

Submitter: Emily Fern Dayton  
On Behalf Of:  
Committee: Joint Committee On Ways and Means  
Measure, Appointment or Topic: HB5006

Dear Senators and Representatives,

My name is Ezme, and I live in Silverton. I am a disabled parent who is caring for a disabled child. We are a homebound family who has struggled to locate caregivers who are willing to follow our illness mitigations, which requires everyone to wear N95 masks, test, and not enter our home if ill or around ill people.

My child and myself have compromised immune systems that require illness mitigations to ensure our survival. Both myself and my spouse have given up our careers in order to provide 24/7 care to ensure our child's survival. My child has medically refracted status seizures which are triggered by illness, heat, constipation, and pain.

A couple of weeks ago my child had a seizure while I was in the restroom, when I returned the caregiver was unaware, since our child's seizures often start subtly. I reacted quickly and provided medication, and we have been on round the clock seizure watch ever since. Thankfully we have medical suction, oxygen and rescue meds to ensure survival.

We can't just call 911 or go to the ER, as our child picks up respiratory viruses that trigger more seizures and breathing problems. AMR supports have caused more harm, and do not know how to safely support our child. We have been in ongoing meetings with local ER's and AMR supports regarding the ongoing safety concerns when we have accessed 911 supports during life threatening events.

We are the only people who know how to ensure our child's survival, and comprehend their subtle body language, and have committed to learning sign language, AAC, communication buttons in order to support multi-modal communication.

We celebrate disability culture and are a proud disabled family. It is not fair that our child is forced to have caregivers in and out of their life who will not prioritize their safety, communication and individuality.

We've had over 15 caregivers in and out of our child's life. Now, our child becomes agitated and distressed with caregivers in the home. Their self harm and harm towards parents has increased due to feeling unsettled by strangers in and out of their life who refuse to learn their language and support their protests.

The pro-eugenics ableist stance of Oregon's support of disabled children who are required to open their arms to a revolving door of caregivers is unacceptable.

Please stop the ban on family members accessing hours to support their disabled children.

Please schedule SB 538 for a vote in JWM and prioritize it for funding. This bill would dramatically improve my child's health and wellbeing, as well as that of our entire family.

Regards,

Ezme (formerly: Emily Fern Dayton)