

Submitter: Audreona Mullens
On Behalf Of:
Committee: Senate Committee On Human Services
Measure: SB646

My name is Audreona Mullens. I am a wife and mother and full time employee in Gresham Oregon. My family is everything to me and the challenges we faced becoming parents could have been greatly alleviated if SB 646 had been in affect. I'm writing this in hopes of persuading you to recognize the lifeline it is for families like mine, families with medically complex children who don't have access to reasonable care via caregivers.

Our son was born in December of 2019, when COVID was still just a whisper of possibility and 7 months later a diagnoses of Spastic Quadriplegic Cerebral Palsy, gross global delay, and epilepsy, and slew of other conditions for our son. He is completely dependent on us for care. We had a newborn baby, a host of new specialists and special skills to acquire and a global pandemic rampaging that cut off access to assistance when we needed it most. We made a decision when our son was born that one of us would have to leave our full time, benefited jobs to take care of our son and all of his needs. I was the one who left work to gain a whole new set of skills, knowledge, and expertise in my sons care. I stayed at home for two years, juggling appointments, medication changes, learning physical therapy and occupation therapy. Learning how to cope with seizures and feeding issues. While all of this was going on we struggled to make ends meet on one income alone. We were alone. We sought to get a caregiver for our son so that I could go back to work and we could be financially secure again. I learned that an arbitrary system decided that our son only qualified for 4 hours of PCW care a week. No agency could fill that position, no family member was able or healthy enough to fill the position and we were without options. During the pandemic a relief option was available to parents to become paid caregivers for their minor children with disabilities but even this option was not available to us as our son still did not qualify for the number of hours necessary.

I was later able to find employment that allowed me to take care of my son first and be an employee second but this is an area of privilege most do not have. Families are straddling poverty lines and living on the margins because the care of our children must come first, but that care is not easy, cheap, or readily accessible to all families with minor children living with disabilities.

SB 646 would allow parents to be able to provide their children with access to quality, patient centered, and humanizing care that only a parent can provide. It would give dignity and recognition to the work we already do. The work our healthcare teams recognize as being the basis for all informed care our children receive. Our doctors,

therapist, and medical staff take their cues from us parents because we know our children's needs best. Even in cases where PCWs are hired, parents have to train them on everything regarding our children. Our children have to build trust with them, and we have to hope they treat our children with respect and dignity.

Parents in support of SB 646 aren't asking to be paid to parent. I'm not asking to be paid to read my son Goodnight Little Blue Truck every night, or paid to tickle his toes and talk him through big feelings he can't physically verbalize. SB 646 would pay me for my expertise on his medications, his physical therapy, his cognitive and occupational therapy. Managing his seizures, his speech therapy, getting him too and from a bevy of doctors appointments. My expertise in helping him to connect to the world at large that often leaves children like him out of the picture. It would pay me for all the medical expertise I have gained for his care without a medical degree and somehow still accruing the debt.

SB 646 is a family stabilizing and even life saving piece of legislation. There is no reason we as Oregonians should be disenfranchising families and children living disabilities the way we have done historically.