My name is Jenny Eckart Hoyt, and I am the Portland mother of an extraordinary daughter who is seven years old who has Cerebral Palsy, deaf/blindness, epilepsy, and Global Developmental Delay. She is non-speaking, a wheelchair user, and requires exclusively one-on-one care. My hope for this bill is that more families get the services that they have been promised but have not been receiving.

As parents, we know our children best, and our care is the gold standard. However, when we are able to get respite and help with our children from a qualified caregiver we should be able to jump at the opportunity. The point of SB 91, and now SB 1565 is to allow us the CHOICE and freedom to use the hours that are allocated to our children through meticulous, frequent, and sometimes heartbreaking assessments. These hours should be earmarked and BUDGETED for by the state, and the failure to do so and simply budget for what has been utilized during a nationwide caregiver and nurse shortage crisis is not putting Oregon's money where their mouth is. I believe this bill should allow parents to use as many of their hours as a paid caregiver as they deem necessary regardless of their utilization of outside resources. Divorcing the child's needs for the service is not how these programs should be operated.

Oregon touts itself on a state with the ideology that children with disabilities should be with their community and not institutionalized. This is absolutely correct, except Oregon is only achieving this on the backs of parents who are doing this labor unpaid. Trying to balance unpaid caregiving with working outside the home causes burnout, mental health problems, and physical injury. Being paid for your labor, as it turns out (with the pilot program of allowing parents to be paid caregivers during the public health emergency) came with excellent outcomes for those of us lucky enough to participate. People finally had the bandwidth to seek out, hire, and train new caregivers to help with their children as participants surveyed reported that they INCREASED their utilization for outside caregivers during the program. We shared the workload and were able to take better care of our children and ourselves, had decreased burnout, and most importantly our children thrived.

I believe the interpretation for the budget for SB91 has not been done in good faith by ODDS. The legislators were under the impression that the $3 million they allocated would be for the INCREASE that paying parents would cost the state, NOT the entire budget for the program. This has caused the program to be painfully small, and it will not serve people in a meaningful way with a cap of 20 hours per week. SB 1565 is a step in the right direction for expanding eligibility, but basing it on utilization rates still excludes a lot of people from coming close to using their full allotment of hours that the state has deemed necessary to help their child reside in their community. Every child who is eligible for SB 91 should be able to choose their parent to fulfill their hours. No more hoops or limitations.

Fund the allocated hours. Fund the program. Fund the promise Oregon is making to our children.

Thank you for your time and consideration,
Jenny Eckart Hoyt