

Department of Health and Social Services

Senior and Disabilities Services Governor's Council on Disabilities & Special Education Patrick J. Reinhart, Executive Director

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April 9, 2015

To: Members of the Alaska House Health & Social Services Committee

RE: HB 99: Voluntary Termination of Life

Dear Representative Seaton, Representative Vazquez, and Members of the Committee:

The Governor's Council on Disabilities and Special Education (the Council) fills a variety of federal and state roles, including serving as the State Council on Developmental Disabilities (SCDD) under the Developmental Disabilities Assistance and Bill of Rights Act. As the state DD Council, we works with Senior and Disabilities Services and other state agencies to ensure that people with intellectual and developmental disabilities (I/DD) and their families receive the services and supports that they need, as well as participate in the planning and design of those services. Our council membership is composed of self-advocates and family members of individuals with intellectual and development disabilities (60%), as well as agency and partner representatives (40%). One of the duties of the state DD Council is providing comments on proposed recommendations that may have an impact on individuals with intellectual and/or developmental disabilities and their families.

The Council is in opposition to HB 99, the Voluntary Termination of Life bill, introduced by Representative Drummond. The Council feels strongly that legalizing physician-assisted suicide has the distinct potential to result in discrimination against those with physical and developmental disabilities. There is public perception that individuals with significant disabilities do not have a high quality of life. As a substantially vulnerable population, individuals with disabilities could be put at risk for coercion, that choosing death over life is a viable option for them. There is real concern that individuals with disabilities may feel pressured into such a choice for fear of burdening their families.

In addition, many individuals with disabilities have family members as their guardians, which presents yet another concern regarding this legislation and its potentially deleterious results. This bill could create a conflict of interest if the guardian stands to benefit in any way from the death of the individual with disabilities. It may be construed as a cost-saving decision if the individual with disabilities required significant costs of care. This is important to remember in a state with high child abuse, domestic violence, and elder abuse rates; not everyone lives in loving, supportive families. It is the job of the Council and other advocacy groups to safeguard this vulnerable population.

There is also the potential that patients could be misdiagnosed as terminally ill and thus make a truly tragic choice based on inaccurate information. With a government-funded or profit-driven

health care system, this legislation should also present some apprehension regarding the potential of patients being denied or delayed life-saving treatments. For example, in Oregon where assisted suicide is legal, some terminally-ill patients have been prescribed expensive treatments by their doctors that are not covered by their insurance. However, these insurance companies offer to cover less expensive treatments, including physician-assisted suicide. This effectively encourages suicide by classifying it as a covered "treatment." How many of those Oregonians who chose assisted suicide did so after receiving notice that potentially life-saving treatments were prohibitively expensive?

People with disabilities already face many obstacles in their daily lives. They do not have full access to appropriate health care, affordable and accessible housing, public transportation, full integration into communities, the list goes on. If this bill passes, people with significant disabilities may feel that their only choice is to end their lives. The Council would rather see a legislative push to improve services and end-of-life care over an assisted suicide bill.

Many other national organizations also stand with the Council in opposition to legalizing physician-assisted suicide, including American Disabled for Attendant Programs Today (ADAPT), Association of Programs for Rural Independent Living (APRIL), Autistic Self-Advocacy Network (ASAN), Disability Rights Education and Defense Fund (DREDF), Disability Section of the American Public Health Association, Justice for All (JFA), National Council on Disability (NCD), National Council on Independent Living (NCIL), National Spinal Cord Injury Association, Not Dead Yet (NDY), TASH, World Association of Persons with Disabilities (WAPD), and World Institute on Disability (WID).

The Council respectfully opposes this bill and the potentially disastrous consequences that could impact Alaskans with disabilities.

Sincerely,

Ric Nelson, Chair

Dean Gates, Legislative Committee Chair

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CC. Representative Charisse Millett, Majority Leader and GCDSE Legislative Member Valerie Davidson, Commissioner, DHSS

Duane Mayes, Director, Senior and Disability Services

Jeff Jessee, CEO, Alaska Mental Health Trust Authority

GCDSE Members