To the Oregon Senate Human Services Committee,

My name is Diane Davis and I live in Hermiston, OR. I am writing on behalf of my Medically Complex 2 ½ year old son, Preston, in favor of Paid Parent Caregiving, but specifically SB 646. When Preston was born, we found out that he had suffered a rare blood clot in his brain while in utero that caused a Tramatic Brian Injury. As a result of this injury, he has Cerbral Palsy, is Deafblind, severely developmentally and physically delayed, is trached due to his inability to swallow, and has a G-tube.

Preston requires around the clock care from frequent suctioning of his trach, mouth, and nose, to medication administration via G-Tube and nebulizer, to preparing and feeding him all of his tube-fed meals. On top of being his mother and providing these nursing services, 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 of his appointments with the help of Medical Transport or a friend as the driver since I have to be next to Preston to provide suctioning.

Paid Parent Caregiving is especially important to those of us in rural Oregon where nursing agencies aren't available. When it was time for my son to be discharged from the NICU, we learned that there aren't any nursing agencies in our area who work with pediatrics, especially children as medically complex as Preston. Eventually, we were able to convince the NICU doctors that I had spent enough time at the hospital with my husband being trained on how to care for Preston that we could handle his care at home. After 75 days in the NICU, we were able to be discharged without the required nursing care because it was simply not available.

As you can imagine, Preston'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 alloted to him each month through CIIS.

I understand that the budget is a big concern. I want to point out that it costs the state half as much to pay me to provide my son's nursing care as it would to pay a nurse to provide that same care. When my son got RSV this winter, I was familiar enough with him and his needs that I was able to act as his nurse and care for him at home with the ventilator, oxygen, and nebulizer we have. Because I was able to care for him, we avoided a costly hospital stay and provided the 1:1 nursing care Preston needs.

Preston's story is not as unique as you might think. There are numerous children like him throughout the state – many living hours away from much needed medical services. These children require extra care and the best, most qualified people available to give them that care are their parents. 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.