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Testimony in Support of LD 815

An Act to Provide Funding for Respite Care and Supplemental Services Provided by the Family Caregiver Support Program

Good morning, Sen. Ingerswen, Rep. Meyer, and all the distinguished members of the Health and Human Services Committee. My name is Sue Hawes. After caregiving for my parents at the end of their lives in the 2010s, I am now caregiving for my husband who suffers from dementia due to epilepsy--my third and likely final round of caregiving.

My husband has suffered from epilepsy since he was 15 years old. When we married, he had maybe one nocturnal (during sleep) seizure a year when he missed a dose of medications. He was always gainfully employed. However, a year after we bought a house and had a baby, he lost his job after having a seizure in the parking lot at work and ended up on Social Security Disability for about eight years. Once he restabilized, he went to work as a Corrections Officer at Cumberland County Jail.

With his income cut in half while on Social Security Disability, I was very afraid for our financial future. With the guidance of my brother, we borrowed the equity from our home as a down payment and bought a three-family building in Portland, moved into one of the apartments, and rented out our home and the other two apartments. Taking that risk twenty years ago proved to be a very good decision for our family.

Which brings me to this bill and why I am here today to urge you to support renewed funding the Respite for ME program through LD 815. Although we live like college students, we have been fortunate to maintain a livable income, preserve our health insurance by paying about $2000 every month in premiums, and keep a roof over our heads. However, I know many caregivers in Maine struggle when a member of the family is medically needy with limited or no income.

The Disability Research Institute estimates that a household containing an adult with a disability that limits their ability to work requires, on average, *28 percent more income* (or an additional $17,690 a year) to obtain the same standard of living as a similar household without a member with a disability.[1] As a result, caregivers too often cannot afford to invest as we have in adaptive equipment in the home to support the caregiver

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[1] "The Extra Costs of Living with a Disability in the U.S.—Resetting the Policy Table," National Disability Institute, October 2020, https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-living-with-disability-brief.pdf

by increasing safety for the care recipient and lessen the stress and worries for the caregiver. Funding Respite for ME through this bill will go a long way in supporting the ability of our state's caregivers to continue caregiving in the home.

For example, I was fortunate to be able to pay $1,800 for a device called a Medacube. It's a medication dispenser specifically designed for patients with dementia. I no longer must set out his 16 daily life preserving anti-seizure pills and worry about whether he will take them properly or forget to take them if I am not home. I don't have to worry that he will end up in the emergency room if he accidentally overdoses as has happened in the past. I now only must dump the bottles of pills into the Medacube and the Medacube controls the correct medication dispensing at the correct time. It texts me if he doesn't take his meds or if one prescription is running low, the Medacube prevents errors in dosing, etc. This one device has increased his medication regime adherence to 100% and gives me extraordinary peace of mind.

Insurance does not pay for medication dispensers such as a Medacube. Caregivers may not have the financial resources to make such a purchase. Funding Respite for ME makes it possible for others to purchase a device such as a Medacube, other adaptive equipment, and assist caregivers in many other situations.

As a state, our unpaid family caregivers, such as myself, are contributing massive man hours keeping care recipients out of the hospital and nursing home, often at a great financial sacrifice for the caregiver. According to AARP, Maine's 166,000 unpaid caregivers are saving Maine taxpayers billions of dollars.[2] The least we can do as a state is provide an adequate and expansive respite fund which caregivers with limited resources can draw on to improve care and support the caregiver's ability to continue to provide care in the home.

I urge you to vote Ought to Pass on this bill and to widely encourage your colleagues to support renewed and ongoing funding for Respite for ME.

Thank you for your time and attention. I am happy to answer any questions now or in the future.

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[2] "The unpaid care provided by the 166,000 caregivers in Maine is valued at $2.9 billion, according to new state data available in AARP's latest report in the Valuing the Invaluable..." https://states.aarp.org/maine/valuing-invaluable-report