

June 20, 2020

Dear Senator Knopp and members of the committee,

Re: Senate Bill 1606

My name is Diane Cole. My husband and I live in Bend, Oregon along with our daughter Anna. Anna is a 28 year old with spina bifida, hydrocephalus, seizures and a nonverbal learning disability. She qualifies for developmental disability services. Anna lives in our home where we can support her with activities of daily living, supported decision making and medical care.

On May 25, 2020 our daughter was admitted to St. Charles for an infection from a pressure sore. When she was admitted she had spiked a fever and was slurring her words. My husband, Jeff was allowed to accompany her into the ER to provide information to them. He was told that no one would be allowed to stay or visit due to COVID-19 restrictions. As of today, our daughter has had 4 surgeries, a colostomy and been in the hospital for 25 days. During that time, she has been asked to sign medical paperwork, make decisions and have more medical procedures than she could count that she did not understand. No one was there to help her make any decisions or talk through the procedures in a way she would understand. She did not know what questions to ask, how to ask them or how to best advocate for herself. No one was allowed to be there to help her communicate with her medical team. When the nurses would help her Facetime us, she was often crying and scared. She wanted one of us there and we were not allowed to be there. We as her parents and caregivers received little information and often it was only when we solicited it were given any at all. It has been hard for us to even explain things to Anna over the phone because without being there, we did not have all of the information.

This week, St. Charles transferred her an hour away to Madras onto their skilled nursing floor. Finally they said she will be allowed 1 visitor per day. We do not know how long she will be admitted here.

This restriction of no parents or caregivers being with their child when they are in the hospital or having surgery will forever be etched in my daughter's memory as the more horrible time in her life. Special needs children of any age need their parents or a guardian with them in circumstances like this. It should be a right of the family to be there so they can advocate and explain to their child.

Respectfully,

Diane Cole

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