



TESTIMONY

In Support Of

LD 296: An Act To Create the Family Caregiver Grant Pilot Program

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Senator Claxton, Representative Meyer and committee members, my name is Brenda Gallant. I am the Long-Term Care Ombudsman. The Maine Long-Term Care Ombudsman Program is a statewide non-profit organization that provides advocacy for older adults and adults with disabilities who receive long-term services and supports in all settings. We serve residents in nursing homes, assisted housing including residential care and assisted living facilities, adult day programs and recipients of home care services. Additionally, we serve patients in hospitals who experience barriers in accessing long-term services and supports.

We are pleased to provide testimony in support of this legislation that requires the department to establish the Family Caregiver Grant Pilot Program in cooperation with the Area Agencies on Aging to expand the uses of the Respite Care Fund established in section 7308 to cover costs associated with in-home care of an adult in accordance with this section. The purpose of the Pilot is to increase the number of families served by the Respite Care Fund, provide a family caregiver grant to increase economic security for family caregivers, and examine the needs of families served by the Respite Care Fund. The Department of Health and Human Services is required to establish a stakeholder group to make recommendations for the development of the Family Caregiver Grant Program.

The great value of family caregivers should not be underestimated, particularly as our state faces a critical shortage of direct care staff. Over and over again, Ombudsman Program staff work with Maine family caregivers who are in many cases the primary support for their loved ones who are older and disabled and in need of care in order to remain in the community. In 2017, approximately 181,000 family members in Maine provide an estimated 152 million hours of

care. Those unpaid hours are worth \$2.2 billion annually. (Valuing the invaluable, AARP) National surveys show that many family caregivers of older adults report financial strain associated with their role as caregivers (NAC and AARP Public Policy Institute, 2015b; Spillman et al., 2014; 2016) Out of pocket expense related to caregiving and the impact on employment due to caregiving responsibilities may have a significant impact on the finances of family members providing care for loved ones. The availability of grant funds for family caregivers proposed in this legislation would no doubt be helpful in providing some needed financial support to families.

The Ombudsman Program provides assistance to older adults and adults with disabilities when they experience barriers in accessing the long-term services and supports they need. Over and over again, we observe the critical role of family members in providing support to loved ones who need care. These family members often provide transportation, grocery shopping, picking up prescriptions, meal preparation, personal care, medication administration and housekeeping. Sometimes family caregivers must provide care that would typically be considered nursing tasks.

These are just two examples of Maine family caregivers whose responsibilities in this role impacted them financially:

A daughter left her job for a year in order to take care of her mother diagnosed with Alzheimer's disease. She took her mother into her home providing care 24 hours a day, seven days a week. In order to be at home without the income she had previously, she took funds out of her 401K. She incurred a penalty for the withdrawal of funds.

A wife whose husband suffered from ALS worked full time while taking care of her husband at night and on the weekend. When home care staff were unavailable or were absent without sufficient notice, the wife would have to stay home from her job to take care of her husband.

In so many ways Maine's long-term services and supports system is reliant upon family caregivers. This is particularly true as our state faces the significant challenges of a greatly reduced workforce that has resulted in many hours of unstaffed home care hours.

The role of family caregivers is critical, reducing costs for long-term services and supports by providing care at home. We urge you to support this legislation that is an important step in recognizing the financial challenges so often faced by family caregivers.

Thank you for your consideration.