

Advocacy in Health Care

A Sample of State and Private Systems

By Kathleen Clark

At least two models exist, one a private system and the other an independent government agency, that illustrate different, but effective, ways to resolve issues arising among patients, health care providers, and the entity that pays for services or provides compensation for harm (the insurer or arm in charge of self-insurance). Kaiser Permanente, the nation's largest not-for-profit health plan, has spent the last decade thoughtfully implementing comprehensive programs to support all those who have been involved in an unanticipated adverse outcome. The Connecticut State General Assembly created the Office of Healthcare Advocate (OHA) in 1999 to promote and protect the interests of covered persons in Connecticut under Managed Care Organization (MCO) health plans.

A managed care plan provides health care services through participating physicians, hospitals, and other health care providers. When MCOs were first introduced, confusion and health care dislocation reigned. It involved a tremendous shift for consumers from an indemnity-type insurance plan, in which the consumer was reimbursed for covered expenses for services to any doctor or hospital of the consumer's choice after the application of deductibles and coinsurance requirements, to health care only through participating physicians and hospitals and only for covered procedures.

The Connecticut OHA is an independent agency that plays a consumer advocacy role. It is funded by insurers in Connecticut, and it educates consumers about their rights and responsibilities to act on their own behalf, acts as a direct advocate for policyholders, holds insurers accountable, analyzes trends, and makes public policy recommendations based on those trends. The OHA website (www.ct.gov/oha/site/default.asp) is user-friendly, containing information for consumers on filing complaints, as well as internal and external appeals. The OHA handled 2,000 cases last year, saving \$5.2 million for consumers, and it

expects to handle almost 3,000 cases this year. According to Kevin Lembo, the state's health care advocate since 2004, Connecticut is the only state in the country that has an independent health care advocacy program. Although most states have some agency that protects consumers, such as an insurance commissioner, no other state has an independent agency.

The educational charge for the OHA is to serve 3.4 million Connecticut consumers with a staff of seven, including two nurses and one attorney. The OHA's continuing goal is to respond to every phone call in the same business day, or at least within 24 hours, which it does. OHA has the benefit of the state's attorney general, who works with the OHA on issues such as rollbacks of rate increases. It also has a small program of volunteers, including pro bono attorneys. The leading sources of referrals are physicians and those individuals already served by OHA. Volunteer speakers inform community groups, such as seniors, expanding awareness of OHA's services throughout Connecticut.

In terms of its advocacy for policyholders, a significant portion of the work of OHA is appearing at administrative hearings, to the extent insurers provide for them, as well as corresponding and otherwise communicating with insurers on behalf of policyholders. OHA does not represent policyholders in court proceedings. Much of OHA's advocacy work involves one particular situation that occurs in 85 percent of its cases: policy rescission for undisclosed information. Lembo said that in these situations, an individual purchases a health insurance policy, pays premiums, gets sick, and submits a claim, to which a carrier responds with rescission. The policyholder is informed that the decision to rescind is based on the insurer's determination that, had particular information been disclosed, the policy would not have been written.

The percentage of Connecticut policyholders who appeal the denial of a claim, including denial based on either rescission or lack of "medical necessity," is below 10 percent, according to Lembo, leaving the other 90 percent who do not appeal without necessary health care. Some of these policyholders use credit cards for necessary health care, some mortgage their homes, and some go without care. To assist the 90 percent, the OHA works hard to inform and educate the consumers of Connecticut that health care advocates are available for them. Because



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Lembo has budget concerns and wants to advocate for the 90 percent, he is setting up a nonprofit, creating the possibility of grant money to increase the size and scope of the OHA's work. The nonprofit will have an advisory board, composed of attorneys and health professionals, all playing an active role in OHA's mission.

Although OHA does not advocate directly for health care providers, physicians often contact OHA directly on behalf of patients having difficulty with their insurers. For instance, a physician who has a number of patients denied coverage for a specific procedure will contact OHA on their behalf. Another common complaint of experienced physicians on behalf of their patients is waiting for lengthy periods after dialing toll-free numbers, and then having to explain clinical decisions to nontrained claims representatives, who then make decisions about patients' needs. In that situation, physicians will seek the advocacy services of OHA. According to Lembo, physicians can stand in the shoes of patients when the patients have exhausted efforts to get denial overturned. Under a recent change in the law, physicians can bring an appeal directly if their patients cannot or will not engage or participate, which is particularly useful to physicians who cannot bill the patient if the insurer doesn't pay.

The OHA plays an active role, pursuant to its charter, in creating, testifying, and monitoring legislation to protect policyholders. For instance, with the assistance of the OHA, a state law was drafted to address the rescission issue, requiring insurance companies to provide a third-party review before issuing a decision to rescind. It passed by the Connecticut legislature in 2009; however, it was vetoed by the governor because the legislation lacked mention of accountability on the part of patients. Legislation will be introduced in 2010 that would cure this patient accountability concern and restrict the grounds for insurers' determinations that particular procedures/processes/medications are not based on "medical necessity"; it also provides that rescission is grounds for external appeal.

In addition to his advocacy for Connecticut health care legislation, Lembo advises and testifies before the U.S. Congress, working with Connecticut's Senator Christopher Dodd and others, on health care reform. In particular, Lembo speaks to the many successes of the Connecticut program and possibilities for taking that thinking and process national.

Kaiser Permanente's support for those who have been involved in an unanticipated adverse outcome is based on Kaiser's mantra: "Do the right thing." To support this organizational value, Kaiser has articulated a guiding principle:

Human error and systems conditions periodically align and combine to contribute to unanticipated adverse outcomes for patients. What is most important is the manner in which we handle these situations. Patient safety and clinician welfare will be best served if we are honest

about unanticipated adverse outcomes with our patients, open with our colleagues and ourselves, and able to handle such occurrences with sympathy and empathy for our patients and our colleagues.

Kaiser recognized very early on a need to provide a supportive infrastructure so that all could follow its guiding principle. In this regard, almost a decade ago, Kaiser Permanente began implementing a communications training program titled "Communicating Unanticipated Adverse Outcomes" (CUAO). The program helps providers understand the importance of good communication before, during, and after an adverse event. Participants role play and receive feedback. It was first implemented as a four-hour program for all physicians, who were expected to take the lead in any disclosure conversations. The program was well received and continues to this day. However, in 2009, Kaiser modified its CUAO program to be multidisciplinary in nature, with the goal of having all members of the health care team trained.

Kaiser also created situation management teams (SMTs) to advise and coach clinicians in communicating unanticipated adverse outcomes, communicating directly with patients/families, when needed. The SMTs were created, in part, to support the implementation of the CUAO program. Leadership recognized that a move toward a more timely and truthful communication between patient and practitioner in the aftermath of an unanticipated adverse outcome required providing a support network for the practitioner, as well as attentive management to patient and family needs. Situation management team training has been provided to every region of Kaiser Permanente. Most locations have formed SMTs or are using an existing infrastructure to accomplish the same objectives.

Shortly after the initial SMT trainings were held, Kaiser Permanente approved piloting an organizational ombudsman/mediator program modeled after a position at the Bethesda Naval Medical Center. Kaiser Permanente's organizational ombudsman program (now called the "HealthCare Ombudsman/Mediator Program," or HCOM) was designed in the winter of 2003 to provide confidential and neutral assistance to patients and providers in resolving care issues. The program began with six pilot sites in 2003; there are currently 28 HCOMs nationally.

As a trusted and informal information source, the HCOM acts as a communication channel, complaint handler, facilitator, and consultant for dispute resolution. The HCOM is not an advocate for the patient, provider, or organization but is an advocate for a fair process for all parties and functions under the four operating principles of independence, impartiality, confidentiality, and neutrality. The goal is to resolve issues at the lowest possible level, at the earliest possible time. Some of these issues may be a result of an unanticipated adverse outcome, but some of them may not. The critical value of

the HCOM role is to take whatever time is necessary to assist the patient and family through difficult situations to provide “shuttle diplomacy” between staff and patient/family, and to flag system issues that can minimize organizational risk and harm to patients. The HCOM also follows up and follows through on promises made and ensures that solutions arising from both disputes and disappointments are fair and equitable.

The HCOMs receive extensive training so they can serve as internal neutrals. They must successfully complete a 40-hour mediation training program, 80 hours of extensive shadowing experiences with seasoned HCOMs, be mentored for a period of 90 days, and participate in reflective practice and monthly peer group meetings. Additionally, the HCOMs are brought together twice a year for further advanced training. Wellness has been an ongoing concern for the HCOM program. Kaiser recognizes this work is extremely difficult and can take a toll on those who provide this service day in and day out. Numerous wellness activities are in place to address the HCOM’s work-life balance.

Kaiser Permanente attorneys and claim managers play an integral role in the resolution process when issues related to compensation occur. Patients and families are often referred to the claims staff, where payments are made quickly to cover out-of-pocket expenses related to the unanticipated adverse outcome. When the matter is resolved through the SMT process alone, no settlement is achieved, and no settlement release is obtained. The patient and family are free to bring further legal action related to the incident to obtain additional compensation or to work with the claims staff to achieve final resolution through settlement prior to formal litigation. In cases where patients prefer to obtain legal counsel, a more formal process is invoked, and HCOMs do not participate in that process.

Personally, it is hopeful to me to write about the Kaiser ombuds-mediator program because my oldest and dearest friend called upon the program three years after her 21-year-old son died at Kaiser in 2003 as a result of medical errors. When Eric died, the ombuds-mediator program was not in existence at Kaiser’s Oakland Hospital. As a result, Eric’s parents were not provided any information by Kaiser about the circumstances of his death, which came at a time when medical errors were buried in secrecy and

obfuscation. As a result, they sued and went to mediation against Kaiser. That mediation involved Eric’s parents in one room with their attorney, the Kaiser health care providers and their attorney in another, and the mediator shuttling back and forth. The case resolved, but Eric’s parents got only money (all that litigation could give them) and were still in the dark about what happened and why. As the family’s advocate, I wrote several letters to Kaiser asking for acknowledgment, apology, and an opportunity for the family to provide firsthand information about what they observed while Eric was in the hospital. Once the ombuds-mediator program was up and running at Kaiser Oakland, I received two calls regarding the most recent of my three letters, starting an open exchange, learning, and healing for Eric’s parents, as well as the health care providers at Kaiser. These exchanges led to several changes in the Kaiser system, based on the observations of Eric’s parents, and an opportunity for Nancy to speak to and answer the questions of 25 urgent care physicians about Eric’s experience at the hospital. Now that the ombuds-mediator program is embedded in the Kaiser system, this type of open exchange and potential for healing goes on all the time. The patients/families play a role in change at the hospital, change that could save the lives of future patients.

For me, I’m very grateful to have witnessed the before and after of this cultural transformation in health care, followed by this opportunity to write about it. As each day goes by, I read of other health care providers around the country, often on the heels of tragedy, who are doing similar work, making similar changes, creating open, transparent, participatory, respectful processes that bring fair and expeditious resolution to medical error situations and give patients and families a voice in improving our health care systems. Lembo has testified before Congress about the OHA in Connecticut, creating and expanding on the possibility that a program such as Connecticut’s can be created on the federal level or in 49 other states. The OHA not only advocates for consumers, but it also empowers consumers in the health care arena. As health insurance issues become more difficult and, often, more adversarial, and as medicine becomes more complicated, empowerment of consumers continues to rise in importance. OHA is an advocacy model we can all learn from and, perhaps, duplicate in our own communities. ♦