

Submitter: Lynne Mason
On Behalf Of:
Committee: Joint Committee On Ways and Means
Measure, Appointment or Topic: HB5006

My name is Lynne Mason, and I am writing to you today about the need to fund Tensy's law, SB538. I am asking you to remove the ban on paying parents as care workers so that very high needs children with disabilities can access the Medicaid services they are already entitled to.

I want to talk a little about how funding this bill will actually save the state money, in both the short term and the long term, from personal experience.

I am one of the 300 original members of the COVID-19 temporary parent caregiver program. My son was classified as service level 5B - very behavioral, with a support plan. Before the temporary program, I could not find support workers, yet I wasn't allowed to access the 295 hours per month we were allotted. I considered a SACU placement for him.

During the temporary program, I made use of the allotted hours to address my son's communication deficits using AAC (Augmentative and Alternative Communication). As a result of that 1:1 communication work, we were able to retire his behavior support plan, reduce his service level to 4, and he has remained stable since 2021.

I understand that SACU placement costs the state of Oregon 105,000 USD per month. The Home and Community based services my son receives now costs the state less than 10,000 USD per month. This is a significant savings that happened within a year of funding my son's support services. Imagine the cost savings over a lifetime at this rate. Now imagine the possible cost savings if everyone with very high behavior support needs could follow in my son's footsteps!

The only reason Tensy's Law, SB 538, is considered to have an additional cost is because there are few available caregivers to pay, so the allotted hours go mostly unused. This is because there is an extremely small pool of caregivers who are willing or able to work with children who are classified as having very high medical or behavioral needs. As it stands now, the parents are expected to work all these support hours themselves, sometimes 2-3 full time jobs worth, without compensation - while somehow making a living on the side. Parents are left with the choice to either struggle under this impossible load, or place their kids in expensive institutional care.

Oregon has taken steps in the right direction, but we can do better. We need Tensy's Law to remove outdated barriers and fulfill our promises.

Thank you for your time.