**Disability Related Concerns About POLST**

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

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

**Committee on Approaching Death**

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Introduction – Why Disability Perspectives Must Be Considered

These public comments are being submitted by Diane Coleman, President and CEO of Not Dead Yet, a national disability rights organization that addresses “end of life” care policies.

Many professionals in the field doubt that the views of disability organizations are relevant. However, while people with disabilities aren’t usually terminally ill, the terminally ill are almost always disabled. Moreover, nondisabled people have a profound fear of the disability that comes with aging and advanced illness. This are among the reasons that our perspective may shed some light on these complex issues.

People with disabilities and chronic conditions also live on the front lines of the health care system that serves (and too often underserves) many people. One might view us as the proverbial “canaries in the coal mine,” alerting others to dangers we see first.

A few weeks ago, the Pew Charitable Trusts’ *Stateline* published an article[[1]](#endnote-1) about POLST entitled “New End-of-Life Measure Quietly Sweeps the Nation,” 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.*

Problem – Using POLST With Non-Terminal People

According to the National POLST Paradigm 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)* Yet 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 when it was found that it was being used for people who did not meet the state’s criteria for POLST eligibility in that they were not terminal.[[6]](#endnote-6)

Some might ask, what’s wrong with using POLST to document the treatment wishes of people with long-term but non-terminal 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.

Problem – POLST Bias Against Life-Sustaining Technologies

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 that needed a yes-no checkmark – 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.”

Problem – POLST Form May Not Reflect Person’s Wishes

The overarching concern about POLST is that an individual’s POLST form may not actually reflect his or her wishes based on informed consent.  Some states do not even require that the POLST form be co-signed by the individual or their authorized surrogate. The physician is simply supposed to fill out the POLST form based on direct and appropriately detailed communications with the individual or surrogate.

Basically, we’re supposed to trust the physician to have those discussions and document them accurately. We’ve already discussed the bias against life-sustaining technologies prevalent in POLST literature and reflected in such professional education tools as the California training video. There are additional reasons for real world concerns about the impact on the physician-patient conversation of factors like insurance coverage denials, medical error, medical malpractice, time constraints on physician visits, contractual constraints on “utilization” (i.e. provision of medical treatments), to name a few.

Another glaring factor that comes to mind is the existence of laws, in many states, which allow physicians to overrule an individual’s advance directive, or individual or surrogate decision, in favor of life-sustaining treatment. These are generally called futility or futile care laws, but they don’t objectively define “futility”.[[8]](#endnote-8) Instead they leave it up to the physician or hospital policy to determine what treatments are required by the prevailing “standard of care” and what treatments are not. Under most such statutes, blanket authority and full legal immunity are vested in the physician and hospital, without meaningful accountability.

In states which allow doctors to make futility judgments that overrule an individual’s decision for treatment, and do not require the individual’s signature on the POLST form, or provide for some type of independent oversight and enforcement, how can we ever be sure that a doctor’s signature on a POLST form reflects the person’s treatment choices rather than the physician’s?

Problem – Lack of Independent Research on POLST

Unfortunately there’s been a lack of independent research, as detailed in a new blog regarding POLST established by attorney Jason Manne[[9]](#endnote-9).

As Manne summarizes in his May 29, 2013 post:

*Certainly there are a large number of studies that have been conducted on the POLST but most of this research has limitations that make generalization inappropriate.  A review of the studies shows that most of them were small, were based upon convenience samples, had confounders that may have influenced the results, and were conducted in settings that had an end-of-life culture that supported limitations on life-sustaining treatment. . . . These studies do not constitute a solid research base from which policymakers and institutional leaders can draw conclusions about the POLST.*

*In fact, there is only one study that may be considered to meet standards of scientific research from which generalization might be appropriate.[[10]](#endnote-10)*

The next three entries explore the articles based on that one NIH-funded study, which was conducted in nursing facilities using POLST in several different states. According to Manne:

*The authors conclude that "with a few exceptions, POLST form orders are largely consistent with the treatments provided" and the POLST represents "a useful strategy for ensuring treatment preferences are honored in the long-term care setting."  An upbeat conclusion is not unexpected given that most of the authors of this study are POLST advocates. However, in my opinion, the results reported in this article are much more mixed.  They suggest that doctors and nursing homes are following the POLST only when they agree with the orders and ignoring the POLST when they think the orders are inappropriate.[[11]](#endnote-11)*

The study’s results also suggest that there may be a pattern in terms of which patient choices were viewed as appropriate and were carefully followed, and which were not. For example, the choice to refuse CPR was followed 96% of the time, but “full code” orders were often not followed.

Problem – Medical Professionals Not Held Accountable

Disability Rights California (DRC), the federally funded disability protection and advocacy agency, issued a report[[12]](#endnote-12) documenting a case in which an individual’s physician revised his POLST form to say the opposite of the patient’s previously and repeatedly expressed wishes to receive life-sustaining treatment. Based on the revised POLST form, the hospital discontinued the patient’s dialysis.

*. . . [A] hospital and its medical staff . . . ignored a patient’s well-documented end of life treatment wishes and, when he lapsed into unconsciousness, decided to terminate his life-sustaining treatment, resulting in his untimely death.*

*Although the hospital and medical staff took this grave course after some thoughtful deliberation, no one who was independent from the hospital or the medical staff and who knew the patient participated in the deliberations – no family member, no close personal friend, no one from the nursing facility which he had called home for years . . ..*

The legal advocacy agency carefully detailed the events leading to the man’s death, including a close look at the results of an investigation by the state Department of Public Health. According to the DRC report:

*Although the Department substantiated the complaint, they found that the facility, “did not violate any State and/or Federal laws or regulations.” Ultimately, the Department took no action against the hospital.[[13]](#endnote-13)*

DRC concluded that the hospital indeed violated applicable laws and regulations. Nevertheless, the hospital appears to have avoided any consequences for its actions.

Problem – The Risk of Over-Interpretation of POLST Orders

A 2012 study in the Journal of Emergency Medicine[[14]](#endnote-14) found that having a living will might give people a false sense of security about getting the treatment they want. Based on survey responses from more than 700 physicians in 34 states, researchers from the University of Pittsburgh Medical Center found that over 50% of physicians misinterpreted a living will as having a "do not resuscitate" (DNR) order when it did not. About the same percentage over-interpreted DNR orders as meaning no treatment except "comfort care" or "end-of-life" care.

The study shows that there is a frighteningly high likelihood that having a living will or DNR order will result in physicians withholding curative treatment that a patient actually wants. What are the reasons for the interpretation problems that have been documented? And what are the risks that the same type of misinterpretation is or will be an issue in the POLST context? Research is needed before sound policies can be developed.

Problem - HR 1173 Should Fund POLST Research, Not POLST Promotion

A federal bill called the “Personalize Your Care Act” was introduced on March 14, 2013, by Representative Earl Blumenauer (D-Oregon), which would provide Medicare funding for physicians to have a conversation with their patients about “end-of-life care.” If done well, we agree that such a conversation can be a good thing, and I object to the “death panel” accusations that obstructed rational discussion of such a provision in the Affordable Care Act.

But there’s another section of the new bill, H.R. 1173, that would provide grants to promote POLST across the country. If we can conclude anything from the current level of information we have about how POLST is being implemented in the states that have it, it’s that many questions remain unanswered, strong reasons for concern exist, and federal funding to promote POLST is premature. The POLST provisions of H.R. 1173 should be amended to fund independent research to answer the serious questions and concerns that many have raised. That’s what the Institute of Medicine and this Committee should support.

Conclusion

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.

Unfortunately the disability community also has a lot of experience with devaluation by physicians and other health care providers, devaluation that leads to pressure to forego life-sustaining treatment.

The California Advocates for Nursing Home Reform Policy Brief[[15]](#endnote-15) contains a detailed description of POLST problems and recommendations that is well worth a close examination by this Committee.

At this point, the limited evidence we have indicates that POLST is less about safeguarding the rights and preferences of the individual patient than it is about relieving some perceived burden of uncertainty on medical providers. It’s time to back away from POLST promotion and to focus instead on identifying, understanding and correcting the mistakes that pose such a clear risk to people’s lives.

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)
8. American Medical Association Opinion 2.037 – Medical Futility in End-of-Life Care, <http://www.ama-assn.org//ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2037.page> [↑](#endnote-ref-8)
9. POLST: Critical Analysis and Comment, <http://polst-views.blogspot.com> [↑](#endnote-ref-9)
10. Jason Manne, “POLST Research – The Many Small Studies,” May 29, 2013, <http://polst-views.blogspot.com/2013/05/polst-research-deficiencies-part-one.html> [↑](#endnote-ref-10)
11. Jason Manne, “POLST Research – The Hickman (2011) Article,” June 3, 2013, <http://polst-views.blogspot.com/2013/06/polst-research-hickman-2011-study.html> [↑](#endnote-ref-11)
12. The Deadly Failure of a Hospital to Follow a Patient's Decisions About his Medical Care, February 2013, <http://www.disabilityrightsca.org/pubs/702601.pdf> [↑](#endnote-ref-12)
13. Id., page 7. [↑](#endnote-ref-13)
14. Mirarchi, Costello, et al., TRIAD III: Nationwide Assessment of Living Wills and Do Not Resuscitate Orders, Journal of Emergency Medicine, Vol. 42, Issue 5, pages 511-520, May 2012, [http://www.jem-journal.com/article/S0736-4679(11)00853-5/abstract](http://www.jem-journal.com/article/S0736-4679%2811%2900853-5/abstract) [↑](#endnote-ref-14)
15. CANHR Policy Brief, Physician Orders for Life-Sustaining Treatment (“POLST”), Problems and Recommendations <http://www.canhr.org/reports/2010/POLST_WhitePaper.pdf> [↑](#endnote-ref-15)