

Partnering with Families: Disclosure and Trust

Demonstrated strategy and results

to improve care delivery and patient satisfaction

through enhanced patient-physician communication

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When an error occurs or an accident happens, it is a defining moment for an organization. How such events are viewed and managed both *expresses* and *shapes* the culture of the organization. When we mean to do well and harm results, we have failed the patient and his or her family. It also affects the care providers at the “sharp end,” the point of care where technical work is done. It is a devastating event. How the organization (through its leaders and policy makers) responds can reinforce a culture of secrecy and blame or advance a culture of safety: open disclosure, analysis, learning, prevention, and face-to-face accountability. In a safety culture, administrative leaders stand shoulder-to-shoulder with affected family and caregivers.

The potential for medical accidents and near-misses in health care is reality. The Institute of Medicine provided a call to action with estimates that between 44,000 and 98,000 people die each year in the United States due to medical errors. Early reports suggest that safety hazards are potentially *three times* higher for pediatric patients than for adults. The debate over the numbers is academic; at Children's Hospitals and Clinics, we believe if *even one* child is harmed or put at risk, that is *too many*.

Children’s response

The organization has embarked on an aggressive patient safety agenda, an ongoing approach to how employees and staff talk about, learn about, and create ever-increasing safety in the complexity of health care. The agenda is designed to:

- **Shape culture** through knowledge and trust
- **Develop infrastructure** to support information and create safe, efficient systems

- **Build a medication administration system** that is world-class and error-free
- **Openly and responsively** disclose and accept accountability in the event of medical accident.

In order to effectively implement this design, Children's recognizes that partnership with patients and their families is an essential foundation. This means that families are involved in all aspects of the care process, including when accidents or near-misses occur. The concept of disclosing medical accidents and near-misses with families is a departure from the comfort zone of many providers. But the greater risk lies in *not* communicating.

Taking the provider/parent relationship one step further

Patients and their families are part of the care team as full partners and contributors in creating safety. Family questions are legitimate and invited. Participation in care is enhanced by information, truth-telling, and disclosure in the care process.

To operationalize the role of the family as a partner in care, a policy was adopted: whenever a family member questions a medication or intervention, the process is immediately stopped, and re-examined. This is considered the "if it *looks* wrong, it *is* wrong" policy of practice.

Encouraging families to participate in care and ask questions is a key addition to a system of continuous checks and balances. And when families feel invited to ask questions and participate in the care of their children, they are more likely to trust the caregivers at the bedside *and* the organization as a whole.

Why disclosure?

Children's prides itself on being family-centered and can demonstrate a long history of involving families at all points of care. But our staff's commitment to patient safety compels us even further. In the rare event of an accident or near-miss, families become part of the follow-up process, immediately and whole-heartedly. This is a departure from historic responses of the risk-management and legal track that distances caregivers, families, and the organization's leadership.

During focus groups and in conversations, families revealed their awareness of care processes and the environment of care. When an accident or near-miss occurs, they want to be the first to know. They have told us that they need to know the story about what went wrong. Families stated two requirements: to know that changes will be made to prevent the same thing from ever happening again, and to know that we are sorry. When these needs are met, family trust in the organization and its staff remains intact and strong.

The needs expressed by family and the growing understanding of accountability in a safety culture helped develop a disclosure policy for Children's. Additionally, a review of the literature and multiple discussions at Children's ethics committee resulted in further support and foundation for a policy of disclosure and honesty. The ongoing dialogue revealed practical problems in the use of terms and definitions, leading to clarifying descriptions of medical accidents, near-miss, and disclosure.

Developing a policy of full disclosure

Children's board of directors endorsed a policy of full disclosure to families as part of its overall patient safety agenda. The policy states "Children's Hospitals and Clinics works with its professional staff to achieve complete, prompt, and truthful disclosure of information and counseling to patients and their parents or legal guardians regarding situations in which a medical accident occurred (1) when there is clear or potential clinical significance or (2) when some unintended act or substance reaches the patient." The title change from "Sentinel Events" to "Medical Accidents and Disclosure; Including Sentinel Events" reflects the culture shift and an emphasis on patient safety and disclosure. The purposes of the policy are to:

- Improve patient and staff safety by decreasing system vulnerability to future accidents;
- Evaluate and improve care provided;
- Reduce the chances for patient morbidity and mortality;
- Restore patient, family, employee, provider, and community confidence that systems are in place to assure future accidents are not likely to recur;
- Emotionally, professionally, and legally support staff who have been involved in events;
- Ensure disclosure of the accident, near miss, or sentinel event to the family, as well as ongoing communication of system improvements to family and caregivers involved in the accident.

Event analysis in disclosure process

A full analysis of each accident is completed to understand the multi-causal components producing the conditions for the event to occur. The disclosure policy helps direct this analysis and sets into motion the processes, and subsequent follow-up, that must take place.

Immediately following an accident or near-miss, a “sequence of event” analysis is conducted. This is followed by a causal analysis study with all key stakeholders to seek to learn what contributing variables existed, and steps to take to eliminate system vulnerabilities and latent error that could realign to produce a future accident. Formal procedures and resources are used to guard against blame, attribution, and hindsight bias – all of which are human tendencies in conditions of a devastating event. While maintaining confidentiality of the patient and providers involved, a case study is created to inform others about the risks so actions are taken to prevent such an event from happening again. The analysis is designed to:

- **Understand** what happened
- **Identify** opportunities for improvement
- **Support** caregivers, patients, and their families
- **Incorporate** this learning into our daily work

Disclosure and truth-telling

In the disclosure process a presumption of truth-telling guides all discussions. Generally the physician managing communication should presume that all information which describes the specific event affecting a patient can and should be disclosed, with the exception of identifying the specific staff members involved in the accident, if unknown to the family. During initial and

follow-up discussion the following subjects may be discussed, although discussion of each subject on this list is not required, nor is discussion limited to these topics:

- that Children's and its staff regret and apologize that an accident has occurred
- the nature of the accident
- the time, place, and circumstances of the accident
- the proximal cause of the accident, if known
- the known, definite consequences of the accident for the patient and potential or anticipated consequences
- actions taken to treat or ameliorate the consequences of the accident
- who will manage ongoing care of the patient
- planned investigation or review of the accident
- who else has been informed of the accident (in the hospital, review agencies, etc.)
- actions taken, if any, to identify system issues which may have contributed to the accident and to prevent the same or similar accidents from occurring
- who will manage ongoing communication with the family
- the names and phone numbers of individuals in the hospital to whom the parents may address complaints or concerns about the process around the accident
- the names and phone numbers of agencies to whom the family could communicate about the accident
- how to obtain support and counseling regarding the accident and its consequences both within Children's and from outside of Children's
- that charges and expenses directly related to the accident will be removed from the patient's account

- that Children's will assist the family in referral to resources to help them obtain compensation if actual damages warrant

It is a thoughtful, well defined process meant to re-establish confidence and maintain a therapeutic relationship.

Protecting staff who report accidents

Staff members who promptly and appropriately report accidents to a patient's immediate caregiver, manager or Children's safety office will not be subject to retaliation and will receive the administrative support of Children's in all matters relating to the accident. This does not require Children's to protect staff members who engage in intentional acts of malfeasance which compromises patient safety.

Continuing the education for staff and families

Patients and families want the truth; we have promised to do no harm. To those ends, targeted learning packets about patient safety for leadership and clinical staff are completed and patient safety packets for patients and families are being developed.

For staff, the safety guides reiterate the importance of moving from a culture of blame and secrecy to one of open communication and analysis of systems.

For families, the packets are intended to help them understand their role as partners in care, encouraging them to ask questions and participate in ongoing communication with caregivers.

Summary

Children's is taking patient safety seriously: from an urgency to find out what is happening, to talking about and disclosing what's happened, to preventing it from happening again. The journey involves ongoing vigilance, organizational learning and ethical obligation to disclose to patients and families when accidents occur. This is Children's promise.

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Biography

Julianne Morath is Chief Operating Officer and Vice President of Care Delivery for Children's Hospitals and Clinics, in Minneapolis-St. Paul, Minnesota. She was a participant-observer with the Harvard Executive Sessions on Medical Accident and Patient Safety and is an elected board member of the National Patient Safety Foundation.

Prior to joining Children's, Morath was System Vice President for Quality, Research, Education, and Performance Effectiveness for Allina Health System in Minnesota. Her career includes

clinical practice, consultation, teaching, and twenty years as a patient-care executive including appointments at the University of Cincinnati Medical Center, Cincinnati, Ohio; Roger Williams Medical Center and Cancer Institute, Providence, Rhode Island; and Abbott Northwestern Hospital and Virginia Piper Cancer Institute in Minneapolis.

Morath holds a bachelor's degree in nursing from the University of Michigan, master's degree in community mental health from the University of California at San Francisco, and has completed doctoral course work in social psychology at the University of Cincinnati. She has multiple faculty appointments and publications, is a frequent speaker, and has received national awards for her professional contributions. She is author of The Quality Advantage: A Strategic Guide for Health Care Leaders.

Terril H. Hart, MD, Vice President of Medical Affairs at Children's Hospitals and Clinics since 1997, is committed to improving children's health. At Children's, Hart provides direction and leadership for performance improvement and quality resources, advises the professional staff on administrative and operational issues, and represents physicians' interests on the leadership team. Additional responsibilities include corporate compliance, safety and risk management, and the clinical operation of many ancillary departments, including lab, pharmacy, and radiology.

Hart along with Ms. Morath provided leadership for Children's patient safety initiative.

Hart has been a respected pediatrician for more than 20 years. In 1994, he was elected the first Chairman of the Board of the newly merged Allina Health System. In that role, Hart successfully

created and sustained a team atmosphere from two disparate cultures, resulting in a strong vision and mission for the corporation. He was re-elected Chairman four times. From 1987 to 1994, he served on the executive committee for Medica Health Plans and its predecessor Physicians' Health Plan. He is the editor of Parents Guide to Child Medical Care, now in its third edition.