

## TESTIMONY

**Hello, Good afternoon, Senator Craven, Representative Farnsworth and members of the committee, my name is Raima Fernald and I am here to testify for LD488 on behalf of my son and all others who receive care under the Home-based care programs.**

Since 2011 my sons John and Chris have been receiving care under the MaineCare home-based care waiver program. Before 2011 they both were receiving care through a PNMI and other facilities. The PNMI provided 24/7 care with 5 or more caregivers /3 fulltime caregivers during the day and 2 fulltime caregivers at night.

The care they received proved to be inadequate and unfair to them. One of my sons almost died and had to be hospitalized for severe dehydration and the other one escaped several times being hospitalized once. Their overall appearance was disgusting and it was apparent they were being neglected. Each of them slowly losing their quality of life due to their illness and much of their medical issues went unnoticed. This is just a few of the many incidences that led me to believe I needed them to be at home and care for them.

The Goold process began and they were each awarded 59 hrs of care per week through the MaineCare home-based care program, (the maximum cap for this program.) The hours were not enough and not negotiable under the current program. I had no choice as I could not leave them with others and live with myself knowing their needs were not being met.

My husband and I met with Governor LePage and others explaining why they needed more hours but according to the current program rules, that was all the hours they could receive.

These past few years have been enormously challenging and their needs never decreased in fact they increased and still the home-based care program did not allow for any more hours. There were many hours that I had to care for 2 severely disabled sons by myself as agencies that were contracted for some of the hours could not provide coverage leaving my sons and me in dangerous situations. Many of times my sons were up during the normal sleeping hours and I would also have to be awake for them and be available during the day without any outside help.

Last March I lost one of my sons due to his illness leaving me still with one son to care for under the same program. His needs are now at a nursing level of care and he will still remain at 59 hours as long as he is kept at home. I could send my son to a nursing home and he would receive full care at a higher cost than what it is now costing the State. I have already gone that route and I am still convinced I can provide him with the best care possible.

The choice to take both of my sons home was the right thing to do. It has been financially hard on our family due to my husband having to focus on my sons care and not his own work while losing money to do so. I took a substantial loss in income because I left a job to care for my sons. My household expenses increased due to having two extra people and so hasn't everything else.

Not all people will want to, or be able to care for their loved ones at home, just as not all families should be allowed to, but the ones that can should receive more help to do so. Right now the State spends an enormous amount of money to send people out of State and in State nursing homes at a considerably higher cost that they would spend if they provided more fairness and flexibility in the current MaineCare program to allow willing family members to care for their loved ones. Many people will not do so because they cannot financially do so. The current program is unfair to consumers and their families, and it creates an unfair incentive to put loved ones in facilities, group homes, nursing homes, and at a greater cost to the State. I ask you please to do what is right for the MaineCare consumers who need care and the families that are willing to provide their loved ones with that opportunity.

Thank you!