DISABILITY RIGHTS VERMONT

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To: House Committee on Human Services
From: A.J. Ruben, DRVT Supervising Attorney
Date: January 30, 2018
Re: Request for Comments on **H. 690**

On behalf of DRVT I thank the Committee for inviting us to testify today regarding **H. 690**, a bill directed in part at amending our Advance Directive laws. DRVT, as the federally authorized disability protection and advocacy system in Vermont pursuant to **42 U.S.C. 10801** et seq., and as the Mental Health Care Ombudsman for the State of Vermont pursuant to **18 V.S. A. §7259**, has extensive experience with the use of Advance Directives in Vermont. DRVT monitors and does outreach in all hospitals in Vermont as well as at many residential care homes throughout the State. In the course of our work we regularly talk with people with disabilities about the benefits of executing Advance Directives and assist people with disabilities to execute, register and amend Advance Directives. DRVT knows from this experience that people with disabilities have reported that the process to create and execute an Advance Directive is an important and positive aspect of their medical care. Our clients tell us often that the ability to have self-determination and a sense of security about their future health care by executing an Advance Directive is a source of strength and contentment for them. DRVT continues to support the easy access to supports and services that allow people with disabilities to learn about, execute and enforce Advance Directives (ADs).

DRVT understands that a main thrust of **H. 690** is to make it easier for people in hospitals or residential care homes to execute AD's by expanding the entities who can be witnesses and "explainers". While DRVT has experienced delays in executing AD's for people with disabilities in hospitals or residential care homes due to the unavailability of statutorily-required parties (witnesses and explainers), generally we have been able to work with community partners to obtain the needed parties to get the AD properly executed. While delays in executing AD's do occur while facilitating the "explainers", DRVT has not experienced anyone being denied the ability to execute an AD solely due to lack of "explainer" availability.

DRVT wishes to highlight the historical concerns raised by our constituents around assuring that people with disabilities in institutional settings are not coerced or confused when signing off on AD's that limit life sustaining treatment. We have had experiences where a person with a disability executed an AD and a DNR that requested no life sustaining treatment, but when asked to confirm that was his intention, the person reported it was not his intention, he did not understand the impact of the documents, and was eager to have DRVT assistance to revise the documents to actually reflect his wishes, which included using all life sustaining efforts.

Concerns about coercion, confusion and conflicts were the stated reasons why the Legislature placed limits on who can witness and verify that the inpatient or residential Principal understood what they were doing and were doing it without coercion. To that end, witnesses cannot be the agent, or the parent, adult sibling, adult child or adult grandchild. **H. 690** proposes to clarify that health care worker can also be a witness, but because health care worker is not on the list of excluded entities, DRVT suggests the law currently does allow for a witness to be a health care provider.

That is clearly not the case for the statutorily-required "explainer", a person required to verify understanding and consent for Principals in or being admitted to hospitals or residential facilities. **18 V.S.A. § 9073 (d) and (e).** While DRVT understands the difficulty in obtaining the services of individuals currently authorized to be "explainers" (those being an ombudsman, a patient representative, a clergy member, an attorney, or a Probate Court designee), we suggest the Committee look at options to expand the pool of explainers without undoing protections against conflicts of interest currently in the law. Employees of facilities that are treating the Principals, and who thus have financial interests in the individual's continued stay and related costs to the facility, may allow their business interests to impact their duty to assure the principal's understanding of and willingness to execute the AD. Undoing the harm that can be caused by such a coercive or inadequately explained process will be much harder than improving the availability of currently legal "explainers" to fill this important role.

DRVT suggests that to remedy the problem of limited availability of "explainers" in facilities, the Committee consider identifying additional groups of independent, professional individuals who could perform the "explainer" role without the appearance or risk of conflict. This list could include any licensed mental health

or medical professional who is not contracted with or employed by the Principal's current facility, members of Area Agency on Aging organizations or other community organizations who have obtained special training on "explaining" in the context of Advanced Directives. The Agency of Human Services, VEN, or the Ombudsman programs could be tapped to provide the required training for these "community-based" explainers.

In addition, the **H.690** proposes to limit the number of Ombudsman programs that can be an explainer in subsections (d) and (e), and DRVT suggests the Committee reconsider that limitation and retain the current language authorizing all State Ombudsman programs to be an "explainer." If the new limit on which Ombudsman program will be allowed to be explainers is accepted, DRVT suggests the Committee consider amending the current definition of Ombudsman found at **18 V.S.A. §9071 (21).**

DRVT also suggests referencing the statutory definition of Patient Representative found at **18 V.S.A § 725**3 when referring to this position in statute in order to clarify that this position is a statutorily-defined term.

Thank you for your consideration of this information.