

TO: U.S. House of Representatives Select Subcommittee on the Coronavirus Crisis
Rep. Jim Clyburn, Chairperson

VIA: Tara Granapathy, Jane Eyre, and Derek Collins, Clerk

RE: Nursing Home Quality and Quality of Life

Thank you for the opportunity to submit a statement for the record to this Subcommittee. My name is Katharine Hay Bradley. I am a citizen of South Carolina. I have been in the field of long-term care since 1975, serving both elderly people and people with disabilities in capacities ranging from direct care and support, to staff supervision, to program development and management, to nursing home administrator, to executive director of a community-based public agency providing lifespan services, and finally, since my “retirement” in 2009, an advocate and founder of a nonprofit organization with a mission to empower other advocates for quality in long-term care. Having provided long-term care services under federal regulations; having been a family member of consumers of long-term care services; and having been an advocate who has also empowered other advocates, I possess a unique set of knowledge, experience, and perhaps some expertise in the field of long-term care from many perspectives.

Let me share one perspective, a personal one. My mother, Carol Hay, was a lifelong activist for social justice, advocating for those whose voices were muffled, ignored, or silenced by the powerlessness of their marginalized station in our society. Whether speaking out for our children’s education, for civil rights, or for protection of our planet and its resources, my mother was strong. Whatever the obstacles confronting her, she would not be silenced. She also had a joyous love of life that never quit. I learned a lot from my mother.

Then, at the age of 72, my mother was diagnosed with dementia. Slowly advancing at first, she remained able to live in her home with my father until the age of 76, when she experienced a sudden and dramatic loss of cognitive and functional abilities. She had to go into a nursing home. The first thing this cruel disease robbed from her was the ability to speak. This strong, outspoken social activist, who had used her voice on behalf of so many, all her life, was suddenly silenced.

In this so-called “Cadillac facility,” affiliated with a prominent denomination of the Christian church, boasting a “caring staff” and a “lofty mission”, my mother’s treatment did not meet even her basic human needs. She lost her ability to perform basic self-care activities such as bathing and dressing. A modest and fiercely independent woman, she was put in the position of having strangers expose and touch her whole body, and in a manner she considered “not even decent.” Yes, she managed to get those words across to me in her desperation to be treated with respect. Because the meager “activities” offered (when they were offered) were not of interest to her, she wandered. She went in other residents’ rooms, so she was physically removed but never offered an alternative to occupy her time. She loved visiting her friends, so she would go up the hall – “eloping!” – and staff physically struggled with her to keep her from leaving her wing of the facility. She was labeled “combative.” She was tied in a wheelchair “to prevent falls.” Of course, this also prevented her from moving about the facility freely. Her requests to get out of her chair were ignored. My 100-lb., frail mother was medicated so she would be “manageable”.

That was my mother’s life in a private-pay, “Cadillac,” “Christian-based” facility with “caring staff” and a “lofty mission.”

I do not fault the staff. They truly believed they were doing their jobs. They seemed very caring and genuinely wanted good for their residents. But they had never been given the tools they needed to do any differently than what they had always done. There was no expectation that the staff would implement even basic activities, recognize individual preferences or personality traits of the residents, or in any way alter their habits in consideration of those they were there to serve. Not even something as simple as helping someone who wanted to get up and walk around. And there were no consequence if they didn't. So they didn't. You see, human nature is to do what is most comfortable. The culture in that and most nursing homes, left to their own devices, becomes what is most comfortable for the staff.

Then came Medicare. Having been a provider of long-term care for 33 years, a Licensed Nursing Home Administrator for 23 of those years, I knew what that meant. There would be an expectation of at least minimum standards of quality of life, consideration of each resident as an individual person, and a mechanism for making sure those standards were met. To say I was relieved is an understatement. I had made many attempts to work with the staff of the facility, offering suggestions and ideas based on my experience with federal funding and regulations, to no avail. But having the federal regulations to support my efforts would give the staff incentive to improve.

I made the decision to take the information I had amassed about my mother's experiences to our state survey agency. They used my concerns to inform their survey, and found that the issues were not just my mother's issues, but were pervasive throughout the organization. Only after the survey team cited the facility for the deficiencies that I had tried to warn them about did things begin to change. And, although the struggle never ceased, the Medicare program and its regulations became the foundation for my mother to experience quality in her daily life; to receive therapies she needed to keep her moving and eating and making the most use of whatever abilities she had left; and to be treated with dignity and respect as a person – in the way staff interacted with her, in the way she spent her time, in the foods she was served, even visiting with her friends. All the things the rest of us take for granted became her plan of required care.

Medicare funding and the regulations that come with it made the difference between my mother's being treated like a list of tasks to be completed before the end of a shift (or not), and her experiencing whatever life she had remaining in ways that were important to her; between being treated like a faceless form in a sea of sedated bodies in wheelchairs, and being respected for who she was and who she had been and what she had accomplished in her life. And, thanks to the way the regulations are designed, even after Medicare no longer paid for her nursing home care, the same quality of care and access to services were required regardless of pay source. So she continued to reap the benefits of that quality of care and treatment until the end of her days.

Public funds and the regulations that require a standard of care and services are our best defense against mistreatment of our loved ones. They are what gave my mother the chance for 5 years of the care and support she needed to have some quality of life in her last years.

Medicare, and its Requirements for Participation, are a lifeline for vulnerable people who cannot speak for themselves. But the federal requirements are only as good as the enforcement of those requirements. Now, providers will tell you they don't need regulations, that they can police themselves. They will tell you that regulations are "punitive" and "burdensome." They will say that they just need money and support, not punishment. They will say they need "help" and "consultation" from CMS to meet the regulations, not laws or enforcement of laws. They will

say that hiring, training, supervising, retaining, and supporting staff is “too expensive” and they are “losing money”. All this blustering is BULL. I know. I did that job for 33 years. I met consumers’ needs, complied with regulations, supported and trained staff, and had an organizational structure and culture that supported these outcomes. Put simply, I cared.

To understand where the providers’ loyalties lie, one need only understand what providers call themselves: an “INDUSTRY”. Long-Term Care is NOT an “industry.” It is a CARING PROFESSION – a profession of providing CARE for human beings. And as for needing “help” and “consultation” to be able to comply with the regulations, providers have had since 1987 to figure this out. So please, do not allow “the industry” to trick you into thinking they are damsels in distress. They are, increasingly, corporate webs devouring nursing homes into their complex ownership mazes, hiding profits at the expense of the well-being of our most vulnerable loved ones. Make no mistake – providing total care 24/7 for frail elderly people IS a HUGE responsibility. One could legitimately call it “burdensome.” But providers have made the conscious choice to enter this field. If they find the “burden” too great, perhaps they should rethink their choice and go into widget-making – an actual “industry”. Leave the caring profession to those who consider this “burden” an honor and a calling – not a cash cow.

Further, do not be tricked into thinking that the Coronavirus pandemic created impossible conditions for nursing homes, who were hapless victims of an unforeseen calamity. They will say that the pandemic is to blame for all their inability to contain the virus, their shortage of Personal Protective Equipment (PPE), the terrible staff shortages, their inability to comply with regulations, and a litany of other disasters. Again, this is BULL. The 1987 regulations and every revision since then have all required best-practice infection prevention and control measures, protective equipment stores, proper sanitation, sufficient staffing to meet resident needs, sufficient training to enable staff to perform their duties competently, and adequate supervision. This pandemic did not create the crises that confronted nursing homes in 2020. It simply laid bare the longstanding inadequacies of a system that had too long gone unaddressed despite the existence of federal regulations and oversight that were supposed to correct inadequacies and prevent them from recurring. Indeed, the pandemic did worsen the already existing, longstanding problems. But lax oversight and weak enforcement for decades created these crises. The pandemic exposed these flaws. My mother’s experience happened well over a decade before the pandemic, between 2009 and 2015. So No, the pandemic did not create the crisis of poor care. Do not let anyone blame the pandemic.

What the pandemic DID do was to provide a vehicle for “the industry” to abandon their duty to care for those they chose to “serve”: suddenly they had a viable, believable excuse for inadequate staff, poor supervision, unworkable or nonexistent “emergency plans”, failure to provide care, etc. When the pandemic laid bare all those pre-existing conditions for all to see, “the industry” screamed “Pandemic! Overwhelmed! We can’t!” CMS responded with waivers of regulations, restrictions of access, reduction and even suspension of oversight. Did these actions contain the pandemic? NO. Nursing home residents continued to bear the largest impact of the Coronavirus Crisis. But in addition, with these changes allowing providers not to perform their core responsibility to provide quality care and quality of life, nursing home residents also now suffered isolation and psychological/emotional neglect; physical neglect including basic human needs like cleanliness, nutrition, even movement; and medical neglect resulting in suffering and unnecessary death. You have all received a copy of the book *Protecting Them to Death: The Impact of Isolation in Long-Term Care*, a project of the Essential Caregiver Coalition. Read it. It gives examples of all these horrors from every state, including each of yours.

This Subcommittee is interested in learning what Congress can do to improve the quality of care and quality of life for people living in nursing homes after the Coronavirus Crisis. THIS is what Congress can do: Congress can mandate that the Center for Medicare and Medicaid Services MUST vigorously enforce the regulations contained in 42 CFR Chapter IV Subchapter G Part 483 Subpart B, “Requirements for Long-Term Care Facilities.” Congress can hold CMS strictly accountable for failure to address poor performance, and especially if it is allowed to continue over time or repeatedly.

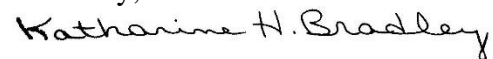
That is a step which can and should be taken immediately, without any changes in existing laws or creation of new laws. Congress can also prohibit waivers of regulations under any circumstances – because there will ALWAYS be “circumstances”. During the Coronavirus Crisis we saw “waiver creep” result in isolation (a.k.a. “imprisonment”), abandonment of individual care plans, extreme declines in physical and mental condition of residents, and preventable illness and deaths – unintended but very real and irreversible damage.

Are there other areas within nursing home long-term care needing attention, improvement, change, new legislation, and other action? Of course. Environments should be more home-like. Staffing levels must be elevated. Training must be not only strengthened, but embedded in the organizational culture of every facility. Supervision must be competent. Leadership must lead by example. And there are many more steps to be taken. It may surprise you to learn that the constructs for these improvements are actually laid out in the current regulations – if only they were comprehended and implemented by providers and strongly enforced by well-trained regulators who understood the underlying concepts and how to recognize true compliance.

The larger issue in long-term care is that nursing homes are not the only victims of this corporate for-profit web exacerbated by poor enforcement. All levels of long-term care, from in-home supports to boarding homes to independent living to assisted living to memory care, ALL are being caught up. Yet there are no federal regulations for most of these types of care. States may or may not regulate one or more of these types of care. State regulations vary tremendously among states and among types of care. Federal regulations, requirements, and enforcement are desperately needed if this country is to see an improvement in how we treat our vulnerable elderly loved ones. This endeavor, of course, is a longer-term project; but Congress must recognize the need and begin to act to address it before the next disaster takes its toll on this fast-growing demographic group of citizens.

Thank you for the opportunity to submit a statement for the record.

Sincerely,



Katharine H. Bradley