March 25, 2024

House Committee on Health and Human Services Rhode Island State House HouseHealthandHumanServices@rilegislature.gov

Re: **Testimony SUPPORTING House Bill 7969**, giving residents of long-term care facilities the right to use electronic monitoring in their rooms

Dear Chair Donovan and Honorable Committee Members.

My husband John had early onset Alzheimer's disease, and in December 2020, when his care needs became more than I could manage at home, I made the very difficult decision to move him to an assisted living memory care facility in Providence—a decision made even more excruciating by pandemic circumstances, in which I didn't know when I would be allowed to see him again. Once it was allowed, I visited a few hours every day, and frequently expressed my appreciation to the staff. My sweet husband had a special place in the hearts of many staff members. Nonetheless, I discovered nine months later that he was the victim of verbal abuse, humiliation, and ongoing neglect.

The facility administrators had not allowed me to have a camera in John's private room, and resisted allowing me to have an Alexa video communication device because they said it would violate the privacy of the staff. It was that device, turned by staff to face the wall so that I couldn't see the room, that enabled me to hear the abusive way John was spoken to and the lack of care he was receiving. After I discovered the abuse, I moved him out, and was able to find only one other facility within 30 miles that would allow me to have a camera in his private room. (The administrators of one facility we toured even turned us away in response to my camera query.) In the new facility, I saw that John was treated with respect and kindness in his room. It made the difference between a sharp "Go to bed!" when he hadn't even been helped into his pajamas yet, and a gentle and solicitous "It's getting late, John. Would you like to get ready for bed?"

Meanwhile, when the Department of Health addressed my complaint with a visit to the original facility 9 months after I filed the complaint, they found it unsubstantiated. It is worth noting that assisted living facilities in RI are surveyed by RIDOH biennially. Once every two years. Nursing homes are required to be inspected once every 15 months. And more than 4500 nursing homes in the US are currently overdue for inspection. On those inspection days, which staff frequently know about in advance, it is highly unlikely that a surveyor is going to witness mistreatment. Of the 80 complaints the LTCOP made to RIDOH in 2023, RIDOH surveyors only cited deficiencies for 16 of them.

My husband was just one victim of many in the US. In 2019, nearly 13,000 complaints of abuse were filed with Long Term Care Ombudsmen. Here in RI, in 2019 the ombudsman's office received an average of two complaints a month of physical and sexual abuse in care facilities. Imagine all the mistreatment we don't hear about, when the victim has lost the capacity for language, is dismissed because of cognitive difficulties or age, or is justifiably frightened of retaliation. A 2019 WHO review of recent studies on elder abuse in institutional settings indicated that 64% of staff reported perpetrating some form of abuse in the past year. In recent months, we've seen headlines about RI facility staff accused of sexual abuse, on-site illegal drug use, gross neglect, dangerous medication errors and falsification of records, theft of residents' pain medication, and numerous resident-to-resident assaults.

I can tell you from personal experience and my experience as a volunteer resident advocate for the State Long-term Care Ombudsman Program that retaliation against residents and families who complain is quite common, and many residents keep quiet out of fear. For those who do file a complaint, time and again, we see RIDOH respond to valid complaints of serious harm and neglect with a survey report that says simply "no deficiencies cited." Even when the complaint is made by the LTC Ombudsman's office, 80% of those complaints in 2023 resulted in no citation.

Clearly, this is a systemic problem that needs to be addressed from many angles, but one very easy way to address the problem in the interim is by empowering residents and their family advocates to hold facilities accountable and monitor their loved ones' care.

Twenty other states have already passed similar legislation, and in my conversations with ombudsmen, legislators, and stakeholders in those states, they report only positive outcomes.

I urge you to support H7969, and I am happy to provide any additional information or answer any questions you may have. Thank you for your consideration.

Sincerely,

Kathleen Gerard, Providence, RI 02903