

I live in Southern Oregon and am the mother and guardian of a 30-year-old man with profound developmental disabilities. I want you to know how important this bill is to me.

I know things are not the same for all people with developmental disabilities, so I can only speak about how COVID and the threat of contracting COVID affect my son Ian, his caregivers, and our family. Ian is almost 31 years old and had a profound brain injury in infancy, which makes him vulnerable, plus he has a seizure disorder. He is blind and cannot talk.

He is vulnerable because he doesn't understand simple concepts like illness or emergency or contagious. Despite 30 years of training, he still does not know how keep himself safe or even at lower risk. He is at high risk if he were to become sick enough to go to the hospital since he cannot speak, cannot see, and he cannot answer simple questions like "if the answer is yes, raise your finger" ... unless you know him very well, you cannot determine his state of consciousness. In other words, he cannot make eye contact nor can he answer a question. He coughs and sneezes in our faces and spits wherever he wants to, despite years of training. He always has a hankie in his pocket but will not always use it to blow his nose and he often just blows into his hand and then flings snot. In other words, he is highly vulnerable. He touches us all the time and cannot understand "hands to yourself" for more than a minute or so. Thank God he is lovable.

Because of his level of functioning and understanding, all who care for him are also vulnerable. He has had to stop going into the community because there is no way to keep him safe there at all. He cannot tolerate wearing a mask. He touches everything and puts things into his mouth. That is partly due to his cognitive functioning and also a lot due to blindness. He HAS to touch us in order to remain safe once he leaves his home. We do a technique called sighted guide, which blind people use to get around the community – they depend on a "sighted" guide. Thankfully, he has been able to go for rides with his staff.

We are so hoping that somehow covid will pass us by. Ian has 9 staff and their families, so all of us are counting on one another to be safe in the community. We're taking it one day at a time. It's a good way to live, really, and this virus reminds us of the importance of that.

It would be a real nightmare for us all if Ian was so sick that he really should go to the hospital. Please support this bill, so that in the event that Ian MUST be hospitalized, someone who knows him well can accompany him and interpret

what is going on for him and for hospital staff. His life might just depend on having that support.

Please do everything to ensure that this bill will be introduced and passed during this special session so that Oregonians with developmental and other disabilities can access healthcare, use support from the people they know and trust while they are hospitalized and have support when making end-of-life decisions.

Thank you.

Mar Goodman, Ian's mom and guardian