



April 16, 2025

Re: Testimony in Support of Senate Bill 538

Dear Co-Chairs Senator Lieber and Representative Sanchez, and Members of the Joint Committee on Ways and Means,

We are writing on behalf of the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) to **urge you to fully fund SB 538**, also known as Tensy's law. As Oregon's Title V public health agency for children and youth with special health care needs (CYSHCN), we see Tensy's Law as a way for Oregon to fulfill its obligation to provide services to which these children with significant disabilities are entitled. Due to workforce shortages and the limited capacity of the current Children's Extraordinary Needs (CEN) Waiver Program, Oregon CYSHCN with the highest medical and behavioral needs are largely unable to access the Medicaid-funded personal care services for which they qualify. This negatively impacts their health and quality of life, as well as that of their family, directly impacting their ability to grow, develop and thrive.

We recommend support and funding for Tensy's Law because:

- **It helps address critical workforce needs.** These children have already been determined by the Office of Developmental Disabilities Services (ODDS) to need extraordinary care beyond what parents and families can provide. However, they suffer due to a lack of qualified caregivers to do this complex and skilled work, meaning many families cannot fill their children's assessed care hours.
- **It promotes health equity.** While the CEN waiver exists to address this workforce shortage, currently only 10% of the 1500 eligible Oregon families can access this program. Further, even for those who do have access, paid care is capped at 20 hours per week. Tensy's Law will expand waiver access to all eligible children and pay for up to 40 hours of care per week – a level commensurate with the needs of families, and in line with what a hired non-parental caregiver would typically provide.
- **We know paying parents as caregivers works.** The Centers for Medicare and Medicaid Services (CMS) recently affirmed: "States are required to ensure individuals have access to needed services and states should strongly consider the authorization of legally responsible individuals [e.g. parents] to meet the requirement of ensuring the delivery of needed services (1)." During the COVID-19 pandemic, Oregon temporarily allowed parents to be paid as caregivers, and this proved an effective way of meeting the state's obligation to provide care for these children. Research from other states also shows that paid family caregiving improves health outcomes for medically fragile children (2).

OCCYSHN

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- **It is a fiscally responsible approach.** This bill will ensure the fulfillment of Oregon’s existing legal obligations. These are hours of care that have already been deemed essential for these children. SB 538 simply ensures that what has been promised is delivered, and that services meet the real-world needs of Oregon families. Tensy’s law may also offer cost savings by preventing costly out-of-home placements and decreasing healthcare expenditures because of children receiving consistent, higher-quality care from their primary caregiver. Simply put, it will ensure that kids get the care they deserve, improving the health and well-being of CYSHCN and their families.

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As Oregon struggles with healthcare workforce shortages, especially in marginalized and rural and frontier communities, there is growing recognition that paying parents to provide this previously authorized care is the right thing to do. **States have a legal obligation to provide these personal care services to eligible children. Tensy’s Law is the only proposed solution to allow Oregon to meet this obligation.**

As the public health agency that works to improve the health and quality of life for children with special health care needs and their families, **we strongly urge you to support SB 538 by scheduling it for a vote in the Joint Ways and Means Committee and prioritizing it for funding.** Please do not hesitate to contact us if you need further information or if we can assist in any way to advance this important legislation.

Sincerely,

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References:

(1) Instructions: Version 3.7 HCBS Waiver Application, July 2024, Page 117.
https://www.reginfo.gov/public/do/PRAViewIC?ref_nbr=202407-0938-020&icID=8072&fbclid=IwY2xjawFXHVleHRuA2FlbQlxMAABHV8NrbijphYfff_wudZoiZFTIOYulytrCKwgLhxkJOiWXdqvZVaBQRcuA_aem_wfrT9iZxCQGVNSy1AKqhcQ. Accessed March 26, 2025.

(2) Carter, K. et al. (2022). *Employing Family Caregivers: An Innovative Health Care Model*. *Pediatrics*. 2022 Jun 1;149(6):e2021054273. doi: [10.1542/peds.2021-054273](https://doi.org/10.1542/peds.2021-054273).