critical to ensuring that the quality of health care in Massachusetts remains of the highest standard." The expert panel making this selection cited Dana-Farber's approach to implementing patient- and family-centered care as best practice for "engaging and empowering patients and their families in every aspect of care throughout the organization, from the bedside to the boardroom."

Include patient- and family-centered care in the criteria for the Malcolm Baldrige Award for health care organizations.

Ensure that the Leapfrog Group's rating system for hospital quality and safety includes effective and sustained partnerships with patients and families as one criterion for its annual ranking of hospitals.

Provide public acknowledgment related to strong performance in the area of patient- and family-centeredness, encouraging such entities as *US News & World Report* to include effective and sustained partnerships with patients and families as one of its criteria for its annual ranking of hospitals.

2. **Develop Federal and other payer regulations and accreditation requirements (e.g., the Centers for Medicare & Medicaid Services (CMS) and The Joint Commission) calling for patient- and family-centered care.** (See Chapter 7 for further information about payer and accrediting organizations and how they can facilitate the development of sustained partnerships with patients and families.)

Mandate partnerships with patients and families at all levels in order to maintain not-for-profit status in hospitals and other health care settings.

**Improving Health Care Quality: An Act Promoting Healthcare Transparency and Consumer Provider Partnerships** (House #2226; Senate #1277) is legislation pending in Massachusetts. Among key provisions of this bill are:

- ◆ Requiring hospitals to establish and convene *patient and family councils* through which consumers would have a voice in improving hospitals' quality of care.
- ◆ Requiring hospitals to establish *rapid response teams* which patients and families can activate when immediate medical attention is needed.
- ◆ Allowing physicians and health care providers to acknowledge a medical error by offering an apology to a patient without fear of *apology* being used in a lawsuit.

Regulate a designated administrative function/position for overseeing patient- and family-centered practices.

Require measurement addressing both process and outcomes associated with quality, safety, and experience of care (see Chapters 6 and 9).



Link reimbursement and accreditation reviews to patient satisfaction scores.

Assure accountability by requiring accurate, honest public reporting. (See page 43 for information about the Ambulatory Quality Alliance’s public reporting initiatives and page 104 for the Cystic Fibrosis Foundation’s collaborative approach to the public release of outcome data for its Centers.)

**Dartmouth-Hitchcock Medical Center** in Lebanon, New Hampshire, is committed to making outcome data transparent and available to the public. The home page of the medical center’s website provides easy access to current quality data. Patient/family perceptions of care are reported in addition to clinical quality indicators. For example, for a clinical procedure such as coronary artery bypass surgery, reports are available on overall patient satisfaction, how effectively pain was managed, how well emotional and spiritual needs were met, and how well patients felt they were involved in making care decisions. Clinical quality indicators specific to diseases or procedures are reported along with explanations of how to interpret the results, and comparisons with national standards or benchmark data when available.

The public reporting of experience of care data through the *Hospital Consumer Assessment of Healthcare Providers and Systems* (HCAHPS) survey, as a requirement for Medicare and Medicaid reimbursement, is a step in the right direction (see pages 98–99 for information about additional survey questions to gather more specific data about patient- and family-centered practice).

### 3. Assure involvement of patients and families at all levels in the health care system.

Assure patient and family participation in policy and program development by setting the expectation that patient and family members sit on hospital committees, including the following:

- ◆ Strategic planning
- ◆ Facility design
- ◆ Patient/family education
- ◆ Discharge/transition planning
- ◆ Information technology
- ◆ Quality improvement
- ◆ Patient safety
- ◆ Risk management
- ◆ Service excellence
- ◆ Interviewing and hiring
- ◆ Staff orientation and education
- ◆ Research
- ◆ Ethics
- ◆ Leadership search
- ◆ Credentialing

Establish the expectation that no renovations or new construction will happen without patient and family involvement in all stages of planning.

Assure that leadership walk-arounds and patient safety rounds include a patient or family advisor.

Patient and family advisors participate in leadership walking rounds for inpatient areas at **Vanderbilt Medical Center** in Nashville, Tennessee. The advisors have designed their own form that guides their participation and observations as part of this process. Plans are underway to extend these rounds to ambulatory care areas.

**Dana-Farber Cancer Institute** in Boston, has a commitment both to patient safety and to involving patients and families in decision-making regarding their own care. These commitments were joined in 2004, when a patient component was added to the Patient Safety Rounds at Dana-Farber. Selected members of the institution’s Adult Patient-Family Advisory Council were trained as Patient/Family Safety Liaisons. The role of the liaisons is to interview current patients about their safety concerns. Dana-Farber has found that eliciting patient perspectives as part of safety rounds yields important insights into patient experiences of care, as well as useful information about potential safety problems. A toolkit developed by Dana-Farber can introduce other institutions to these safety rounds procedures.

Involve patients and families in the development of measurement tools for patient- and family-centered care.

Patient and family advisors at the **University of Washington Medical Center** in Seattle wanted to develop a more accurate way to measure progress toward the implementation of patient- and family-centered care in health care settings. This led to a collaborative multi-health care system effort to develop a series of custom patient satisfaction questions, piloted on the Press Ganey Satisfaction Survey. The Associate Director for Patient- and Family-Centered Care at the Medical Center facilitated development of these questions by a workgroup of patient and family advisors and staff from 12 hospitals. For further information about this process and the list of questions (see pages 98–99).

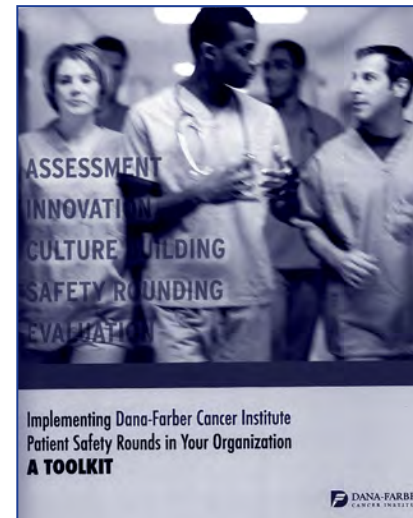
Involve patients and families in the accreditation process for The Joint Commission.

At the opening session for a site visit, leadership at **Dana-Farber Cancer Institute** informs The Joint Commission that they should not be surprised if they encounter patient and family advisors while conducting tracers in the clinical areas because they are integral to the organization’s work. Both Dana-Farber and the **MCG Health System** in Augusta, Georgia, have invited patient and family advisors to participate in the debriefing conference at the end of The Joint Commission site visits. Both organizations include patient and family advisors in the leadership session during the site visit because these advisors are

so important to their improvement efforts, and they believe that they are part of the organization's leadership strength. These advisors have helped reviewers understand the priorities and perspectives of patients and families.

**4. Ensure that patient and family perspectives, including their experiences of care, are key drivers in changing and improving care processes and structures.**

At **Dana-Farber Cancer Institute**, there are patient and family advisory councils for both the adult and pediatric oncology programs. Patient and family advisors have helped shape efforts to improve patient safety. After safety leaders invited patients to participate in developing a project to bring cockpit-style teamwork training skills to patients and their families, these advisors recommended a teamwork safety campaign with very clear, specific messages targeted to patients and their families. As it has developed, the “You CAN” campaign urges patients and families to Check, Ask, and Notify. The campaign emphasizes that safety is the responsibility of Dana-Farber staff and faculty, however patients and families CAN help to ensure safe care especially in hand washing and chemotherapy safety. Patient and family advisors, prepared for their roles in talking with patients and families about the experience of care, are the ambassadors for this campaign. Colorful posters will also be used to reinforce the messages of the campaign.



In July 2007, a physician was appointed Chief Experience Officer at the **Cleveland Clinic**, in Ohio, to lead the development of the Office of Patient Experience. This office was created by the CEO, who recognized that patients and families need and want more from the health care system than solely a good clinical outcome. The mission and vision of the Office is to provide a set of services that empowers patients and their families to be partners in their care, offer tools to address the stress and anxiety associated with illness, and support and partner with them to help them navigate on their journey. The office will undertake redesigning the patient experience by listening to the voice of the patient through the creation of Patient and Family Advisory Councils within each of their Institutes. In addition, they will map not only the clinical flow, but also the emotional and physical needs of the patient. “Putting patients first in all we do” is the cornerstone of the mission of the Office of Patient Experience and the entire organization.

**Establish patient- and family-centered hospital/unit rounds for care coordination and clinical teaching that include patient/family members in all deliberations.**

**Cincinnati Children's Hospital Medical Center** was the recipient of the 2006 American Hospital Association's McKesson Quest for Quality Prize.

Quality improvement has been the driving force for transformational change within both inpatient and outpatient programs at Cincinnati Children's Hospital Medical Center. The hospital is committed to advancing the practice of patient- and family-centered care and to improving the experience of care for patients and families. The senior leadership ensures support for this effort both at the organizational level and within specific clinical microsystems.

Partnering with families occurs on multiple levels—at the Family Advisory Committee, on quality improvement teams, on unit-based committees, and in care decisions everyday.

Families are no longer viewed as visitors, and units are open 24/7. On all units, families are encouraged to be present for rounds and given choices about how they would like to participate. The charge nurse and bedside nurse participate in these rounds and ensure that discharge goals are printed out daily and available to the patient and family. Physician orders are written on a laptop in the patient's room during rounds. Residents review orders out loud so that everyone, including the patient and family, can hear them and verify accuracy. Family-centered rounds encourage families to be active participants in decision-making and development of discharge goals. Faculty physicians believe family-centered rounds allow for improved teaching on the wards. They are able to model effective communication with patients, families, and nurses, and give real-time feedback to residents and students while they interact with families.

Emerging quality improvement data at Cincinnati Children's indicate the following:

- ◆ Patients are being discharged sooner.
- ◆ Medical order entry error rates have been reduced from approximately 7-9% to 1%.
- ◆ Faculty report that patient- and family-centered rounds are a more effective way to teach.
- ◆ Families are more involved in development of the Plan of Care and decision-making.

Cincinnati Children's is now working with several other children's hospitals to promote evaluation of family-centered rounds.

**Learn from collaborative practices integral to hospice and end-of-life caregiving models and adapt to care processes across the continuum of care.**

**5. Integrate a patient- and family-centered care philosophy into the mission, vision, values, definition of quality, strategic plan, and personnel practices in health care settings for both acute and long-term care.**

Institutional and departmental vision and mission statements can reflect patient- and family-centered priorities and inform the development of the strategic plan.

**Evergreen Hospital Medical Center** is a public hospital in Kirkland, Washington. Its purpose statement is:

“Working together to enhance the health and well-being of every life we touch.”

The vision for the Fetal Medicine Department at Evergreen integrates the concept of partnership with the most sophisticated clinical care:

“Create an environment of service combining information and technology with a genuine caring for families that makes them full partners in their healthcare.”

Patients and families can inform the selection of key personnel in healthcare facilities thereby assuring that partnership priorities are acknowledged from the start.

A family advisor serves as a member of the 12-person Selection Committee for a new Chief Nursing Officer at the **University of Washington Medical Center** in Seattle. (See page 70 for how other hospitals have involved patient and family advisors as part of the selection process for leadership positions.)

The Human Resources Department at **Children’s Hospital & Regional Medical Center** in Seattle, has integrated the concepts of partnership in position descriptions, the performance appraisal system, and the *Children’s Service Standards*. Listed below are expectations included as essential functions for all hospital employees:

- ◆ *ACCOUNTABILITY: Delivers exceptional family-centered care, maintains a positive attitude, responds timely to needs, addresses concerns, and ensures patient safety.*
- ◆ *RESPECT: Respects the diversity of all individuals and each family’s unique experience. Practices courtesy. Ensures parents serve an essential role in their child’s care and are involved in care choices.*
- ◆ *TEAMWORK: Effectively teams with patients, families, and staff. Ensures well-coordinated care by collaborating with the family, keeping them informed, and coordinating with other members of the team.*

The **Memorial Healthcare System** of the South Broward Hospital District in Broward County, Florida, a large, public, five-hospital system, recognizes patient- and family-centered care as an organizational priority. At the system level and at the institution level for each of the hospitals, an organizational commitment to patient- and family-centered care is reflected in a number of practices, including the following:

- ◆ Patient and Family Advisory Councils are established or forming at all system hospitals, the Primary Care Services System, and the Memorial Cancer Institute.
- ◆ Patient and family advisors are being integrated into satisfaction, facility design, and safety improvement teams, and are helping to develop a system-wide palliative care initiative.
- ◆ The system convenes an annual symposium for patient- and family-centered care.
- ◆ Training for patient- and family-centered care, and for creating partnerships with patients and families, is incorporated into the system’s quarterly leadership retreats.
- ◆ Each hospital has a designated director for patient- and family-centered care.
- ◆ The health system’s standards of performance include behaviors related to patient- and family-centered care. All new employees must sign a document attesting to their commitment to these behaviors.
- ◆ A multi-media training program featuring partnerships and patient and family stories is shown to all employees.

The Memorial Healthcare System was recently awarded the prestigious Foster G. McGaw Award for excellence in community service by the **American Hospital Association**.

**Perham Memorial Hospital and Home** is a critical access rural hospital, located about 200 miles northwest of Minneapolis. The hospital has 25 acute care beds and an adjacent 96-bed nursing home. Perham provides comprehensive outpatient services, as well as home care.

During the past seven years, the Perham Memorial Home changed from a medical model of care to a social model. Its goal is to create an environment that aims at “creating home and strengthening community.” The first step in the process of change was to involve families, residents, and staff in defining what “home” means in this community. Instead of being organized around staff efficiencies, services are based on residents’ needs and routines—the customs



they've acquired over a lifetime of productive, independent living. This profound change in organizational culture has led to promising improvements, such as a decrease in falls, weight gains for frail patients, and reductions in negative behaviors, as well as an overall increase in resident, family, and staff satisfaction.

Based on the success with the long-term care facility, hospital leadership reached out to the community and involved patients, families, and community members in developing a philosophy of patient- and family-centered care to guide policy, program and practice, and the design of facilities for the acute care hospital. Patient and family advisors are currently participating in site visits to other facilities with staff to learn about innovation and best practices.

Perham Memorial Nursing Home has been lauded as a pioneer for culture change. The Chief Executive Officer of Perham Memorial Hospital and Home was selected as the 2007 Administrator of the Year by the Minnesota Health and Housing Alliance.

**Lead by example with a CEO and a CPO (Chief Patient Officer) who oversee efforts to advance the practice of patient- and family-centered care.**

The CEO of **Banner Desert Medical Center** in Mesa, AZ, states the following in a letter to patients and families on the hospital's website:

*"Our patient care delivery model is centered on holistic care. This means the care and service provided to each patient are not just based on physical or medical needs, but also take into account your spiritual and emotional well-being. We want to work with you to help set goals for your care and recovery. We encourage patients and their families to be involved in decisions about their own health care. Be sure to ask about Partners in Caring, a philosophy at Banner Desert that supports a family member or close friend's involvement in your care and comfort during your hospital stay."*

Innovations designed to implement the patient- and family-centered approach include the following:

The patient handbook emphasizes the importance of partnership and information sharing, and the concept of patient and family members as essential members of the health care team.

Nurses conduct shift report at the bedside with patients and families as part of the process.

**Assure that patient and family representation among the trustees and on the board reflects the demographics of the hospital's patient population and that a significant number of hospital board members are patients and family members.**



**Combine an internal self-assessment and external independent assessment of patient- and family-centered activities.**

A series of self-assessment tools are available from the **Institute for Family-Centered Care**. These assessment inventories are designed to help staff, physicians, administrative leaders, patients, and family leaders think about how patient- and family-centered care is operationalized in a particular setting or department. They are designed for use with an interdisciplinary team that includes patient and family advisors. The tools assist in determining priorities for change and improvement. Many who have used these inventories have found that the process of completing the tool has educational value, because it helps inform participants about the core concepts and strategies of patient- and family-centered care.

**Measure the impact of patient and family collaboration.**

**6. Provide information and training for health care providers, staff, administrators, trustees, patients, and families for creating and sustaining effective partnerships.**

**Educate trustees, board members, CEOs, and medical and nursing administrators to create a culture supportive of patient- and family-centered practice (see Chapter 7).**

The **Governance Institute** in San Diego conducts research studies, tracks health care industry trends, and showcases the best practices of leading health care boards across the country. The Institute is committed to providing the essential knowledge and solutions necessary for hospitals and health systems to achieve excellence in governance.

The Governance Institute could become a resource on best practices for patient- and family-centered care and partnerships with patients and families relevant to governing bodies and their roles to ensure quality, safety, and wise stewardship of resources. Trustees need to be knowledgeable about patient- and family-centered care and understand their role in ensuring its implementation. For example, in hiring a chief executive, how do they determine his or her competency in patient- and family-centered care, and how do they ensure that patient and family advisors are part of board-level quality, patient safety, and risk-management deliberations? (See page 115 for further information about sharing stories related to patient safety with trustees.)



The **Center for Healthcare Governance** is another potential resource for trustees on best practices related to partnerships with patients and families and enhancing quality, safety, and cost efficiencies. This organization seeks to be a primary source for innovative thinking, information, tools, and counsel to effect excellence in health care governance by engaging hospital teams consisting of trustees, executives, and clinical leaders.

The 2007 Fall *Quality Summit* convened in Lebanon, New Hampshire, for the **Dartmouth-Hitchcock Alliance** focused on “Patient- and Family-Centered Care: Partnerships for Quality and Safety.” Attendees included trustees, senior executives, and directors of quality from ten member hospitals and a behavioral health center.

Clearly define what effective and sustained partnerships are: clarify goals, aims, and definitions of standards for these partnerships to help ensure appropriate processes and structures.



The Patient Experience team of the **Calgary Health Region** in Alberta, Canada, is focusing on patient- and family-centered care in all hospitals and other health care settings as a way to improve the experience of care. Partnerships with Patient Experience Advisors are a key element of this strategy. The website will include the Region’s definition of patient- and family-centered care and information about the role of Patient Experience Advisors. Guidance, resources, and assistance with facilitation of collaborative endeavors are available to health care organizations in the region (see pages 138–139 for further information about the Calgary Health Region and its Patient Experience team).

Provide administrators, health care personnel, and patients and families with leadership and partnership training, strategies, tools, and resources for sustaining partnerships (see Chapters 5, 6, and 10 for further information).

Connect with other hospitals that have established patient- and family-centered care, interview or conduct site visits, then customize their recommendations to the unique organizational culture.

Find champions in various disciplines to help model and promote patient- and family-centered care to their colleagues.

Develop checklists of effective patient- and family-centered practices that can be used in training, evaluation, and personnel appraisal processes.

(The checklist on page 30 can be used as a handout for educational programs to elicit discussion and explore ways to partner with patients and families.)

Disseminate success stories through employee newsletters, annual reports, hospital intranets, and public websites.

**7. In academic medical centers, involve patient and family faculty in the education of the next generation of practitioners and administrators (see Chapters 4 and 5).**

Require the use of a patient- and family-centered curriculum in schools of medicine, nursing, allied health, and health administration.

Include patient and family members as faculty in schools of medicine, nursing, allied health, and health administration.

Include patient and family members in health care provider orientation, grand rounds, inservice education, and continuing education.

## PROMOTING DIALOGUE AND PARTNERSHIPS IN CARE

Those who practice patient- and family-centered care. . .

- ❑ Actively respect and incorporate patients' and families' strengths, traditions, beliefs, and value systems in all aspects of the care.
- ❑ Acknowledge that the word "family" is variously defined.
- ❑ Recognize the important influence of the larger community on the patient and family.
- ❑ Explicitly encourage patients' and families' participation in care and decision-making—to a level they desire and that is developmentally appropriate.
- ❑ Encourage patients and families to share their observations, ideas, and suggestions for the plan of care.
- ❑ Acknowledge the expertise of patients and families.
- ❑ Provide complete information in ways patients and families prefer and find useful and affirming.
- ❑ Ask patients and families about their learning goals and priorities and how they prefer to learn.
- ❑ Make written, electronic, and audiovisual resources available to enhance patients' and families' access to information and support.
- ❑ Use language that reflects an emotional connection with the patient and family even when explaining the technical aspects of a disease or treatment.
- ❑ Help staff, patients, and families find common ground when disagreements occur.
- ❑ Offer a variety of ways for patients and families to express satisfaction or dissatisfaction with care.
- ❑ Ask patients and families to participate as faculty for staff orientation, continuing education programs, and classes for professionals-in-training.
- ❑ Invite patients and families to participate in formulating policy and planning and evaluating programs for the hospital.

Source: *Institute for Family-Centered Care, 2007*

## FOR FURTHER INFORMATION. . .

- For the most recent references on this topic, please see the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>
- The American Hospital Association McKesson Quest for Quality Prize criteria and application can be found at <http://www.aha.org/aha/news-center/awards/quest-for-quality/overview.html>.
- To learn more about Planetree's Patient Centered Designation Program, visit <http://www.planetree.org/patient-centered-hospital-designation.html>.
- Information about the Pioneer Network can be found at <http://www.pioneernetwork.net>.
- To read about the 2007 winners of the Picker Awards for Excellence visit <http://www.pickerinstitute.org/pickeraward.htm>.
- Information about the Blue Cross Blue Shield of Massachusetts \$100,000 Health Care Excellence Award and Dana- Farber Cancer Institute's, the 2008 recipient, distinguishing features for advancing the practice of patient- and family-centered care can be found at <http://www.businesswire.com/news/google/20080414005209/en>.
- The Malcolm Baldrige Award criteria and application process are described at [http://www.nist.gov/public\\_affairs/factsheet/baldafaqs.htm](http://www.nist.gov/public_affairs/factsheet/baldafaqs.htm).
- The Leapfrog Group's Hospital Quality and Safety Survey is available at <http://www.leapfroggroup.org/cp>.
- Learn more about Health Care for All at <http://www.hcfama.org>.
- Dartmouth-Hitchcock Medical Center presents their Quality Reports online at <http://www.dhmc.org/webpage.cfm>.
- To view and also to listen to patient stories at Vanderbilt Medical Center, visit <http://www.mc.vanderbilt.edu>.
- For an overview of patient- and family-centered care and family advisors at University of Washington Medical Center, see <http://www.uwmedicine.org/Facilities/UWMedicalCenter/ClinicsAndServices/FamilyAdvisors/index.htm>.
- Dana-Farber Cancer Institute's Toolkit for Patient Safety Rounds is available online at <http://www.dana-farber.org/pat/patient-safety/patient-safety-resources/patient-rounding-toolkit.html>. The following article can be accessed at <http://psnet.ahrq.gov/public/weingart.pdf>:
  - ◆ Weingart, S. N., Price, J., Duncombe, D., Connor, M., Sommer, K., Conley, K. A., et al. (2007). Patient and family involvement: Patient-reported safety and quality of care in outpatient oncology. *Journal on Quality and Patient Safety*, 33(2), 83-94.

- To read an article outlining why Cincinnati Children’s Hospital Medical Center (CCHMC) received the AHA McKesson Quest for Quality Prize see <http://www.cincinnatichildrens.org/about/news/release/2006/7-quality-award.htm>. Find out more about CCHMC’s efforts to advance the practice of patient- and family-centered care and the linkages with quality and safety at <http://www.familycenteredcare.org/profiles/prof-cinn.html>.
- A profile on Evergreen Hospital Medical Center is located at <http://www.familycenteredcare.org/profiles/prof-evergreen.html> and an example of commitment to quality and partnering with families at Evergreen is at <http://www.evergreenhealthcare.org/NR/rdonlyres/1E078BA0-6C47-4407-A784-4622008C879B/0/RoundsNLSpr07.pdf>.
- The website for Children’s Hospitals & Regional Medical Center in Seattle is <http://www.seattlechildrens.org/home>.
- Perham Memorial Hospital and Home in Perham, MN, can be found at <http://www.pmhh.com>.
- A copy of the letter from the CEO of Banner Desert Medical Center to patients and family members is posted at <http://www.bannerhealth.com/Locations/Arizona/Banner+Desert+Medical+Center/Guest+Services/CEO+Welcome.htm>. A description of Banner Desert Medical Center’s “Partners in Caring Program” can be found at <http://www.bannerhealth.com/Locations/Arizona/Banner+Estrella+Medical+Center/Guest+Services/Partners+in+Caring.htm>.
- Efforts to change the practice of nurse change of shift report to include the patient and family are described in the following resources:
  - ◆ Anderson, C. D., & Mangino, R. R. Nurse shift report: Who says you can’t talk in front of the patient? *Nursing Administration Quarterly*, 2006.
  - ◆ “Shifting Perspectives Kaiser Permanente’s Nurse Knowledge Exchange ensures smooth, consistent and positive patient hand-offs” is written up at <http://xnet.kp.org/newscenter/stories/nat/2007-03-01-a.html>.
- The “Promoting Dialogue and Partnerships in Care” checklist and the following self-assessment inventories are available on the Institute for Family-Centered Care’s website at [www.familycenteredcare.org](http://www.familycenteredcare.org):
  - ◆ General hospitals and pediatric hospitals.
  - ◆ Hospital design and design planning.
  - ◆ Personnel practices.
  - ◆ Emergency departments for both adult and pediatric settings.
  - ◆ Adult, pediatric, and newborn intensive care.
  - ◆ Adult and pediatric ambulatory settings.
  - ◆ Geriatric and long-term settings.
  - ◆ Medical education.
- Calgary Health Region’s website is <http://www.calgaryhealthregion.ca>.

# CREATING PARTNERSHIPS IN AMBULATORY SETTINGS

### Key recommendations at a glance...

1. Develop and support partnerships among administrators, providers, patients, and families to improve quality and safety in ambulatory care.
2. Assure that patterns of care in ambulatory settings are patient- and family-centered.
3. Develop and disseminate approaches to education and training to advance partnerships with patients and families in ambulatory care.
4. Assure that approaches to evaluation of ambulatory care are patient- and family-centered.
5. Use regulatory and other incentives to develop and sustain patient- and family-centered practice in ambulatory settings.
6. Use payer requirements to promote patient- and family-centered practice in ambulatory settings.

*“...patient-centered care, in its essence, is about partnerships.”*

Thomas Bodenheimer and Kevin Grumbach  
*Improving Primary Care: Strategies and Tools for a Better Practice, 2007*

**A**mbulatory settings provide an ideal opportunity for health care providers to work in partnership with patients and families to individualize plans of care. These partnerships are critical in optimizing individual and family health. Ambulatory settings need structures and processes in place to develop and sustain effective partnerships with patients and families at all levels to promote health, prevent

illness, and to enhance quality, safety, and the experience of care. With the current momentum for change in primary care and specialty care in ambulatory settings, it is essential that patient and family advisors are active participants in redesign and quality improvement efforts.

The following strategies are proposed to help make patient- and family-centered care a reality in ambulatory settings.



## 1. Develop and support partnerships among administrators, providers, patients, and families to improve quality and safety in ambulatory care.

The **Institute for Healthcare Improvement (IHI)** is coordinating a national, multi-year initiative, funded by the **Robert Wood Johnson Foundation**, to improve care for individuals with chronic conditions in ambulatory settings. During the initial phase, six clinical practices were part of a *Pilot Collaborative on Self-Management Support*. During Phase Two, 20 ambulatory teams participated in the *Quality Allies: Improving Care by Engaging Patients* collaborative to test improvements in collaborative self-management support. This initiative included patients and families on the national advisory council and the faculty team. Each of the 20 teams recruited and prepared patients and families to serve as members of their improvement teams. The **California HealthCare Foundation** also provided funding and participated in Phase Two of this project. The third phase of this initiative, the *New Health Partnerships Virtual Learning Collaborative*, began in spring 2007. Nine interdisciplinary teams are working to advance the practice of self-management support in various types of ambulatory settings. Patients and families are active members of each of these improvement teams.

*New Health Partnerships* has created an online community, [www.newhealthpartnerships.org](http://www.newhealthpartnerships.org). This website was designed collaboratively by and for clinicians, administrative leaders, patients, and families. It provides information, resources, best practice examples, and opportunities for discussion to support improved communication, self-management, support, and advocacy, to enhance collaborative self-management support.

The **Whitby Mental Health Centre (WMHC)** in Whitby, Ontario, has long recognized the benefits to engaging patients and families as partners in care and within the organization. They include clients and families on their 17-member Board of Directors. The vision and values for the Centre were determined with significant client, family, and community participation. There is an active Patient Council that brings the patient and family voice into developing and implementing Centre activities. Patients and families are involved in safety initiatives, programming and facility design, and educational and public awareness programs. The Patient Council works with community organizations to build support for the Centre's vision of "recovering best health, nurturing hope, and inspiring discovery." WMHC has been recognized by the government of Ontario for their initiative titled, *Stomp Out Stigma Summits*. This program offers the public the opportunity to hear different stories of people living well with mental illness. These stories promote proper diagnosis and treatment as well as instill hope in individuals, families, and communities.

Through partnerships with patients and family members, develop national standards of patient- and family-centered ambulatory care.

The concept of the "medical home" was first described over 25 years ago as a strategy to promote family-centered, community-based, coordinated care for children with special health care needs and has been subsequently adapted to more broadly apply to primary care for other populations. The pediatric medical home model emphasizes care that is "accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective."

In March 2007, a joint consensus paper articulating the core principles of the "*Patient-Centered Medical Home*" was released by the **American Academy of Family Physicians**, the **American Academy of Pediatrics**, the **American College of Physicians**, and the **American Osteopathic Association**. The statement promotes the medical home as "an approach to comprehensive primary care for children, youth, and adults—a health care setting that facilitates partnerships between individual patients and their personal physicians and, when appropriate, the patient's family."

The consensus paper states that quality and safety are hallmarks of the medical home and describes partnerships as essential elements:

The "...care planning process [is] driven by a compassionate, robust partnership between physicians, patients, and the patient's family;" and, "patients and families participate in quality improvement activities at the practice level."

Further information about medical home innovation can be found on pages 39 and 142–143.

**Include patients and families as partners in all levels of decision-making in ambulatory care, from the design of ambulatory care facilities to its governance, management, committee structure, quality and safety teams, and in the clinical encounter itself.**

**Ocean Park Health Center** is a community clinic affiliated with the San Francisco Department of Public Health, providing care to a multicultural and largely immigrant population. Ocean Park established a Patient Advisory Council. This group has elected officers and developed a mission statement. Council members recommended changes for the waiting room redesign, and have assisted with translation and evaluation of patient education materials. The Center participated in the Quality Allies national collaborative (see page 34) to advance the practice of patient- and family-centered collaborative self-management support for patients with chronic conditions.

Patient advisors participate on the quality improvement team, teach classes in the "Healthier Living" series, and train peer support group facilitators at **Humboldt Del Norte IPA** in Eureka, California, another Quality Allies site.

**The Children's Hospital of Philadelphia** has over a decade-long rich experience of sustained patient- and family-centered care in its inpatient settings. Though much of the patient- and family-centered culture has been transferred from inpatient to outpatient settings, leadership understands the importance of focusing on assessing, planning, and implementing patient- and family-centered care in its many ambulatory settings.

Patients and families have led a committee to define the unique needs of outpatient families, catalog best programs across the varied ambulatory sites, identify inconsistencies, and establish priorities.

First on the list of outpatient priorities was to ensure that the perspectives of patients and families were incorporated into the electronic medical record (EMR) implementation in all outpatient settings. Patients and families have been partners in the design and use of the EMR. An EMR advisory group that includes patients, families, physicians, and nurses is now creating tips and guidelines for both families and professionals on how to maintain the care partnership when a computer monitor sits between the physician and patient.

The next step is the implementation of the patient portal to the EMR. Patient and family input was invaluable to determining project scope and goals and will continue to help drive decisions of portal access, security, and use.

Within a few years of opening a family resource center at its inpatient facility, hospital leadership asked families and staff to adapt the resource center template for outpatient settings and implement it in all of the hospital's community-based Specialty Care Centers. Today, each of The Children's Hospital of Philadelphia's major ambulatory centers has a distinct resource space for families within the outpatient waiting area. This model provides outpatient staff and families access to information and web destinations at the point of care delivery and diagnosis. Families are able to leave their appointment with printed information, resources, and website bookmarks for future research about their child's health care.

Patients and families from diverse backgrounds and diagnoses are also working with ambulatory administrators at The Children's Hospital of Philadelphia on a special task force to improve all aspects of care coordination.

**Tailor approaches to advancing the practice of patient- and family-centered care to the structure, characteristics, and populations served in specific ambulatory settings, for example:**

- ◆ Community health centers
- ◆ Mental health centers
- ◆ Integrated delivery systems
- ◆ Private practices
- ◆ Primary care and specialty practices
- ◆ Ambulatory care clinics

- ◆ Ambulatory surgery centers
- ◆ Emergency rooms and centers
- ◆ Urgent care centers
- ◆ School clinics

The **Los Lunas Clinic** is part of the **Presbyterian Healthcare Services**, New Mexico's only private, nonprofit, statewide health care system. The clinic, located in a semi-rural area, opened in the fall of 2006. Potential patients, participated in the interviews of applicants for provider positions. A Patient and Family Council was then planned to provide a structure for sustained involvement of patients and families in the clinic.

A three-person team from the health system provided assistance to the clinic at the beginning, helping to select patient and family advisors, developing agendas and role-modeling meeting facilitation for this new collaborative endeavor. Eventually, these activities were assumed by on-site staff.

Membership of the initial council included three patient and family advisors and five staff members (two physicians, a manager, and the heads of clinical and clerical services). Membership quickly expanded to include eight patient and family advisors and the original five staff members.

Soon after the Council's creation, members did a walk-through of the clinic, studying all phases of operations from the patients' and family members' perspective. Based on this experience, the Council made a list of areas where improvements could be made. A form to track progress toward implementing the desired changes was developed. Council members also regularly talk with clinic patients to elicit their perspective of the experience of care.

The Los Lunas Patient and Family Advisory Council has become a de facto council for the entire health system. Its activities and structure serve as a model for establishing councils elsewhere in the system, beginning with other primary care services and progressing to specialty clinics.

The **MCG Health System**, an academic medical center in Augusta, Georgia, has three Patient and Family Advisory Councils for ambulatory care.

In 2001, MCG worked with the **Walton Rehabilitation Hospital** to create a Patient and Family Advisory Council for the **Augusta Multiple Sclerosis Center**. There are currently 15 patient and family members. Among the staff and physicians who attend the meetings regularly are the medical director, a clinical psychologist, administrator for the clinic, the MS physician assistant, MS certified nurse clinician, staff nurse, and a research professional. Among the projects the council has assisted with are the design and relocation of the clinic, parking accessibility, access to psychological care, and the development of the electronic personal health record system. The volume of patients followed by this clinic has grown substantially in the last five years. Currently the Council is working with staff to develop a study to evaluate the clinic's approach to care and its impact on patient activation.

MCG's Family Practice Center created a Patient and Family Advisory Council in 2006. Fourteen patient and family members, the Family Medicine Center Manager, Family Medicine Nursing Coordinator, and Director of Ambulatory Patient Access Services serve on the council. As the program evolves, residents and physicians will be asked to join. Others are involved as requested by the council. The Manager of the Family Medicine Center serves as the staff liaison for the council. Data is gathered from patients in the waiting areas through questionnaires and surveys and is shared with the council to help plan changes. Customer service at the front desk area has improved. The Council involvement in clinic meetings has been energizing and improved overall staff attitudes.

By request of patient advisors, patient education programs have been developed or planned for the near future. These include orientation to the Family Medicine Center and integration of health education into computers in the exam room and other patient areas.

Patient and family advisors are also asked to participate in projects separate from the Council, such as participation in monthly staff meetings and on the Safety Committee.

The **Physician Practice Group (PPG) of the Medical College of Georgia** has the newest patient and family advisory council at MCG. The medical group's mission is to support clinical, educational, and research purposes of the Medical College of Georgia. Its values statement includes a commitment to patient- and family-centered care as shown below:

- ◆ **Quality** – deliver the highest quality care.
- ◆ **Service** – serve all segments of Georgia's population.
- ◆ **Integrity** – act with honesty and integrity in all interactions.
- ◆ **Patient/Family-Centered Care** – promote the principles of patient- and family-centered care.
- ◆ **Diversity** – embrace the rich multi-culturalism of our society.
- ◆ **Discovery** – create new knowledge.
- ◆ **Education** – train future healthcare professionals.

In addition to the advisory council, PPG leadership has mandated patient- and family-centered training for ambulatory clinics, and patient- and family-centered concepts will be a major driver for the design of a new ambulatory clinic.

**MaineHealth** is an integrated not-for-profit, community-owned, comprehensive health system headquartered in Portland, Maine, providing the continuum of care from prevention and health maintenance through tertiary services, rehabilitation, chronic care, and long-term care. A Patient and Family Advisory Council for its quality improvement programs on depression in primary care and mental health/primary care integration was established in 2006. The Advisory

Council is meeting regularly to offer the patient and family perspective for program development, editing of program materials, and development of linkages to community resources.

**South County Pediatrics** is a community-based teaching practice of **UMass Memorial Health Care** located in Webster, Massachusetts. The practice has a long history of involvement with maternal and child health initiatives, including immunization registries, chronic disease management (asthma and obesity) and care coordination, and is an active participant in community-based initiatives involving school-based services, HeadStart, and access to mental health services. South County Pediatrics has an active parent advisory group, which participates in quality improvement activities as well as efforts to create a more family-centered environment. Over the past two years, a parent-nurse-provider team has been responsible for the development of children with special health care needs (CSHCN) registry and individual family care plans within the practice. The medical home team has recently begun to refine the tools used to aid in the transition of care for youth with special health care needs to adult systems of care. This practice is part of the **Central Massachusetts Medical Home Network Initiative**, a U.S. Maternal and Child Health Bureau funded system development project. The project is co-led by physicians and parent leaders. (See pages 142–143 for further information about partnerships with families in a statewide medical home improvement initiative.)

## 2. Assure that patterns of care in ambulatory settings are patient- and family-centered. (See page 46 for a checklist for Patient- and Family-Centered Ambulatory Care.)

**Develop approaches that enhance administrators' and other ambulatory personnel's understanding of patient and family perspectives.**

Part of the orientation for a new nursing Senior Clinical Director responsible for Ambulatory Programs at **Cincinnati Children's Hospital Medical Center** in Ohio involves shadowing patients through their ambulatory care visits. This encourages an understanding of the flow of care from the patient and family perspective.

One of the initial improvement activities that teams from the **New Health Partnerships Virtual Learning Collaborative** (see page 34 for more information) were asked to complete with their patient and family advisors was a walk-about of their center. An additional walk-about was scheduled later in the project with other patient and family advisors to assure the perspective of the patient and family are continuously integrated into improvement cycles. The second walk-about focused specifically on how care processes supported self-management and the concept of patients and families as key partners on the care team.



At the **Children’s Hospital of Alabama’s Cystic Fibrosis Center**, one of the New Health Partnerships’ sites, the physician sponsor charged with executive leadership for the improvement team conducted a walk-about of the center with an adolescent patient and her mother to learn from and document the patient and family perspective of the center’s environment and processes of care.

**Improve information gathering at the point of care by using effectively designed care processes, communication strategies, and information technology tools.**

**The John D. Stoeckle Center for Primary Care Innovation** at Massachusetts General Hospital is exploring innovative patient- and family-centered approaches to ambulatory care.

The mission of The John D. Stoeckle Center is to redesign and revitalize primary health care in order to effectively meet the needs of patients and their families, doctors, and other professionals who deliver primary care; to provide an extraordinary experience of care for patients and their families; and to create an exciting and fulfilling professional life for current and future generations of primary care practitioners. The Center will accomplish these things by focusing on research, innovation, education, advocacy, and policy reform.

Several innovative initiatives related to improving communication and information sharing include:

- ◆ *Developing and testing “Pre-Visit Preparation Packets” for annual visits for older men and women and well-child visits.* These packets are intended to prepare patients and families to be active partners in prioritizing their needs during an office visit and help them prepare their questions to make the best use of time. Patients, families, and clinicians are providing feedback about the content and the process for sharing and using the packets.
- ◆ *Improving “Patient and Family Participation in Decision-Making in Primary Care” for patients who are considering routine screening options, diagnostic or treatment decisions.* Using the electronic medical record, providers can “e-prescribe” videos that provide patients with the most current clinical evidence and interviews with other patients who have selected the different options to prepare

We are shifting toward	Implications for design
1 Focus on health & life balance	design solutions that address a person's lifestyle, family history and experience, not just symptoms
2 Continuous healthcare	design healing solutions that support patients' needs anytime, anywhere
3 Iterative experiences	design the ability to continuously measure and adapt to patients' and providers' goals over time
4 Collaboration	design solutions which allow for dialog among care staff and with patients and their families
5 Team-based experiences	design solutions that involve multi-disciplinary teams where appropriate
6 Treatment goes to patient	design solutions that consider the patient as the center (instead of the medical staff or location)
7 Mass customization	design solutions that allow for efficiency but also allow for personalized experiences
8 Transparency	design solutions that allow staff and patients to easily see and use necessary information and processes at all times

patients for shared decision-making. The “e-prescriptions” are sent to the Massachusetts General Hospital’s Blum Patient Family Learning Center, and the Center mails the videos or DVD’s to the patient with a self-return mailer.

The **Baylor Pediatric Cystic Fibrosis Center** in Houston has modified the electronic medical record so that the goal for self-management discussed and agreed to by the patient, family, and provider are carried over and can be seen on the “History of Present Illness” screen for the next visit.

**Honor patient and family preferences in communications by asking how they want to be addressed, how they prefer to be communicated with (e-mail, phone), and with what frequency.**

**Provide for patient/family and provider collaboration in care planning, in care coordination, and in the co-creation of care plans and self-management support.**

The **Bellin Family Medical Center** at the Ashwaubenon, Wisconsin, site participated in the national Quality Allies collaborative to advance the practice of self-management support (see page 34). Systems of care and specific care practices changed. Data collected during the collaborative showed increases in the number of patient-directed goals being developed and in patient knowledge of the care team, processes, and available resources. More families or support persons participated in the clinic visit, goal setting, and participation in patient care. Measures of outcomes, such as HbA1c levels, and patient satisfaction showed improvement over the last year. There was also an increase in the percentage of patients meeting targeted clinical indicators for blood pressure, HbA1c, and LDL cholesterol levels. Patient and family advisors participated on the team redesigning care practices and changes to the system of care. Inspired by this experience, the Bellin system is working to establish patient advisory boards in the majority of the clinics. Patient and family advisors are involved in such activities as offering peer support, developing patient education materials, and participating on the Planned Care Group Committee.

**Disseminate examples of best practice for patient- and family-centered care in ambulatory care.**

The **Institute for Family-Centered Care’s** website features primary care as one of its “special topics.” This section of the website describes key recommendations and promising practices for creating partnerships with patients and families and advancing the practice of patient- and family-centered primary care, profiles patient and family advisors in primary care settings, and includes guidance for how to initiate these partnerships in ambulatory settings.

The **John D. Stoeckle Center for Primary Care Innovation**, the **Massachusetts General Physicians Organization**, and the **Center for Integration of Medicine and Innovative Technology** are partnering to transform primary care.

An interdisciplinary team that includes patients and families is designing the “Ambulatory Practice of the Future.” The practice will incorporate new models of care to address the care experience, communication and information-sharing, web-based tools that support a virtual practice, and innovative office design models. The practice will open in 2008.

The Stoeckle Center is also conducting a national study of 12 patient-centered primary care practices. These practices all scored above the 85th percentile on clinical and organizational issues evaluated by the *Consumer Assessment of Healthcare Providers and Systems*® (CAHPS) survey and other patient surveys. The study results and in-depth case studies of each practice will be available on the Stoeckle Center and **The Commonwealth Fund** websites.

**3. Develop and disseminate approaches to education and training to advance partnerships with patients and families in ambulatory care.**

**Help clinicians answer the “What’s in it for Me” question.**

Encouraging clinicians to articulate how partnerships with patients and families benefit their work facilitates change in practice. The tool shown at the right can be used as part of learning sessions.

**Develop curricula and resources to support professionals in redesigning ambulatory care and in developing partnerships with patients and families in ambulatory settings.**

New educational resources are now available to transform how mental health services are provided.

The President’s **New Freedom Commission on Mental Health** issued *Achieving the Promise: Transforming Mental Health Care in America* in 2003. The Commission’s vision was that families “must stand at the center of the system of care.” In 2004, the Federal **Center for Mental Health Services** (CMHS) commissioned the **Federation of Families for Children’s Mental Health** to define “family-driven care” and develop a toolkit to facilitate implementation. *Shifting Gears to Family-Driven Care: An Ambassador’s Guide and Tool Kit*, released in 2006, is designed to assist families, practitioners, and advocates to promote understanding and educate others about this approach to care.

PARTNERSHIPS WITH PATIENTS AND FAMILIES		
WHAT’S IN IT FOR ME?		
Benefits to staff and physicians	Benefits to patients and families	Benefits to the ambulatory program

Opportunities for new partnerships with patients and families:

Next Steps:

Assure that a percentage of continuing education requirements for ambulatory health care provider recertification are met by education in patient- and family-centered care.

**4. Assure that approaches to evaluation of ambulatory care are patient- and family-centered.**

**Require that ambulatory settings use a variety of approaches to learning directly from patient and family perspectives, experience, and expertise.**

In efforts to design a statewide system of care that more effectively integrates mental health and physical health care in the primary care system, the **Maine Health Access Foundation** funded a series of meetings to learn from patients and families about what was important to consider in making service delivery improvements (see page 144 for more information).

**Create ways to publicly report patient experience data at the provider and practice/group level.**

The **CAHPS** survey measures patient and family perceptions of the care experience in the ambulatory setting. Public reporting of CAHPS data is being used in innovative projects.

**AQA**, formerly known as the Ambulatory Care Quality Alliance, a broad-based collaborative of physicians, consumers, purchasers, health insurance plans, and others, seeks to improve quality and safety through public reporting of data. AQA is coordinating a pilot project that began in 2006 to encourage public reporting of quality data.

One of the AQA pilot sites, the **Wisconsin Collaborative for Healthcare Quality** recently established a website to post an interactive Performance and Progress Report regarding its 28 members. Members of the collaborative publicly report clinical outcomes and data based on the IOM six aims of the Institute of Medicine report, *Crossing the Quality Chasm*. Three items from the CAHPS survey are currently being reported under “patient-centeredness,” including the patient perspective of how well a doctor communicates.

The **Massachusetts Health Quality Partners**, another AQA pilot site, includes additional CAHPS items in their measures. The public can compare clinics and practices across patients’ ratings of how well a physician knows their medical history as well as their values and beliefs and across a series of questions that measure self-management support.

Develop and disseminate evaluation and research about patient- and family-centered care in the ambulatory care setting (*see Chapter 6 regarding research issues*).

The **PeaceHealth Medical Group** in Eugene, Oregon, received funding from the **Agency for Healthcare Research and Quality** to study medication safety from the perspective of patients. The study will recruit patients between the ages of 50-75 who use at least one medication in the management of a chronic condition. Through qualitative interviews, information about how patients manage medications in the home environment will be collected and analyzed. Working with patients, a Failure Modes Effect Analysis will be conducted to identify management risks in the processes. The results will shed light on medication errors from the patient perspective and strategies for primary care providers to use in partnership with patients to increase patient medication management safety. Patients and families will serve as advisors throughout the study process.

#### 5. Use regulatory and other incentives to develop and sustain patient- and family-centered practice in ambulatory settings.

Link demonstration/measurement of standards for patient- and family-centered care to the licensing and accreditation of ambulatory practices.

Encourage the continued integration of patient- and family-centered care into The Joint Commission Ambulatory Care Standards.

Include patient- and family-centered care criteria in the National Committee for Quality Assurance (NCQA) standards required as part of maintaining physician certification.

Develop a community board with a majority of members who are patients and families for each ambulatory practice, similar to the model that has been used by Community Health Centers.

The **Family HealthCare Center** is a Community Health Center in Fargo, North Dakota, and thus has a community board. It also has a Patient Advisory Council that has participated in the development of the Center's website and in the planning, implementation, and evaluation of group visits.

Include patient- and family-centered care criteria in the American Board of Medical Specialties standards required as part of maintaining physician certification.

Require practices to use the CAHPS surveys to collect feedback from patients and to publicly report their results.

Incorporate patient experience of care survey results in pay-for-performance programs.

Establish a Patient- and Family-Centered “seal of approval” for ambulatory centers or other recognition programs for demonstrating excellence in patient- and family-centered care.

#### 6. Use payer requirements to promote patient- and family-centered practice in ambulatory settings.

Fundamental change is needed in the way physicians are compensated for primary care and to support ongoing patient/clinician relationships and efficient access to useful information and support.

The current movement toward creating patient-centered medical homes in adult primary care through such endeavors as the *New Model*, being piloted by **TransforMED**, offers an opportunity to test new approaches to reimbursement. This also provides a timely opportunity to include patient and family advisors in the redesign of systems of care and of the reimbursement system. With the appropriate reimbursement system, the engagement of patients and families in care can be encouraged and supported.

Require ambulatory care settings to have a Patient and Family Advisory Council for Medicaid, Medicare, or other payer reimbursement.

Require that ambulatory settings meet other standards of patient- and family-centered care in order to receive federal reimbursement.

Provide incentive payments to physicians to advance the practice of patient- and family-centered care.

Promote interdisciplinary collaboration by restructuring reimbursement to target the ambulatory practice rather than just the physicians.



## PATIENT- AND FAMILY-CENTERED AMBULATORY CARE: A CHECKLIST

- ❑ The ambulatory setting has a definition of quality that includes the experience of care for patients and families.
- ❑ First impressions are positive and welcoming to patients and their families.
- ❑ Physician and staff practices convey to patients and their families that they are respected and encouraged to be integral members of the health care team.
  - △ Physician and staff practices reinforce that care will be individualized for patient and family goals, priorities, and values.
  - △ There are programs, policies, and approaches in place to support patients and their families in developing goals and action plans for care and self-management of their chronic condition.
- ❑ Patients and their families have access to useful health information and support.
  - △ Patients and, when appropriate, families have timely access to visit notes, medication lists, and other clinical information (lab, x-ray, and other test results).
  - △ Information and educational resources are available in a variety of formats and media and in the languages and at the reading levels of the individuals served.
  - △ Patients and their families are involved in developing and testing the information and education materials and programs.
  - △ Patients and their families are involved in teaching or facilitating programs and group activities for patients and their families.
- ❑ Peer support and family-to-family support are made available systematically to patients with chronic conditions and their families.
- ❑ Strategies are in place to ensure patient and family access to useful community resources and programs.
- ❑ Strategies are in place to reduce the cultural and linguistic differences between staff and the patients and families they serve.
- ❑ Care is coordinated within the practice or clinic, between health care settings and with subspecialists, and with other support services.
  - △ Patients and their families assist with the development and evaluation of this care coordination system.
- ❑ Patients and their families are involved in the ambulatory setting's patient safety programs—for each clinical encounter and in developing safe systems of care.
- ❑ Patients and their families are involved in orientation, staff development, and education of professionals-in-training.
- ❑ Patients with chronic conditions and their families are involved in the planning, implementation, and ongoing evaluation of chronic care.
- ❑ Patients and their families are involved in processes to document the effectiveness and cost efficiency of care.
- ❑ The physical facility supports patient- and family-centered practice and access to information and peer education and support.
- ❑ Patients are asked to evaluate their experiences with care in the practice and with other services on a regular basis.

Source: Institute for Family-Centered Care. An excerpt from *Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: Recommendations and Promising Practices*, (2008). Available at: <http://www.familycenteredcare.org/tools/downloads.html>

## FOR FURTHER INFORMATION . . .

- For the most recent references on this topic, please see the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>
- *Improving Primary Care: Strategies and Tools for a Better Practice* by Thomas Bodenheimer and Kevin Grumbach was published by McGraw-Hill in 2007.
- Information about the New Health Partnerships' Initiative, the Quality Allies Initiative, and the Pilot Collaborative on Self-Management Support can be found at <http://www.ihl.org/IHI/Programs/StrategicInitiatives/NewHealthPartnerships.htm>.
- New Health Partnerships' resources, tools, information, and stories are available at <http://www.newhealthpartnerships.org>.
- American Academy of Pediatrics. (2004). Policy statement: Medical home initiatives for children with special needs project advisory committee. *Pediatrics*, 113(5), 1545-1547. This can be downloaded at <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;110/1/184>.
- For information about creating partnerships with families in ambulatory settings, visit the Center for Medical Home Improvement at [www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org). Practical assessments and resources for providers in community practices and families serving on improvement teams and the complete *Medical Home Improvement Kit* including measurements, strategies, and *A Guide for Parent and Practice "Partners" Working to Build Medical Homes for CSHCN* are available on the site.
- The full text of the *Joint Principles of the Patient-Centered Medical Home* can be downloaded from [http://www.acponline.org/hpp/approve\\_jp.pdf?hp](http://www.acponline.org/hpp/approve_jp.pdf?hp).
- A comprehensive self-assessment inventory for patient- and family-centered ambulatory care is available from Institute for Family-Centered Care at [www.familycenteredcare.org](http://www.familycenteredcare.org).
- Profiles on The Children's Hospital of Philadelphia and Cincinnati Children's Hospital Medical Center and their partnerships with families are featured at <http://www.familycenteredcare.org/profiles/prof-phil.html> and <http://www.familycenteredcare.org/profiles/prof-cinn.html> respectively.
- The Primary Care section of the Institute for Family-Centered Care's website is located at <http://www.familycenteredcare.org/advance/topics/primary-care.html>. *Advancing the Practice of Patient- and Family-Centered Care: How to Get Started* can be downloaded from <http://www.familycenteredcare.org/advance/topics/pc-howtogetstarted.html>.
- The work of The John D. Stoeckle Center for Primary Care Innovation at Massachusetts General Hospital is described at <http://www.massgeneral.org/stoecklecenter/jstoeckle.htm>.

- Information about the National Federation of Families for Children’s Mental Health and the resource, *Shifting Gears to Family-Driven Care: An Ambassador’s Guide and Toolkit* can be found at <http://www.ffcmh.org>.
- Maine Health Access Foundation’s Patient-Centered Care long-term priority initiative is described at <http://www.mehaf.org/promote-patient-centered-care.aspx>.
- *The CAHPS® Improvement Guide: Practical Strategies for Improving the Patient Care Experience* published in 2003 has many useful examples for improving primary care based on the information derived from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey. The *Improvement Guide* can be downloaded from [https://www.cahps.ahrq.gov/content/resources/QI/RES\\_QI\\_CAHPImprovementGuide.asp?p=103&s=31](https://www.cahps.ahrq.gov/content/resources/QI/RES_QI_CAHPImprovementGuide.asp?p=103&s=31). Information about the CAHPS is available at <https://www.cahps.ahrq.gov/default.asp>.
- The work of the AQA is described at <http://www.aqaalliance.org>. Information about two of AQA’s pilots sites, *Massachusetts Health Quality Partners* and *Wisconsin Collaborative for Healthcare Quality* can be found at <http://www.mhqp.org/default.asp?nav=010000> and <http://wchq.org>.
- Information about the PeaceHealth Medical Group can be found at <http://www.peacehealth.org/Oregon/WhoWeArePHMG.htm>.
- The work of TransforMED is described at <http://www.transformed.com>.

# EDUCATING HEALTH CARE PROFESSIONALS

### Key recommendations at a glance...

1. Envision the education of health professionals as intrinsically patient- and family-centered, and develop and support efforts to realize this vision.
2. Integrate patient- and family-centered competencies into all course work and clinical experiences, from the basic sciences and early clinical didactic aspects of education to internships and residencies.
3. Ensure active patient and family involvement in the education of future health care professionals.
4. Ensure that clinical learning environments create opportunities for students and trainees to acquire skills and observe patient- and family-centered care in practice.
5. Involve patient and family faculty in the education, orientation, and continuing education programs for health care professionals and administrators.
6. Provide training to patient and family faculty members on approaches to effective teaching of health care personnel and support them in their teaching roles.
7. Evaluate student experiences of patients and families as teachers and disseminate data on effectiveness.
8. Support and encourage educators in implementing the incorporation of patient- and family-centered information and skills into health professional education.

*“What residents say to patients may be words we will remember all our lives: words can hurt our sense of self and future, or be magnificently healing.”*

An MCG Behavioral Health Patient Advisor and  
Peer Counselor, MCG Health System, Augusta, GA

**I**ntegrating patient- and family-centered concepts and teaching strategies into the curricula and learning environments of medical schools, residency programs, schools of nursing, and schools of allied health is essential to bringing about transformational change in health care. Health care professionals benefit from understanding patient and family perspectives. Health care professionals also need to be prepared to practice in a collaborative manner that

engages the patient and family in care and decision-making and that wisely uses the expertise of other health disciplines. Strategies to support patient- and family-centered change in the education of health care professionals are proposed below.

The following strategies are proposed to help make patient- and family-centered care a reality in educational settings.

**1. Envision the education of health professionals as intrinsically patient- and family-centered, and develop and support efforts to realize this vision**

Create national standards, in collaboration with patients and families, identifying patient- and family-centered competencies for students and trainees across all disciplines.

In collaboration with patients and families, clearly define the professional knowledge, behaviors, and skills reflecting competence in patient- and family-centered care with emphasis on collaboration and partnership.

The **Accreditation Council for Graduate Medical Education's (ACGME) Outcomes Project** has developed a list of desired competencies for residents and requires individualized planning for each resident based on these competencies. See competences listed below and how they relate to patient- and family-centered principles.

ACGME is also exploring how to integrate concepts and skills for patient- and family-centered care into residency training. In 2007, the organization's Council on Strategic Initiatives held a symposium focused on developing a framework for change. One team presenting at the symposium described implementing patient- and family-centered care in an academic medical center. This presentation sparked an exploration of the implications of patient-centered care in residency training. ACGME has convened a task force on patient- and family-centered care and will develop a white paper on its significance for accreditation. ACGME will meet with stakeholders in 2008 to further explore these issues.

Required Competencies for Graduate Medical Education and Corresponding Patient- and Family-Centered Principles	
Core Competency	Patient- and Family-Centered Principles
Patient care	Collaborative partnerships with patients and families
Medical knowledge	Patient- and family-centered care literature (e.g., Society of Critical Care Medicine, 2007 report on patient-centered care)
Practice-based learning and improvement	<ul style="list-style-type: none"> <li>• Partnering with patients to help them manage chronic illness</li> <li>• Working with patient advisors on performance improvement initiatives</li> </ul>
Interpersonal and communication skills	<ul style="list-style-type: none"> <li>• Engaging in two-way dialogue</li> <li>• Embracing all four patient- and family-centered care core concepts</li> </ul>
Professionalism	<ul style="list-style-type: none"> <li>• Introductions made 100% of the time</li> <li>• Information sharing that is timely, affirming, and useful</li> <li>• Respect for privacy and family beliefs and concerns</li> </ul>
Systems-based practice	<ul style="list-style-type: none"> <li>• Health care team includes the patient and his/her family</li> <li>• Facilitation of diverse groups</li> </ul>

*Adapted from: Sodomka, P. for MCG Health, Inc. Presentation to the Advisory Group on Patient-Centered Care of the Accreditation Council for Graduate Medical Education; March 2007; Chicago, IL.*

The *Quality and Safety Education for Nurses* project, funded by the **Robert Wood Johnson Foundation**, began the second phase of its effort to change nursing education to strengthen nurses' commitment to quality and safety early in 2007. Patient-centered care is one of the core competencies that was selected to guide the curriculum. The second phase establishes a learning collaborative of 15 pilot nursing schools to demonstrate integration of the competencies into curricula. Project staff are also working with representatives from advanced-practice nursing organizations to consider how to adapt graduate education. The curriculum weaves patient-centered care with the other core competencies throughout the learning sessions. A variety of methods and activities are used to bring the perspective of the patient and family to the forefront and help nursing students learn to integrate quality and safety with patient-centered care. To promote widespread use, the curriculum is available online for free at the new website, launched in April 2007.

**2. Integrate patient- and family-centered competencies into all course work and clinical experiences, from the basic sciences and early clinical didactic aspects of education to internships and residencies.**

**3. Ensure active patient and family involvement in the education of future health care professionals.**

A multi-pronged approach at the **Medical College of Georgia (MCG)** in Augusta demonstrates the system's commitment to integrating patient- and family-centered care across all settings where students and trainees learn and where faculty practice.

A commitment to advancing the practice of patient- and family-centered care has become a requirement for newly recruited leaders for the clinical care settings, clinical learning environments, and the academic campus of the **MCG Health System**.

Twenty-six patient and family faculty have been appointed and trained to share their stories and participate in a variety of educational settings for students and trainees across all disciplines.

Behavioral health patient and family advisors provide an initial orientation to psychiatry residents at all four levels of the residency program.

The **Medical College of Georgia Center for Patient- and Family-Centered Care** also offers an internship that is open to all graduate students. Interns learn first-hand about patient- and family-centered approaches to care and are introduced to the knowledge, skills, attributes, and organizational commitment necessary to make it a reality.



Patient and family educators can influence the practice of future physicians and nurses in a variety of forums.

In 1994, senior leaders at **The Children's Hospital of Philadelphia** and its larger academic community, including the **University of Pennsylvania**, began partnering with family members to support the hospital's education mission. Each year, the family faculty selects and trains parents to tell their stories within a standard curriculum on patient- and family-centered care. Parents share positive stories exemplifying sensitive care, as well as less positive stories shared with constructive criticism. Family faculty share the podium with hospital and university faculty during educational programs.

The goal of the program is to shape the practice of future physicians, nurses, administrators, and health care professionals through a variety of forums:

- ◆ The family faculty, who developed curricular materials for a course called, "Doctoring 101," now teach that required course at the **University of Pennsylvania School of Medicine**. Medical students learn to understand illness from the perspective of patients and families. They explore such topics as delivering difficult news, managing critical conversations, living with illness and disability, and death and dying.
- ◆ The family faculty co-teach in undergraduate and graduate programs at the **University of Pennsylvania School of Nursing** and **University of Pennsylvania School of Social Work**. Topics include patient- and family-centered care, collaborative care models, communication at the bedside, and therapeutic relationships. Student feedback indicates that seminars including family input have a greater impact than other modes of teaching.
- ◆ A family consultant teaches an annual seminar on family-centered care and shared decision-making to advanced-practice nursing students at the University of Pennsylvania. This seminar is simulcast to advanced-practice nursing students at **St. Jude Hospital** in Memphis, Tennessee.
- ◆ Family leaders have partnered with nursing faculty to co-author articles in publications such as *Pediatric Nursing*.
- ◆ In early 2007, the **University of Pennsylvania School of Nursing** invited a patient advocate to serve on its advisory board.

The hospital's future plans include creating a task force to examine training opportunities to promote health in vulnerable populations.

During orientation, all first-year residents in obstetrics and gynecology meet with members of the **University of Washington Medical Center's** Patient and Family Advisory Council. Advisors use resource materials that they themselves have developed to assist medical students in building patient- and family-centered communication skills. The first efforts were so successful that, at the residents'

request, family advisors now meet with residents again during their second year to review and enhance their communications skills.

Patients living with life-threatening illness are teachers in an elective course for first-year medical students at **Harvard Medical School**. In the course, students learn to elicit and value the patient's perspective; they learn about the power of listening, about the kinds of supports that help patients and families manage illness, and about the human experience of a life-threatening illness.

Educators at the **Medical College of Georgia School of Nursing** invite patients and families to serve as guest faculty in order to better integrate patient- and family-centered concepts into the nursing curriculum.

For example, in one class, a family faculty member shared her experiences as a breast cancer survivor. She described the many challenges she experienced in her health care treatment and some personal feelings about dealing with cancer. This kind of classroom experience, bringing patient-centered perspectives to nursing students, opens doors to developing true partnerships with patients.

#### Offer opportunities for patients and families to be involved in the selection of trainees.

At the **University of Washington Medical Center** in Seattle, a parent advisor is a decision-making member of the team that interviews and selects candidates for residencies in obstetrics/gynecology.

#### Offer opportunities for patients and families to be involved in the selection of faculty.

At the **Medical College of Georgia**, patient and family advisors participate in the interview process of candidates for key leadership positions in clinical settings and for chairs of departments within the school of medicine.

#### Increase patient and family involvement on curriculum committees within and across specific schools and disciplines.

The **Medical College of Georgia** has a Curriculum Development Task Force for Patient- and Family-Centered Care which includes patient and family advisors among its members. In 2007, this Task Force will pilot a course for students in the schools of medicine, nursing, allied health, dentistry, and graduate studies. This interdisciplinary course is co-taught by health care professionals and patient/family faculty. It will build on MCG's "Professionalism Day," which occurs at the start of each school year, is attended by all new students in all schools (approximately 800), and is hosted by a family leader.

Encourage involvement of patient and family faculty as educators in a variety of roles and settings as a required element of curriculum in pre-clinical and clinical years. For example, have patient and family faculty participate as:

- ◆ Guest lecturers.
- ◆ Patients and family members for simulated learning experiences.
- ◆ Hosts of home visits.
- ◆ Mentors over an extended period of time.

**Parent to Parent of Vermont**, with its partnerships with the **University of Vermont's College of Medicine**, has been a pioneer in the development of family faculty programs. The educational programming demonstrates a variety of roles that families can play in the education of health care professionals.

*Medical Education Project:* Third-year medical students participate in a three-session seminar that includes a home visit with a family where the family is the teacher about family-centered care, health care experiences, and life with a child with special needs.

*Medical Student Leadership Groups:* First-year medical students participate in small group discussions with a faculty mentor and guests who present on a variety of topics during their first semester. Families participate in one of these sessions and share their insights and perspective about interactions with medical professionals.

*Families In Resident Student Teaching:* Over a period of three years the pediatric residents learn in depth about family-centered care. Family faculty are particularly involved in the first year. They meet with first-year residents in a round table discussion format to explore issues about community resources and their expectations of pediatricians.

*Vermont Interdisciplinary Leadership of Health Professionals:* This a graduate level educational program at the University of Vermont, part of a larger national program called LEND (Leadership Education in Neurodevelopmental Disabilities) programs in other states. Trainees and fellows learn from an interdisciplinary team as they participate in community assessments, leadership training, and service delivery. Family faculty and trainees work together in developing a “project” for the family as part of the course.

#### 4. Ensure that clinical learning environments create opportunities for students and trainees to acquire skills and observe patient- and family-centered care in practice.

The “hidden curriculum” for clinical practice during rotations and clerkships has a powerful influence on student learning, behavior, and attitudes. If these learners do not experience patient- and family-centered care and meaningful collaboration with patients, families, and other disciplines, it gives them permission to dismiss the concept that has been presented in the classroom. Role models and mentors for the development of effective communication and collaboration skills are essential to the learning process.

It is important to note that many of the examples of best practice in educational settings are from organizations that have also made a commitment to patient- and family-centered care in the clinical setting.


#### 5. Involve patient and family faculty in the education, orientation, and continuing education programs for health care professionals and administrators.

To communicate the hospital’s vision and values for partnering with patients and families, family faculty at **The Children’s Hospital of Philadelphia** teach at every new employee orientation.

**Primary Children’s Medical Center** in Salt Lake City, Utah, offers an RN Residency Program to prepare new nurses for practice in pediatrics. The course includes a presentation on family-centered care by a teenage patient with a chronic, complex medical condition and her mother. In program evaluations, nurses consistently rate the teen patient’s presentation as the most helpful educational session in developing their understanding of how to provide family-centered care.

The **MCG Health System** in Augusta, Georgia, offers all staff members a variety of educational programs designed to strengthen patient- and family-centered skills and knowledge. As one example, MCG holds half-day learning labs throughout the year for staff from departments or programs in which specific efforts are under way to improve practice. Each learning lab features a panel of expert patients or family members who have experienced care in the department or program involved. Also, at an annual conference, MCG patient and family advisors share their perspectives on what is working well in the system and where improvements could be made and staff members share recent innovations in patient- and family-centered care.


**Staying the Course with Patient- and Family-Centered Care**



MCG Health System faculty, staff, patients and families are invited to attend a special patient- and family-centered care (PFCC) educational conference. MCG Health System is committed to providing and enhancing the PFCC philosophy within our organization and to find better ways to meet the needs of our patients and families. Join us for this exciting conference as we review where our journey began and where it is taking us.

**Conference Objectives:**


- Promote understanding of patient- and family-centered care and how it can be applied to any area.
- Explore examples of excellence and innovation in patient- and family-centered programs including policy, practice, education and facility design.
- Understand the roles and importance of collaborating with patient and family advisors.

**Keynote Speaker**  

**William Schwab, MD**  
 Professor, Department of Family Medicine  
 University of Wisconsin

**Tuesday, May 15**  
 MCG Large Auditorium  
 First session: 8 a.m. to 12 p.m.  
 Second session: 1 to 5 p.m.

To register, please call MCG Organization Development and Professional Learning Center at 706-721-2281 or e-mail [wlow@mccg.edu](mailto:wlow@mccg.edu).

Sponsored by:  
 Quality and Safety Steering Committee  
 PFCC and Customer Service Team  
 Family Services Development  
 Human Resources Division  
 Center for Patient- and Family-Centered Care



Ensure that patients and family members are included as presenters in conferences and seminars offering continuing education opportunities for health professionals.

Family leaders from **The Children's Hospital of Philadelphia** co-present with hospital staff and university faculty at national conferences and leadership forums.

A young Native American woman receiving methadone treatment for a chemical dependency participated on a patient and family panel at the April 2007 *Hospitals Moving Forward with Patient- and Family-Centered Care* seminar sponsored by the **Institute for Family-Centered Care**. She shared her perceptions of health care, describing what was supportive and what was alienating and disempowering. Seminar participants experienced her presentation and discussions with her as a powerful way to understand the link between patient- and family-centered care and cultural competence.

**6. Provide training to patient and family faculty members on approaches to effective teaching of health care personnel and support them in their teaching roles (see pages 132–134 for examples of this type of training).**

**7. Evaluate student experiences of patients and families as teachers and disseminate data on effectiveness.**

Between 2003 and 2005, 29 sets of student evaluations were received on presentations made by **Medical College of Georgia** patient and family faculty in three nursing and medical schools. A sampling of comments from the evaluations follows:

- ◆ *This is really a great part of the curriculum – to remind us of the effects of compassion from [the physician], the value of building a real relationship. It means a lot to be reminded of the choice we have to treat the patient, or to merely treat the disease.*
- ◆ *See what being a caregiver really meant.*
- ◆ *Really personalized what families go through.*
- ◆ *It's really good to put a face on the diseases we study.*
- ◆ *The family-centered perspective is often lost in all of the content of medical school. It is good to have this experience.*

In 2005, the **Children's Hospital & Regional Medical Center** in Seattle, Washington, conducted a study examining the impact of parents as educators. A parent-graduate of the the Newborn Intensive Care Unit (NICU) provided training in communication skills during the annual competency improvement training for NICU nurses.

All of the surveyed nurses reported the parents-as-faculty experience as very-to-extremely helpful to them in their daily work, and 80% reported that the opportunity to hear parents' experiences increased their confidence in responding to future families' needs. Seventy-three percent of the nurses reported that the parents-as-faculty experience helped them identify communication skills that they needed to improve. Analysis of nurses' responses to open-ended questions about their experience of the parent-as-faculty session revealed the following themes: 1) care team members can foster development of parental self-efficacy by having the parent provide "normal baby" care such as a bath; 2) parents' ability to integrate information undergoes a maturation process during their time in an intensive care unit and how information is presented needs to be in consideration of this maturation process; 3) parents appreciate having care-team members guide them through end-of-life decision-making especially around holding their child. The surveyed nurses also indicated that this educational program should be made available to all care team members.

**Lucile Packard Children's Hospital** at Stanford in Palo Alto, California, has a long history of integrating patient- and family-centered care into practices and policies. A recent initiative has focused on training nurses to enhance communication at the bedside. Two pilot studies have been conducted to investigate the effects of the training on disclosure of medical errors by oncology nurses and communication in the pediatric intensive care unit. The first study, which is now completed, used technology to simulate real-life situations. Families worked with the research team to create the training scenarios, act in the simulations, and debrief with the trainees. Results showed significant increases in nurses' communication self-efficacy to use a family-centered approach to disclose errors. In addition, 94% of the trainees gave the parent involvement aspect the highest rating.

The **William E. Boyle, Jr. MD Community Pediatrics Program** (the Boyle Program) at the Children's Hospital, **Dartmouth-Hitchcock Medical Center**, has offered educational programs to medical students and residents since 1998 to advance patient- and family-centered care. For the first two years of training, students are paired with a community member who has a chronic illness or condition. Over two years, their involvement with the children and the parent partners allows them to build a greater understanding of the impact of illness and the child's and family's perspective of illness and care. Pediatric residents are provided with community experience and complete a three-year children's advocacy project. Also families serve as faculty for residents.

In 2006, the Boyle Program conducted an evaluation of the program using an appreciative inquiry approach. Twenty-one individuals were interviewed, including medical students, pediatric residents, community and hospital staff partners, and families who participated as faculty and/or advisory board members. Medical learners reported increased patient- and family-centered knowledge and skills including:



- ◆ Greater understanding of patients' strengths as well as limitations;
- ◆ Improved communication and relationship-building skills;
- ◆ Enhanced compassion; and
- ◆ Greater willingness to partner with community groups and advocate within the community.

Recommendations from the students and residents to improve the program included additional training in advocacy, increased continuity of care and relationships, especially among the residents and the family faculty members and their children, and an increase in accessing resources and support groups. The leaders of the program also believed that the program has enhanced the reputation of the medical center.

**Ensure curriculum continuity for patient- and family-centered learning and practice across all of the years and stages of education, including new employee orientation, bedside rounds, grand rounds, and other continuing education offerings.**

The **Memorial Healthcare System** (MHS) of the South Broward Hospital District in Broward County, Florida, has developed an integrated series of learning experiences to facilitate culture change and build understanding of and commitment to patient- and family-centered care.

- ◆ MHS new employee orientation programs emphasize that patient- and family-centered care is an organizational priority. Nursing personnel receive additional orientation that operationalizes many of the concepts. At the system's flagship **Memorial Regional Hospital** and at **Joe DiMaggio Children's Hospital**, patient and family advisors regularly act as faculty during a one-hour segment of each facility's orientation program.
- ◆ All employees attend an inservice program about patient- and family-centered care featuring videos in which patient and family advisors and hospital staff candidly describe their experiences working in partnership. The program is facilitated by staff and by patient and family advisors.
- ◆ Patient and family advisors are also among the faculty for an 8-hour continuing education class, "An Introduction to Patient- and Family-Centered Care," during which staff develop action plans for their personal and team practice.
- ◆ MHS includes presentations about patient- and family-centered care by patients, family members, staff, and physicians in each of its quarterly leadership development sessions.

- ◆ Learning and support materials for these various educational efforts include a comprehensive toolkit and a quarterly newsletter. Both are available to all employees via the health system's website.

## 8. Support and encourage educators in implementing the incorporation of patient- and family-centered information and skills into health professional education.

**Identify and support hospital and clinic-based educators who are passionate advocates for patient- and family-centered change.**

**Support faculty development in building the following patient- and family-centered skills:**

- ◆ **Applying partnership approaches in their clinical practices.**

The **Institute for Healthcare Communication** (IHC), established in 1987, is a nonprofit organization dedicated to advancing the quality of health care by optimizing the experience and process of health care communication through four major activities: education, advocacy, research, and partnerships. IHC creates and disseminates innovative educational programs and services, and advocates for the importance of communication among all providers, patients, and families as an essential aspect of health care. IHC's highly interactive educational programs assist clinicians and other health care team members to enhance their communication, counseling, and self-management support skills. Communication skills programs are based on a patient- and family-centered model of care that emphasizes the value and impact of collaborative partnerships between clinicians and patients and family members. IHC programs are disseminated using a faculty development model that provides faculty with advanced communication skills training, as well as teaching and coaching skills. Since 1987, the IHC has trained over 600 faculty and conducted more than 9,000 workshops for more than 120,000 clinicians and health care workers. Training is enhanced by the extensive use of standardized patients to provide feedback and patients' perspectives. Actively engaging patients and families, and their stories, in clinician training sessions has proven to be a highly effective strategy for enhancing awareness about the value of patient- and family-centered models and approaches.

- ◆ **Teaching patient- and family-centered concepts in classroom settings.**

Physician and nurse palliative care educators acquire teaching and clinical skills through *Teaching and Learning End-of-Life Care*, a two-week, intensive faculty development program at **Harvard Medical School**. Learning to teach through interactive and relationship-building experiences with dying patients and bereaved families is a major focus of the course.



Patients and families share their experiences in faculty-moderated sessions. This program, where teaching professionals learn from patients and families, offers an educational model which catalyzes improved clinical practice, more effective faculty development, and commitment to organizational change.

◆ **Serving as role models and mentors for patient- and family-centered practice, especially through the rounding process.**

Including patients and families in multidisciplinary rounds provides an opportunity to enhance communication and shared decision-making. The interaction among the team members and the patient and family members provides students and trainees with models for effective communication.

In the neonatal intensive care setting, parents clearly indicate the value of participation in bedside care rounds. Parents were asked how they felt about being present when the care team talked about their baby on “rounds” as part of a web-based survey tool (*How’s Your Baby*). In responses from 1,495 parents from 10 centers that were part of the **Vermont Oxford Network**, 83% felt positive or very positive about the experience. Typical comments were “excellent,” “(felt like) part of the team,” “loved it (being there)” and “essential.” Negative responses related to how they were treated when present—“rude,” “condescending,” and “ignored.” Only two parents specifically expressed that they did not wish to be present.

Conducting rounds collaboratively with patients and families is often a new experience for faculty. It is not the way most faculty were trained, but it is a skill that can be taught. A listing of articles about conducting rounds in ways that encourage the presence and participation of families can be found on pages 62–63.

**Provide financial incentives to support education in patient- and family-centered care based on defined metrics for excellence in teaching on the topic.**

## FOR FURTHER INFORMATION . . .

- For the most recent references on this topic, please see the Institute’s *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>
- The Accreditation Council for Graduate Medical Education’s Outcomes Project can be found at <http://www.acgme.org/outcome>.
- Information about the Quality and Safety Education for Nurses project, funded by the Robert Wood Johnson Foundation, can be found at <http://www.qsen.org>.
- The benefits of family faculty programs for health professionals, patients, and family members are elaborated in <http://www.familycenteredcare.org/advance/topics/med-benefits.html>.
- For more on family involvement in professional education, read about Medical College of Georgia at <http://www.familycenteredcare.org/profiles/prof-mcg.html>.
- More on the Medical College of Georgia’s Center for Patient- and Family-Centered Care can be found at <http://www.mcg.edu/centers/cpfcc>. MCG Health System’s patient- and family-centered programming is described at [http://www.mcghealth.org/Patient\\_Visitor\\_Info/patient-family\\_center-care/index.html](http://www.mcghealth.org/Patient_Visitor_Info/patient-family_center-care/index.html).
- A description of the Family Faculty program at The Children’s Hospital of Philadelphia is located at [http://www.chop.edu/pat\\_care\\_fam\\_serv/fam\\_lead\\_action.shtml/#2](http://www.chop.edu/pat_care_fam_serv/fam_lead_action.shtml/#2).
- Information about patient and family advisors at the University of Washington Medical Center is on the following website at <http://www.uwmedicine.org/Facilities/UWMedicalCenter/ClinicsAndServices/FamilyAdvisors/index.htm>.
- Information about the Harvard Medical School Center for Palliative Care can be found at <http://www.hms.harvard.edu/cdi/pallcare/practicalaspects.htm>. For brief articles about health professionals learning from patients living with terminal illness, look at:
  - ◆ Block, S. D., & Billings, J. (2005). Learning from the dying. *The New England Journal of Medicine*, 353(13), 1313-1315.
  - ◆ Sullivan, A. M., Lakoma, M. D., Billings, J. A., Peters, A. S., Block, S. D., & the PCEP Core Faculty. (2005). Teaching and learning end-of-life care: Evaluation of a faculty development program in a palliative care program. *Academic Medicine*, 80, 657-668.
- Parent to Parent of Vermont’s Family Faculty Programs and its partnerships with the University of Vermont’s College of Medicine are described at <http://www.parentparvt.org/ffi.html>.
- Vermont Interdisciplinary Leadership of Health Professionals (VT-ILEHP) and the University of Vermont’s partnership with Parent to Parent are available at <http://www.uvm.edu/~vtilehp>.

- Information about *Hospitals and Communities Moving Forward with Patient- and Family-Centered Care: An Intensive Training Seminar Enhancing Quality and Safety for Patients and Their Families* can be found at <http://www.familycenteredcare.org/events/seminars.html>.
- To find more on family-centered care at the Seattle Children's Hospital and Regional Medical Center's website, see [http://www.seattlechildrens.org/home/patients\\_families/family\\_centered.asp](http://www.seattlechildrens.org/home/patients_families/family_centered.asp).
- To access information on partnerships at the Lucile Packard Children's Hospital at Stanford in Palo Alto, CA, visit <http://www.lpch.org/clinicalSpecialtiesServices/COE/Transplant/LiverTransplant/familyCenteredCareLiverTransplant.html>.
- The William E. Boyle, Jr. MD Community Pediatrics Program (the Boyle Program) at the Children's Hospital, Dartmouth-Hitchcock Medical Center is found at [http://www.dhmc.org/webpage.cfm?site\\_id=2&org\\_id=586&gsec\\_id=0&sec\\_id=0&item\\_id=32377](http://www.dhmc.org/webpage.cfm?site_id=2&org_id=586&gsec_id=0&sec_id=0&item_id=32377).
- For information on the family-centered efforts at the Memorial Regional Hospital and the Joe DiMaggio Children's Hospital, go to <http://www.familycenteredcare.org/profiles/prof-joe.html>.
- The home page for Institute for Healthcare Communication (IHC) website is <http://www.healthcarecomm.org>.
- Parents' preference for being present during rounds and the web-based survey tool, *How's Your Baby*, are discussed in the following article:
  - ◆ Saunders, R. P., Abraham, M. R., Crosby, M. J., Thomas, K., & Edwards, W. H. (2003, April). Evaluation and development of potentially better practices for improving family-centered care in neonatal intensive care units. *Pediatrics*, 111(4 Pt 2), e437-e439.
- Data from the *How's Your Baby* survey was presented at the following meeting:
  - ◆ Edwards, W. H., & Nickerson, J. (2004, December). *Parents on Rounds*. Presented at Hot Topics in Neonatology, Washington, DC.
- The following articles offer useful information and perspectives for conducting rounds in ways that encourage the presence and participation of patients and families:
  - ◆ Davidson, J. E., Powers, K., Hedayat, K. M., Tieszen, M., Kon, A. A., Shephard, E., et al. (2007). Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. *Critical Care Medicine*, 35(2), 605-622.

- ◆ Fletcher, K. E., Furney, S. L., & Stern, D. T. (2007). Patients speak: What's really important about bedside interactions with physician teams. *Teaching and Learning in Medicine*, 19(2), 120-127.
- ◆ Landry, M., Lafrenaye, S., Roy, M., & Cyr, C. (2007). A randomized, controlled trial of bedside versus conference-room case presentation in a pediatric intensive care unit. *Pediatrics*, 120(2), 275-280.
- ◆ Muething, S. E., Kotagal, U. R., Schoettker, P. J., Gonzalez del Rey, J., & DeWitt, T. G. (2007). Family-centered bedside rounds: A new approach to patient care and teaching. *Pediatrics*, 119(4), 829-832.
- ◆ Simmons, J. M. (2006). A fundamental shift: Family-centered rounds in an academic medical center. *The Hospitalist*, 10(3), 45-46.
- ◆ Sisterhen, L. L., Blaszak, R. T., Woods, M. B., & Smith, C. E. (2007). Defining family-centered rounds. *Teaching and Learning in Medicine*, 19(3), 319-322.



# EDUCATING HEALTH CARE LEADERSHIP

### Key recommendations at a glance...

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1. Articulate and define key patient- and family-centered skills, competencies, and attitudes needed by leaders and integrate them into all applicable undergraduate and graduate training programs for health care administrators, managers, and leaders.
2. Develop and disseminate a core curriculum on patient- and family-centered concepts that faculty can teach in health care management and health services master of business administration programs, master of public administration programs, and master of health care administration programs.
3. Integrate patient- and family-centered concepts into the review criteria of organizations that accredit and certify health administration, management, and leadership training programs.
4. Encourage the involvement of patient and family advisors in interviews for candidates seeking admission to graduate programs in health administration/management and in the hiring of administrative, medical, and nursing leaders.
5. Integrate concepts of patient- and family-centered care and partnerships with patient and family advisors into orientation and continuing education programs for health care administrators, trustees, and involve patient and family faculty as presenters in these programs.
6. Assure that organizations promoting best practices in health care management and governance include patient- and family-centered care among their best-practices criteria.
7. Integrate patient- and family-centered concepts into member-education programs of professional organizations that represent health care administrators and executives.
8. Reach out to and involve health care organizations that represent diverse cultural and ethnic constituencies as a means of fostering the development of patient- and family-centered administrative leaders, representative of the diversity of communities served.



Health care leaders set the tone and expectations for institutional and system-wide approaches to care. For this reason, it is critical that they be trained in concepts, applications, and strategies of patient- and family-centered care. Such information should be fully integrated in the curricula and learning environments for health administration graduate education programs, internships, and fellowships. Patient and family advisors should be part of the faculty in these graduate programs, as well as in orientation and in-service education programs for senior staff.

Unfortunately, curricula of graduate education programs, accrediting criteria for

these programs, and continuing education programs for health administrators, currently include little or no information on patient- and family-centered care or on the role of health care administrative leaders in advancing this approach to care and in integrating it into the management and infrastructure of health care organizations. The June Expert Panel Meeting participants thoughtfully identified opportunities to integrate patient- and family-centered concepts in existing leadership organizations.

Providing patient- and family-centered health care requires systemwide transformation, which can happen only when leaders model the way.

*“We need to correct the misperception that patient- and family-centered care is a health care ‘model.’ Instead, we have to help administrators recognize that patient- and family-centered care represents a profound change in organizational culture. It changes the way the work is done and how decisions are made.”*

A Participant at the Expert Panel Meeting on Patient and Family Partnerships, June 2006

**1. Articulate and define key patient- and family-centered skills, competencies, and attitudes needed by leaders and integrate them into all applicable undergraduate and graduate training programs for health care administrators, managers, and leaders. (see pages 77–78 for a checklist for integrating patient- and family-centered concepts within educational programs for health care leaders).**

Leadership is key to transformational change in health care organizations.

Leaders who have been effective in advancing the practice of patient- and family-centered care and in creating change in organizational culture possess skills, competencies, and attitudes such as the following:

- ◆ Realization that leaders cannot delegate patient- and family-centered care—they must own it.
- ◆ Recognition that the perceptions and insights of patients and families are essential to quality improvement and to the redesign of health care, and that the active engagement of the patient and family in clinical encounters will lead to the best outcomes.

- ◆ A thorough understanding of their own values and beliefs regarding the experience of care, the ability to convey these values and beliefs to their leadership team, and the ability to model these values in their actions.
- ◆ A willingness to encourage and support partnerships with patients and families at all levels of the organization.
- ◆ The ability to be a good listener.
- ◆ Openness to new ideas—a “can do” attitude.
- ◆ The ability to remove barriers.
- ◆ The ability to participate in and facilitate groups composed of individuals with diverse perspectives and backgrounds.
- ◆ A commitment to support staff and physicians but also to hold them accountable for their behaviors.

The *NQF Safe Practices for Better Healthcare* published by the **National Quality Forum** in 2006 speak clearly to partnerships with patients and families to ensure safety and the leadership accountability for these partnerships:

Create and sustain a healthcare culture of safety.

**Practice Element 1:** Leadership structures and systems must be established to ensure that there is organization-wide awareness of patient safety performance gaps, that there is direct accountability of leaders for those gaps, that an adequate investment is made in performance improvement abilities, and that actions are taken to assure the safe care of every patient served...

Structures and systems should be in place to provide a continuous flow of information to leaders from multiple sources regarding the risks, hazards, and performance gaps that contribute to patient safety issues...

**Direct Patient Input:** A structure and system should be established to obtain direct feedback from patients regarding the performance of the organization. Information from satisfaction surveys is not enough—patients and/or patients’ families representing the population served should be included in the design of educational meetings or participate on formal committees that provide input to the leadership regarding the management of safety and quality issues within the organization.

The **Economic and Social Research Institute** (ESRI), a nonprofit organization that focused on research and policy analysis in health care and in the reform of social services, prepared a report for the **W. K. Kellogg Foundation** in 2006 that outlined best practices for integrating patient-centered care into improving the systems of care for underserved populations. ESRI conducted a literature review and explored five exemplary programs—the Cambridge Health Alliance, Massachusetts General Hospital, G.A. Carmichael Family Health Center, the Senior Health and Wellness Center, and the Health Choice Network. The report suggests that there are leadership and organizational supports and processes that are critical to success. These include:

- ◆ Feedback and measurement of the patient experience and patient- and family-centered care accompanied by accountability for addressing concerns and deficiencies.
- ◆ Encouragement of patients and families as key members of the health care team and involvement at the program and policy level.
- ◆ Development of the workforce through hiring, training, and supporting employees to reflect and value the diversity of the community they serve; and to prepare and support staff to be part of patient-centered teams.
- ◆ Explicit commitment of leadership to patient- and family-centered care and willingness to serve as role models.
- ◆ Involvement in quality improvement and other evaluative projects to explore the applications of patient- and family-centered strategies and processes with underserved populations.
- ◆ Implementation of technology that supports communication among providers, patients, and families.
- ◆ Integration of patient-centered care into key institutional priorities and culture.

## 2. Develop and disseminate a core curriculum on patient- and family-centered concepts that faculty can teach in health care management and health services master of business administration programs, master of public administration programs, and master of health care administration programs.

The development and dissemination of a core curriculum on patient- and family-centered leadership and management would expedite the integration of this content in graduate education programs. The curriculum should include well-defined objectives, teaching strategies, interactive exercises, and support materials such as prepared multi-media presentations. Content should include the following:

- ◆ Guidance on how to develop a shared vision for patient- and family-centered care.
- ◆ The importance of including the experience of care in any definition of health care quality.
- ◆ The evidence base and business metrics for patient- and family-centered care.
- ◆ The benefits of partnering with patient and family advisors in policy and program development, professional education, quality improvement, patient safety, and research.

- ◆ Strategies for building effective partnerships with patient and family advisors.
- ◆ Application of patient- and family-centered concepts and strategies in human resources management.
- ◆ Principles of evidence-based facility design, collaborative design planning, and design that supports the practice of patient- and family-centered care.
- ◆ Integration of patient- and family-centered concepts into the building of all information technology systems (clinical, administrative, and financial as well as patient portals and electronic personal health records).
- ◆ Measurement of patient and family perceptions of care and collaboration with patient and family advisors in responding to these perceptions.

Creating a network of lecturers who would be available to teach in health administration academic programs would further expedite the inclusion of this content in graduate school curricula.

## 3. Integrate patient- and family-centered concepts into the review criteria of organizations that accredit and certify health administration, management, and leadership training programs.

The **Commission on Accreditation of Healthcare Management Education (CAHME)** is an interdisciplinary, nonprofit organization committed to ensuring the quality of education of health care managers and administrators. Through a voluntary peer review process, CAHME accredits these graduate education programs. As part of the accreditation process, CAHME teams make site visits to health care management educational programs. CAHME establishes benchmarks and sets standards for the field.

This organization is positioned well to integrate the following in its accreditation criteria and asks that graduate education programs demonstrate how they are preparing students to:

- ◆ Involve patient and family advisors in quality improvement, patient safety, policy and program development, facility planning, information systems development, and human resource functions.
- ◆ Create organizational structures that support and sustain effective participation of patient and family advisors.
- ◆ Demonstrate how to measure the patient- and family-centered competencies of students who will serve as leaders and managers in health care organizations.

**4. Encourage the involvement of patient and family advisors in interviews for candidates seeking admission to graduate programs in health administration/management and in the hiring of administrative, medical, and nursing leaders.**

At **Dana-Farber Cancer Institute**, patient and family advisors participate in interviewing candidates for the chief operating officer and chief nursing officer positions and are usually involved in the hiring of all patient care-related management staff.

At the **H. Lee Moffitt Cancer Center & Research Institute** in Tampa, Florida, patient and family advisors are interviewing candidates for the chaplain position.

Patient and family advisors at the **University of Washington Medical Center** in Seattle have been appointed to the search committee for the new nurse executive.

**5. Integrate concepts of patient- and family-centered care and partnerships with patient and family advisors into orientation and continuing education programs for health care administrators and trustees, and involve patient and family faculty as presenters in these programs.**

Change the culture among health care administrative leaders so that patient and family partnerships are viewed as essential to quality, safety, and optimal outcomes.

Address fears some senior leaders may have about “losing control” as a result of the involvement of patient and family advisors in quality improvement and the redesign of health care.

Provide senior staff ongoing opportunities to hear and share patient and family stories and to participate in other experiential learning activities.

*“In more than two decades of collaborating with patients and families, we have found that patients and families are not asking for unreasonable changes.”*

Michele Lloyd, Senior Vice President for Family Services and Health Information Management,  
The Children’s Hospital of Philadelphia

*“Collaboration means that no one interest group is always right. It means taking what you think, and what I think, and what someone else thinks, and coming up with something that works for everyone.”*

Bev McConnell Crider, Family Leader  
Manager, Family-Centered Care,  
Children’s Hospital of Michigan

From: *Essential Allies: Families as Advisors*, 1995.

**Stories are a powerful way to change organizational culture. Listening to and talking with patients and families puts a human face on statistical and survey information.**

Prior to hiring family members for paid positions and appointing them to positions on major institutional committees and task forces, the chief executive officer of **The Children’s Hospital of Philadelphia** convened a regular executive forum to bring families together with the senior executive team to hear stories and candidly explore opportunities for improvement.

As part of a strategic organizational priority to create the “exceptional patient experience” and advance the practice of patient- and family-centered care, senior executives for the **Spectrum Health System** in Grand Rapids, Michigan, open their meetings with a patient and family story.

**Promote patient- and family-centered care as a key concept for health care executives in a variety of continuing education forums.**

The **Patient Safety Leadership Fellowship**, sponsored by the **Health Research and Education Trust** of the **American Hospital Association**, serves as an example of a fellowship where health care leaders could learn how to involve patients and families on patient-safety and medication-reconciliation committees and how to partner with patients and families in teaching safe communication practices to staff.

The **American Organization of Nurse Executives’** program for aspiring nurse leaders is another learning opportunity where future executives can develop proficiency in leadership for advancing the practice of patient- and family-centered care.

**Encourage the development of mentoring and training programs within hospitals and health systems.**

The **MCG Health System** in Augusta, Georgia, offers a two-year fellowship for master’s level students in health care administration. Fellows participate in a variety of patient- and family-centered activities, such as planning for the annual conference on patient- and family-centered care, facility design planning,



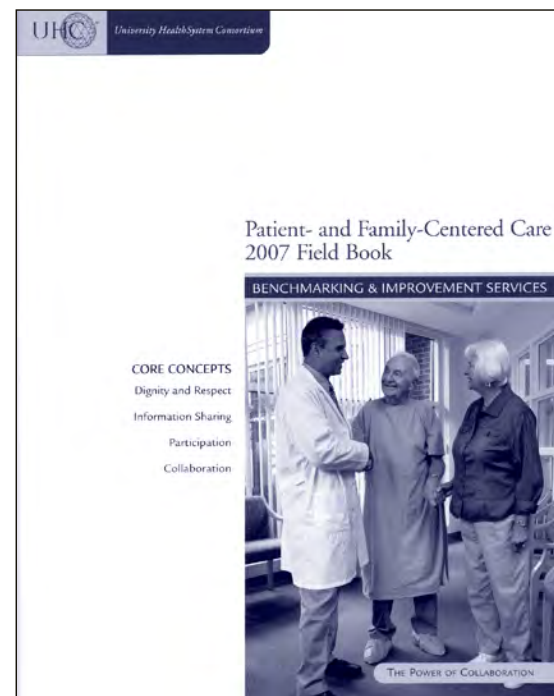
attending patient and family advisory council meetings and other meetings, and participating on task forces that include patient and family advisors.

The **Medical College of Georgia Center for Patient- and Family-Centered Care** has a patient- and family-centered care internship for graduate students in the public health informatics program. In addition to participating in some of the activities described above, interns coordinate projects related to family faculty, education, and organizational change activities. The interns also conduct a research project focused on patient- and family-centered care.

#### 6. Assure that organizations promoting best practices in health care management and governance include patient- and family-centered care among their best-practices criteria.

The **University HealthSystem Consortium (UHC)**, based in Oak Brook, Illinois, is an alliance of the clinical enterprises of 97 U.S. academic health centers (AHCs) and their 153 affiliated hospitals. UHC provides its members with resources aimed at improving performance in clinical, operational, and financial areas. A patient- and family-centered care benchmarking study was recently completed. Its objectives were as follows:

- ◆ To assist UHC members in determining their patient- and family-centered strengths and improvement opportunities.
- ◆ To identify useful metrics for monitoring progress in achieving patient- and family-centered goals.
- ◆ To develop an aggregate database of patient- and family-centered practices in academic health centers.
- ◆ To discover how AHCs are successfully implementing patient- and family-centered core concepts to address the principles of quality care outlined by the Institute of Medicine.



Cover art reprinted with permission of University HealthSystem Consortium

Twenty-six organizations completed a survey and self-assessment tool. Participants also submitted 70 reports describing patient- and family-centered improvement initiatives that they had implemented. A literature review was conducted, and six organizations were visited or interviewed about their patient- and family-centered practices.

The benchmarking project identified the following seven leadership strategies for implementing patient- and family-centered core concepts within health care organizations:

1. Collaborate with patients and family advisors to incorporate patient- and family-centered concepts into the institution's mission, vision, values, plans, safety initiatives, philosophy, and scope of care.
2. Ensure that senior leaders model patient- and family-centered concepts and hold staff accountable for achieving and maintaining patient- and family-centered goals.
3. Conduct an organizational self-assessment to identify and prioritize patient- and family-centered improvement opportunities; select performance measures, collect baseline data, monitor performance; and collaborate with patient and family advisors to interpret the data, and to design and implement improvements.
4. Create a paid patient and family leader position (supported by appropriate budget and resources) to coordinate patient- and family-centered initiatives across the enterprise.
5. Work with early adopters and share success stories to incrementally implement patient- and family-centered concepts across the organization.
6. Recruit physician champions to incorporate patient- and family-centered concepts into education, and encourage the use of patient/family advisors as faculty.
7. Ask, "Have we gotten patient/family input on this plan?" before moving forward to interpret data and/or design and implement any changes.

UHC recently launched a ***Patient- and Family-Centered Care Implementation Collaborative*** to assist members in addressing improvement opportunities identified through the benchmarking project. Eighteen organizations are networking with AHC colleagues to implement performance improvement strategies related to:

1. Increasing patient and family participation in care;
2. Working effectively with patient and family advisors and councils;
3. Improving scheduling, registration, and billing and payment practices; and
4. Measuring the outcomes of patient- and family-centered care initiatives.



The **American Hospital Association** (AHA) has developed resources for administrative and governance leaders that would be useful in the curricula for health care leaders and in continuing education programs. For example:

- ◆ AHA's *Strategies for Leadership Series* includes the *Patient- and Family-Centered Care Toolkit*. The toolkit includes a video that defines patient- and family-centered care and profiles of leaders in two hospitals; a video discussion guide; a hospital self-assessment inventory; and guidance and a bibliography for beginning the process of change.
- ◆ The criteria for the AHA's McKesson Quest for Quality Prize outlines essential considerations for aligning efforts to enhance quality, safety, and the practice of patient- and family-centered care. These criteria can be used to guide interdisciplinary family/professional learning projects.
- ◆ AHA's new Quality Center is designed to assist hospitals with resources needed to enhance their quality improvement processes. The Center suggests that hospitals consider and discuss questions such as the following:
  - ▼ How can board members be engaged to advance patient-centered care in our organization?
  - ▼ How do we overcome staff resistance to partnering with patients and families in care planning and delivery?
- ◆ "Engaging Patients & Families: A High-Leverage Tool for Health Care Leaders," a recent article from the Quality Center that appeared in the print and online editions of *Hospitals and Health Networks*, provides an excellent framework for a team-based case study learning experience for future leaders.

### 7. Integrate patient- and family-centered concepts into member-education programs of professional organizations that represent health care administrators and executives.

The **American College of Healthcare Executives** (ACHE) is the leading professional development organization for health care administrators, providing credentialing and education programs. With grant funding, ACHE has held educational programs titled, *Patient- and Family-Centered Care—Good Values, Good Business*.

The **Institute for Healthcare Improvement** (IHI) has strengthened the emphasis on and involvement by patients and families across its programs. Components of this effort include extensive content coverage on the IHI website ([www.ihl.org](http://www.ihl.org)) and in the *100,000 Lives Campaign* and the *5 Million Lives Campaign*; as faculty in the *IMPACT* program and the *New Health Partnerships* and

*Transforming Care at the Bedside* strategic initiatives. Specifically, within the Governance Leadership intervention of the 5 Million Lives Campaign ("Getting Boards on Board"), organizations are encouraged to involve patients and families in quality improvement efforts and specifically on trustee committees supporting quality and safety. Within IHI's own programming, patient- and family-centered care is being more deeply emphasized.

The **American College of Healthcare Executives** (ACHE) collaborated with the **Institute for Healthcare Improvement** in the publication of the article, "Patients and Families: Powerful New Partners for Healthcare and for Caregivers," in the *Health Executive* journal. The article describes some of the "drivers" for the development of patient and family partnerships. The article profiles a variety of ways that trustees and executive and clinical leaders are demonstrating their commitment to partnering with patients and families and learning from them about the experience of care and how to make change and improvement in systems of care.

The purpose of the **National Center for Healthcare Leadership** (NCHL) is to develop, educate, and support effective health care management leadership to meet the current and future health care needs in the United States.

NCHL has developed leadership competencies based on the **Institute of Medicine's** (IOM's) *Crossing the Quality Chasm* report. NCHL acknowledges achievement of the quality aims set forth in that document as a measure of success in leadership development. Like the IOM, it recognizes a patient-centered approach as an integral component of quality health care. Each of these competencies can be examined from a patient- and family-centered perspective, and educational activities can be developed that prepare individuals to be leaders for advancing the practice of patient- and family-centered care.



8. Reach out to and involve health care organizations that represent diverse cultural and ethnic constituencies as a means of fostering the development of patient- and family-centered administrative leaders representative of the diversity of communities served.

Seek candidates for graduate education programs, scholarships, and fellowships from health care organizations that represent diverse cultural and ethnic constituencies as one way to develop patient- and family-centered health care executives representative of diverse communities.

The following organizations represent diverse constituencies. Participation by members of these groups could have a beneficial effect on efforts to develop leaders with the knowledge and skills to advance the practice of patient- and family-centered care across all health care settings.

- ◆ Asian & Pacific Islander American Health Forum
- ◆ Diversity, Inc.
- ◆ Institute for Diversity in Healthcare Management
- ◆ Medicaid Health Plans of America
- ◆ National Association of African Americans in Human Resources
- ◆ National Association of Black Nurses
- ◆ National Association of Health Services Executives
- ◆ National Black MBA Association
- ◆ National Center for Cultural Competence
- ◆ National Forum for Latino Healthcare Executives
- ◆ National Indian Health Board
- ◆ National Medical Association
- ◆ National Society of Hispanic MBAs
- ◆ Society for Human Resource Management
- ◆ The Conference Board —Diversity and Inclusion Program
- ◆ The Society of Hispanic Diversity Professionals
- ◆ Women in Healthcare

## EDUCATING HEALTH CARE EXECUTIVES: APPROACHES FOR DEVELOPING PATIENT- AND FAMILY-CENTERED KNOWLEDGE, SKILLS, AND ATTITUDES

Graduate education programs preparing future health care executives:

- Involve patient and family advisors in interviews for candidates seeking admission to these graduate programs.
- Define key patient- and family-centered skills, competencies, and attitudes in the program of studies.
- Provide coursework and other learning opportunities intended specifically to enable students to acquire these skills, competencies, and attitudes.
- Include the following content in the curriculum:
  - △ Guidance on how to develop a shared vision for patient- and family-centered care.
  - △ The importance of including the experience of care in any definition of quality.
  - △ The evidence base and business metrics for patient- and family-centered care.
  - △ The benefits of partnering with patient and family advisors in program development, professional education, quality improvement, patient safety, and research.
  - △ Strategies for building effective partnerships with patient and family advisors.
  - △ Application of patient- and family-centered concepts and strategies in human resources management.
  - △ Principles of evidence-based facility design, collaborative design planning, and design that support the practice of patient- and family-centered care.
  - △ Integration of patient- and family-centered concepts into the building of all information technology systems (clinical, administrative, and financial).
  - △ Measurement of patient and family perceptions of care and collaboration with patient and family advisors in responding to these perceptions.
- Include experiential learning opportunities such as the following:
  - △ Shadow patients and families through both inpatient and outpatient experiences.
  - △ Spend time with patients and families in non-clinical settings:
    - Visit in the home of a woman who has experienced a complicated pregnancy and/or delivery; or, visit in the home or other community setting with a family caring for a child with special needs or an adult family member with a chronic condition (physical or mental).
  - △ Attend meetings of a hospital's or an ambulatory practice's patient and family advisory committee.
  - △ Serve on a multidisciplinary design planning committee that has consumers as members.
  - △ Participate on a quality improvement team with patients, families, and staff.

- △ Develop patient and family educational materials collaboratively with patient and family advisors.
- △ Attend a peer support or family-to-family support group meeting that is facilitated or co-facilitated by a patient or family leader.
- △ Serve on a hospital-wide patient- and family-centered care steering committee.

#### Accreditation criteria for graduate education programs:

- Require the programs to demonstrate how they are preparing students to:
  - △ Involve patient and family advisors in quality improvement, patient safety, policy and program development, facility planning, information systems development, and human resource functions.
  - △ Create organizational structures that support and sustain effective participation of patient and family advisors.
- Require the programs to demonstrate how they are measuring the patient- and family-centered competencies of students who will serve as leaders of health care organizations.

#### Credentialing programs for health care executives include the following:

- Patient- and family-centered content in all educational programs to better prepare health care administrators for their roles as leaders for improving quality, safety, and the experience of care.
- Patient and family faculty present and co-present at educational offerings.
- Patient- and family-centered content is included in tests for membership and for advancement to fellow status. For example, test questions might explore the role of patients and families in patient safety or how evidence-based design supports the presence and participation of families in hospital settings.

#### Continuing education for health care executives provides:

- Patient safety fellowships with opportunities to learn how to involve patients and families on patient safety and medication reconciliation committees and how to partner with patients and families in teaching safe communication practices.
- Fellowships for quality improvement, cultural competence, and health literacy with opportunities to learn how to partner with patients and families. For example, for cultural competence leadership training, patients and families from diverse backgrounds participate as faculty, sharing stories about their care experiences. To build knowledge and skills for partnerships, with these same patient and family faculty, a class assignment could be to form a quality improvement team to make changes in a clinic or hospital.

#### Resources for health care executives:

- The organizations promoting best practices in health care management and governance include patient- and family-centered care among their best practices criteria, resources, and bibliographies.
- A resource library for health care executives includes materials on creating partnerships with patients and families and leading change in organizational culture that supports the practice of patient- and family-centered care.

Source: Institute for Family-Centered Care, 2007.

## FOR FURTHER INFORMATION...

- For the most recent references on this topic, please see the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>
- A comprehensive report on the National Quality Forum's Safe Practices for Better Healthcare 2006 Update, with current evidence, updated approaches for implementation, and measures can be ordered from [http://www.qualityforum.org/publications/reports/safe\\_practices\\_2006.asp](http://www.qualityforum.org/publications/reports/safe_practices_2006.asp).
- The report, *Patient-Centered Care for Underserved Populations*, can be downloaded from the W. K. Kellogg Foundation at <http://www.esresearch.org/documents%5F06/Overview.pdf>.
- The Commission on Accreditation of Healthcare Management Education can be found at <http://cahme.org>.
- For more on the Dana-Farber Cancer Institute and patient- and family-centered care and their advisory councils, see <http://www.dana-farber.org/pat/support/default.html>.
- The H. Lee Moffitt Cancer Center and Research Institute patient and family advisory program is described at <http://www.moffitt.org/site.aspx?spid=80181D9FB4A840E7BA758742545908A1&ForwardFrom=9291AA1A21A6449582889B247D93F6E2>.
- Information about patient and family advisors at the University of Washington Medical Center can be found at <http://www.uwmedicine.org/Facilities/UWMedicalCenter/ClinicsAndServices/FamilyAdvisors/index.htm>.
- A description of the Family Faculty program at The Children's Hospital of Philadelphia can be found at [http://www.chop.edu/pat\\_care\\_fam\\_serv/fam\\_lead\\_action.shtml/#2](http://www.chop.edu/pat_care_fam_serv/fam_lead_action.shtml/#2).
- For more on Spectrum Health System in Grand Rapids, MI, see [www.spectrum-health.org](http://www.spectrum-health.org).
- Find out about the Patient Safety Leadership Fellowship sponsored by the Health Research and Education Trust of the American Hospital Association by visiting <http://www.hret.org/hret/about/pslf.html>.
- Information about the American Organization of Nurse Executives is available at [http://www.aone.org/aone\\_app/index.jsp](http://www.aone.org/aone_app/index.jsp).
- Information about the Center for Patient- and Family-Centered Care and its Leadership Program at the Medical College of Georgia in Augusta can be found at <http://www.mcg.edu/centers/cpfcc/index.html>.
- Contact Kathy Vermoch at [Vermoch@uhc.edu](mailto:Vermoch@uhc.edu) or 630-954-1030 with questions about University HealthSystem Consortium's (UHC) patient- and family-centered initiatives. An executive summary is available through UHC.
- For information on AHA's Strategies for Leadership Series, "Toolkit on Patient- and Family-Centered Care," go to <http://www.aha.org/aha/issues/Quality-and-Patient-Safety/strategies-patientcentered.html>.



- The AHA McKesson Quest for Quality Prize is outlined at <http://www.aha.org/aha/news-center/awards/quest-for-quality/overview.html>.
- Read about AHA's new Quality Center in an article by its director at [http://www.hhnmag.com/hhnmag\\_app/jsp/articledisplay.jsp?dcrpath=HHNMAG/PubsNewsArticle/data/2006May/060509HHN\\_Online\\_Mayfield&domain=HHNMAG](http://www.hhnmag.com/hhnmag_app/jsp/articledisplay.jsp?dcrpath=HHNMAG/PubsNewsArticle/data/2006May/060509HHN_Online_Mayfield&domain=HHNMAG) or go to its website at <http://www.ahaqualitycenter.org/ahaqualitycenter/home.do>.
- Visit <http://www.ache.org> for the American College of Healthcare Executives (ACHE).
- The article, "Patients and Families: Powerful New Partners for Healthcare and for Caregivers," published in the January 2008 issue of the *Health Executive* journal is included in the guidance resource, *Advancing the Practice of Practice of Patient and Family-Centered Care: How to Get Started*. This document can be downloaded at <http://www.familycenteredcare.org/tools/downloads.html>.
- The website for the National Center for Healthcare Leadership (NCHL) is <http://www.nchl.org/ns/index.asp>. A summary of the NCHL Health Leadership Competency Model is found at <http://www.nchl.org/ns/documents/CompetencyModel-short.pdf>.
- The following are websites for the diverse constituencies that could be included in the movement to expand the practice for patient- and family-centered care:
  - ◆ Asian and Pacific Islander American Health Forum: <http://www.apiahf.org>.
  - ◆ Diversity Inc.: <http://www.diversityinc.com>.
  - ◆ Institute for Diversity in Healthcare Management: [http://www.ache.org/policy/diversity\\_resources.cfm](http://www.ache.org/policy/diversity_resources.cfm).
  - ◆ Medicaid Health Plans of America: <http://216.250.255.79/home/index.cfm>.
  - ◆ National Association of African Americans in Human Resources: <http://www.naaahr.org>.
  - ◆ National Association of Black Nurses: <http://www.nbna.org>.
  - ◆ National Association of Health Services Executives: <http://www.nahse.org/eweb/StartPage.aspx>.
  - ◆ National Black MBA Association: <http://www.nbmbaa.org>.
  - ◆ National Center for Cultural Competence: <http://www11.georgetown.edu/research/gucchd/nccc/about.html>.
  - ◆ National Forum for Latino Health Executives: <http://www.nflhe.org>.
  - ◆ National Indian Health Board: <http://www.nihb.org>.
  - ◆ National Medical Association: <http://www.nmanet.org>.
  - ◆ National Society of Hispanic MBAs: <http://www.nshmba.org>.
  - ◆ Society for Human Resource Management: <http://www.shrm.org>.
  - ◆ The Conference Board – Diversity and Inclusion Program: <http://www.conference-board.org>.
  - ◆ The Society of Hispanic Diversity Professionals: <http://www.nshp.org>.
- An annotated bibliography for a resource library for health care executives is available at <http://www.familycenteredcare.org/advance/supporting.html>.



# EVALUATION AND RESEARCH

### Key recommendations at a glance...

1. Support research and evaluation to document the contribution of partnerships with patients and families to safe, effective health care.
2. Encourage partnerships with patients and families in research processes.
3. Develop collaborative projects to investigate outcome measures, study designs, and research and evaluation processes for patient- and family-centered care.
4. Increase public and private funding for patient- and family-centered research initiatives.
5. Assure dissemination of research related to patient- and family-centered care.
6. Encourage the adoption of evidence-based practice related to patient- and family-centered care.

For many years, patient- and family-centered care was promoted simply because it made sense. Intuitively, it seemed the “right thing” to do. Anecdotal evidence for its effectiveness soon began to accumulate. Nonetheless, as medicine moves increasingly to an evidence-based approach, additional research documenting the benefits of patient- and family-centered care and of partnerships with patients and

families is needed. In keeping with the principles of patient- and family-centered care, patients and families must be involved in the research process.

This chapter sets forth suggestions for how to stimulate and develop an evaluation and research agenda to systematically measure outcomes and inform practice related to patient- and family-centered care.

## 1. Support research and evaluation to document the contributions of partnerships with patients and families to safe, effective health care.

The **American Academy of Orthopaedic Surgeons** (AAOS) includes research as one approach to ensuring the development of a culture of patient-centered care in residency programs and in individual orthopaedic practices.

AAOS has partnered with the **Institute for Healthcare Communication** to develop a nationwide Communications Skills Mentoring Program for orthopaedic residents. By 2008, trainees in all 150 orthopaedic residency programs in the United States will be expected to have been in, or have made plans to be involved in, an AAOS course in patient-centered communication. AAOS has also set a goal that 25 percent of AAOS members will have completed the course by that time.

Patient satisfaction surveys, administered before and after the training, will be used to track the training effectiveness.

**Maine Medical Center** in Portland has adopted a Partnership Care Delivery model and is combining approaches to evidence-based research with its commitment to patient- and family-centered practice.

The hospital's **Center for Nursing Research and Quality Outcomes** and the **Nursing Research Council** developed an innovative Clinical Scholar Series. The program consists of workshops that provide nurses with the skills, knowledge, and tools needed to understand the research process. Nurses then form small groups where they design and develop a research project with assistance from a research mentor and the hospital's research nurse coordinator. The Clinical Scholars serve as resources for promoting the integration of evidence-based research into clinical practice.

Research topics currently being considered for further study include conducting change of shift reports in the room with the patient and family, conducting interdisciplinary rounds with the patient and family, and developing shared goals with the patient and family at the beginning of every shift.

A recent article published in the *British Medical Journal* reported findings from a synthesis of studies on patient-centered care and patient engagement in care and decision-making. The authors conclude that while there are gaps in the research base, the evidence points to patient engagement as an effective strategy to enhance quality and safety.

At **The Children's Hospital of Philadelphia** measuring outcomes of family-centered care initiatives is part of the annual operating plan. The specific initiatives measured in fiscal year 2008 include care coordination, patient and family waiting room experience, and effectiveness of family-centered care resources and training. The hospital has partnered with in-house research staff to develop measurement tools unique to these initiatives. These data collection tools

are combined with patient satisfaction survey data, staff and family focus group findings, and qualitative surveys to create an integrated metric for measuring and advancing family-centered care. Once the initiatives are fully implemented, the data will provide information on the outcomes of new policies, programs and resources designed in partnership with patients, families, and healthcare professionals. The strategic vision of The Children's Hospital of Philadelphia is to fully integrate family-centered care into the operational goals of the organization. The hospital's philosophy for measurement is for the strategic vision to guide the measurement, not for measurement to guide the vision. The hospital's vision is to fully integrate the philosophy of family-centered care into the patient and staff experience. Measuring the progress of the initiatives noted above is one component of realizing that vision (see page 36 for more information about The Children's Hospital of Philadelphia).

**Identify existing measures for patient- and family-centered care and determine if they are associated with meaningful changes** (see pages 98–99 for new patient and family perceptions of care questions as one type of measurement).

**Develop and validate meaningful measures for patient- and family-centered care.**

The **Medical College of Georgia Center for Patient- and Family-Centered Care** in Augusta hired a health systems researcher to meet with faculty, staff, and patient/family advisors to develop a plan for furthering research related to partnerships with patients and families and to define a set of useful and valid metrics.

A team of researchers from the **University of Cincinnati** and **Ohio State University** developed and pilot-tested the Senior Empowerment and Advocacy in Patient Safety Survey to assess elderly patients' views about their participation in patient safety activities within ambulatory care settings. To insure that the survey was grounded in the patient experience, input and feedback from elderly individuals was sought through individual interviews, focus groups, and pre-testing at various stages of development. The researchers hope that this instrument will be used in initiatives that educate and encourage seniors to be their own advocates within their health care experiences.

## 2. Encourage partnerships with patients and families in research processes.

The **Consumer Quality Initiatives** (CQI) was born out of the efforts of consumers who advocated that individuals receiving mental health services and their families have opportunities to be more involved in decision-making at the

state level. Established in 2000, CQI is on the cutting edge of using a community participatory action research framework to guide research and evaluation.

In 2005, the **National Institutes for Health** issued a request for proposals that for the first time included involvement of consumers in the research process. CQI held meetings with consumers and families to identify key priorities to guide their grant application process. CQI, in partnership with the **Boston University School of Public Health**, applied for and was awarded a grant to establish the **Boston Community-Academic Mental Health Partnership** in 2006.

CQI's goal is to establish "a mechanism through which community members can inform and participate in all aspects of the research process; from question generation, to the design and conduct of research studies, to the interpretation of results, and dissemination." Their target populations are adults with severe and persistent mental disorders and children with severe emotional disturbance.

Research at the **Beach Center on Disability at the University of Kansas** has long addressed topics pertinent to patient- and family-centered care and uses a collaborative approach to this research. The Center's Participatory Action Research (PAR) is a collaborative method for conducting research. All stakeholders—professionals, individuals with special needs, and families—are involved in planning, conducting, and disseminating research studies.

Beach Center PAR studies have included:

- ◆ Collaboration with leaders of Parent to Parent programs to design, implement, and disseminate efficacy research on these programs.
- ◆ Collaboration with a community-based parent resource center for families of children with disabilities to examine disability policies, partnerships among providers and between families and providers, and quality of life.
- ◆ Collaboration with culturally- and linguistically-diverse populations to determine how to improve the well-being of individuals with disabilities and their families.

**Lucile Packard Children's Hospital** (LPCCH) at Stanford has developed a collaborative program of family-centered care research and program evaluation. Parents of LPCCH patients are involved in all aspects of research—from conceptualization of study questions to involvement in study interventions to translation of study findings into improved program functioning. They also co-author publications.

LPCCH uses a theoretical behavioral change framework, called social cognitive theory, for research studies as well as program interventions. This framework supports the institution's family-centered approach of encouraging individual self-efficacy, as well as team efficacy, and of promoting family-centered partnerships in program development and policy setting as well as in clinical care.

A current LPCCH research project involves the design, implementation, and evaluation of a nurse communication training program. Parents from the Family-

Centered Care Department worked with an interdisciplinary team to create training scenarios, develop survey questions, and act as parents in the training scenario for family-centered communication related to disclosure regarding medical error.

Patients and families are central to research planning at the **Center for Effective Collaboration and Practice** (CECP). A project of the **American Institutes for Research**, CECP is funded under a cooperative agreement with the federal **Office of Special Education Programs** with supplemental funding from the federal **Center for Mental Health Services**. Under the Center's guidance, researchers, practitioners, families, and consumers are involved in efforts to bridge the gap between research and practice. The Center has developed a Family Panel and a Consumer Panel to advise on projects and to review publications. The Family Panel is comprised of leaders of national and state family organizations. The Consumer Panel is comprised of current and prior users of mental health services.

A parent of a child with special health care needs has been actively involved in research at the **Center for Children with Special Needs at Children's Hospital & Regional Medical Center** in Seattle. She serves as a co-investigator on the *Building on Family Strengths* study funded by the Agency for Healthcare Research and Quality. The purpose of this study is to measure the effects of a family-centered intervention on parental self-efficacy to manage their child's chronic illness, ability to involve their child in developmentally appropriate shared care-management, parental coping behavior, parental emotional health, and perceived family quality of life. She co-authored an article with other members of the research team. Published in *Families, Systems, & Health*, the article describes the roles for families in the research process and the strengths and challenges of involving families in research.

**Working collaboratively, develop guidance that will help families make decisions about whether or not to participate in research endeavors, particularly in clinical trials.**

**The Joint Commission** has developed a brochure for patients considering participation in clinical research. Part of the Commission's "Speak Up" Patient Safety Initiative, the brochure explains concerns and suggests questions patients should consider before agreeing to participate in a research study. It is available in English and Spanish.

The Patient and Family Advisory Council at **H. Lee Moffitt Cancer Center & Research Institute**, Tampa, Florida, regularly hosts educational programs for patients and families. One session, entitled "Clinical Trials—Everything You Wanted to Know," is presented by the Center's Associate Center Director for Clinical Investigations. Following the presentation, patients, families, and friends are invited to a lunch with the Patient and Family Advisory Council. (For further information about how the Moffitt Cancer is collaborating with patients and families, see page 146.)



Experience has shown that a number of common misconceptions often prevent patients from participating in a clinical trial. The Patient and Family Advisory Council at **Dana-Farber Cancer Institute** in Boston, in collaboration with **Brigham and Women's Hospital**, **Massachusetts General Hospital**, and **Beth Israel Deaconess Medical Center** has produced an audiovisual program and booklet designed to address these misconceptions. The award-winning video, entitled *Entering a Clinical Trial: Is it Right for You?*, features patients and clinicians who explain the purpose and nature of clinical trials and offer suggestions to help patients decide whether or not to enroll in a study. The booklet is available in English and Spanish.

### 3. Develop collaborative projects to investigate outcome measures, study designs, and research and evaluation processes for patient- and family-centered care.

Investigators at the **Orelena Hawks Puckett Institute** recently completed several research syntheses and meta-analyses of family-centered studies conducted by more than 20 research teams in eight different countries. These reports include descriptions of how family-centered practices have been measured, the outcomes that were the focus of investigation, and how studies using different research designs can be compared and contrasted. The studies included more than 12,000 parents and other caregivers, and they were conducted in hospitals, private practices, rehabilitation centers, early childhood intervention programs, family support programs, as well as other settings.

Findings from the research syntheses showed which outcomes were directly or indirectly related to family-centered care. Family-centered practices were most strongly related to outcomes that were the focus of professional helpgiving practices, and were indirectly related to outcomes not the direct focus of helpgiving. The outcomes examined in the studies reviewed by the Puckett Institute investigators included satisfaction with practitioner and program practices, personal control beliefs, parent and family well-being, parenting confidence and competence, family quality of life, and child behavior and functioning.

Collaborative efforts are now common both nationally and internationally. The Puckett Institute in collaboration with other investigators in the United States and abroad continues to add to the knowledge base regarding the makeup of family-centered practices and the outcomes that can and cannot be expected to be affected by family-centered care.

### 4. Increased public and private funding for patient- and family-centered research initiatives.

The **National Institute on Disability and Rehabilitation Research** has funded a number of research and training centers in children's mental health. One of these, the **Portland State Research and Training Center** in Oregon is dedicated to collaboration with family members, service providers, policymakers, and other concerned parties to promote community-based, culturally-competent, family-centered services for families and children. The Center's activities build on family strengths by supporting research in areas such as cultural competence, values clarification related to family partnerships at all levels of the health care system, and leadership development. The Center provides research assistance and technical support to communities receiving grants under the Center for Mental Health Services' Comprehensive Mental Health Services for Children and their Families.

The **Leadership Education in Neurodevelopmental and Related Disabilities** (LEND) fellowship program at **The Children's Hospital of Philadelphia** (CHOP) includes a fellowship for a family member caring for a child with special needs. As part of the fellowship, the family fellow is expected to complete a Research Leadership Project over the course of the year. The project must be a collaboration between two or more individuals, preferably individuals from at least two professional disciplines. The goal of the research project is for the family fellows to gain experience in conducting research culminating in a product that can be disseminated professionally through publications or presentations.

The CHOP LEND program has had two cohorts that included a Family Fellow. Each fellow joined an interdisciplinary research team that was exploring parents' perspectives of the Department of Social Work and Family Services' family meetings. One family fellow examined whether parents' perspectives of their experiences in family meetings differed on the basis of their race or ethnicity. The other family fellow explored parents' perspectives on the effectiveness of communication based on different types of locations of family meetings. Both family fellows and the research team were enthusiastic about their collaboration. More significantly, involvement of the family fellows demonstrated to the health care professionals that including family members as advisors and as members of the research team adds value to the research study (see pages 132 and 133 for more information about the LEND program).

The **Agency for Healthcare Research and Quality** (AHRQ) is encouraging research into promoting patient-centered care and using various outcome measures related to it. For example, in December 2006, it announced an RFA titled, *Ambulatory Safety and Quality: Enabling Patient-Centered Care through Health IT*. Instructions in the RFA highlighted the expectations that projects:



[I]nvestigate novel methods or evaluate existing strategies for using health IT [Information Technology] to create or enhance patient-centered models of care in the ambulatory setting. Applicants are expected to demonstrate how patient-centered care can improve health outcomes, patient safety, and patients' reported experience with care.

The focus of projects to be funded will include one or more of the following: shared decision-making and patient-clinician communication, personal health records, integration of information across transitions in care, and patient self-management of chronic conditions.

The **Medical College of Georgia** is one of the 16 projects funded and will be studying the effectiveness of a patient-centered electronic personal health record on patients with hypertension. Investigators from the Medical College of Georgia are working with Cerner Corporation, the Institute for Family-Centered Care, providers, and patients and families to design and evaluate the personal health record.

The 2003 **President's New Freedom Commission on Mental Health** Final Report recommends that the federal government initiate and sustain a public-private partnership to:

- ◆ Advance knowledge;
- ◆ Disseminate findings; and
- ◆ Recognize those treatments and services that should be considered to be evidence-based.

The research partnership should comprise all stakeholders, including providers, families, and consumers.

## 5. Assure dissemination of research related to patient- and family-centered care.

**Define what patient- and family-centered care and relevant outcomes mean to patients, families, administrators, and health care professionals, and target the analysis and dissemination of findings to specific audiences.**

Single-room facility design is recognized as being supportive of patient- and family-centered care because it promotes dignity, privacy, family presence at the bedside, and confidential communication among patients, families, and providers. The **IDEAS Institute** received funding from **The Commonwealth Fund** to complete a literature review and exploratory study comparing shared rooms versus private rooms in nursing homes. The study, *Exploring the Value of Private Bedrooms in Nursing Homes*, reports that older adults and their families greatly prefer private rooms. The results suggest that private rooms are associated with lower rates of anxiety, aggression, and infection rates. Because of the concerns over construction and operational costs, the investigators discuss

findings related to costs. Information about this study is available at the websites of the IDEAS Institute and The Commonwealth Fund. The investigators recently published an article in *The Gerontologist* summarizing the study and results.

## Promote and request journal article submissions about patient- and family-centered care and related research.

### Encourage every journal to have at least two patients or family members on its editorial board.

*Pediatric Nursing* invited Deborah Dokken, a parent advocate, to be the guest editor for a six-article series on family roles in family-centered care. The articles are being published in the "Family Matters" column, which for the past 10 years has highlighted patient- and family-centered concepts and initiatives.

## 6. Encourage the adoption of evidence-based practice related to patient- and family-centered care.

Since its founding in 1996, the **Association of Cancer Online Resources** (ACOR) has pioneered patient-to-patient online communities. Several years ago, ACOR received a grant from the **Health e-Technologies Initiative**, a national program funded by the **Robert Wood Johnson Foundation** to study how and why Internet resources for peer-to-peer support are used by cancer patients.

In 2005, the team published baseline data showing how subscribers use cancer-related mailing lists as well as their initial reactions to such lists. In 2007, they published the results of an analysis of the types and characteristics of support offered on cancer-related mailing lists. A significant finding was that informational support was found to be more important than emotional support in the listservs studied. Technical information and explicit advice about how to communicate with health care providers were found to be the most common topics.

**The Commonwealth Fund** requested that the **National Center for Cultural Competence** develop a report on the evidence-base for cultural and linguistic competency in health care. The report, published in October 2006, reviews the literature and documents the outcomes, including health, mental health, and cost benefits. The authors also note the gaps in the knowledge base and make recommendations reflecting the need for patients, families, and other stakeholders to be involved in research, program planning and implementation, and policymaking.

## FOR FURTHER INFORMATION

- For the most recent references on this topic, please see the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>
- The American Association of Orthopedic Surgeon's Communications Program is described at <http://www3.aaos.org/education/csmp/index.cfm>.
- Information about the Institute for Healthcare Communication can be found at <http://www.healthcarecomm.org>.
- The Clinical Scholar Model at the Center for Nursing Research and Quality Outcomes and the Nursing Research Council at Maine Medical Center can be accessed at [http://www.mmc.org/workfiles/mmc\\_nursing/ClinicalScholarModel.pdf](http://www.mmc.org/workfiles/mmc_nursing/ClinicalScholarModel.pdf).
- The article discussing the evidence base for patient-centered care and patient engagement is Coulter, A., & Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients. *BMJ*, 335, 24–27.
- The Senior Empowerment and Advocacy in Patient Safety Survey is discussed in the following article: Elder N. C., Regan S. L., Pallerla H., et al. (2007). Development of an instrument to measure seniors' patient safety health beliefs: The Seniors Empowerment and Advocacy in Patient Safety (SEAPS) survey. *Patient Education and Counseling*, 69(1-3), 100-7.
- Information about the mission and research, evaluation, and quality improvement activities of mental health consumer-led organization, Consumer Quality Initiatives (CQI), can be found at <http://www.cqi-mass.org>.
- Information about Participatory Action Research (PAR) is featured on the website for the Beach Center on Disability at the University of Kansas at [http://www.beachcenter.org/families/partnerships/participatory\\_action\\_research.aspx](http://www.beachcenter.org/families/partnerships/participatory_action_research.aspx).
- Some of Lucile Packard Children's Hospital's family-centered research efforts are described at <http://www.lpch.org/forPatientsVisitors/PatientServices/FamilyCenteredCare/research.html>.
- The following article has recently been published: Wayman, K.W., Yaeger, K. A., Sharek, P. J., Trotter, S., Wise, L., Flora, J., & Halamek, L. P. (2007). Simulation-based medical error disclosure training for pediatric healthcare professionals. *Journal of Healthcare Quality*, 29(4); 12–19.
- The structure and work of the Center for Effective Collaboration and Practice are described at <http://cecp.air.org/center.asp>.
- For more information about families as co-investigators read, Uding, N., Sety, M., & Kieckhefer, G. M. (2007). Family involvement in health care research: The "Building on Family Strengths" case study. *Families, Systems, & Health*, 25(3), 307-322.
- Copies of the Joint Commission's Speak Up Campaign materials and brochures about patient and family participation in research are available at no charge at [http://www.jointcommission.org/PatientSafety/SpeakUp/speak\\_up\\_research\\_studies.htm](http://www.jointcommission.org/PatientSafety/SpeakUp/speak_up_research_studies.htm).
- The Patient and Family Advisory Program for the H. Lee Moffitt Cancer Center and Research Institute is featured on the Center's website at <http://www.moffitt.usf.edu/Site.aspx?spid=80181D9FB4A840E7BA758742545908A1>.
- The booklet and video, *Entering a Clinical Trial: Is it Right for You?*, can be downloaded from Dana-Farber's website at <http://www.dana-farber.org/res/clinical/trials-info/default.html>.
- Articles written by investigators at the Puckett Institute about research of family-centered care include:
  - ◆ Dempsey, I., & Dunst, C. J. (2004). Helppgiving styles and parent empowerment in families with a young child with a disability. *Journal of Intellectual and Developmental Disability*, 29, 40-51.
  - ◆ Dunst, C. J., & Dempsey, I. (2007). Family-professional partnerships and parenting competence, confidence, and enjoyment. *International Journal of Disability, Development, and Education*, 54, 305-318.
  - ◆ Dunst, C. J., Hamby, D. W., & Brookfield, J. (2007). Modeling the effects of early childhood intervention variables on parent and family well-being. *Journal of Applied Quantitative Methods*, 2(3), 268-288.
  - ◆ Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2006). Family support program quality and parent, family and child benefits (Winterberry Press Monograph Series). Asheville, NC: Winterberry Press.
  - ◆ Dunst, C. J., Trivette, C. M., & Hamby, D. W. (in press-a). Influences of family-centered practices on child, parent, and family functioning (Winterberry Monograph Series). Asheville, NC: Winterberry Press.
  - ◆ Dunst, C. J., Trivette, C. M., & Hamby, D. W. (in press-b). Meta-analysis of family-centered helppgiving practices research. *Mental Retardation and Developmental Disabilities Research Reviews*.
- The Portland State Research and Training Center in Oregon is described further, and useful links are provided, at <http://www.rtc.pdx.edu/index.php>.
- The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) at The Children's Hospital of Philadelphia is described at <http://www.chop.edu/consumer/jsp/division/generic.jsp?id=79426>.

- The Agency for Health Care Research and Quality (AHRQ) Request for Applications (RFA) cited in the text can be accessed at <http://grants1.nih.gov/grants/guide/rfa-files/RFA-HS-07-007.html#PartII>. Further information about can be found at: <http://www.ahrq.gov>.
- President's New Freedom Commission on Mental Health Final Report, 2003 can be downloaded from <http://www.mentalhealthcommission.gov/reports/reports.htm>.
- To learn more about the IDEAS Institute, visit their website at <http://www.ideasinstitute.org>. Read about their study on private versus shared rooms in nursing homes in Calkins, M. P., & Cassella, C. (2007). Exploring the cost and value of private versus shared bedrooms in nursing homes. *The Gerontologist*, 47(2), 169-183.
- More information about elder care is available on the Commonwealth Fund's website at [http://www.commonwealthfund.org/topics/topics\\_list.htm?attrib\\_id=15316](http://www.commonwealthfund.org/topics/topics_list.htm?attrib_id=15316).
- The *Pediatric Nursing* journal is described at <http://www.pediatricnursing.net/index.html>.
- Association of Cancer Online Resources (ACOR) clearinghouse for online resources providing information, support, and community for cancer patients and families is available at <http://www.acor.org>.
- Articles describing research by the Health e-Technologies Initiative and ACOR advancing the understanding of cancer patient use of online peer support resources can be accessed at the following sites:
  - ◆ Meier, A., Lyons, E. J., Fryman, G., Forlenza, M., & Rimer, B. K. (2007). How cancer survivors provide support on cancer-related internet mailing lists. *Journal of Medical Internet Research* 9(2). Full text available at <http://www.jmir.org/2007/2/e12>.
  - ◆ Rimer, B. K., Lyons, E. J., Ribisl, K. M., Bowling, J. M., Golin, C. E., Forlenza, M. J., et al. (2005). How new subscribers use cancer-related online mailing lists. *Journal of Medical Internet Research*, 7(3). Full text available at <http://www.jmir.org/2005/3/e32>.
- Further information about the Health e-Technologies Initiative research related to the use of technology and interactive applications (i.e., Internet, interactive TV and voice response systems, kiosks, personal digital assistants, CD-ROMs, DVDs) for health behavior change and chronic disease management can be found at <http://www.hetinitiative.org>.
- The National Center for Cultural Competence hosts a website at <http://www11.georgetown.edu/research/gucchd/nccc>. The paper, The Evidence Base for Cultural and Linguistic Competency in Health Care, can be downloaded from the site.

# THE ROLE OF PAYERS AND ACCREDITING AND LICENSING ORGANIZATIONS

### Key recommendations at a glance...

1. Enhance licensing and certification requirements relating to patient- and family-centered skills.
2. Assure that accrediting organizations and those that set standards for health care place a high value on requirements related to patient- and family-centered care, emphasizing the link to health care quality and safety.
3. Provide payers with emerging data on cost benefits of patient- and family-centered care.
4. Assure that payers recognize and expect patient- and family-centered practices in both hospital and ambulatory settings as requirements for reimbursement.
5. Incorporate patient- and family-centered care requirements (e.g., Consumer Assessment of Healthcare Providers and Systems [CAHPS] patient experience-of-care surveys, patient and family involvement in quality improvement activities, and the creation of patient and family advisory councils) into pay-for-performance standards.

The health care system extends beyond hospitals, ambulatory care settings, health care providers, and administrators. Licensing organizations, accrediting organizations, and payers also play key roles in shaping the system.

These groups can encourage and support partnerships with patients and families that enhance quality, safety, and the experience of care. Following are some recommended approaches.



## 1. Enhance licensing and certification requirements relating to patient- and family-centered skills.

The following professional organizations have begun to recognize patient- and family-centered concepts in their standards:

- ◆ The physician competencies established by the **Accreditation Council for Graduate Medical Education (ACGME)** required for accreditation of residency training programs serves as a model for other health professions (see page 50).
- ◆ The **American Board of Internal Medicine** has incorporated patient experience-of-care surveys into its recertification process for internists. Internists can submit a subset of the *Consumer Assessment of Healthcare Providers and Systems (CAHPS)* survey question data from their patients to comply with Board recertification requirements.
- ◆ The **American Board of Medical Specialties** is incorporating CAHPS surveys and peer-to-peer interaction data into the recertification processes for a broad range of medical specialties.

Include patients and families on licensing and certification boards.

Obtain patient and family input in determining standards for patient- and family-centered skills in every health care profession.

Include patient- and family-centered content in certification tests.

Require continuing education related to patient- and family-centered care and to partnerships with patients and families as a condition for licensure.

## 2. Assure that accrediting organizations and those that set standards for health care place a high value on requirements related to patient- and family-centered care, emphasizing the link to health care quality and safety.

Encourage The Joint Commission to continue to support patient- and family-centered care and to develop criteria by which it can be measured.

The Patient and Family Advisory Group, established in 2006, advises the **Joint Commission International Center for Patient Safety**, **The Joint Commission**, and the **Joint Commission Resources (JCR)/Joint Commission International (JCI)** regarding current and evolving patient safety issues. The Advisory Group also provides advice and guidance on the development of patient safety solutions developed as part of The Joint Commission's and JCI's role as the **World Health Organization's Collaborating Centre for Patient Safety Solutions** (see page 114 for further information about this advisory group).

In 2006, **The Joint Commission** published a book titled, *Patients as Partners: How to Involve Patients and Families in Their Own Care*. Replete with guidelines, suggestions, and examples from a variety of settings, this book is designed to help health care providers and organizations with best practices benchmarking and survey preparations. This resource is designed to support the development of a culture of safety in health care settings and to support partnerships with patients and families, using the following approaches:

- ◆ Strategies for developing provider/patient and family partnerships;
- ◆ Guidance for targeted patient/family education programs; and
- ◆ Attention to the health literacy and education needs of varied populations.



In 2007, The Joint Commission made the active involvement of patients in their care a patient safety strategy (see page 121 for further information). Later this same year, The Joint Commission published a resource titled, *Patients as Partners: Toolkit for Implementing National Patient Safety Goal 13*, to guide organizations in developing meaningful participation in care and safety.

Encourage the National Quality Forum to endorse standards/asures for patient- and family-centered care.

The **National Quality Forum (NQF)** is a nonprofit organization created to improve health care through endorsement of consensus-based national standards for the measurement and public reporting of health care performance data. In 2006, the *NQF-Endorsed™ Definition and Framework for Measuring Care Coordination* was published. The standards outlined in this document speak clearly to the need for the engagement of the patient and family in care coordination, planning, and decision-making. Highlights from the document are shown below:

- ◆ Care coordination is a function that helps ensure that the patient's needs and preferences for health services and information sharing across people, functions, and sites are met over time.
- ◆ Communication—available to all team members, including the patient and family.
- ◆ The plan of care is jointly created and managed by the patient/family and a team coordinated by the health care home.

- ◆ Jointly with the patient/family, care coordination assesses progress toward goals and refines the plan of care as needed to accommodate new information or circumstances.
- ◆ Patient education about his or her condition, treatments and medications, patient self-management support, and financial resources are necessary components of a joint plan of care.
- ◆ The plan of care includes community and non-clinical services, as well as traditional healthcare services that respond to a patient's needs and preferences and contribute to achieving the patient's goals.
- ◆ HIPAA-compliant communications with patients, families, and providers should occur as needed through various communications methodologies. Use of structured asynchronous communications such as e-mail or web-messaging, as well as traditional methods, should be encouraged and appropriately reimbursed.
- ◆ Patient and/or family surveys of their experience with the processes and outcomes of care coordination efforts are essential to measure the safety, effectiveness, efficiency, and timeliness of care coordination in an equitable fashion.

Involving patients and families in designing, implementing, and evaluating care coordination systems is consistent with the concepts and emerging best practices discussed in this report. (See page 67 for information about NQF Safe Practices for Better Healthcare that encourage the participation of patients and families on quality and safety committees.)

#### Enhance standards delineating how hospitals and ambulatory settings can involve patients and families in policy and program development, quality improvement, patient safety initiatives, and health care redesign.

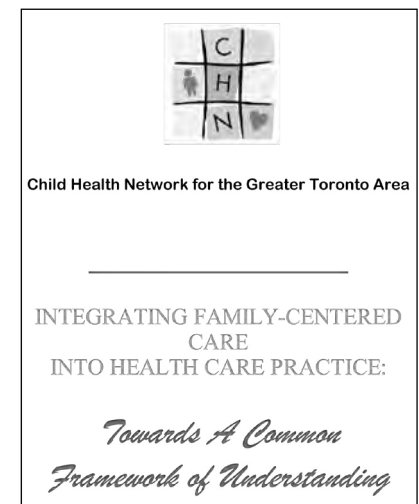
Patient-centered care has been a major priority for the **National Health Service (NHS)** in the United Kingdom since 2000. The NHS has mandated that hospitals and primary care clinics demonstrate that they are collaborating with patients and carers (the British term for “families”) as a condition of payment for services delivered.

In 2006, the NHS proposed further change in the health care system, from a system based on patient passivity to a system that embraces patients as entrepreneurs. Current reforms are focused on transferring decision-making from the national level to the local practice level, with the patient at the core. Evidence shows that involving participants in decision-making and building meaningful relationships with providers at the community level result in improved health outcomes. The active engagement of the patient is occurring at two levels—the clinical level and the quality improvement level.

An example of engagement at the clinical level is the **Expert Patient Programme**, a patient-led chronic illness self-management program. Its success is the result of the patient driving the health care system, with the provider seen as one of many team members.

An example of engagement in quality improvement is the **Patients Accelerating Change (PAC)** program, jointly supported by the **National Clinical Governance Support Team** and the **Picker Institute Europe**. PAC provides resource materials and training to prepare patients to participate in clinical governance and other quality improvement activities. Since PAC was launched in 2003, patients and carers have been involved in many innovative changes and improvement efforts.

The **Child Health Network for the Greater Toronto Area (CHN)** was created under a mandate from the Ministry of Health of Ontario to form a regionalized network of hospitals, community access centers that provide care to homes and schools, and providers. The network's goal is to assure the delivery of “high-quality, accessible, family-centered care for mothers, newborns, children and youth.” To guide its efforts, network leaders developed an educational and collaborative process to develop standards for family-centered practice to use as benchmarks and to inspire change and improvement. Families and representatives from the Network's hospitals and Community Care Access Centres participated in the development of these standards. The standards were published in 2003 and include a statement about the benefits of family-centered care, “Enhancing awareness of the fact that FCC is not about spending more money, time and energy to achieve something ‘new’ but rather, it is about integrating FCC principles into everyday practice in ways that will contribute to reducing workloads, saving money, time and energy (p.14).”



The Network's strategic operating plan for 2007 is guided by the following values:

- ◆ **FAMILY-CENTERED CARE:** *Enhancement of quality and family-centered care across the Network that is predicated on advancing consistent use of leading practices and standards identified in the CHN's Family-Centered Care document.*
- ◆ **COLLABORATION:** *Strengthening partnerships, interaction, and linkages across the Network.*
- ◆ **EVIDENCE-BASED PRACTICE AND ADVICE:** *Building on ongoing efforts to enhance quality improvement initiatives and knowledge transfer are critical elements in all of the CHN's work.*

Progress has been made in many of the Network's maternity and pediatric programs since the standards were published. Because many of these programs are located in hospitals and facilities where services are shared with adult programs, there is growing recognition that family-centered care must become the standard for patients of all ages. (See pages 28 and 138–139 for how another Canadian region, the Calgary Health Region, is advancing the practice of patient- and family-centered care and partnering with patients and families.)

Assure that The Joint Commission has physician, nurse, administrator, and patient/family surveyors on every survey team.

Establish the expectation that health care senior executives are to meet regularly with patient and family advisors.

Require collection of patient experience data that address the four principles of patient- and family-centered care (dignity/respect, information sharing, participation, and collaboration).

*Patient-Driven Quality*, a new service developed by the **Picker Institute Europe** jointly with **CHKS**, an independent provider of health care information, will enable hospitals in the United Kingdom to analyze data drawn from three sets of indicators—patient-reported experiences, clinical data, and patient-reported outcomes—over time and in particular clinical areas and to assess these indicators against national benchmarks.

While the *Consumer Assessment of Healthcare Providers and Systems*® (CAHPS) and the *Hospital CAHPS* (HCAHPS) surveys capture some of the patient and family perspective, some health care leaders and patient and family advisors saw the need for additional metrics to measure patient- and family-centered practices more specifically.

A set of five questions related to core concepts of patient- and family-centered care was developed through a partnership among staff and patient and family advisors from 12 health systems, a researcher from **Press Ganey**, and the **Institute for Family-Centered Care**. The questions are as follows:

- ◆ Degree to which you and your family were able to participate in decisions about your care?
- ◆ How well staff explained their roles in your care?
- ◆ Degree to which the staff supported your family throughout your health care experience?

- ◆ Degree to which your choices were respected to have family members/friends with you during your care?
- ◆ Degree to which staff respected your family's cultural and spiritual needs?

These questions are now included among Press Ganey custom questions. An organization can choose to use any or all of these questions and benchmark with others. Additional questions are being developed.

Use public service announcements or newspaper advertisements to inform the public about accreditation surveys and opportunities to participate in them.

Provide training for citizens, patients, and families who want to participate in accreditation processes.

### 3. Provide payers with emerging data on cost benefits of patient- and family-centered care.

An article in the February 2007 *American Journal of Managed Care* describes an 18-month study conducted by **Blue Shield of California**. The study involved 756 health maintenance organization members with late-stage illness who had access to the same benefits and provider network. Half the members were blindly assigned to receive usual case management (UCM) and half to receive patient-centered management (PCM). PCM included working with a care manager to develop individual goals based on disease state, treatment options, pain management, and end-of-life decisions. Survival rates were the same for both groups. Results included:

- ◆ Emergency room visits reduced by 30%.
- ◆ Hospital admissions reduced by 38%.
- ◆ Hospital days reduced by 36%.
- ◆ Home care use increased by 22%.
- ◆ Hospice use increased by 62%.
- ◆ \$18,000 cost reduction per patient.
- ◆ Total overall costs for PCM members was 26% less than the total for UCM members.

In addition to studying the cost and utilization data, an independent firm measured patient and family perspective of PCM and found that 98% of the patients or their family members surveyed reported that they thought PCM was a useful service for very ill patients and 86% believed that it improved the patient's quality of life.



#### 4. Assure that payers recognize and expect patient- and family-centered practices in both hospital and ambulatory settings as a requirement for reimbursement.

Several efforts are under way in California to redesign the health care delivery system to improve patient-centered care, to align patient experience improvements with pay-for-performance measures, and to test new measures. The **California Quality Collaborative (CQC)** sponsored by the **Pacific Business Group on Health (PBGH)** and the **California Association of Physician Groups (CAPG)** brings together purchasers, health plans, physician groups, and public health advocates in various health care redesign initiatives.

The *Diabetes and Cardiovascular Care Collaborative* was one of CQC initiatives. When this collaborative ended in 2005, the nine California physician groups and 13 practices that had worked together on redesigning care at the practice level had achieved the following:

- ◆ All groups adapted information systems to make patient information more usable at the point of care.
- ◆ All practices made changes to support patient self-management, such as group visits, scheduling planned care visits, screening for depression, office staff follow-up on patient action plans, and medication adherence.
- ◆ 100% improved in at least one pay-for-performance related measure.
- ◆ 92% of the groups exceeded national benchmarks for at least one measure; 77% exceeded benchmarks for at least two.
- ◆ Together, practices outperformed the state averages for HbA1c and LDL control by 20 percentage points.

CQC recently launched a *Patient Experience Collaborative* that identified 12 changes to improve doctor-patient communication, access to care, and care coordination. The PBGH is planning to spread this work statewide. (See pages 35–39 for further information about collaborating with patients with chronic illness and their families to redesign systems of care at the practice site.)

In June 2007, the **Sorry Works! Coalition**, an advocacy group that encourages disclosure and apologies after adverse events and medical errors, and **Physhield**, a medical malpractice insurer for physicians, announced that they are partnering to provide disclosure training to Physhield’s insured physicians and potential insured physicians.

The President of Physhield stated, “When it comes to medical liability, nothing is more empowering for physicians than the ability to maintain effective communication with patients and their families following adverse events.” (See page 120 for more information about disclosure and apology.)

#### 5. Incorporate patient- and family-centered care requirements (e.g., CAHPS patient experience-of-care surveys, patient and family involvement in quality improvement activities, and the creation of patient and family advisory councils) into pay-for-performance standards.

Offer incentives, such as increased reimbursement or other recognition, for doctors/practices/providers who demonstrate patient- and family-centered care.

Encourage the Centers for Medicare & Medicaid Services (CMS) to require Quality Improvement Organizations (QIOs) to provide training and technical assistance for improvement efforts related to patient- and family-centered care and to creating partnerships with patients and families.

Include the expectation for partnerships with patients and families in the quality improvement, safety initiatives, and health care redesign sections of the CMS Conditions of Participation for hospital and ambulatory programs.

Link federal reimbursement for services to organizational requirements for patient and family advisory committees and to other organizational evidence of a commitment to partnerships.

Include the expectation for partnerships with patients and families at the clinical level, including patient perception of access to useful information and support, in the CMS Conditions of Participation for hospital and ambulatory programs.

Encourage health plans to limit their networks to providers who demonstrate a commitment to patient- and family-centered care.



## FOR FURTHER INFORMATION...

- For the most recent references on this topic, please see the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>
- Information about the ACGME Outcome Project and required resident physician competencies are described at <http://www.acgme.org/Outcome>.
- Activities and the roster for the Patient and Family Advisory Group for the Joint Commission International Center for Patient Safety are available at <http://www.jcipatientsafety.org/22775>.
- To obtain a copy of *Patients as Partners: How to Involve Patients and Families in Their Own Care* and *Patients as Partners: Toolkit for Implementing National Patient Safety Goal #13*, order from Joint Commission Resources at <http://www.jcrinc.com/25372>.
- Projects of the National Quality Forum (NQF) are described at <http://www.qualityforum.org>. The *NQF-Endorsed TM Definition and Framework for Measuring Care Coordination* document can be downloaded from [http://216.122.138.39/pdf/reports/ambulatory\\_endorsed\\_definition.pdf](http://216.122.138.39/pdf/reports/ambulatory_endorsed_definition.pdf).
- The National Health Service (NHS) website with the byline, *Putting you first... NHS Choices is the new service that helps you to make the most of your health and get the best out of the NHS* can be found at <http://www.nhs.uk/Pages/index.html>.
- A new nonprofit company has been organized for the Expert Patient Programme, a patient-led chronic illness self-management program in the United Kingdom. Information is available at <http://www.expertpatients.co.uk/public/default.aspx>.
- Picker Institute Europe activities and resources are listed at <http://www.pickereurope.org>. Links to Patients Accelerating Change and their new initiative, *Patient Driven Quality*, can be found on this site as well.
- The Child Health Network for the Greater Toronto Area and its family-centered care initiatives are described at <http://www.childhealthnetwork.com/chn/family.htm>. The standards for family-centered care can be downloaded from <http://www.childhealthnetwork.com/chn/FamilyCenteredCare.htm>.
- Information about the Agency for Healthcare Research and Quality's CAHPS program for patient experience data can be found at <https://www.cahps.ahrq.gov/default.asp>.
- The article, "Patient-Centered Management of Complex Patients Can Reduce Costs Without Shortening Life," from the February 2007 issue of the *American Journal of Managed Care* is available for download at <http://www.ajmc.com/ViewIssue.cfm?Menu=1&ID=2076>.
- The California Quality Collaborative supported by the Pacific Business Group on Health and the California Association of Physician Groups is featured at <http://www.breakthroughcare.org>.
- The new Partnership between Physhield and Sorry Works! Coalition is described at [http://www.physhield.com/in\\_the\\_news/physhield\\_and\\_sorry\\_works-announce\\_partnership.html](http://www.physhield.com/in_the_news/physhield_and_sorry_works-announce_partnership.html).

# THE ROLE OF PROFESSIONAL ASSOCIATIONS AND DISEASE-SPECIFIC ORGANIZATIONS

### Key recommendations at a glance...

1. Assure that key personnel at professional associations and disease-specific organizations understand the importance of patient and family partnerships to their organizations and within the broader health care system.
2. Use the organizational/association capacities to promote the understanding and application of patient- and family-centered care among members.
3. Develop practice guidelines for the implementation of patient- and family-centered care and partnerships.
4. Use association/organizational resources to promote and develop models of patient- and family-centered care in practice.
5. Develop tools, strategies, and support resources to encourage the implementation of patient- and family-centered approaches to care.
6. Develop pilot projects to promote patient- and family-centered care.
7. Use partnerships as part of research, training, and other projects promoting patient- and family-centered care.

Professional associations have the ability to influence health care providers' views of best practice and to begin to change the culture of care from this vantage point. Disease-specific organizations connect with certain providers and also with large numbers of individuals and families affected by the disease who can offer critical input and receive tremendous personal benefit from partnerships with health care providers. These associations and organizations can develop practice

standards, toolkits, and pilot projects. They can collect, analyze, and disseminate data important to developing and sustaining partnerships.

The following strategies suggest approaches that both professional associations and disease-specific organizations can implement to facilitate the practice of patient- and family-centered care and the creation of partnerships with patients and families.

1. **Assure that key personnel at professional associations and disease-specific organizations understand the importance of patient and family partnerships to their organizations and within the broader health care system.**

Educate board and staff members of associations and organizations regarding both the importance and the practical implications of patient- and family-centered care.

Assure that these organizations and associations include members who are patients and families in governance and on key committees.

The **American Academy of Pediatrics** (AAP) Section on Home Care had experience working with families in developing formal guidelines. Section members found the experience beneficial and explored strategies to formalize parent involvement in their work.

In 2006, the formation of a Parent Advisory Group (PAG) was approved by the American Academy of Pediatrics Section on Home Care. Currently the PAG has five members who are parents or guardians of children with special health care needs and have experience in working with health care professionals to advocate for improved quality and safety in pediatric health care.

The primary intent of the PAG is to partner with the Section on Home Care. A secondary purpose is to serve as a pilot initiative to encourage family/professional partnerships throughout AAP committees, boards, and groups to improve quality and safety, policy development, professional education, and facility design.

The **Cystic Fibrosis Foundation** is actively partnering with individuals and family members in a number of their committees and initiatives:

- ◆ In 2003, an adult with cystic fibrosis (CF) and a parent of a child with CF were added to the Cystic Fibrosis Foundation's Education Committee. This group identifies and reviews CF-related patient and family resources.
- ◆ Since 2004, an individual with CF has served as a member on the CF Foundation's Quality Improvement Initiative Strategic Planning Advisory Committee and has assisted with efforts to release outcome data for all CF Care Centers.
- ◆ An individual with CF and a parent representative co-chair a Foundation Task Force that is focused on empowering members of the CF community to become involved in quality improvement initiatives at their local CF Care Centers.
- ◆ In 2007, as the CF medical community identifies the national standards of care for infants with CF diagnosed through newborn screening, parents will be included in the review of the literature, discussions, and writing of the final documents disseminated to the CF community.

2. **Use the organizational/association capacities to promote the understanding and application of patient- and family-centered care among members.**

Develop position papers related to patient- and family-centered care and partnerships.

Four membership organizations, representing the majority of primary care providers in the United States recently released, "Joint Principles of the Patient-Centered Medical Home." The **American Academy of Family Physicians** (AAFP), the **American Academy of Pediatrics** (AAP), the **American College of Physicians** (ACP) and the **American Osteopathic Association** (AOA) have jointly spoken out on the importance of the medical home concept and the need to put it into practice more broadly.

These organizations support the concept of a patient-centered medical home because of their belief that it will strengthen partnerships between providers and patients/families, improve the health of patients, and improve the health care system by providing comprehensive, coordinated care, increasing efficiency and quality, and decreasing both risk and cost.

The consensus statement stipulates that, "patients and families participate in quality improvement activities at the practice level." In describing the experience of care, "patients participate in decision-making and feedback is regularly sought to ensure patients' expectations are being met."

3. **Develop practice guidelines for the implementation of patient- and family-centered care and partnerships.**

Develop position papers related to patient- and family-centered care and partnerships.

The **American College of Critical Care Medicine** and the **Society of Critical Care Medicine** convened a joint task force that recently published clinical care guidelines for supporting families in patient-centered intensive care settings.

In a February 2007 article in *Critical Care Medicine*, the task force defines evidence-based practice related to the following aspects of patient- and family-centered care in the intensive care unit: family presence, participation in rounds, presence during resuscitation, improved and more frequent communication, environmental considerations, joint decision-making, family support, spiritual support, cultural competency, and supporting staff in partnering with patients, families, and others.

In addition to offering practical recommendations in these aspects of family-centered care, the guidelines emphasize that embracing the family as a central part of the critical care team is essential for supporting the “timely restoration of health or [the] optimization of the dying process for critically ill patients.”\*

Several recent publications articulate best practice and define standards for family-centered approaches:

- ◆ In 2003, the **Society of Pediatric Nurses** and the **American Nurses Association** (SPN/ANA) published *Family-Centered Care: Putting It into Action*, an evidence-based practice manual for pediatric nurses.
- ◆ Another 2003 publication, the SPN/ANA *Scope and Standards of Pediatric Nursing Practice*, sets forth the standards for pediatric nursing. This document includes family-centered care both as the context for care and as a standard of practice. The upcoming edition of the standards, currently in revision, will be a collaboration among the Society of Pediatric Nursing, the American Nurses Association, and **National Association of Pediatric Nurse Practitioners** (NAPNAP).
- ◆ NAPNAP’s brief document titled, “Scope and Standards of Practice: Pediatric Nurse Practitioner,” includes the following two statements stating a direct expectation of family-centered care:
  - ▼ Formulate a holistic, culturally-sensitive, family-centered plan of care in collaboration with the child and family as active participants.
  - ▼ Involve family/child in decision-making regarding plan of care and responsibilities.

Develop certification or accreditation processes directly related to or incorporating concepts, principles, and application of patient- and family-centered care and partnerships.

#### 4. Use association/organizational resources to promote and develop models of patient- and family-centered care in practice.

Offer incentives, awards, and other recognition for innovations in patient- and family-centered care and for exemplary partnerships.

\* Accessed 3/10/07 on p. 616 of the article “Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005” at <http://www.sscm.org/NR/rdonlyres/DE862386-5B65-4DDF-99A2-CCCD31782322/0/PFGuideline.pdf>.

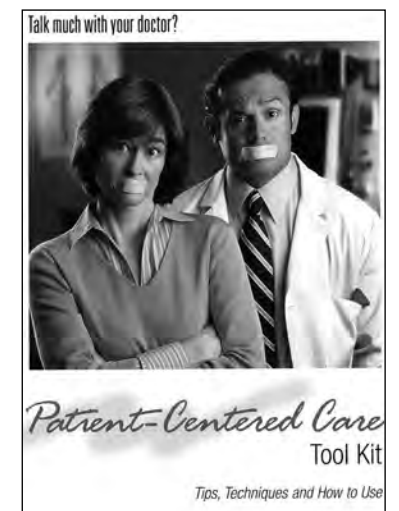
In 2004, the **Society of Critical Care Medicine** established an annual Family-Centered Care Award.

- ◆ This award recognizes innovative efforts to improve care for critically ill and injured patients, their families, and others chosen by the patient. Award criteria include the following:
  - ▼ Project linked to direct patient care.
  - ▼ Moves the field forward and raises the standard for family-centered care.
  - ▼ Demonstrates innovation and provides models for emulation.
  - ▼ Evidences interdisciplinary efforts to improve care inclusive of families in the ICU.
  - ▼ Provides comprehensive services.
  - ▼ Fosters support for families of critically ill patients in ways that are meaningful to the family.
  - ▼ Includes the family in efforts to provide care to critically ill patients during their ICU stay, inclusive of end-of-life care.
  - ▼ Provides data for evaluation of effectiveness.

#### 5. Develop tools, strategies, and support resources to encourage the implementation of patient- and family-centered approaches to care.

The **American Academy of Orthopaedic Surgeons** has developed a toolkit for a campaign to educate both its members and the public in principles and practices of patient-centered care:

- ◆ The Academy’s patient-centered care initiative “Getting Better Together” calls for partnerships among orthopaedic surgeons, patients, and families to ensure that patients and families are respected, well-informed, and actively involved in decision-making regarding their orthopaedic care.
- ◆ The Academy is developing resources and tools to help its members better understand and implement patient-centered care. A letter was sent to members inviting them to show commitment to patient-centered care by signing a pledge to provide this approach to care routinely. Each member signing this pledge will be listed on the Academy’s website and will receive a certificate that can be displayed in his or her waiting room or office.





- ◆ The Academy has also developed a toolkit that members can use to educate patients and family members about patient-centered care. The outreach theme is “Talk much with your doctor?” The kit includes a short film and samples of public service announcement print, radio, postcard, and poster information and PowerPoint presentations. Instructions and guidance on using these toolkit materials in the community are provided (see page 11 for further information about AAOS activities).

The **National Association of Emergency Medical Technicians (NAEMT)** continues its efforts to further the practice of patient- and family-centered care.

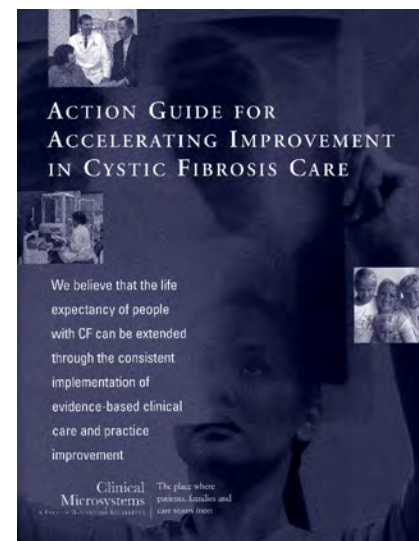
- ◆ In 2006, the Board of Directors (NAEMT), passed a resolution to ensure that family-centered care will be included in all NAEMT’s educational programs. The Prehospital Trauma Life Support, Advanced Medical Life Support for adults, and Emergency Pediatric Care courses will all include family-centered concepts, skills, and teaching strategies.

This Board resolution enables NAEMT to build on their experience in advancing the practice of family-centered pediatric emergency care and apply successful strategies and lessons learned to building a patient- and family-centered system of care for adult patients and their families.

The **Cystic Fibrosis Foundation** has developed a number of useful tools related to advancing the practice of patient- and family-centered care and quality improvement.

The Foundation’s *Action Guide for Accelerating Improvement in Cystic Fibrosis Care* has been disseminated to all accredited CF care centers across the United States. The guide is intended to help CF center staff members, and individuals with CF and their families, partner together to evaluate and improve how well their CF care center functions. The guide provides a framework for patient and family involvement and includes practical tools, forms, a DVD, and step-by-step processes to improve care and satisfaction and to build partnerships between staff and people with CF and their families.

The CF Foundation has also created a *Quality Improvement Toolkit* designed to be used by patients, family members, and providers. The on-line toolkit focuses on the CF Foundation’s seven goals for improving health care, which include enhanced health measures, decision-making support, access, and patient and family partnerships with the health care team. The toolkit addresses creating networks, developing an advisory group, and linking with health care center and hospital administration, and offers practical tips for building successful partnerships. The toolkit also includes several webcasts (see page 104 for further information about the CF Foundation).



## 6. Develop pilot projects to promote patient- and family-centered care.

As efforts move forward to redesign and improve primary care in the United States, the opportunity to create pilot projects that exemplify partnerships in the planning, implementation, and evaluation of the medical home for adult patients has become timely.

Measurement of outcomes, costs, and perceptions of this collaborative, coordinated care will be important to advancing the practice of and payment for patient- and family-centered primary care (see page 105 for further information about the medical home).

## 7. Use partnerships as part of research, training, and other projects promoting patient- and family-centered care.

The **Mental Health Association of Orange County, New York** and the **Center for Mental Health Services Research at the University of Massachusetts Medical School** worked collaboratively on a federally-funded, family-centered intervention project for the **Substance Abuse and Mental Health Services Administration**. A parent participated on the research team.

The research evaluated the effectiveness of the *Invisible Children’s Project*, a home-based, family-centered case management service for parents who are mentally ill and their children.

A family study methodology was used to examine multiple family outcomes—including hospitalization, employment, housing status, social support, children’s school attendance, custody status, and parenting and system outcomes such as cost effectiveness. Study conclusions support a family-centered approach to mental health case management services and offer recommendations for implementing such a service.

## FOR FURTHER INFORMATION . . .

- For the most recent references on this topic, please see the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>
- A profile on the CF Foundation's partnerships with patients and families is featured at [www.familycenteredcare.org/profiles/prof-cysticfibrosis.html](http://www.familycenteredcare.org/profiles/prof-cysticfibrosis.html).
- Cystic Fibrosis Foundation's Quality Improvement Toolkit is featured at [www.cff.org/LivingWithCF/QualityImprovement](http://www.cff.org/LivingWithCF/QualityImprovement). To obtain a copy of the Action Guide, call 1-800-FIGHTCF.
- For the "Joint Principles of the Patient-Centered Medical Home" press release and guiding principles, go to [www.acponline.org](http://www.acponline.org).
- The Society for Critical Care Medicine's Family-Centered Care award and the innovative projects it has recognized are displayed at <http://www.sccm.org/Membership/Awards/Pages/Family-CenteredOverview.aspx>.
- The upcoming edition of the *Scope and Standards of Pediatric Nursing Practice* is available at [www.pedsnurses.org](http://www.pedsnurses.org).
- To download *Scope and Standards of Practice: Pediatric Nurse Practitioner*, go to [www.napnap.org/Docs/FinalScope2-25.pdf](http://www.napnap.org/Docs/FinalScope2-25.pdf).
- For more information about the American Academy of Orthopedic Surgeons' Patient-Centered Care initiative, visit [http://orthoinfo.aaos.org/pcc/Bulletin\\_0805\\_PCC.pdf](http://orthoinfo.aaos.org/pcc/Bulletin_0805_PCC.pdf).
- The Invisible Children's Project: [www.nmha.org/children/invisibleChildrensProject.pdf](http://www.nmha.org/children/invisibleChildrensProject.pdf).
- Resources related to the Invisible Children's Project for the Mental Health Association of Orange County, NY, and the Center for Mental Health Services Research at the University of Massachusetts Medical School: <https://secured.nmha.org/children/invisibleresources.cfm>.

# CREATING PARTNERSHIPS WITHIN QUALITY IMPROVEMENT AND PATIENT SAFETY ORGANIZATIONS

### Key recommendations at a glance...

1. Involve patients and families in the planning and implementation of patient safety and quality improvement programs.
2. Encourage organizations to network and develop partnerships with patients and family members in safety and QI initiatives.
3. Promote initiatives to engage patients and families in safety and quality improvement efforts at the institutional level.
4. Provide education and training for administrative leaders and frontline staff and physicians on partnering with patients and families in safety and quality improvement initiatives.
5. Prepare patients, families, and providers to partner at the clinical level to assure safe care.
6. Develop public awareness programs to broaden understanding of patient safety and quality improvement efforts and of the key roles for patients and families in such efforts.

*“Invite patients and families to share their stories as one way to spark improvement.”*

A Participant at the Expert Panel Meeting on  
Patient and Family Partnerships, June 2006

Safety, medical errors, and quality of care are among key concerns for many health care consumers. Traditionally, these realms have been kept somewhat hidden from the public. Developing partnerships in these arenas can demystify these concerns, benefit safety and quality improvement (QI) efforts, and bring the experience and expertise of patients and

families to address some of the health care system’s most intractable problems.

The following recommendations address ways in which quality improvement and patient safety organizations can partner with patients and families to further safety and QI efforts.

## 1. Involve patients and families in the planning and implementation of patient safety and quality improvement programs.

Partnerships with patients and families are becoming increasingly important to the work of the **Institute for Healthcare Improvement (IHI)**, as illustrated by the following recent developments:

- ◆ A Senior Vice President position has been created with dedicated responsibility for leadership of IHI efforts to advance the practice of patient- and family-centered care and foster the development of partnerships with patients and families, linking them with IHI quality and safety endeavors.
- ◆ A Patient- and Family-Centered Care Community of Interest has been created to foster dialogue and the sharing of information.
- ◆ Patient and family faculty made presentations at the most recent IHI National Forum on Quality Improvement in Health Care and IHI's Office Practice Summit meetings. More than 20 scholarships for patients and families to attend the Forum were provided.
- ◆ Patient and family faculty have been appointed to the faculty teams for both the *Transforming Care at the Bedside* and the *New Health Partnerships* strategic initiatives. In addition, all participating teams in the New Health Partnerships project have recruited patient and family members as active participants on improvement teams.
- ◆ More than 120 organizations participated in a web-based educational program on partnering with patients and families in quality improvement hosted by IHI and **Cincinnati Children's Hospital Medical Center**.

The **National Patient Safety Foundation (NPSF)**, since its inception, has had patient and consumer representatives on its Board and has insisted on the inclusion of the patient and family perspective in all of its work. Its Patient and Family Advisory Council was the first of its kind and authored the seminal white paper, *Patients and Families in Patient Safety: Nothing About Me Without Me*. Its recently revised Board structure has signaled its further commitment to patient and family work by moving from having an advisory council to having an established Patient and Family Committee of the Board, which is focused on the continued development of patient, family, and community programs.

In 2007, the Patient and Family Program Committee developed and enhanced the patient and family portion of the NPSF's website and continues to further build upon educational outreach to patient and families. As part of the newly designed website, the Committee created a web-based patient and family discussion forum, providing a space for patients and family members to connect

with one another, share resources, and find information. The Committee is also developing a Community Patient Safety Education and Awareness Pilot program, designed to connect community members with the work NPSF is already doing with their Stand Up for Patient Safety member hospitals and to further enhance the patient-family-provider relationship by delivering critical tools and resources into the hands of the patients and their families.

NPSF's Annual *National Patient Safety Congress* has always had a patient and family plenary and a focus in its breakout tracks on strategies and approaches for effective partnering between patients and providers. NPSF offers patient and family scholarships for individuals to attend this meeting and to learn more about patient safety and how to become an effective member of the health care team. In May 2007, the Annual National Patient Safety Congress incorporated partnerships in several ways. First, one of the articulated objectives for the Congress was to describe effective and appropriate methods to involve patients and families in efforts to reduce medical error. Second, conference attendees included patients and family members as well as providers. Third, the Congress offered several workshops with patient and family presenters related to patient- and family-centered care and safety.

NPSF presents the Socius Award each year at its Annual National Patient Safety Congress. Socius is the Latin word for "partner." This award is given in recognition of work that promotes positive and effective partnering between patients/families and providers in pursuit of improved patient safety. In 2007, the award went to **North Carolina Children's Hospital** in Chapel Hill for its "Family Alert" program, which offers families in the hospital a way to report an emergency and receive rapid response if they believe their child needs immediate attention. The hospital was singled out not only for the program itself but also for the collaboration with patients and families in planning, implementing, and evaluating the program.

The **Joint Commission International Center for Patient Safety's Patient and Family Advisory Group** is charged with the following responsibilities:

- ◆ Counsel the Center on current and evolving patient safety issues that are of concern to the public. Identify and address issues of importance to patients and families, such as disclosure of medical errors, apology, and support for those who have been harmed by medical errors.
- ◆ Suggest how the Center can best address these issues through leveraging its patient safety activities.
- ◆ Advise the Center as to which approaches to solving patient safety problems are most meaningful to recipients of care.
- ◆ Provide technical assistance in the development of solutions, as well as in their implementation.
- ◆ Provide input and advice in the development of advisories and informative materials directed to consumers regarding their role in patient safety.



- ◆ Provide advice as to how best to incorporate attention to health literacy and elimination of health disparities into safety improvement efforts.
- ◆ Suggest ways that the Center can collaborate with patient safety advocacy groups, health care organizations, and health care professionals to promote patient involvement in their care.
- ◆ Provide counsel as to which avenues (e.g., Internet, libraries, media) for providing patient safety information to the public are most effective.

Additional information about this Patient and Family Advisory Group can be found on page 94.

In 2004, the **World Health Organization** (WHO) launched the *World Alliance for Patient Safety* program, to build international leadership; create coalitions of nations, stakeholders, and individuals; and develop action programs to improve the safety and quality of health care. *Patients for Patient Safety*, a critical component of the Alliance, gives voice to patients around the world who have been harmed by the system. This network of patients and families has partnered with health care professionals, government agencies, and ministries to conduct patient safety workshops in London, San Francisco, Ukraine, Argentina, Spain, and Egypt in the past year. Future workshops are planned for Africa, Europe, and the Western Pacific region.



Patient and family leaders are also serving on the governing bodies for each of the World Alliance's action areas:

- ◆ Global Patient Safety Challenge;
- ◆ Reporting and Learning;
- ◆ Taxonomy for Patient Safety;
- ◆ Research for Patient Safety; and
- ◆ International Safety Solutions.

The project has also developed a powerful DVD, titled *Patient Safety: Patient Voices*, that profiles patient and family leaders from around the world and their collaborative endeavors to build safer health care systems (see page 9 for information about workshops developed for patient and family leaders engaged in patient safety endeavors).

## Create partnerships with patients and families in setting priorities for the Institute for Healthcare Improvement's 5 Million Lives Campaign and other major patient safety initiatives.

The **Institute for Healthcare Improvement's 5 Million Lives Campaign** challenges hospitals to adopt 12 specific changes in care and processes that save lives and reduce patient injuries. It builds on the initial work of the **100,000 Lives Campaign**. More than 3,600 U.S. hospitals are participating in the Campaign.

Patient and family stories are among the resources available through the Campaign. The Getting Boards on Board initiative of the 5 Million Lives Campaign encourages trustees to become involved in accelerating organizational progress toward safe care, to devote at least 25% of the Board's agenda to quality and safety, and to have at least one conversation with a patient or family member of a patient who has experienced significant harm at their organization during the year. "We suggest that the CEO should investigate the story behind an important medical error—interviewing patient, family, and staff. At a minimum, the CEO should tell the story in detail at a board meeting. Ideally, ...[the CEO brings] in the patient, family and staff... This is an effort to put a 'human face' on the data." (James Conway, Senior Vice President, IHI)

## 2. Encourage organizations to network and develop partnerships with patients and family members in safety and QI initiatives.

In 2007, **Consumers Advancing Patient Safety** (CAPS) launched a new membership initiative and online resource. The site links CAPS members with a global network of consumers, health care providers, policymakers, researchers, and others committed to a partnership approach to improving the safety of health care. The CAPS website includes:

- ◆ Community discussion boards to facilitate networking and to provide a space for consumers to dialogue about taking active roles as advocates in shaping regulatory and governmental policy;
- ◆ An area to upload personal correspondence, draft materials, presentations, and working documents members feel would be useful for others in a shared files repository; and
- ◆ A section that includes links to journal articles, news stories, and press announcements that are available on the Internet, as well as websites.

In addition to an extensive resource collection that includes tools, articles, books, reports, and links to other patient safety organizations, the site includes stories that show how individuals have brought about positive change in health care through grassroots activities. One of the principles of CAPS is to foster effective partnerships and collaboration to improve consumer involvement in patient safety initiatives. CAPS members who have experienced medical harm/error are invited to share their stories with CAPS on the site.

NPSF brought the **Partnership for Clear Health Communication (PCHC)** under its umbrella in May 2007 to form the Partnership for Clear Health Communication at the National Patient Safety Foundation. The Partnership's health literacy and communication capabilities will be applied to its work in patient safety to assist patients and families in becoming more informed and involved participants in their health care. One of the signature programs of the Partnership for Clear Health Communication at the National Patient Safety Foundation is Ask Me 3. Ask Me 3 is a program that promotes three essential questions that patients should ask their health care providers in every health care interaction:

- ◆ What is my main problem?
- ◆ What do I need to do?
- ◆ Why is it important for me to do this?

In reflecting on the merging of the two organizations, Diane Pinakiewicz, NPSF President, stated, "PCHC has been at the forefront of health literacy. NPSF looks forward to continuing this important work to improve patient safety and achieve better health outcomes."

Since its beginning more than six years ago, the annual *Canadian Healthcare Safety Symposium* (named the Halifax series, after the city that hosted the initial conference) has earned a reputation across Canada and in international patient safety circles, as helping to create an awareness of patient safety issues and bring new knowledge of safety theories and practices to health-care leaders, clinicians, and planners.

The safety conference held in Calgary in October 2005 was opened with an evening public forum. At the forum, **Calgary Health Region** President and CEO, Jack Davis, stressed that "patient safety is something everyone, including patients and their families, must work together to address." Six families and patients shared their safety-related health care experiences in a video that was presented to the audience of 300 members of the public and conference delegates.

The experiences and observations of these patients and family members sparked a lively discussion where many challenges were identified. One theme that emerged from the discussions was the need for improved communication. A second was to avoid finger pointing when safety issues are identified.

Some speakers praised the progress that has been made in Calgary, while others focused on the work that remains to be done. All agreed that only by continuing to collaborate (patients and families working together with providers) could the Calgary Health Region achieve its goal of creating a "culture of caring."

**Encourage organizations to collaborate in the development of models and materials to enhance patient and family partnerships in safety and quality improvement initiatives.**

The *Walworth County Patient Safety Council* of **Aurora Health Care** based in Milwaukee, Wisconsin, received the 2007 Cheers Award from the **Institute for Safe Medicine Practice**. This award honors individuals and organizations that are leaders in the prevention of medication errors and adverse drug events. Aurora Health Care received funding from the **Agency for Healthcare Research and Quality** to develop an initiative focusing on partnerships to improve patient safety. The patient safety council was created as part of this initiative. It is made up of 11 patients and 12 healthcare providers who are focusing on improving medication safety for seniors in the community. Two toolkits, *How to Develop a Community-Based Partnership Council* and *How to Create an Accurate Medication List in the Outpatient Setting Through a Patient-Centered Approach* were developed as part of this initiative. These resources are available through the **Consumers Advancing Patient Safety** organization.

### 3. Promote initiatives to engage patients and families in safety and quality improvement efforts at the institutional level.

Increasing awareness among health care administrative leaders and trustees that partnering with patients and families is a priority for enhancing and assuring patient safety and the quality of care. A checklist with questions for leaders to ask during an initial self-assessment about the degree to which their organization is partnering with patients and families to enhance safety and quality can be found on page 124.

Involve patients and families as members and leaders of safety and QI initiatives such as:

- ◆ Quality committees;
- ◆ Safety committees;
- ◆ Improvement and safety initiatives;
- ◆ Safety "walk-arounds;"
- ◆ Processes for reviewing data related to QI initiatives;
- ◆ Root-cause analysis;
- ◆ Morbidity and mortality committees;
- ◆ Risk management teams; and
- ◆ Adverse events committees.



**MemorialCare Medical Centers** health system in Southern California has placed leadership responsibility for advancing the practice of patient- and family-centered care with the Vice President for Performance Improvement for the system. A system-wide Patient & Family Experience Valued-Added Team (VAT) reports to this Vice President. The interdisciplinary team includes patient and family advisors. Among its goals is to expand the number of patients and families on committees and design teams. One of the products that has been developed by the VAT is an information folder for patients admitted to the hospital. The information included in the folder encourages patients and families to become involved in care and decision-making and helps them plan for the transition to home or other settings. The folder also includes guidance for how patients and families can help in assuring safety. The VAT is rolling out system-wide training for all staff and is implementing several tactics to support patient- and family-centered care.

Each hospital within the system is appointing a leadership position to facilitate hospital-wide and unit-based patient- and family-centered initiatives and is beginning to recruit and involve patient and family advisors in improvement efforts.

Since 1998, the **Vermont Oxford Network (VON)**, an international organization devoted to improving the quality and safety of newborn intensive care, has sponsored a series of national quality improvement collaboratives (NICQ) to advance the practice of family-centered care within newborn intensive care. The NICQ 2007 collaborative involves multidisciplinary teams from 47 North American hospitals. These teams are working for two years to make measurable improvements in the quality and safety of care for newborns and their families. A major goal is to engage parents as team members. A parent serves on the Advisory Board for the collaborative. At the Fall 2007 meeting, 29 of the 47 teams included parents as members.

Authors from **Catholic Healthcare Partners** in Cincinnati, OH, and the **Risk Management and Patient Safety Institute** in Shelburne, VT, collaborated in the development of the article, "Including Patients in Root Cause and System Failure Analysis: Legal and Psychological Implications." The article includes a comprehensive, practical guide to prepare an organization and patients for this experience.

Convey the expectation that most patient safety and quality teams will include more than one patient or family member (ideally, a team of 8 to 12, would have at least three or four patient/family members).

Use patients and family members who are members of safety and quality improvement teams to interview other patients and families about their concerns for quality and safety (see page 21 for information about patient safety rounds at Dana-Farber Cancer Institute).

Partner with patients and families to develop safe systems for handling the transitions in care.

#### 4. Provide education and training for administrative leaders and frontline staff and physicians on partnering with patients and families in safety and quality improvement initiatives.

The **Institute for Healthcare Improvement (IHI)** has several Learning and Innovation Communities that involve patients and families as faculty and as members of the quality improvement teams. For example, the Community focused on transforming medical/surgical care includes among its faculty a family member of an adult patient who has had orthopedic surgery, and some of the Community's QI teams include patients or family members. Support is provided to assist the teams in learning how to partner with patients and families in improvement efforts (see pages 6, 34, and 141 for more information).

**New Health Partnerships** is a Virtual Learning Community. It consists of nine teams from different institutions participating in a collaborative to further the implementation of collaborative self-management support in ambulatory settings. An expectation was set from the beginning that each team would have at least three patient and family members. Patient and family advisors serve as faculty members for the project (see pages 6, 34, and 39 for more information).

A key part of the learning for these collaboratives is having patients, families, staff, physicians, and administrative leaders acquire skills and experience in working together on QI teams.

The **Arizona Hospital and Healthcare Association (AzHHA)**

has created the **Safe and Sound** initiative to encourage health care providers to involve patients and families in improving patient safety.

Each month a new idea is introduced to physicians and staff. An innovative format is being used to draw attention to this guidance. Bright "Forget Me Not" seed packets are designed for each month of the year with one safety goal being represented each month. A card with suggestions for strategies to follow-through on the safety goal is inserted into each seed packet. Safety goals such as the patient's role in safe medication usage and roles for patients and families on hospital committees are among those included in the first year. The initiative starts in January 2008 and will be evaluated each year. Patients and families participate as chairperson and members along with providers on the committee that developed this program.



Develop and disseminate guidance to administrators, physicians, and staff for acknowledging medical errors and supporting physicians, staff, patients, and families who have experienced error.

The **Sorry Works! Coalition**, an organization of doctors, lawyers, insurers, and patient and family advocates, is dedicated to promoting full disclosure and apologies for medical errors as a “middle-ground solution” in a medical liability crisis. Literature reviews, data, training, and a resource on disclosure and apology are available through this organization, as is information on state laws related to apology.

Sorry Works! is now working with **Physhield**, a medical malpractice insurer for physicians, to provide training to health care professionals. Both organizations participated in a **Joint Commission** educational program in June 2007 to provide physicians and other clinicians tools and guidance to develop policies and practices for effective disclosure (see page 100 for more information about this partnership).

Founded in 2002 by a woman who experienced a serious medical error, the **Medically Induced Trauma Support Services (MITSS)** provides training, resources, and support services to those affected by medical errors and adverse events. MITSS works with patients and families, and clinicians, as well as organizations, in promoting communication and support after a medically induced trauma.

In 2006, MITSS added practicum students from health care graduate programs to its staff. These individuals assist MITSS staff in their work and also gain experience that will benefit them in their careers.

**Develop patient- and family-centered curriculum and resource materials for safety and QI professionals.**

There are opportunities to include educational content on how to partner with patients and families in courses and fellowships for patient safety and quality improvement leaders. The involvement of patient and family faculty in graduate studies and continuing education of these professionals will enrich their understanding of partnerships and how they can enhance safety efforts (see Chapter 4 for further information about engaging patients and families in the education of health care professionals).

**Encourage safety and QI professionals to help with cultural change in their institutions.**

## 5. Prepare patients, families, and providers to partner at the clinical level to assure safe care.

Goal #13 of **The Joint Commission's** 2007 national patient safety goals includes the requirement to “Encourage patients’ active involvement in their own care as a patient safety strategy.” The Joint Commission’s Frequently Asked Questions Sheet on this goal underscores that, “There is an active component of this requirement: not just giving patients/clients/residents permission to ask questions and express concerns and telling them how to do it, but actively *encouraging* their participation.” Solely providing patient education materials to the patient and family is not sufficient to meet this requirement, the document notes. *Patients as Partners: Toolkit for Implementing National Patient Safety Goal 13* has been published by the **Joint Commission Resources** to assist administrators and providers in these efforts.

**Condition H** (for Help), developed at the **University of Pittsburgh Medical Center (UPMC)**, is an innovative approach to involving patients and families in patient safety. Unlike the traditional rapid response procedures such as Condition A (for arrest) or Condition C (for critical), which are called by providers, Condition H is called by patients or families when they believe that immediate medical attention is required. Patients and families were involved in planning and piloting of this new program. UPMC plans to have Condition H operational in all hospitals within its health system by 2008.

## 6. Develop public awareness programs to broaden understanding of patient safety and quality improvement efforts and of the key roles for patients and families in such efforts.

**Develop and provide education to patients and families so that they understand their role in patient safety based on knowledge and information, not fear.**

The **Partnership for Healthcare Excellence**, funded initially by **Blue Cross Blue Shield of Massachusetts** has now become a statewide, broad-based coalition with participants from every segment of the health care community. Members include consumer associations, disease and advocacy organizations, doctors and insurers, business groups, public health advocates and other health care leaders. The Partnership’s goals are:

- ◆ To educate the public about the variations in health care quality;
- ◆ To provide information and tools needed to improve the quality of their own care; and
- ◆ To inspire patients and families to advocate for overall health care system change such as increased use of electronic medical records and e-prescribing.



In October 2007, the Partnership launched a multimedia public education campaign to encourage consumers to become active participants in their health care. In an op-ed article appearing in the *Boston Globe*, Jim Conway, Chair of the Partnership, states "We start, of course, from a position of strength: excellent physicians, hospitals, and other health professionals committed to delivering the best possible care. But some of the most important voices in the conversation have not yet been fully heard. They are patients and their caregivers, and they, as much as providers and institutions, must be fully engaged in improving the quality of care."

**The Joint Commission** and the **Centers for Medicare and Medicaid Services** have developed guidance for patients and families.



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**The Joint Commission**

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**SPEAK UP**

**Facts about Speak Up Initiatives**

In March 2002, The Joint Commission, together with the Centers for Medicare and Medicaid Services (CMS), launched a national campaign to urge patients to take a role in preventing health care errors by becoming active, involved and informed participants on the health care team.

The program features brochures, posters and buttons on a variety of patient safety topics. Speak Up™ encourages the public to:

- Speak up if you have questions or concerns, and if you don't understand, ask again. It's your body and you have a right to know.
- Pay attention to the care you are receiving. Make sure you're getting the right treatments and medications by the right health care professionals. Don't assume anything.
- Educate yourself about your diagnosis, the medical tests you are undergoing, and your treatment plan.
- Ask a trusted family member or friend to be your advocate.
- Know what medications you take and why you take them. Medication errors are the most common health care errors.
- Use a hospital, clinic, surgery center, or other type of health care organization that has undergone a rigorous on-site evaluation against established state-of-the-art quality and safety standards, such as that provided by the Joint Commission.
- Participate in all decisions about your treatment. You are the center of the health care team.

**PULSE of New York**, a nonprofit grassroots organization, is dedicated to improving patient safety and strengthening partnerships among patients and families, health care providers, and community organizations to educate and advocate. PULSE of New York offers training courses for hospitals, health care systems, and community programs that include topics such as "Family-Centered Patient Advocacy Training," "Caring in a Crisis," and "Introduction to Patient Safety." The advocacy training is offered to families of patients who may be going for surgery or other procedures or who have been diagnosed with a serious condition and may be spending increased time in health care settings. Patients are encouraged to select one or two support people to take this course that is offered in the hospital, physicians' offices, or community programs. In addition to training programs, PULSE of New York assists in developing Public Service Announcements and posters, offers fact and tip sheets, and publishes an online newsletter. Two new publications will be available in 2008, *Teaching Patient Safety: An Educators Guide* and *Family-Centered Patient Advocacy: A Training Manual*.

Disseminate information through newspapers and magazines about current health safety initiatives and opportunity for public involvement.

As part of its Informed Patient Series, the *Wall Street Journal* described the work of patients and families who have experienced harm and who are now working to improve health care safety. The **Josie King Foundation**, created by the family of a child who died because of medical error, was the feature of the story. Among the Foundation's activities is the creation of a website that will encourage the public to share stories; provide information, support, and advice from medical and legal experts; and offer resources to hospitals. The article describes other consumer-driven organizations such as **Persons United Limiting Substandards and Errors in Health Care, Medically Induced Trauma Support Services, and Consumers Advancing Patient Safety.**



Sorrel King in 2000 with her daughter Josie, who died a year later at age 18 months

## Patients, Families Take Up The Cause of Hospital Safety

*Grass-Roots Movement Offers Support, Information to People Affected by Medical Errors*

By LAURA LANDRO

**W**HEN HER 18-month-old daughter Josie died after a series of medical mistakes at Johns Hopkins Children's Center in Balti-

harm. Often working in tandem, they are becoming an increasingly powerful and vocal force world-wide, working with hospitals, governments and nonprofit groups to help formulate safety policies and lobbying for legislation in the U.S. and other countries to protect patients.

They are using the Web to spread the message, creating online communities to share strategies for preventing medical errors and provide support and advice to consumers who have experienced

Please turn to the next page

## TRUSTEES, ADMINISTRATORS, AND MEDICAL, NURSING, AND PATIENT/FAMILY LEADERS: INITIAL QUESTIONS TO ASK FOR ENHANCING PATIENT SAFETY AND QUALITY

Patient- and family-centered care provides the framework and strategies to enhance quality and safety within an organization. Partnerships with patients and families at all levels of care are an essential aspect of patient safety.

### Leadership

- Do the organization's vision, mission, and philosophy of care statements reflect the principles of patient- and family-centered care and promote partnerships with the patients and families it serves?
- Has the organization defined quality health care and does this definition include how patients and families will experience care?

### Patients and Families as Advisors

- Do patients and families serve on patient safety and quality improvement committees and work groups?
- Is patient safety a regular agenda item for the organization's patient and family advisory council?
- Are patient and family advisors involved in developing strategies to inform patients and families about their role in patient safety? About ways they can promote safety and prevent errors?
- Do patients and families serve on committees and task forces planning, implementing, and evaluating the use of information technology?

### Patient and Family Participation in Care

- Are patients and families viewed as essential members of the health care team?
- Are patients and families encouraged and supported to participate in care planning and decision-making?
- Are the organization's policies, programs, and staff practices consistent with the view that families are allies for patient health, safety, and well-being and not visitors?

### 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?
- Are patients and families encouraged to be present and to participate in rounds and nurse change of shift?
- Do patients have easy and continuing access to their medical records?
- Are patients and families encouraged to review their medical records and work with staff and physicians to correct inaccuracies?
- Are patients and families provided with practical information on how to best assure safety in health care?

### Human Resources

- 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?
- Do orientation and education programs prepare staff, physicians, students, and trainees for patient- and family-centered practice and collaboration with patients, families, and other disciplines?
- Do patients and families participate in the teaching of staff, physicians, students, and trainees about medical errors and how to disclose a medical error with a patient and family?

## FOR FURTHER INFORMATION...

- For the most recent references on this topic, please see the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>
- The Institute for Health Care Improvement "Learning and Innovation Communities" are further described at <http://www.ihl.org/IHI/Programs/InnovationCommunities>.
- Information about the "Virtual Learning Communities" of New Health Partnerships can be obtained at the following websites:
  - ◆ [www.newhealthpartnerships.org](http://www.newhealthpartnerships.org).
  - ◆ <http://www.ihl.org/NR/rdonlyres/84CD1D8B-7515-4F36-AAB0-E1E534933FE3/0/NHPLearningCommunityCharter.doc>.
- Activities of the National Patient Safety Foundation (NPSF) are described at <http://www.npsf.org>.
- NPSF's 2003 National Agenda for Action: Patients and Families in Patient Safety "Nothing About Me Without Me" can be downloaded from <http://www.npsf.org/download/AgendaFamilies.pdf>.
- A description of NPSF's Socius Award and the 2007 recipient, North Carolina's Children's Hospital, can be found at <http://www.unhealthcare.org/site/newsroom/news/2007/May/socius>.
- Activities and the roster for the Patient and Family Advisory Group for the Joint Commission International Center for Patient Safety are available at <http://www.jcipatientsafety.org/22775>.
- The World Health Organization's patient safety partnership efforts with patients and families are highlighted at [http://www.who.int/patientsafety/patients\\_for\\_patient/en](http://www.who.int/patientsafety/patients_for_patient/en).
- Materials for IHI's 5 Million Lives Campaign, including resources for patients and families and for trustee and executive leadership can be downloaded from <http://www.ihl.org/IHI/Programs/Campaign/Campaign.htm?TabId=2#>.
- To learn more about Consumers Advancing Patient Safety, see <http://www.patientsafety.org>.
- The press release about the merger between the Partnership for Clear Health Communication (PCHC) and the National Patient Safety Foundation can be found at <http://npsf.org/pr/pressrel/2007-05-4.php>.
- Information about Ask Me 3 is available at <http://www.askme3.org>.
- Partnerships for Clear Health Communication can be found at the National Patient Safety website at <http://www.npsf.org/pchc>.



- The Calgary Health Region's 2007 Quality, Safety, and Health Information Annual Report can be downloaded from [http://www.calgaryhealthregion.ca/qshi/annual\\_report\\_2007\\_nov23.pdf](http://www.calgaryhealthregion.ca/qshi/annual_report_2007_nov23.pdf).
- Two toolkits developed by Aurora Health Care in Milwaukee, Wisconsin, are available on the website for Consumers Advancing Patient Safety. *How to Develop a Community-Based Partnership Council* can be downloaded at <http://patientsafety.org/page/109387>. *How to Create an Accurate Medication List in the Outpatient Setting Through a Patient-Centered Approach* can be downloaded at <http://patientsafety.org/page/109587>.
- Information about the Vermont Oxford Network's 2007 NICQ collaborative is described at <http://www.vtoxford.org/home.aspx?p=/quality/nicq/current.htm>.
- The article about partnering with patients in the root cause analysis process can be found in the following journal:
  - ◆ Zimmerman, T. M., & Amori, G. (2007). Including patients in root cause and system failure analysis: Legal and psychological implications. *Journal of Healthcare Risk Management*, 27(2), 27-34.
- The press release for the Sorry Works! Coalition—Physhield partnership is available at the <http://www.sorryworks.net/article49.phtml>.
- The educational programs and resources produced by the nonprofit organization, Medically Induced Trauma Support Services, are described at [www.mitss.org](http://www.mitss.org).
- Responses to frequently asked questions about The Joint Commission's Patient Safety Goal 13 can be downloaded from [http://www.jointcommission.org/NR/rdonlyres/4EDAB705-F663-4D29-9449-EC0191063BD0/0/07\\_NPSG\\_FAQs\\_13.pdf](http://www.jointcommission.org/NR/rdonlyres/4EDAB705-F663-4D29-9449-EC0191063BD0/0/07_NPSG_FAQs_13.pdf).
- Facts and promotional resources about The Joint Commission's various Speak Up Campaigns are available at [http://www.jointcommission.org/GeneralPublic/Speak+Up/about\\_speakup.htm?prin](http://www.jointcommission.org/GeneralPublic/Speak+Up/about_speakup.htm?prin).
- Further information about Condition H, its implementation at the University of Pittsburgh Medical Center can be found at <http://www.upmc.com/ConditionH>. A Toolkit for Condition H is also available for purchase at <http://www.pulseamerica.org>.
- Resources to encourage active engagement of patients in their health care are available at the website for the Partnership for Healthcare Excellence at <http://www.partnershipforhealthcare.org>.
- Jim Conway's article, "Partnering for Better Care," *Boston Globe*, October 29, 2007, can be read at [http://www.boston.com/news/globe/editorial\\_opinion/oped/articles/2007/10/29/partnering\\_for\\_better\\_care](http://www.boston.com/news/globe/editorial_opinion/oped/articles/2007/10/29/partnering_for_better_care).
- Descriptions of three consumer-driven safety organizations can be found at:
  - ◆ <http://www.josieking.org>.
  - ◆ <http://www.pulseamerica.org>. PULSE of NY, a statewide network, has resources available at <http://www.pulseofny.org>.
  - ◆ <http://www.mitss.org>.

# SUPPORTING PATIENT AND FAMILY MEMBERS AS ADVISORS AND LEADERS

### Key recommendations at a glance...

1. Assure that professionals recognize the important roles patient and family advisors and leaders can play in improving health care and redesigning systems of care.
2. Provide encouragement and support for developing and sustaining roles for patient and family advisors and leaders in all aspects and at all levels of the health care system.
3. Provide resources, training, and support to sustain the work of patient and family advisors and leaders.

Patients and families have ideas, expertise, and perspectives that can inform change and improvement within the health care system. However, to effectively participate as advisors, partners, and leaders in health care redesign and improvement, patients and family members need information, training, support, resources, and opportunities.

Health care leaders, providers, and other staff can create opportunities to develop and sustain collaborative endeavors with patients and families. They can facilitate the development of patient and family advisory and leadership positions.

Organizations can demonstrate commitment by supporting the involvement of patients and families in policy and program development, quality improvement initiatives, education of professionals, and research. They can offer resources, support, and training to ensure success.

Government agencies and private funders can make resources available that build on the ideas, commitment, and competencies of patient and family advisors and support the development of patient and family leaders.



## 1. Assure that professionals recognize the important roles patient and family advisors and leaders can play in improving health care and redesigning systems of care.

Educate health care professionals and leaders of health care organizations about the value of partnerships and the potential of advisory and leadership roles for patients and families.

In 2002, the editors of the *British Medical Journal (BMJ)*, established a patient advisory group to provide feedback to the journal specifically for readers in the United Kingdom and within certain specialty areas. In 2007, the editors acknowledged the benefit of patient advisors to the journal and to its audience and committed to expanding the scope of patient advisory involvement. They pledged to seek out patient involvement around the world and across fields of medicine.

Offer consulting and workshops to provide support for institutions and organizations considering new roles for patients and families.

Promote patient and family advisory roles in all aspects of health care organizations, including policymaking, administration, clinical care, quality assurance, education, and research.

Patient and family leaders who have participated in peer support, identify this support as an essential first step. Reciprocity, according to them, is what motivates and inspires them to become patient and family advisors.

**Parent to Parent-USA (P2P-USA)** is a national nonprofit organization committed to assuring access and quality in Parent to Parent support across the country. Their website highlights statewide organizations that include parent to parent support as a core program and are committed to implementing evidence-based practices. The website connects people to statewide Parent to Parent programs, provides technical assistance to statewide programs, supports networking of Parent to Parent professionals, and provides information for parents, family members, and professionals interested in peer support. Parent to parent programs provide emotional and informational support to families most notably by matching parents seeking support with an experienced, trained support parent. P2P-USA also convenes annual leadership meetings and provides access to relevant research studies.

**Family Connection of South Carolina** supports families serving in a variety of roles. It provides training to families interested in peer support, preparing them to take roles in supporting others with similar concerns. The experience of providing peer support provides an excellent foundation for future advisory roles.

Family Connection's *Partners in Policymaking Program* educates families for a different role—to serve as partners with policymakers at the local, state, and national levels.

Broadly disseminate stories of patient and family advisors and leaders and their contributions to health care.

In a six-part series in *Pediatric Nursing*, a family leader discusses roles parents can play in furthering family-centered care. The roles described range from advocate for one's own child, to advisory roles within health care institutions and organizations, to education of health care professionals, to employment in health care organizations, to participation on national health-related advisory boards. Included in the articles are parents' own descriptions of how they developed and gained confidence as they assumed their new roles.

A recent article in the *Wall Street Journal*, described the ways in which patients and families are serving as advisors in hospitals.

The website of the **Institute for Family-Centered Care** features profiles of patient and family advisors serving in a variety of roles in health care institutions and organizations.

The online community for *New Health Partnerships* includes profiles of patient and family advisors working in ambulatory settings to advance the practice of patient- and family-centered collaborative self-management support.

The PBS television series, *Remaking American Medicine*, profiled the advisory and leadership roles of patient and family advisors. (See pages 2–3 for further information about this series.)



## 2. Provide encouragement and support for developing and sustaining roles for patient and family advisors and leaders in all aspects and at all levels of the health care system.

Develop resource materials and accumulate evidence of best practices to encourage role development for patient and family advisors and leaders.

**Family Voices**, a parent-advocacy organization, gathered materials developed by states that support family involvement in Maternal and Child Health and Children with Special Health Care Needs programs. These materials are available on the Family Voices website as the *Title V Toolbox for Family Participation*. This toolbox is updated as new materials become available.

Employ patient and family leaders in meaningful positions at all levels in the health care system.

**The Children's Hospital of Philadelphia** has over 12 years' experience in employing family consultants in both full- and part-time positions. Currently, the Hospital has four full-time, family consultants.

In 2004, the **University of Washington Medical Center** in Seattle created a half-time position for a Patient- and Family-Centered Care Program Coordinator. Funded originally for three years by the hospital's Service League, the position is now covered through the regular operating budget. The Coordinator is responsible for recruiting and preparing patient and family advisors to serve on various councils and operating committees throughout the medical center. She also serves as the liaison for four advisory councils and works closely with the Associate Director for Patient- and Family-Centered Care.

A health care consumer serves as the Director of the Consumer Office of the **Massachusetts Department of Public Health HIV/AIDS Bureau**. The Director held a number of positions before assuming the management role; these included serving as a volunteer in HIV crisis services to serving on the Statewide Consumer Advisory Board (SWCAB) to a position within the Consumer Office. The Director and staff coordinate the SWCAB, provide technical assistance to other advisory groups in the state, and work with all departments in the AIDS Bureau to ensure that services, programs, and policies are designed and implemented with input from people within the HIV community. (See page 140 for further information about the agency's advisory board.)

One of the core mission areas of the **United Hospital Fund**, a 125-year-old public charity devoted to improving health care in New York City and beyond, is aging and chronic care. The Fund's *Families and Healthcare Project* focuses on developing partnerships between health care professionals and family caregivers for these patient populations. The director of this project is a woman who has long-term experience as a family caregiver. Recent program accomplishments include the following:

- ◆ A Family Caregiver Grant Initiative worked with seven New York City hospitals to develop caregiver support and training programs;
- ◆ A research study addressed "How Family Caregivers Manage When Formal Home Care Services End; and
- ◆ An initiative called, "Inventing the Wheel: Family Caregivers as Partners in Health Care," is stimulating culture change in hospitals, nursing homes, home care agencies, and community health centers.

Develop realistic expectations for patients and families serving as advisors and an understanding of the need for flexibility in scheduling, tasks, and responsibilities for these advisors.

Provide training and clear role descriptions for patient and family advisors.

The **Institute for Family-Centered Care** has prepared the following guidance materials, all of which are available on its website:

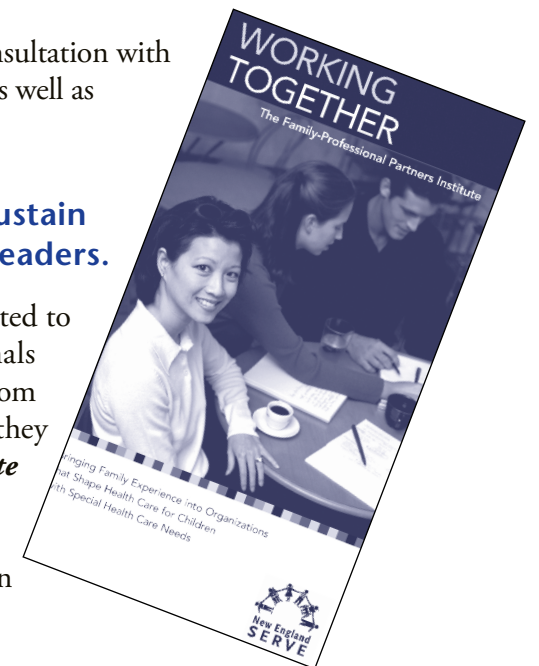
- ◆ *Selecting, Preparing, and Supporting Patient and Family Advisors.*
- ◆ *Tips for How to be an Effective Patient or Family Advisor: A Beginning List.*
- ◆ *Tips for Group Leaders and Facilitators on Involving Families on Committees and Task Forces.*
- ◆ *Advancing the Practice of Patient- and Family-Centered Care: How to Get Started.*

At **Children's Hospital & Regional Medical Center**, Seattle, a parent leadership training curriculum has been developed and piloted. It prepares parents to become effective presenters and provides them with the skills necessary to use their experiences to inform best practices in a variety of settings relevant to parents of children with special health care needs.

The development of the curriculum was guided by consultation with Washington State parent leaders and family advisors, as well as national experts.

## 3. Provide resources, training, and support to sustain the work of patient and family advisors and leaders.

Established in 1983, **New England SERVE** is dedicated to facilitating partnerships among health care professionals and the families they serve. In 2004, with funding from the **Maternal and Child Health Bureau (MCHB)**, they launched the **Family-Professional Partners Institute** to continue to promote roles for families who have children with special health care needs in program development, education, training, and research within





health care organizations. The Institute reaches out to health care organizations to foster interest in building time-limited and structured partnerships with families, with the goal that these partnerships will be sustained by the organization after its launch through the Institute. Currently, the Institute has established partnerships with 16 health related organizations in Massachusetts. Organizations and family partners are prepared and supported to work together. Family partners are interviewed by the partnering organization, but are hired by the Institute as part-time employees for the six month partnership establishment period. Parent partners are given training and are assigned an experienced parent mentor to support them. The Institute provides the health-related organizations the technical assistance and individual consultation they need to sustain these partnerships. Organizational partners and parent partners have reacted enthusiastically to the partnerships. Based on their interest in maintaining networking opportunities with each other and sustaining the partnerships, the Institute is creating a way for these organizations and family partners to stay connected.

**Designate a staff liaison to recruit patient and family advisors, coordinate training, provide mentorship, and assure opportunities for meaningful participation in the institution or organization.**

The *New Health Partnerships Virtual Learning Collaborative*, an improvement initiative created to promote collaborative self-management support for individuals with chronic conditions, supports the involvement of patients and families as members of the improvement teams in a variety of ways including:

- ◆ Each team has a designated staff liaison for the patient and family advisors.
- ◆ Regular monthly calls are held for patient and family advisors and the staff liaisons.
- ◆ Three designated patient and family advisory faculty members are available to provide support to the teams as needed.

**Prepare less experienced patients and family members for participation in meetings and educational sessions, linking them with an experienced patient or family member whenever possible.**

**Provide education and training or facilitate access to professional training in leadership and advocacy.**

The *Leadership Education in Neurodevelopmental and Related Disabilities* (LEND) program at **The Children's Hospital of Philadelphia (CHOP)** provides interdisciplinary leadership training involving didactic educational seminars, participation in projects that address family-collaboration and community-based partnerships, and research training. LEND is funded by the federal **Maternal and Child Health Bureau (MCHB)** and is one of 36 programs in 29 states.

In 2005, with support from MCHB, CHOP launched a Family Leadership discipline, providing a funded LEND fellowship for a parent or family member of a child with special health care needs. The Family Fellow is integrated among the health care professional fellows as a peer and a partner in every aspect of the fellowship training. For the family member, this provides an opportunity to learn about various health conditions, policies, ethical concerns, program development, advocacy, and other pertinent topics.

The LEND Fellowship has three core components: the Community Education and Liaison Program (to develop community partnerships that serve to enhance the health infrastructure of the community); the Family Collaboration Program to enhance the fellows' understanding of the experiences and perspectives of family members); and a Research Leadership Program (see page 87 for further information about the fellows' research learning opportunities).

The *Leadership Education in Neurodevelopmental Disabilities* (LEND) program at **The Nisonger Center** in Columbus, OH, annually recruits one parent and one sibling trainee to participate in interdisciplinary, leadership training along with graduate and postgraduate students in ten health-related disciplines. The primary objectives of the program are to develop high levels of clinical expertise, skills and competence, and leadership attributes that will lead to the improved health status of infants, children and adolescents with or at risk for neurodevelopmental and related disabilities and their families. The program focuses on advancing professionalism in the care of children with disabilities.

The parent and sibling trainee devote ten hours a week for nine months in all aspects of the LEND leadership curriculum and are paid a stipend.

The *Leadership Education in Neurodevelopmental Disabilities* (LEND) program at **Cincinnati Children's Division of Developmental and Behavioral Pediatrics** also provides a family member of a child with developmental disabilities the opportunity to train along side students from other disciplines. The family member must complete the same rigorous requirements as the other LEND trainees, with adaptations to the competencies to reflect the unique nature of "family" as a discipline. The LEND family traineeship allows the family member to gain important leadership and advocacy skills, while providing the other trainees with the invaluable perspective of a family member. To qualify for the family traineeship, the applicant must be a family member of a child with a developmental disability, have proven advocacy skills, and a desire to advocate for all children with disabilities. The family member receives a stipend and must be able to dedicate 20 hours a week for nine months to the program.

Systems of care communities funded by **Substance Abuse and Mental Health Services Administration** are now required to involve families in the implementation of their evaluation activities. Among the ways they can be included are by providing feedback on the design and objectives of the evaluation, conducting interviews, analyzing data, and interpreting and reporting results.

One of these communities is the *Columbia River Wraparound*, a group comprised of family, youth, community leaders, and staff of agencies that provide services to children with serious emotional and behavioral disturbances and their families. The goal of the project is to develop, implement, and evaluate systems of care that will provide comprehensive services to children and families.

In May 2003, the project team published a report that summarized the results of an evaluation of their program that trains family members to participate in evaluation projects. They also investigated professional/family member evaluation teams to identify strategies that promote collaborative relationships in evaluation teams.

Currently, the project team is developing training materials for evaluators to work in partnership with family members and have developed a 10-module comprehensive training curriculum on Family-Evaluator Collaboration.

Project staff are developing resources to assist evaluators and family members who are working collaboratively on evaluations.

**Assure that patient and family advisors have access and training to use computers, Internet, and medical libraries.**

**Assure that patient and family advisors and leaders have access to professionals in leadership positions within and outside the institution or organization.**

**Encourage peer mentoring and peer support for patient and family advisors and leaders.**

**Family Voices** has created the *National Center on Family/Professional Partnerships for Children and Youth with Special Health Care Needs*, funded by the Maternal and Child Health Bureau. The goals of the Center include increasing youth and family member leadership capacity, as well as expanding opportunities for partnerships in health care practice and policy development. The Center provides technical assistance and mentoring activities; promotes communication and information sharing; and offers training institutes, teleconferences, and conferences.

*Quality Allies: Improving Care by Engaging Patients*, a project funded by the **Robert Wood Johnson Foundation** and the **California HealthCare Foundation** to improve chronic care, offered a dedicated listserv for patient and family members of the improvement teams and patient and family faculty. Time was set aside at each formal learning session for patient and family advisors to meet as a group for informal discussion, problem-solving, and sharing of ideas.

**Assure funding for patient and family advisor programs.**

## FOR FURTHER INFORMATION...

- For the most recent references on this topic, please see the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>
- The following article describes the commitment of *BMJ* to patient involvement in the editorial process: Lapslee, P., & Godlee, F. (2007). Involving patients in the *BMJ*. *BMJ*, 334(7608), 1334.
- The resources of Parent to Parent USA are described at <http://www.p2pusa.org>.
- To learn about Family Connections of South Carolina, visit <http://www.familyconnections.org>.
- Deborah Dokken and Elizabeth Ahmann's six-part series in *Pediatric Nursing*, "The Many Roles of Family Members in Family-Centered Care" begins in the November/December issue—Volume 32(6)—<http://www.pediatricnursing.net/issues/06novdec>.
- The *Wall Street Journal* article titled, "Hospitals Boost Patients' Power as Advisers," can be downloaded at <http://online.wsj.com/public/article/SB118652860268491024.html>.
- For more on profiles of patient and family advisors serving in a variety of roles in health care institutions and organizations, visit the Institute for Family-Centered Care website at <http://www.familycenteredcare.org/advance/pafam.html>.
- The on-line community for New Health Partnerships which includes profiles of patient and family advisors in ambulatory settings can be found at <http://www.newhealthpartnerships.org>.
- A description of the four-part PBS television series, *Remaking American Medicine*, is available at [www.pbs.org/remakingamericanmedicine](http://www.pbs.org/remakingamericanmedicine).
- The regularly updated materials from Family Voices for families within Title V programs are located at [www.familyvoices.org/toolbox](http://www.familyvoices.org/toolbox).
- The Family-Centered Care philosophy at The Children's Hospital of Philadelphia is described at [www.chop.edu/pat\\_care\\_fam\\_serv/our\\_philos\\_care.shtml](http://www.chop.edu/pat_care_fam_serv/our_philos_care.shtml).
- To read about patient and family advisors, and patient- and family-centered care at University of Washington Medical Center, visit <http://www.uwmedicine.org/Facilities/UWMedicalCenter/ClinicsAndServices/FamilyAdvisors/index.htm>.
- At the Massachusetts Department of Public Health HIV/AIDS Bureau, the Director of the Consumer Office is a health care consumer. To find out more, go to <http://www.mass.gov/dph/aids>.
- The Families and Health Care Project of the United Hospital Fund is highlighted at [http://www.uhfnyc.org/pubs-stories3220/pubs-stories\\_list.htm?attrib\\_id=5026](http://www.uhfnyc.org/pubs-stories3220/pubs-stories_list.htm?attrib_id=5026).



- Further information on family-centered care initiatives at Children’s Hospital & Regional Center in Seattle is found at [http://www.seattlechildrens.org/home/patients\\_families/family\\_centered.asp](http://www.seattlechildrens.org/home/patients_families/family_centered.asp).
- To learn more about New England SERVE and the Family-Professional Partners Institute, visit <http://www.neserve.org>.
- To learn more about two LEND programs, visit: The Nisonger Center at <http://medicine.osu.edu/LEND> and The Children’s Hospital of Philadelphia at <http://www.chop.edu/consumer/jsp/microsite/microsite.jsp?id=79400>.
- The National Center on Family/Professional Partnerships for Children and Youth with Special Health Care Needs, created by Family Voices, is described at <http://www.familyvoices.org/info/ncfpp/resources.php>.
- To read more about the 20 teams who participated in the Quality Allies project, visit the Institute for Healthcare Improvement’s website at <http://www.ihl.org/IHI/Programs/StrategicInitiatives/NewHealthPartnerships.htm?TabId=1>.

# THE ROLE OF FOUNDATIONS, GOVERNMENT AGENCIES, AND CORPORATIONS

### Key recommendations at a glance...

1. Create opportunities for foundation staff, government personnel, and business leaders to become knowledgeable about patient- and family-centered care and to use this knowledge to direct/coordinate projects that foster widespread use of partnerships with patients and families.
2. Model partnerships with patients and families in organizational structure and in the ways in which foundations, agencies, and corporations function.
3. Prioritize funding to support and sustain partnerships with patients and families.
4. Identify and profile models and early adopters/champions of patient- and family-centered approaches in all types of organizations, and encourage learning from their successes.
5. Fund the collection and analysis of data to build understanding of and demonstrate the case for partnerships with patients and families, and for patient- and family-centered practices.
6. Encourage corporations that fund health care innovations to involve patient and family advisors in program development and quality improvement and to integrate patient- and family-centered concepts and strategies in all health care programming.
7. Identify common barriers for individuals and organizations seeking funding for projects that involve partnering with patients and families, and develop strategies for overcoming these barriers.

Involving patients and families in collaboration in the health care system will require major changes in approaches not only to care but also to health care management. This effort will need a commitment of interest, effort, time, and finances for education and training, resource and materials development, and research.

The following recommendations suggest strategies that public- and private-sector organizations can use to support collaborative efforts—among patients, families, providers, foundations, federal and state agencies, and others—to ensure the availability of resources that will advance the development of partnerships with patients and families in health care.

**1. Create opportunities for foundation staff, government personnel, and business leaders to become knowledgeable about patient- and family-centered care and to use this knowledge to direct/coordinate projects that foster widespread use of partnerships with patients and families.**

Foundation and government agency personnel who participate in conferences and other activities focused on patient- and family-centered care and partnerships with patients and families are in an excellent position to apply these strategies as they design new funding programs and work with grantees and contractors. This is exemplified in work done in the late 1980s and early 1990s to define and advance the practice of family-centered care for children with special health needs, women infected and affected by HIV/AIDS, and children with serious mental health conditions. Government and foundation personnel participated in educational activities that brought together patients, families, and health care professionals. Because of this work, these funders recognized the need to support opportunities to learn about collaboration and to bring grantees together to learn from each other.

In crafting the language of grant program descriptions and in evaluating proposals and grantee progress reports, funders can ensure that potential grantees and contractors truly understand the meaning of patient- and family-centered care.

**2. Model partnerships with patients and families in organizational structure and in the ways in which foundations, agencies, and corporations function.**

The **Calgary Health Region** in Alberta, Canada, is a large integrated health care system. It is responsible for the health of more than one million people who live in its 40,000 sq. km boundary. The agency's Vision, Mission, and Values shape its programs, priorities, allocation of resources, and the way it works:

**VISION:** Healthy Communities

**MISSION:** Leaders in Health, A Partner in Care

**VALUES:**

**Caring, Respectful Relationships as shown by:**

- ◆ Providing patient- and family-centered care
- ◆ Showing respect, equality, and fairness
- ◆ Being compassionate
- ◆ Maintaining dignity
- ◆ Valuing contribution

**Quality and Safety as shown by:**

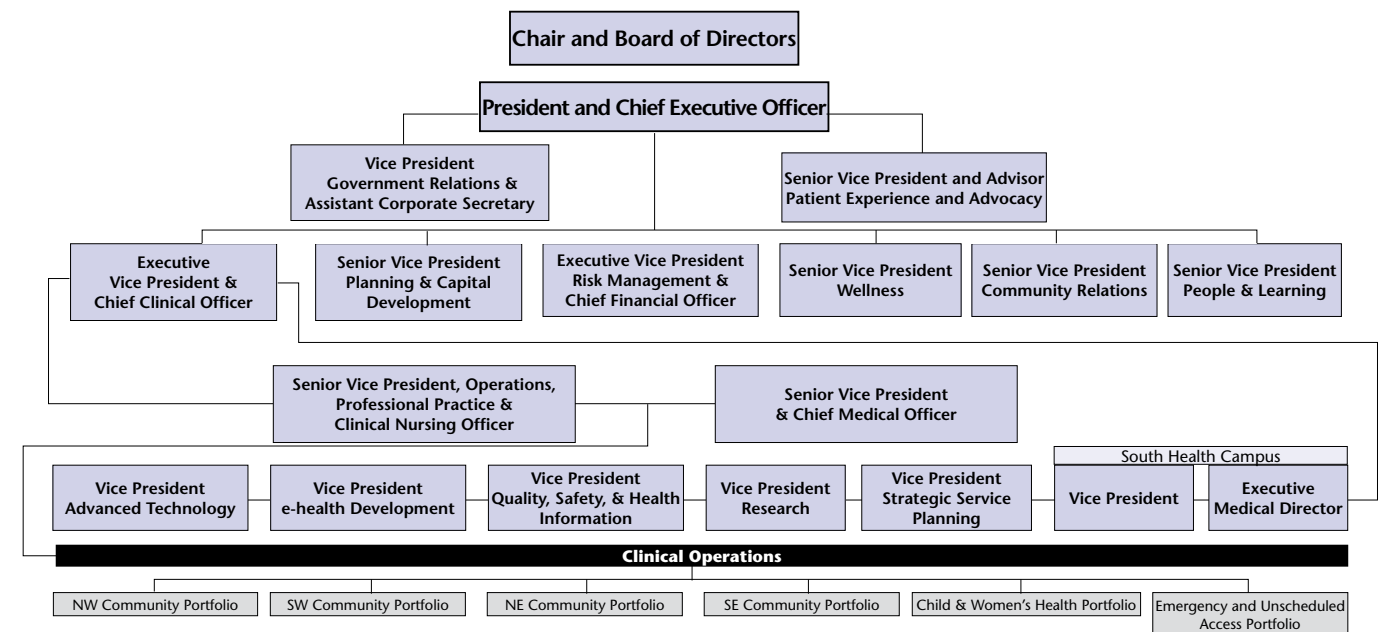
- ◆ Committing to safety
- ◆ Providing accessible services
- ◆ Working in partnerships
- ◆ Providing best practice, evidence-based care

**Accountability as shown by:**

- ◆ Being honest
- ◆ Building trust and being trustworthy
- ◆ Displaying integrity and the highest level of ethical behavior
- ◆ Being accountable for our decisions and actions

In 2005, the Region created a Patient Experience portfolio, reporting directly to the Chief Executive Officer, to advance the practice of patient- and family-centered care across the region in all of its programs (see organizational chart shown below). The Patient Experience Team is encouraging a variety of strategies to promote patient- and family-centered care, including engaging patients and families in a number of regional councils and committees such as the Patient and Family Safety Council, quality improvement teams, and involvement in capital planning projects. The Region is working with **Planetree** to engage front-line hospital managers and staff in advancing the practice of patient- and family-centered care. Partnerships with patients and families are integrated throughout this process.

The Patient Experience Team serves as a resource for creating effective partnerships with patients and families, providing written, audiovisual, and web-based materials, facilitation, and assistance to hospitals, ambulatory clinics, and community programs within the region.





The **Massachusetts Department of Public Health HIV/AIDS Bureau** has a Statewide Consumer Advisory Board (SWCAB) consisting of 30 members, all living with HIV. Potential members must apply, be interviewed, be selected by the staff and four current Board members, and be approved by the Director of the HIV/AIDS Bureau. Board membership is chosen to reflect the demographics of the population with HIV. All SWCAB members must serve on some other community-based board to ensure that they are providing input from their community to the Board and from the Board to their community.

The SWCAB directly advises the Bureau on services and policies for people living with HIV in Massachusetts. Board members work with the Consumer Office to review programs, policies, and services to assure that the HIV/AIDS community is being well served.

In addition to the SWCAB, the Massachusetts HIV/AIDS Bureau requires that all agencies receiving state funding for HIV-related programs and services have a Consumer Advisory Board or similar mechanism to get input from clients. The director for the Consumer Office is an individual living with HIV (see page 130 for further information about this role).

This multi-tiered consumer influence has been beneficial. Despite substantial budget cuts over the past five years, the state has been able to make positive changes based on clients' feedback and to secure most-needed services.

**Require patients and families to be co-leaders in all "title" (federal statutory codes impacting health care in states and communities) programs and participants at all meetings of "title" agencies.**

Title V is the federal legislation administered by the **Maternal and Child Health Bureau** to promote the health of mothers, infants, children, and adolescents with special health care needs. One item included in the National Performance Measures for block grants measures the extent to which states include families in policy and program development and implementation has developed and regularly updates the *Title V Toolbox for Family Participation* to facilitate participation of families in all Title V programs. The toolbox includes materials and guidance for recruiting, training, and supporting family representatives, as well as information about measuring family involvement.

**Include specific requirements for collaboration with patients and families, in all calls or requests for proposals.**

In 2003, the **Robert Wood Johnson Foundation** (RWJF) and the **Institute for Healthcare Improvement** created *Transforming Care at the Bedside* (TCAB), an innovation community, to develop a framework for change on medical/surgical units in hospitals built around improvements in five main categories:

- ◆ Safe and Reliable Care
- ◆ Vitality and Teamwork
- ◆ Patient-Centered Care
- ◆ Value-Added Care Processes
- ◆ Transformational Leadership

In Phase III of TCAB, 10 TCAB hospitals are testing, refining, and implementing changes in each of these categories. RWJF expects that the TCAB teams will include a patient and family advisor, a physician, and a representative from a school of nursing.

The **Hulda B. and Maurice L. Rothschild Foundation** is a private philanthropy whose primary interest is improving the quality of life for elders in long-term care environments through model programs, resources, and research.

The Foundation is committed to a collaborative process, integrating seniors and their families into the design, planning, and programming of skilled nursing facilities. Foundation President Robert Mayer has said, "If we are truly to improve the way we support and care for elders, they and their families must be part of that services delivery system. From the physical design of space to the nature of services available, residents are in the best position to impact their own environments positively."

**Develop funding priorities collaboratively with patients and families.**

**Design projects or requests for proposals collaboratively with patients and families.**

**Assure that patients and family members are involved in all steps of the foundation or agency grant-review process.**

### 3. Prioritize funding to support and sustain partnerships with patients and families.

In 2005, **St. Luke's Health Initiative** (SLHI), a health foundation in Arizona that focuses on meeting the needs of underserved populations, went through a complete redesign to focus on creating patient- and family-strengths-based partnerships in health care and on building community involvement through shared leadership and expertise.

To promote the health of the people in Arizona, SLHI now uses the following core strategies:

- ◆ Investment in and leverage of community capacity;
- ◆ Provision of technical assistance to communities; and
- ◆ Efforts to inform and enrich public policy dialogue.

In 2006, SLHI funded nine community partnerships for health care. Among the funded projects are:

- ◆ **Promotoras de Bienstar**, which hires and trains community members to promote two health-related issues each year for five years.
- ◆ **MATForce**, which collaborates with individuals recovering from methamphetamine addiction to improve interventions for people struggling with addiction.

Meanwhile, two long-term SLHI programs continue to support strengths-based partnerships in other ways. The **Family Involvement Center** promotes family involvement in policy, program, and service delivery in mental health care systems. **Heart and Soul** uses lay health advisors to promote cardiovascular health in the African-American community.

The federal **Maternal and Child Health Bureau** has a long-standing commitment to advancing the practice of family-centered care for children with special health needs through partnerships with families. The agency has funded several collaboratives related to the pediatric medical home, and always conveys the expectation that grantees will partner with families in all phases of their work.

The state of Minnesota has had a long history of promoting and advancing Medical Home throughout the state. In 2002, the Minnesota Title V Children with Special Health Needs section at the Minnesota Department of Health received an MCHB Medical Home grant, with which they began the **Minnesota Medical Home Learning Collaborative**. In 2005, the health department was awarded a President's New Freedom Initiative Grant to continue this work and its Minnesota Medical Home Learning Collaborative is a recognized leader in the movement.

Twenty-one teams are working to spread the medical home concept throughout the state. Each team is formed from a primary care practice within its own community. Teams consist of at least two parents who have children with special health care

needs, a primary care physician, and a person chosen by the physician who can serve in the role of care coordinator, such as an RN, LPN, or nurse practitioner. The teams meet twice a month. The parent members receive stipends for their work.

Three times a year, all the teams gather for a learning session. Family-centered care and parent/professional collaboration skills are taught to new teams. Veteran parents help to train the new parent members.

All the primary care practices have made significant changes to their practices and clinics. The specifics are tailored by and to the people in each clinic setting. Examples of positive changes include:

- ◆ The identification within the clinic of children with special needs, and the development of a registry.
- ◆ The development and implementation of care plans.
- ◆ Chronic care management, such as:
  - ▼ Longer appointments;
  - ▼ Special appointment times; and
  - ▼ Special access to physicians or care coordinators.
- ◆ Improvements in the physical space within the clinic, such as having a wheelchair scale and pictoboards.
- ◆ Coordination to meet the needs of the family in the community and promotion of family networking opportunities.

As of March 2008, there are 23 primary care teams participating in the Minnesota Medical Home Learning Collaborative. One of the teams is a family practice team that will focus on redesigning systems of care for adults with chronic illness. Prior to beginning to work with the collaborative, this team identified three adult patient partners to participate. Each of these patients asked to have their spouses join them because they view them as essential members of their health care team.

Minnesota has a state-level leadership team consisting of 12 to 15 members, mostly from the state government and academia, which meets monthly. Some members are physicians. Two parents serve on this leadership team.

The state is collecting data and working on outcome surveys. Information from parents is included to help measure improvements in outcomes. The state will be publishing the results in the future.

Improving clinical outcomes and the quality of life for Californians with chronic conditions is a goal of the **California HealthCare Foundation** (CHCF) in Oakland. One of CHCF's objectives is to increase patient and family participation in all aspects of chronic disease management. This work builds on prior CHCF-funded efforts to develop patient-centered information technology (e.g., personal health records), promote self-management support, and work with consumer advocacy organizations in moving this agenda forward.

CHCF supports projects that involve patient- and family-centered approaches. One priority is to fund initiatives that will give patients and families active roles in managing their care using technology and related support tools, accessing self-care resources in their communities, and interacting with trusted intermediaries such as consumer advocacy organizations and community organizations. The focus also includes working with providers and payers to encourage including patients as partners in care. Strategies designed to help meet this goal include improving the provision of self-management support through working with health systems to ensure patients and families are involved in care delivery, creating systematic ways to engage patients in self-care (e.g., phone or web-based systems), and promoting the measurement of patient experience and engagement. In addition to these measures, clinical outcomes will be documented. Efforts are being made by the Foundation to identify projects within these strategic areas where patients and families can be engaged to guide and further these improvements.

**Invest in activities that build understanding of, and the skills needed for, effective partnerships among patients, families, and health care professionals.**

As most states, Maine faces challenges in providing affordable, accessible, comprehensive, high-quality health care. The **Maine Health Access Foundation** (MeHAF) is a leader in promoting change and innovation in responding to these challenges. MeHAF is also acknowledged as a leader in fostering partnerships. MeHAF's long-term priorities include supporting innovative, patient-centered health care delivery and management systems that are structured to address patient-identified needs.

MeHAF supports a project whose goal is to more effectively integrate physical and mental health care within primary care settings. The Foundation is funding meetings with patients and families as part of the process.

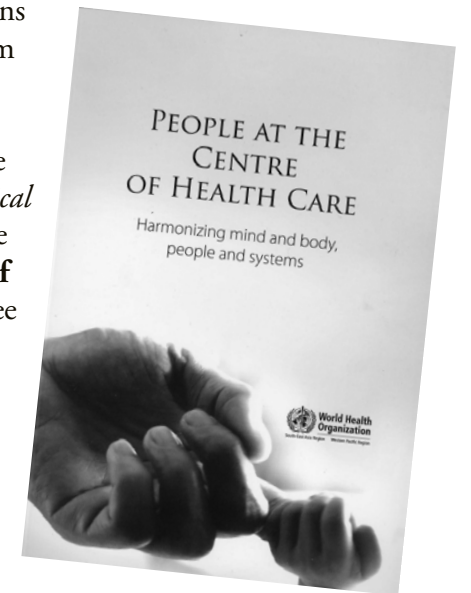
MeHAF has funded scholarships for low-income, uninsured individuals to participate in training with health care professionals and other patient and family advisors to learn how to advance the practice of patient- and family-centered care and to be effective advisors.

*Project HealthDesign* is an initiative, co-funded by **Robert Wood Johnson Foundation** and **California HealthCare Foundation**, to support programs that are designing innovative personal health records that serve to encourage patients and their families to become active partners in their own health care. The **San Francisco Center of Excellence for Breast Cancer Care**, one of the funded sites, is creating a customized care plan for patients with breast cancer. The intent of this project is to prepare and support patients and their families to participate in care planning and decision-making with care providers. Breast cancer survivors are on the development team and the project is conducting comprehensive user-testing with patients and families.

**4. Identify and profile models and early adopters/champions of patient- and family-centered approaches in all types of organizations, and encourage learning from their successes.**

**The Commonwealth Fund** is supporting educational sessions designed to encourage the application of lessons learned from pediatric medical home initiatives and partnerships with families to the redesign of adult primary care. These sessions are particularly timely given the February 2007 release of the consensus paper, *Joint Principles of the Patient-Centered Medical Home* by the **American Academy of Family Physicians**, the **American Academy of Pediatrics**, the **American College of Physicians**, and the **American Osteopathic Association** (see pages 35 and 105).

The Western Pacific and South-East Asian regions of the **World Health Organization** has recently launched an initiative, *People-Centred Health Care: Reorienting Health Systems in the 21st Century*. This initiative is intended to encourage the development and adoption of policies that insure the provision of safe, high-quality health care for all. The concepts and strategies of this initiative are consistent with patient- and family-centered care as defined in this report. The key characteristics of people-centred health care, as stated on their website, are shown in the chart on p. 148.



**5. Fund the collection and analysis of data to build understanding of and demonstrate the case for partnerships with patients and families, and for patient- and family-centered practices.**

**Undertake assessments of existing programs before funding new projects to avoid duplication and to maximize benefits across projects.**

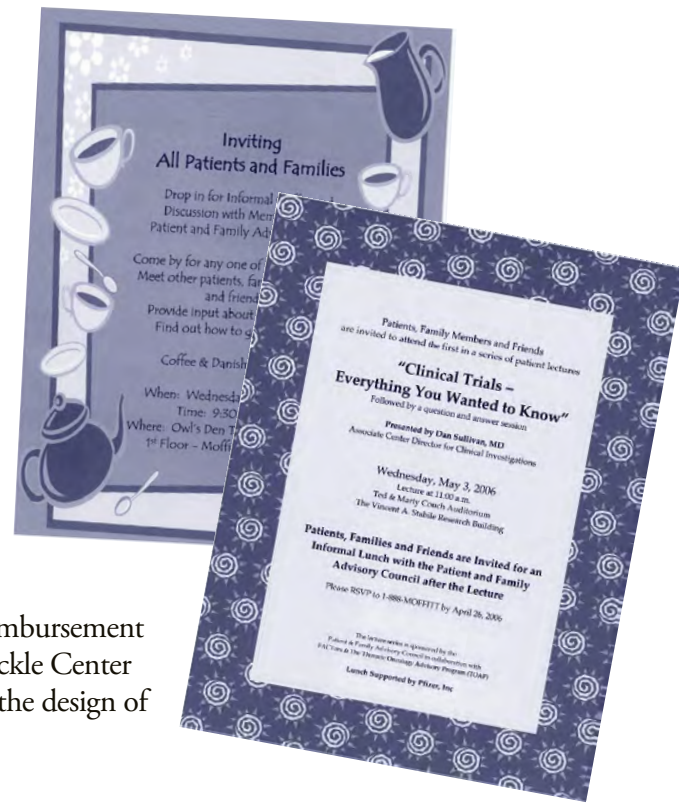
**Develop the evidence for patient- and family-centered care, including the return on investment associated with involving patients and families in health care redesign that will include impact on clinical outcomes, patient safety, patient loyalty and patient generated development support (see pages 4–5).**

**6. Encourage corporations that fund health care innovations to involve patient and family advisors in program development and quality improvement and to integrate patient- and family-centered concepts and strategies in all health care programming.**

The **Pacific Business Group on Health** (PBGH) is encouraging the active participation of patients and families in the health care system and facilitating public reporting of useful quality data. A current collaborative is seeking to improve the Patient Experience (see page 100 for further information on PBGH).



Corporations that are self-insured often have a vested interest in piloting patient- and family-centered innovations as potentially cost-efficient ways to provide health care. For example, **Massachusetts General Hospital** has a self-insurance program for its employees. This provides the MGH, the **Massachusetts General Physicians Organization**, and **The John D. Stoeckle Center for Primary Care Innovation** an opportunity to test new models of care coupled with new reimbursement models for primary care outside the confines of the current reimbursement system (see pages 40–41 for how The Stoeckle Center is partnering with patients and families in the design of the Primary Care of the Future).



In 2005, the **Pfizer Pharmaceutical Company** provided a seed grant to convene a patient forum at the **H. Lee Moffitt Cancer Center & Research Institute** in Tampa, Florida. The purpose of the forum was to introduce patient- and family-centered care and the opportunity to become involved in collaborative processes for change.

The Patient and Family Advisory Council plans and hosts educational sessions now for patients and families and uses these sessions as a way to learn directly from patients and families about the experience of care and opportunities for improvement.

Within the past three years, patient and family advisors have been integrated into the following:

- ◆ Quality and Performance Improvement Committee and the Quality Committee of the Board
- ◆ Moffitt Safety Oversight Committee
- ◆ Hospital Operations Committee
- ◆ Clinic Steering Committee
- ◆ Total Cancer Cabinet Advisory Meeting and the Total Cancer Care External Advisory Board
- ◆ On-Time Initiative, Quality Improvement Ambulatory Team
- ◆ Chaplain Search Committee
- ◆ Cancer Survivorship Advisory Committee

## 7. Identify common barriers for individuals and organizations seeking funding for projects that involve partnering with patients and families, and develop strategies for overcoming these barriers.

Structure funding criteria in ways that reward organizations genuinely seeking to partner with patients and families in quality improvement and health care redesign.

During the 1990s, when the **Maternal and Child Health Bureau** was developing emergency services for children, it made additional funds available to grantees that included families on their improvement teams.

Acknowledge challenges in obtaining buy-in among staff and physicians to partner with patients and families in quality improvement and health care redesign and adequately support the time and effort it takes to change organizational culture.

Disseminate information about funding opportunities (grants and seed money) related to the patient- and family-centered care initiatives.

Funders can also ensure that grantees are committed to meaningful partnerships and that they understand that patient- and family-centered care involves working with patients and families and not doing things to or for them. It is a fundamental change in relationships in health care—one that engages patients and their families in decisions related not only to care but also to planning, implementing, and evaluating policies and programs.



**KEY CHARACTERISTICS OF PEOPLE-CENTRED HEALTH CARE INCLUDE:***For individuals, patients and their families:*

- ◆ Access to clear, concise and intelligible health information and education that increase health literacy;
- ◆ Equitable access to health systems, effective treatments, and psycho-social support;
- ◆ Personal skills which allow control over health and engagement with health care systems: communication, mutual collaboration and respect, goal setting, decision-making and problem solving, self-care; and
- ◆ Supported involvement in health care decision-making, including health policy.

*For health practitioners:*

- ◆ Holistic approach to the delivery of health care;
- ◆ Respect for patients and their decisions;
- ◆ Recognition of the needs of people seeking health care;
- ◆ Professional skills to meet these needs: competence, communication, mutual collaboration and respect, empathy, health promotion, disease prevention, responsiveness, and sensitivity;
- ◆ Provision of individualized care;
- ◆ Access to professional development and debriefing opportunities;
- ◆ Adherence to evidence-based guidelines and protocols;
- ◆ Commitment to quality, safety and ethical care; and
- ◆ Team work and collaboration across disciplines, providing coordinated care and ensuring continuity of care.

*In health care organizations:*

- ◆ Accessible to all people needing health care;
- ◆ Commitment to quality, safe and ethical care;
- ◆ Safe and welcoming physical environment supportive of lifestyle, family, privacy and dignity;
- ◆ Access to psychological and spiritual support during the care experience;
- ◆ Acknowledgement of the importance of all staff - managerial, medical, allied health, ancillary – in the delivery of health care;
- ◆ Employment and remuneration conditions that support team work people-centred health care;
- ◆ Organisation of services that provide convenience and continuity of care to patients; and
- ◆ Service models that recognise psycho-social dimensions and support partnership between individuals, their families and health practitioners.

*In health systems:*

- ◆ Primary care serves as the foundation;
- ◆ Financing arrangements for health organisations that support partnership between health practitioners and people accessing health care;
- ◆ Investment in health professional education that promotes multidisciplinary team work, good communication skills, an orientation towards prevention, and integrates evidence about psychosocial dimensions of health care;
- ◆ Avenues for patient grievances and complaints to be addressed;
- ◆ Collaboration with local communities;
- ◆ Involvement of consumers in health policy; and
- ◆ Transparency.

*Source: World Health Organization—People at the Centre of Care Initiative***FOR FURTHER INFORMATION...**

- For the most recent references on this topic, please see the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>
- The Calgary Health Region maintains a website at <http://www.calgaryhealthregion.ca>.
- Information and history of the Maternal Child and Health Bureau can be found at <http://mchb.hrsa.gov/about/default.htm>.
- The *Title V Toolbox for Family Participation* developed and updated by Family Voices can be accessed at <http://www.familyvoices.org/toolbox>.
- The Robert Wood Johnson Foundation can be accessed at <http://www.rwjf.org>.
- A program summary and information about the Transforming Care at the Bedside initiative can be found at the Institute for Healthcare Improvement site at <http://www.ihl.org/IHI/Programs/StrategicInitiatives/TransformingCareAtTheBedside.htm>.
- For more information about the Hulda B. and Maurice L. Rothschild Foundation, see [http://www.hpm.umn.edu/nhregsplus/hulda\\_b\\_&\\_maurice\\_l\\_rothschild\\_foundation.htm](http://www.hpm.umn.edu/nhregsplus/hulda_b_&_maurice_l_rothschild_foundation.htm).
- Learn more about the community-based programs supported by St Luke's Health Initiative at <http://www.slhi.org>.
- An article describing the Minnesota Medical Home Collaborative can be downloaded at <http://www.mnaap.org/PDF/mnmed0106.pdf>.
- The website for the California HealthCare Foundation is <http://www.chcf.org>.
- Information about the Maine Health Access Foundation and a listing of their resources and publications can be found at <http://www.mehaf.org>.
- Read more about Project HealthDesign at <http://www.projecthealthdesign.org>.
- Information about the Commonwealth Fund's Patient-Centered Care Initiative can be found at [http://www.commonwealthfund.org/topics/topics\\_list.htm?attrib\\_id=15313](http://www.commonwealthfund.org/topics/topics_list.htm?attrib_id=15313).
- The consensus paper, *Joint Principles of the Patient-Centered Medical Home*, can be downloaded from <http://www.aafp.org/online/en/home/press/aafpnewsreleases/20070301releases/20070305pressrelease0.html>.
- Information and related documents and links for the Western Pacific Region of the

World Health Organization's initiative, People-Centred Health Care: Reorienting Health Systems in the 21st Century can be found at <http://www.wpro.who.int/sites/pci>.

- The Pacific Business Group on Health offers additional information on consumer engagement at [http://www.pbgh.org/programs/consumer\\_engagement.asp](http://www.pbgh.org/programs/consumer_engagement.asp).
- Learn more about The John D. Stoeckle Center for Primary Care Innovation at <http://www.massgeneral.org/stoecklecenter/jstoeckle.htm>.
- The website for the H. Lee Moffitt Cancer & Research Institute is <http://www.moffitt.usf.edu>.

## Appendix A

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## VISIONING

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Developing a shared vision for improving health care by advancing the practice of patient- and family-centered care was a foundational undertaking at the June 2nd meeting.

Meeting participants, including patient and family advisors, health care providers, administrators, policymakers, and representatives of payers and foundations were arranged in small groups, each with a facilitator. The first task each group faced was to envision the ideal health care system, and the ways it would demonstrate meaningful, sustained partnerships with patients and families. To encourage this visioning process, the groups were given four prompts. One hundred fifty-six total responses were tallied, broken down as follows by the specific prompt:

1. What do you really care about? (22);
2. What are your hopes? (46);
3. What if ... ? (58); and
4. What matters most? (30).

Several common themes emerged. These are detailed below, followed by key responses to each of the four prompts:

### Common themes

- ◆ The “hospital of the future” is realized with patients and families at the top of the hierarchy.
- ◆ Patient- and family-centered care develops from being a gold standard to becoming an everyday occurrence in all health care settings.
- ◆ Leadership and incentives for patient- and family-centered care, including models for partnering and strategies for sustainability, are provided by The Joint Commission, the Accreditation Council for Graduate Medical Education, the Centers for Medicare & Medicaid Services, and others.
- ◆ Payers demonstrate their valuing of patient- and family-centered care both by funding initiatives in this area and by linking reimbursement to patient and family satisfaction and related outcomes.
- ◆ Foundations and public funding agencies require patient and family involvement in research and quality improvement studies, whenever appropriate.
- ◆ Significant patient and family involvement becomes the norm in all aspects of and at all levels in health care settings; in health care provider education and training; and in health-related organizations, agencies, and policymaking groups.



- ◆ Consumer education and training assist progress in the realization of patient- and family-centered care.
- ◆ Access to health care is universal, from preventive care to hospice, at times and locations convenient to patients and families.
- ◆ Continuity of care is aided by readily accessible electronic or patient-carried medical records.
- ◆ Safety is paramount, including physical, mental, and spiritual safety for patients and families. Medical errors and adverse events are eliminated.

### What do you really care about?

- ◆ Universal access, equity, and justice become givens in health care.
- ◆ All health care is safe, humane, compassionate, culturally-competent, and focused on patient and family needs and priorities.
- ◆ Continuity of care for each patient occurs through all settings, and includes coordinated discharge planning, support and education for those living with medical conditions, and ongoing, long-term support for caregivers.
- ◆ Health care emphasizes not only clinical outcomes but also the experience of care. This includes respect for patient and family dignity and protection from physical, emotional, and spiritual harm.
- ◆ The focus of patient and family education is on supporting informed decision-making and active involvement of patients and families in decisions.
- ◆ Health care providers are caring and compassionate.
- ◆ Health care providers experience joy in their work.
- ◆ Providers, patients, and families bridge the divide of income, education, culture, and language to engage in partnerships characterized by:
  - ▼ Two-way communication;
  - ▼ Respect for patient and family knowledge;
  - ▼ Real and active listening by health care providers; and
  - ▼ Full participation of patients and families.

### What are your hopes?

- ◆ The hospital of the future is realized in the not so distant future.
- ◆ Patients and families are included as partners in substantial numbers at all levels of care delivery as well as in the research, organizational, and business segments of the health care industry. This includes serving on quality improvement teams, policymaking councils, and hospital boards.

- ◆ Examples of how to encourage, build, and sustain partnerships are developed and disseminated.
- ◆ Patients and family members are involved in the selection and training of health care professionals through regular, ongoing roles in schools for health care professionals (on admissions committees and as faculty) and in health care settings (in hiring, orientation, and continuing education).
- ◆ All hospitals in the United States provide patient- and family-centered care without financial or organizational constraints, facilitated by:
  - ▼ The Joint Commission, ACGME & CMS providing leadership;
  - ▼ Payers such as CMS, TRICARE, and others funding patient- and family-centered initiatives and related research, basing reimbursement on compliance with standards of patient- and family-centered care; and
  - ▼ The government providing support through legislative mandates.
- ◆ Patients without family, who are unable to advocate for themselves, have similar care experiences to those who can and do advocate for themselves.

### What if....

- ◆ Mutual respect and caring are so perfected that you don't have to delineate a balance between the patient, family, and health care providers, and doing what is right is just like breathing.
- ◆ Patients and families are at the top of the health care hierarchy.
- ◆ Patients and family members serve as advisors for all health care legislation.
- ◆ Equal access to high-quality, coordinated health care is considered a right across the spectrum of needs—including primary care, specialty care, hospital care, home care, hospice, and the transitions between each—and is available to patients and families across the spectrum of resources, schedules, insurance, race, culture, education, language, and geographic location.
- ◆ Patient- and family-centered care is integrated across all levels of the health care system, is supported by incentives, and is a key criteria of care for the National Committee for Quality Assurance, The Joint Commission, Medicare, Medicaid, and private payers.
- ◆ Accreditation for schools for health care professionals and health care settings of all types, requires inclusion of patients and families—of all races, ethnicities, cultures, education, incomes, diagnoses, and geographic settings—in every type of training, planning effort, candidate search and interview process, performance review, administrative committee, quality improvement effort, policy development, and research projects.

- ◆ Children and youth are taught patient- and family-centered values and strategies at school, and health care consumers feel empowered to demand safe, effective, patient- and family-centered care.
- ◆ Access and continuity are assured by portable or electronic, integrated medical records, and prompt phone or e-mail access.

### What matters most?

- ◆ Sustainable development of a patient- and family-centered health care system occurs within the next several years.
- ◆ A health care system is developed that is safe, compassionate, equitable, and characterized by honesty, mutual respect, and inclusiveness.
- ◆ A simplified, integrated care system is developed, and results in a less harried and safer experience for the patient and the provider.
- ◆ Levers in the system encourage or mandate patient and family advisory committees in all primary care settings.
- ◆ Professionals receive a different type of education in order to support patient- and family-centered practice in all settings.
- ◆ Patients and families are offered education, access to useful information, and opportunities to choose their own level of involvement as equal partners in clinical care, quality improvement, design, and other decision-making activities in the health care system.
- ◆ Innovative, exciting changes that engage patients, families, and health care providers result in measurable, improved care outcomes on all six of the Institute of Medicine dimensions: safety, effectiveness, efficiency, timeliness, patient-centeredness, and equity.

## QUESTIONS ON WHICH REPORT RECOMMENDATIONS ARE BASED

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1. How can we ensure that every hospital has structures and processes in place to develop and sustain effective partnerships with patients and families to enhance quality, safety, and the experience of care?
2. How can we ensure that every ambulatory setting has structures and processes in place to develop and sustain effective partnerships with patients and families to enhance quality, safety, and the experience of care?
3. How can patient- and family-centered concepts be fully integrated in the curriculum and learning environments for medical schools, residency programs, and schools of nursing and allied health?
4. How can patient- and family-centered concepts be fully integrated in the curriculum and learning environments for graduate education programs and fellowships in health administration?
5. How can we best stimulate and develop an evaluation and research agenda to systematically measure outcomes and inform practice related to patient- and family-centered care?
6. How can payers and accrediting and licensing organizations encourage, support, and set expectations for effective partnerships with patients and families that enhance quality, safety, and the experience of care?
7. How can professional associations and disease-specific organizations facilitate the practice of patient- and family-centered care and the creation of partnerships with patients and families?
8. How can quality-improvement professionals and organizations partner most effectively with patients and families? How, specifically, can IHI partner with patients and families in the 100,000 Lives Campaign?
9. How can organizations concerned primarily about patient safety most effectively promote the development of partnerships among patients, families, and health care professionals?
10. What do patient and family advisors and leaders want and need in order to participate meaningfully in quality improvement and in the redesign of health care?
11. What strategies will best overcome the barriers to partnerships in health care settings, facilitate patient- and family-centered practice, and ensure the development of effective, sustained partnerships in all health care settings and academic programs?
12. What are the most effective strategies that can be used to obtain resources to support this work?
13. How can foundations and federal and state agencies further the development of effective, sustained partnerships with patients and families in health care?





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Founded as a nonprofit organization in 1992, the Institute for Patient- and Family-Centered Care provides essential leadership for advancing the practice of patient- and family-centered care. In 2010, the Institute's name was changed from the Institute for Family-Centered Care to the Institute for Patient- and Family-Centered Care to more clearly articulate the Institute's commitment to partnerships with both patients and families. By promoting collaborative, empowering relationships among patients, families, and health care providers, the Institute facilitates patient- and family-centered care in all health care settings serving individuals of all ages and their families.

The core concepts of patient- and family-centered care are:

- **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 health care leaders collaborate in policy and program development, implementation and evaluation; in facility design; and in professional education, as well as in the delivery of care.

The Institute serves as a resource for policy makers, administrators, program planners, clinical providers, educators, researchers, design professionals, and patient and family advisors and leaders for advancing the practice of patient- and family-centered care. The Institute convenes international conferences and in-depth, nationally acclaimed seminars for interdisciplinary, patient/family/professional teams, and publishes a monthly e-newsletter. Through the development and dissemination of materials, policy and research initiatives, training, technical assistance, and on-site consultation, the Institute is a central resource for increasing the understanding and skills necessary to build effective partnerships with patients and families.

Visit the Institute's website at [www.ipfcc.org](http://www.ipfcc.org) for additional resources, tools, schedule of events, profiles of patient and family advisors and leaders, and profiles of organizational change.

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