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PERSONS WITH DISABILITIES
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Testimony of the Office of Protection and Advocacy for Persons with Disabilities
before the
Public Health Committee

Presented by: James D McGaughey
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Good morning and thank you for this opportunity to comment on **Raised Bill No. 413, An Act Concerning the Department of Public Health's Recommendation Regarding Medical Orders for Life-Sustaining Treatment.** This bill would authorize the Department of Public Health to establish two pilot programs in different regions of the State where Medical Orders for Life-Sustaining Treatment (MOLST) could be used to document decisions about treatment options that have been made by people who are approaching the end of their lives after discussions with their physicians or other healthcare providers.

Our Office's support for this measure is rooted, in part, in experience we have gained from participating on the Connecticut Fatality Review Board for Persons with Disabilities – a group of professionals with backgrounds in medicine, human services and law enforcement that is charged by an Executive Order with reviewing circumstances surrounding the deaths of people with intellectual and developmental disability and investigating selected matters. In the process of conducting those fatality reviews we have encountered situations where the wishes of people who were approaching the ends of their lives were not respected. These were people who were quite capable of making their own decisions about medical treatment, and who had been clear about the types of interventions they did and did not want. In some cases they had even executed advance directives. Their Intellectual Disability was not the issue, but the fact that they had been transferred between facilities and the "paperwork" had not caught up to them was. I believe that the MOLST program contemplated in this bill could have made a difference for those individuals. Because MOLSTs are medical orders, dated and issued by a physician, nurse practitioner or physician assistant, utilizing a standardized format and specifying the types of life-sustaining measures a person who is approaching the end of his or her life has decided he or she wants, they can accompany a person wherever they go, and can be relied on by liability-wary healthcare providers, including hospitals and Emergency Medical Services.

The concept underlying this legislation derives from the work of the National POLST Paradigm Task Force. (POLST stands for Physician Orders for Life-Sustaining Treatment; the term "medical orders" is now preferred because it is recognized that providers other than physicians may be in a better position to have the thoughtful and sometimes lengthy discussions with people who are making choices and decisions, and because state statutes are increasingly authorizing nurse practitioners and physician assistants to write and sign medical orders.) Ideally, the decisions reflected on a MOLST are made after a series of conversations between the patient and medical provider, and they are subject to regular reviews and updates as the patient returns for follow-up care and monitoring, and, possibly experiences changes in his or her health status. To date, POLST/MOLST programs exist in some form in 15 states, and efforts are underway to develop them in 28 others.

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The experience in those states has not been uniformly positive: the program in Delaware had to be suspended for a time because providers were routinely completing the forms without regard to whether patients were terminally ill; and, notwithstanding the voluntary nature of POLST/MOLST programs, in other states some long term care facilities have been found to be routinely insisting on the completion of POLST/MOLST forms for all residents. Indeed, our sister Protection and Advocacy agency in California investigated a situation where a physician unilaterally re-wrote the POLST for a patient with intellectual and developmental disabilities, leading to a denial of life-sustaining treatment the person had chosen. Equally troubling, training materials and checklists that have been developed in some states clearly steer people away from things like feeding tubes and Bi-PAPs, even though people with certain types of progressive disabilities find that using such technology has significantly improved the quality of their lives and enabled them to live for many years – even decades - longer than would have otherwise been the case. Even a member of the National POLST Paradigm Task Force sees problems with the way POLST/MOLST is being implemented in some jurisdictions:

I think it's way too easy for the POLST to be treated like a checklist. It really should be about the conversation but right now we don't have a system that really incentivizes organizations to invest in education, in time, in people who have the skills to hold these conversations. (Susan B. Hickman, Ph.D., testimony before the Institute of Medicine, August 12, 2013.)

Against this background of problematic implementation in other states, when a proposal for a MOLST pilot came before this Committee last year, disability advocates testified in opposition. The basic concept was not the problem. But, there were real concerns about the details of implementation: What kind of safeguards would be in place to ensure that MOLST forms truly reflected people's wishes? How would people be informed about their options? What kind of training would providers receive about presenting and properly using MOLST, especially with people with disabilities and other discrete populations? How could Connecticut ensure that MOLST would not become just another "checklist" that routinely discouraged people with significant or progressive disabilities from choosing the kinds of assistive interventions and care that could help them live good quality lives for many years, just because this might involve "tubes and wires"?

Questions like these prompted DPH to convene an expanded MOLST working group which included our Office, the Department of Developmental Services, and representatives from the disability community. The result is the language in the bill before you – a much improved proposal. It is now clear that MOLST will only be used to effectuate a patient's request for life-sustaining treatment when a physician has determined that the patient is "approaching the end stage of a serious, life-limiting illness or is in a condition of advanced, chronic, progressive frailty". The patient, or the patient's legally authorized representative must countersign the MOLST form, and must promptly be given a copy. Prior to participating in the pilot program, providers who will be signing MOLSTs must participate in a training program that stresses the importance of discussing patients' goals and covers a number of specific, relevant topics. Lastly, the advisory group for the pilot will now include patient advocates, including but not limited to advocates for persons with disabilities. (In fact, such a working group already exists and is diligently exploring various questions related to underserved populations; provider, patient and public education; possibilities for policy development and regulatory frameworks; and, data gathering and analysis.)

With these improvements, our Office believes the MOLST pilots that would be authorized by this legislation will be able to explore, and, hopefully demonstrate the value of the MOLST concept without encountering the problems experienced in other states. Accordingly, I urge you to act favorably on this bill.

Thank you for your attention. If there are any questions I will try to answer them.