

Submitter: Lisa Tschudi
On Behalf Of: SB 538
Committee: Joint Committee On Ways and Means Subcommittee On Human Services
Measure, Appointment or Topic: SB5547

I urge your vigorous support of Tensy's Law, SB 538, which deserves your attention to schedule a hearing. The proposed changes could well be considered a "cost per case" or "current service level" adjustment. SB 538 would increase access to Oregon's Children's Extraordinary Needs (CEN) waiver; allow parents of minors to be personal support workers; and ensure this compensation comes from already-obligated funding. These personal support worker hours are already existing positions that almost anyone other than parents can fill.

My daughter Oriana utilizes "home and community based" services through Medicaid for disability related care about twelve hours a day. That's over two full time jobs, still now that she is an adult. SB 538, Tensy's Law will not change my daughter's services whatsoever because, being over 18, my daughter is already eligible to hire myself and her dad. Yet we feel strongly enough about the bill that we drove four hours to be at this meeting. Like most families utilizing home and community based services, we have never found non parental caregivers to work the entirety of my daughter's necessary service hours. And sometimes it is simply far more appropriate for parents of younger children to provide disability related care.

Tensy's law fulfills a promise by the state to provide care for children like my daughter. It does not allocate additional services, merely allows parents to work the very same hours that are already allocated to these children. Many of these hours, while very much needed, go unused because of workforce shortages and the fact that for some children, it is simply not appropriate or safe to hire non-family employees. When those jobs have high turnover rates, it is especially inappropriate for some kids to have non-family providers. Families thus are frequently left with little to no actual support to ensure they can provide care at home.

My family was fortunate that we were able to meet all our basic needs financially through my husband's employment alone while I cared for my daughter unpaid for 18 years. If Tensy's Law been in place when my daughter was young, my husband and I would have been able to provide her with more stable housing, more investment in therapies like the equestrian therapy which challenged and strengthened her balance, and better integration into our community by participation in events that required money or other additional time and effort from a child's adult. In fact, partly due to the income we currently earn as DSPs when we lost our house in the Alameda wildfire in 2020, we were able to very quickly obtain other housing. Where we landed is the house that Oriana lives in and prefers to live in, where she is a valued member

of our household and community.

Care needs do not go away because they aren't met with public services. Instead, they become far more expensive directly and indirectly both to the state and to individual families. I would argue that there would never be better care than parents provide at any price, thus to allow parents to fill the exact same positions at the same rates of pay for care hours which others can fill is an incredible bargain to the state. I humbly submit that also as a matter of demonstrating the values of choice and community inclusion for children with disabilities, allowing parents to be paid as direct support providers makes sense. Please support SB 538.