

Research Brief

We are pleased to provide you with this summary of recent research by one of our faculty members, in keeping with our commitment to disseminate research findings to leaders in the field. We hope that you and your colleagues find this to be of interest.

—Roger Feldman, Ph.D., acting division head

Moving from Research to Action

Robert L. Kane, M.D., Minnesota Chair in Long Term Care and Aging, Division of Health Services Research and Policy

Researchers like me are aghast when they see the results of their work being challenged on the basis of personal anecdotes, but personal experience is hard to ignore. It is even harder when one realizes that a lifetime of study, a thorough understanding of the system and a long list of personal contacts cannot make the health care system work the way you think it should.

Several years ago I had to deal with obtaining long-term care for my mother. This three-year experience turned into a nightmare with system failures at every step of the way. The acute care hospital where she was admitted with her stroke was ill equipped to care for a confused older person and unwilling or unable to provide useful assistance in planning her discharge. The rehabilitative institution was equally unable to manage physical disability in a demented person. A series of assisted living institutions promised much more than they could or would deliver and solved the problem by insisting that we hire our own personal care attendants. Repeated hospitalizations and emergency room visits revealed just how poorly the health care system manages frail older persons. Trying to organize primary care showed how poorly physicians communicate with other care staff and just how fragmented our system is.

One hand does not know what the other is doing. Little is done to encourage effective exchange of information or useful observations on the status of patients. Little anticipatory planning is done. What we have is a system that creates and then responds to crises. We

celebrate the firefighters but not the forest rangers. Persons who have trouble negotiating the system or bring underlying frailties are at special risk. In a world that presumably celebrates consumerism, we give no voice to the consumers or their advocates, who are usually seen as disruptive forces. In truth, the last place you want to exert your buying power is lying half naked on a gurney writhing in pain.

As I spoke about my frustrations from this experience with colleagues at meetings and other gatherings, it became evident that I was not alone. Many people of my age who had spent their careers studying health care and long-term care had equally vivid war stories. It seemed the time to mobilize all this frustration toward some positive end.

PPECC (Professionals with Personal Experience with Chronic Care) was created to give voice to these powerful testimonies. The goal of the organization is to create a credible voice to urge the need for constructive change in the way our health care system is organized. While we worry a great deal about how to pay for this care, we seem inappropriately less concerned about what we are buying. The current system is poorly aligned with the real needs of contemporary America, which is an aging country suffering from chronic diseases.

This fledgling organization has grown rapidly. We now have over 600 members (professionals with stories to tell). Many of these stories have been captured; more remain. My mother's story will shortly appear as a book (Robert L. Kane and Joan C. West. *It Shouldn't Be This Way*. Vanderbilt University Press, Nashville, TN). Other stories have been posted on our web site (www.ppecc.org). Our goal is to take these stories to the public. We plan Congressional testimony, appearances on talk shows, op ed pieces and whatever other strategies will serve to raise the community conscience about the need for serious reform. The goal of PPECC is to raise the consciousness of America about this poorly kept secret: The health care system is out of sync with the realities of today's illness patterns. Major changes are needed. Alas, major forces stand to gain from the status quo.

We welcome new members. Please contact us at the web site or by e-mail at kanex001@umn.edu.