

Dear Joint Interim Committee on the First Special Session of 2020,

On behalf of the Oregon Hospice and Palliative Care Association, please accept these comments regarding Draft Bill LC52:

- Our Association supports the language in Sections 1 and 2;
- We are neutral on Section 3;
- I have concerns about the following language in Section 5 (1)(a) and (b):

SECTION 5. If the Governor has declared a state of emergency under ORS 401.165 or has proclaimed a state of public health emergency under ORS 433.441, a health care provider licensed or certified in this state must immediately notify the system described in ORS 192.517 if:

(1) A person acting on behalf of a patient with an intellectual or developmental disability authorizes the:

(a) Withholding or withdrawing of life-sustaining procedures or artificially

administered nutrition and hydration; or

(b) Transfer of the patient to hospice care; or

(2) A patient with an intellectual or developmental disability is denied services, care, equipment or treatment based on crisis care guidance.

I am concerned that this language in Section 5 will be interpreted to mean that *because* a notification must be immediately made when (1) (a) or (b) above are *authorized*, these actions will then not be taken. It is possible to infer that because of this language in the bill:

- patients for whom resuscitation efforts or curative treatments would be futile may continue to receive futile care and

- patients who are eligible to receive hospice services will not receive a timely referral to hospice.

I believe the intent of the bill language is to require notification but not to delay these actions when appropriate to meet a patient's care needs. I suggest having Section 5 include the language which clarifies this intent, by adding this statement: "The requirement to immediately notify the system should not result in a delay in appropriate care processes" (or words to that effect).

In many situations in which a person is receiving hospital care, a patient and/or health care representative or family members choose to have the patient transferred to hospice care, to stop receiving life-sustaining treatments and to focus on quality of life. We want the same quality of life and palliative care to be available to patients with intellectual or developmental disabilities and without needless delay.

Thank you for consideration of this concern regarding the current language in Section 5 of LC52.

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