Submitter:	Emily Dayton
On Behalf Of:	
Committee:	Senate Committee On Human Services
Measure:	SB646

Dear Senate Committee on Human Services,

As a parent to a child who has disabilities and chronic, complex medical conditions, I support the importance of passing SB 646 in order to support my child's decision to be cared for and supported by her parents.

I appreciate that the bill was created in collaboration with disabled parents and parents of children with disabilities to establish a program that is fully supportive and inclusive.

As a individual who has disabilities and is caring for a child who has disabilities, I can attest to the challenges with locating a qualified and loving caregiver for my child. Even pre-pandemic, we had 12 caregivers in 2 years rotating in and out of our child's life; which increased illness transmission, hospitalizations, and our families concerns for our child's safety.

Individuals with intellectual disabilities such as my child are seven times more likely to experience sexual abuse: https://disabilityjustice.org/sexual-abuse/
Thus a revolving door of strangers is a dangerous and unsafe situation especially for individuals who have intellectual disabilities.

We are grateful to finally have located a stable and committed caregiver for our child. However, even when our caregiver is providing support, I am still in the home to do extra tasks such as medical case management, and help during potential medical emergencies such as seizures, and breathing concerns.

The impact of passing an inclusive bill that supports all parent caregivers to be paid to care for their disabled child will save the state of Oregon millions in hospital emergencies bills and costly medical foster care.

In both September and November our child had serious medical crises that needed AMR support. Unfortunately, in both situations we were not provided with adequate care and support. In September when our child caught Covid-19, we were denied admittance at OHSU; and in Nov when she caught rsv the 911 paramedic stated that both pediatric hospitals were on divert.

In both situations we setup our child's room into a hospital room and provided round the clock care. We reached out to ODDS for nursing support or any assistance with the 24/7 suctioning needed to keep her from aspirating and for her seizures. We were informed that they could try to locate an untrained/ unknown caregiver to support, or that we could look into having her admitted into medical foster care.

It was astonishing to me that there is more support for institutionalizing your child with disabilities then supporting parents who are wanting to keep their child safe and cared for in the presence of their own home.
SB 646 will help children with disabilities be fully supported and cared for by their parents. It gets rid of all the bureaucratic red tape that has hindered the k plan from truly supporting disability access and inclusion.

Kind Regards,

Emily Fern Dayton, MS (She/They)
Anti-ableism activist/ Parent