

Dear Oregon Senators, Representatives, and staff,

I ask that SB 1606 pass this Special Session so that **“Oregonians experiencing disability can access healthcare with support from people they trust while they are hospitalized and have support when making end of life decisions...**

this is an emergency and is directly related to the COVID-19 crisis. These changes cannot wait until next year because people with disabilities are experiencing these barriers to health care today.”

I want to share personal reason that I’m supporting SB 1606 for important change. My 5 year old daughter is unable to talk or walk or advocate for herself in any way due to a rare syndrome. We as parents need to be with her 24/7 due to her medically fragile and chronically complex conditions. She is one of many in a unique situation where parents can make the difference between life and death even with medical experts present. I had no clue families lived like this outside of occasional emergencies.

I can tell you story after story. The one that stands out the most is that we had a 24 hour EEG where we had a button to push when we saw what we thought was seizure activity. Our daughter was having subclinical seizures as well as other seizures. The neurologist reviewed the video video and did not see all of the activity but we had pushed the button, we saw and were there for her. These were moments where we were able to be with her secure her airway , and support her when hospital staff and even experts could not. She has never been without us or her support care. She will be at the same cognitive level her whole life.

We respect the rules but her being alone is not an option. Please adjust laws and make compassionate exceptions for people like us.

We are your friends, neighbors, the people behind you in line at the grocery store; we are often quietly living stressful unique lives but we need some extra legislative help today.

-Michael Paruch

Silverton OR