

March 26, 2025

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

Re: Testimony SUPPORTING HB 5170, to support family councils in nursing homes in RI

Dear Chair Donovan and Honorable Committee Members.

Thank you for the opportunity to submit this testimony in support of House Bill 5170.

ABC-RI stands for the rights and interests of all Rhode Islanders residing in long-term care facilities. We strongly support HB 5170 because it is designed to help families advocate more effectively for their loved ones residing in nursing homes who are unable to advocate for themselves.

Nursing homes are required by federal regulations to allow family councils, and where they exist they have proven very beneficial for residents, families, and facilities alike. This amendment simply applies the language from our assisted living facility bill to nursing homes so that they are aligned in elements that make it easier for families to form independent councils.

On average, over 40% of residents in long term care have a dementia diagnosis which can inhibit their ability to advocate for themselves, and make care-partner support very important. Nursing homes frequently have separate dementia care units, in which families of residents rarely have a means to come together and advocate for their loved ones. Some facilities may convene support groups, but when these groups are led by staff members, rather than by family members, they are not family-directed or resident-centered, and many advocates are not comfortable sharing problems or complaints for fear of reprisal.

The National Consumer Voice for Quality Long-Term Care, a leading resident and family consumer advocacy organization, reports that "Family councils can play a crucial role in voicing concerns, requesting improvements, supporting new family members and residents, and supporting facility efforts to make care and life in the facility the best it can be." Recognizing family members as care-partners in both nursing homes and assisted living provides a vital connection for the resident, family members, and facilities.

Industry lobbyists have argued that administrators are "always happy to put together a meeting of family members if requested," but family members often want the ability to meet independently, and in conversation with numerous administrators, many have been reluctant to support such activities. Some

of our most enlightened administrators already encourage independent family councils, but they are very much the minority.

The bill includes a clause to prevent any family member from participating in the council against the wishes of their resident. There is no cost to the residents or the facility, no need for involvement from the DOH, and the State Ombudsman's Office is available to support facilities and families in the establishment and support of the councils. Councils can indeed *decrease* managerial workload, as families speaking with one voice is more efficient than individual complaints and meetings with numerous care-partners. California benefits from similar legislation, and Connecticut has recently passed their own version.

We urge you to support HB5170, to help nursing home resident care-partners advocate together if they choose.

Thank you for your time and attention, and for all of your work on behalf of all Rhode Islanders.

Sincerely,

Kathleen Gerard, ABC-RI