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Partnering with Patients and Families
To Design a Patient- and Family-Centered
Health Care System

A Roadmap for the Future

A Work in Progress

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HEALTH CARE SYSTEM: A ROADMAP FOR THE FUTURE

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Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care Delivery System: A Roadmap for the Future

Background Paper for June 2nd Meeting

A Work in Progress

Introduction

“Fixing” the problems that plague health care in the United States, most experts now agree, demands system-wide solutions. The health care system must be redesigned, and that enormous task must be undertaken collaboratively by all key stakeholders—health care professionals, administrators, planners and policy makers, and payers, as well as by patients and their families. Such partnerships must begin with a shared understanding of the problems, and a shared commitment to work together to solve them. Only then can an action plan for redesigning the health care system be developed and implemented.

This paper provides background information to facilitate the development of an action plan to ensure that sustained, meaningful partnerships with patients and families are 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. The paper was drafted at the request of the Robert Wood Johnson Foundation in preparation for a one-day invitational meeting convened by the Institute for Family-Centered Care (IFCC) and the Institute for Healthcare Improvement (IHI) in Cambridge, Massachusetts on June 2, 2006. The meeting will bring approximately 25 patient and family advisors together with administrative and clinical leaders from hospitals and other health care organizations and leaders from foundations and the IHI.

The goals for the meeting are:

To advance the conversation to develop a shared vision and action plan for improving health care by advancing the practice of patient- and family-centered care and creating partnerships with patients and families in all health care settings and within the organizations and agencies having an impact on health care.

To outline specific action steps and develop recommendations for:

- How to engage and support patients and families and 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, resources, structures, processes, and community to support and sustain this work.

To build commitment and synergy among participants and their organizations to advance patient- and family-centered care and to ensure that meaningful and sustained partnerships are an essential component of quality improvement and the redesign of health care in the future.

The purpose of this paper is to give meeting participants a common ground and to facilitate discussions during the June 2nd meeting. It begins by tracing the development of the term *patient- and family-centered care*. It then discusses the organizational and societal forces that have contributed to the current momentum for partnership building. The next section of the paper illustrates what patient- and family-centered care and partnerships look like in action; the examples are in some cases accompanied by evaluation and research findings that document the positive impact of patient- and family-centered change. The paper then lists a number of factors that experience and research have confirmed are essential to advancement of patient- and family-centered care; this is followed by a discussion of common barriers to progress. The paper concludes with the outline of key components of a plan for moving toward developing an action plan for building and sustaining partnerships among patients, families, and professionals in health care to achieve the outcomes of quality care desired by all. This section will serve as a basis for small-group discussions on June 2nd.

Patient- and Family-Centered Care Defined

Efforts to enhance patient and family partnerships in health care redesign must be based on a shared understanding of key terms that often come up in the health care literature and in discussions of quality improvement. Of these terms, none may be as critical as patient- and family-centered care. A brief history of how this term developed and of the organizations and individuals that contributed to the definition is therefore a necessary foundation for informed, productive discussions of engaging patients and families in the redesign of health care.

Balint and colleagues introduced the term *patient-centered medicine* in 1969.¹ The term *patient-centered care* was coined by the Picker Commonwealth Program for Patient-Centered Care, subsequently the **Picker Institute**, in 1988. At that time, this group began to do research aimed at documenting patients' needs and preferences in order to understand the patient's definition of high quality care. The group also began to explore models of care that could better address those needs. This research began with qualitative research aimed at understanding how patients and their families defined the *quality of care* in hospitals and, ultimately, across the continuum of care. The Picker Commonwealth Program for Patient-Centered Care used findings from focus groups and interviews with patients and families to create survey instruments that measure the patient's experience of care. These surveys, conducted by the Picker Institute for health

care organizations in the United States, Canada, and Europe, measured patients' experiences in eight dimensions of care: access; respect for patients' values and preferences; coordination of care; information, communication, and education; physical comfort (including help with activities of daily living); emotional support; involvement of friends and family; and preparation for discharge and transitions in care. In addition to safe and technically excellent care, these dimensions are deemed to be the most critical aspects of the care experience by patients and their families.²

In the United States, childbearing women and families helped drive family-centered changes within maternity care in the 1960s and 1970s. Early in the 1980s, families of children dependent on technology who were living in hospitals sought to work in a more collaborative manner with health care professionals and successfully advocated for legislation that would enable them to care for their children in home and community settings. In the 1980s, U.S. Surgeon General C. Everett Koop, the Maternal and Child Health Bureau of the **U.S. Department of Health and Human Services**, the **Association for the Care of Children's Health**, and other organizations collaborated with families in defining and providing leadership to advance the practice of family-centered care. These efforts focused on children with special health care needs in hospitals, in home and community care, and in public health programs. At the end of the 1980s, these leaders collaborated with women and families infected and affected by HIV and AIDS and applied similar principles and strategies to the development of family-centered systems of care for these patients and their families.^{3, 4, 5}

The term *patient- and family-centered care* has evolved over the past six years as an effort to build on the nature of the ideal care experience that the Picker Institute and others defined and to link this perspective with the concept of collaboration in planning, implementing, and evaluating systems of care. Patient- and family-centered care 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 allies for quality and safety within the health care system.^{2,6,7} It 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.^{8,9,10} Family members are more than surrogates to be called on when the patient is unable to make decisions on their behalf; they are essential members of the care continuum and care-giving team. It acknowledges the literature that confirms that social isolation is a health risk factor and hospital and ambulatory care policies and practices should not separate patients and families in caregiving and decision-making.

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 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.¹¹

This definition encompasses and acknowledges the infrastructure needed to create partnerships and to transform the experience of care and of caregiving for patients, their families, and for health care providers. Patient- and family-centered care describes the essential elements necessary to cultivate partnerships at the bedside, in care plan decision-making, healing relationships, and individual patient/professional interactions. More broadly, it provides a framework for formal partnerships with patient and family participation on advisory councils, committees and design teams.

Building Momentum for Patient- and Family-Centered Care: Organizational Support

In 2001, the **Institute of Medicine (IOM)** issued a highly influential report entitled *Crossing the Quality Chasm: A New Health System for the 21st Century*,¹² which analyzes the problems facing the U.S. health care system and sets forth recommendations for its improvement. Patient- and family-centered care offers the framework and strategies to enhance the quality and safety of health care and to make the recommendations in this report a reality.

For example, in its “Six Quality Aims for Improving Care,” the IOM report defines patient-centered care as “care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.”^{12(p40)} Partnerships among professionals, patients, and families are essential to such a caregiving process.

The *Quality Chasm* report also sets forth “10 Rules to Redesign and Improve Care.”^{12(p61-62)} All ten rules are consistent with patient- and family-centered approaches. Among the most relevant are:

Care based in continuous healing relationships. Patients should receive care whenever they need it and in many forms ... [T]he health care system should be responsive ... 24 hours a day, every day ... access to care should be provided over the Internet, by telephone, and by other means in addition to face-to-face visits.

Customization based on patient needs and values. The system of care should be designed to meet the most common types of needs, but have the capability to respond to individual patient choices and preferences.

The patient as the source of control. Patients should be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions ... The health system should ... accommodate differences in patient preferences and encourage shared decision-making.

Shared knowledge and the free flow of information. Patients should have unfettered access to their own medical information and to clinical knowledge. Clinicians and patients should communicate effectively and share information.

The need for transparency. The health care system should make information available to patients and their families that allows them to make informed decisions when selecting a health plan, hospital, or clinical practice, or choosing among alternative treatments. This should include information describing the system's performance on safety, evidence-based practice, and patient satisfaction.

Patient- and family-centered principles have a key role in the “Chain of Effects for Improving Healthcare Quality,” a third focus of the *Crossing the Quality Chasm* report. The IOM defines four levels of care and sets forth criteria that define quality care at each level. Collaboration with patients and families and the active participation of patients and families in care and decision-making are relevant to all four levels of the transformational change in health care envisaged by the IOM.

At the *experience* level: Care should be provided in a manner that is respectful, assures the candid sharing of useful information in an ongoing manner, and supports and encourages the participation of patients and families. Patients and families can contribute to the process of gathering information about patient and family perceptions of care as well as analyzing and responding to collected data.

At the *clinical microsystem* level: Patients and family advisors should participate as full members of quality improvement and redesign teams, participating from the beginning in planning, implementing, and evaluating change. Design of the experience of care should respect the patient and family, optimize access to that care, allow for participation, and support and stimulate activation and commitment to achieving their clinical goals.

At the *organizational* level: The perspectives and voices of patients and families are vital to quality improvement, planning, and policy and programmatic development at the organizational level. Patients and families should participate as full members of key committees such as patient safety, facility design, quality improvement, patient/family education, ethics, and research. Patient and family faculty programs should be an integral part of all schools and clinical programs preparing health professionals and administrative leaders. Patient and family advisory councils should

report to senior leadership, patient and family faculty programs should function in a way that assists academic institutions in achieving their academic mission.

At the *environment* level: The perspectives of patients and families can inform local, state, federal, and international agency policy and program development. These agencies, along with accrediting and licensing bodies, are in a position to set the expectation and develop reimbursement incentives that encourage and support the engagement of patients and families in health care decision-making at all levels. Policies developed and issued by these agencies also affect programs in graduate and undergraduate schools for the health professions and health care administration. For these reasons, these agencies are in an excellent position to support initiatives that build the collaborative skills of patients, families, and health care professionals, and agency personnel.

The Institute for Family-Centered Care is a non-profit organization that provides leadership for changes in health care that emphasize communication and relationships and sustained partnerships with patients and families. The Institute's mission is to advance the understanding and practice of patient- and family-centered care in all settings where individuals receive care and support. For more than a decade, the Institute has produced and disseminated guidance publications, videos, and web-based resources on how to collaborate with patients and families and apply patient- and family-centered concepts to policies, programs, facilities, staff practices, and professional education. The Institute also convenes a biennial international conference and in-depth seminars for interdisciplinary teams that include patient and family advisors that lead to change in the organizational culture of hospitals.

IOM recommendations confirm the value of the efforts of private, nonprofit organizations such as the Institute for Family-Centered Care, the Picker Institute, Planetree, New England SERVE, **Zero to Three**, the **American Academy of Pediatrics**,¹³ the **Society of Pediatric Nurses** and the **American Nurses Association**, the **Association of Maternal and Child Health Programs**, the **National Association for Children's Hospitals and Related Institutions**, **Family Voices**, the **Federation of Children with Special Needs**, the **Federation for Children's Mental Health**, and the **National Alliance on Mental Illness**, all of which have worked through their respective constituencies for more than a decade to advance the practice of patient- and family-centered care.

In addition, federal agencies such as the **Maternal and Child Health Bureau**,¹⁴ the **Substance Abuse and Mental Health Services Administration**, the **Centers for Medicare & Medicaid Services**, and the **HIV/AIDS Bureau** have been working for many years to create partnerships with patients and families in building systems of care. Improvement initiatives within the **Department of Defense** have likewise focused on patient- and family-centered change in recent years.

The priority that groups such as the **Joint Commission on Accreditation of Healthcare Organizations (JCAHO)**, the **National Committee for Quality Assurance (NCQA)**, the **Institute for Healthcare Improvement (IHI)**, and the **American Hospital Association**

(AHA) are giving patient- and family-centered care in their long-term organizational agendas is validation of the essential role these core concepts play in health care improvement and design. is encouraging. For example:

- In 2006, JCAHO convened its first patient and family advisory committee and published a book “Patients as Partners: How to Involve Patients and Families in Their Own Care.”¹⁵
- IHI has made patient- and family-centered care an area of innovation and research for 2006 and assured that such care is mainstreamed in all major programs, including the Institute’s 100,000 Lives Campaign, Quality Allies, and Transforming Care at the Bedside agendas.
- NCQA is creating a patient- and family-centered physician practice recognition program that will reward medical groups for patient- and family-centered practice design and interventions.
- In 2004, AHA collaborated with the Institute for Family-Centered Care to produce and disseminate a Toolkit on Patient- and Family-Centered Care to the chief executive officer of every hospital in the United States.¹¹ AHA’s McKesson Quest for Quality Prize recognizes hospitals that have demonstrated the commitment and exceptional ability to align their efforts in quality, patient safety, and patient- and family-centeredness.

The **Agency for Healthcare Quality and Research (AHRQ)** and the **Center for Medicare & Medicaid Services (CMS)** have supported the development of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys which measure the patient and consumer experience of care across the continuum of care, including health plans, medical groups, individual physicians, in-center hemodialysis centers, hospitals, nursing homes, home care services and assisted living facilities. CMS publicly reports data from many of the CAHPS surveys on its Web site, as do many other sponsors across the country. The National CAHPS Benchmarking Database also publishes an annual report on patients’ experiences of care. In addition to these efforts, many business provider coalitions such as the **Massachusetts Health Quality Partnership**, the **Pacific Business Group on Health** and large payers are publicly reporting these data to help consumers make informed choices about providers and are incorporating these surveys measures in pay-for-performance programs.

The **National Quality Forum’s (NQF)** mission is to improve American healthcare through endorsement of consensus-based national standards for measurement and public reporting of healthcare performance data that provide meaningful information about whether care is safe, timely, beneficial, patient-centered, equitable, and efficient. The NQF consensus approval process involves all stakeholders in the health care system, including patient and consumer groups. The consumer members have been very active and effective in pushing the adoption of measures that are publicly reported to consumers and that help them make informed choices about providers and health care services. NQF consumer members are also leading the Consumer Disclosure project to help select and standardize publicly reported measures of quality.

Professional organizations such as the **American College of Physicians and American Board of Medical Specialties** (ABMS) have been engaged in similar pursuits, as have scores of individual researchers. The ABMS will use a subset of questions from the CAHPS clinician-group survey as part of its maintenance of certification program for board-certified physicians in the future.

Patient and family centered care is at the heart of nursing practice. In 2003, the **Society of Pediatric Nurses** and the **American Nurses Association** (SPN/ANA) published *Family-Centered Care: Putting It into Action, The SPN/ANA Guide to Family-Centered Care*.¹⁶

The **Accreditation Council of Graduate Medical Education** (ACGME) recognizes that knowledge of medical science alone is not sufficient for physicians of the future and that effective communication is essential to quality and safety. In order to work toward that objective, the ACGME Outcome Project articulates the expectation that residents must demonstrate competency in the following six areas: patient care, medical knowledge, practice-based learning and improvement, interpersonal and communication skills, professionalism, and systems-based practice. All ACGME-accredited residency programs must demonstrate how their curricula and teaching strategies ensure resident competency in each of these six areas. Integrating core concepts of patient and family-centered care and the opportunity to learn from patient and family faculty in residency training programs is seen as essential in meeting the goals of the Outcome Project. Also by July 2006, all ACGME-accredited residency programs will be required to have individualized learning plans for residents.

Momentum for patient- and family-centered care crosses national borders. In the United Kingdom, the **National Health Service** (NHS) has mandated that there be structures in place in all NHS hospitals and primary care clinics that support patient and carer (family) participation in quality-improvement efforts. Patients Accelerating Change is a program in the United Kingdom bringing patients together with clinicians and managers in hospitals and primary care settings to transform health care services. The **Picker Institute Europe** and the NHS Clinical Governance Support Team are helping prepare and support people for this collaboration. Across Canada, patients and families are increasingly engaged with provincial and national efforts to improve quality, with a particular focus on access and patient safety.

Also on the international level, the **World Health Organization** launched the *World Alliance for Patient Safety* in 2004. Patient and families are at the center of this international effort to improve patient safety. *Patients for Patient Safety*, one of six action areas of the **World Alliance**, is designed to ensure that the perspectives of patients and families are a central reference point in shaping this important work. (http://www.who.int/patientsafety/patients_for_patient/en/).

Building Momentum for Patient- and Family-Centered Care: Social Forces for Change

The organizational momentum for patient- and family-centered care described above is often based on the need to respond to a number of social forces for change that confront the U.S. health care system. For example, widespread public attention on the incidence of medical error has fueled a consumer-driven national agenda. The focus on medical error and patient safety has become a powerful platform for advocacy, partnerships, and change. Groups such as the Patient and Family Council of the **National Patient Safety Foundation (NPSF)**, **Consumers Advancing Patient Safety (CAPS)**, **Partnerships for Patient Safety (p4ps)**, **PULSE**, and **Medically Induced Trauma Support Services (MITSS)**, which focus on improving the safety of care, have emerged. Other groups, such as **SorryWorks**, are focusing efforts on apology and disclosure.

Technology is a second factor supporting consumer-driven efforts. The advent of the Internet has greatly increased consumer access to health information. A 2004 paper from the Pew Internet and American Life Project states that 95 million Internet users reported that they seek online information about health-related topics, including specific diseases and conditions, treatments, diet, fitness, and medications.¹⁷ Federal agencies such as the **National Institutes of Health** and the U.S. **Department of Veterans Affairs** are working to ensure that consumers are guided to credible and accurate health information sites. Projects such as the **Markle Foundation's** Personal Health Technology Initiative and the **Robert Wood Johnson Foundation's** Health e-Technology Initiative are focused on enhancing the ability of patients and families to use personal health records and other health technologies to become active partners with their health care providers.

Many health care organizations have converted to or are in the process of converting to electronic medical records. This presents an opportunity to create a charting and documentation system that supports patient- and family-centered practice rather than traditional provider-centered practice. Documentation forms and templates need to capture patient and family priorities, goals, concerns, and observations and assist the patient and family as well as health care professionals in ensuring consistency and coordination of care across settings. Portals need to be designed to ease patient (and family, when appropriate) access to information in the medical record. Patients and families should be involved in efforts to design electronic documentation systems as they are at the **MCG Health System** in Augusta, Georgia and at **Partners HealthCare, Group Health** and **Kaiser Permanente**. (www.mygrouphealth.org, www.kponline.org, www.patientgateway.org.)

A third force for change is a growing emphasis on health literacy. Consumers cannot be informed participants in their care if information is provided to them in a format they cannot understand. Many studies have shown that patients with poor literacy skills receive less preventive care, have less knowledge about chronic conditions, perform more poorly at asthma self-care, use health care services at a higher rate, and have worse outcomes on a variety of measures than do patients with better literacy. Initiatives that engage patients who are late readers as partners, such as the Patient Safety

Committee for the **Iowa Health System**, are beginning to address the issues of health literacy as well as national initiatives sponsored by the AMA and **Pfizer**.

The trend toward earlier hospital discharge and expanded home care has stimulated a need for programs for training and supporting family caregivers. Planning for discharge should begin well before day of discharge, and patients and families should participate in the discharge-planning process. Many studies of medical error have indicated that a large percentage of these errors occur at transition points in the health care delivery process. Better coordination of discharge planning, supported by ongoing, informed communications among professionals, patients and families can help overcome such problems. Increasing attention is being given to the redesign of discharge planning processes and these efforts need to include patients and families in the planning processes.

Another factor supporting patient and family partnerships in health care is the emergence and application of current evidence-based principles in the design of acute-care hospitals, ambulatory facilities, nursing homes, and other facilities, as well as of individual units. Health administrators, health care providers, and design professionals today realize that supportive health care facility design is an integral ingredient of quality care. These leaders recognize that, as Horsburgh has written, one way to improve design is simply by “listening to ... patients—they are critical to designing spaces that enable patients to heal.”¹⁸ There is an unusual amount of activity in health care facility construction and renovation today. This creates a unique opportunity to involve patients and families in all stages of the design-planning process. Through collaborative design planning, health care environments can be created that more effectively support family presence and participation, support staff in collaborating within and across disciplines and with patients and families, and promotes safety. The Center for Health Design’s Pebble Project is promoting this approach in health systems across the US.^{19, 20}

Remaking American Medicine, a four-part primetime television series intended for broadcast on **PBS** in October 2006, has as an overarching theme, patient- and family centered care. The goals of *Remaking American Medicine* and its associated outreach campaign, is to stimulate a national dialogue about the importance of improving American health care, raise awareness about opportunities for improving the quality of health care, facilitate the development of local coalitions that will amplify the messages of the campaign, and encourage Americans to become active participants in their own care and in transforming the health care system.

Discussions of patient and family partnerships related to underserved communities, individuals with low literacy, and other at-risk populations often reveal the misperception that these individuals cannot participate effectively in collaborative endeavors. While certainly complex, the recently published paper *Patient-Centered Care for Underserved Populations: Definition and Best Practices*, prepared for The **W. K. Kellogg Foundation**, makes a clear case for the utility, applications, and results.²¹

All of the work referenced above responds to a growing clarity from patients and families around the world. The Institute for Healthcare Improvement described patients and families increasingly expecting 100% of the time to:

- To be listened to, taken seriously, and respected as a care partner.
 - To have my family/care-givers treated the same.
 - To participate in decision-making at the level I choose.
- To be always told the truth.
 - To have things explained to me fully and clearly.
 - To receive an explanation and apology if things go wrong.
- To have information communicated to all my care team.
 - To have my care timely and impeccably documented.
 - To have these records made available to me if requested.
- To have coordination among all members of the health care team across settings.
- To be supported emotionally as well as physically.
- To receive high quality, safe care.²²

These current forces, combined with the foundation for patient- and family-centered care built over the past quarter century, have led to important advances in a number of health care settings, most notably in pediatrics, maternity, newborn intensive care, HIV/AIDS, and children’s mental health. Today, forward-thinking leaders have begun to apply the concepts that have worked so well in these areas to a wider variety of settings. Some examples of this progress are cited in the following section.

Collaboration with Patients and Families in Quality Improvement and Health Care Redesign: What Does It Look Like? How Do We Know It Works?

Hospitals

- The **MCG Health System** (MCG) in Augusta, Georgia, has been committed to collaborating with patients and families since 1993, when it began planning for the construction of a Children’s Medical Center. collaborated with clinicians and administrative leaders in developing the vision and philosophy for the new hospital. The Children’s Medical Center has ranked among the highest in patient/family satisfaction in a national database of comparable hospitals since it opened in 1998. Since the late 1990s, MCG has been working to integrate patient- and family-centered care within the infrastructure of the entire organization, thus extending it beyond pediatrics. MCG’s senior leaders have made a commitment to these efforts. Patient- and family-centered values are clearly defined and included in the organization’s strategic plan. The human resources department ensures that new staff possess attitudes and skills consistent with patient- and family-centered care. Behaviors for customer service and for patient- and family-centered care have been defined, and both sets of behaviors are included in position descriptions and MCG’s performance-review system.

More than 125 patient and family advisors are currently involved in collaborative endeavors at MCG. These individuals serve on Health Partners—a patient and family advisory council for all adult clinical programs, a Family Advisory Council and a Children’s Advisory Council for the Children’s Medical Center, a

Patient and Family Advisory Council for the Multiple Sclerosis Clinic, and the Patient Safety and Medicine Reconciliation Committees. For information about the MCG Patient and Family Faculty Program and curricular revisions, see page 20 in the professional education section. Patient- and family-centered care has become the business model for the organization. It has had an impact on each of MCG's business metrics, namely, finance, quality, safety, satisfaction, and market share.

The quality improvement data emerging over the past three years for MCG's Neuroscience Center of Excellence adult inpatient unit are as follows:

- Patient satisfaction scores rose from the 10th to the 95th percentile.
- Length of stay in the neurosurgical unit decreased by 50%.
- Medical error rate fell by 62%.
- Discharges (volume) increased 15.5%.
- The nursing staff vacancy rate fell from 7.5% to 0%, with a waiting list of five RN's.
- Positive change in perceptions of the unit by faculty, staff, and house staff.^{23, 24}

■ *Pursuing Perfection* is an IHI program funded by the **Robert Wood Johnson Foundation** to implement the recommendations of the IOM *Crossing the Quality Chasm Report*. As a Pursuing Perfection project that aligns with their strategic plan, **Cincinnati Children's Hospital Medical Center** is committed to advancing the practice of patient- and family-centered care and to improving the experience of care for patients and families. The Hospital's senior leadership is ensuring that there is support for this effort at the organizational level and within clinical microsystems. Quality improvement has been the driver of transformational change within this academic medical center's inpatient and outpatient programs. Partnering with families occurs on multiple levels: at the Family Advisory Committee, on quality-improvement teams, on hospital-wide teams and unit-based committees and task forces. Families are no longer viewed as visitors, and units are open 24/7. On many units, families are encouraged to be present for rounds and given choices about how they would like to participate. These patient- and family-centered rounds are linked with the patient's discharge goals. The charge nurse/bedside nurse participate in these rounds and ensure that discharge goals are printed out daily and available for 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.

The emerging quality improvement data indicate:

- Patients are being discharged sooner.
- Medical order entry error rates have been reduced from 7%-9% to 1%.

- Faculty report that patient- and family-centered rounds are a more effective way to teach.
- Families are involved in decision-making.²⁵

■ At **Concord Hospital** in Concord, NH, an interdisciplinary team that included patient and family members worked to implement several initiatives consistent with patient- and family-centered principles within its adult cardiac surgery program. Two of the changes were the introduction of a collaborative approach to rounds that involves all disciplines and the creation of a peer support program. Peer mentors were involved in the development of various aspects of the program. But the most profound change at Concord Hospital related to the way rounds were conducted. The cardiac team changed the traditional, practitioner-centered, physician-led rounds in favor of a nonhierarchical approach that involves all members of the care team as well as the patient and family. The new approach to rounds featured a structured way for reviewing the patient's care over the previous 24 hours, for planning care for the next 24 hours, and for openly discussing and tracking any "glitches" in care. The hospital was recognized in 2002 for Collaborative Rounds with the John M. Eisenberg Award presented by JCAHO and NQF. Data from the program during this time period showed remarkable improvements in clinical outcomes, patient satisfaction, and staff satisfaction.²⁶ Despite positive outcomes, the process changes could not be sustained.

One reason for Concord's inability to maintain its momentum may be a failure to recognize that creating ongoing, sustainable partnerships with patients and families requires profound changes in organizational culture and leadership behaviors. Creating such partnerships, experience at this hospital and others has shown, will initially produce benefits but will also cause tension within the organization, as individual practitioners adopt the new practices in varying degrees. Senior leaders must be prepared for this phenomenon. When problems inevitably arise, they must remain grounded in a shared vision that interdisciplinary collaboration, combined with partnerships with patients and families, leads to the best outcomes and to high-quality, safe care.

Support from midlevel managers is also key for developing and sustaining the changes in processes that undergird change in organizational culture. Managers must be given opportunities to learn to lead in an empowering way that enables exploration and reflection, rather than mandate and "education." Changes in practices related to communication and coordination of care, for example, usually require that staff acquire new skill sets. An organization must be willing to provide its staff members and teams time and support not only for training but also for reflective practice.

Finally, introducing and sustaining culture change involves sequential power shifts. This shift must begin within traditional practitioner hierarchies, then gradually expand to include patients and families. Clinical teams may need to

learn how to collaborate across and within disciplines before they can collaborate effectively with patients and families.

- **Maine Medical Center** in Portland is a 606-bed community teaching hospital serving the entire state of Maine and northern New England. Enhancing communication within the organization and between the hospital and the communities it serves is a priority for **Maine Medical Center**. In 2004, the Strategic Initiative Alignment Team that included a family advisor developed a white paper on patient- and family-centered care and submitted it to senior administration. As a result of this document, advancing the practice of patient- and family-centered care has been integrated within the hospital's patient safety work. It is now a central focus of the hospital's three-year strategic plan, entitled *Safe Patient- and Family-Centered Care: A Partnership of Patients, Families, and Caregivers*. The hospital has a Patient and Family Advisory Council for adult health care and a similar council for the **Barbara Bush Children's Hospital**. Pilot projects were initiated in six specific clinical areas. Efforts are now underway to spread best practices and lessons learned. The Volunteer Services Department is collaborating with clinical and administrative leaders to recruit, train, and support patient and family advisors to serve on teams for specific clinical areas. Progress and the tracking of outcomes are built into the strategic planning process and are monitored by hospital senior leadership.

- In 1997, **Dana-Farber Cancer Institute (DFCI)**, **Brigham and Women's Hospital**, and **Massachusetts General Hospital** combined their adult oncology programs to create the Dana Farber/Partners CancerCare Program. As one of the initial activities, patients and families were asked to envision the ideal experience for cancer care. They also participated in the development of tools to measure patient perceptions of and satisfaction with care and in efforts to improve patient safety at DFCI after a tragic chemotherapy overdose.

Since that time, patients and families have taken on increasingly responsible roles in all aspects of DFCI planning and program development. DFCI now has both an Adult and a Pediatric Patient and Family Advisory Council. Among the Councils' many accomplishments are the following:

- Revamped the process by which patients are admitted to and move through the Emergency Department.
- Established a central office and support staff to support the councils and a phone line, for patients and families to access the Council.
- Worked on passage of the Massachusetts Pediatric Palliative Care Bill.
- Worked to reduce waiting times in clinics and infusion.
- Developed an end-of-treatment transition program in pediatric oncology which has been widely implemented and is now being expanded to adult care.
- Participated in the planning of renovations for all inpatient, ambulatory, radiology, and radiation therapy areas.

- Published articles in *Inside the Institute*, the hospital bi-weekly newsletter, and *Side by Side*, the quarterly newsletters by patients and families for patients and families and the hospital community.
- Rounding on inpatient and outpatient care units.
- Participated in the implementation of a family participation in rescue events policy.

In addition to their work on the two central councils, members contribute to decision-making and planning processes at DFCI in numerous other ways. At least one Council member participates on almost every management and operating committee at the Institute. As a result, Council members have the opportunity to gain firsthand familiarity with DFCI's broad scope of operations. For example, the Council chair serves on DFCI's Clinical Operations Working Committee and the Clinical Operations Group. The Council Chair also is a member of the Clinical Operations Leadership Team of the **Dana-Farber/Brigham and Women's Cancer Center**. Other members of the Council serve on the Joint Quality Improvement/Risk Management Committee (the Board of Trustees Quality Committee), the Patient Safety Committee, the Zakim Center for Integrative Therapies Executive Committee, the Diversity Committee, and the Art and the Environment Committee, as well as other ad-hoc and ongoing task forces and committees.

DFCI has successfully navigated through a 10-year period of enormous transition, change, and growth. At all levels of the institute, patient- and family-centered care is considered a key factor in this overall success and specifically enabling: high levels of ambulatory patient satisfaction, very low levels of medication error, consistent and dramatic volume increases, and high levels of staff satisfaction.

- In 2002, the **University of Washington Medical Center** in Seattle made a long-term commitment to advance the practice of patient- and family-centered care. A high-level Patient- and Family-Centered Steering Committee was appointed; the work of this group is overseen at the executive level by the Chief Nursing Officer. Following initial training and technical support on how to create partnerships with patients and families, the Medical Center created Patient and Family Advisory Councils for three clinical areas—Rehabilitation, Oncology, and Perinatal Care.
- Across the United States, there are very few quality-improvement committees and councils that involve childbearing women and families in improving maternity care. The **Birth Center at United Hospital** in St. Paul, Minnesota is a notable exception. The Birth Center has had a Family Advisory Council since 1997. Council members participated in the redesign of obstetrical services at United Hospital. They consolidated parent education materials into a single manual. They made recommendations for grief support for families who had experienced a perinatal loss. A parent was appointed to the Perinatal Loss Committee. The Council recently collaborated with the John Nasseff Heart Hospital Advisory Council on women's heart health issues and intergenerational health issues,

bringing women's perspectives and ideas to these important public health concerns.

- **Boston Medical Center** serves a diverse population in an urban community. In the 1990s, with leadership from the Pediatrics Department, a *Parents as Partners* Program was created to provide a centralized structure to advance the practice of family-centered care and to support the involvement of families in the Department's quality-improvement efforts for the Department. Improving outcomes and patient/family satisfaction were goals for this work. A staff liaison position was created at the departmental level, and a member of the community whose children received care in the hospital was appointed to it. Parents became involved in advisory roles and helped develop and staff a variety of innovative programs. Parent advisors tackled issues such as reducing the number of unkept appointments, developing programs to encourage father involvement in their children's health care and development, and enhancing family-centered, culturally competent communication skills for medical students and residents.

Despite this initial success, the central, department-wide coordination was eliminated in 2002 because of fiscal pressures. Since that time there has been no central coordinator and no unified means for recruiting, training, and supporting family advisors. Each clinical area within pediatrics is responsible for taking on this responsibility individually. Since the disbanding of the central program, patient satisfaction scores, which increased dramatically following the introduction of the centralized program, have fallen. Experiences at other similar institutions indicate that the absence of the central coordinator may be a key reason for this discouraging loss of momentum. Having a designated staff liaison for collaborative endeavors facilitates the ongoing, effective participation of patient and family advisors. Such a position is particularly important for organizations serving diverse communities which may have less experience in participating in quality improvement work.

Ambulatory Settings

- Partnering with patients, families, and clinicians is an essential component of all initiatives at the **John D. Stoeckle Center for Primary Care Innovation at Massachusetts General Hospital**. It is a central theme of its innovation, education, and research activities. The Center's Advisory Board has four seats dedicated to primary care patients: two representing adult practices and two representing pediatric practices. Plans are under way to create a Patient and Family Advisory Council in each of the Center's primary care practices, beginning with patient involvement in the design of pilot projects and work related to the design of the Ambulatory Practice of the Future (APF).

Patients and families have participated in the development and piloting of innovative approaches to primary care such as:

- Dissemination of the “Foundation for Informed Medical Decision Making” decision support videotapes to primary care patients through the use of electronic reminders and e-prescriptions. The tapes are e-prescribed by the primary care clinician and then mailed to patients’ homes by staff of the Blum Patient and Family Resource Center.
- Pre-Visit Preparation and Medication Reconciliation: Dissemination of pre-visit preparation forms and a list of the patient’s current medications for updating as part of the primary care appointment reminder letters.

The Center’s general seminars and its APF seminars focus on topics where patient and family involvement is critical. Patients and family members often work with professional faculty in presenting and facilitating these seminars. Seminar topics have included health literacy, e-mail communication with clinicians, the use of interpreters for non-English-speaking primary care patients, a chronic disease management model for patients with diabetes, and applying universal design principles to improve the physical environment for patients, staff, and clinicians. The theme for the Center’s APF seminars is effective methods of partnering with patients and families. These seminars are focusing on such topics as ways to create effective patient and family advisory councils and effective methods of involving patients in collaborative self-management programs. The Center is involved in teaching about patient- and family-centered care and shared decision-making in the **Harvard Medical School** “Doctor-Patient III” course and in its program for MD-MBA’s.

- The mission of the **Center for Medical Home Improvement (CMHI)**, at the Crotched Mountain Foundation in Greenfield, New Hampshire, is to establish and support networks of parent/professional teams to improve the quality of primary care medical homes for children and youth with special health care needs and their families. A *medical home* is a process of care offered by primary care providers in partnership with families of children with special health care needs. CMHI’s model for change and improvement is one of practice-based quality improvement. It blends parent insight, professional knowledge, and planned care to build primary care medical homes.

The following results emerging from this collaborative approach to quality improvement are based on surveys of 83 families before and two years after medical home improvement:

- The number of families with written care plans doubled.
- Hospital stays and hospital days were significantly reduced. Prior to beginning the medical home improvement process, 9% of children had between 4 and 10 stays in a year; two years later, only 1% of children had that range of hospital stays.
- Family focus groups and surveys increased by 30%.
- Parents’ worries about their child’s health were cut in half.

- School absences were reduced by more than half.²⁷

The CMHI Web site has practical assessments and resources for providers in community practices and families serving on quality improvement teams, including the Medical Home Improvement Kit with measurements, strategies, and “A Guide for Parent and Practice “Partners Working to Build Medical Homes for Children with Special Health Care Needs,” can be downloaded from this site (<http://www.medicalhomeimprovement.org>).

- The medical home concept has been embraced by both the **American College of Physicians**, which brings internal medicine physicians into the rethinking of primary care practice through its initiative called *The Advanced Medical Home* (http://www.acponline.org/hpp/adv_med.pdf), and the **American Academy of Family Physicians**, which in its *Future of Family Medicine* report (<http://www.futurefamilymed.org/index.html>) advocates for a "new model" of care based on patient-centered care provided through a medical home. These initiatives build on the pediatric experience with medical home as well as on the chronic care model. As internal medicine and family medicine clinicians seek to improve approaches to health care delivery, they will benefit from the active involvement of patients and families in the development of their practice redesign efforts.
- The mission of the **National Center for Cultural Competence (NCCC)** in Washington D.C is to increase the capacity of health and mental health programs to design implement, and evaluate culturally and linguistically competent service delivery systems. It has developed cultural and linguistic competency self-assessment tools for organizations and similar assessment tools for health care practitioners. *Is Your Youth with Special Health Care Needs Prepared to Partner with the Medical Home?* is a recent NCCC publication available on its Web site <http://gucchd.georgetown.edu/nccc/documents/TransitionArticle.pdf>. An article on youth as advisors will be available in the near future.

NCCC is working with the **Bureau of Primary Health Care (BPHC)** to assist BPHC and its funded programs (Community Health Centers, Migrant Health Centers, Health Care for the Homeless grantees, Healthy Schools, Healthy Communities grantees, Health Care for Residents of Public Housing grantees, Primary Care Associations and Primary Care Offices) to provide high quality primary health care services that are culturally and linguistically competent and that reflect the principles of patient- and family-centered care.

- The **Commonwealth Fund** devoted millions of dollars to the Picker/Commonwealth Program and to the Picker Institute. It has recently launched a Patient-Centered Primary Care initiative, which presents another opportunity to involve patients and families in the planning, implementation, and evaluation of new approaches to primary care (http://www.cmwf.org/programs/programs_list.htm?attrib_id=11936).

Professional Education

- Since 1999, faculty from the **University of Pennsylvania School of Medicine** have partnered with patients and families who serve as teachers dedicated to shaping the practice of future physicians. This work evolved from the family-centered initiatives at the **Children’s Hospital of Philadelphia** that began in 1992. Parents whose children are cared for at The Children’s Hospital of Philadelphia are guest Family Faculty for a “Doctoring 101” course. The curriculum and format were created by the Family Faculty. The semester-long, required course explores topics such as delivering difficult news, critical conversations, living with illness and disability, and death and dying. In this powerful forum, medical students have a unique opportunity to understand illness from the perspective of patients and families.
- The **University of Pennsylvania School of Nursing** has likewise made efforts to include patient and family as faculty. Families of chronically ill patients from The Children’s Hospital of Philadelphia share a long partnership with faculty at the University of Pennsylvania School of Nursing, both in the undergraduate and graduate programs. Family leaders share the podium with nursing school faculty, teaching about patient- and family-centered care, collaborative care models, communication at the bedside, and therapeutic relationships. A family consultant teaches an annual family-centered care seminar to advanced-practice nursing students at the University of Pennsylvania which is simulcast to advanced-practice nursing students at St. Jude Hospital in Memphis, Tennessee. Feedback from nursing students indicates these family-led seminars have the greatest impact of all the education opportunities they experience. Family leaders have also partnered with nursing faculty to co-author articles in publications such as *Pediatric Nursing* on family-centered topics including, family as faculty, therapeutic relationships, the language of labeling patients and families, and establishing safe, effective, family-centered partnerships at the bedside. Family leaders have co-presented with nursing school faculty on these topics at national nursing leadership forums.^{28, 29}
- The **MCG Health System** and the **Medical College of Georgia** in Augusta are integrating patient- and family-centered care in the five schools within the Health Sciences University and its clinical sites. The first step was the creation of a Patient and Family Faculty Program. Twenty-eight patient and family faculty were recruited and trained for teaching in a variety of venues in the nursing school, medical school, and schools of allied health. A directory is available to faculty that lists the patient and family faculty and presents brief summaries of their experience and topics they can speak on. MCG is conducting a comprehensive assessment of how patient- and family-centered care is integrated in all levels of the curriculum. Patient or family advisors **are included in the search processes** for academic department chairs. The expectation to further the understanding and practice of patient- and family-centered care is included in

faculty employment contracts. The **Medical College of Georgia** has recently created the Center for Patient- and Family-Centered Care to further the research agenda.

- A parent advisor is an integral, decision-making member of the team that interviews candidates and chooses candidates for residencies in obstetrics/gynecology at the **University of Washington Medical Center**. All first-year residents spend time during orientation with Patient and Family Advisory Council members. Families developed resource materials to assist the medical students and residents in developing communication skills. The first efforts were so successful that now, at residents' request, family advisors meet with residents during their second year to review and to enhance their ability to communicate effectively with families.
- Patients living with a life-threatening illness are teachers of first-year medical students at **Harvard Medical School**. 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, about the experience of illness and treatment from the patient and family.³⁰

Quality Improvement Organizations and Initiatives

- As noted earlier in this report, the **Center for Medical Home Improvement** is using quality-improvement methodology and partnerships with patients and families, physicians, and office staff to transform primary care practices. This work is happening in communities and in statewide and national collaboratives. Other quality improvement activities are described below.
- The **National Initiative for Children's Health Care Quality** (NICHQ) is now involving families in a number of its quality improvement endeavors. One of its current programmatic areas is providing seamless, evidence-based, family-centered care for children with chronic conditions.
- The **Robert Wood Johnson Foundation** funded IHI to lead a three-year national initiative called *Quality Allies: Improving Care by Engaging Patients*. This project, also supported in part by the **California HealthCare Foundation**, is focused on improving the capacity of individuals with chronic conditions, their families, and ambulatory care providers to engage in collaborative self-management. Collaborative self-management support is the care and encouragement provided to people with chronic conditions to help them understand their central role in managing their illness, make informed decisions about care, and engage in healthy behaviors. The leadership team includes representatives from **Rush Medical College**, the **John H. Stroger Hospital of Cook County**, the **MacColl Institute**, the **Institute for Healthcare Communication**, the **Institute for Family-Centered Care**, and the **White Mountain Research Associates**. Twenty ambulatory practices from across the

nation were selected to participate. Patients with chronic conditions and their families have been active participants in the development and implementation of this project, serving on the national advisory board, as faculty, and as members of each of the 20 teams. The request for proposals to participate in this innovation community stated that each team must include patients and families as full members. Patients and families are participating in the development of an online community for patients, families, providers, and community agencies. For more information see the program site at <http://www.ihl.org/IHI/Programs/QualityAllies/QualityAllies.htm>.

- Since 1995, the **Vermont Oxford Network (VON)**, an international organization devoted to improving the quality and safety of newborn intensive care (NIC), has sponsored a series of quality improvement collaboratives. VON began exploring family-centered newborn intensive care in 1998, and since that time has integrated it within its collaboratives. In the NIC/Q 2000 collaborative, families assisted in the development of the project's evaluation tools, participated in site visits, attended collaborative meetings, and spoke at national meetings. In NIC/Q 2002, families' perspectives helped guide the development of a Web-based resource on evidence-based, family-centered newborn intensive care for providers and family advisors. A family member served as a consultant to the collaborative and was invited to serve as a co-investigator on a study on patient safety funded by the **Agency for Healthcare Research and Quality**. In the current initiative, 12 newborn intensive care units (NICUs) are participating in an improvement project titled "Your Ideal NICU," and at least one parent serves on the quality improvement team for each center. In addition to participating in the collaborative, these parents are actively involved in their units as advisors. They perform a variety of roles, including leading family advisory groups, coordinating and providing peer-to-peer support, developing family resource centers, providing training for physicians and staff, and training and mentoring other family advisors.

- As a grantee in the IHI Pursuing Perfection initiative 2001-2006 (see page 13), **Whatcom County** brought together the community practices and programs (**Family Care Network North Cascade Cardiology**, the **Center for Senior Health**, and **SeaMar Community Health Center**) with **St. Joseph Hospital** of the **PeaceHealth System**, to be a "learning lab" for the implementation of IOM *Crossing the Quality Chasm* recommendations. The centerpiece of the **Whatcom County** Pursuing Perfection initiative is the *Shared Care Plan*, a Web-based tool that facilitates communication between patients, families, and their health care team members. Neither a medical record nor a substitute for such a record, the *Shared Care Plan* is instead a personal health record with a link to the medical record that aids in medication reconciliation. The Plan is accessible to all members of a participating patient's team at the discretion of the patient. The plan provides a user-friendly way for patients to share information with their Care Teams to help manage their chronic conditions and promote the flow of information. A sample *Shared Care Plan* can be viewed at

<http://www.sharedcareplan.org>. Patients and families had a key role in designing the Shared Care Plan. As a result, the Plan responds to a major concern commonly voiced during the planning meetings. As one family member put it, “The electronic medical record is fine, but it doesn’t solve the problem. It doesn’t help me manage my chronic condition, when I have more than one doctor or organization involved in that care.”

Discussions revealed that patients and families wanted, among other things, a record that captured a broad range of information—information that would follow them across settings: clinical information was just the start. For example, they emphasized the importance of including in the plan other key pieces of patient data, such as information on living conditions, dietary restrictions, spirituality, and preferred learning styles. Families wanted the tool to answer the question, “What are the things about me as a person that are important to know?” The Shared Care Plan is an example of how patient and family involvement can be instrumental in the development of tools that solve complex and often-intractable problems such as coordination of care.

Professional Associations and Disease-Specific Organizations

- Advances in clinical care have resulted in improvements in life expectancy and quality of life for people with CF. Despite these successes, much work remains to be done.

The mission of the **Cystic Fibrosis Foundation** is to ensure the development of the means to cure and control CF and to improve the quality of life for patients with the disease. The Foundation’s investments in research, drug discovery, and drug development are paving the way for future progress. The Foundation is also committed to a vision of exemplary care at all of its care centers in order to extend the quality and length of life for people affected by this disease.

In its newly adopted strategic plan, the CF Foundation articulates the belief that strong partnerships among patients, families, and care providers are essential to achieving optimal outcomes for patients with chronic conditions such as CF. Such partnerships will make it possible to customize care to the needs and preferences of patients with CF and will catalyze the incorporation of self-management strategies and promote patients’ adherence to their medical regimens. To truly deliver patient- and family-centered care, the CF Foundation believes that it must incorporate the perspectives of people with CF and their families in all its work.

A patient served on the planning group that initiated the process of developing a strategic plan for quality improvement for CF patients. A patient co-chairs the People with CF and Family Task Force, which is developing tools for patients and families to use to work with the Foundation’s centers for quality improvement.

Incorporating people with CF and their families into the improvement work is a priority focus of the Foundation's current Learning and Leadership Collaborative IV. The poster session for this collaborative featured all the ways that CF Centers have created structures to support the involvement of patients and families in quality improvement and health care redesign. To launch a new Family Advisory Council, the Connecticut CF Center planning a brainstorming session on "Barriers to Perfect Care." From the ideas generated by families, an agenda for change was developed. At Johns Hopkins CF Center, an adult patient is helping to redesign clinic processes to minimize the risk of infection. Because of the risk of infection, he is involving other patient advisors in this initiative through email.

- The **American Academy of Orthopaedic Surgeons (AAOS)** has made a commitment to create a culture of patient-centered care in the organization and in individual orthopaedic practices. AAOS defines patient-centered care as "the provision of safe, effective, and timely musculoskeletal care achieved through cooperation among the orthopaedic surgeon, an informed and respected patient (and family) and a coordinated health care team." As part of a campaign, "*Getting Better Together*" *Through Patient-Centered Care*, AAOS has developed a set of tools and resources for its membership. It has asked each member to sign a pledge for how he or she will work with patients and families and that members display this pledge in their offices. A goal of the AAOS's Communications Skills Mentoring Program, which has been under way for the past few years, is that residents in all 150 orthopaedic residency training programs nationwide undergo an AAOS course in Patient-Centered Communication by 2008, and that 25% of AAOS members also complete the course by that time. AAOS will do patient satisfaction surveys before and after participation in the training and will track the effectiveness of the training in various ways. Additional research projects are planned. The former president of AAOS summarizes the work, "We're doing this together. We're a partnership. We're a team. When we have that attitude, I think that the outcomes are better from both perspectives; both the physician and the patient."

Patient Safety Organization

- The **National Patient Safety Foundation (NPSF)** was founded to promote safer medical care through the prevention of medical error and to improve the health care system for all patients. Collaboration with patients and families is an essential element in NPSF's work.

In 2001, the NPSF established a Patient and Family Advisory Council that included 11 patient and family members and nine health care professionals from the board of the Foundation. The purpose of the Council is to provide guidance and patient and family perspectives on all of NPSF's activities. The Council created the *National Agenda for Action: Patients and Families in Patient Safety—Nothing About Me, Without Me* to disseminate the Council's recommended strategy for developing a patient- and family-centered culture of care in which

patient safety can be optimized. This document is a call to action to all hospitals, health systems, and national and local health care organizations to involve patients and families in systems improvement and patient safety programs. In developing this document, the Council solicited input and review from hospital-based patient and family advisory groups and various health care organizations.

In 2006, as a part of a restructuring of its governance, the NPSF transformed the Patient and Family Advisory Council into a Patient and Family Program Committee with many of the same members, as well as others with expertise that will be critical to achieving and sustaining effective partnerships with patients and families across the health care system, such as cultural competence, health literacy, and patient and family-centered care. This committee will guide NPSF's work to partner with patients and families. Patients and families are members of the NPSF Board of Directors and the Board of Governors.

In addition to these activities, NPSF has supported the work of the WHO Patients for Patient Safety Initiative and similar activities being led by JCAHO. It has included a workshops and presentations on strategies to involve patients and families in safety initiatives at its annual Congress for years.

- **Consumers Advancing Patient Safety (CAPS)** is a consumer-led nonprofit organization formed to be a collective voice for individuals, families, and healers who wish to prevent harm in healthcare encounters through partnership and collaboration. CAPS envisions a partnership between consumers and providers to create global healthcare systems that are safe, compassionate, and just.

CAPS is partnering in a variety of ways including:

- Partnering for Patient Empowerment through Community Awareness (PPECA) is a collaboration among patient safety advocates, health sciences librarians, health care institutions, and public libraries. During the first half of 2005, several informational sessions were held at public libraries throughout Northern Illinois to raise awareness and educate consumers on patient safety issues. PPECA was developed in collaboration with **Consumers Advancing Patient Safety**, the **Health Learning Center** of Northwestern Memorial Hospital, **Zipperer Project Management**, and the **Metropolitan Library**.
- CAPS continues to expand its international consumer base through partnerships with the **World Health Organization (WHO)**, the **International Alliance for Patient Organizations**, and other global patient organizations to develop the world's richest and largest body of consumer patient safety knowledge to contribute to global initiatives in patient safety research, solutions, reporting and other campaigns;
- CAPS has partnered with **Midwest Airlines** and **Aurora Healthcare Systems** on a community-based safety and medication use program focused on senior healthcare consumers.

- The **Physician Mutual Insurance Company** has invited CAPS to join them as faculty on their OB Collaborative and other initiatives to contribute consumer wisdom and input on patient safety issues.

■ **Parents of Infants and Children with Kernicterus (PICK)** formed in 2000 with the intention of partnering with the healthcare system to work together in the eradication of kernicterus through both a healthcare systems- based approach in conjunction with a parent education campaign. PICK created the KPPC (Kernicterus Prevention Partnership Campaign), a partnership of agencies and organizations including PICK, JCAHO, CDC, HRSA, AAP, NIH, **Harvard School of Public Health**, **March of Dimes**, AWHONN, NANN, AHRQ, AHA, P4PS, and others that are working together on a public education campaign. The focus of the campaign is to educate parents of the potential dangers of jaundice and to empower and activate parents to partner with their pediatrician/provider and to participate in the safety of their newborn.

PICK’s work in collaboration with a variety of agencies and organizations has resulted in:

- JCAHO issuing 2 sentinel event alerts on the prevention of kernicterus;
- AAP issuing their revised guidelines for jaundice management in 2004;
- CDC’s issuance of the MMWR on kernicterus, a jaundice alert sheet, a congressional briefing on kernicterus and granting of funds dedicated to researching the underlying causes of the reemergence of kernicterus as well as the creation of a public education campaign;
- NQF including kernicterus or bilirubin levels of 30 mg/dcl or greater as a “never event”;
- HRSA grants to fund focus groups with expecting parents to craft messaging for a kernicterus public education campaign; and,
- The **Hospital Corporation of America**’s adoption of a universal pre-discharge bilirubin test for all newborns.

Federal and State Agencies

Several federal agencies have a longstanding commitment to collaboration with individuals with chronic conditions and their families. Among those whose progress has been particularly notable are the Children with Special Health Care Needs Division of the Maternal and Child Health Bureau of the **Department of Health and Human Services (DHHS)**, the **Center for Mental Health Services (CMHS)** of the **Substance Abuse and Mental Health Services Administration (SAMHSA)**, the **Department of Education** and its Office of Special Education and Rehabilitative Services (OSERS), and the **National Institute on Disability and Rehabilitation Research (NIDRR)**. In describing how the principles reflected in a patient- and family-centered approach to care can best be integrated into the culture of federal and state agencies, Dr. Bernard Arons, former Director of CMHS, said, “Families must be part of the grant development process, implementation, and proposal review. In order to build skills [for this collaboration], CMHS funds state and local family networks

with a strong component of family-to-family support. Many of the networks are led by families.³¹

Factors that Facilitate Collaboration

As a result of the growing experiences of organizations such as those described in the previous section, health researchers, administrators, and planners, as well as health professionals, patients, and families, now have a much better understanding of the factors that facilitate the development of successful, sustainable partnerships with patients and families. Experience in a variety of health care organizations—hospitals, community-based practices, professional organizations, state and federal agencies—has shown that the following factors facilitate the development and sustainability of partnerships.

- Having senior leaders who are knowledgeable about and committed to collaboration with patients and families.
- Designating a staff member, with patient- and family-centered knowledge and skills to serve as a liaison for collaborative endeavors.
- Creating a variety of ways for patients and families to serve as advisors within an organization and ensuring that they can contribute meaningfully to decision-making—that their presence is not merely tokenism.
- Recruiting patients and families continually for various terms of service to support sustainability and ensuring that these individuals represent the diversity of the community served.
- Investing in orientation and training in patient- and family-centered care and in strategies for effective collaboration for patients, families, staff, and physicians.
- Investing in educational and planning activities for patients, families, physicians, and staff to engage in together in order to develop trusting relationships and understanding of shared and differing perspectives.
- Supporting the development of patient and family leaders.
- Providing staff and physicians with ongoing support and mentoring to address challenges related to collaborating with patients and families as they arise.
- Understanding that patient- and family-centered care is cost-effective—that initial investments in training are modest and will be quickly repaid in terms of increased family and patient satisfaction, improved staff satisfaction and retention rates, and greater market share.
- Ensuring that everyone involved realize that moving toward patient- and family-centered care is a process and that they trust this process and one another.
- Measuring outcomes.
- Celebrating accomplishments and rewarding efforts.

Lessons Learned from the Field

The experiences of **Concord Hospital** and **Boston Medical Center** (see pages 14 and 17) provide instructive examples concerning the importance of cultural change and the

need for centralized leadership that may be useful to other organizations. Other examples of valuable lessons learned are summarized here.

The **Alberta Heritage Foundation for Medical Research (AHFMR)** in Canada established the Health Technology Assessment (HTA) program to investigate the impact of health technology on the health care system. HTA has a history of engaging funders, government agencies, manufacturers, health care professionals, insurance agencies, and others in its work. Through its partnership with international colleagues, HTA decided in 2005 to explore ways to increase the involvement of consumers as critical stakeholders for health technologies.

One outcome of that work is an HTA paper, published in December 2005, which reviews the literature and analyzes barriers to and opportunities for consumer involvement in health care technology.³² Barriers cited in the paper include time constraints, the need to find consumers with appropriate time and expertise, and insufficient resources to provide reimbursement and training for consumers. Strategies for increasing opportunities include involving consumers on projects with longer timeframes, widening literature searches to include articles expressing consumers' views, identifying consumers in the early stages of projects, and working with other programs within AHFMR to increase overall capacity to involve consumers.

Growing experience in working collaboratively with patients and families has also clarified the types of individuals who can contribute most in their advisory roles. Patients and families, like health care professionals, need training for advisory roles. Many health care facilities have found the following criteria useful in guiding the selection of patient and family advisors to participate in collaborative quality improvement and redesign initiatives.

- The ability to share personal experiences in ways that others can learn from them.
- The ability to see the bigger picture.
- An interest in more than one issue.
- The ability to speak candidly in a group.
- The ability to listen and hear other points of view.
- The ability to connect with people.

Barriers to Collaboration

Despite the success of individual efforts such as those described above and the growing diversity of settings in which patient- and family-centered care has been introduced, comprehensive integration of patient- and family-centered concepts in policies, programs, and practices remains the exception rather than the rule. Most advances continue to take place in pediatric and maternity units and in acute-care hospitals. Extension across clinical areas, practices, or organizations remains limited.

Research and experience reveal a number of common barriers to the implementation of partnerships and to advancing the practice of patient- and family-centered care. Among them are the following:

Attitudinal Barriers

- Fear that patients' and families' suggestions will be unreasonable.
- Fear that patients and families will compromise confidentiality.
- Belief that a customer service program is sufficient to ensure patient satisfaction and involvement.
- Perception that there is a lack of evidence for patient- and family-centered practices .
- Belief that patient- and family-centered care is not necessary (“We are knowledgeable, caring professionals. We know what’s best for our patients. We are all patients.”)
- Belief that patient- and family-centered care is time-consuming and costly resources.
- Belief that their patients are too poor, too violent, too uneducated, too humble to be engaged or to engage.

Educational Barriers

- Lack of understanding and skills for collaboration on the part of health care professionals and administrators as well as of patients and families.
- Leaders' lack of understanding of patient- and family-centered and its benefits.
- Organizations unprepared to provide patient and family members with the training and support needed to participate effectively in collaborative endeavors.

Organizational Barriers

- Lack of guiding vision.
- Tendency to implement either a top-down approach to initiating partnerships with insufficient effort put in to building staff commitment, or the tendency to implement a grass-roots effort that lacks leadership, commitment and support.
- Organizational culture.
- Scarce fiscal resources and competing priorities.
- Inadequate organizational leadership.

Moving Forward

The preceding sections of this paper have laid the foundation for this final section. Outlined here are a series of 13 questions that participants in the June 2nd meeting explored in small-group sessions. The questions are applicable to the full range of organizations, agencies, and institutions involved in health planning, delivery, and evaluation as well as reimbursement. Drawing on their varied and extensive training and experience in health care, as well as ideas sparked by this paper, participants were asked to develop a set of recommendations in response to each question. The recommendations will be based on the group's shared vision of patient- and family-centered care and will

demonstrate how health care professionals, administrators, researchers, payers, and patients and families can move forward as partners to achieve that vision.

- How can we ensure that every hospital has designed structures and processes that ensure the development of effective and sustained partnerships with patients and families to enhance quality, safety, and the experience of care? (Both civilian and military hospitals).

Recommendations to be developed at the June 2nd meeting:

- How can we ensure that every ambulatory setting has designed structures and processes in place that ensure the development of effective and sustained partnerships with patients and families to enhance quality, safety, and the experience of care?

Recommendations to be developed at the June 2nd meeting:

- How can patient- and family-centered concepts be fully integrated in the learning environments and the curriculum for medical schools, residency programs, and schools of nursing and allied health?

Recommendations to be developed at the June 2nd meeting:

- How can patient- and family-centered concepts be fully integrated in the learning environments and the curriculum for graduate education programs and fellowships in health administration?

Recommendations to be developed at the June 2nd meeting:

- How can we best stimulate and develop an evaluation and research agenda to systematically measure the outcomes related to patient- and family-centered care and inform practice?

Recommendations to be developed at the June 2nd meeting:

- How can payers and accrediting and licensing organizations encourage, support, and set the expectation for effective partnerships with patients and families that enhance quality, safety, and the experience of care?

Recommendations to be developed at the June 2nd meeting:

- 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?

Recommendations to be developed at the June 2nd meeting:

- How can quality-improvement professionals and organization partner more effectively with patients and families? How specifically can IHI partner in the 100,000 Lives Campaign?
Recommendations to be developed at the June 2nd meeting:
- How can organizations concerned primarily about patient safety most effectively create partnerships among patients, families, and health care professionals?
Recommendations to be developed at the June 2nd meeting:
- What do patient and family advisors and leaders want and need to participate meaningfully in quality improvement and in the redesign of health care?
Recommendations to be developed at the June 2nd meeting:
- What strategies will best overcome the barriers to partnerships in health care settings, facilitate patient- and family-centered care, and ensure the development of effective, sustained partnerships in all health care settings and academic programs?
Recommendations to be developed at the June 2nd meeting:
- What are the most effective strategies to obtain resources to support this work?
Recommendations to be developed at the June 2nd meeting:
- How can foundations and federal and state agencies further the development of effective, sustained partnerships with patients and families in health care?
Recommendations to be developed at the June 2nd meeting:

Resources

For the most recent references on this topic, please see the *Leadership and Organization Change* in the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>

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