

Joint Interim Committee on The First Special Session
900 Court Street NE, Suite 254
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(sent electronically)

June 23, 2020

RE: LC 52, Ensuring Access to Health Care for High Risk Populations

Senate President Courtney and Speaker Kotek, Vice Chairs, Senate Republican Leader Girod and House Republican Leader Drazan, and Members of the Joint Interim Committee on The First Special Session of 2020:

On behalf of Oregon's 62 acute care hospitals we appreciate the opportunity to provide input on Legislative Concept 52 relating to ensuring access to health care for high risk populations. The intent of this legislative concept is to continue to ensure that there are no conditions to treatment for patients with intellectual and developmental disabilities when seeking care at a hospital. The proposal ensures that at least one support person is present during an emergency visit or hospital stay for this population.

OAHHS supports this intent. OAHHS recommends several changes to the proposed LC to ensure the bill achieves this outcome without unintended consequences that could discourage providers from end of life discussions with patients when appropriate and necessary or significantly increase risk to providers, patients, their family members, and support persons who are acting to honor the wishes of the patient.

SECTION 1 Conditions of Care

This section is not limited to patients with intellectual and developmental disabilities and, instead, would impact all patients and the critical and sensitive conversations that providers need to have with their patients. While the section is focused on ensuring that patients are not treated differently if they do not have a POLST, Advanced Directive or other instructions, the reality is if a person has a POLST, Advance Directive, or other instructions hospitals and clinicians are able to ensure that we are acting in accordance with the patient's wishes.

OAHHS recommends the following to improve this Section:

1. **Delete Section (2)(b-c).** These sections (b)(c) are duplicative to section (1)(a) and the additional vague language in sections (b) and (c) is likely to lead to confusion by providers and result in reducing critical end of life discussions between providers and their patients. Section (2)(a) achieves the intent of this section, codifying federal

law, without putting these necessary discussions at risk. Section 2(b) and 2(c) can be deleted without diminishing the impact of codifying in state law a clear prohibition on conditioning treatment of a patient to signing a POLST or advanced directive.

2. **Delete Section (2)(d).** It is unclear what this provision is intended to address that is not already addressed. The intent of this provision should be clarified or deleted. If it is not deleted, we suggest adding the word “solely” after “based” and before “on”.

SECTION 2 Hospital Visitation Policies

One important way to prevent the spread of infectious disease during a pandemic is to limit the number of people who enter health care facilities or certain areas of a health care facility. Hospitals face an enormous challenge in minimizing infectious disease transmission and ensuring patients have the support they need when receiving care. To mitigate the spread of COVID-19, there has been state and federal guidance and requirements applicable to visitation that have evolved throughout the COVID-19 emergency. Limiting visitors has helped limit the spread of COVID-19 but has also placed unimaginable stress on patients, families, and health care workers.

We agree that there is an important need for our patients who are living with intellectual or development disabilities to have a support person present at all times during their hospital stay, including during the COVID-19 emergency period. We applaud the intent that this section of LC 52 in creating assurances for our patients and their families.

LC 52 requires hospitals to inform a patient, at the time the hospital services are scheduled and at the time of hospital admissions of the patient’s right to support persons as well as post the hospital’s policy and requirements for support persons at the entry points to the hospital and on the hospital’s website. How is a hospital to know which patients this applies to when they are scheduling services? This portion of the bill is to go into effect immediately. We are concerned that some hospitals may not be able to meet these standards of public notice (website and entry points) on the effective date, which could be as soon as June 25th.

1. **OAHHS recommends that the notification at the time the hospital services are scheduled and at the time of hospital admissions should be deleted.** How will hospitals know which patients this applies to?
2. **OAHHS recommends that the implementation date for requirement of the postings of information be 30 days after the signing of the bill.** This will allow hospitals and health systems time to update their existing policies and operations and develop and post the required signage.
3. **OAHHS recommends that the definition of “physical” needs to be further clarified.**

SECTION 3 – 7

OAHHS supports the intent of the legislation to ensure people with disabilities are able to have a support person with them at all times when in the hospital and to codify in state law

the federal law that prohibits conditioning of treatment on signing a POLST or advanced directive. Sections 1 – 2 with the above recommended changes achieve this goal.

OAHHS recommends the deletion of Sections 3-7. These need further discussions regarding the intent and ensuring that the language supports the intent. Following are questions for each section, in attempting to better understand the objective and, when possible, recommendations to improve the sections for clarity.

SECTION 3 Penalties

Hospitals are not above the law and we should be held accountable for violations of the law. However, the proposed penalties of suspending or revoking a hospital's license may be an unduly heavy punishment for these two provisions.

SECTION 5 Governor Declared Emergency

Requires health care providers to report to ORS 192.517 if a person acting on behalf of a patient with an intellectual or developmental disability authorizes the withholding or withdrawing life-sustaining procedures or artificially administered nutrition and hydration or authorizes the transfer of the patient to hospice care. Furthermore, if the patient is denied services, care, equipment, or treatment based on Oregon's crisis care guidance, that too needs to be reported.

Without further discussion about what this process would look like and what happens after the notification this section could lead to our patients received life sustaining care against their stated wishes. It could also lead to the family members and designated care givers of our patients being subject to investigation leading to further trauma during and already devastating and traumatic time. This section requires further thoughtful and collaborative discussion to understand the intent and achieve it without putting our patients, their families and their support persons through an additional traumatizing experience when a decision about end of life care has been made properly. We look forward to understanding the process for which this reporting will be streamlined from a hospital to the reporting entity.

SECTION 6 Life-sustaining withholding or withdrawing

It is unclear what role is expected for hospitals under this notification plan. Notification appears to be the only requirement for this section, leaving it unclear when it is appropriate, after notification, for life-sustaining procedures to be withheld or withdrawn. This amendment creates risk for those making the decision when designated under subsection (2) or (3), which may be a patient's family member or other individual or a health care provider. OAHHS asks that this section be clarified to explain the expectations of hospitals. For example, if a family member is designated under subsection (2) then that family member would be required to make the notifications. How will the hospital obtain assurances that the required reporting was performed prior to the withholding or withdrawing of life-sustaining procedures?

SECTION 7 Crisis Care

Every hospital, every provider, and every Oregonian hopes that we will not see the mass cases of COVID-19 that our colleagues, family and friends experienced in Washington, New

York or other states where crisis care was being considered. No one wants to make crisis care decisions. It is our understanding this amendment was created to address crisis care concerns. The amendment is drafted to apply at all times, however.

This section raises many concerns for Oregon hospitals.

Accordingly, OAHHS recommends the following revisions to Section 7:

- The definition of “Medical resources” is unclear as to how these terms will be measured or if there are existing standards of care for the following terms:
 - Provider staff time.
 - Level or intensity of patient care.
 - Laboratory testing.
- Section 7 (6) is very broad and is a general non-discrimination provision related to denial of medical treatment and to limitations or restrictions in any manner on the allocation of medical resources. This proposal is not focused on crisis care issues and is a departure from the rest of the bill which is more narrowly focused on patients living with intellectual and development disabilities. There is concern that this will have a significant unintended consequence for patient care that have nothing to do with discriminatory practices. For example, certain drugs may not be indicated for patients with advanced age, gender identified at birth or other disabling conditions, but based on this language the failure to administer a requested drug to a patient based upon contradictions of the drug may be deemed as discriminatory treatment by the provider. This language requires more time to ensure unintended consequences are addressed.
- Section 7 (6) line 5, we recommend replacing “based on” to “because of”.

NEW PROPOSAL: Sunset Clause

If Sections 3-7 cannot be deleted from this bill, and even if modified, the language should sunset on July 1, 2021 to allow time for stakeholders to convene, assess and consider the proposed approaches, and develop policy language that minimizes the potential for unintended consequences for the 2021 session. This entire process has moved forward without engagement from stakeholders who are charged with implementing the proposed laws. Effective laws are those that are well-understood and implemented as intended. Bringing stakeholders together to build a consensus approach is necessary. This has been a very rushed and reactive process.

Closing

This is a critical policy issue and potential bill that requires appropriate time and discussion with all stakeholders. We have been asked to juxtapose the importance of the intent of this bill with the unintended consequences of rushing this bill without the benefit of formal, extended conversations. We appreciate the Senator’s leadership and highlighting the need for attention on these issues from the individuals and families who need our continued support during this time. We remain committed to having these conversations to improve the experiences of our patients in a safe manner.

Respectfully,

A handwritten signature in black ink, appearing to read "Andi Easton". The signature is fluid and cursive, with the first name "Andi" written in a larger, more prominent script than the last name "Easton".

Andi Easton
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