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May 22, 2015

Honorable William Monning
California State Senate
Capitol Building, Room 313
Sacramento, CA 95814

Honorable Lois Wolk
California State Senate
Capitol Building, Room 5114
Sacramento, CA 95814

Re: SB 128 (Wolk) – Oppose

Dear Senators Monning and Wolk:

Disability Rights California, a non-profit advocacy organization which advances and protects the rights of Californians with disabilities, now opposes SB 128. We appreciate the thoughtful discussion we had with you and with your staff members, and we recognize your good intentions in introducing this bill.

From our advocacy work, we know that in medical settings the lives of people with disabilities are not always valued as highly as those of people without disabilities, which has led to the failure to offer or the denial of medical treatment, supports and services. In the last year, we have had clients with developmental disabilities who were denied cancer treatment explicitly because of their developmental disability.

In addition, in society at large, people with disabilities and seniors are subject to fears and stereotypes that devalue their lives. Some people considering assisted suicide are experiencing disability, caused by their underlying diagnosis, for the first time.

Our analysis applies, as always, to the actual content of this specific bill, rather than the concept of assisted suicide.

Our board, comprised of persons with disabilities and family members of persons with disabilities, adopted principles on physician-assisted suicide, which specify the protections which should be in place. Guided by those principles, we believe that SB 128 lacks sufficient safeguards and has the potential to undermine the safety of people with disabilities. For example:

- There is no oversight of the fatal dose once it has been dispensed. There is no way to know whether the patient has changed her mind but is given the dose anyway.
- We cannot assume that everyone around the person contemplating assisted suicide will act solely in the best interests of the patient. According to the National Council on Aging, “in almost 90% of elder abuse and neglect incidents, the perpetrator is a family member. Two-thirds of perpetrators are adult children or spouses. Interpersonal violence also occurs at disproportionately higher rates among adults with disabilities.”
- SB 128 relies on the premise that physicians can reliably predict whether a patient will die within six months. The Oregon data shows that some people who took the fatal dose in 2014 had received it in 2012 or 2013, meaning that their doctors’ predictions had been off by as much as two years. It is reasonable to infer that some people who took the fatal dose, relying on their doctors’ predictions, could have lived months or years more.

Many adults with disabilities recount their parents’ stories of being told by doctors that their children would never live to be adults. This month, actress Valerie Harper helped kick off National Womens’ Lung Health Week; in January 2013, she received a diagnosis of terminal cancer, with death predicted only a few months away.

SB 128 allows many problematic practices:

- It protects physicians or other providers who act “in good faith” even if the physician misdiagnoses, declines to provide medical treatment for the underlying condition, declines to approve palliative care, encourages assisted suicide as preferable to other alternatives, or knows about and does not report coercion or influence by anyone.
- Allows people with a financial stake in the death, including heirs and facility staff to be a witness to the written declaration requesting assisted suicide.
- Allows people with absolutely no knowledge of the patient to assess whether the patient is under duress, fraud or undue influence.
- Allows physicians who are new to the patient (e.g., nursing home attending and consulting physicians) to make and confirm a diagnosis and approve the lethal drug.
- Allows someone to obtain the lethal dose from the dispensing entity with absolutely no oversight of what happens after the drug is dispensed.

SB 128 does not:

- Ensure and document that the patient is safe from coercion or influence at all times, including during the written and oral request and after the initial request for the drug, so that if the patient changes her mind, the drug is no longer available.
- Ensure and document that the request for assisted suicide originated from the patient and forbid health providers or insurers from offering or suggesting it.
- Ensure and document how the physicians and witnesses determined whether the patient is clear in her or his wishes, is not under duress or experiencing coercion or undue influence, and if the decision conflicts with a previous statement or document, such as one requesting continuing treatment or extraordinary life-sustaining treatment.
- Ensure and document that each patient who requests a lethal drug is provided information about and guaranteed provision of alternatives, such as palliative care, hospice care, personal assistance services,

further medical treatment and peer support and counseling. Provision of a list of services does not satisfy this requirement. (The patient has the right to refuse the alternatives and the refusal should be documented in writing.)

- Ensure that individuals with disabilities, including seniors, are offered medical treatment on a non-discriminatory basis and require the treating physician to sign a statement stating that no treatment has been denied because of the nature or extent of a person's disability prior to authorizing a lethal drug. (The patient has the right to refuse any medical treatment and that refusal should be documented in writing.)
- Ensure that managed care entities and other health insurance companies have not overruled the physician's treatment decisions because of the cost of care.
- Prior to prescribing a lethal drug, require and document a review of the individual's Advance Directive and/or Physician's Order for Life Sustaining Treatment and ensure that the individual's instructions regarding withdrawal of treatment and palliative care have been honored. For individuals who do not have an Advance Directive or Physician's Order for Life Sustaining Treatment, it does not require that anyone provide information and independent assistance in completing an advanced directive prior to authorizing a lethal drug.
- Allow the patient to decide whether the official cause of death shall be the lethal drug or the underlying diagnosis.
- Require stakeholders, including representatives of people with disabilities, to design the regulations, oversight, specific safeguards, reporting requirements, and the collection and publishing of data on a variety of measures, including but not limited to: the race, ethnicity and income of the people who request the lethal prescription; the degree to which predictions of date of death are accurate, including the predictions by doctors who prescribe the lethal dose; patterns of prescription, which might be related to "doctor-shopping."

For all these reasons, we oppose this bill. Please contact us if you would like to discuss our position.

Sincerely,

A handwritten signature in black ink that reads "Deborah Doctor". The signature is written in a cursive style with a large, sweeping initial "D".

Deborah Doctor
Legislative Advocate
Disability Rights California

cc: Kathy Smith, Senior Legislative Aide, Office of Senator Monning
Monica Schmalenberger, Consultant, Office of Senator Wolk
Honorable Chair and Members, Senate Appropriations Committee