

Submitter: Cari Pagan
On Behalf Of:
Committee: Senate Committee On Health Care
Measure, Appointment or Topic: SB538

Hello,

My 12 year old daughter Nina has a genetic syndrome, refractory epilepsy, intellectual disability, autism and is non speaking. Nina is a resilient, affectionate young lady who has fought hard to survive and make gains against many odds. She is very physically active and unaware of danger, she has PICA and will eat household cleaners, soap, strings, bottle caps...she will bang her head and bite herself when frustrated or uncomfortable....she must have someone monitoring and assisting her every minute of every day and that person must be her father or myself. Nina qualifies for over 400 hours of caregiving hours per month and 120 hours of 2 caregivers at a time per the Oregon Needs Assessment but she utilizes only about 1/4 of those hours because there is a crisis level shortage of caregivers. My husband and I have had to drastically reduce our work hours to care for her resulting in us rotating which bills, utilities and student loans to pay each month. We sacrifice our careers, health, personal freedom, time with family and friends, sleep, and financial security to keep Nina in our home, safe and well cared for and we wouldn't have it any other way but it shouldn't result in us being in constant crisis. SB 538 would make our life sustainable. The state will pay any other person over the age of 18 without a felony to care for Nina, anyone but her parents. These hours have already been allotted so this bill should not add cost unless the state never intended to support its most impacted children with these hours deemed necessary to keep them safe and stable. Please lift the ban on parent paid caregivers and allow Oregon to follow through with its promise to help its most vulnerable families.