Hello, my name is Krystal Matthews, I live in Medford, Oregon. I’m speaking today on behalf of our son, who is physically disabled, he has cerebral palsy spastic quadriplegia. Eastyn was born at 27 weeks he spent 80 days in the NICU and my husband and I are the only ones trained and qualified to recognize when he is choking, or to help people understand him as he has a speech and language disorder.

He has gone through numerous surgeries just to be able to eat and use his legs. Prior to these surgeries he couldn’t eat, and his legs were in so much pain he often would wake up in excruciating pain. He also suffers from swallowing issues, which makes him a choking risk and a fall risk due to his mobility issues, he also suffers from reactive airway disease and has a very poor immune system. He will be 9 in July. Our son is home full time with me, except for his days at school. My role as his mother and caregiver is to help him navigate a world that expects disabled people to appear more neurotypical in order to be allowed to be accepted in society. I believe the opposite to be true. When we learned of his medical and physical disabilities, our family did everything in our power to understand how he experiences life so we could mold our home and life to accommodate him.

He qualified for Jackson County developmental services when he was about 3, we started with super low hours due to his age, and over the years as his needs have progressed his hours have gone up. I had high hopes I could find a qualified and reliable caregiver for him, but due to the caregiver shortage I never was able to. The ones I did find were unreliable or didn’t work well with my son, one went as far yelling and screaming at him, which was absolutely appalling that someone would do that, and second no consequences wherever given for such emotional abuse. Since then, I have continued to fill that role as full time caregiver, above and beyond typical expected parenting duties, with all the love, respect, advocating and determination for him. I am not able to work as a result of the care I provide for him, I work in the medical field, and they would need reliability and due to my son's care and needs I am not able to commit to that. Often, he has extensive surgeries, and they unfortunately can't be done locally. All his specialists require us to travel to Portland, Or for several days at a time, and it's often every 3 months. I also act as his secretary scheduling his many appointments, ensure that insurance is covering his care, manage his medical equipment suppliers, and get him to all his appointments. Our day usually starts at 6AM and goes till 12AM. He requires daily living support and around-the-clock care due to his inability to move on his own. For him to bathe it takes two people due to his size and inability to sit upon his own strength. As you can imagine, Eastyn’s care is very time-consuming. My husband and I are the only ones trained to care for him and as such should be able to utilize the caregiver hours allotted to him each month through Jackson County DDS.

I am in favor of any form of Parent Paid Caregiving, but please consider supporting SB 646 as it seems to be the most inclusive bill and one that would be a relatively seamless transition from the temporary program that has been in place up to this point.

Thank you for your time and consideration.