

Hon. Tina Riley

Jay, ME

3/29/2023

Senator Baldacci, Representative Meyer, and members of the Joint Standing Committee on Health and Human Services, thank you for the opportunity to speak in support of LD 346, "An Act to Clarify the Requirements for Family Caregivers." I am before you as a parent and a caregiver, representing a segment of our population that has too much on their plate to focus on telling you their stories.

My son, Bryan, has Duchenne muscular dystrophy. I have watched his body fail, bit by bit, for over twenty years now. He has never dressed himself, brushed his teeth, or showered independently. He stopped walking at the age of twelve. I was working as a mill electrician but I spent most of my energy jockeying his IEP, insurance, waiver program updates, medications, and therapies, and making the four-hour round trip to appointments with each of his specialists. His failing mobility added the job of repositioning him several times each night.

For a while, a caregiver came in at 4:30am so my husband and I could go to our jobs at the mill but she burned out. Unable to find a replacement caregiver and exhausted from the 24/7 workload, I had little choice but to walk away from my career to care for my son.

Had he needed an actual nurse at his bedside, the state would pay a parent who is qualified to deliver that service, if the requirements were met. But my son needed assistance with "ADLs," not medical care. I was fully qualified to do that job and no one was available to provide the care he needed, so I did it unpaid. Some families in that situation are financially sunk, forced to live on welfare in spite of the workload they cannot shirk.

Today, I am paid to care for him through a program that has guardrails and layered checks to ensure that he is well cared for. The State recognizes that he gets better care at a lower cost than he would in a nursing home, which is his only alternative. The only thing that has really changed is that he's an adult, which seems an odd metric to decide whether parents are eligible to be paid to provide this care.

A few years ago, I sponsored a similar bill that unanimously passed this committee but then died of covid. Then a small appropriation was set aside for a pilot program to address this need. But DHHS chose to ignore the Legislature's directive, and they have opposed this idea at every turn. I would have some patience for this if their arguments were cogent. I will unpack that if it pleases the Committee.

Today, we can solve two problems - a lack of workers, and overloaded families living with financial ruin. In certain situations, paying the parent of a minor to provide for the child's "extraordinary needs" is the best solution for everyone involved. Keeping parents on welfare to ensure that they are eligible for services is a poor approach to meeting the needs of disabled children, particularly given that a child in need of this program would almost certainly be on or eligible for a Katie Beckett waiver.

Parents who are trying to meet their families' basic needs and provide care for their disabled children's "extraordinary needs" need a common-sense solution. I invite the Committee and the Department to create guidelines that will ensure the needs of the children and taxpayers are well-guarded. We can either hand these families welfare or we can pay them to do the job that we would routinely pay any other eligible person to do.