chapter 2

Regulatory Impact on Change

"For every thousand hacking at the leaves of evil there is only one striking at the root."- Henry David Thoreau

My Nursing Home Experience - By Imogene Eligio, Age 87

I entered the nursing home on a stretcher on Good Friday. The ambulance attendants wheeled me through the front door of the assisted living area. No one was in the office and the reception desk was unattended even though it was around 10:30 a.m. I later learned it was always like this on weekends and holidays.

After checking in at the nursing station, the driver took me to room 224 and placed me on my back on a flowered polyester bedspread covering a sagging mattress. The thin pillows were of little comfort. No staff person spoke to me when I rolled in. After a few minutes on the bed in my hospital clothes and shoes and with no cover, someone came in to say I could rest there until time for the mid-day meal in the dining room.

Although I could walk if assisted, I could not pull myself to a sitting position, turn on my side or get out of bed. So there I was, trapped in a strange place, weak, sick and totally dependent. I could not even reach the call button. I learned this was a common predicament.

As I waited I looked around and saw I had a roommate. She slept, attached to machines that surrounded her bed and made soft wheezing noises. I could see she must be extremely ill. I felt uneasy in the presence of a woman I did not know and who possibly was dying.

Around noon a sober-faced nurse came to take me to the dining room. Dressed only in my hospital bathrobe and shoes, I walked with her through the central hall and past the nursing station. I was surprised to see patients in rehabilitation sharing rooms with those who were chronically ill or suffering from dementia.

Near the nursing station, patients were parked against the walls, watching each other being given medications from a tiered cart. There was little interaction among them. Many made vocal sounds indicating dementia. My heart went out to them as I looked into their eyes while we slowly walked by.

The nurse seated me at a table opposite a glare of light from a large window with a beautiful view of the harbor. I had no appetite, so a kind CNA escorted me back to my room, opened the bed and helped me under the covers where I slept.

I had chosen to come here for rehabilitation therapy following radical surgery because of the facility's reputation as one of the best in the state. The 42-bed nursing home is attached to 24 assisted living units. I lived in the former for 15 days and the latter for six months.

Some of the assisted living residents called the nursing home "the other side" — a place no one wanted to be. Some never even wanted to visit friends there. Many of my friends who have gone through rehab in other nursing homes tell me one of the most important goals of their recovery was to "get out of that awful place."

Although I do not consider my nursing home an awful place, I certainly left there as soon as I possibly could. When I realized I was stuck there, I decided I would be cheerful and cooperative and cultivate a positive attitude. It helped, but I stumbled and faltered many times. One reason was the lack of personal space and privacy. Originally designed for one occupant, our rooms were crowded with two patients and their beds, side tables and chairs; one dresser with only six small drawers and one closet. The lighting was poor, consistently either too dark or too bright and glaring.

Our "private" bathroom (toilet and wash basin) was big enough for a wheelchair, but sparsely furnished with a small cabinet, an inadequate number of towels and no washcloths. It supposedly was cleaned every other day but not well.

Patients who were mobile could escape their cramped quarters by venturing into the hallways or the large room surrounding the nursing station and staff offices (i.e., Control Central). The dining room was sometimes available, but staff often held meetings there. Patients who were wheelchair bound or afflicted with dementia were parked near the nursing station where they watched the activity, dozed and received medications from a med tech pushing a large cart.

My first nursing home bathing experience made me yearn for my warm shower at home. Two or three times a week each patient was taken to a colorless, chilly corner of a bathing room where there was hoisting equipment. There, I sat in a cold metal chair while tepid water was run over me. An attendant rubbed me with a washcloth and detergent, and then dried me with a thin towel as I shivered.

There appeared to be no controlling who walked through the nursing home. One night after 11 p.m., a man appeared at my bedside to take my blood pressure. I had never seen him before. He said he was from an outside agency because the assigned RN had not appeared. (There was obviously a high rate of staff turnover because even during the short time I was in the nursing home there were many new faces). I never saw the man again. When I inquired, no regular staff seemed to know him.

Another day a man appeared, saying he was my occupational therapist (OT) and I should get up and meet with him. Since I already had an assigned OT, I refused. He told me my refusal would look really bad on my chart.

By the third day in the nursing home my usual defenses were no longer holding up and I was feeling pretty down. During the first two days I was able to reach my newspapers and began to adapt to the new routine, but there were times when my room was crowded with my roommate's polite but noisy relatives, separated from me by only a flimsy, white cloth curtain. When neither of our families was visiting, I was left alone with this silent woman.

I was told she was in a coma and expected to die soon. After supper while waiting to be put to bed I realized no one in her family would be with her that night if she died. I would be her only witness. I felt great sorrow for her aloneness and unnerved by my assigned, un-requested role in this second most important event in the

woman's life – her death. When the aide came to help me to bed I was hysterical. With the aide's help I went, crying, to the nursing station. After pouring out my story to Cindy, the RN on duty, I was calmer but could not stop crying. Cindy was at once empathic, human and marvelously professional. She called my daughters at my request. They came immediately and helped Cindy find a bed for me in another room.

The next morning I learned my roommate died during the night. A wave of guilt washed over me as I struggled with the feelings I had deserted a friend when she needed me.

As I write these remembrances I am surprised how angry I am at the system our country has created to house and care for old citizens. It is shamefully inadequate, joyless, bland – often even cruelly neglectful and abusive.

During my own experience I was dismayed by the lack of personal autonomy and involvement by residents in making decisions about their personal lives, and the pervasive assumption staff knew what was best for us better than we knew for ourselves.

Although the caregivers in assisted living and nursing homes are almost always people of good will and kindly intent, they, too, are trapped in a destructive, stultifying and exceedingly complex system that, bound by government regulations and corporate greed, is seemingly impervious to change.

I am angry. I want a better life for my peers and myself. I have a passionate wish that our children will enjoy a happier and more meaningful old age than our generation is currently having. After all, we produced the Baby Boomers who are running our country but who, too, are beginning to grow old and sick.

It is time for today's elders to describe publicly their personal experiences as they seek good health care, appropriate housing and social networks. Many caregivers do their best to advocate for us, but we need to speak for ourselves. We, the consumers, must push society to reform the eldercare system.

I am one old woman speaking up.

Working to make the world better for our children – isn't that what loving mothers, fathers, uncles and aunts are supposed to do?

**Special thanks to Imogene Higbie for contributing to this chapter with these reflections on her own nursing home experience. The authors thank her for communicating her experience as a way to advocate for millions of others who share her story.*

Imogene Higbie speaks for millions of others, many who cannot speak for themselves. But as a society, we stopped listening for so long we've become deaf.

Out of our deafness arose and flourished a rigorous regulatory system so ominous in the nursing home culture it has become like the tail that wags the dog. Although providers are discovering a new path that will antiquate current oversight methods, charting a course through today's regulatory interpretations, surveys and punitive enforcements is risky and difficult. Nonetheless, these challenges do not prevent the transformation we advocate.

In fact, the Omnibus Budget Reconciliation Act of 1987 (OBRA 87) calls for standards consistent with those advocated by the culture change movement regarding resident choice and interdisciplinary approaches to service. Also, certain aspects of culture transformation are officially supported by the Department of Health and Human Services' Center for Medicare/Medicaid Services (CMS). In its most recent 8th Scope of Work, CMS designed an education program to encourage providers to adopt practices to change the culture of their nursing homes. In its promotional video highlighting the Pioneer Network, a national organization that is creating culture change in aging services across the country, CMS highlights the value of such practices and states, "The time has come" for deep-rooted change and surveyors should not stand in its way. For a large bureaucracy, this stance is especially bold and visionary.

The Nursing Home Survey and Enforcement System is Broken

But while the CMS flagship steers in one direction, the rest of the fleet sails in another as if following a different compass. Federal and state survey and enforcement divisions are not yet consistently on the same course to the future, and apparently the incongruity between the direction they are headed and the expressed desire for change is yet to be reconciled. While it is true the nursing home system is broken, the survey and enforcement system is broken alongside it.

In all fairness, there are multiple arms and legs within any large regulatory bureaucracy, and the job of regulating America's nearly 16,500 nursing homes is enormous. In addition, there are bad apples among providers in the industry, so some could argue that we have made our own bed. But it is time for us all to make a new bed.

We know there is a problem with how service is currently provided.

But, instead of fixing it, we continually refine and hone a regulatory process that blindly looks past unnatural, regimented and cold environments and services that drain the life out of people, while using carefully designed systems to root out infractions.

The irony is that nursing homes, while in dire need of change for reasons other than survey outcomes, produce higher clinical standards than do hospitals. If hospitals had the same inspection system as nursing homes and the same public reporting of results, people would be afraid to enter them.

Hospitals have minimal paper-based inspections because the hospital industry has an enormously powerful membership association and political lobby. It is said that nursing homes are the most regulated industry, second only to nuclear power. Inspection consequences are unforgiving. Infractions are publicly reported in extreme language designed to reinforce fear. The culture of inspections, while sometimes civil, is punitive.

The unfortunate truth is that many providers, right or wrong, are afraid to make deep change for fear of negative regulatory consequences. Paradoxically, it is not unusual for facilities like the one described by Imogene Higbie to be deficiency-free and have solid survey compliance and performance. If they comply with the regulations, their slate is clean No matter that people are awakened on a time schedule, bathed by hoist and dip, and lined up for rigidly scheduled mealtimes.

On their way to inspect infection rates and safety outcomes, regulators and providers alike will walk past slumping and vacantly detached residents. Both are blind to the reality that no infection is more invasive, no condition more unsafe than the loss of self as perpetuated by= the current nursing home culture. Elders' loss of self has been the norm for so long, the regulatory system looks past it in search of non-compliance and infractions. If slumping residents don't fall, have no bed sores, stay hydrated, have no outward symptoms of physical pain and infections are controlled or prevented, their care providers will be viewed by regulators as being in compliance.

Punitive Systems Do Not Produce Desired Results

While regulations are necessary, punitive oversight systems are not the answer for improving long-term care. Punitive systems have shown no history of creating positive change in any setting, yet we keep sharpening the teeth of the nursing home regulatory system. The federal survey and enforcement system is no longer looking for trends; it now looks for and cites situational imperfections. State agencies know it, but they also know that federal surveyors who review state survey results will follow up behind them. Federal oversight and comparative surveys of state agencies grading surveyors on how well they capture *all* deficient practices perpetuate this trend. Although it could be argued that this process serves a purpose, the most common scopes cited are those with "potential for harm."

Above all, regulators do not adequately measure what is most important to

people living in nursing homes: Quality of life. *How do I feel about my life? Do I control my own life? Do I eat what and when I want? Do I decide the rules in my own house? Do I have purpose?* Even if regulators ask these questions, rarely is it truly followed up on and/or supported by actual citations in order to draw attention to true quality of life issues. Instead, regulators measure mechanical care and deem it appropriate if it is provided in a mechanical fashion. Dr. Bill Thomas, a Harvard trained physician and founder of the Eden Alternative, says it best: Medical treatment should be the servant of genuine human caring, never its master. The survey and enforcement system perpetuates clinical treatment as the "master."

Correctly implemented, the Household Model and other deep culture change methods can easily satisfy residents, families, physicians and staff. The Household Model provides what everybody has been starving for all along. Ironically, the struggle now is to satisfy government. Experience shows that providers adopting new approaches consistent with the Household Model will have their day of struggle with the regulatory system. This is an evolutionary reality over which we must not lose heart.

Pioneering Organizations Must Take the Regulatory Risk

Provider organizations that lead in implementing the Household Model and other deep change strategies have discovered many new realities while cutting "wagon-ruts" into virgin prairie. They have learned it truly is possible to replace regimented systems with resident-directed systems; anecdotal evidence abounds about how doing so dramatically improves residents' quality of life.

They also discovered that replacing old militaristic management approaches with coaching, teaching and resource bearing leadership can yield great results. Staff turnover rates usually drop considerably. Resident satisfaction soars. Families become more involved and engaged. Staff becomes passionate about what they do and pour their hearts into truly helping elders reclaim home and the authorship of their own life stories.

However, deep change is a monumental thing in a deeply indoctrinated, regulated and entrenched system like long-term care. Until the whole nursing home sector, including state and national associations and regulatory bodies, redesign support systems to help normalize changes proven successful by innovative providers, individual organizations will continue to require extraordinary energy to transform their cultures. All systems supporting the nursing home – dining, housekeeping, clinical and purchasing services, to name a few – must be retooled to fit a new context. To date, no retooled support systems exist in the long-term care marketplace.

The early pioneers of the Household Model have had to be driven by passion and fortitude, knowing that they are on hallowed but shaky ground. When an organization passionately pushes against a deep norm, the pendulum tends to swing too far in the direction they seek in order to establish new realities. During an advanced phase of organizational evolution, successful Household Model (and other culture change organizations) can become so relaxed in the comfortable, homey environments they have created, they become too lax in meeting basic standards of practice.

For example, employees in small household kitchens that have the aromas, sounds and feel of their own kitchens at home may behave as they do at home rather than routinely and properly washing their hands between functions. The regulatory system has no tolerance for it, nor should it. However, data from pioneering organizations indicate it is a predictable part of the change process that must be lived through and readjusted.

Regulators and Providers Must Find Equilibrium

The problem is, systems in the traditional model were designed for an old context of "We know what's best for you," "This is our place and you fit our rules" and "We provide clinical intervention as we see fit on our schedule not yours."

Many of the old tasks must continue, but they must be altered, adjusted and redesigned within the new context of "What is best for you?" "This is your home, how can we best serve you" and "We provide services to you with your permission at a time that works for you."

Otherwise, transferring the old systems used as they were originally designed into the new Household Model will pull an organization that is trying to change back into its old ways. New systems are called for that anchor the organization in important standards of practice yet fit the philosophies and practices that characterize the new culture. Providing these systems is a primary reason for this book and the accompanying kit components. Most of the critical systems, including infection control, quality assurance, dining and clinical services, MDS procedures and others have been assembled and presented within this kit, redesigned to fit the context of the Household Model. The regulatory system must and surely will, over time, redesign the tools in their chest to better fit this new way. It's the between-now-and-then period that creates risk for change agent organizations.

"There is a natural tension between complying with regulations, standards of practice and 'creating home' with residents…but this tension can and must lead to the creation of very effective care delivery within a humane system," says Patricia Maben, former Director of Long Term Care, Kansas Department on Aging. "Front running pioneers are the ones who must have courage to find and establish that balance. And they need to know that the system may not be friendly to them in the process."

We must recognize we are in the throes of change at all levels of long-term care. Presently, CMS and state survey processes do not place nearly enough value on the truly remarkable and visible quality of life improvements resulting from the Household Model and similar strategies.

Nonetheless, CMS has recently published updated interpretive guidelines around quality of life indicators and outcomes for the survey process. There are already many quality of life regulations in place, but states are in the process of implementing these new interpretive guidelines that, in some instances, are consistent with culture change values, principles and methodologies.

Although this signals a shifting of the tide, Household Model provider organizations (together comprising a small minority in the long-term care arena) are still finding their legs amidst deep sea change. Systems like the ones provided in this kit will help, but more are needed.

Even while outwardly supporting change, the regulatory system seems to have little or no tolerance for the inevitable evolutionary struggles that must occur as transformational and pioneering organizations break ground for the entire industry.

Within the decade, the regulatory system most likely will hold all nursing homes accountable for many of the new principles advocated herein, while the number of providers adopting deep change methodologies will increase dramatically. This will bring about more commercially produced, complimentary systems that support these methodologies, and normalization no doubt will occur.

All Must Change; Not Just Providers

For the culture of nursing homes to truly change in a sustainable way, however, all stakeholders must change in similar ways. As CMS and state regulatory agencies begin requiring changes, they are obligated to consider these same changes within their own systems. The regulatory system they ultimately establish, while it should have the teeth to deal strongly with providers who do not routinely comply, should also focus on educating, coaching, and assisting providers during and between surveys as a primary methodology for ensuring quality. Such a system would be effective while creating a partnership in mission and purpose.

Know this: Providers cannot be the only modelers of change and continue having the strain of regulatory consequence on their backs without partnership commitment.

Lack of partnership in the change evolution will result in failure or mitigated success.

A father with belt in hand may get his children to mind in the moment, but that is all he will get. He won't have a healthy child no matter how strictly he insists on healthy behavior. A father who wants deep change and growth has to set the example--he has to be what he desires for his children. Realizing the full potential of deep change can and will occur only when all stakeholder groups make the same change.

Undoubtedly, there are risks in creating change consistent with the principles of the Household Model and the culture change movement within our current regulatory environment. Nonetheless, radical changes not only are worth the risk, they are necessary. Providers must take the first step. Risk taking is part of the making of "wagon-ruts" referred to in the Foreword. They are needed to ensure other stakeholders will follow suit.

An undeniable awakening is spreading across the land in long-term care. Regulations will neither produce nor prevent this emerging reality. The spirit of change in the way elders are served has been born and is growing and flourishing.

Objectively identifying and facing up to the status quo is the first step on the pathway to transformation.

Moving toward the solutions is the second step. A clear vision of what *can be* is what truly motivates us to actually change. We must see and understand what we can move towards before we can let go of what we have. Regulations or no regulations, we must replace institution with home.