Oregon DD Coalition | Advancing Opportunities

June 22, 2020

To: Co-Chair Senator Peter Courtney
Co-Chair Speaker Tina Kotek
Vice-Chair Senator Fred Girod
Vice-Chair Representative Christine Drazan
Members of the Joint Interim Committee On The First Special Session of 2020

From: Katie Rose, Chair, Oregon Developmental Disabilities Coalition
Leslie Sutton, Policy Director, Oregon Council on Developmental Disabilities

RE: LC 52: Access to Care for Oregonians with Disabilities

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Dear Senator Courtney, Speaker Kotek, Senator Girod, Representative Drazan, and members of the committee:

The Oregon Developmental Disabilities Coalition (DD Coalition) is a group of approximately 38 organizations and individuals across Oregon that advocate for and promote quality services, equality, and community integration for Oregonians with intellectual and developmental disabilities (IDD) and their families. Our members represent advocacy groups (including self-advocacy organizations), family peer supports, DD residential providers, DD supported employment providers, and Support Services Brokerages.

When faced with difficult healthcare decisions, we all need support to understand and work through our options for care. However, we know people with intellectual and 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 last 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 introduce and support LC 52 during the Special Session commencing this week.**

The pandemic and subsequent shortage of resources has stressed our medical care system. Unfortunately, Oregonians with IDD are experiencing discrimination, coercion and lack of access to 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. Visitors are often a support to the hospital staff as well as the person admitted, increasing efficacy and better

outcomes for everyone. Hospitals have been reluctant to allow people with disabilities necessary supporters as a reasonable accommodation under the Americans with Disabilities Act, despite Oregon Health Authority (OHA) guidance[1] otherwise. OHA does not have resources to enforce its guidance.
2. People with IDD are being asked to sign "do not resuscitate" or "do not intubate" orders without proper support to understand the documents and choices at hand. People with IDD have been led to understand that these documents are a requirement of hospital care. They are not offered support to understand the serious consequences of signing these documents.
3. People with IDD are 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 are going to the ER only to be sent home with serious injuries or illnesses without adequate testing or diagnostic imaging. This can lead to more expensive hospital stays in the future, or sometimes, death.

LC 52 seeks to provide clarity for the people accessing healthcare and the medical personnel. This legislation will address these issues for people with IDD, physical disabilities, and other high-risk conditions by:

- Mandating hospitals allow support people access 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 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] **This legislative concept is not about punishing hospitals; it is about supporting a system under stress to make good choices in difficult moments for all Oregonians.**

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[1] https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le2282.pdf

[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/

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We urge you to provide hospitals with clarity and support to make the right choices for people in their care. Ensure that all Oregonians can have equitable access and expectation of high-quality healthcare. Please introduce and support LC 52 to the during the Special Legislative Session starting this week.

Thank you for your leadership and your consideration for all Oregonians weathering the crisis now and in the future.

Thank you.