Testimony of

Ms. Diane Coleman

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Introduction

Personal History

Mr. Chairman, Vice-Chairman, members, thank you for the opportunity to address this Subcommittee. My name is Diane Coleman. I have a Juris Doctorate and Masters in Business Administration from the University of California at Los Angeles, and am a member of the California bar, on inactive status. During the last twenty-four years, I have been employed first as an attorney for the State of California, then as Co-Director of an assistive technology center in Nashville, Tennessee, and now I am the Executive Director of Progress Center for Independent Living in Forest Park, Illinois, a nonprofit nonresidential service and advocacy center operated by and for people with disabilities.

I have had a neuromuscular disability since birth, and have used a motorized wheelchair since the age of eleven. From 1987 through 1995, I volunteered as a national organizer for ADAPT, also known as the American Disabled for Attendant Programs Today. I continue to advocate, speak and guest lecture on long-term care issues within Illinois.

When I was six years old, my doctor told my parents that I would not live past the age of 12. A few years later, the diagnosis changed and so did my life expectancy. Over time, I learned that respiratory issues would probably develop. I have friends who've used nighttime ventilators for years, so I knew what symptoms to watch for, and four years ago, started using a breathing machine at night. I had two other friends, one in her 30's and one in her 50's, who needed the same thing. But their doctors discouraged them from it, reinforcing their fears, and either didn't know or didn't disclose what the medical journals said would happen as a result. At an early age, they each went into respiratory distress, and died within a month from infections. A number of my other friends have been pressured by hospital employees to sign do-not-resuscitate orders and other advance directives to forego treatment, coupled with negative statements about how bad it would be if they became more disabled. Frankly, I'm becoming worried about what might happen to me in a hospital if I have a heart attack or other medical crisis. I have appointed my health care proxy, but will the decisions I have entrusted to him be followed by my health care providers? I am not at all convinced that decisions to live are any longer treated with the same respect by health care providers as decisions to die. In fact, I am sure they are not.

Not Dead Yet

Ten years ago, I was on my way to testify before the House Constitution Subcommittee about the opposition to legalized assisted suicide coming from national disability rights organizations. Many of us were worried about Jack Kevorkian, whose body count was 70% people with non-terminal disabilities, and we were worried about two Circuit Courts declaring assisted suicide a constitutional right. Kevorkian even had a legal defense fund provided by the Hemlock Society, later renamed "End-of-Life Choices" and now merged with "Compassion in Dying" to form "Compassion and Choices." In 1996, disability activists had begun to think that we needed a street action group like ADAPT to address the problem (see www.adapt.org), and it was actually the head of ADAPT, Bob Kafka, who thought of our name, taken from a running gag in Monty Python and The Holy Grail, "Not Dead Yet." From our viewpoint, assisted suicide laws would create a dangerous double standard for society's response to suicidal expressions, an unequal response depending on one's health or disability status, with physicians as gatekeepers. That sounds like deadly discrimination to us and, frankly, we've been disappointed that the U.S. Dept. of Justice didn't use our civil rights law, the Americans With Disabilities Act, instead of the Controlled Substances Act, to challenge the Oregon assisted suicide law. Like other minority groups, we feel that discrimination is best addressed on the federal level, and states rights have too often meant states wrongs.

The Problem of the Culture War

The first thing I want to emphasize is that I'm sick and tired of the hypocrisy on both sides of the culture war in this debate.

During the primary election campaigns this year, I still heard of candidates using the Schiavo case to fuel the culture war. My personal hero during that crisis has been conveniently forgotten. Senator Tom Harkin raised the legitimate concerns of people with disabilities. In a press conference held on March 18, 2005, he said:

Where there is a genuine dispute as to what the desires of the incapacitated person really are, then there ought to be at the end some review by a federal court outside of state jurisdiction. You might say, 'Why a federal court?' State courts vary in their evidentiary proceedings and in their process -- fifty different ones. . . . Every review of that, up through the state courts, is basically on the procedure, not upon the first facts. In a case like this, where someone is incapacitated and their life support can be taken away, it seems to me that it is appropriate -- where there is a dispute, as there is in this case -- that a federal court come in, like we do in habeas corpus situations, and review it and make another determination.

I'm sick and tired of our opponents on this issue, often our liberal or progressive allies on other issues, who over simplify the dangers facing disabled people who depend on others for basic needs. Court appointed and statutory guardians have potential conflicts of interest. The most common are the spouse and adult child, who are also the most common perpetrators of elder abuse. If we were talking about child abuse, everyone would admit that there is a legitimate role for government intervention, carefully balanced against privacy rights. Do people in guardianship deserve less? Nor can we trust state courts as the final word. If we were talking about death penalty cases, most would admit that the courts are far from infallible, and that a right of federal review is an important protection for the constitutional rights of the accused. Do people in guardianship deserve less?

I'm also sick and tired of our allies on this issue, often our conservative opponents on other issues, who see assisted suicide and euthanasia as violating their principles, but see no contradiction as they slash budgets for the health care we need to survive. The Republican Governor of Missouri has cut Medicaid funding for feeding tubes and ventilators, establishing a difficult procedure to get these devices, with most who try to use it reportedly failing to get what they need. Jeb Bush just cut Medicaid coverage for the food that goes in the feeding tube by adding similar burdensome procedures. The irony is not lost on us, but media exposure in Florida put this action on hold. This is nothing less than back door euthanasia. And let's face it, much of the struggle at the state level flows from federal cuts. Back door euthanasia.

Disability rights groups have a unique perspective, informed by both our principles and our experiences. Our principles embrace non-discrimination, civil rights and self-determination. Our collective experiences include monumental struggles against the crushing oppression of a health care system that devalues us and a society that fears significant disability as a fate worse than death. We are consumers on the front lines of the health care system, facing your worst fears with grace and dignity, yet we have been pushed to the margins and even excluded outright from the debate on these issues.

I am sick and tired of our opponents who claim that Not Dead Yet represents only a few. Twenty six national disability groups strongly questioned the use of conflicted evidence to justify Terri Schiavo's euthanasia by starvation and dehydration. Since then, thirty-seven organizations have adopted a Statement of Common Principles, affirming the civil and constitutional rights of people with disabilities, whatever our age or type of disability, but especially those under the decision-making authority of a third party.

I am even more sick and tired of our opponents who falsely claim that Not Dead Yet is a puppet of the Christian right, or funded by pro-life groups (which our bylaws prohibit). One blogger, Working For Change columnist Bill Berkowitz, recently claimed that our attorneys on our three Schiavo amicus briefs were "foot soldiers" of the religious right and funded by conservative foundations. But our attorneys never received a penny for their services on behalf of Not Dead Yet and the 16 national disability rights groups that joined our briefs, and these attorneys work for a prominent disability rights organization in Chicago, Access Living.

Why are our opponents so intent on misleading people about who we are? Perhaps they think that is the best way to stop people from hearing what we have to say. We will never be silenced. But who will question the simplistic rhetoric and decide to listen?

The topic of this hearing is broad, and could include five areas of concern to us: assisted suicide, passive euthanasia based on a surrogate's decision to withhold treatment, passive euthanasia based on a physician's decision to withhold treatment (aka futility judgments), active euthanasia, and denial of health care by a health plan or government insurer (aka back door euthanasia).

Assisted Suicide

What's It Got To Do With Disability?

Assisted suicide is supposedly about terminal illness, not disability, so many question the legitimacy of disability groups "meddling" and trying to "take away" what they see as the general public's right to choose assisted suicide, some say when they're terminally ill, others say when they're suffering. The stated criteria vary between Compassion and Choices and Final Exit Network, among others, and some people switch group affiliations and eligibility criteria depending on the audience.

The disability experience is that people who are labeled "terminal," based on a medical prediction that they will die within six months, are -- or will become -- disabled.

The real issue is the reasons people ask for assisted suicide. Although intractable pain has been sold as the primary reason for enacting assisted suicide laws, it's really a "bait-and-switch" situation. The reasons doctors actually report for issuing lethal prescriptions are the patient's "loss of autonomy," "loss of dignity" and "feelings of being a burden."

Those feelings often arise when a person acquires physical impairments that necessitate relying on other people for help in tasks and activities formerly carried out alone. Those are disability issues. In a society that prizes physical ability and stigmatizes impairments, it's no surprise that previously able-bodied people equate disability with loss of dignity.

Studies of patient attitudes toward assisted suicide and euthanasia confirm that "[p]atients' interest in physician-assisted suicide appeared to be more a function of psychological distress and social factors than physical factors." "When patients ask for death to be hastened," another study concluded, "the following areas should be explored: the adequacy of symptom control; difficulties in the patient's relationships with family, friends, and health workers; psychological disturbances, especially grief, depression, anxiety, ..." And another study exploring psycho-social factors provided the following analysis:

The desire for euthanasia or assisted suicide resulted from fear and experience of two main factors: disintegration and loss of community. These factors combined to give participants a perception of loss of self. . . . Symptoms and loss of function can give rise to dependency on others, a situation that was widely perceived as intolerable for participants: "I'm inconveniencing, I'm still inconveniencing other people who look after me and stuff like that. I don't want to be like that. I wouldn't enjoy it, I wouldn't, I wouldn't. No, I'd rather die."

Participants frequently used the notion of dignity to describe the experiences associated with disintegration: . . ."You've become a bag of potatoes to be moved from spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors' appointments or wheeled in a wheelchair, and it really does take away any self-worth, any dignity, or any will to continue to live."

. . . Loss of community entailed the progressive diminishment of desire and opportunities to initiate and maintain close personal relationships, owing to loss of mobility, exclusion and alienation by others, and self-isolating actions by participants. . .

Participant: "I think we should all be allowed to die with our dignity intact."
Interviewer: "OK and what do you mean by dignity?"
Participant: "Um, the ability to perform simple things like, you know, going to the bathroom on your own and not through a bag, um, breathing with your own lungs, . . . I used to be somebody, but now, like I mean, you know, I'm no better than like a doll, somebody has to dress me and feed me and I guess it's uh, I don't know how to explain it, really."
These are common words for newly disabled people.
Disability groups, however, object to the implicit claim that any of us need to die to have dignity. Needing help in dressing, bathing and other intimate daily tasks does not rob a person of autonomy and dignity. Unfortunately, popular culture has done virtually nothing to educate the public about how people with severe disabilities actually live autonomous and dignified lives. Our lives are portrayed as tragedies or sensationalized as heroism, but the real life issues and coping styles that most people will need if they live long enough are left out of the picture. No wonder people who acquire disabilities so often see death as the only viable solution.

But studies show that whether or not they are terminally ill, people who ask for assisted suicide or euthanasia usually change their minds.

The Problem of Physicians as Gatekeepers of Assisted Suicide

The disability rights movement has a long history of healthy skepticism toward medical professionals, and there's an established body of research demonstrating that physicians underrate the quality of life of people with disabilities compared with our own assessments. Our skepticism has grown into outright distrust in our profit-driven health care system.

It should be noted that suicide, as a solitary act, is not illegal in any state. Disability concerns are focused on the systemic implications of adding assisted suicide to the list of "medical treatment options" available to seriously ill and disabled people. The Oregon Law grants civil and criminal immunity to physicians providing lethal prescriptions based on a stated claim of "good faith" belief that the person was terminal, acting voluntarily, and that other statutory criteria were met. This is the lowest culpability standard possible, even below that of "negligence," which is the minimum standard theoretically governing other physician duties.

As the Oregon Reports on physician-assisted suicide make clear, the state has not been able to assess the extent of non-reporting or noncompliance with the law's purported safeguards, but only obtains brief interviews with physicians who file their paperwork. There are no enforcement provisions in the law, and the reports themselves demonstrate that non-terminal people are receiving lethal prescriptions. As the Oregonian newspaper stated on March 8, 2005 in "Living with the dying 'experiment,'" examining the case of David E. Prueitt who woke from his assisted suicide after two weeks and did not try again, "The rest of us . . . still need an answer from a system that seems rigged to avoid finding one."

This is the system that controls eligibility for assisted suicide under the Oregon law. Physicians decide who's terminal and who isn't, despite well-known problems with prediction. Physicians decide what "feasible alternatives" to disclose to the individual. I can't help but note, however, that these same doctors have never been required to disclose any financial conflicts of interest they might have in determining what course of treatment to recommend. We're all supposed to take it on faith that no doctor will be influenced by the financial terms of his or her health plan contracts in the information and advice they give. Physicians also decide if the individual's judgment is impaired, if the desire to die seems rational to them.

The Oregon law immunizes physicians from being accountable for each of these decisions.

The reasons doctors actually report for issuing lethal prescriptions are the patient's "loss of autonomy" (86%), "less able to engage in activities" (85%), "loss of dignity" (83%), and "feelings of being a burden" (37%). People with disabilities are concerned that these psycho-social factors are being widely accepted as sufficient justification for assisted suicide, with most physicians not even asking for a psychological consultation (14%) or the intervention of a social worker familiar with home and community based services that might alleviate these feelings. The societal message is "so what?" or "who cares?"

The primary underlying practical basis for the physician's determination that the individual is eligible for assisted suicide is the individual's disabilities and physical dependence on others for everyday needs, which is viewed as depriving them of what non-disabled people often associate with "autonomy" and "dignity," and may also lead them to feel like a "burden." This establishes grounds for physicians to treat these individuals completely differently than a physically able-bodied suicidal person would be treated.

In effect, the Oregon Law gives physicians the power to judge whether a particular suicide is "rational" or not based on his or her evaluation, or devaluation, of the individual's quality of life, and then to actively assist certain suicides based on that judgment. The Oregon Death With Dignity Act authorizes and empowers physicians to discriminate in their response to a patient's expression of the wish to die based on the patient's disability. This should be viewed as a violation of the Americans with Disabilities Act, which prohibits such discrimination.

The Impact of Assisted Suicide Laws on Others

But perhaps the most important question is not whether the rights of the few people who request assisted suicide and get it have been compromised, though that is a concern, but whether legalizing these individual assisted suicides has a broader social impact. Does it matter that a society accepts the disability-related reasons that people give for assisted suicide, declares the suicide rational and provides the lethal means to complete it neatly? Does it harm people who are not deemed eligible for assisted suicide under the current version of the law, but nevertheless experience severe illnesses and newly acquired disabilities as a loss of dignity and autonomy?

To assess that, I think we should look at the fact that Oregon has the fourth highest elder suicide rate in the country. From the disability rights perspective, this is not surprising. In the face of constant social messages over nearly two decades that needing help in everyday living robs one of dignity and autonomy, makes one a burden and justifies state sponsored suicide, maybe Oregon's elders have taken this disgusting and prejudicial message to heart.

What looks to some like a choice to die begins to look more like a duty to die to many disability activists. I have yet to see an article in which the Oregon health authorities who profess concern about the high rates elder suicide rates go so far as to even mention the Oregon Death With Dignity Act, much less examine the social message behind it. From a disability rights perspective, the potential connection seems obvious.

The Erosion of Protections for People in Guardianship

Assisted suicide laws and practices do not stand in isolation, but arise in the context of a larger health care system that also includes substitute decision-making affecting the lives of people who are deemed "incompetent" or not capable of making and communicating their own decisions. Determinations of "incompetence" are made both formally through the courts, and informally, depending on state laws and health care provider policies. A competent individual may direct their future medical care during a potential period of incompetence through the use of an advance directive. An advance directive can specify the medical treatments that an individual would accept or refuse in various circumstances. In addition or in the alternative, an advance directive can designate a substitute or proxy whom the individual trusts to weigh the complex information and factors that may be involved in a specific health care decision.

Health care decisions for people deemed incompetent are generally governed by state laws. Substitute decision-makers may be proxies chosen by the individual while competent, or surrogates appointed according to a priority list established in state law (the list usually beginning with the spouse and ending with the public guardian). Surrogate decisions are supposed to be based on what the individual's wishes would have been, if competent.

However, most states have laws permitting health care providers to avoid compliance with advance directives. When the provider refuses to withhold or withdraw treatment the patient doesn't want (a rarity these days), these provisions are referred to as "conscience clauses" and usually require some effort to transfer the patient to another provider. When the provider refuses to provide desired care (common these days), these provisions are called "futile care" policies.

Several court cases have arisen from family disputes involving people who became incompetent without executing an advance directive. Before the well-known case of Terri Schiavo in Florida, there was the case of Robert Wendland in California. Both Mr. Wendland's wife and mother agreed that he was not in a "persistent vegetative state," and that he had not left clear and convincing evidence of his wishes. Nevertheless, his wife argued that she should be able to remove his tube feeding anyway. A state statute, based on a national model health care decisions code, gave her the right to starve and dehydrate him even if he had expressly requested food, and forty-three bioethicists filed a friend of the court brief in agreement, under the authorship of Jon Eisenberg.

Ten disability rights organizations filed in support of the mother's view, and against the general presumption that no one would want to live with his disabilities, which was being used to justify lowering constitutional protections of his life. Ultimately, the California Supreme Court agreed that Mr. Wendland's life could not be taken without clear and convincing evidence of his wishes. Unfortunately, this ruling was issued three weeks after he died from pneumonia, having been deprived of antibiotics.

By the time the Schiavo case reached major national attention in 2003, twenty-six national disability organizations had taken a position that Terri Schiavo should receive food and water, due to the highly conflicting evidence of her wishes and the fact that she had not chosen her own guardian. We were deeply disturbed to see court after court uphold questionable lower court rulings. This time, Jon Eisenberg and 55 bioethicists supported the removal of food and water. Disability rights groups were also disturbed that the court allowed most of Terri Schiavo's rehabilitation funds to be spent on her husband's lawyers, that she was denied a properly fitted wheelchair, a swallowing test and therapy, the potential for oral feeding, speech therapy, and the freedom to leave the hospice with her parents, even temporarily. Despite media reports to the contrary, the autopsy report was not inconsistent with a finding that she was in a minimally conscious state and could have benefited from these things. And we were concerned that adult protective services did not intervene, and the state protection and advocacy agency tried but proved powerless.

It would appear that the prevalent prejudice that no one would want to live like Terri Schiavo translated into her guardian's unfettered right to treat her at best as a prisoner, at worst as though she was already dead. Too many of us have been told by someone that he or she could not stand to live the way we are. Too many of us have been forced into institutions and locked away.

Nevertheless, the perspectives of such prominent national groups as The Arc of the United States (formerly the Association for Retarded Citizens), the National Spinal Cord Injury Association, the National Council on Independent Living, and many others were consistently ignored by most of the press, as well as the courts.

Unfortunately, the anecdotal evidence suggests that Terri Schiavo's case may be the tip of a very large and almost fully submerged iceberg. I've been a health care advocate for a couple decades, often joining street protests against government health cuts. One mission of the end-of-life care movement is a good one, to educate health care providers about how to provide good palliative care, but another mission is to shape public policy on health care. It appears that a certain line of thought in bioethics has pretty much taken over the policy-making work. This line of thought involves a lifeboat approach, deciding who gets thrown out.

This week, I received a phone call from a woman with three children and an ex-husband who died Sunday. She had found Not Dead Yet on the internet. Her ex-husband, age 35, had been in a car wreck on April 2nd. She said that he had been on a ventilator until two weeks ago, but had been weaned from it. She described ways in which he seemed to be slowly improving in responsiveness. But from the beginning, the doctors in Peoria, Illinois, had urged the man's mother and all of his family to withhold treatment. Last Thursday, they finally persuaded his mother to remove his food and fluids. Had he survived until Monday, a lawyer was set to go into court and argue that the mother should not have been guardian due to alcoholism and other factors that made her susceptible to pressure, but too late. I'm getting too many calls like this from people being pressured.

For the last three decades, mainstream bioethicists have told the press and the public that euthanasia is about "compassionate progressives" versus the "religious right" and have equated their proposals with "patient autonomy" and the "right to die". Nevertheless, these bioethicists are actually talking about the legal parameters for statutory guardians and health care providers to medically end the lives of people with disabilities, especially cognitive disabilities, on a discriminatory, non-voluntary and involuntary basis. Based on their well-funded policy work, it often takes more documentation to dispose of our property than to dispose of our lives. This affects people with brain damage resulting from birth injuries, accident or trauma, strokes and dementia, and other causes.

One of the leaders of the end-of-life care movement, Dr. Ira Byock, was interviewed by Ragged Edge Magazine, a leading disability rights publication. He stated that Partnership for Caring and Last Acts, national leaders in the movement until they disappeared under a cloud late in 2004, had excluded the disability perspective, and that this exclusion was "deliberate and irresponsible." What's especially disturbing is that they had fifteen years and hundreds of millions in funding from prominent foundations, and set up surrogate decision-making protocols to end the lives of people with intellectual disabilities, without seeking the input of such individuals and the established organizations that address issues of self-determination for people who have less typical ways of receiving, processing and communicating information.

What might other disability groups have brought to the discussion table?

There are many journal articles about the problems with advanced directives. A consistent finding in several funded studies is that people change their minds about what treatments they want, and what level of disability they will accept, as they move through the experience of having increasing disabilities. The disability community has a response to that, to use a popular phrase, "well, duh."

And you may have seen reports of an Alzheimer's study in 2004. It confirmed previous studies that caregivers have a lower opinion of their relative's quality of life with Alzheimer's than the persons themselves have, and found an explanation for the discrepancy. The caregivers project their own feelings about the burden of care-giving onto the person they care for. Once again, the disability community response is "well, duh." And these are the very caregivers who make life-ending decisions.

Policies on removal of food and water have serious and far-reaching implications. Many people in nursing homes are on feeding tubes not because they cannot eat orally, but because there are not enough staff to help them eat. One study also found that in for-profit nursing homes, African-Americans with dementia are taken off hand feeding and put on a feeding tube sooner in the disease process than their white counterparts. Abracadabra, the individual is then on "life support," the kind that can be removed by a third party decision-maker.

Another key issue for protection of people in guardianship is the problem of state guardians, who may have an inherent conflict of interest due to the state's role in Medicaid. The Kentucky Supreme Court ruled in 2004 that a public guardian may deprive life sustaining treatment from a man labeled mentally retarded, despite the financial conflict of interest for a state guardian of a ward on Medicaid. Another state guardian case involved Haleigh Poutre, an 11-year-old girl in Massachusetts who was allegedly beaten into a coma by her stepfather and whom the state wanted to remove from life support earlier this year. The resulting legal dispute bought a little time. The court agreed to remove life support, but by then Ms. Poutre defied physician pronouncements, woke up and was transferred to rehabilitation.

Futility

Now, increasingly, another type of third party medical decision threatens older and disabled people, decisions by physicians in open opposition to the patient, their surrogate or their advance directive, i.e. futility. A big part of many futile care policies is an Ethics Committee that holds meetings to persuade the family that they should agree with the doctor and thereby avoid the potential for litigation. This was the strategy suggested in a 1999 article in the Journal of the American Medical Association. But if the doctor can't convince the surrogate to withhold treatment, then they may overrule the surrogate.

Futile care policies provide that a doctor may overrule a patient or their authorized decision-maker in denying wanted life-sustaining treatment. Futile care policies do not generally require that the treatment be objectively futile, but allow doctors to use subjective criteria such as quality of life judgments as grounds for denying treatment.

Studies consistently demonstrate that physicians and other health care providers rate the quality of life of people with significant disabilities and illnesses significantly below the individual's rating of their own quality of life. These health care providers may also be financially penalized for providing too much health care (contracts call it "over-utilization"). We've learned that lawyers rarely take wrongful death cases involving people with significant illnesses, because damages are generally calculated based on lost earnings, and cause of death may be hard to prove. So there's very little protection for consumers with expensive needs.

Recently, a Texas futility case received some media attention.

Andrea Clark, a conscious heart surgery patient in Houston was sentenced to die before her time in Texas under its "Futile Care" statute. An "ethics committee" told her family that life support would be removed ten days after they were given notice. The Texas law allows the ethics committee to give only 48 hours notice for a meeting, but HIPAA allows providers 72 hours before medical records must be provided to the family. Both before her surgery and when not drugged into unconsciousness afterward, Ms. Clark herself made her wishes in favor of treatment very clear. She had reportedly been declared terminal five years earlier and repeatedly survived her predicted demise. Through massive efforts, including protests and legal wrangling, the hospital relented and Ms. Clark spent an extra week with her family, including her 23-year-old son, before she died. But why did her family have to fight for her wishes to be honored?

Disability rights leader Bob Kafka said of the Texas law, "The essence of the futility law embraces involuntary euthanasia. The ability of a doctor to overrule both the patient and their surrogate in withdrawing life-sustaining treatment is a violation of the principle of patient autonomy. This law can't be fixed, it needs to be killed - or euthanized."

Active Euthanasia

My colleague Dr. Carol Gill, a disabled psychologist, delivered a keynote address at a 2001 conference, sponsored by Neiswanger Institute for Bioethics and Health Policy, at Loyola University of Chicago. She detailed the events leading up to the death of her mother-in-law, who had become increasingly disabled over a seven year period, and lived in an assisted living facility. A duaghter was the woman's guardian. The mother was hospitalized after a stroke. Though she had not had a swallowing test, the mother was on a feeding tube. At one point, the guardian/daughter and doctor withheld feeding for four days without the agreement of the rest of the family, but mother kept asking for ice cream, so they relented. But by then she was weakened, and soon seemed to be nearing the end of her life. One morning, the daughter asked the doctor to get it over with, so her morphine dose was increased until she died. I thought about Dr. Gill's story when I heard the news about a new law in Colorado.

On April 4th, the Governor signed a bill pushed by the pro-assisted suicide advocacy group, Compassion and Choices. Senate Bill 102 protects doctors and caregivers from being prosecuted under the manslaughter statute for giving palliative care to the terminally ill. According to one of the bill's proponents, "No Colorado physician delivering palliative-care medications has been charged with manslaughter, but many physicians have hesitated to prescribe painkillers to terminally ill patients out of fear of prosecution." Now, I always thought they were afraid of prosecution under drug laws, not manslaughter statutes.

Why didn't they seek immunity from drug laws? What is the motivation for manslaughter immunity? What group besides doctors could be powerful enough to get a statute to protect them from a non-existent problem of prosecution just because they wrongfully deny patients pain relief? How is that that the medical profession is afforded such lack of accountability?

Years ago, Kathryn Tucker of Compassion and Choices wrote about a case involving non-voluntary withholding of food and water, and concluded that "a wide chasm exists between the requirements of Washington state law and medical practice" when it comes to health care decisions. There are two ways to respond to that problem. One is to enhance consumer protection by increasing the accountability of health care providers. The other is to rewrite the laws to correspond to actual practice. This is already being done for surrogacy laws and futility laws. Is the Colorado statute another example of the same phenomenon, ensuring that doctors won't risk prosecution for active euthanasia of people who have agreed to palliative care?

Back Door Euthanasia - Rationing and Budget Cuts

Back before the patient autonomy movement of the 1970's and 1980's, doctors did make all the life and death decisions. Now, some doctors think that patients and their families have gone too far in demanding medical treatment for people who are too old and have advanced chronic health impairments. Some physicians and lawyers think that health care resources need to be rationed, and that physicians know best who should receive health care.

These lifeboat bioethicists seem to think of themselves as progressives, but oddly they never spend much energy on ways to cut unnecessary costs before cutting lives. My sister recently started a new career as a medical assistant at a practice with 25 doctors in Michigan. She said that four days out of five, she doesn't have to buy lunch because it's catered in by pharmaceutical companies. Marketing costs. But rather than spending all that professional brain power on conquering the waste and inhumanity of a profit-driven health care system, these bioethicists are pushing new health care decisions laws to kill disabled people who aren't going to die soon enough for their taste without a little push.

In the face of these developments, the disability rights movement has expertise to bring. But we also have an attitude about disability that diverges from the mainstream, especially the mainstream of bioethics. Frankly, I think that's why we were deliberately excluded from the last decade of policy making conducted off the public radar screen, why the right-wing-left-wing script was so important to these bioethicists, no matter how untrue and exclusionary.

Basically, the bioethicists have warped the palliative care movement into a life-ending movement. They've had hundreds of millions of dollars to work with, and they've used it to build a steamroller that's decimating the civil and constitutional rights of people whose lives are viewed as too marginal to merit support. This affects more than the disability community of today, it affects everyone, directly or through family, sooner or later. A privileged few are making the rules for who lives and who dies, but it's happening behind closed doors and has not been subject to public discussion. The Texas chapter of Not Dead Yet just resigned from a Texas Advance Directives Coalition, calling for just such a public discussion. But this is relevant in all states and at the federal level as well.

If the bioethics debate can't hold up to open public scrutiny, then how can it legitimately determine what our nation's health care policies will be?

While disagreeing with mainstream bioethics, the conservatives have their own way of rationing health care. Instead of basing it on the person's health status, they base it on their economic status. For those who depend on publicly funded health care, especially in this aging society, federal and state budget cuts pose a very large threat.

I can't help but note that much of the power of the end-of-life movement has come from the fact that Medicare did not cover prescription drugs, including pain relievers. It was pure extortion to require people to agree to forego curative treatment in order to get pain relief, and I've been terribly disturbed to see that the new Medicare prescription drug coverage does not include the primary pain relieving medications, continuing the pattern of extortion that forces people to agree to hospice, refuse curative treatment, and accept a potentially premature death in order to receive pain relief.

How Can Federal Legislators Help?

OPEN PUBLIC DISCUSSION

Foster open public discussion of these policies. At this point, people find out about futility when a family member is denied treatment they want. We think that futility policies are unconstitutional, but the wider public needs to know before policy actions can be formulated. And disability rights groups must be included.

MEANINGFUL FEDERAL REVIEW

Under Medicare and Medicaid law, you could provide for meaningful federal review of contested third party decisions to withhold treatment in the absence of an advance directive or personally appointed surrogate. Uphold a clear and convincing evidence standard with teeth in it. Uphold a presumption for food and fluids.

CONGRESSIONAL STUDY

Ever since the Cruzan decision in 1990, people with disabilities, old and young, have been starved and dehydrated based on surrogate or health provider decisions, but we don't know who, why, how or what factors were involved. We also know that physicians are overruling patient autonomy and denying treatment under futility policies. You could ask for all hospitals to send you their futility policies. Congressional examination of the impact of existing policies is necessary.

STATE-BY-STATE REVIEW OF LAWS AND POLICIES

Funding for a disability-rights-based state-by-state review of guardianship and health care decisions laws is needed, along with comprehensive efforts to develop reforms to safeguard against non-voluntary and involuntary euthanasia.

PUBLIC EDUCATION BY PEOPLE WITH DISABILITIES

There should be funding for public education about the perspectives of people living with significant disabilities on the difference between end-of-life decisions and decisions to end the lives of disabled people who are not otherwise dying.

OLMSTEAD IMPLEMENTATION, PASSAGE OF MICASSA

The civil rights of people with disabilities to long-term supports in the community under the U.S. Supreme Court decision in Olmstead should be implemented. We call for passage of the Medicaid Community Attendant Services and Supports Act, which would allow people receiving Medicaid funding to have a life in the community instead of being forced into a nursing home. This bill also includes consumer-directed options that maximize personal responsibility and reduce costs.

SUSTAIN GOVERNMENT FUNDED HEALTH CARE PROGRAMS

Conservatives who honestly supported efforts to protect the life of Terri Schiavo should work on a bipartisan basis with moderates and liberals to ensure continued appropriate funding of Medicare and Medicaid.

Conclusion

To conclude, regardless of our abilities or disabilities, none of us should feel that we have to die to have dignity, that we have to die to be relieved of pain, or that we should die to stop burdening our families or society. Cognitive abilities must not be allowed to determine personhood under the laws of the United States. Reject the script you have been given by the right to die and the right to life movements. Instead, listen to the disability rights movement. We are your advance guard, in anticipation of the aging of our society, with decades of experience in living with disability and on the front lines of the health care system. We offer a very different vision, as well as the practical know-how and leadership to help build a society that respects and welcomes everyone.