Testimony of Gerard Queally, President and CEO of Spectrum Generations, the Central Maine Area Agency on Aging

To Joint Standing Committee on Health and Human Services 132nd Maine Legislature, First Regular Session

In Favor of LD 709 (if amended) – An Act to Establish the Respite for ME Program; and

In Favor of LD 815 – An Act to Provide Funding for Respite Care and Supplemental Services Provided by the Family Caregiver Support Program

Delivered in person on March 14, 2025

Honorable Senate Chair Henry Ingwersen and Honorable House Chair Michelle Meyer and all other Honorable Members of the Joint Standing Committee on Health and Human Services Committee,

I am Gerard Queally, President and CEO of Spectrum Generations, the Central Maine Area Agency on Aging.

It is my request that you allow me to provide simultaneous testimony on both LD 709 and LD 815, since both proposed pieces of legislation are intertwined, and to view them in isolation would be a mistake.

On the surface LD 709 appears at worst a rebranding, changing the name of the current “State Respite Care Program” delivered by the five Maine Area Agencies on Aging (AAA) to the recently popularized COVID-19 era “Respite for ME” (R4ME) nomenclature. A rebranding can be a useful marketing strategy and if that is what the Department of Health and Human Services (DHHS) is hoping to achieve, I applaud them. A rebrand without a noticeable product enhancement could eventually be perceived by the voting public as a renaming gimmick. This is the first intersection between LD 709 and LD 815.

Under the current State Respite Care Program (OADS Section 68) is an Alzheimer’s/Dementia program and Spectrum Generations receives $190,973; the state allows $27,430 to be used as Older Americans Act Title IIIE federal match to our Family Caregiver Program. That leaves $163,543 for actual caregiver respite, of which 10% ($16,354) can be used to administer the program. Subsequently, over the course of the year we deliver $147,189 to approximately 40-50 people. To put it in perspective, there are approximately 7,500 people living with Alzheimer’s/Dementia in our six-county catchment area.

Let us compare that to R4ME for the two years it was in operation (FY23-24). During that two-year period, we were allocated $585,100 each year (a **2-year total of $1,170,200**) and distributed on average $569,105 **(a 2-year total of $1,138,209**) to 178 people each year (**2-year total of 357 people**). That is a <u>97% distribution of dollars allocated</u>. There was a great need; and that need still exists today.

LD 815 funds that existing need. Spectrum Generations, based on the Intra-state Funding Formula (IFF), would receive approximately 26% of the funds proposed, or $585,000. This directly equates to the demand we were allocated and distributed in the original R4ME program.

LD 709, without LD 815, is just a name change. With LD 815, LD 709 has the potential to positively affect people’s lives. Without LD 815, there is a danger in using the brand R4ME and for the voting public to expect more and unfortunately receive a great deal less. That is a bad marketing strategy.

The second point of intersection between LD 709 and LD 815 is in the text of LD 709 that directs DHHS to administer the R4ME program. The language rings of rulemaking and the rules of distributing funds under the current State Respite Care Program (OADS Section 68) and the former R4ME were quite different. Both either had or have arduous requirements that fail the voting public. I ask the HHS Committee to walk here carefully.

The current State Respite Care Program (OADS Section 68) is an Alzheimer’s/Dementia respite care program. Very noble in its purpose, while also very limiting. And it is exceedingly difficult to get consumers and caregivers who are in crisis to use the service because of its restrictions. It requires a physician’s written diagnosis; that can take 6-8 months. It does not allow chore services (i.e., snow removal, gutter cleaning, etc.) which are in high consumer demand. It is liquid asset test limited, at $50K for individuals and $75K for a couple. Nearly all consumers with modest savings are typically excluded. While the maximum benefit is $5,303, only $2,000 is authorized for home modifications, which is another high demand request. It is a reimbursement program, so the person must spend their money first and have receipts before receiving any assistance. This is a barrier, as people do not have the money to spend upfront. The caregiver can request their contractor directly bill our agency; however, that requires a great deal of time and administrative coordination that becomes time consuming and adds costs. And while the State Respite Care Program pays for services like Personal Support Services or Adult Day Programs, workers or agencies providing these services are very limited in staffing and/or location availability and when available, $5,303 equates to no more than 160 hours of service. Again, the expense must be incurred to be reimbursed.

When active, R4ME had its own share of problematic regulations, especially during its inception. Initially DHHS mandated protocols were data collection driven and not focused on getting funds into the hands of the consumer. The focus was on following administrative rules and not helping people. The program was over-regulated. In fact, in 2022 Spectrum Generations was suspended by OADS for two weeks for being too eager to help consumers navigate the process. Unfortunately, it was not us who were penalized but the people who needed the service. Eventually the program became less regulated and consumer focused but still intimidating for the community and very confusing for the AAAs. The evolving and uncertain rules added administrative costs to the AAAs that were never reimbursed by the state.

I mention these rules as obstacles not because there should not be rules. This is taxpayer dollars, so of course there should be rules and accountability across the board. What I am attempting to express is that OADS is too far removed from direct community experience and engagement on this topic to be able to put forth helpful rulemaking that will benefit all. This harsh assessment is based on 15 years of experience as an AAA CEO. Too many times, we have cautioned or advised OADS on rules surrounding delivered services to older adults only to be ignored and left to deal with the consequences to consumers. Eventually most problems are sorted out (reality gets in the way of bureaucracy) but always to the initial detriment of those we are attempting to serve.

Therefore, I would propose that LD 709 be amended to direct DHHS to consult with the AAAs to jointly work together to develop rulemaking and report back to this Committee on what administrative regulations are put forward for an R4ME-type program by October 01, 2025.

Finally, I urge you to fully fund LD 815 as requested.

Thank you for your time and consideration.