

Co-Chairs and Members of the Committee,

My name is Diane Davis from Hermiston, and I am asking you to remove the ban on paying parents as care workers and support Tensy's Law, SB 538. This will allow Medically Fragile children like my 4 year old son, Preston, and other high needs children around the state access to the Medicaid services they are already entitled to.

As a result of a brain injury in utero and a still undiagnosed genetic disorder, Preston is Deafblind, has Cerebral Palsy, seizures, and is globally delayed. Preston is trach, vent and G-tube dependent and requires around the clock care.

Oregon has promised children like Preston a way to be served in their homes and communities; however, those services are often not fully utilized. This is especially the case for those of us here in rural Oregon where nursing agencies aren't available and qualified support workers are either hard to find or simply not available.

When we are able to find a support worker willing to help Preston, we are only able to use a third of his approved hours due to a lack of availability. While I love the support workers who have helped Preston, they are usually young college students with a high turnover and don't have the necessary training needed in the case of an emergency. As a result, my husband or I have to be home when they are working to provide backup and don't ever truly get much needed respite.

I understand that the budget is a big concern. I want to point out that it costs the state half as much to pay me to provide my son's nursing care as it would to pay a nurse to provide that same care. The ironic thing is that the state is willing to pay my underqualified 18 year old son to care for Preston, but not Preston's expert caregiver, his mom.

Preston's story is not as unique as you might think. There are over a thousand children like him throughout the state with their own stories. These children require extra care and the best, most qualified people available to give them that care are their parents.

This isn't about politics. It's about common sense. We need Tensy's Law, SB 538. Fund the kids, not the system. Thank you for your time.