Assisted Suicide Laws

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Introduction

Thanks much, Diane.

Like Diane, I'd like to speak for a while and then open it up for Q&A; please hold your questions until then. If you have questions before then, do write them down!

SLIDES 1, 2, 3

Here at DRLIB, we are looking at many issues where our perspective is at serious risk of being lost in the tumult of other views and interests in society. The legalization of assisted suicide may be one of the biggest ones that come up as proposals for major public policy change, regularly and often.

By which I mean, there are bills, initiatives, and lawsuits to legalize assisted suicide in at least a few states, sometimes more, every year. Almost all are defeated. Some come close to becoming law, and rarely, but sometimes, one does, in fact, become law, I hate to say.

So, did you figure out yet which side we're on? [laughter]

While many people know that Oregon, Washington State, and Vermont have legalized assisted suicide, it is less well known that approximately half the states in the U.S. have either defeated bills to legalize it, or have passed laws explicitly banning it.

What they've banned—what assisted suicide, when legalized, is—and it's not easy to say simply—is making it legal for a doctor (generally speaking, a doctor), to prescribe lethal drugs (often thought of as an easy-to-swallow single pill, but actually not so, at all—it's an onerous to do), to someone who, theoretically, is terminally ill and requests it. It alters long-standing state laws that, in essence, say it is illegal for anyone, a doctor or anyone else, to take an action to cause a death.

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In many cases, the bills or referenda are defeated due to the efforts of an opposition coalition spanning the political spectrum from left to right. These coalitions typically represent disability rights organizations, physicians and other health care workers, hospice organizations, and Catholics and other right-to-life organizations. In some cases, they also include organizations representing the Latino community, poor people, and workers.

And quite a few highly-recognized national disability rights organizations are on record in opposition, include ADAPT, several independent living organizations including the National Council on Independent Living or NCIL, the Autistic Self-Advocacy Network or ASAN, DREDF (where I work), the National Council on Disability, of course Not Dead Yet, and the World Institute on Disability.

The opposition to the legalization of assisted suicide is often mischaracterized as driven exclusively by religious conservatives, but most current opposition coalitions include many people and organizations whose opposition is based on their progressive politics.

Other key opponents to legalizing assisted suicide include the American Medical Association—that's the AMA—and its state affiliates, the World Health Organization, the American College of Physicians, the National Hospice and Palliative Care Organization, the American Cancer Society, and the League of United Latin American Citizens (or LULAC). Many prominent Democrats and liberals also oppose legalization, including Bill Clinton, Ralph Nader, and noted civil liberties journalist Nat Hentoff.

Supporters focus on superficial issues of choice and self-determination. It is crucial to look deeper. Legalizing assisted suicide would not increase choice and self-determination, despite the assertions of its proponents. It would actually augment real dangers that negate genuine choice and control. More on that later.

When we work against assisted suicide proposals, we must, in a way, ask people to separate their private wishes for what many may hope to have available for their individual selves some day—a hope that often fails to understand how assisted suicide actually operates—and, instead, look at the significant dangers of legalizing assisted suicide as public policy in our society as a whole. Assisted suicide would have many unintended consequences.

So, like many issues in disability rights, our view asks people to shift their view from seeing this as a medical issue for an individual—one-by-one, and rather, to see how it affects society—that is, all people.

Polls show that the more the public considers assisted suicide, the less they like it. Ask during Q&A if you want details on that.

Two more introductory thoughts:

1. To effectively defeat proposals to legalize AS, we need to talk about Oregon, which provides proponents their model, and where assisted suicide has been legal since 1997. Because otherwise, proponents will respond to our every argument with, and I quote, "But that problem has not occurred in Oregon." So you will hear a lot about Oregon in this talk.

   It's true that other recent proposals have diverged, usually for the worse. But none solve any of the problems found over the years in Oregon.

2. Also, I won't have time to cover the intense politics of terminology on assisted suicide; feel free to ask about that, too, in Q&A. What I will say is that we use the term "assisted suicide." We don't use the euphemisms of the proponents. There are usually two they use. One is "aid in dying," which could mean anything, including "plumping the pillow and mopping the brow." The other, "death with dignity," is a term that is so offensive on so many levels, we could spend all day!

We, that is, opponents of legalization, have also begun to introduce a different term, which I will use at times today: "doctor-prescribed suicide." Because that's what it is! It means the same thing as assisted suicide.

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Legal Alternatives Available Today

The movement for the legalization of assisted suicide is driven by anecdotes of people who suffer greatly in the period before they die. But the overwhelming majority of these anecdotes describe either situations for which legal alternatives exist today, or situations in which the individual would not be legally eligible for doctor-prescribed suicide.

It is legal now in every U.S. state to receive sufficient palliative care—that is, comfort care, including painkillers—to be comfortable. This is an area where US health care has improved a lot, though not *enough*. And today we know that robustly-prescribed painkillers at the end of life, will not hasten death. Really! That taking lots of painkillers hastens death, is a myth. Look at the "Recommended" reading by Drs. Herbert Hendin and Kathleen Foley — and search for "does not hasten death".

> ("We now know that that proper use of pain medications in patients with chronic pain, as well as patients at the end of life, does not hasten death. Studies have demonstrated that dying patients who received morphine lived longer than those who did not receive

> morphine." Herbert Hendin and Kathleen Foley, "Physician Assisted Suicide: A Medical Perspective," *Michigan Law Review*, June 2008, pp. 1634 – 1635.)

But most important and least understood: for anyone who is dying in pain, it is currently legal in every U.S. state, to receive palliative sedation, which is when the dying person is sedated to unconsciousness, so discomfort is relieved during the dying process, until he or she passes peacefully due to their underlying medical condition, *not due to the sedation*, and not necessarily *withdrawing nutrition or hydration*—depending on the individual.

Knowing about palliative sedation makes a lot of people realize that AS is not necessary.

> ("When all else fails to control patients' pain at the end of life, it is appropriate for physicians to sedate such patients to unconsciousness, according to new ethical policy adopted at the AMA Annual Meeting in June [2008]." [American Medical News, July 7, 2008] But it had been coming as an accepted medical practice for a long time before.)

Thus, there is already a legal recourse for painful deaths that does not raise the serious problems of legalizing assisted suicide.

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Reasons Specifically Related to Disability

But why are we against this seemingly good and merciful thing? I'll start with the objections we have to assisted suicide laws that are specifically about the disability community.

There are many other reasons as well, reasons that affect everyone.

Today I will go over both the key disability-related reasons, and the general reasons that ALSO affect the disability community very directly, even though the word "disability" may never be used when giving the argument.

Diane laid the basis for many of our concerns that are directly disability-related, including the Bouvia and McAfee cases (the "Give me liberty or give me death" cases), and the prejudice about quality of life: health care workers have a great difference in their view of our quality of life, than we do!

So there are many reasons related directly to the disability community, but for me, here are the 4 biggest ones we haven't already talked about.

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1. Suicide Prevention or Suicide Assistance?

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In a stunning and very original analysis, our own Diane Coleman wrote:

The "public image of severe disability as a fate worse than death … become[s] grounds for carving out a deadly exception to longstanding laws and public policies about suicide intervention services [by intervention, we're talking about suicide prevention services. That's me talking, now back to Diane] … Legalizing assisted suicide means that some people who say they want to die will receive suicide intervention, while others will receive suicide assistance. The difference between these two groups of people will be their health or disability status, leading to a two-tiered system that results in death to the socially devalued group."

SLIDE 9 & 10

I will read this while we look at the graphic:

This cartoon shows a wheelchair user in front of a Suicide Prevention Program with many steps up to the door. But around the corner, there's a wheelchair ramp leading to another door labeled "Assisted Suicide."

Created, by the way, by Amy Hasbroucke.

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2. Consider the Netherlands

Doctor-prescribed suicide began to be legally tolerated in the Netherlands in the early 70s. Let me quote Dr. Herbert Hendin, an international expert on suicide prevention:

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"The Netherlands has moved from assisted suicide to euthanasia [meaning lethal injections, so, something the doctor does, not something the individual does], from euthanasia for the terminally ill to euthanasia for the [long-term] chronically ill, from euthanasia for physical illness to euthanasia for psychological distress and from voluntary euthanasia to nonvoluntary and involuntary euthanasia. Once the Dutch accepted assisted suicide it was not possible legally or morally to deny more active medical [assistance to die], i.e. euthanasia, to those who could not effect their own deaths. …

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… Nor could they deny assisted suicide or euthanasia to the chronically ill who have longer to suffer than the terminally ill or to those who have psychological pain not associated with physical disease. To do so [was seen as] a form of discrimination. Involuntary euthanasia [that is, when the person has not asked for it] has been justified as necessitated by the need to make decisions for patients not [intellectually] competent to choose for themselves."

Though our country often resists learning any lessons from outside our borders, there is much to be learned. The Netherlands shows the slide toward broadening so-called strict restrictions on assisted suicide.

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3. Terminal Illness Prognosis – A Fundamental Loophole

(This one is really both disability-related and general)

The Oregon and Washington laws are based on the faulty assumption that it is possible to make a clear distinction between those who are terminally ill with six months to live, and everyone else. Everyone else is supposedly protected and not eligible for doctor-prescribed suicide.

But it is extremely common for medical prognoses of a short life expectancy to be wrong. Studies overwhelmingly indicate how many errors are made, often predicting death when people may live for decades.

This situation can lead people to give up on treatment and lose good years of their lives.

[MG then asked these questions of the audience:]

- How many of you have had a terminal prognosis? **[Quite a few raised hands]**
- How many of you long outlived it? **[Quite a few raised hands]**
- For how long have you outlived it? **[Varying periods including "decades"]**
- And how many of you *know someone* who long outlived a terminal prognosis? **[The great majority of participants]**

Let's talk about Jeanette Hall of Oregon, who was diagnosed with cancer in 2000 and told she had six months to a year to live. She knew about the assisted suicide law, and asked her doctor about it, because she didn't

want to suffer. Her doctor encouraged her not to give up, and ultimately she decided to fight the disease. Jeanette had both chemotherapy and radiation. It is now [about] 14 years later, and Jeanette wrote in a letter to the editor, "I am so happy to be alive! If my doctor had believed in assisted suicide, I would be dead. I thank him and all my doctors for helping me… Assisted suicide should not be legal."

(from Jeanette Hall letter to the editor - http://articles.boston.com/2011-10-04/bostonglobe/30243525_1_suicide-doctor-ballot-initiative)

But not all doctors are like Jeanette Hall's.

All this poses considerable danger to people with new or progressive disabilities or diseases, who may often be misdiagnosed as terminally ill but who in many cases outlive these prognoses by years or even decades.

Research overwhelmingly shows that people with new disabilities frequently go through initial despondency and suicidal feelings, but later adapt well and find great satisfaction in our lives. However, the adaptation usually takes considerably longer than the mere fifteen-day waiting period required by many assisted suicide proposals and the Oregon and Washington laws.

In that early period before one learns the truth about how good one's quality of life can be, it would be all too easy, if doctor-prescribed suicide is legal, to make the final choice, one that is irrevocable.

Here is the story of Dr. Richard Radtke, my friend and colleague, also a well-known academic oceanographer from Hawaii, who finally passed away in 2012. Richard had a very disabling form of muscular sclerosis for over 30 years. In the period after onset of the disease, doctors often classified him as terminally ill. He experienced severe depression for two years. Had assisted suicide been legal, he acknowledges that he would have chosen it, and died long before.

Notwithstanding his extremely limiting disability, he had a successful academic career, was a happily married father, and in retirement, was the president of a charitable foundation. He was very grateful for his long, varied life. How many people like Richard Radtke is our society prepared to sacrifice as collateral damage from the legalization of assisted suicide?

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4. Danger to People with Depression and Psychiatric Disabilities

Doctors are very often unable to diagnose depression – yet psychological assessments not required by assisted suicide laws, and even when they occur, they're defined as a single visit. Moreover, a doctor who thinks a patient should receive lethal drugs can "shop" for a psychologist or psychiatrist who will make a finding the doctor agrees with.

"A request for assisted suicide is … usually made with as much ambivalence as are most suicide attempts. If the doctor does not recognize that ambivalence as well as the anxiety and depression that underlie the patient's request for death, the patient may become trapped by that request and die in a state of unrecognized terror."

> (Dr. Herbert Hendin, 1996. "Suicide, Assisted Suicide and Euthanasia: Lessons From the Dutch Experience.," Testimony. U.S. House of Representatives, Committee on the Judiciary, Oversight Hearing, April 29.)

Most cases of depression among terminally ill people can be successfully treated. Yet primary care physicians are generally not experts in diagnosing depression. Where assisted suicide is legalized, the depression remains undiagnosed, and the only treatment consists of a lethal prescription.

Some of you may have read about Michael Freeland, who had a 40-year history of acute depression but received lethal drugs in Oregon. When provided high-quality medical and social services, his desire for doctor-prescribed suicide vanished.

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QUESTIONS / DISCUSSION

BREAK FOR LUNCHEON BANQUET

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There are many other reasons that impact everyone - they also impact people with disabilities heavily, but may never use the word "disability" when you explain them …

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The Myth of Free Choice and Self-Determination

Assisted suicide proponents have a mantra: free choice and self-determination. But in reality, legalizing doctor-prescribed suicide actually diminishes individual choice and control. Particularly in situations of family dis-harmony and abuse.

As Margaret Dore, an elder law specialist in Oregon, has pointed out, the assisted suicide laws in OR and WA state, on which every policy proposal we see are based, allow an heir who will benefit from the patient's death, to help the patient sign up for the lethal dose.

Once the lethal dose is issued by the pharmacy, there is no oversight. No witness is required when the lethal drugs are taken. Let's say the patient changes her mind, or isn't ready. Someone else putting the lethal dose in the patient's feeding tube or IV nutrition bag, cannot be prevented. The abuser can apply an alternate method, like suffocation. Even if the patient struggled, who would know? Her lethal dose request would provide an alibi.

There is also danger that people choose assisted suicide due to external pressure. Elderly individuals who don't want to be a financial or caretaking burden on their families, for example. The percentage of reported Oregon cases attributed to patients' reluctance to burden their families has risen shockingly, from 12 percent in 1998, to 45 percent in 2007.

Nothing in these laws protect patients when family pressures, whether financial or emotional, distort the ill person's choice.

The impact of pressures to choose assisted suicide was illustrated when Rob Miller, Director of the pro-assisted suicide group Compassion & Choices of Washington, commented on the death of Linda Fleming, the first reported death under Washington State's assisted suicide law. When asked if he knew that Fleming, who was divorced, had had financial problems, had been unable to work due to the new onset of a disability, and was forced to declare bankruptcy in 2007, Miller said he was unaware of all that, but that her case presented "none of the red flags" that would cause his organization to reconsider supporting her suicide request.

> (William Yardley, *First Death for Washington Assisted-Suicide Law*, New York Times, May 22, 2009, www.nytimes.com/2009/05/23/us/23suicide.html?_r=1&scp=2&sq=linda+fleming&st=nyt)

Also very troubling is widespread elder abuse in the U.S. The perpetrators are often family members. Such abuse could easily lead to pressures to "choose" assisted suicide.

> (The National Elder Abuse Incidence Study (NEAIS) was conducted by the National Center on Elder Abuse at the American Public Human Services Association. It showed that, in one year in the 90s, 450,000 elders age 60 and over were abused, according to a study of observed cases. In almost 90 percent of the elder abuse and neglect incidents with a known perpetrator, the perpetrator was a family member, and two-thirds of the perpetrators were adult children or spouses. The study was updated recently with similar, shocking numbers.)

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Deadly Mix

“Deadly mix” - Deadly combination of legalizing doctor-prescribed suicide and our broken, profit-driven health-care system in the U.S.

The cost of the lethal medication generally used for assisted suicide used to be $300; in any case, well under $1000, far cheaper than the cost of treatment for most long-term medical conditions. The incentive to save money by denying treatment already poses a significant danger. The danger is far greater where assisted suicide is legal.

Direct coercion is not even necessary. If insurers deny or even merely delay approval of life-sustaining, expensive health care treatment, many individuals might be steered toward hastening their deaths.

Once doctor prescribed suicide becomes a medical treatment – it’s the cheapest one. Do we think profit driven health insurers will do the right thing, or the cheap thing?

Barbara Wagner and Randy Stroup, Oregonians with cancer, were both informed by the Oregon Health Plan that the Plan wouldn’t pay for their chemotherapy, but would pay for their assisted suicide. Though called a free choice, for these patients, assisted suicide was a phony form of freedom.

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I will read this while we look at the graphic:

And just to show we’re not the only ones this notion has occurred to, here’s a cartoon of a health care executive at a desk, commenting to a colleague, in letters probably too small to read, “We’re able to hold down healthcare costs through assisted suicide.”

A related problem I’ll call *legal erosion* of patient protections. The death of Wendy Melcher in 2005 occurred when two nurses, Rebecca Cain and Diana Corson, gave Melcher large overdoses of morphine and phenobarbital. They claimed that she had requested assisted suicide, but they administered the drugs without her doctor’s knowledge, in clear violation of the law. Yet no criminal charges were filed against the two nurses. Proponents of assisted suicide argue that this case has no connection to it. But it is a strong indication of the erosion of public protections that come with assisted suicide. The case prompted the newspaper, the Oregonian, to write, “If nurses—or anyone else—are willing to go outside the law, then … the protections built into [Oregon's] Death with Dignity Act are for naught.”

Supporters of doctor-prescribed suicide frequently make the claim that where it is legal, there is no longer any underground practice of assisted suicide. No documentation is ever offered to support this claim. But Melcher's death suggests the exact opposite. It appears that underground assisted suicide is thriving in Oregon, due to the breakdown in legal rules and codes of conduct that elsewhere protect medical patients, a breakdown that may be an inevitable by-product of assisted suicide's legalization.

I won't give all the documentation now – but it's in the readings. Including a study about how health care in Oregon got worse, not better, after the assisted suicide law passed!

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Other Failures of "Safeguards" in the Oregon Law

One of the myths about assisted suicide in Oregon is that it is highly regulated and has strong safeguards. We've already examined quite a few of those failed safeguards. Here are more.

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Doctor Shopping

Shopping for another doctor can get around any so-called safeguards.

Take the example of Kate Cheney, an elderly woman with cancer whose doctor said "no" to her request for lethal drugs due to her increasing dementia and concern about pressure from Cheney's adult daughter. But the family found another doctor and Kate Cheney soon died.

(By the way, the law does not require doctors experienced in end-of-life care; two botox dermatologists could start a clinic for doctor-prescribed suicide.)

But it gets worse. It's common knowledge in Oregon that if your doctor says NO to your request for the lethal agent, call the organization Compassion & Choices—they are the boosters, the ideological supporters of legalization—and they will refer you to doctors who don't *say* "no."

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See how a few doctors have prescribed the vast percentage of Oregon's reported assisted suicides. Dr. Peter Goodwin, Compassion & Choices'

former Medical Director, said that about 75 percent of those who died using Oregon's doctor-prescribed suicide law through the end of 2002, did so with the organization's assistance. In 2003, the organization was involved in 79 percent of reported assisted suicide deaths.

And "in 2008 the proportion of C&C PAS deaths increased to 88 percent (53/60) of all [OPHD] reported deaths."

> (Dr. Ken Stevens, *The Proportion of Oregon Assisted Suicides by Compassion & Choices Organization*.)

As long as we're on that organization, Compassion & Choices, well, there's a lot in a name, but this particular name is held by the same organization that, before a number of mergers and splits, used to be called "The Hemlock Society." The thing they're best at is PR.

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"Good faith" Standard

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The Oregon and Washington State laws legalize negligence by doctors via the "good faith" provision, which states that no practitioner will be liable if they act in good faith, something nearly impossible to disprove, which makes all the other safeguards effectively unenforceable.

For everything else doctors do, they are liable if they are negligent. But with doctor-prescribed suicide, even if negligent, practitioners cannot be found violating the law, as long as they practice in good faith.

(Again, credit to Amy Hasbroucke for the slide)

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Minimal Data And Fatally Flawed Oversight

Oregon's annual reports on their assisted suicide statistics, highly praised by proponents as informative, actually tell us very little. In reality, we don't know what is happening under the Oregon law.

A. ***Reporting requirement lacks teeth.*** Doctors who fail to report to the state that they prescribed lethal drugs, face no penalty. Though reporting is required on paper, no investigations take place to ensure the reports are made.

B. ***Non-compliance is not monitored.*** The Oregon Public Health Division (OPHD) does not monitor underreporting, noncompliance, or violations. Many of Oregon's reports clearly acknowledge that the State cannot confirm compliance with the law.

C. ***Important questions go unasked.*** For example, the State does not talk to doctors who **denied** requests to prescribe lethal drugs for patients, nor to families. These doctors who first said "no" may have viewed the patients as not meeting legal requirements, important information if one wishes to evaluate the law's outcomes. **Nor** does the state talk to families.

D. ***No investigation of abuse.*** The State has no resources or even authority to investigate violations. All the abuses we've discussed, such as Michael Freeland, Kate Cheney, and Wendy Melcher, only the media have brought them to light—not an oversight body whose job it should be.

E. ***No autopsies.*** Autopsies are not required, opening the door to another Dr. Kevorkian, most of whose victims were **not** terminally ill

• How many, pardon my language, old-timers, are here who fought against what Dr. Jack Kevorkian was doing?

F. ***Underlying data is destroyed annually.*** Most egregious of all, the State of Oregon has acknowledged that after each annual report is published, the underlying data is destroyed, so no outside party can conduct objective research. Now, that is not required by their law—but for whatever reason, they've admitted they do it.

Doctor-prescribed suicide is practiced in Oregon in secret and without oversight. In this lax context we must assume that any abuses that come to light are the tip of the iceberg.

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The Political Landscape

Final Exit Network

In addition to what we've already talked about, the political landscape in the US today includes several groups such as Final Exit Network (FEN). Instead of working to legalize doctor-prescribed suicide, they skirt laws against it, helping individuals one-by-one to kill themselves, with things like plastic bags over the head, and if the individual changes their mind and resists, the FEN volunteers hold their hands down.

There have been some prosecutions of people in these groups for violating laws against assisted suicide.

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ACLU

Another thing to know is that the American Civil Liberties Union (or ACLU), our friend on many issues, has not been our friend on this one. On the state level, they are usually pro-legalization.

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Cross-Constituency Coalitions

Before we end (and see a great little movie), a word about working in cross-constituency coalitions against proposals to legalize assisted suicide (another name for the same thing would be multi-constituency coalitions). For example, I've worked for years in "Californians Against Assisted Suicide." Similar coalitions have worked well in many states now.

I want to address some possibly-controversial political realities—the elephant in the room.

I'm not asking anyone to identify themselves—no need to raise hands—but here are a few thoughts for those of you who consider yourselves liberals or somewhere on the left. (While not universal, I think most disability rights advocates in the US, do identify that way.)

A lot of us are surprised, and sometimes uneasy, to find that some of our allies in working against legalization are right-to-life groups, and other organizations that are faith-based. We're "strange bedfellows," as the saying goes.

It's important to remember all the groups that also oppose legalization: the AMA, the League of United Latin American Citizens; groups in the political center. Thus, our coalition spans the political spectrum from right to left. The centrist groups are often forgotten; the media ignore them; and disability advocates are alleged to be somehow under the misleading influence of the Catholic Church, or a tool of the right wing (I've been doing this work for 15 years, and I know no disability advocates who are tools of the right wing).

Other times, we are simply ignored by the media. In some states, it requires great persistence to get our opposition taken seriously; to get the reporters out of their stereotypes and ruts.

All these things can be challenges. Yet, even so, most of the time, the only way to successfully beat back proposals to legalize assisted suicide is our ability to form multi-constituency coalitions, where each group leaves its views on other issues outside the door, and come together to work on one thing: opposing the legalization of assisted suicide.

Short Movie

OK, your reward for being a wonderful, patient group is a short animated movie by none other than our filmmaker, Norm Kunc! It's called "Euthanasia at the Water Cooler."

http://youtu.be/zqrqWkxMhmw

OR

www.youtube.com/watch?v=zqrqWkxMhmw&feature=youtu.be