Head in the Sand: The Failure of the Assisted Living Industry in Minnesota to Respond to 20 Years of Warning Signs and Implement a Licensure

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The 16 warning signs are presented below in chronological order:

Warning Sign #1 – 1997

A U.S. General Accounting Office (GAO) report [2] entitled *Long-Term Care: Consumer Protection and Quality of Care Issues in Assisted Living* found, "Some stakeholders are concerned that the rapid rate of assisted living market development may be outpacing many states' ability to monitor and regulate care furnished by providers" and that according to experts, "consumers can find themselves in a facility unable to meet their expected needs." The report called for an examination of the "effectiveness and adequacy of existing models of oversight and regulation."

Warning Sign #2 – 1999

A U.S. GAO (1999) study [3] entitled *Assisted Living: Quality of Care and Consumer Protection Issues* examined quality of care and consumer protection problems in ALRs in California, Florida, Ohio, and Oregon. Using state licensing inspection survey deficiencies, ombudsman complaints, and Adult Protective Service allegations that state officials verified, GAO found that the states cited more than 25% of the 753 facilities in its sample for five or more quality of care or consumer protection related deficiencies or violations during 1996 and 1997. State officials attributed most of the problems identified to insufficient staffing and inadequate training, exacerbated by high staff turnover and low pay staff. In addition, GAO identified numerous examples of vague, misleading, or even contradictory information contained in written marketing materials that residences provided to consumers.

Warning Sign #3 – 2003

A hearing before the U.S. Senate Special Committee on Aging [4] (April 29, 2003) entitled *Assisted Living: Examining the Assisted Living Workgroup* (ALW) *Final Report.* The comprehensive (375-page) ALW Final Report is entitled *Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulation, and Operations*.

The ALW Final Report was based on 18-month of work of 50 national stakeholder organizations (including, among others, representatives of consumer advocates, provider sector, health care professionals, and regulators and accrediting bodies).

The report included 110 recommendations specific to ALRs (i.e., using a process requiring a two-third majority vote to decide whether a recommendation should be made). Selected examples of domains under which recommendations were made, include, oversight, accountability, and enforcement; protections against deceptive marketing practices; quality indicators; policies and procedures pertaining to care and safety of residents with dementia (such as security measures for residents at risk of leaving the ALR unattended); initial and ongoing interdisciplinary assessment and care planning; pre-move in screening; safe medication management; and protection of residents rights. In addition, the ALW recommended the development of a state licensure of ALRs "to provide the state with appropriate regulatory oversight of assisted living." The full list of ALW's recommendations is presented in Appendix B of the ALW Final Report. The Senate hearing examining the ALW Final Report consisted several indicators of concern and calls for action. Selected examples include:

Senator Ron Wyden, Oregon, stated, "We have got to have a safety net to ensure that every vulnerable older person in this country in every assisted living facility has certain basic protections, because they continue to be some of the most vulnerable people in our society"

Stephen McConnell, Vice President for Advocacy and Public Policy, Alzheimer's Association, Washington, DC, stated, "One of our basic principles is that "essentials must be provided and states should mandate these, for example, basic safety." He added, "There are very few states that provide protections for people with dementia in all assisted living facilities. If they do it at all, it is really only for special care units." It is important to note that research has shown that "68% to 89% of residents with moderate to severe dementia do not live in special care facilities or units" in residential care/ALRs. [5]

Warning Sign #4 – 2004

Assisted living residences (ALRs) are considered the fastest growing residential care option for elders in the U.S. where half of the residents have dementia [6]

Warning Sign #5 – 2005

A book entitled *It Shouldn't Be This Way: The Failure of Long-Term Care* [7] by the late Professor Robert L. Kane and Joan C. West dedicated two chapters to traditional *Assisted Living* and *The Dementia Unit* (also within ALR) based on their experience caring for their mother with dementia. Examples of lessons learned from their painful journey include, ALRs "are often designed more to attract families than to help residents," lack of full disclosure during admission, salespersons' promises to families that their loved one's care needs will be met prove baseless, the imbalance of power between consumers (residents and families) and staff/ALR, and lack of staff training in tracking medical conditions and reporting changes in a resident's status. The authors concluded, "assisted living is not a parking place for older persons, especially those with cognitive problems. Continued family advocacy and involvement is essential." They added, "outside observers worry that an unregulated assisted living industry would force us to relive the checkered past of nursing homes" (i.e., series of scandals in the 1980s that uncovered very deficient care).

Warning Sign #6 – 2007

The assisted living industry is reported to experience an unprecedented growth between the mid-1980s and the mid-2000s. Specifically, "by 2007, there were close to one million residents nationwide." [8]

Warning Sign #7 – 2008

Douglas D. Pace & Karen Love [8] assert,

> "Providers have generally not taken responsibility for proactively addressing systemic problems within their industry but instead behave like ostriches (i.e., "taking an ostrich-like posture – namely, refusing to acknowledge publicly problems with quality of care, believing that what they do not own up to does not exist"). They have left it to other stakeholders, including even the U.S. Government Accountability Office, to weigh in about significant, widespread, long-standing problems in the industry, such as medication management, insufficient staffing to meet residents' needs, inadequate staff training, inconsistent quality of care seven days a week, and questionable marketing and disclosure practices."

These national experts added, "The assisted living industry is not currently under fire, and this is an ideal time for it to focus on strengthening and improving itself. Waiting until crisis strikes to make needed changes is shortsighted and disingenuous." They observed, "If leaders of assisted living are wise, they will find ways to enhance accountability among all stakeholders, at all levels, before a major crisis provokes massive public outcries."

Warning Sign #8 - 2009

A large-scale study by professors Hawes and Kimbell [9] entitled *Detecting, Addressing and Preventing Elder Abuse in Residential Care Facilities*, found, "significant challenges to effective detection, investigation and resolution of elder abuse in residential care facilities." The researchers called for an investigation of "the underlying causes of elder abuse in residential care facilities."

Warning Sign #9 – 2011

A study entitled *Mistreatment in Assisted Living Facilities*: *Complaints, Substantiations and Risk Factors* by professors Philips and Guo [10] asserted, "data are very clear that assisted living facilities population is increasingly resembling the nursing home population with regards to physical and cognitive problems." While differences between these two resident populations remain, [11] residents' medical, functional, cognitive impairments and various forms of distressing and harmful behavioral expressions are substantial in many ALRs.

Warning Sign #10 – 2012

In an interview with PBS Frontline on November 10, 2012 [12], professor Catherine Hawes, a leading national authority, describes the ALR industry as "a ticking time bomb." She added, "Weak regulation and inconsistent training standards could soon mean a surge in preventable deaths at the nation's assisted living facilities. We are going to see more deaths and more injuries. We've created a situation where it's almost impossible for this not to occur."

Warning Sign #11 – 2013

A study by professor Castle [13] entitled *An Examination of Resident Abuse in Assisted Living Facilities* surveyed 1,500 ALRs from all 50 states using mailed questionnaire to administrators and direct care workers. The study found that residents' characteristics associated with high levels of abuse include residents with dementia and with physical limitations. In addition, lower staffing levels were associated with abuse of residents. While abuse by staff was found to be relatively uncommon (i.e., resident-to-resident "abuse" was reported by respondents to be more common than staff abuse), staff verbal and psychological abuse of residents (e.g., humiliating remarks) was "an area where substantial improvements could be made."

Warning Sign #12 – 2013

A Frontline and ProPublica investigation entitled *Life and Death in Assisted Living* [14] revealed major gaps in care and serious safety problems pertaining to residents of one of the largest ALR chains in the U.S.

Warning Sign #13 – 2013/2014

The National Study of Long-Term Care Providers (second wave; 2013-14) [15] shows that 58% of ALR residents in Minnesota were over 85 years old, 39% had dementia, and substantial portion of residents needed assistance with activities of daily living, including bathing (60%), dressing (43%), toileting (37%), walking (26%), bed transfer (26%), and eating (24%). Over one-third of ALR providers were reported to serve only residents with dementia or have a "dementia care unit." In addition, one out of every five residents in ALRs relied on Medicaid for their long-term care.

In addition, a troubling report entitled *Deadly Neglect* [16] found that hundreds of seniors in San Diego County California have suffered broken bones, deadly bed sores, sexual assaults, and other injuries at ALRs. At least 27 seniors in the county have died since 2008 from injuries and neglect in these residences. Beyond an increase in complaints alleging poor care over the past 5 years, a series of systemic problems were identified in the report, including, among others, minimal fines for deaths that have no deterrent effect (a statutory maximum fine of $150 if the state concludes a resident's death was caused or hastened by the ALR's lack of proper care; in comparison, if you kill a California Condor, it is $25,000, says Chris Murphy, a San Diego advocate for elders who founded Consumer Advocates for Residential Care Facility for the Elderly [RCFE] Reform after her mother's death in ALR), weak state oversight of ALRs (such as failing to monitor or correct dangerous, sometimes lethal, conditions in the residences), state law requiring unacceptable intervals of 5 years between inspections, and deplorable staff training standards. Paul Greenwood, Deputy District Attorney, said, "This type of crime is only going to get more widespread in the months and years to come. We have a duty to clean up the RCFE industry, to highlight the good ones and target the bad ones."

Warning Sign #14 – 2014

A national study shows that seven out of ten residents in ALRs have some level of cognitive impairment (29% mild impairment, 23% moderate impairment, 19% severe impairment). [17]

Warning Sign #15 – 2015

According to the National Consumer Voice for Quality Long-Term Care, complaints of abuse, gross neglect, and exploitation in ALRs across the country as reported by the LTC ombudsman program grew by 22% between 2010 and 2015. [18]

A review of practices and states' regulatory activity in ALRs across the country [19] entitled *Policies to protect persons with dementia in assisted living: Déjà vu all over again?* found "similarity of circumstances in contemporary assisted living to those preceding the passage of the Nursing Home Reform Act of 1987" (known as OBRA, 1987). The "many shortcomings in providing care to skilled nursing facility residents across the U.S." as described in 1986 Institute of Medicine report [20] have led to the passage of the act.

Crisis Reported – November 2017

A report by the Star Tribune shows that the number of residents in ALRs in Minnesota has "doubled over the past decade." [1] In addition, the number of beds in ALRs in 2017 was nearly twice the number of beds in nursing homes (54,125 versus 28,647, respectively). [21]

A Star Tribune Special Report *Left to Suffer* [1] (November 12-16, 2017) exposes a crisis at the Minnesota Department of Health's (MDH) Office of Health Facility Complaints and in LTC homes across Minnesota. The series, which focused largely on ALRs as well as residents with dementia and "memory care" units within ALRs, reported on hundreds of elder residents who were neglected, abused beaten, sexually assaulted, or robbed every year while leaving in senior care homes.

Warning sign # 16 – 2018

A GAO study [22] entitled *Medicaid Assisted Living Services: Improved Federal Oversight of Beneficiary Health and Welfare is Needed.* The study found that only 22 states were able to provide data on "critical incidents" – cases of potential or actual harm to Medicaid beneficiaries (such as abuse, neglect, exploitation, unexplained death). In one year, those states reported on more than 22,921 incidents including physical, emotional or sexual abuse of residents.