

Good Morning,

I am Jennifer Santiago, a resident of Milwaukie, writing as the President of the Oregon Support Services Association, a statewide advocacy group representing our 14 Support Service Brokerages.

Our healthcare systems are under unprecedented stress during this time, forcing difficult decisions. In such an environment, we need to protect equal access. In Oregon, people with intellectual or developmental disabilities (IDD) are being denied healthcare, coerced into signing “do not resuscitate” orders, and dying both from COVID-19 and treatable disease, as recently as this week. Many of these situations could have been prevented. 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 introduce and support the passage of LC 52 during the Special Session starting on June 24, 2020.

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 very capable of directing their own lives. Only the people themselves, and those they have chosen to support and partner with them in their lives, will know. These chosen supporters, both paid and unpaid, must be allowed as visitors to support quality outcomes and understanding of the people receiving care. These supporters provide 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 introduce and support the passage of LC 52 during this Special Legislative Session.

Thank you.

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