



Oregon State Senate

June 22, 2020

RE: LC 52, Access to Essential Care for People with Disabilities

Dear President Courtney, Speaker Kotek and Members of the Committee:

Thank you for taking time to consider LC 52, an urgently needed measure to ensure Oregonians with disabilities are protected from health care discrimination and unintended consequences during the COVID-19 Pandemic.

COVID-19 has put significant new pressures on our health care system and has magnified longstanding barriers to quality care for people with disabilities. Since COVID-19 appeared in Oregon, people with disabilities have faced increased pressure to consent to DNR/DNI orders. In addition, restrictive hospital visitation policies have failed to comply with the ADA and denied people with disabilities the accommodations necessary to access quality care. In OLIS, you will find several of these stories. I would like to highlight a couple here:

Here are three examples:

- (Eastern Oregon) An individual with ID/DD was taken to a hospital with COVID-19. Entry to the ER for the staff from her group home was denied. While **alone in the hospital**, the individual was asked to sign a **“do not intubate order”** without any support to understand what she was signing. She was **denied a ventilator** as a result. In addition, the hospital informed the group home they would need to **obtain such orders for any other clients** that would come to the hospital. Fortunately, Disability Rights Oregon was able to intervene, have the order lifted, and transfer the patient to a different hospital where she did receive a ventilator. Because of this, she survived COVID-19.
- (Portland Metro area) An individual with ID/DD and significant physical and communication disabilities was taken to hospital with urgent non-COVID related needs. Her support staff from her 24 hour care program, including her nurse, were **not initially permitted to support her in the hospital**. In addition, the hospital continued to **pressure the providers to sign a DNR order on behalf of the individual**, dismissing their arguments about her desire to live and quality of life. This patient died.
- (Central Oregon) A 27 year old with developmental and communication disabilities had a medical emergency. She **does not have a legal guardian** because she chose to utilize **Supported Decision Making** to retain more of her independence. Her father was with her in the emergency room but **not allowed to stay with her** when she was admitted. After admission, she was kept in the hospital for **25 days and endured 4 surgeries without ever**

having a support person allowed to assist her. She was never permitted to have a visitor, even when she was asked to **consent to care and sign documents that she could not understand.**

- (Midvalley) An older individual with ID/DD was taken to the hospital with COVID related symptoms. A housemate was already in the hospital. Multiple staff and housemates had tested positive for COVID-19. He was initially **denied COVID testing** and the hospital informed the group home they were **discharging him for hospice care at the group home.** The group home did not have capacity to care for him, and pointed out they had COVID positive residents in their home and needed to know if this gentleman also had COVID. After four days, a test was finally administered and he was COVID positive. He died the next day.
- (Midvalley) My constituent is a man with an intellectual disability. He is nonverbal and receives his nutrition through a feeding tube. He has been treated for pneumonia at least once a year for the last several years, but always recovers. With the support of his friends and staff he lives a full and happy life. In April, he was taken to the hospital with pneumonia. His care providers had to **advocate fiercely for a COVID test despite his symptoms.** In addition, despite his inability to verbally communicate and his cognitive needs, he was **not permitted to have any support person** with him in the hospital to help facilitate care. The physician suggested to the group home that he be **discharged with comfort measures only**, meaning his **nutrition would be withheld.** There was nothing different about his condition as it related to his prior bouts of pneumonia, and no explanation of why his nutrition should be removed at this time. Fortunately, a **guardian intervened** and he was treated with antibiotics and loving care. He has **fully recovered.**

For individuals with disabilities and their families, these stories have the effect of causing them to delay or avoid medical care. In many cases, despite being at very high risk for contracting COVID and having severe complications, individuals and their support people fear the hospital experience, lack of support and potential coercion to make end of life decisions even more than they fear the virus. This is an emergency because these issues continue in communities across the state every day and are putting the lives of people with disabilities of all types at risk.

LC 52 seeks to address these issues by clarifying certain protections available to people with disabilities under federal law in Oregon state statute.

Section 1: Ensures people aren't told they must sign a POLST or DNR order to be admitted to the hospital or to receive care.

- **End of life planning is always voluntary.** This section restates the federal Patient Self Determination Act to clarify that an individual's decision to complete or not complete an advanced planning document such as a POLST or advanced directive, cannot be a condition of care. This is restated three times to cover three scenarios that have occurred:
 - 1) Facility can't tell an individual they are required to complete the documents to receive care or be admitted to hospital;
 - 2) Facility can't tell a third party (such as a guardian, health care representative, group home, adult foster home or long term care facility) that they must ensure such documents are complete prior to bringing person to facility; and
 - 3) Facility can't tell third party such documents must be completed to receive care

Section 2: Ensures hospital patients with disabilities have access to necessary supports to facilitate care. This section ensures that regardless of a hospital's visitor policy, exceptions must be made to comply with the Americans with Disabilities Act to ensure that individuals with disabilities may have a support person present as needed to facilitate care. This language is consistent with the order that came out of US Health and Human Services Office of Civil Rights in Connecticut last week. This section:

- Allows patient to identify at least three such individuals who do not all have to be permitted in at same time unless necessary to facilitate care. Access at any one time may be limited to the minimum number of individuals necessary to facilitate care
- Signs about ability to access support must be posted and information provided to patient
- Requires a patient have access to at least one support person if necessary to facilitate care at all times during the hospital stay, including the emergency room
- Allows hospital to screen support person and deny access to those who don't meet criteria related to infection and symptom control
- Allows hospital to require use of PPE and compliance with other safety measures
- Allows hospital to limit the total number of support people at any one time, over the course of a day, or over the course of an admission to the minimum number of support persons necessary to facilitate care and disability related needs of the individual
- Requires patient have opportunity to have support person present for any discussion related to the decision to elect hospice care or to make decisions about the provision or withholding of life sustaining treatments
- Defines disability to include cognitive or mental health disability (would include ID/DD and dementia) that impacts ability to make medical decisions/follow medical advice; physical disabilities requiring more support for safety and activities of daily living than can typically be provided by hospital staff; is deaf, hard of hearing or has other condition that creates a barrier to communication with hospital staff; has behavioral health needs that can be more effectively supported by a support person
- **Oregon Developmental Disabilities and Disability Rights Oregon notified in certain situations**
 - Current law requires a DHS case manager to be notified prior to the withdrawal of life sustaining measures if the decision is not made by the individual. This clarifies that for a person with intellectual and developmental disabilities that is Oregon Developmental Disabilities.
 - During a declared public health emergency, hospitals would be required to immediately notify Disability Rights Oregon when medical care is denied to a disabled person on the basis of crisis care guidelines or the decision to withhold or withdraw life sustaining measures or elect hospice is made for a person with a disability when:
 - The person with a disability did not make the decision themselves
 - The person has no legal guardian or legal representative, or the state or political subdivision of the state is the individual's legal guardian
- **Prohibits discrimination in allocation of health care resources.** Language restating that decisions about allocation of resources may not be made based on the protected class of a patient, including disability, race or age.

Section 3 Allows licensing action for violation of Sections 1 and 2

Section 4 Technical language adding to ORS

Senator Sara Gelser
Senate District 8

Section 5 Notification to DRO

During a public health emergency declared by the Governor, Disability Rights Oregon will be notified in the following situations:

- A decision is made to deny care to a person with ID/DD under crisis care guidance; or
- A hospice election is made for an individual with an intellectual or developmental disability

These notifications only occur if:

- The individual did not make the decision themselves
- The individual has no guardian or legal representative or if the state of Oregon is the individual's guardian

DRO is granted authority to receive this information and access medical records under existing state and federal law

Section 6 Notification to DHS

Under current law, DHS is given certain notifications regarding end of life care and people who have case managers through the Department. This section clarifies that this applies to individuals with ID/DD just as it applies to elderly individuals and individuals with physical disabilities.

Section 7 Nondiscrimination in Provision of Care

This section clarifies that decisions about provision of care, including in a crisis care situation, cannot be made based upon a person's protected class, including disability, race or age. This is consistent with an order released in April by US Health and Human Services, Office of Civil Rights.

Thank you again for taking the time to consider this testimony and the testimony of others. This bill truly meets the spirit of the First Special Session as it is an emergency and is directly related to the COVID crisis.

For your reference, below my signature I have included relevant citations to federal law and US Health and Human Services Office of Civil Rights on which this concept is based.

I remain available for any questions you may have.

Sincerely,

Sara Gelser
Chair, Senate Human Services Committee
Sen.saragelser@oregonlegislature.gov

End of Life Planning is Always Voluntary

Patient Self Determination Act 42 U.S. Code § 1395cc (3)(f)(c) requires that a hospital “**not to condition the provision of care or otherwise discriminate against an individual** based on whether or not the individual has executed an advance directive” <https://www.law.cornell.edu/uscode/text/42/1395cc>

2015 Message from Oregon Adults and People with Disabilities Program asserting POLST cannot be mandatory for admission. Message starts: “It has come to our attention that at times facilities are incorrectly requiring POLST upon admission.”

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Senate District 8

<https://www.oregon.gov/DHS/PROVIDERS-PARTNERS/LICENSING/APD-AFH/Alerts/polst-information-for-afh-providers.pdf>

Access to Support Persons in Hospital

June 2020 mediated settlement through US HHS/OCR

<https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html>

March 2020 Bulletin from US HHS/OCR regarding Civil Rights and COVID-19

<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

Nondiscrimination in Crisis Care Guidelines

March 2020 Bulletin from US HHS/OCR regarding Civil Rights and COVID-19

<https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

HHS/OCR resolution with Pennsylvania over discriminatory Crisis Care Guidelines, April 2020

<https://www.hhs.gov/about/news/2020/04/16/ocr-resolves-civil-rights-complaint-against-pennsylvania-after-it-revises-its-pandemic-health-care.html>

HHS/OCR resolution with Alabama over discriminatory Crisis Care Guidelines, April 2020

<https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html>

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Please note: The office phone is only checked periodically due to telework during the COVID-19 pandemic

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