

Peter Rice
Disability Rights Maine

May 3, 2021

Senator Ned Claxton, Chair
Representative Michele Meyer, Chair
Joint Standing Committee on Health and Human Services
Cross Office Building, Room 209
Augusta, Maine 04333

Re: LD 1624 Resolve, To Create a Stakeholder Group To Identify the Needs of Long-term Care Family Caregivers

Dear Senator Claxton, Representative Meyer, and Members of the Joint Standing Committee on Health and Human Services:

My name is Peter Rice and I am the Legal Director at Disability Rights Maine, Maine's designated protection and advocacy agency for Maine citizens with disabilities.

Family caregivers are an essential and overlooked piece of the long-term care assistance system in Maine.

All of MaineCare's waiver programs must comply with the federal home and community-based settings rule. Those federal rules require each recipient of waiver services to have a backup plan. However, those backup plans are written, family caregivers are really the backup plan. When workers call in sick, take vacation, quit to take other, higher paying jobs, or are stranded by snow storms, families have to step in to provide their loved ones needed services. It can be for short periods of time, or, as is more often the case, long periods of time. Family caregivers have to know how care for the needs of their loved ones without receiving the training that paid staff receive.

When nurses who provide private duty nursing services to recipients cannot take their shift, it falls to family caregivers to take up the slack and provide nursing services that the family caregiver may have never been trained to provide, but have learned how to provide by experience, and are expected to provide.

Family caregivers provide services when workers are done for the day. Service recipients require services when workers are no longer on duty. Service recipients may have need for more services than called for in the plan of care. It falls to family caregivers to provide those services.

We know there is a shortage of direct care workers. Family caregivers fill in those gaps.

Family caregivers often risk their job when required to provide care. They have to take sick time or family medical leave in order to provide services, even when jobs do not provide sick time. Traditionally, they not been able to be paid to provide services for loved ones. They can risk their entire family's wellbeing in order to provide service to a loved one.

Family caregivers are often isolated. There are few resources for them to rely on. They learn how to provide sometimes difficult services on their own. They have to learn how to navigate a complex system of rules and regulations in to ensure that their loved ones get the services they need.

This bill is the first step in addressing a need that has not been recognized for a long time.

Please vote ought to pass on LD 1624, Resolve, To Create a Stakeholder Group To Identify the Needs of Long-term Care Family Caregivers.

Thank you.

Sincerely,

/s/ Peter M. Rice
Peter M. Rice, Esq.
Legal Director