You Tube Video Link: <http://youtu.be/yJa8S2pNPro>

**Disability Related Concerns About POLST**

**Public Comment by Diane Coleman of Not Dead Yet**

**Submitted by Video to the Institute of Medicine’s**

**Committee on Approaching Death**

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I’m Diane Coleman with Not Dead Yet, a national disability rights organization that addresses “end of life” care policies.

Many in this field doubt that the views of disability organizations are relevant. But, while people with disabilities aren’t usually terminally ill, the terminally ill are almost always disabled. People with disabilities also live on the front lines of the health care system that serves (and too often underserves) many people. Therefore, our perspective can shed some light on these complex issues.

A few weeks ago, the Pew Trusts’ *Stateline* published an article[[1]](#endnote-1) about POLST and I was gratified that the author contacted me about the disability perspective. The article reflected our concerns as follows:

*“How do we know the POLST medical order actually reflects the desires of the individual?”  [We worry] that depending on how POLSTs are presented, they can make life-sustaining treatments—such as the use of feeding tubes—seem unbearable, even though many disabled people are able to live full lives because of them.*

According to the National POLST Task Force site[[2]](#endnote-2):

*…[T]he intended audience for use of POLST … is patients for whom the health care professional’s response to the surprise question- “Would I be surprised if this patient died in the next 12 months?”- is “No, I would not be surprised.” These include: (1) seriously ill patients with life-limiting progressive advanced illness; and (2) patients with advanced frailty.*

Those criteria are much broader than the hospice definition of terminal, and sweep in many disabled people, people with muscular dystrophy, multiple sclerosis, Parkinson's, and many other conditions, including me. Many of us are working, raising families, and living normal lives with some adaptations. Medical professionals specializing in disability understand this “paradox”, but most practitioners do not.

It’s clear that POLST is being used with people who are not terminal. The one-year surprise question is unreliable, yet two state laws even extend POLST to those with a 5-year prognosis.[[3]](#endnote-3) The California Advocates for Nursing Home Reform report that *nursing facilities pressured* ***all*** *residents to have a POLST.[[4]](#endnote-4)* People with non-terminal disabilities are forced into nursing facilities every day in this country due to the inability to secure appropriate home care services.[[5]](#endnote-5)

We also see that Delaware suspended use of POLST because it was being used for non-terminal people.[[6]](#endnote-6)

Some might ask, what’s wrong with using POLST to document the treatment wishes of people with long-term disabilities?

One problem is that POLST requires a simple “yes” or “no” choice regarding each type of life-sustaining treatment, without allowing different choices for the same treatment depending upon the context, events and circumstances surrounding the need for the treatment. This only makes sense for someone who is expecting to die soon, regardless of the specific situation that arises.

Another concern we have is the pervasive negative bias against life-sustaining treatments in POLST literature. While some distinguish between short term and long-term use of technologies, I haven’t seen anything that acknowledges successful long-term use of feeding tubes or ventilators. This creates a very serious problem with informed consent.

Even with tracheostomies and ventilators, some people are able to work, go to school, and live in their communities. As an agency director, I myself have employed two women with “trach-vents” over my career and many others with serious, progressive, chronic conditions.

One advocate I know suggested that we need a disability educational campaign called “We love our tubes” or “Tube Pride.”

I just watched a POLST training video[[7]](#endnote-7) from the California project. A leading doctor modeled how to explain and fill out the POLST form. He presented only one scenario for each of the four treatments – feeding tube, CPR, antibiotics and a ventilator – to a female patient who uses oxygen but mentioned that she still goes hiking.  He did not present even one alternative scenario for each type of treatment.  In each case, he clearly steered her toward a certain result, and that is what she “chose.”

In the interest of time, I’ll submit additional concerns and resource materials in written form. Meanwhile I hope you can see that the disability community has knowledge and life experiencewith serious, progressive, chronic conditions and life-sustaining technologiesthat ought to be part of informed consent disclosures, but is not. That needs to change.

1. Michael Ollove, New End-of-Life Measure Quietly Sweeps the Nation, Stateline, June 20, 2013 <http://www.pewstates.org/projects/stateline/headlines/new-end-of-life-measure-quietly-sweeps-the-nation-85899484943> [↑](#endnote-ref-1)
2. National POLST Paradigm Task Force [http://www.polst.org/develop-a-program/program-requirements/#](http://www.polst.org/develop-a-program/program-requirements/) Level 3: Program Requirements for Endorsed POLST Paradigm Programs [↑](#endnote-ref-2)
3. New Jersey and Nevada. [↑](#endnote-ref-3)
4. CANHR Policy Brief, Physician Orders for Life-Sustaining Treatment (“POLST”), Problems and Recommendations <http://www.canhr.org/reports/2010/POLST_WhitePaper.pdf> [↑](#endnote-ref-4)
5. See, e.g., [www.adapt.org](http://www.adapt.org). [↑](#endnote-ref-5)
6. Delaware Health and Social Services, Division of Public Health, Medical Orders for Life-Sustaining Treatments (MOLST) Form, November 14, 2012, <http://www.medsocdel.org/Portals/1/In%20the%20News/MOLST%20Form%20Letter%20111412.pdf> [↑](#endnote-ref-6)
7. POLST: Honoring Patients’ Wishes for Treatment, Part 3: Having the POLST Conversation, University of California Television, Coming of Age Lecture Series, UC Davis Health System Center for Healthy Aging, <http://www.medsocdel.org/Portals/1/In%20the%20News/MOLST%20Form%20Letter%20111412.pdf> [↑](#endnote-ref-7)