Good afternoon, I’m Beckie and I live in Hermiston,

I’m asking that SB 1606 pass this Special Session so that **Oregonians experiencing disability can access healthcare, use support from people they trust while they are hospitalized and have support when making end of life decisions.** Everyone deserves access to healthcare and support from people they trust to help them understand their care and communicate with doctors. Today, too many people experiencing disability are not able to access healthcare, are denied support from people they trust while they are hospitalized or having end of life discussions.”

We know this first hand, our son has refractory epilepsy with intellectual disabilities. He has been air-lifted just about every 2 years to Portland since the age of 6 months, he is now 27 years old. We have dealt with all kinds of doctors and their opinions of how we should allow them to treat him. Some understood our quest for a quality of life for our son vs. a quick fix in the hospital and sent home, while others tried to intimidate us into thinking their solution was the only way, by dragging in the whole medical team to intimidate us and others where bold enough to make the comment, “ Well do you think we should be treating him when he is in this condition?” which, my replay back to them was, “Are you saying by us choosing quality of life for our son is determining the quality of care that he will get.? We have a list of 27 years… The only thing that has kept him a live this far is our faith, and our determination to be by his bedside day/night while in the hospital to advocate for him. We are his legal guardians and he has a POLST and I pray that in the event that he should ever make it to the hospital without us next to him, the doctors will honor it until we get there and not just make their own decisions, due to the fact that our son is cognitively 3-4 years old and will not be able to make decisions for himself. He has behaviors, which are his words, and in order to know why he is having certain behaviors you need to know him. He says NO a lot and his NO has lots of meanings. It can mean no, yes, a seizure, (he may be feeling a seizure coming on), it means frustration, (He’s frustrated with trying to put a puzzle together or something he’s working on). No can mean, he’s teasing you. So for somebody to just make the assumption that “He said NO so I didn’t do it would be incorrect, because they do not know our son.

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. Our son is very high risk at getting COVID-19 and we could be admitted to the hospital at any time. Without SB 1606 it would continue to make things difficult as we have already witnessed in the hospital before; and we have all the right things in place to advocate for our son, like having legal guardianship. For instance, once when he was hospitalized, they told me I couldn’t stay in the room with him over night so I stayed at the Ronald McDonalds house. In the early mornings they had to do blood draws, every morning, I tried to be there early, hoping I would get to our son's room before they did. Except for one morning they had tried to draw his blood earlier than normal and our son, while tied to his bed with those hand restraints, said no and spit at them. They were in for the second time, experiencing the same thing and as I rounded the corner, the lab tech was on the phone saying, "I've asked him if I could draw his blood and he told me no, he is an adult you know". When they got off the phone they asked me if I was his parent, and they said, we have tried getting blood twice this morning, but he's told us no and since he's an adult we need to respect that; and if we would have known he would spit at us, we could have worn a face shield. I asked if they've looked at his records, we have been coming here for 20+ years and you guys have on file that he is not his own guardian, we are; that is why I need to stay with him. Without SB 1606 it will further delay people's care in the hospital, just like getting my son's blood work done. If I were allowed to stay with my son they could have had the blood work done and worn their face shield, and moved on to help other patience.

I want to say thank you for taking the time to read this and ask that you PLEASE support SB 1606 so our love ones have the support that they need while they are in the hospital.

Have a great day,
Beckie

Everyone you meet is fighting a battle you know nothing about..Be Kind. ☺
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