You Tube Video: <http://www.youtube.com/watch?v=4f0utgWt7a4>

Comments on Futile Care Laws and Policies

by Diane Coleman and Not Dead Yet

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I’m Diane Coleman with Not Dead Yet and comment today to urge NCD to take a leadership role in addressing the problem of futile care laws and policies which allow doctors to deny life-sustaining treatment to people with disabilities who want and need it.

The judgment that a health care treatment is futile may sound like it could be based on an objective scientific medical assessment, but if it were, it would probably fail to meet “medical necessity” criteria and thus not be covered by insurance. The real issue is that futility decisions are too often based on a physician’s subjective quality-of-life judgments. Today, I’d like to focus on a legislative remedy that developed in Oklahoma to prohibit such quality-of-life judgments.

In May 2013, Oklahoma passed the Nondiscrimination in Treatment Act (NITA), which states: “A health care provider shall not deny to a patient a life-preserving health care service the provider provides to other patients, and the provision of which is directed by the patient or [surrogate] . . . on the basis of a view that treats extending the life of an elderly, disabled, or terminally ill individual as of lower value than extending the life of an individual who is younger, nondisabled, or not terminally ill.”[[1]](#endnote-1) I like the sound of that.

The provision has not gone into effect yet, but has already received some pretty intense criticism about which disability rights advocates should be aware.

The Pew Trusts’ *Stateline* reported that “Oklahoma’s ‘Life-Preserving’ Law Raises Questions for Doctors.”[[2]](#endnote-2)

According to the article, Elise Dunitz Brennan, a prominent health care attorney in Tulsa, said she fears doctors will now refuse to inform patients or their proxies of the true risks of some … procedures for fear of being seen as violating the law.

These criticisms are misleading and specious. Disclosures of the potential risks and benefits of medical treatment are required for informed consent and could never violate the Oklahoma provision. Only actions denying desired health care could do so.

Another critic is Professor Thaddeus Pope, who wrote about the Oklahoma law in a piece entitled “Defending Disability Discrimination.”[[3]](#endnote-3)Pope argued that the new law’s “blanket prohibition rests on a limited and inaccurate assumption that considerations of an individual’s disability could never have the possibility of beingrelevant to the appropriateness of medical treatment.  Settled principles of law and ethics have rejected such a proposition for decades.”

Pope gave an example of an institutionalized person with mental illness who allegedly would not be able to handle his medications and other transplant care requirements to be eligible for a transplant. When the individual brought an ADA lawsuit in the matter, the Eighth Circuit dismissed the challenge in a manner “consistent with a uniform pattern in U.S. Courts of denying disability discrimination claims concerning life-sustaining treatment.”

While I can’t claim to be an expert in the case law on disability discrimination in the health care system, I suspect that Pope is right about what the courts have been doing, and it constitutes a life-threatening problem for people with disabilities. I urge NCD to take a leadership role in addressing this critical concern.

1. Nondiscrimination In Treatment Act, <http://www.oklegislature.gov/BillInfo.aspx?Bill=HB1403> [↑](#endnote-ref-1)
2. M Ollove, Oklahoma’s ‘Life-Preserving’ Law Raises Questions for Doctors, *Stateline*, May 16, 2013, <http://www.pewstates.org/projects/stateline/headlines/oklahomas-life-preserving-law-raises-questions-for-doctors-85899476549> [↑](#endnote-ref-2)
3. T Pope, Defending Disability Discrimination, Bioethics.net, May 31, 2013, <http://www.bioethics.net/2013/05/defending-disability-discrimination/> [↑](#endnote-ref-3)