

## *Death with Dignity HB 15-1135*

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Any debate on this contentious issue should involve two distinct categories; that of decision-making as an individual and that of the broad legal, economic and systemic considerations that impact broad groups of people including individuals with disabilities. Most debates are based superficially on individual choice but they ignore the larger issues that impact people who are traditionally discriminated against, particularly in the medical field, which highly values perfection and cures.

These five rationales provide arguments against the Death With Dignity bill.

- 1) Attitudinal fear and bias toward disability is reflected in the medical system, even more so than in society in general,
- 2) A profit driven medical system creates deadly interactions with persons with disabilities,
- 3) The myth of free choice and self-determination is just that, given the lack of choice in living circumstances for many,
- 4) Loopholes exist and are inconsistent in determination of terminal illness prognosis,
- 5) Legal safeguards cannot guarantee compliance with persons with disabilities.

### *National organizations oppose legalization of assisted suicide*

- World Health Organization
- American Medical Association
- American College of Physicians
- National Hospice and Palliative Care Organization
- American Cancer Society
- League of United Latin American Citizens (LULAC)
- ADAPT (American Disabled for Attendant Programs Today) - In place of legalization, we will call for adequate home and community-based long-term care, universal health coverage, and a range of social supports that provide true self-determination for everyone.
- Assn of Programs for Rural Independent Living
- Autistic Self Advocacy Network
- Disability Rights Center

- Arc National - Despite well-intended laws designed to protect people with Intellectual Disabilities, our constituents can be unduly influenced by authority figures such as doctors, health care workers, social workers, family, guardian/conservators, and friends, resulting in a lack of true informed consent.
- Disability Rights Education and Defense Fund/Marilyn Golden – Data suggests that pain is rarely the reason why people choose assisted suicide. Instead, most people do so because they fear burdening their families or becoming disabled or dependent.
- Justice For All - The current system of health services, particularly managed care, provides economic incentives for rationing health care, and can lead to the encouragement of physician-assisted suicide.
- National Council on Disability
- National Council on Independent Living
- National Spinal Cord Injury Association
- Not Dead Yet/Diane Coleman – “As one of countless disable people who have survived a terminal prediction based on a faulty diagnosis, I can’t help but become concerned when the accuracy of a terminal prognosis determines whether someone gets suicide assistance rather than suicide prevention.”
- TASH
- The World Association of Persons with Disabilities
- The World Institute on Disability

### **Attitudinal Influences**

Fear, bias, and prejudice against disability play a significant role in assisted suicide. Supporters advocate its legalization by suggesting that it is needed for pain and discomfort at the end of life. But the overwhelming majority of the people in Oregon who have reportedly used that state's assisted suicide law wanted to die not because of pain, but included the loss of autonomy (89.9 percent), the loss of the ability to engage in activities that make life enjoyable (87.4 percent), the loss of dignity (83.8 percent), and the loss of control of bodily functions (58.7 percent). Most of these reasons could be avoided by providing an alternative to the current nursing home industry.

### **Profit Driven System Gives Weight to Bias**

A significant problem with legalization is the deadly interaction between assisted suicide and profit-driven health care. Again and again, insurance companies and managed care bureaucracies have overruled physicians' treatment decisions because of the cost of care. These actions have sometimes hastened patients' deaths. Financial considerations can have similar results in non-

profit health plans and government-sponsored health programs such as Medicare and Medicaid, which are often under-funded.

The cost of the lethal medication generally used for assisted suicide is about \$300, 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 is far greater where assisted suicide is legal. If patients are denied necessary life-sustaining health care treatment, or even if the treatment they need is delayed, many will, in effect, be steered toward assisted suicide.

A 1998 study from Georgetown University's Center for Clinical Bioethics underscores the link between profit-driven 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 deadly impact of legalizing assisted suicide would fall hardest, whether directly or indirectly, 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.

### *The Myth of Free Choice*

As Paul Longmore of the U. of CA./Berkeley wrote, "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."

Assisted suicide strikes many people as a cause to support when they first hear about it. But upon closer inspection, there are many reasons why legalization is a serious mistake. 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.

Others may 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 of Not Dead Yet 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." Medicaid dollars still have a strong institutional bias when it comes to community vs. institutions or nursing home expenditures.

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—a full range of social supports currently unavailable to many, if not most people. 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.

## **No Legal Guarantees**

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 and 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, and we now know this will not hasten death. And perhaps least understood, for anyone who is dying in discomfort, it is currently legal in any U.S. state to receive palliative sedation, wherein the dying person is sedated so discomfort is relieved during the dying process. Thus, there is already a legal recourse for painful deaths. These alternatives do not raise the serious difficulties of legalizing assisted suicide.

## **The Fundamental Loophole of Terminal Illness Prognosis**

Current 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 assisted suicide.

But it is extremely common for medical prognoses of a short life expectancy to be wrong. Studies indicate 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, prediction is unreliable. Prognoses are based on statistical averages, which are nearly useless in determining what will happen to an individual patient. Thus, the potential reach 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.

## **Good Faith: A Safeguard for Doctors, Not Patients**

There is one foolproof safeguard in the Oregon and Washington laws. Unfortunately, it is for physicians and other health care providers rather than for patients—the good faith standard. This provision holds that no person will be subject to any form of legal liability, whether civil or criminal, if they act in good faith. However, a 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 alleged safeguards effectively unenforceable.

I appreciate your time and consideration in this critical issue.

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