



Oregon Council on
Developmental Disabilities

BETTER TOGETHER

June 21, 2020

To: President Courtney, Speaker Kotek and members of the Joint Interim Committee on the First Special Session of 2020

From: Leslie Sutton, Policy Director, Oregon Council on Developmental Disabilities

RE: LC 52 Guaranteeing Access to Appropriate Lifesaving Care and Treatment for People with Disabilities

President Courtney, Speaker Kotek and members of the Joint Interim Committee on the First Special Session of 2020:

Thank you for your continued leadership in the COVID-19 crisis. We are all better off when we can access healthcare when we need it and have our care options presented in a way that we understand. However, we know people with intellectual or developmental disabilities (IDD) are being denied access to healthcare, denied access to support people who will help them understand and communicate their medical decisions 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.

To better understand the experience of people with IDD during this crisis, I have spoken to people with IDD, their families, providers and case managers. Several themes stand out that demonstrate people with IDD are experiencing discrimination, coercion and lack of access in healthcare.

1. Hospital “no visitor” policies are 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) guidance¹ otherwise. OHA does not have resources to enforce its guidance.
2. Upon admission to hospitals or ERs, and sometimes before, hospitals are asking people with IDD to sign “do not resuscitate” or “do not intubate” orders. 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 are going to the ER, not allowed support from people they trust to help them advocate, 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.

¹ <https://sharesystems.dhsoha.state.or.us/DHSForms/Served/le2282.pdf>,

4. Oregon’s Crisis Care Guidelines, which govern healthcare rationing, allow consideration of “quality of life” and “lifespan” in the provision of care. Although Oregon is not officially rationing care, many people with IDD and their families are terrified that they will not get equitable healthcare in Oregon’s hospitals today. They are making the difficult decisions to forego hospital care until they can be assured that they will be given fair and equitable care without discrimination.

Legislative Concept 52 is a step toward ensuring 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. Legislative Concept 52 does this by:

- Mandating hospitals allow support people to patients as required by the Americans with Disabilities Act, consistent with the order recently released by US Health and Human Services and current Oregon Health Authority guidelines.
- Clarifying that Crisis Care Guidance may not include provisions that consider the presence of a disability as a determinant factor in the decision of who gets care and who does not.
- Ensuring that people are not pressured to make end of life decisions on the basis of their disability or as a condition of receiving care.
- Ensuring that people can have support from people they choose if they are discussing lifesaving or end of life care.

We also know people with IDD are at higher risk of developing serious complications from COVID-19 due to co-occurring conditions.² People with IDD will need to go the hospital during this pandemic. It is important that they have people they trust with them to help them understand their medical options, make decisions and communicate those decisions. LC 52 can ensure that they will have the support they need.

Thank you.

² Current CDC guidelines indicate that people with underlying conditions such as heart or lung conditions or diabetes are at particular risk for COVID-19 complications. People experiencing Autism are at greater risk of health complications including immune, metabolic and heart conditions. Croen L.A. *et al.* *Autism* Epub ahead of print (2015) **PubMed**, People with Cerebral Palsy are at risk for respiratory and cardiovascular diseases <https://www.cerebralpalsy.org/information/respiratory-health>, <https://cerebralpalsynewstoday.com/2018/10/01/cardiovascular-disease-is-more-prevalent-in-patients-with-cerebral-palsy/> 1 in 2 People with Down Syndrome are born with a heart defect <https://www.ndss.org/resources/the-heart-down-syndrome/>