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Thank you for the opportunity to give testimony on H.874 on behalf of the Vermont Center for Independent Living.

VCIL is supportive of Section 1 of the bill, which provides statutory authority for a family member or person with a known close relationship to the patient to elect hospice care on behalf of the patient. The most important piece of this provision is the directive that any decision made by persons under this expanded authority "shall protect the patient's own wishes in the same manner as decisions made by an agent". The ability to access hospice care can make a critical positive difference in the quality of an individual's life as they approach death. This recommended change in existing authority will enable more Vermonters to have the comfort of hospice care with the knowledge that the care will be covered by Medicaid/Medicare.

VCIL also supports Section 2 of the bill which extends the deadline for rulemaking on DNR/COLST orders until July 1, 2016. We believe that decisions about the critical issue of who may give informed consent on DNR/COLST orders are complicated and require much more time, discussion and input from the legislature than the current deadline allows. DNR/COLST orders are critical medical decision making tools and people with disabilities have a history of cultural bias to overcome in terms of having other people making those decisions on their behalf.

The reality is that people with disabilities receive different medical care than people without disabilities. People with the same medical needs can receive very different procedures or face very different medical decisions based on whether or not they are a person with a disability. For example, my adult son with autism exhibited some unusual behavior last September that necessitated an emergency complete physical. Although the doctor asked good questions and was very thoughtful, my son was never asked to disrobe. When was the last time any of us went for a physical and were never asked to remove our clothes? A person without disabilities would never be given a physical that way. When my son was seven and had fallen off a swing, the doctor diagnosed him with a sore throat and tried to send us home – i.e. get us out of the office. After my insistence on an x-ray (over the pediatrician's objection), my son was found to have a broken leg. My son's autism and his inability to speak compromise his medical care, even when it shouldn't. Sadly, these are not isolated incidents. This is the world people with disabilities live in. Ask any person with a disability and you are likely to hear examples of inadequate medical care.

When you are talking about DNR and COLST orders, that compromised care takes on literal life and death proportions. Annually, Not Dead Yet - an organization of people with disabilities, holds a day of remembrance commemorating the lives of people with disabilities who have been

killed by their families or caregivers. Every year the number of murdered grow but the press coverage often focuses more on the "burden" families faced caring for a person with disabilities than on the crime committed against the person murdered. The lives of people with disabilities are simply valued differently.

In that context, VCIL wants to ensure that the discussion and decision making about who can give informed consent for DNR and COLST is done carefully, by the legislature and not through rulemaking, and with the input and participation of the disability community.

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