

Hello, Co-Chairs and Members of the committee, my name is Kali Grunnet and I live in South East Portland, Oregon. I live with Brooks, my three-year-old, Kai, my four-year-old, and their father, Rafael. Brooks has cerebral palsy. He survived a traumatic birth after my placenta completely erupted and he was born dead. After 16 minutes, he was miraculously resuscitated. He is our absolute miracle, and the strongest person I've ever met. Due to the oxygen deprivation during birth, he was diagnosed with Hypoxic Ischemic Encephalopathy. We spent two months in NICU, this is when my entire reality drastically changed. It was a terrifying experience but I still remember the comfort and peacefulness I finally felt after I was able to hold him that very first time. He was five days old. He had to be "cooled" after birth for 72 hours to stop the brain cells from dying and preserve the remaining brain cells from becoming damaged. Those were the hardest days of my life, I felt so helpless as I held his tiny hand and watched him sleep with all those cords everywhere. But when I finally held him in my arms that first time I knew I would do everything in my power to provide a happy life for him. I would give him the best quality of life I possibly could. I wanted to protect him from all the pain and the fear. He was connected to life support that first week and triumphantly pulled through even though the doctors warned us his chance of surviving a week was grim. He is a fighter, he never gave up, and I will never give up on him. Instead, I have given up my career and my personal hopes and dreams to provide quality care for him, sometimes 24 hours a day. He is my hero, and I am so blessed to have him here with us, but relying on one person's income for our entire family to survive on these past three years has been stressful and challenging. We can barely afford groceries. We can't afford to go on a family vacation. I am limited to taking him to parks and libraries because they are free. I would love to take him to museums, the zoo, the movie theatre, but we can't afford luxuries in life on just his dad's income alone supporting all four of us, and Brooks deserves all of life's pleasures after all the pain he's been through and all the suffering he's endured in his first few years of life. Brooks has spent more time in hospitals (5 months last year) and has been through more pain than most people will experience in their entire lifetime.

So, I am begging you to consider removing the ban on paying parents as care providers so that very high needs children with disabilities like my son can access the Medicaid services they are already entitled to. I was a preschool teacher before I became a mom. But after Brooks was born, I realized it would be impossible to remain in the classroom and provide the level of care he needs at home so I left the workforce to take care of him. He has a hearing impairment, a vision impairment, cerebral palsy, epilepsy, dystonia, hypertonia, GERDS, nonverbal, he requires a feeding tube to provide 100% of his nutritional needs. His list of diagnosis's is very long. Brooks is silly and sweet but you have to really get to know him to understand him. I know him best. Having to train someone else to take care of him takes weeks, and the DSP can be very unreliable; he's been through 7 Direct Support Persons, they quit without notice or warning, some of them would not show up to their shifts, I have found DSPs to be fleeting and unreliable. Training someone to care for him temporarily is exhausting. My son can always rely on me, I am dependable and I care about my children more than anything in the entire world. I am the best person for this job to provide care for him. Brooks has speech therapy weekly, occupational therapy weekly, and early intervention every Wednesday. He has feeding therapy and physical therapy biweekly. He sees a multitude of specialists. He requires all his food to be blended and then bolus fed to him every single hour of the day. He also has prescriptions to be filled, and I'm always on the phone with insurance advocating for equipment and procedures he needs. Taking care of him is a full-time job with no pay. I deserve to be paid. My family deserves to live more comfortably. Paying me to be Brooks care giver would give us an incredibly better quality of life. We could afford better quality food and resources. We could afford more therapy and we could afford to go out on outings that would circulate

money back into our community and stimulate Brooks mind. Please schedule SB 538 for a vote in Joint Ways and Means and prioritize it for funding. This bill would dramatically improve my child's health and wellbeing, as well as that of our entire family. The reason Tensy's Law, SB 538, is considered to have additional costs is because of the state's inability to provide home care for children like Brooks. 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 so desperately need and are entitled to receive. Paying parents for the care work we provide in lieu of our own careers ensures that our children receive consistent, high-quality care from the person who knows them best. This would stabilize so many families.

During the COVID-19 allowance, Oregon families reported that their disabled children were happier, healthier, and making progress. Now you have the power to make that positive change permanent and give families like ours the chance to thrive. We deserve a happier life. We need Tensy's Law to remove outdated barriers against parent care givers for their children with disabilities which would provide families like ours with a significantly better quality of life.

Brooks is entitled to receive supportive care for life, so why not grant me, his mother, the person who loves and cares about him more than anything else in the entire world, the opportunity to provide him with top quality care and support.

Thank you for considering,

Kali Grunnet