

Submitter: Oriana Horneck
On Behalf Of:
Committee: Joint Committee On Ways and Means
Measure, Appointment or Topic: HB5006

Hello, my name is Oriana Horneck and I have a 9-year-old son named Avery. We live in Portland and we support Tensy's Law SB 538, the paid parent caregiver program. Avery was born with an ultra rare condition called KCNA2 epileptic encephalopathy. He has been significantly impacted his whole life and will continue to need 24/7 care for the entirety of his life.

Avery has been assessed to need over 400 hours a month of attendant care. These hours are guaranteed to him. If we hire someone to fill them, they will get paid. So it does not make any sense to say that financially the state cannot afford to change the rules in favor of parent caregivers. The only reason an expense has been assigned to this bill is because ODDS is not actually budgeting for the hours our children are determined to need, only what's used. They are not fulfilling their duty to provide these services.

Most children, including my own, are unable to staff the hours because of the workforce shortage. There are not enough qualified people for these positions. Parents, who know their children and their care best, are the most qualified for the job and will contribute to the workforce.

Finally, it has been proven time and again that when our highest needs kids are cared for by their parents, they have less hospital visits and are overall healthier. This relieves strain on health insurance costs as well as hospital capacity.

These children deserve better. They deserve the right to choose their caregiver and if they want mom and dad, then they should get that. Please pass Tensy's Law, SB 538.