

Submitter: Emily Sisk
On Behalf Of: Neva Randy William Arlo
Committee: Senate Committee On Human Services
Measure: SB646

Hello.

My name is Emily Sisk. I am writing on behalf of my four disabled children William, Neva, Randy and Arlo in support of SB 646.

There are so many things that we anticipated when we began adopting medically fragile children. Sleepless nights, lots of appointments, endless medical supply boxes everywhere, etc

What we didn't anticipate..was how difficult it would be for us to find any kind of assistance or in person support for our children. Even with hundreds of hours available, finding someone who is willing to drive to our rural community and who is qualified to provide the level of care needed for our children, has proven impossible.

During cold and flu season, our house is essentially on lock down. We move all therapies to virtual. We don't see family during holidays unless they quarantine first. Because bringing in someone from outside of our home can often mean a PICU stay for one or more of our children. Part of the "level of care" required of our children is someone committed to limiting exposures to common viruses such as the common cold and the flu. As you can imagine, asking someone to avoid the public for months on end isn't typically something people are willing to agree to as a term to their employment.

Additionally, the specific behaviors of several of our children (ptsd from long hospital stays, attachment issues due to changes in caregivers prior to adoption, sensory meltdowns, etc) can make bringing in outside help extremely detrimental to the wellbeing of our kids.

These hours were intended to improve our children's quality of life. To help them remain safely in their home. To help keep them healthy. To support them in their community. Which is exactly what they have done during the PHE....when our children's most trusted care providers, my husband and myself, were able to act as paid caregivers.

Please consider moving SB 646 forward. It is the most equitable, inclusive and responsible choice for Oregon's most vulnerable children.