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Members of The House Finance Committee:

My name is Gina Cairone, and my daughter, Sophia Cairone, is a direct recipient of Medicaid home nursing services as she is completely disabled due to a birth injury. She requires assistance in all she does and meets an institutional level of care. She needs 24-hour care and is allotted 69 private-duty nursing hours per week throughout the state. However, I cannot and likely will never have them filled. The reimbursement rates in Rhode Island are so low no one is willing to work for that paltry amount. The rate increases proposed in House Bill H 7298 are far below what the OHIC report recommends. The governor is not following the recommended funding increases in total. As it stands, Rhode Island's reimbursement rate is 40% lower than that of Massachusetts. Home care is already the lowest paid of all the nurses in Rhode Island, and most children with nursing needs are already not getting their allotted hours fulfilled. Why would anyone want to work for 40% less pay when Massachusetts is just down the road? The state of Rhode Island has an obligation to fulfill its promise to the children of Rhode Island and the Federal Government regarding providing life-saving home nursing services required to keep them home, healthy, and out of hospitals and institutions.

As I age, it is harder to care for her all the time physically; it's only a matter of time before I get an injury that could affect my ability to give care. Sophia is 75 lbs. and picking her up all day takes a toll. Not sleeping and getting woken up several times a night takes a toll on parents; no one can be expected to realize this burden without help. In addition, this affects not just us but the public at large. I am an RN and can no longer work full-time because I have minimal assistance with Sophia. I need to be able to change my schedule at a moment's notice should the one nurse I have call out. I was a full-time Emergency Room nurse before her birth; now, I am unable to do that. My other child gets minimal help from me because I am busy keeping Sophia alive. The ripple effect touches the entire community beyond the immediate effect of leaving these children without care and parents overburdened.

***The fact that the governor just hosted a state-wide event to address chronic absenteeism in school-age children directly opposes his actions of not following the recommendations of the study he commissioned. What about disabled children needing nurses who can't attend school because they have no nurse to take them? Or do disabled children not count? Did he only mean able-bodied children matter when it comes to absenteeism?***

I urge you to implement the rate increases recommended in the OHIC report. To do anything less is to send a direct message to Rhode Island's most needy and vulnerable population: disabled children. It says loud and clear, "You don't count, and you don't matter."

This is Sophia. I urge you to let her and others like her know she counts and that her health and well-being matter.

Sincerely,

Gina Cairone, mom and caregiver to Sophia Cairone

