

National Commission on Long Term Care 2005  
Testimony  
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Mr. Kerrey, Mr. Gingrich and esteemed members of the National Commission for quality Long Term Care. I am Rose Marie Fagan, Executive Director of the Pioneer Network. The Pioneer Network, formed in 1997, is a national network of change agents pioneering a new vision for long term care that is life-affirming, satisfying, meaningful and humane. The Pioneer Network's mission is to advocate and facilitate deep system change and transformation in the culture of aging.

Over the years, countless testimony and data have provided evidence and consequences of poor care. Medical/industrial model environments are facilities; they are NOT HOME! Practices don't express dignity, and respect for individuality nor do they respond to basic human needs--one being the need for relationships. Institutional environments destroy the human spirit for residents and for staff.

- You see, it is not enough to just be kept clean, safe, fed and dry. We must raise the bar on our expectations. And among our Great Expectations, we expect to live with hope. We will create the bed that we ourselves will lie in someday, in part by evolutionary means--by improving nursing homes incrementally. But if we want to really make deep system change, we also need to advocate for transformation of the culture and that is more "radical and expansive".

Good people work in these care settings. It is not the people. It is the system. The system is broken; it is failed. That much we know. And we also know that the system doesn't work for anyone--not the resident, staff, regulators, government, family, NO

ONE. The system is oppressive and robs us of our humanity. We know all this. But as Aristotle said, "To know is not enough." I am here to ask for a call to action to break the vicious cycle of dysfunction in a system that has us "marching" to the rhythm of regulation and regimentation. What we really want, in our hearts, is to "Dance". We want to follow the natural rhythm of our relationships and daily routines. We want to dance to the rhythm of "rampant normalcy". When we continue with harmful practices that destroy the human spirit, we become an accomplice in violating that person's rights. We must each decide to be either an accomplice? Or a liberator? It is a moral decision. The Choice is OURS!

The solutions have been defined and include all aspects of the environment: physical, organizational and psycho-social-spiritual. Replace institution with home. Flatten the hierarchy to create self-led work teams who are based in households where residents live. The living routine is based on principles that we already are familiar and comfortable with in our own lives and in our own homes. This transformation is anchored in values and beliefs, returns control to residents and those who work closest with them. To do this, we must overcome most of our assumptions about what is quality, what we measure as quality. We call this work culture change. Early adopters of culture change (pioneers) (on the bell curve, they will represent 15% of homes on the journey for 3-15 years) have demonstrated that transforming the way people live and work in long term care is doable in the current regulatory and reimbursement systems. And transforming institutional facilities into humane, life-affirming, satisfying and meaningful home environments results in positive resident, staff and financial outcomes.

The following recommendations will contribute to solutions for the long- term care crisis:

1. Develop the political will to close chronically poor performing facilities. On the bell curve, these outliers represent 15% of nursing facilities. We all know who they are in our communities. Poor care is expensive and these facilities are a drain on resources. Their poor performance often results in more regulation. These bad apples are spoilers for the good people who are willing to work to transform their facilities into homes. Poor performers repeatedly just pay the fines and don't improve. Often times don't even pay the fines. We must drive them out of business.
2. Provide incentives to make it safe for the 70% under the bell curve to transform into home and community environments. Cost, staff shortages, and regulation are not barriers. FEAR is the real barrier. Through stakeholder collaboration and statutory change, create regulatory environments that support culture change. Move away from the current adversarial regulatory model to a consultant model with the prerogative to move to enforcement when the indicators are there. Reduce paperwork by 50% to provide more hands on time with residents.
3. Distinguish between symptoms of the problem and the problem. See the system as a whole multi-stakeholder system so we can approach the change in proactive systematic way and not go from symptom to symptom. The problem is that the system is based on the wrong premise. We need to change the whole premise from institution to home and create a system in all its aspects to support this transformation. Symptoms of the problem include staff shortages, high cost, poor care, abuse, among others. Naysayers to culture change say basically two things: a) it costs too much, and b) the surveyors won't let us. Both of these are proven untrue. Both are symptoms of the problem. As for cost, after an initial increase for training,

revamping, and sometimes remodeling (a good but not required item), costs decrease since staff retention increases and residents are happier and healthier. As for the federal regulations, the early adopters (pioneers) worked with their state survey agencies and found essentially no barriers, except for a few minor things. Regulation is not the solution nor is it the barrier. Regulation obscures vision but is not a barrier. However, the adversarial and punitive survey process is a barrier.

4. Fund a demonstration project in every state for research and development that is supported by necessary waivers and a collaboration with the Quality Improvement Organizations, surveyors, regulators, advocates to create a climate for change and for providers to take risks. An open competition will enable the best ideas to flourish. Projects must integrate technology and culture to allow us to develop new methods.
5. Do not attempt to fix the problems with more laws and regulations. We don't need any more laws or regulations. We have a law-- The Nursing Home Reform Law of 1987 (OBRA 87). Its passage 18 years ago, brought with it standards and regulations that would ensure residents the right to care and services to "attain or maintain the highest practicable physical, mental, and psycho-social well-being." To implement the intention of OBRA requires a cultural transformation in all aspects of the nursing home environment and in public policy. It calls for quality jobs, and quality workplace, a home living environment for residents and a public policy that supports a new way of living and working that restores resident rights to autonomy, dignity, choice, self-determination.
6. Provide incentives to replace existing housing stock built in the traditional medical/hospital model, with buildings consistent with culture change. Wherever incentives

are used, we must include not only physical environment, but the cultural environment as well. We must build home environments; be they in an urban or rural setting, places where small groups of people dwell in home where they not only belong, but continue to grow and direct their lives and remain part of the community.

7. Pay for performance needs to be an incentive, consistent with culture change outcomes; and not impede the transformation from institutional facilities into home environments. Cutting reimbursement because people get well is a premise that provides an incentive to keep people sick, low functioning and dependent. Pay for performance should reward positive resident outcomes and the factors that contribute to them such as staff retention and continued learning and growth. The system needs to regularly reevaluate what the appropriate pay for performance criteria.
8. Fund research that measures what really matters to those we serve. A meeting on research, Pragmatic Innovations, took place in April 2005. Out of that meeting, emerged a consensus for a substantive research agenda. A report of that meeting is included in this packet.

I will close with a story from Kansas of a daughter who very distressed to have her mother move from her beloved family home into Meadowlark Hills Nursing Home because her mother wanted to remain at home until she died. The mother lived there in a household in the culture change concept with other residents. When her mother died the daughter spoke at the memorial service and said, "it was my mother's wish to die at home. And she did. She died at home at Meadowlark Hills." That story was Kansas. My story of my own mother's death is similar. She died in a pioneering home in New York State. Cultural transformation is possible because it is happening in a small example of

homes pioneering this change. Please call on us. The Pioneer Network is stands ready and is eager to assist. Thank you for the opportunity to participate in this public hearing.