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Section of
**Individual Rights
 and Responsibilities**
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Human Rights



Assisted Suicide and Disability

Another Perspective

By Diane Coleman

"I don't want to live like this one more day," she said firmly. "I've had enough." She had been forced, at 26, to leave her masters program. Her car had been repossessed. Following a miscarriage, her marriage had broken up. Her brother had drowned. And now her mother had been diagnosed with cancer.

One night, she turned up in a hospital, moaning that she just wanted to die. She was a competent adult, and her reasons for living were gone, so the hospital should not interfere. In fact, the doctor should cooperate, so she would not have to worry about botching her suicide and making things worse. She had lost more than most could bear. She just wanted the suffering to end. So she called a lawyer to sue the hospital to help her end it all.

Let us say that this is a hypothetical. If it were a question on a law school essay test, what would the issues be? What laws would apply? Would she win or lose? Lose, right?

But it is not a hypothetical. It is a real case. Elizabeth Bouvia "won" the right to starve herself in a hospital while receiving morphine and comfort care. What facts are missing from the synopsis above? Well, chief among them was that she was born with cerebral palsy, and she used a wheelchair to get around.

The case galvanized the disability community in southern California from 1983 to 1985. Members provided everything from expert testimony to street protests, calling attention to something that was obvious to people with disabilities and completely foreign to everyone else: Ms. Bouvia wanted to die, not because of her disability, but because of social losses that could move anyone to despair. Community members also wanted to question-and change-the assumption that, in a case like Ms. Bouvia's, the simple fact

of disability changes everything.

Not Dead Yet is a national disability rights group that opposes the legalization of assisted suicide and euthanasia. Many of our allies in the civil rights and health care movements have found this hard to understand. Isn't this about individual autonomy and rights, they ask? No, we say, it's about disability discrimination, a profit-oriented health care system, and a legal system that does not guarantee the equal protection of the law.

Disability Discrimination

In 1989, the U.S. Civil Rights Commission issued a 153-page report entitled "Medical Discrimination Against Children with Disabilities." Among the events considered by the Commission was an experiment conducted from 1977 to 1982 at the Children's Hospital of Oklahoma. Doctors there developed a "quality of life" formula for babies with spina bifida, taking into account the socioeconomic status of the baby's family to determine what to advise families about a simple but life-and-death procedure. Better-off families were provided a realistic and optimistic picture of their child's potential. Poor families were provided a pessimistic picture. All of the families who were given an optimistic picture asked for medical care for their children. Conversely, four out of five poor families agreed not to treat their children, and twenty-four babies died. The U.S. Civil Rights Commission concluded:

To accept a projected negative quality of life . . . based on the difficulties society will cause . . . , rather than tackling the difficulties themselves, is unacceptable. The Commission rejects the view that an acceptable answer to discrimination and prejudice is to assure the "right to die" to those against whom the discrimination and prejudice exists.

Parents' early beliefs about what their disabled children's lives can or will be like are very much shaped by health care providers. But the majority of people with disabilities acquire their disabilities some time after birth. Their beliefs about what life with a disability is like are shaped by a society that devalues people with disabilities. Then, when they become disabled, their beliefs about what their own lives with disabilities will be like are shaped by health care providers. So the story remains the same. Newly injured people may be particularly at risk. Eight thousand people injure their spinal cords each year, and 99,000 are hospitalized with moderate to severe head injuries. In the critical period after injury, many people who now enjoy their lives report that they could easily have been swayed to "choose" death.

Society has established ways of responding to someone who expresses a desire to die. If you see someone on a ledge, you do not yell "Jump!" and you certainly do not push. In theory, suicide intervention involves asking why-and trying to address the factors leading to despair. Many professionals have legal duties in this regard. But now we hear proposals to carve out an exception for people with disabilities, generally people with expensive disabilities, old or young, terminal or even just "incurable." A bill being considered in New Hampshire, for example, defines a "terminal illness" as any incurable condition that shortens one's overall life span, and the Hemlock Society's Website defines it merely as an incurable one.

Under the Americans with Disabilities Act (ADA), a disability is defined in part as a "physical or mental impairment that substantially limits one or more of the major life activities of [the] individual," such as seeing, hearing, learning, working, and self-care. It is also well established that the ADA covers persons with cancer or HIV. People with terminal illnesses generally qualify as people with disabilities. Moreover, health care providers are subject to the nondiscrimination provisions of the ADA. What has not been considered by most civil rights defenders is that any double standard for suicide intervention that is based on whether a person does or does not have a disability violates the ADA. That includes the assisted suicide law that went into effect in Oregon over a year ago.

The Economics of Healthcare

Today, adding economic pressures to the medical discrimination that existed at the time of the Civil Rights Commission report, Medicare and Medicaid are facing major budget crises. Medicare already does not pay for prescription medications. Since 1998, the nation's top health maintenance organizations have been pulling out of state Medicaid programs that serve poor, elderly, and disabled people. Federal courts have been upholding the rights of private health insurance companies to cap HIV/AIDS benefits at \$25,000 in policies that cap other benefits at \$1 million. This threatens to force individuals with AIDS into the weakening publicly funded system. There is apparently no legal reason that such caps could not contractually be placed on other expensive conditions as well.

Of course, disability is not the only basis of health care discrimination. Poverty and race are well-documented factors in access to health care. On June 17, 1998, the Journal of the American Medical Association reported that people of color are significantly less likely to receive pain medication than whites, even aspirin. This study involved over 13,000 cancer patients and confirmed the racial differences found in previous studies. Recent reports show that the number of the uninsured in the United States is now at 44 million and continues to rise.

The Oregon assisted suicide law is now offered as a "model" approach to legalization. But how does this "carefully crafted" statute, supposedly filled with safeguards, address the harsh realities of today's profit-driven health care system, a system that offers few choices to the people whose need for services is a drain on the bottom line?

Perhaps most relevant is the informed consent provision. Everyone who receives assisted suicide must first be informed of "the feasible alternatives, including, but not limited to, comfort care, hospice care, and pain control" (Section 3.01(2)(e)). These feasible alternatives are not defined in the lengthy definitions section of the law. Nor does the law require that any desired alternatives, feasible or otherwise, be paid for. The law does not even provide for payment as a "last resort," only when all other payment options prove unavailable.

Unfriendly Courts

The civil courts have already established numerous precedents for treating people with significant but nonterminal disabilities in the same way that terminally ill people are treated. The Bouvia case mentioned previously was followed by a line of several cases the disability community now refers to as the "give me liberty or give me death" cases. In them, people with quadriplegia who use ventilators-people like Christopher Reeve-asked not to be forced to live in nursing homes for lack of home health services, but that liberty interest was ignored. They subsequently gave up and asked for assisted death. The media had no qualms publicizing that as a crusade for liberty, and the courts expanded the right to refuse treatment, resulting in many deaths. Offering a right to die as the only alternative to a nursing home cannot be considered a victory for liberty.

The criminal court system has not provided equal protection for people with disabilities, either. Jack Kevorkian has claimed 130 victims, most of them not terminally ill, and all killed well outside the parameters of any proposed assisted suicide bill. Nonetheless, he was only prosecuted for seven deaths, and only convicted of one. In addition, studies of sentencing patterns when parents kill their disabled children show a disturbing lack of parity to sentences imposed when parents kill nondisabled children. From prosecutorial discretion to conviction and sentencing disparities, people with disabilities do not see much evidence that the courts treat their lives as being as valuable as their nondisabled counterparts'.

Significant evidence exists that neither the civil nor the criminal court systems will

enforce the "safeguards" in the Oregon law. The law's culpability standard is the lowest possible, mere "good faith" compliance. There are no investigatory provisions, and the statute does more to secure every form of legal immunity for all participants in assisted suicide than it does to secure individual rights. "Safeguard" problems that have already been reported in the press-involving depression, active euthanasia, family coercion, and lack of informed consent-have passed with little comment.

Since the Oregon law immunizes all participants in an assisted suicide, to what extent might it be interpreted by the public as permission to pressure or even hasten the deaths of family members without the involvement of health care providers? According to a study by the National Center on Elder Abuse, 450,000 seniors were abused or neglected in 1996. Among known perpetrators, 90 percent were family members, and two-thirds of those involved the spouse or an adult child. The Federal Bureau of Investigation reports that 55.9 percent of all homicides of children up to age eleven are committed by family members, as are 21.2 percent of homicides of persons over age fifty. Yet these significant indicators of risk have been ignored by assisted suicide proponents or treated as irrelevant.

Unfriendly Courts

In March 1997, a leading bioethics journal, The Hastings Center Report, published a cover article entitled "Is There a Duty to Die?" The article led off with favorable comments on former Colorado Governor Richard Lamm's claim that the elderly have a duty to die.

On December 3, 1997, the Hemlock Society issued a widely ignored press release in which its Executive Director, Faye Girsh, called for laws allowing family members and other "agents" to procure court orders to kill "a demented parent, a suffering severely disable [sic] spouse, or a child" if their lives are "too burdensome to continue."

More recently Professor Peter Singer has been recruited into a tenured and endowed chair in bioethics at Princeton University. Singer works to popularize a utilitarian ethic holding that it is moral to kill newborns with even minor health impairments and that older children and adults with significant cognitive disabilities can also be morally killed. His theories provide a theoretical foundation for nonvoluntary euthanasia, partly as a means of rationing health care. What is often overlooked is that Princeton University's president chairs the National Bioethics Advisory Commission appointed by the U.S. president.

Conclusion

Discrimination against any minority, including people with disabilities, should not be put up to majority vote. The Supreme Court found that federal law trumped states rights on discrimination in 1954. Assisted suicide and euthanasia are lethal forms of discrimination, and the Supreme Court should decide against state sovereignty once again.

Assisted suicide has been marketed to the American public as a step toward increasing individual freedom, but choice is an empty slogan in a world full of pressures on people with chronic illnesses and disabilities. Now is not the time to establish a public policy securing the profits of a health care system that abandons those most in need and would bury the evidence of their crime.

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