



# Scholl Institute of Bioethics

# Bioethics Review

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**The Scholl Institute of Bioethics is a nonprofit, Judeo-Christian organization that addresses bioethical issues including euthanasia, physician-assisted-suicide, the withholding or withdrawing of food and water from non-dying patients, brain death, organ transplantation, genetic engineering, and the rights of disabled or mentally ill persons.**

## The Disabled, PAS and Euthanasia

by Elizabeth Hanink

Every disability rights organization that addresses the difficult topic at hand has issued public statements that oppose physician-assisted-suicide (PAS) and euthanasia. Why? Because anyone who understands basic human nature, as well as cultural trends or public health data can see, people with disabilities are particularly vulnerable to these increasingly common practices.

Not only do many healthy able-bodied individuals entertain the idea that a life with some limitations is not worth living, they often try to impose this view on people with disabilities. In the Netherlands, and soon Canada, it is legal to euthanize the mentally ill and those with autism. Just recently, Britain's National Health Service (NHS) determined that a nineteen-year-old woman, fully alert and conscious, but suffering from a range of life-threatening diseases, lacked the mental capacity to make decisions for herself. Consequently, the NHS discontinued her dialysis, against her will, and she died.

What specifically do disability rights organizations fear? According to the National Council on Disability's "The Danger of Assisted Suicide Laws," there are two basic problems (1) safeguards have limitations and (2) lack of data collection, oversight and investigation of mistakes or abuse are built into the law.

Let's look at each of these.

What is wrong with the safeguards? Generally, they include consultation with a second physician, mental competence,

terminal illness, the ability to self-ingest, as well as a waiting period and a freely given written request.

These provisions are inadequate and can be easily circumvented. If your own doctor does not support your decision to end your life because he judges you to be depressed, or perhaps with a less serious prognosis, you can find another. If you cannot self-ingest medication, who will know if you had help? No witnesses are required.

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We assume that if a patient does not wish to end his life, it won't happen, and instead medical care will be provided. This is not necessarily true as insurers have increasingly offered to pay for cheaper life-ending medications in lieu of expensive life-sustaining care. Disabled people often have greater costs that place them at the mercy of

decisions based on economic considerations. When a major gap exists between informing a patient of options and having those options available, such lack of support can be demoralizing and lead to requests for assisted suicide. In fact, these sorts of concerns, rather than uncontrolled pain, are more often the underlying reason behind requests for aid-in-dying.

If the only alternative appears to be nursing home placement, support from exhausted family members, or isolated suffering (thanks to the opioid crisis, chronic pain sufferers are often seen as drug-seeking), then death can seem attractive. Social Security Disability for those who worked at one time or who were disabled before

adulthood does not provide significant funds. Help with personal and household care is very limited and beyond the means of many. The fear of institutionalization is ever present. Most certainly, under such circumstances, consent is not freely given.

Family pressure is real, but not all of it comes from malicious intent. The desire to see suffering in a loved one come to an end, the idea that she might be better off dead, can seem benign; but in fact, if expressed in any way can make the person with disability feel pressure to end it all.

Faulty diagnoses are a considerable danger, as are erroneous prognostications of life expectancy. The newly diagnosed can be overwhelmed by the implications of serious and progressive disease. Demoralization and depression (which can itself be a disability if severe) are common and cloud thinking. Yet very few people are referred to mental health services even when required by “safeguards.”

To add to the danger, current laws provide broad immunity for everyone involved. Protection from criminal and civil liability based on a “good faith” belief that the law is being followed is a very low standard indeed and makes other safeguards impossible to enforce. How do you disprove a claim of acting in “good faith”?

The second category of danger is a threat for all of us, but particularly disabled people. There is an extreme lack of transparency in all the data surrounding PAS. For instance, many questions about assisted-suicide-laws cannot be answered because there are strict privacy and confidentiality clauses structured into every law so far enacted. California’s law says, “The information shall not be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding” (Section 443.19).

No one can assess the extent of non-compliance or under-reporting. Even family members cannot uncover the facts or take any action. Death certificates are legally falsified to show, not assisted suicide, but the underlying terminal disease as the cause of death. Proponents insist that no abuses or even medical complications have occurred under PAS laws. But the Disability Rights Education and Defense Fund (DREDF) has compiled examples in several categories thanks to media, patients, and families. The documented problems include economic pressures and coercion, doubts about self-administration, medical complications, and doctor-shopping.

Even what minimal data there is shows several important points: In Oregon, apart from the law’s first year, people whose illnesses did not result in death within six months have received lethal prescriptions in all twenty years the law has been in effect. This means that people are not within six months of death when the drugs are prescribed. Furthermore, the reasons for people requesting PAS are not gathered from the patients themselves but from their physicians after death has occurred. The report required from physicians uses checkboxes that list a limited number of reasons for requesting PAS. If a request was for a different, not listed reason—perhaps a less acceptable reason—who knows what might be entered. And, again according to DREDF, the reports are based on an uninformed analysis of how to address disability-related issues. Most ominously, after-death reports require no evidence of consent or self-administration. No current legislation requires a third party to witness the act. Who knows how much coercion is present if no outsider sees the suicide? Sadly, the trend over time is to collect and report even less data. In California the state is not required to report on the reasons for requesting lethal drugs and, so far, these figures remain unknown.

But why are disabled people, struggling with long-term but not fatal conditions, particularly vulnerable? Part of the problem is that we don’t see them. Many are institutionalized. Many do not leave their homes. Those that do often sit in separate, more accessible places or use special transportation. Unless we have a disabled family member or work with disabled people, many of us will go years without seeing them. We have no idea what just getting ready for work or school entails.

When we do recognize disabled people, often we are aghast. And that can lead to thinking that a life that requires significant extra help is not one that should continue. It is “not dignified” to need help with eating, in the bathroom, or to wear diapers, or drool, or speak unclearly, much less publicly rant at the moon. Similarly, we think no one can find meaning in life without the ability to exercise certain freedoms or use certain talents.

It is because of these circumstances that disabled people are most at risk. The much-ballyhooed safeguards written into end-of-life legislation don’t protect anyone except medical personnel and misguided families. We can do better.

*The author is Elizabeth Hanink who is a former member of the Scholl Executive Committee.*