

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

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 our very high needs children with disabilities can access the Medicaid services they are already entitled to. Please fund and pass Tensy's Law, SB 538.

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 a decade, those services have never been fully utilized, sometimes to devastating effects due to lack of caregivers.

I am the proud mother of a 15-year-old daughter, Frankie with Rett Syndrome, medically refractory epilepsy 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 spinal and pelvic fusion surgery, a gj tube placed and a VNS to try to help control her seizures. She is a brilliant, beautiful, and expressive young woman who uses an eye gaze device, facial expressions and gestures to communicate. She loves music, being outdoors, the ocean and all things girl. She also requires 24/7 care in which I am the most qualified person to provide. Not just because I have a knowledgeable background, because I know all things Frankie. She is my absolute favorite person in the world, and the care I provide for her makes her feel happy and safe. I am an educated woman. 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! We are the hardworking individuals providing this care and let's be clear, there is a difference between caregiving and parenting.

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 in which we are the most qualified to provide is fiscally responsible. The over 18 age requirement and passing a background check does not make an individual qualified to care for our children. Furthermore, this keeps families together, pays back into the system and society as a whole, gives us a sense of worth, keeps our children safe, and drains other resources (EBT, TANF, SSI, Food Banks, Hospitals and so on 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. It's time to pass legislation that is tangible and not based on broken promises. 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 our care work in lieu of our 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, stabilizes families in their own homes and will benefit our state financially.

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 and we have provided the data to prove this. 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 SB 538 to remove outdated barriers and fulfill broken promises.

Fund the kids, not the system. It will be reciprocal.

Thank you for your time.

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