

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

Hello Committee members, please support fulfilling the promise Oregon made to keep our most vulnerable and severely disabled children safe and in their homes. This measure will remove the ban on paying parents for their caregiving work. Oregon has already allocated these hours for our children and allow any adult over 18 without a felony on record to work....anyone EXCEPT their own parents despite the fact that our children need this care 24/7 and it's not possible to be at work outside of the home and be in home caring for them at the same time. There are no care workers. It's a position that is historically nearly impossible to fill and in the last 5 plus years as become impossible to find care workers especially for these children with the most severe needs....seizures, feeding tubes, medical emergencies as a daily occurrence, aggressive behavior, fecal smearing, non verbal, loud screeching, lifting, eloping....this is difficult work for low pay.....so parents are left in an impossible position and it's is not sustainable. My 12 year old daughter Nina was born with a genetic syndrome, autism and epilepsy. She is non verbal with complex behavioral and medical needs that require either my husband or myself to be available for her 24 hours a day. And she often doesn't sleep though the night. We have sacrificed our careers, social lives, family relationships, and overall well being to keep her safe and thriving in her own home. The many dreams we once had for ourselves, her and our family have all been dissolved and now we give everything and work harder then we ever thought possible to simply keep her safe and gaining independence. She is learning how to communicate, toilet herself , and safely be around other people. She is an amazingly resilient, joyous and fierce young girl who deserves to be safe and well cared for. We will give everything we have to make that happen but it is becoming less sustainable as Nina becomes older and physically stronger. We are maxing out the credit cards we juggle due to having to trade our jobs outside our home for the job of care providing for her and grandparents can no longer physically help with her. There is a severe shortage of care providers. We have only been able to find one support worker for her in 5 years despite being signed up with every single agency possible and scouring community, colleges, friends, care.com etc. Oregon has already granted the hours for the caregiving deemed necessary to keep Nina living in her home safely. SB 538 should be a budget neutral bill because these hours have already been allotted. It would cost the state 10 times the amount for each child with this severity of needs to be cared for outside of their home and the rates of abuse are upwards of 80% in these institutionalized type settings. Please do the right thing and ensure Oregon doesn't turn its back on our most vulnerable disabled children.

Thank you,  
Cari Pagan