

Testimony in Opposition of HB 1135

Presented before the Colorado House Public Health Care and Human Services Committee Public Hearing

Friday, February 6, 2015

Good morning Madam Chairperson, and members of the committee,

My name is Carrie Ann Lucas. I am here today on behalf of Not Dead Yet and the Center for Rights of Parents with Disabilities. I am 43 years old, and I live in and work in Windsor. I am a disabled woman, a mother, an attorney and a business owner. I am a parent to four children with disabilities, two of whom are dependent on medical technology to live. I and the organizations I represent are opposed to HB 1135.

I am a person with multiple disabilities. I have a progressive neuromuscular disease that has caused me to lose muscle function throughout my entire body. I have weakness in every muscle in my body, including my facial and eye muscles. My organs are affected, I have low vision, and I am very hard of hearing. I have a gastrostomy tube, and I am dependent on a ventilator to breathe. Without my ventilator, I don't have years to live. I don't have 6 months, 6 weeks, or 6 days, I have hours. I have a terminal condition – very much like ALS, and I would be covered by this bill. I understand the sponsors have said this bill is not for the disabled, but respectfully Ms. Ginal, you are incorrect. This bill directly affects me, my family and my community.

If I were to become depressed, either situational depression, or major depression, and this bill passes, I could go to my doctor and ask for a lethal prescription. Because I have a disability, and because physicians are terrible at evaluating quality of life of people with disabilities, I would likely be given that lethal prescription, rather than be referred for mental health treatment. And if my doctor did not give me the lethal prescription, I could simply doctor shop until I found one who would. A woman in my situation but without my disabilities would not get a lethal prescription, and would most likely encounter a vigorous effort to ensure she did not take her life. That is disability discrimination.

Webster's defines suicide as action of killing oneself intentionally. That is what this is. Language should be honest. The title of the bill is highly offensive. It suggests my family and friends who have passed were undignified because they did not choose suicide. It suggests that those who rely on attendant care to assist with personal care are undignified. Why do some people equate needing help with basic bodily functions to a loss of dignity? We are not a nation of middle schoolers. There is something wrong with society if people would literally rather die of embarrassment than utilize assistance.

I am expensive to keep alive. I acknowledge that. I have had to fight to ensure that I have access to attendant care to live in the community. I have had to fight insurance denials that refused to pay for my ventilator and other equipment necessary to live. I have had to fight efforts to place a do not resuscitate order in my medical file. In a profit driven healthcare system, just as happened

to Barbara Wagner and Randy Stroup in Oregon, people will die needlessly when insurance companies refuse to pay for necessary medications and equipment, and instead offer to pay for a much cheaper lethal prescription.

I do not want to die, I am not ready to die. I do not want to be driven towards death by a system that devalues my life. I have a lot of living to do. I have four children who depend on me being alive. I have dozens of clients who rely on me as their lawyer. This bill affects me and my community, and I ask that you vote against this bill.