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PUBLIC HEALTH COMMITTEE
Testimony regarding Raised Bill 413
An Act Concerning the Department of Public Health's Recommendations
Regarding Medical Orders for Life-Sustaining Treatment
March 14, 2013

Senator Gerratana, Rep. Johnson, and members of the Public Health Committee:

My name is Cathy Ludlum, and I am here to express my support for Connecticut's pilot project around Medical Orders for Life-Sustaining Treatment, Raised Bill 413.

You may recall that last year I joined my colleagues in the disability community in fighting against an earlier version of the bill. It wasn't that we opposed the concept. Of course people should have choices over what treatments they receive and when enough is simply enough. On the other hand, as similar efforts in other states have demonstrated, if this type of program is not well designed, it can result in premature and unintended death.

So what changed?

The Connecticut Department of Public Health, and especially Suzanne Blancaflor, invited the disability community to the table. Our concerns were listened to, and together we have created what we all think is a good piece of legislation.

What the Connecticut MOLST bill has that the other states lack is Section (e). This carefully crafted section contains guidelines and safeguards to make these medical orders more reflective of people's choices. Although it can never eliminate the risk of death from unconscious biases and mistakes, this language should significantly reduce the risk. It requires that people be made fully aware of the risks as well as the benefits of their choices. Everyone who has ever had a medical procedure or taken a prescription medicine has seen

consent forms or other literature outlining the intended outcomes as well as the possible side effects. As a tool, MOLST is just as powerful, and it needs to be treated with the same level of respect and caution.

It is significant that Section (e) requires a patient's or surrogate's signature for the MOLST form to be valid. Some other states have fallen short in this area. The same section requires that medical practitioners sit down with their patients and have serious discussions about their illness and possible courses of treatment. Only in this way can the true wishes of the patient be identified, documented, and implemented. MOLST is not a checklist, and it should never be handed to someone with the words, "Here, just fill this out."

The Department of Public Health has worked hard to make sure that diverse voices were heard in the creation of this bill. As a member of the MOLST Steering Committee and Co-Chair of the Underserved Populations Workgroup, I know how much has been involved in trying to get this right. But I think we are pretty close.

There are three changes that I think would make the bill even better.

First, Section (e)(4)(D) needs a comma between "language" and "disability." Otherwise, you end up with "language disability." I suppose there is such a thing, but that is not what the sentence is about.

Second, in the same section, there is a list of personal characteristics that may affect how MOLST is explained or implemented. As it stands, this list reads, "Race, ethnicity, age, gender, socioeconomic position, immigrant status, sexual minority status, language disability, homelessness, mental illness and geographic area of residence." Notably absent is "religion." I suggest that this category be added, as people's religious beliefs and practices will undoubtedly affect their perceptions and choices.

Third, I know how long it takes to get a new effort off the ground. I do not think one year is sufficient for the pilot to give us the information we need going forward. I therefore recommend that the length of the pilot be increased to two years.

Once again, I am pleased to offer my support to Raised Bill 413 as long as the safeguards in Section (e) remain in the legislation. Connecticut has developed a MOLST program that is unique, better designed, and more collaborative than any other in the country. I am proud to be a part of that.

Thank you for your time and attention.