

April 20, 2018

Testimony to the New York State Assembly Health Committee on the Death with Dignity Act

Hello and thank you for the opportunity to testify here today. The New York Association on Independent Living (NYAIL) is strongly opposed to A.2383A, known as the Medical Aid in Dying Act, which would legalize physician assisted suicide in New York State.

A major concern for people with disabilities is that assisted suicide reinforces negative perceptions about being disabled and the idea our lives are not worth living. Fears of becoming disabled and facing functional loss, whether the cause is injury or illness, are often reported by doctors as reasons patients request assisted suicide in states where it is legal. Oregon released data from 2017 which showed that the top three end-of-life concerns cited by Oregon patients requesting suicide pills had nothing to do with physical pain and suffering. These concerns were: decreasing ability to participate in enjoyable activities; loss of autonomy; and loss of dignity¹. The disability community strongly opposes the belief that requiring the assistance of another individual for activities of daily living, such as dressing, bathing and toileting, is undignified or a legitimate reason for New York State to legalize physician assisted suicide.

Most people become disabled toward the end of their life. The disability community understands that becoming disabled and losing the ability to do things like walk, dress or go to the bathroom independently is very difficult and causes depression. Yet, this law does not have adequate safe guards to ensure people are not seeking this option due to depression or other concerns which can be addressed. Though supporters of the proposed legislation frequently insist that as a key safeguard, depressed people are ineligible, psychological screenings are not required, leaving it to a physician to determine whether someone requires a psychological evaluation.

In Oregon, Michael Freeland was a 64 year old man with a 43-year medical history of acute depression and suicide attempts². Yet, the doctor he consulted with when seeking assisted suicide medication said he didn't think that a psychiatric consultation was "necessary." In fact, Oregon's statistics for the years 2011 – 2014 show that each year, only 3% of patients (or fewer) were referred for psychological evaluation or counseling before receiving their prescriptions for lethal drugs. The proposed Medical Aid in Dying Act only mandates an

² Gregory Hamilton, M.D. and Catherine Hamilton, M.A., *Competing Paradigms of Responding to Assisted-Suicide Requests in Oregon: Case Report_*, presented at the American Psychiatric Association Annual Meeting, New York, New York, May 6, 2004.

¹ Oregon Death With Dignity Act: 2015 Data Summary

attending physician refer the patient for a mental health screening if they lack the capacity to make the decision.

If you are still wondering why the disability community is so opposed to legalizing physician assisted suicide, consider the reports that came out of Oregon in January. Oregon state officials have confirmed that people with chronic conditions like Diabetes are eligible for physician assisted suicide if they stop treatment³. According to Craig New, a Research Analyst for the Oregon Health Authority, who studies the Death with Dignity Act "The law is best seen as a permissive law, and states only that patients must have a terminal illness with six months or less to live. It does not compel patients to have exhausted all treatment options first, or to continue current treatment. It is up to the patient and doctor to discuss disease and treatment options. But if the patient decides they don't want treatment, that is their choice." New goes onto say that if a patient can't afford treatment, then they can be considered terminal under the law as well. Diabetes and many other chronic diseases can be treated and allow people to live long lives. This interpretation creates a serious danger for people with disabilities and chronic conditions. Oregon's law allows people with disabilities who could otherwise seek treatment to kill themselves with the help of a doctor. There are no safeguards in the proposed legislation to ensure this is not permitted in New York.

NYAIL is also concerned about the deadly mix between our profit-driven health care system and legalizing assisted suicide, which will be the cheapest so-called treatment. Direct coercion is not even necessary. If insurers deny, or even merely delay, expensive live-saving treatment, the person will be steered toward assisted suicide. Take Barbara Wagner and Randy Stroup: two Oregon residents who had cancer. Both Wagner and Stroup were prescribed treatments, but their health plans denied the prescribed treatment, offering physician assisted suicide as an alternative ⁴. What happened to these patients underscores the danger of legalizing assisted suicide in the context of our broken U.S. health care system.

Proponents of physician assisted suicide often argue that this option is necessary to prevent suffering at the end of life. This is not the case as there are alternative options to prevent suffering. It is already legal in New York for individuals to refuse life-sustaining treatment at any time, and to create an advance directive to cease treatment under any circumstance they choose if they are no longer able to make and communicate decisions. Palliative care is available and can provide pain relief to ensure a person is not in pain, even in those rare cases in which total palliative sedation is required. Unfortunately, medical schools do not mandate their students learn about end of life options and so may not be educating their patients on all their options. New York should invest in educating the community about these options and focus on promoting and expanding palliative care so that it is an available option to anyone facing a painful illness.

³ Bradford Richardson, <u>Diabetics eligible for physician-assisted suicide in Oregon,</u> <u>state officials</u> <u>say</u>, The Washington Times, January 11, 2018.

⁴ Kenneth R. Stevens, Jr., M.D., *Oregon Rationing Cancer Treatment But Offering Assisted Suicide to Cancer Patients—Paying to Die But Not to Live_*, Physicians for Compassionate Care Educational Foundation, June 6, 2008, (accessed July 9, 2009).

People vastly prefer to live and die in their homes, as opposed to a hospital. Unfortunately, hospice is not always an available option for people facing terminal illness, and is severely underutilized in New York State, which is 48 among the states in using hospice services. There are barriers for people who live in assisted living facilities from getting hospice services. There are also barriers to people receiving home care once on hospice. The State should focus on addressing these barriers rather than on legalizing physician assisted suicide.

Finally, the disability community is deeply concerned about coercion and abuse. The proposed legislation is based on the laws in Washington and Oregon, which have proven to have ineffectual safeguards against abuse. One upsetting example from Oregon is Kate Chaney, an 85-year-old woman with dementia who died by assisted suicide⁵. She first approached her physician, who would not prescribe her the lethal prescription. She then went to a second doctor, who ordered a psychiatric evaluation, which found that Cheney lacked "the very high level of capacity required to weigh options about assisted suicide." Cheney's request was denied, and it has been reported that her daughter "became angry." A second evaluation was then done with another psychologist, who insisted on doing the evaluation with Chaney alone. Disturbingly, the psychologist deemed Cheney competent while still noting that her "choices may be influenced by her family's wishes and her daughter, Erika, may be somewhat coercive." Cheney soon took the drugs and died, but only after spending a week in a nursing home. This is a very disturbing example of doctor shopping and the lack of safe quards in place in Oregon.

A.2383/S.3151A does not prevent a coercive family member or caregiver from doctor shopping with the individual to find a physician who will provide the fatal drug, such as in the case of Kate Chaney. There is nothing in the proposed legislation that would prevent an abusive caregiver or family member from steering the individual toward physician assisted suicide, witnessing the request form, picking up the lethal dose, and even administering the drug. Because no independent witness is required at the death, there is no assurance of self-administration or even consent.

For all of the reasons above, we strongly urge the Assembly's Health Committee not to pass this dangerous legislation.

Respectfully submitted,

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⁵ DHS news release, "No authority to investigate Death with Dignity case , DHS says," March 4, 2005.