

Submitter: Maria Jolley
On Behalf Of: Lucas Jolley
Committee: Senate Committee On Health Care
Measure, Appointment or Topic: SB538

Hello,

My name is Maria Jolley, I'm a mom of Lucas Jolley, born in 2017. Lucas Jolley is ONA 5 M, on 4 seizures meds, brain surgery in the past, VNS, keto diet and still with uncontrolled seizures activity. Lucas doesn't walk, talk and in diapers. In the past I wrote many letters and emails to Oregon government, yet, it seems the most vulnerable families are NOT a priority for Oregon State. No money, no budget for our disabled kids! I'm not asking for any charity or welfare, I'm just asking to be allowed to work as my son's caregiver just like any stranger in Oregon can. My husband and I are also medical providers and trained way better, then just any stranger to take care of medically fragile child. Families with disabled children don't deserve to barely survive because we had to leave our jobs or work part time. We deserve to be employed as caregivers to provide the best care with parents love, rather than unreliable/not available stranger caregivers