DREDF

DISABILITY RIGHTS EDUCATION & DEFENSE FUND

Why Assisted Suicide Must Not Be Legalized

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Prologue

In 1999, faced with a bill in the California legislature to legalize assisted suicide, the Disability Rights Education and Defense Fund (DREDF) joined ten other nationally prominent disability organizations in adopting a position against the legalization of assisted suicide and euthanasia.[1] (see sidebar)

The 1999 California bill went down to defeat, due in part to an opposition coalition spanning the political spectrum from left to right. That coalition represented disability rights organizations, workers, poor people, physicians and other health-care workers, hospice organizations, Catholics, and right-to-life organizations. The opposition to legalization of assisted suicide is often mischaracterized as composed of religious conservatives, but most current opposition coalitions include many persons and organizations whose opposition is based on their progressive politics.

A similar coalition defeated a referendum on the same proposal in Maine in 2000. What happened in Maine is a perfect example of the general public's typical reaction to assisted suicide proposals. Early polls showed strong support, before the general public was educated about the dangers of legalization. As this education occurred, the polls slowly but steadily shifted, with the opposition gaining in each. At the time of the election, polls showed the opposition exceeding the support, and the referendum failed.

Since then, DREDF has worked with similar coalitions in California, Hawaii, and Vermont to defeat the same bill.

The Reasons DREDF Opposes Legalization of Assisted Suicide

Assisted suicide seems, at first blush, like a good thing to have available. But on closer inspection, there are many reasons legalization is a very serious mistake. Supporters often focus solely on superficial issues of choice and self-determination. It is crucial to look deeper.

We must separate our private wishes for what we each may hope to have available for ourselves some day and, rather, focus on the significant dangers of legalizing assisted suicide as public policy in this society as it operates today. Assisted suicide would have many unintended consequences.

- **A very few helped - a great many harmed.**

The movement for legalization of assisted suicide is driven by anecdotes of people who suffer greatly in the period before death. But the overwhelming majority of these anecdotes describes either situations for which legal alternatives exist today, or situations in which the individual would not be legally eligible for assisted suicide. It is legal in every U.S. state for an individual to create an advance directive that requires the withdrawal of treatment under any conditions the person wishes. It is legal for a patient to refuse any treatment or to require any treatment to be withdrawn. It is legal to receive sufficient painkillers to be comfortable, even if they might hasten death. And if someone who is imminently dying is in significant discomfort, it is legal for the individual to be sedated to the point that the discomfort is relieved. Moreover, if someone has a chronic illness that is not terminal, that individual is not eligible for assisted suicide under any proposal in the U.S., nor under the Oregon Death with Dignity Act (Oregon is the only state where assisted suicide is legal). Furthermore, any individual whose illness has brought about depression that affects the individual's judgment is also ineligible, according to every U.S. proposal as well as Oregon's law. Consequently, the number of people whose situations would actually be eligible for assisted suicide is extremely low.

The very small number of people who may benefit from legalizing assisted

Currently, these twelve nationally prominent disability organizations have stated their opposition to the legalization of assisted suicide:

American Disabled for Attendant Programs Today (ADAPT) - ADAPT advocates for the civil rights of people with disabilities, old and young, to receive long term care services in the community instead of being warehoused in nursing homes and institutions.

American Association of People with Disabilities (AAPD) - AAPD is the largest national nonprofit cross-disability member organization in the United States, dedicated to ensuring economic self-sufficiency and political empowerment for the more than 56 million Americans with disabilities.

Association of Programs for Rural Independent Living (APRIL) - APRIL is the national association of centers for independent living, statewide independent living councils, and other organizations working with people with disabilities living in rural areas.

Disability Rights Education and Defense Fund (DREDF) - DREDF is the foremost national law and policy center on disability civil rights in the USA. Founded in 1979, DREDF played a leadership role in the passage of the Civil Rights Restoration Act, the Fair Housing Amendments Act, and the Americans with Disabilities Act.

Justice For All (JFA) - Justice For All and its extensive email network were formed to defend and advance disability rights and programs in the U.S. Congress.

National Council on Disability (NCD) - The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress on issues affecting 56 million Americans with disabilities.

National Council on Independent Living (NCIL) - NCIL is the national association of hundreds of consumer-controlled Centers for Independent Living, non-residential grassroots advocacy and service organizations operated by and for people with disabilities.

National Spinal Cord Injury Association - The National Spinal Cord Injury Association is an international nonprofit organization for people living with spinal cord injury. Their mission is to enable people with spinal cord injuries to make choices and take actions so that they might achieve their highest level of independence and personal fulfillment.

Not Dead Yet (NDY) - NDY is a grassroots disability rights group formed to oppose the movement to legalize assisted suicide and euthanasia.

TASH - TASH is a civil rights organization for, and of, people with mental retardation, autism, cerebral palsy, physical disabilities and other conditions that make full integration a challenge.

World Association of Persons with Disabilities (WAPD) - WAPD advances the interests of persons with disabilities at national, state, local and home levels.

World Institute on Disability (WID) - WID is an international public policy center dedicated to carrying out cutting-edge suicide will tend to be affluent, white, and in possession of good health insurance coverage. At the same time, large numbers of people, particularly among those less privileged in society, would be at significant risk of harm.

research on disability issues and overcoming obstacles to independent living. It was founded by Ed Roberts, the "father" of the independent living movement.

Source: Not Dead Yet Website, with updates from NDY staff in a personal interview, March 26, 2003.

• Managed care and assisted suicide - a deadly mix.

Perhaps the most significant problem is the deadly mix between assisted suicide and profit-driven managed health care. Again and again, health maintenance organizations (HMOs) and managed care bureaucracies have overruled physicians' treatment decisions. These actions have sometimes hastened patients' deaths. The cost of the lethal medication generally used for assisted suicide is about $35 to $50, 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. This danger would be far greater if assisted suicide is legal.

Assisted suicide is likely to accelerate the decline in quality of our health care system. A 1998 study from Georgetown University's Center for Clinical Bioethics underscores the link between profit—driven managed health care and assisted suicide. The research found a strong link between cost—cutting pressure on physicians and their willingness to prescribe lethal drugs to patients, were it legal to do so. The study warns that there must be "a sobering degree of caution in legalizing [assisted suicide] in a medical care environment that is characterized by increasing pressure on physicians to control the cost of care" (Sulmasy et al., 1998).

The deadly impact of legalizing assisted suicide would fall hardest on socially and economically disadvantaged people who have less access to medical resources and who already find themselves discriminated against by the health care system. As Paul Longmore, Professor of History at San Francisco State University and a foremost disability advocate on this subject, has stated, "Poor people, people of color, elderly people, people with chronic or progressive conditions or disabilities, and anyone who is, in fact, terminally ill will find themselves at serious risk" (Longmore, 1999).

Rex Greene, M.D., Medical Director of the Dorothy E. Schneider Cancer Center at Mills Health Center in San Mateo, California and a leader in bioethics, health policy and oncology, underscored the heightened danger to the poor. He said, "The most powerful predictor of ill health is [people's] income. [Legalization of assisted suicide] plays right into the hands of managed care."[2]

Supporters of assisted suicide frequently say that HMOs will not use this procedure as a way to deal with costly patients. They cite a 1998 study in the *New England Journal of Medicine* that estimated the savings of allowing people to die before their last month of life at $627 million. Supporters argue that this is a mere .07% of the nation's total annual health care costs. But significant problems in this study make it an unsuitable basis for claims about assisted suicide's potential impact. The researchers based their findings on the average cost to Medicare of patients with only four weeks or less to live. Yet assisted suicide proposals (as well as the law in Oregon) define terminal illness as having *six months* to live. The researchers also assumed that about 2.7% of the total number of people who die in the U.S. would opt for assisted suicide, based on reported assisted suicide and euthanasia deaths in the Netherlands. But the failure of large numbers of Dutch physicians to report such deaths casts considerable doubt on this estimate. And how can one compare the U.S. to a country that has universal health care? Taken together, these factors would skew the costs much higher (Rowen, 1999).

• Fear, bias, and prejudice against disability.

Fear, bias, and prejudice against disability play a significant role in assisted suicide. Who ends up using assisted suicide? Supporters advocate its legalization by arguing that it would relieve untreated pain and discomfort at the end of life. But *all but one* of the people in Oregon who were reported to have used that state's assisted suicide law during its first year wanted suicide *not* because of pain, but for fear of losing functional ability, autonomy, or control of bodily functions (Oregon Health Division, 1999). Oregon's subsequent reports have documented similar results. Furthermore, in the Netherlands, more than half the physicians surveyed say the main reason given by patients for seeking death is "loss of dignity" (Birchard, 1999).

This fear of disability typically underlies assisted suicide. Said one assisted suicide advocate, "Pain is not the main reason we want to die. It's the indignity. It's the inability to get out of bed or get onto the toilet ... [People] ... say, 'I can't stand my mother – my husband – wiping my behind.' It's about dignity" (Leiby, 1996). But as many thousands of people with disabilities who rely on personal assistance have learned, needing help is not undignified, and death is not better than reliance on assistance. Have we gotten to the point that we will abet suicides because people need help using the toilet?

Diane Coleman, President and Founder of Not Dead Yet, a grassroots disability organization opposed to legalizing assisted suicide, has written that 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 … 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" (Coleman, 2002).

• Undiagnosed depression underlies requests for assisted suicide.

Suicide requests from people with terminal illness are usually based on fear and depression. As Herbert Hendin, M.D., Medical Director of the American Foundation for Suicide Prevention and a leading U.S. expert on suicide, stated in Congressional testimony in 1996, "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" (Hendin, 1996).

Most cases of depression among terminally ill people can be successfully treated.[3] (U.S. Catholic Conference, 2001). 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.

- **Supposed safeguards are illusory.**

Assisted suicide proposals and Oregon's law 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 assisted suicide. But it is extremely common for medical prognoses of a short life expectancy to be wrong. Studies show that only cancer patients show a predictable decline, and even then, it's only in the last few weeks of life. With every disease other than cancer, there is no predictability at all (Lamont, 1999; Maltoni, 1994; Christakis and Iwashyna, 1998; Lynn, 1997). Prognoses are based on statistical averages, which are nearly useless in predicting what will happen to an individual patient. Thus, the potential effect of assisted suicide is extremely broad, far beyond the supposedly narrow group its proponents claim. The affected group could include many people who may be mistakenly diagnosed as terminal but who have many meaningful years of life ahead of them.

This also poses considerable danger to people with new or progressive disabilities or diseases. 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 their lives (Harris, 1986; Gerhart, 1994; Cameron, 1994; Ray and West, 1984; Stensman, 1985; Whiteneck, 1985; Eisenberg and Saltz, 1991). However, the adaptation usually takes considerably longer than the mere two week waiting period required by assisted suicide proposals and Oregon's law. People with new diagnoses of terminal illness appear to go through similar stages (New York State Task Force, 1994). 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 assisted suicide is legal, to make the final choice, one that is irrevocable.

- **Other alleged safeguards.**

Neither do other alleged safeguards offer any real protections. In Oregon's law and similar proposals, physicians are not permitted to write a lethal prescription under inappropriate conditions that are defined in the law. This is seen as a "safeguard." But in several Oregon cases, suicidal patients engaged in "doctor shopping." When the first physician each of these patients approached refused to comply with the request for assisted suicide because the patient didn't meet the conditions of the law, the patient sought out another physician who agreed. The compliant physicians were often assisted suicide advocates. Such was the case of Kate Cheney, age 85, as described in *The Oregonian* in October 1999. Her physician refused to prescribe lethal medication, because he thought the request, rather than being Ms. Cheney's free choice, actually resulted from pressure by her assertive daughter who felt burdened with care giving. So the family found another doctor, and Ms. Cheney soon used the prescribed drugs and died.

Another purported safeguard is that physicians are required to discuss alternatives to assisted suicide. However, there is no requirement that these alternatives be made available. Kate Cheney's case exemplifies this. Further, the Kate Cheney case demonstrates the shocking laxness with which safeguards in Oregon are being followed. Ms. Cheney decided to take the lethal medication after spending just a week in a nursing home, to give her family a break from caretaking. The chronology shows that Cheney felt she had only three choices: burdening her family, the hell of a nursing home, or death.

After reading about the case of Kate Cheney, Diane Coleman of Not Dead Yet sent a letter via the Internet to Dr. Robert Richardson, a physician involved in Cheney's care. It stated, in part:

> In my role as a long term care advocate, I have heard for years of Oregon's claim to operate the most progressive long-term care programs in the country, model programs that emphasize in-home and community based services, even for the most frail elderly. What in-home services was Ms. Cheney receiving? How is it that Ms. Cheney had to spend a week in a nursing home to give her family respite from caregiving? Did Ms. Cheney and her family know of other respite options? If not, who failed to tell them? How can their actions have been based on the informed consent promised in Oregon's law? Or did the family choose the nursing home respite option with the knowledge of other alternatives (an even more disturbing possibility)? What ongoing support options were explored to reduce the daily need for family caregiving? There are many ways to resolve the feeling of being a burden on family, and the family's feelings of being burdened. In what depth were these issues explored? In this context, family relationships are complex, and the emotional dynamics could not realistically be uncovered in a brief consultation.
>
> It appears from the newspaper account, as well as your response to Dr. Hamilton, that these issues were not meaningfully addressed. Ms. Cheney appears to have been given the message that she had three choices - to be a burden on family, to go to a nursing home, or to die. After a week in a nursing home, an experience I wouldn't wish on my opponents except perhaps to educate them, it appears that Ms. Cheney felt she had only one option. How is this a voluntary and uncoerced decision based on informed consent? (Coleman, 2002, p. 226)

Coleman never received an answer from Dr. Richardson.

There *is* one foolproof safeguard in current assisted suicide proposals and Oregon's law - but it is for HMOs and physicians: the "good faith" standard. This "safeguard" provides that no person will be subject to any form of legal liability if they acted in "good faith." The claim of a "good faith" effort to meet the requirements of the law is virtually impossible to disprove. Moreover, this particular provision renders all other "safeguards" effectively unenforceable. Even more alarming, for all other medical procedures, practitioners are liable under a much stronger legal standard, that of negligence. Yet, even if negligent, practitioners of assisted suicide will not be found violating the law, as long as they practice in good faith.

Diane Coleman continues, "…is society really ready to ignore the risks, tolerate the abuse, marginalize or cover up the mistakes, and implicitly agree that some lives - many lives - are expendable, in order to enact a law that immunizes health care providers and other participants in assisted suicide?" (Coleman, 2002, p. 227)

- **So-called "narrow" proposals will inevitably expand.**

Proponents claim that assisted suicide will be narrowly limited to those who are terminally ill, but these so-called "narrow" proposals will inevitably be expanded. The New York State Task Force on Life and the Law wrote in 1997: "Once society authorizes assisted suicide for ... terminally ill patients experiencing unrelievable suffering, it will be difficult if not impossible to contain the option to such a limited group. Individuals who are not (able to make the choice for themselves), who are not terminally ill, or who cannot self-administer lethal drugs will also seek the option of assisted suicide, and no principled basis will exist to deny (it)" (New York State Task Force, 1997).

The longest experience we have with assisted suicide is in the Netherlands, where active euthanasia as well as assisted suicide are practiced. The Netherlands has become a frightening laboratory experiment because assisted suicide and euthanasia have meant that "pressure for improved palliative care appears to have evaporated," according to Herbert Hendin, M.D., in his Congressional testimony in 1996. Hendin was one of only three foreign observers given the opportunity to study these medical practices in the Netherlands in depth, to discuss specific cases with leading practitioners, and to interview Dutch government-sponsored euthanasia researchers. He documented how assisted suicide and euthanasia have become not the rare exception, but the rule for people with terminal illness in the Netherlands.

"Over the past two decades," Hendin continued, "the Netherlands has moved from assisted suicide to euthanasia, from euthanasia for the terminally ill to euthanasia for the 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. 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 would be a form of discrimination. Involuntary euthanasia has been justified as necessitated by the need to make decisions for patients not [medically] competent to choose for themselves" (Hendin, 1996). Hendin describes how, for a substantial number of people in the Netherlands, physicians have ended their patients' lives without consultation with the patients.

U.S. advocates of legalization, attempting to distinguish the Oregon experience from that in the Netherlands, argue that the numbers of reported users of assisted suicide in Oregon are low. But in fact the number of people requesting lethal drugs has grown. In the beginning, the numbers were low in the Netherlands as well, but usage grew along with social acceptance of the practice. There is no reason to believe that legalization in the U.S. would not be followed, in twenty years or more, with the kind of extraordinary growth that has taken place in the Netherlands.

Furthermore, assisted suicide proponents and medical personnel alike have established that taking lethal drugs by mouth is often ineffective in fulfilling its intended purpose. The body expels the drugs through vomiting, or the person falls into a lengthy state of unconsciousness rather than dying promptly, as assisted suicide advocates wish. Such ineffective suicide attempts happen in a substantial percentage of cases. Estimates range from 15% to 25% (JAMA, 1998, p. 512; Humphrey, 1994). The way to prevent these "problems," in the view of euthanasia advocates, is by legalizing lethal injections by physicians - that is, legalizing active euthanasia. This is an inevitable next step if society first accepts assisted suicide as a legitimate legal option.

Assisted suicide proponents tell us that none of these things will happen here. But why not? How can the proponents, or anyone, stop it? If the next step is wrong, then taking this step is tantamount to taking the next step.

- **Claims of free choice are illusory.**

Assisted suicide purports to be about free choice and self-determination. But there is significant danger that many people would take this "escape" due to external pressure. For example, elderly individuals who don't want to be a financial or caretaking burden on their families might choose assisted death. In Oregon's third year Report, "a startling 63% of [reported cases] cited fear of being a ‘burden on family, friends or caregivers' as a reason for their suicide" (United States Conference of Catholic Bishops, 2001).

Also very troubling, research has documented widespread elder abuse in this country. The perpetrators are often family members (National Elder Abuse Incidence Study, 1996).[4] Such abuse could easily lead to pressures on elders to "choose" assisted suicide.

In addition, leaders and researchers in the African-American and Latino communities have expressed their fears that pressures to choose death would be applied disproportionately to their communities (Page, 1999; Montemayor, 1999; Ann Arbor News, 1997; Detroit Free Press, 1997).

Still others would undergo assisted suicide because they lack good health care, or in-home support, and are terrified about going to a nursing home. As Diane Coleman noted regarding Oregon's law, "Nor is there any requirement that sufficient home and community-based long-term care services be provided to relieve the demands on family members and ease the individual's feelings of being a ‘burden' … The inadequacy of the in-home long-term care system is central to the assisted suicide and euthanasia debate" (Coleman, 2002, p. 224).

While the proponents of legalization argue that it would guarantee choice, assisted suicide would actually result in deaths due to a *lack* of choice. Real choice would require adequate home and community-based long-term care; universal health insurance; housing that is available, accessible, and affordable; and other social supports. In a perverse twist, widespread acceptance of assisted suicide is likely to *reduce* pressure on society to provide these very kinds of support services, thus reducing genuine options even further,[5] just as Herbert Hendin observed that widespread use of euthanasia in the Netherlands has substantially decreased pressure there for improved palliative care, by decreasing demand for it (Hendin, 1996).

As Paul Longmore has stated, "Given the absence of any real choice, death by assisted suicide becomes not an act of personal autonomy, but an act of desperation. It is fictional freedom; it is phony autonomy" (Longmore, 1999).

Footnotes

[1] Currently, these twelve nationally prominent disability organizations have stated their opposition to the legalization of assisted suicide:

American Disabled for Attendant Programs Today (ADAPT) - ADAPT advocates for the civil rights of people with disabilities, old and young, to receive long term care services in the community instead of being warehoused in nursing homes and institutions.

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Source: Not Dead Yet Website, with updates from NDY staff in a personal interview, March 26, 2003.

[2] Personal communication, November 1, 2002, based on Mann, 1997.

[3] "There is a consensus among doctors that the vast majority of suicidal wishes among the sick and elderly are due to treatable depression." U.S. Catholic Conference, 2001.

[4] 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 1996, 450,000 elders age 60 and over were abused, according to a study of observed cases. In almost 90% 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.

[5] Laura Remson Mitchell, a public policy analyst, consultant, and writer who specializes in disability and health-care issues, has explored this concept in articles and other writings. Personal correspondence, March 13, 2003.

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