

To our legislative leaders,

When accessing healthcare, we all feel vulnerable, and need support to understand the choices we must make. However, people with intellectual or developmental disabilities (IDD) in Oregon are being denied healthcare, coerced into signing “do not resuscitate” orders, and dying both from COVID-19 and treatable preventative disease as recently as this week. LC 52 is a step toward fixing these inequities and saving the lives of Oregonians with disabilities. We are asking for your urgent action to add LC 52 to the list of bills to be considered during the Special Session next week.

Our experience of 20 years serving people with IDD who live in their own or family homes in communities across Oregon has shown us that people with IDD are not all the same. Some people with IDD do not present as having a disability at all. Others may appear to have little capacity for choice, when in fact they are quite capable of directing their own lives. Only the people themselves and those have chosen to support and partner with them in their lives will know. These chosen supporters must be allowed as visitors to support quality outcomes, and safety for both people seeking care, and the hospital and medical personnel.

In these few months since COVID-19 swept into Oregon, we have seen:

1. Hospital “no visitor” policies denying people with IDD support from family, friends, or providers who they trust to explain care options and facilitate communication with healthcare staff. Hospitals have been reluctant to allow people with disabilities a visitor as reasonable accommodation under the Americans with Disabilities Act, despite Oregon Health Authority (OHA) guidance otherwise. OHA does not have resources to enforce its guidance.
2. People with IDD asked to sign “do not resuscitate” or “do not intubate” orders upon and sometimes prior to admission to hospitals or ERs. People with IDD have been led to understand that these documents are a requirement of hospital care. Often people are not offered support to understand the serious consequences of signing these documents.
3. People with IDD coming to the hospital with COVID-19 symptoms and being sent home on hospice without a COVID-19 test or treatment.
4. People with IDD going to the ER only to be sent home with serious injuries or illnesses without adequate testing or imaging. This leads to future, more expensive hospital stays or sometimes, death.

We do not believe that these things are being done with ill intent. They are being done by a system making quick decisions without adequate clarity and support to uphold Oregon’s shared values for each person, in each moment. Our values live or die in these moments, along with our citizens; we must get these choices right.

We know that the COVID-19 pandemic has stressed our systems, taxing us as individuals and as a society. We urge you to support LC 52 in the Special Legislative Session.

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