Submitter:	Michael Paruch
On Behalf Of:	My daughter
Committee:	Senate Committee On Human Services
Measure:	SB646

Dear Senate Committee on Human Services,
I am in favor of SB 646 and its broad inclusion of Oregon's vulnerable children with disabilities and or behavior issues. Many parents represented don't really get to parent much because separate from loving our child, we have a high stakes "job" like no other, we are doing medical tasks 24/7 and frequently on call.

As a paid parent caregiver during the federal Covid emergency and a stakeholder here, I testify that our daughter's quality of life and wellbeing improved drastically in many ways. She may not be alive without our extra time for skilled care and casework during the pandemic. We have personal story after story and anecdotal evidence to compare to countless hardship stories from peers across the country and world who didn't have Oregon's paid caregiver benefit.

Caregiving for people with my daughters rare genetic syndrome is described in the Orphaned Journal of Rare Diseases, "...Such <family caregiver> dedication has been associated with a greater risk of physical and psychological distress, as well as depleting socioeconomic resources in the family unit, due for example to changes in employment situation..." (S. Berrocoso et. al. 2020). We have tried flexible and remote jobs, and tried learning from experienced parent peer support but before qualifying to be a paid parent caregiver as the pandemic started we were not able to use any of our 400 hours each month.

More than one DSP provider and PSW dropped us due to complex care required for my daughter. Since she was born in 2015, we have had a revolving door of 12 variously qualified or motivated PSW workers. Quality workers left several times disrupting my daughters progress, losing our training efforts, betraying the emotional trust we carefully built. They pursued education or better paying jobs.

Legislators should pay close attention to the number of K plan hours that went unused before the federal emergency and pandemic and think of those as representing hours of pain and suffering for the vulnerable and their families to bear.

We are a family who's loved one also needs 2:1 care, (in a market shortage of DSPs/PSWs) that means both parents actively supporting my daughter as well as having a DSP/PSW much of the day and night, sometimes with hospital level equipment (oxygen, suction, nebulizer, feeding pump, anti-seizure bridge meds, rescue meds, other equipment and meds during emergencies).

The benefits are hard to quantify. She is happier, healthier, and making faster developmental gains. As parents, we can barely work part time jobs but we are better people with her in our lives and we now contribute from a disability pride lens to make society a better place. I tell skeptical or judgmental people who know we are paid that my daughter may not ever be able to hold a job to “contribute” to society but the positive influence and joy she brings cant be quantified. Her smile reminds us all that no matter what challenges we face, our lives have value, and we can make the world a better place in our own way, to celebrate disabilities as differences that many “typical” people also have to varying degrees, even often unseen.

Sincerely,
Michael Paruch
Silverton OR
Marion County