



**INSTITUTE FOR
HEALTHCARE
IMPROVEMENT**

Patients and Families

Powerful new partners for healthcare and for caregivers.

The Institute for Healthcare Improvement's (IHI) 5 Million Lives Campaign includes an intervention on governance leadership, more commonly known as Getting Boards on Board. Trustees, executives and clinical leaders have responded positively to this relatively new expectation that hospital boards have an active and directly engaged role to play in their organization's quality and patient safety agenda. Beyond that, trustees at nonprofit hospitals increasingly see their oversight through the eyes of patients, families, citizens and communities. This evolution has come about in part because trustees and executive leaders are bringing patients and families—with their voices and stories—into the boardroom and into the conversation; this is shaking things up, making accountability real and enabling everyone to act.

In line with the Getting Boards on Board intervention of the 5 Million Lives Campaign, many hospital boards of trustees begin their meetings with a story of harm and systems failure as seen through the eyes of the patient, family or both. In some cases boards view videos, and in others they take a deep dive into a patient's story as told by the CEO and executive leadership. In many instances, the patient and family being discussed are in the board

room. Delnor-Community Hospital in Geneva, Ill., uses these approaches. Cincinnati Children's Hospital Medical Center and Exempla Healthcare in Denver begin their board meetings with a patient story. Some organizations also are including patients and families in board and leadership retreats. Boston's Beth Israel Deaconess Medical Center recently began a trustee retreat by talking with three patients about their different care experiences.

IHI's 5 Million Lives Campaign is one of many drivers to engage with patients and their family members. Other drivers include the variation in patient experience as measured in HCAHPS; the new Joint Commission Leadership Standards and National Patient Safety Goal 13; the revised National Quality Forum safe practices, with their emphasis on organizational culture and patient and family inclusion; the movement for communication and disclosure when patients are harmed; increased data showing that a satisfied patient is an activated patient; growing consumerism and patient- and family-centered care movements; and, simply, patients and families around the world saying, "Listen to me, respect me and trust me as a partner in care."

Patient satisfaction and patient experience surveys, along with focus groups, will continue to be used to gauge how well the healthcare system serves patients. These tools also are rapidly being improved upon. For example, trustees and executive leaders across the United States and North America are increasingly learning from and about patients through ongoing partnerships. Here are some examples:

For more than 10 years, the Dana-Farber Cancer Institute in Boston has welcomed four patients, parents or family members onto its board's quality committee as regular participants. By the end of 2007, Cincinnati Children's Hospital Medical Center and the Medical College of Georgia were expected to add patients and family members to board-level committees. According to Lee Carter, board chair at Cincinnati Children's Hospital Medical Center, trustees already sit on hospital patient and family advisory groups. At Springfield Hospital in Vermont, Gerry Mittica, chairman of the board, and Thomas Crawford, FACHE, CEO, meet monthly with a Patient Experience Team that is composed of patients who have been hospitalized, use hospital services or both, and their families. Additionally, to ensure transparency, the board

chair and CEO work in tandem to review patient complaints and compliments. Jack Davis, president and CEO of the Calgary Health Region, is leading a transformation within his region with respect to patients and families at every level of the engagement process.

At the executive level, during the last 12 years, Susan Grant, RN, a chief nursing officer in a number of organizations, brought together executive leadership, patients and family members at Dana-Farber Cancer Institute, the University of Washington and Emory Healthcare. Executive WalkRounds have become a patient safety standard in many organizations, and, increasingly, executives at organizations such as Kaiser Permanente include interviews with patients and families as part of these rounds. The Joint Commission places a very high-profile consumer advocate, Ilene Corina, on its board of directors and celebrates the seemingly endless learning from its own patient and family advisory council. Trustees and executives at Maine Medical Center welcome patients and family input throughout its organization and specifically into its strategic planning process. The John D. Stoeckle Center for Primary Care Innovation at Massachusetts General Hospital has four primary care patients on its advisory board. Matthew Van Vranken, executive vice president, Spectrum Health System/ president, Spectrum Health Grand Rapids, attends the monthly meetings of the Spectrum Health Patient and Family Advisory Council. He created an executive level position at Spectrum—vice president for Patient Affairs—to provide leadership and facilitation to create the

ideal patient experience and effective, sustained partnerships with patients and families. The principles of patient- and family-centered care are guiding this work.

Many organizations, including most children's hospitals, Planetree

organizations and our nation's NICUs, are privileged to have patient and family advisory programs where trustees and executive leaders have ongoing contacts through partnered work. Others, such as the Iowa Health System, are engaging consumers and executive leaders around

the issue of improving health literacy. Each of these organizations say they get enormous contributions from listening to patients and families.

While there are courageous examples to celebrate, there is much more work to do. Two recent meetings—one

with hospital trustees and executive leaders and one with the Vermont Oxford Network (a collaborative of neonatal intensive care units)—included reports from organizations stymied in their efforts to move their patient- and family-centered care work beyond the NICU or beyond

pediatrics. Each saw broad applicability to adult environments, but others in their organizations worried about issues of transparency, perceived risk, unreasonable expectations and staff concerns. They are looking to trustees and executive leaders to make a commitment to patient- and family-centered care, to move it from a discussion of “if” to a discussion of “when and how,” and to realize the benefit of these new partnerships.

The great news is there are extraordinary resources available through IHI, the Institute for Family Centered Care, The Joint Commission, Planetree and many other professional and health-care organizations. During the last few years, a plethora of white papers, toolkits, how-to guides, videos and fact sheets were introduced, ranging from how to begin the work to how to take it to organizations dealing with minority and underserved populations. These four Web sites are great places to start: www.ihl.org; www.familycenteredcare.org; www.jointcommission.org; and www.planetree.com.

Whether you are talking to the Institute of Medicine, healthcare insurers, trustees and executives, the nurse in the NICU, or consumers, it is clear that to make the transformation we need in healthcare, we must have an active partnership with patients and families. This will require new skills in listening, learning and partnering. Amazing and courageous organizations, executives and trustees are out there ready to show us the way. ▲

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