

June 23, 2020

Joint Committee of the First Special Session

900 Court St, NE

Salem, OR 97301

Subject: LC 52

Chair Courtney, Chair Kotec, and members of the Committee,


Thank you for the opportunity to provide input on LC draft 52 which would provide protections for people with disabilities seeking acute medical care. It is with urgency and compassion that I am writing in opposition to LC 52. I write as a leader in palliative care, an Oregon POLST coalition member, and a father of an adult son with a disability who would be personally adversely affected by this legislation if passed. As written this bill would create an oppositional relationship between physicians, nurses, hospitals and their patients with disabilities who may be near the end of their lives or suffering from a life defining illness.

Section 5 As written, it is not operational in a state of emergency. Patients with well thought out advance care planning may be subjected to care they don't want while the healthcare system notifies the State and waits for permission to implement a well thought out plan. Patients without advance care planning would find it puts up barriers from having thoughtful and meaningful conversations between the health care team and the person with a disability and their advocate to search out their goals of care and implement them in a timely manner. As both the patient advocate and the physician would be concerned with an investigation by the State into their decisions of medical care.

In our current state of emergency, wonderful experts from medical ethicist, public health, critical care, emergency medicine, patient advocacy groups have come together to outline best practices for all of Oregon. The piece that we are the most uncomfortable with as a society is IF we enter a situation where we lack resources, how are we going to sort out equitably without prejudice if we are forced to ration care? Members from 10 statewide health systems have come together to do just that and have a circulating draft document "A Model Approach to Allocation of Scarce Resources in Crisis Care," adapted with Oregon Crisis Guidance, 2018, Version 5.1, 2020.05.15.

As healthcare professionals when we operate in a crisis, a well thought out emergency plan that can be implemented in real time is critical. Clear guidance from the State with a statewide approach is equally critical. Finally, guidance to then take the decisions locally to a particular hospital and patient are vital. The above document does just that. LC 52 does not.

Section 1&2 restates federal law (<https://www.congress.gov/bill/101st-congress/house-bill/4449>)



H.R.4449 - 101st Congress (1989-1990): Patient Self Determination Act of 1990 | Congress.gov | Library of Congress

H.R.4449 - Patient Self Determination Act of 1990
101st Congress (1989-1990) Rep. Levin, Sander M. [D-MI-17] (Introduced 04/03/1990) House - Ways and Means; Energy and Commerce. House - 07/02/1990 For Further Action See H.R.5067 . (All Actions) This bill has the status Introduced. Here are the steps for Status of Legislation:

www.congress.gov

) and is thus redundant. In my 20+ years of practice, the only institutions where this is an issue has been nursing homes and long-term care facilities. They pressure patients/families to complete POLST or advance directives thinking they are helping. This is misguided through lack a of education and understanding as to what those documents really mean and when they are or are not appropriate.

My experience with our pandemic is one of education and outreach to the community to provide appropriate guidance to any citizens with serious illness who have expressed a prior wish to limit care and engage those who are frail to ask if they wish any advance care planning. Knee jerk reactions by some to limit care to people with advanced illness, age, or disability have been met with strong opposition in our medical communities, hospitals, ethics boards, and policy champions.

Persons with disabilities are unfortunately like all minority groups in our country with regard to health care. They get too little preventative care, early disease diagnosis, disease management and ongoing care, and in general too much futile care near the end of life. I would urge you as legislative leaders to abandon LR 52 and push resources, time, and laws towards protecting and encouraging the autonomy of our disable residents. Facilitate education around advance care planning that is appropriate for all adults and assist them to document who their needed support people are, who has their authority to help them negotiate care for them in crisis and explore/articulate their current goals for health care are (these change over time). Encourage or mandate clinicians in our State to have education about how to have those hard conversations with patients about advance care planning and knowing when to ask if a POLST is right you someone. Specify education for populations with special needs is absent from most clinicians' education.

What Oregon needs is better education to health care workers and the public as to the purpose of a POLST and Advance Directive not an emergency STOP button at the crisis point in a health care emergency. That is what LC 52 is, the emergency brake on a subway train in rush hour system in NYC. Efforts should be directed to the patient as the driver behind advance care planning and deciding if and when they want to limit medical care.

Thank you for your time and consideration. Please contact me for any clarification or questions.

Respectfully,

Thomas M. Steele, MD, FACP

4395 NW Honeysuckle Dr.

Corvallis, OR 97330

971-237-2746