Disability Rights Toolkit for Advocacy Against Legalization of Assisted Suicide

"If this bill passes, some people's lives will be ended without their consent, through mistakes and abuse. No safeguards have ever been enacted or proposed that can prevent this outcome, which can never be undone."

– Marilyn Golden, Disability Rights Education & Defense Fund

Introduction

The purpose of this Toolkit is to give disability rights advocates an organized set of resources to assist in defeating proposals to legalize assisted suicide in state legislatures. The Toolkit is divided into seven brief sections, each consisting of basic information and links to related resources with more information. The seven sections are:

1. Why disability advocacy groups oppose legalizing assisted suicide
2. Educating and organizing disability opposition
3. Meeting with legislators and policy leaders
4. Testifying at hearings
5. Working with the media
6. Conducting direct actions – leafleting, rallying
7. Working in coalition

All of the major national disability groups that have taken a position on assisted suicide oppose bills to legalize the practice as a matter of public policy. The disability role in defeating these bills has increased in visibility and importance in the last few years as both media and various stakeholders have acknowledged our effectiveness. It is critical that our voice be heard wherever assisted suicide bills are introduced and considered.

1. Why disability advocacy groups oppose legalizing assisted suicide

Proponents of legal assisted suicide for the terminally ill frequently claim that the opposing views of disability organizations aren't relevant. Nevertheless, although people with disabilities aren't usually terminally ill, the terminally ill are almost always disabled. People with disabilities and chronic conditions live on the front lines of the health care system that serves (and, sadly, often underserves) dying people. One might view us as the "canaries in the coal mine," alerting others to dangers we see first, but, unlike the canary, we loudly object to being seen as expendable.

A. Background:

Not Dead Yet initially formed in 1996 to help articulate a disability rights critique of proposals to legalize assisted suicide. Some of our initial observations, issues and concerns are as valid today as they were in the early years,[1] some even more so:

Suicide v. Assisted Suicide

It should be noted that suicide, as a solitary act, is not illegal under any state's statutes. 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.

Physicians Are Assisted Suicide Gatekeepers

Anyone could ask for assisted suicide, but physicians decide who gets it. Physicians must predict, however unreliably, whether a person will die within six months. Physicians judge whether or not a particular request for assisted suicide is rational or results from impaired judgment.

Disability is the Issue

Although intractable pain has been emphasized as the primary reason for enacting assisted suicide laws, the top five reasons Oregon doctors actually report for issuing lethal prescriptions are the "loss of autonomy" (91%), "less able to engage in activities" (89%), "loss of dignity" (81%), "loss of control of bodily functions" (50%) and "feelings of being a burden" (40%). *(Death With Dignity Act Annual Reports)* These are disability issues.

We Don't Need To Die to Have Dignity

In a society that prizes physical ability and stigmatizes impairments, it's no surprise that previously able-bodied people may tend to equate disability with loss of dignity. This reflects the prevalent but insulting societal judgment that people who deal with incontinence and other losses in bodily function are lacking dignity. People with disabilities are concerned that these psycho-social disability-related factors have become widely accepted as sufficient justification for assisted suicide.

Physicians Misjudge Quality of Life

In judging that an assisted suicide request is rational, essentially, doctors are concluding that a person's physical disabilities and dependence on others for everyday needs are sufficient grounds to treat them completely differently than they would treat a physically able-bodied suicidal person. There's an established body of research demonstrating that physicians underrate the quality of life of people with disabilities compared with our own assessments. Nevertheless, the physician's ability to render these judgments accurately remains unquestioned. Steps that could address the person's concerns, such as home care services to relieve feelings of burdening family, are not explored. In this flawed world view, suicide prevention is irrelevant.

Broad Agenda, Incremental Strategy, Not Just for the Terminally Ill

The political agenda of many assisted suicide organizations includes expansion of eligibility to people with incurable but not necessarily terminal conditions who feel that their suffering is unbearable, without examining the cause of the suffering or whether it can be alleviated.

Health Care Cuts Severe

For seniors and people with disabilities who depend on publicly funded health care, federal and state budget cuts pose a very large threat. Many people with significant disabilities, including seniors, are being cut from Medicaid programs that provide basic help to get out of bed, use the toilet and bathe.

Involuntary Denial of Care

Most people are shocked to learn that futility policies and statutes allow health care providers to overrule the patient, their chosen surrogate or their advance directive and withhold desired life-sustaining treatment. With the cause of death listed as the individual's medical conditions, these practices are occurring without meaningful data collection, under the public radar.

Window Dressing Safeguards, Immunity Law for Physicians

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 and acting voluntarily. This is the lowest culpability standard possible, even below that of "negligence," which is the minimum standard theoretically governing other physician duties. The Oregon Health Division does not investigate the reports filed by doctors who issue lethal prescriptions.

Disability Discrimination

Legalized assisted suicide sets up a double standard: some people get suicide prevention while others get suicide assistance, and the difference between the two groups is the health status of the individual, leading to a two-tiered system that results in death to the socially devalued group. This is blatant discrimination.

Unacceptable Losses

Disability is at the heart of the assisted suicide debate. Some people fear disability as a fate worse than death. Proponents of legalized assisted suicide are willing to treat lives ended through assisted suicide coercion and abuse as "acceptable losses." We are not.

B. Where We Are Today

Assisted suicide advocates paint themselves as "compassionate progressives," fighting for freedom against the religious right. That simplistic script ignores inconvenient truths that are all too familiar to disability advocates, such as:

- Predictions that someone will die in six months are often wrong.
- People who want to die usually have treatable depression and/or need better palliative care.
- Pressures to cut health care costs in the current political climate make this the wrong time to add doctor-prescribed suicide to the "treatment" options.
- Abuse of elders and people with disabilities is a growing but often undetected problem, making coercion virtually impossible to identify or prevent.

Despite the frequent claim that Oregon's experience has disproven the concerns of opponents of the Oregon law, the Oregon Reports as well as independent news reports and journal articles show otherwise:

- People who are not within six months of dying are getting lethal prescriptions.
- Depression is not identified or treated (only 6% have been referred for a psychological consult).
- People have been denied prescribed medical treatments by insurers but offered assisted suicide as an alternative.
- About half of the assisted suicide deaths in Oregon did not have a health provider present at the time of death, so there is no evidence of self-administration of the lethal dose or consent in those cases.

Because assisted suicide is such a controversial topic, discussions can often turn into debates. A short cartoon video by disability activist Norm Kunc captures some of the flavor of such discussions:

Euthanasia at the Water Cooler

In order to be well prepared for debate on the issue, and even just to answer one's own questions about the various key arguments, it is a good idea to become familiar with the kinds of information and resources that have been compiled by the Disability Rights Education & Defense Fund (DREDF). Everything on DREDF's public policy page on assisted suicide is useful, but the following short items are especially important:

- Article by elder law attorney Margaret Dore: What do we advise our clients?
- DREDF's Key Objections to the Legalization of Assisted Suicide
- Oregon: So-called Safeguards & Minimal Data
- Dr. Gregory Hamilton article on the particular dangers to people with psychiatric disabilities and depression
- Some Oregon and Washington State Assisted Suicide Abuses and Complications

The key arguments against legalizing assisted suicide can be summarized as follows:

- **Deadly mix:** Assisted suicide is a deadly mix with our profit-driven healthcare system. At $300, assisted suicide will be the cheapest treatment. Assisted suicide saves insurance companies money.
- **Abuse:** Abuse of people with disabilities, and elder abuse, are rising. An heir or abusive caregiver may steer someone towards assisted suicide, witness the request, pick up the lethal dose, and even give the drug — no witnesses are required at the death, so who would know?
- **Mistakes:** Diagnoses of terminal illness are too often wrong, leading people to give up on treatment and lose good years of their lives.
- **Careless:** No psychological evaluation is required. People with a history of depression and suicide attempts have received the lethal drugs.
- **Pressure:** Financial and emotional pressures can also make people choose death.
- **Unnecessary:** Everyone already has the right to refuse treatment and get full palliative care, including, if dying in pain, pain-relieving palliative sedation.
- **No true safeguards:** The safeguards are hollow, with no enforcement or investigation authority.
- **Our quality of life underrated:** Society often underrates people with disabilities' quality of life. Will doctors & nurses fully explore our concerns and fight for our full lives? Will we get suicide prevention or suicide assistance?

For a longer and thoroughly referenced article, structured with a very helpful table of contents, DREDF Senior Policy Analyst Marilyn Golden's Why Assisted Suicide Must Not Be Legalized is excellent.

2. Educating and organizing disability opposition

Similar to most members of the general public, many disability advocates have only heard the assisted suicide debate as conveyed through the lens of the media, limited by sound bites and other constraints. Disability rights leaders in each state are needed to educate and organize our community, ensuring that people with disabilities, as well as family members and professionals, have the tools to work effectively in opposing assisted suicide bills.

To introduce advocates to the issue, an article in an organizational newsletter can be a good start. Feel free to use "Why Do Disability Rights Organizations Oppose Assisted Suicide Laws?" or contact Not Dead Yet about reprinting one of the published op-eds linked on our website. The handouts listed in Section 1 above are also excellent educational resources. In addition, a leaflet summarizing the key arguments above is available.

Well-informed disability advocates are important to organizing disability opposition by:

- Enabling disability organizations to take formal positions opposed to assisted suicide proposals.
- Enabling disability advocates to communicate effectively to policy makers, media and the general public.

Disability organizations and advocates can obtain assistance from Not Dead Yet and DREDF in educating members, consumers, staff and board by emailing dcoleman@notdeadyet.org, jkelly@notdeadyet.org or mgolden@dredf.org.

If disability advocates in your state want to form a disability organization to help carry the message, two approaches have been taken: a) establish a state Not Dead Yet group such as Not Dead Yet Colorado, or b) establish a state Second Thoughts group such as Second Thoughts (Massachusetts) or Second Thoughts Connecticut. The name "Second Thoughts" reflects the notion that assisted suicide laws may sound like a good idea at first, but on second thought, the dangers of mistake and abuse are too great.

3. Meeting with legislators and policy leaders

A critical process throughout a state's consideration of an assisted suicide bill is individual meetings with legislators and other key policy makers. Disability organizations should not be new to this, considering the work that so many do to resist budget cuts and other policy changes that threaten great harm to people with disabilities.

As with many disability issues, there's potential for bipartisan support of our position. However, the partisan trend on assisted suicide runs the reverse of most of our issues. This makes our perspective all the more critical in the debate.

To help disability advocates convey our perspective, DREDF has developed a legislative briefing booklet which we encourage advocates to print and distribute to legislators:

A Progressive Case Against Assisted Suicide Laws

Most assisted suicide bills use the same language as the Oregon assisted suicide law, with some variations and exceptions. Information and analyses of some specific state bills can be found at http://www.patientsrightscouncil.org/site/ and http://www.choiceillusion.org.

4. Testifying at hearings

Legislative committee hearings are an important opportunity to communicate the reasons for disability rights opposition to assisted suicide laws. When disability advocates are able to describe personal experiences that relate to the reasons for opposing these laws, the effect can be both powerful and persuasive.

For example, one advocate in Massachusetts spoke about being diagnosed with ALS and told how

little time he had to live. Decades later, he is still alive, and grateful that there was no assisted suicide law back at the time that he might have used it and then lost so many good years of life. A disabled geriatric social worker talked about the sad realities of elder abuse and how the so-called "safeguards" in assisted suicide laws cannot protect vulnerable elders from assisted suicide coercion and abuse.

For online examples of testimonies by disability advocates in various states, some are included on the NDY website under "Legislative Efforts." Additional examples are attached to Not Dead Yet Press releases, such as Second Thoughts Massachusetts to Testify against Assisted Suicide Bill H 1998 and Disability Advocates From Not Dead Yet and New Jersey Disability Organizations Testify Against Assisted Suicide Bill Despite Short Notice of Committee Hearing.

5. Working with the media

Assisted suicide is different than many disability issues in that the press often considers it an important subject to cover. There are six primary ways to work with the media:

- Give interviews on camera or by telephone
- Issue media advisories stating your basic position on the issue and availability for interviews, and providing contact information
- Issue press releases describing key activities such as giving testimony, participating in press conferences
- Submit letters to the editor and online comments to stories on the issue
- Write and pitch opinion pieces for the editorial pages of key newspapers
- Meet with editorial boards to urge them to oppose assisted suicide proposals

If you are contacted for an interview, please contact NDY or DREDF (dcoleman@notdeadyet.org, jkelly@notdeadyet.org or mgolden@dredf.org) for helpful tips and relevant updates on the issues.

When speaking with a reporter, who may be focused on an individual story of someone who favors legalizing assisted suicide, remember two key points:

- If you only consider an individual, assisted suicide laws might seem OK—but we must look broadly across society, at all the people who stand to be harmed. And there are many!
- If assisted suicide is legal, some people's lives will be ended without their consent, through mistakes and abuse. No safeguards have ever been enacted, or even proposed, that can prevent this outcome, which can never be undone.

Hopefully, you will have the chance to go into greater depth with reporters about the significant dangers, risks, and harms that concern us. Assisted suicide is a unique issue that breaks typical ideological boundaries and requires us to consider those potentially most vulnerable in our society—those who bear risks that are not well understood by the general public. E.g.:

- There's a deadly mix between our profit-driven health care system and legalizing assisted suicide, which will be the cheapest so-called treatment. In insurers deny, or even merely de-

lay, expensive live-saving treatment, the person will be steered toward assisted suicide. Will insurers do the right thing, or the cheap thing? Direct coercion is not even necessary.

- A similar thing happens to people with disabilities, who have often been denied treatment and care that we need, because our lives are undervalued, or people think we're better off dead. Our community is keenly aware of these dangers.

- Elder abuse, and abuse of people with disabilities, are a rising problem. Where assisted suicide is legal, an heir (someone who stands to inherit from the patient) or abusive caregiver may steer someone towards assisted suicide, witness the request, pick up the lethal dose, and even give the drug — no witnesses are required at the death, so who would know?

- Diagnoses of terminal illness are too often wrong, leading people to give up on treatment and lose good years of their lives.

- Financial and emotional pressures can also make people choose death.

- There are no real safeguards; for example, for people with depression and psychiatric disability. Michael Freeland, with a 40-year history of major depression, got lethal drugs in Oregon. Do we want death on demand for anyone, regardless of the risk?

- For anyone dying in discomfort, palliative sedation is legal in all 50 states, providing comfort from pain at the time of death. The patient is sedated to the point where the discomfort is relieved while the dying process takes place. Thus, today there is a legal solution to any remaining painful and uncomfortable deaths; one that does not raise the very serious hazards of legalizing assisted suicide.

- Assisted suicide bills are defeated when people learn the facts. In 2014, they failed in Massachusetts, New Hampshire, and Connecticut.

It should also be emphasized that arguments that refer to religious principles or "pro-life" concerns are counterproductive with a general audience and media. While other groups may articulate those arguments, they are not part of the disability rights framework. When disability advocates have raised those arguments along with the other concerns, reporters have tended to focus only on the "culture war" issues, which fits the narrative promoted by pro-assisted suicide organizations. The talking points above are more consistent with a disability rights analysis.

Some of the key dangers of legalizing assisted suicide are summarized in a short leaflet. It's often helpful to have this leaflet or a similar short summary with you during an interview. For additional information, updates and tips in preparing for a press interview, please email dcoleman@notdeadyet.org, jkelly@notdeadyet.org or mgolden@dredf.org. In addition:

a) Make sure the media outlet reporter has your name, and any title and organization affiliation you may want to use, as well as your e-mail address and phone number.

b) Record for your records the reporter's name, which media outlet they're from, and their e-mail address and phone number.

c) Ask them at the beginning or end of the interview, to please e-mail you a link to the story, when it appears.

The NDY website contains examples of:

- Media advisories and press releases
- Op-eds (opinion pieces)
- Press coverage quoting disability advocates

Media advisories and releases can be distributed through professional services such as PRWeb or PRNewswire for a fee, or by email or fax to a distribution list that advocates develop locally. Press contacts for submitting letters to the editor and opinion pieces are usually posted online by each publication.

Most of these activities require an advocate to be well versed on the issue. Consulting the materials in Section 1 above is critical. Disability organizations and advocates can obtain additional guidance from Not Dead Yet and DREDF in working with media by emailing dcoleman@notdeadyet.org, jkelly@notdeadyet.org or mgolden@dredf.org.

6. Conducting direct actions – leafleting, rallying

Sometimes direct action strategies are useful. Proponents of assisted suicide may conduct public gatherings to discuss the issue, but it is all too common for them to say that their only or primary opposition comes from the religious right. They ignore or minimize the opposition of physician organizations, hospice and palliative care organizations and disability rights organizations. Disability advocates can download and peacefully distribute a leaflet at such events to counter that false message.

Other forms of direct action are possible, depending on the skills and experiences of the disability group involved. Sometimes these strategies are also initiated by other groups that oppose these bills. Not Dead Yet has experience with a variety of types of direct action and strongly advises careful consultation with NDY leaders before considering these strategies in the context of state assisted suicide proposals. (Contact dcoleman@notdeadyet.org or jkelly@notdeadyet.org.)

7. Working in coalition[2]

Disability advocates in several states have now had experience working in cross-constituency coalitions against proposals to legalize assisted suicide (another name for the same thing would be multi-constituency coalitions, or single-issue coalitions).

Many of us, as disability advocates, 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, and to remind the media and the general public, about all the groups that also oppose legalization: the American Medical Association, the National Hospice and Palliative Care Organization, the League of United Latin American Citizens; all groups in the political center. Thus, the 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 influence of the Catholic Church, or a tool 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 we come together to work on one thing: opposing the legalization of assisted suicide.

Conclusion

The perspective of the disability rights organizations and advocates that oppose legalization of assisted suicide are an essential part of the public debate, in keeping with the fundamental principle, "Nothing About Us Without Us!" By using this Toolkit and the related resources and links, disability advocates can bring our wisdom to the public debate and, if we are successful, protect the lives of all who are endangered by the public policies that assisted suicide proponents would enact.

[1] Not Dead Yet Disability Activists Oppose Assisted Suicide As A Deadly Form of Discrimination

[2] Adapted from DREDF Senior Policy Analyst Marilyn Golden's remarks at the Disability Rights Leadership Institute on Bioethics.