Submitter:	Courtney Coleman
On Behalf Of:	SB 538
Committee:	Joint Committee On Ways and Means
Measure, Appointment or Topic:	HB5006

Co-Chairs and Members of the Committee,

My name is Courtney Coleman, and 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.
Oregon has promised these children a way to be served in their homes and communities instead of much more expensive institutional and out-of-home placements. But for more than 10 years, those services have never been fully utilized, sometimes to devastating effects.

I am the proud mother of a 15-year-old daughter named Frankie with Rett Syndrome and CAA. As Frankie has gotten older, her medical complexities have become more involved. Right at the height of our pandemic, she had to have pelvic and spinal fusion surgery, a g-tube placed and a VNS to help try to control her seizures. She is a brilliant, beautiful, and expressive young woman who uses eye gaze and gestures to communicate. She loves music, being outdoors, going to the beach, and all things girl. She also requires 24/7 care in which I am the most qualified person to provide it. Not just because I have a good medical background (both learned and through education), but also because I know all things Frankie. She is my favorite person in the world, and the care I provide for her makes her feel happy and safe. I am an educated woman with an unfinished Master's in Special Education due to my child's needs. I am not a lazy individual who wants to sit back and collect a paycheck at my daughter's expense. Those of us fighting for paid parent legislation are doing so because our children deserve the best care to thrive, not just survive! Working a traditional 9 to 5 is not feasible in our lives given our children's complexities and uncertainties. The ability to be paid a wage for the incredibly hard work we are more qualified to provide than the states over 18 and passing a background check, keeps families together, pays back into the system, gives us a sense of worth, keeps our children safe, and drains other resources (EBT, TANF, SSI, etc) far less.
The only reason Tensy's Law, SB 538, is considered to have an additional cost is because of the state's inability to provide home care for these children. By refusing to recognize parents of minors as part of the home care workforce, the state is making it harder for children to get the support they need and are entitled to.

This isn't about politics. It's about common sense. Paying parents for their care work in lieu of their own careers is a simple, cost-effective solution to many problems. It ensures children receive consistent, high-quality care from the people who know them best and stabilizes families in their own homes.

We know this works. During the temporary COVID-19 allowance, Oregon families reported that their disabled children were healthier, happier, and making progress. The stability and continuity of care made a real difference. You have the power to make that positive change permanent.

Oregon has taken steps in the right direction, but the system remains inefficient and restrictive. We need Tensy's Law to remove outdated barriers and fulfill our promises.

Fund the kids, not the system.

Thank you for your time.

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