

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 support 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 has the potential to save the state a lot of 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 behavioral support plan in place. Before the temporary program, I could not find support workers who were willing or able to work with my son because of his behaviors; yet because of the current rule that prohibits parents from being paid as their child's support, I also wasn't able to access the 295 hours per month we were allotted. I considered a SACU (Stabilization and Crisis Unit) placement for him more than once.

When we were invited into the temporary program, I decided to make use of the allotted hours to address my son's communication deficits using AAC (Augmentative and Alternative Communication), since many professionals had told me that for nonspeakers, concerning behavior is often a form of communication; and that as his communication skills increased, his behaviors could be expected to decrease, because a more effective alternative would be available.

That turned out to be exactly right.

After a few months 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, and that it is proving somewhat complicated to return individuals to home and community based services after SACU placement, for whatever reason. In contrast,

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 in less than 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. This is unsustainable.

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.