

9320 SW Barbur Blvd, Suite 240, Portland OR 97219 Telephone: 503 636 1676 Website: <u>www.AutismSocietyOregon.org</u> Direct Email: <u>Tobi@AutismSocietyOregon.org</u>

Federal Tax ID #: 93-0771249

April 16, 2025

RE: In Support of SB 538 (Tensy's Law)

To: Co-Chairs Lieber and Sanchez, Co-Vice Chairs Girod and Gomberg, and members of the Joint Committee on Ways and Means:

My name is Tobi Rates. I'm the Executive Director of the Autism Society of Oregon (ASO). I'm also an Oregon resident and the mother of 2 young Autistic adults, including my younger son, Jake, who had the highest level of support needs and passed away in 2023 at the age of 18.

The Autism Society of Oregon is the largest Autism non-profit organization in Oregon. Our mission is to create connections empowering everyone in the Autism community with the resources needed to live fully. We represent everyone in the Autism community. Through our programs, we reach over 25,000 people each year throughout Oregon. We do not charge for our services.

Both personally and on behalf of ASO, I'm respectfully requesting you to please schedule SB 538 (Tensy's Law) for a vote in the Joint Committee for Ways and Means and prioritize it for funding. This bill would remove the ban on paying parents as care workers so that very high needs children with disabilities can access the Medicaid services to which they are already entitled. SB 538 saves the state money, avoids costly legal risks, and fulfills our promises to our children with developmental disabilities who have very high behavioral health or medical needs.

Based both on personal experience and from hearing from people all around the state, I know that Oregon is failing to provide adequate in-home care for these children. While parents of disabled adults can be paid caregivers, this option isn't available to parents of disabled minor children, leaving many families with impossible choices.

Our children are not typically developing children. They are, by definition, children with extraordinary care needs and they meet stringent criteria for institutional-level care to receive care hours. Some children simply cannot tolerate a nonparent care giver due to their disability. Other parents would be happy to forego being a paid provider but can't find care providers. Disqualifying parents from being paid caregivers for their disabled minor children means the paid parent services past age 18 for only 4 months and 3 weeks. Many other disabled children with very high support needs, including the namesake for this bill, are unlikely to make that milestone. Please help us to care for our children in their own homes while they are children and are still here.

On behalf of the Autism Society of Oregon and personally, I am respectfully requesting your support to please schedule SB 538 (Tensy's Law) for a vote in Joint Committee for Ways and Means and prioritize it for funding. Thank you very much for your consideration.

Respectfully submitted,

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Tobi Rates Executive Director Autism Society of Oregon