Senator Gratwick, Representative Hymanson and members of the Joint Standing Committee on Health and Human Services:

My name is Jess Maurer and I’m the Executive Director of the Maine Council on Aging (MCOA). The MCOA is a broad, multidisciplinary network of more than 75 organizations, businesses and older community members working to ensure we can all live healthy, engaged and secure lives as we age at home and in community settings. I am submitting testimony in support of LD 84.

The MCOA has identified supporting informal family caregivers as a top priority and with good reason. There are an estimated 170,000 informal family caregivers in Maine. These are spouses, children, grandchildren and other relatives caring for aging and disabled adults who have difficulty living independently. Many of these caregivers are caring for the more than 37,000 people in Maine who are living with some form of dementia. Informal family caregivers are quite literally the backbone of the long-term care system – without them, our system of caring for aging and disabled adults would fall apart. Without them, it’s estimated that Maine would have to spend $2.2 billion annually to provide the same level of care.

We support this legislation to allow a home care consumer’s spouse to be employed as a personal support specialist (PSS) through an agency. People who are served by the Section 19, Home and Community Benefits for the Elderly and Adults with Disabilities are nursing home eligible. Instead of utilizing this significantly higher cost level of care, people served by Section 19 stay at home and receive services that support them living at home, usually including support provided by a personal support specialist (PSS). A PSS provides support with activities of daily living, activities that can be very personal, like using the toilet, showering, getting dressed, etc. There can be little doubt that most of us would prefer to have a spouse assisting us with these activities rather than a stranger. And, of course, one spouse often performs these activities as the other spouse is declining and before that person applies for and receives any state benefits.

There are three compelling reasons to allow a spouse to be compensated as a PSS under Section 19. First, Maine’s severe and persistent direct care worker shortage means that 6,000 hours of authorized PSS care under Section 19 go unstaffed each week, not because we don’t have funding, but because we don’t have workers. When the option is to go without care or have your spouse perform uncompensated care, of course the spouse will provide uncompensated care. However, the spouse should not have to provide uncompensated care when someone else was supposed to provide that care. Second, as care needs increase, some spouses would have to leave or reduce employment in order to be able to provide a sufficient level of care. It’s estimated that more half
of our nation’s informal care providers are employed. A couple should not have to impoverish themselves because the spouse can provide the best care but would have to give up gainful employment to provide that care. If the care provided would have otherwise been compensated for the care if it was provided by anyone other than a spouse, the spouse should be compensated for the care. Finally, we should always want the best, least intrusive care for people. Sometimes, this means a spouse should perform that care – and sometimes not. But, the option should be available. As this is an option for spouses of people who receive similar services under Section 63, it should be available for spouses performing the same services under Section 19.

A report released in September 2016 by the National Academies of Sciences says, “…the need to recognize and support family caregivers is the most significantly overlooked challenge facing the United States society.”

Maine should take every action allowable to support every kind of informal family caregiver, including spouses. I urge you to vote in favor of LD 84 to demonstrate to family caregivers that Maine values their contributions. Thank you.

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