Submitter:	Gina Mueller
On Behalf Of:	SB 538
Committee:	Joint Committee On Ways and Means
Measure, Appointment or Topic:	HB5006

Greetings Co-Chairs and Members of the Committee,

My name is Gina Mueller, and I am writing to ask you to remove the ban on paying parents as care workers, so that profoundly high needs children with disabilities can access the Medicaid services to which they are entitled.

Oregon has promised these children a way to be served in their homes and communities, instead of institutions. But for more than 10 years, those services have never been fully accessible, sometimes to devastating effects.

My 15 year daughter, Lili, is profoundly medically-fragile, and requires round-the-clock care - she is non-verbal, wheelchair-bound, cannot use her arms or hands, requires multiples medications, oxygen, has a g-tube for feeding, and has debilitating, irretractable seizures. She is entitled to hundreds of hours of care through the state per month. There have not been safe, appropriately-qualified caregivers available for several years, and as a result, I had to leave the workforce. Now, I provide care round-the-clock for our daughter, while my husband works every day to BARELY keep our family afloat.

The funds are there – the state would pay for a stranger to come into my home tomorrow. But, as we know, there is a nationwide caregiver shortage. AND, we also know that parents are the safest, most committed, most loving and devoted caregivers for their children. They are also the most consistent workers, with less costs associated with training and turnover.

Beyond the financial benefits for both the state and families, there is an important, moral question to consider - if you had a significantly-disabled child who could never report to you if a care worker was abusing or mistreating them, how would you feel? Probably like us, in that the safest, most loving, most logical plan is to have parents who are already doing the work, be paid for their services with money that is already allocated to those children.

The only reason Tensy’s Law, SB 538, is considered to have an additional cost is because of the state’s failure to provide a functional home care system. By refusing to recognize parents of minors as part of the homecare workforce, the state is making it harder for children to get the support they desperately need. Why does it make sense to pay parents when their kids are 18, but not as minors?

Paying parents for the care-work they do in lieu of their own careers is a simple, cost-effective solution to many problems. It ensures children receive consistent, high-quality care from the people who know them best, and stabilizes families in their own homes.

We know this works. During the temporary COVID-19 allowance, Oregon families reported that their disabled children were healthier, happier, and making progress. The stability and continuity of care made a life-changing difference. You have the power to make that positive change permanent.

Thank you for your time and consideration.

Gina Mueller