Comments on Futile Care Laws and Policies

by Diane Coleman and Not Dead Yet

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I’m commenting today to continue to urge NCD to take a leadership position in addressing the problem of so-called futile care laws and policies which allow doctors to deny life-sustaining treatment to people with disabilities who want and need it. Futile care laws and policies allow doctors to overrule the autonomous health care decision of an individual or their authorized surrogate in favor of treatment.

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) The article quoted a law professor saying, “It’s getting almost to the point that you need a government permit in order to die in this state.”

According to the article, critics say that the law –

*. . . will inhibit doctors from discussing the full range of options to patients near the end of life, raising the likelihood that they will undergo invasive, costly and often futile medical interventions with the pain and risks those procedures entail.*

*While the Oklahoma State Medical Association remained neutral on the final bill, Jennifer Clark, palliative care director at the University of Oklahoma’s School of Community Medicine here, emerged as the leading medical opponent of the legislation.*

*Her concern, she said, is that the law will force doctors to perform surgeries with extremely low chances of success but high risk for death or further harm to patients already in fragile condition. “There are situations where we cannot take that person to surgery because we think it’s certain death, but under this law, we’d have no choice,” Clark said.*

*Palliative care experts fear the new law will prevent doctors from having honest and candid conversations with patients at the end of life to make the medical condition completely clear and the various options and the ramifications of each. 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 of those procedures for fear of being seen as violating the law.*

*“If you try to educate a health proxy about the alternatives, when does it become going against the proxy’s wishes versus trying to provide education?” Brennan said. “This law totally interferes with the collaborative decision-making process.” She said she now would advise her physician clients not to raise objections to risky surgeries if that’s what a patient or proxy wants.*

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 “[t]his 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 stated that, “Even disability rights advocates concede this much,” linking only to the Autistic Self-Advocacy Network’s policy brief against disability discrimination in organ transplantation.[[4]](#endnote-4)  While a person’s disability could conceivably involve a medical factor that is relevant to organ transplant eligibility, the overarching point of the ASAN policy brief is that it is a violation of federal nondiscrimination laws to deny transplant eligibility simply based on the fact that an individual has a disability.

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. Implicitly, Pope also accused the institution of being unable to manage his medications, and generally ignored any concept of support services for medication management in or out of a community setting. Pope concluded that the “discrimination was justified” and noted that, when the individual brought an ADA lawsuit in the matter, the Eighth Circuit agreed 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 what they have been doing 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)
4. A Ne’eman, et al., Organ Transplantation and People with I/DD: A Review of Research, Policy and Next Steps

 <http://autisticadvocacy.org/2013/03/asan-releases-policy-brief-on-organ-transplant-discrimination/> [↑](#endnote-ref-4)