# Physician Assisted Suicide a Huge Threat to Disabled

*Testimony of Diane Coleman, J.D. and Carol Gill, Ph.D.*

Most proponents of physician-assisted suicide would say that a representative of the disability community does not really belong on this panel today. They would say that physician-assisted suicide pertains to people who are terminally ill, not disabled.

The concerns of people with disabilities were similarly dismissed as irrelevant in the context of withdrawal of life-sustaining treatment or "passive euthanasia." Nevertheless, courts did not carefully protect non-terminal people with disabilities from a too hasty "final exit." Indeed, court after court declared that people with disabilities were essentially the same as people with terminal illnesses, stating that routine disability-related health care was artificially prolonging life, or that it did not matter how extended the individual's life-expectancy might be if their quality of life rendered their life "meaningless." This occurred in numerous appelate court cases involving people with quadriplegia, often locked away in nursing homes without hope of in-home support services, and it even occurred in a case involving a woman with cerebral palsy.

No court, or professional whose judgment the courts respected, examined the suicidal feelings of Elizabeth Bouvia, David Rivlin, Larry McAfee, Hector Rodas or Kenneth Bergstedt. All courts attributed the individual's desire to die to their physical disabilities per se rather than to events and circumstances in their lives, such as a miscarriage, loss of spouse and confinement to nursing homes. All courts superficially concluded that the individual's despair was not suicidal, not treatable or deserving of appropriate intervention. These individuals were granted a so-called "right to die" without being offered adequate supports for living. These highly publicized cases are the tip of an unexplored iceberg, one that proponents of physician-assisted suicide prefer to ignore. But the legal foundation for applying physician-assisted suicide to non-terminal people with disabilities is already firmly entrenched in our judicial system, and disabled people are beginning to feel that we are riding on the Titanic.

People with disabilities do **not** have adequate protection from either the courts or disability organizations. The courts have consistently excused parents who have murdered children with disabilities. A woman in Wisconsin escaped sentencing after admittedly starving her son with cerebral palsy to death. She said she was responding to family pressure and the message of a T.V. show on euthanasia. A west coast mother recently killed her brain injured non-verbal teenaged daughter. The judge said her actions were understandable, that other parents could be expected to react in the same way. He sentenced her to **community service**. Meanwhile, disability watchdog organizations are losing funding. There have never been enough of these to serve people with disabilities adequately; now many are forced to shut down.

2) People with disabilities and incurable chronic diseases have experienced a long history of persecution and genocide. At the turn of the century, Chicago's Ugly Law ordered people with visible disabilities to hide themselves from public view. In the 1930's, 200,000 people with disabilities were put to death by Nazi physicians who were inspired by the contemporary euthanasia movements of England and the U.S. Three years ago, a European judge ordered a hotel to refund money to a vacationing couple because they claimed their holiday was ruined by the presence of disabled people in the dining room. A physically disabled German man committed suicide after verbal and physical assaults by skinheads. There has been a rise in hate crimes against people with disabilities, internationally. A U.S. government report on child abuse recently found that children with disabilities are twice as likely to be abused as children who are nondisabled, simply because their disabilities. Suffice it to say, contempt for life with disability is very much around us. In this context, we should be extended more protections of our lives, as a minority group at risk, instead of fewer protections.

3) Assisted suicide will **not** remain confined to the imminently dying. Individuals and groups who have spearheaded this push for assisted suicide have clearly intended people with disabilities to be targeted once laws are relaxed for terminally ill people. In ***Final Exit,*** Hemlock Society founder Derek Humphrey writes: "What can those of us who sympathize with a justified suicide by a handicapped person do to help? . . . When we have statutes on the books permitting lawful physician aid-in-dying for the terminally ill, I believe that along with this reform there will come a more tolerant attitude to the other exceptional cases." Kevorkian has openly admitted that he designed his suicide device as an answer for quadriplegics. He has said that he perceives physical disability as a cause of extreme human suffering that can be addressed by "medicide." He also argued, as did the Nazis, that society will benefit from the deaths of incurably disabled people. Chillingly, he wrote: ". . . the voluntary self-elimination of individual and mortally diseased or crippled lives taken collectively can only **enhance** the preservation of public health and welfare." The courts have not prevented this man from following through on his intention to "enhance" society by eliminating people with disabilities who despair in the face of society's crushing oppression.

4) Assisted suicide enthusiasts have reinforced public prejudice and fear regarding disability. They describe our physical status or our simple need for human assistance, tools and technology as "pitiful," " helpless," "hopeless," "miserable," and inherently "undignified." This is an insult to our lifestyles. For example, many people with disabilities routinely manage incontinence through a variety of methods advertised in numerous disability magazines. These negative labels also promote myths about disability and "quality of life." Experienced people with disabilities have learned that there's more to life than toileting independently. Research consistently indicates that "quality of life" is determined by social supports and meaningful involvement in one's environment, not degree

of disability. Most people with disabilities say that public misconceptions about disability trouble them far more than their physical limitations. If promoters of assisted suicide genuinely cared about people with disabilities, they would stop contributing to these negative public attitudes. Instead, they exploit disability prejudice in their public statements and expensive political advertisements to frighten the public into endorsing assisted suicide.

5) As long as people with disabilities are disenfranchised and treated as unwelcome and costly burdens on society, assisted suicide is forced "choice." Assisted suicide is not a free choice as long as people with disabilities are denied adequate healthcare, affordable personal assistance in our own homes, assistive technology, equal education, nondiscriminatory employment, and free access to our communities' structures and transportation systems. Based on recent developments in both public and private managed care, it is already possible in some states for impoverished disabled, elderly and chronically ill people to get assistance to die, but impossible for them to get shoes, eyeglasses, and tooth repair. Indeed, the 9th Circuit Court decision in effect recognizes assisted suicide as an acceptable solution to the economic burdens of healthcare. The so called "right to die" has become the "duty to die," with Court approval.

6) The great majority of problems that lead people with disabilities, chronic conditions, and even terminal illnesses to seek hastened deaths are remediable through other means, such as assisted independent living outside of nursing homes, sophisticated pain management, death counseling for individuals and families, augmentative communication technology, hospice support, etc. Unfortunately, our nation's health care system has not responded adequately or consistently to these important human needs. Most citizens, particularly poor citizens, must fight for access to health care every step of the way. Many physicians have limited knowledge or skills in pain management, and no knowledge of even the most simple and inexpensive disability-related technology and services. To legalize assisted suicide in a country that has been a pioneer in suicide prevention is a backward step into primitiveness.

7) Physicians must not be given the power to decide who lives and who is escorted to death. As disabled historian Hugh Gallagher warns, the Nazi experience demonstrates how easily compassionate and well-educated physicians can lose their moral compass. Furthermore, research shows that physicians learn very little about disabled people during medical training, they are poor at diagnosing treatable depression, they are often uninformed about options such as pain management and supported living for people with disabilities, and they have a high suicide rate, themselves. Moreover, research shows that physicians consistently and dramatically underestimate quality of life for people with disabilities compared to the assessments of people with disabilities themselves. In addition, most individuals with disabilities report longstanding problems with physicians, citing disability prejudice, ignorance about the disability lifestyle, and medical abuse as commonly issuing from physicians. It is unlikely

that doctors will become more careful and accountable for out lives when current permissive attitudes about physician-assisted suicide are given the status of law.

8) The 2nd Circuit Court decision illustrates the logic that propels us down the slippery slope to endangerment. In numerous court cases since 1985 involving "passive euthanasia", "right to die" proponents have argued that passively withdrawing life supports was neither suicide nor mercy killing -- it was just letting nature take its course. Now, the Court's decision articulates that there is no essential difference between assisted suicide and death from withdrawal of life supports. Will the next decision challenge the distinction between assisted suicide and mercy killing, or the distinction between voluntary requests to die and proxy requests or decisions made without consent at all? That is exactly what happened in the Netherlands--a country often cited by assisted suicide proponents as the model for the U.S. Specifically, according to a Dutch governmental report in 1990, 5,941 persons were given lethal injections without consent. Of those, 1,474 were fully competent, according to their physicians. In 8% of the cases, doctors admitted there were unexplored options. Regardless of options, they euthanized unconsenting patients because of such express reasons as "low quality of life," "no prospect of improvement," " the family could not take any more." (***Doctor Assisted Suicide and the Euthanasia Movement***, ed. by Gary E. McCuen.)

9) In fact, people with disabilities have already been endangered by relaxation of laws and policies protecting their lives. Medical rehabilitation specialists report that quadriplegics and other significantly disabled people are dying wrongfully in increasing numbers because emergency room physicians judge their quality of life as low and, therefore, withhold aggressive treatment. Disabled people who need ventilators are often not offered assisted breathing as an option. Those who already use ventilators report that they are increasingly asked by medical personnel to consider "do not resuscitate" orders and withdrawal of life support. Children with non-terminal disabilities who never asked to die are killed "gently" by the denial of routine treatment. People with relatively mild disabilities are routinely denied life saving organ transplants. Many people with disabilities are terrified that managed care will further abridge their already limited options for life-extending treatments. Oregon's attempt to ration healthcare based on "quality of life" judgments (judgments made by nondisabled people) demonstrated how quickly the deck can be stacked against the lives of people with costly conditions. In the Netherlands, where disabled children, and adults with multiple sclerosis, quadriplegia, and depression are commonly assisted to die, disabled citizens express fear. Some carry wallet cards asking not to be euthanized. Dutch physicians follow a practice not to offer assisted ventilation to quadriplegics. Those who visit the U.S. have expressed surprise to see quadriplegics actively engaged in life with the use of costly portable ventilators and mouth-controlled power wheelchairs. Not surprisingly, the hospice movement is virtually non-existent in the Netherlands. When assisted death is a ready solution, there is little incentive to develop life-enhancing supportive services for "incurables."

10) Many proponents of physician-assisted suicide have expressed the belief that adequate safeguards can be adopted to protect vulnerable people from various forms of pressure and abuse if the practice is legalized in conformance with the 2nd and 9th Circuit court opinions. This view is at best naive and at worst deliberately misleading. Similar statements were made during the last decade in the context of the withdrawal of life-sustaining treatment, but no meaningful safeguards have been established. In particular, people with disabilities are notably absent from hospital medical ethics committees. If, in fact, proponents of physician-assisted suicide believe that adequate safeguards against treatable suicidal feelings can be established, then they should be willing to allow physician-assisted for any citizen, regardless of their health status, after those safeguards have been observed. However, no one has proposed that physician-assisted suicide be made available to all citizens on a non-discriminatory basis. Indeed, science fiction movies have been made depicting the atrocities of such a practice in futuristic society. But it appears that such practices are acceptable today if "only" applied to a loosely defined group of seriously ill or impaired individuals. The fact is that proponents of physician-assisted suicide are willing to risk the lives of hundreds of thousands of severely disabled people who are not terminally ill in order to secure a right to active euthanasia that would effectively shield them from legal scrutiny of their conduct. People with disabilities protest this cavalier devaluation of our lives.

11) Assisted suicide is discriminatory. As a policy, it singles out ill and disabled people as fitting subjects for dying. Meanwhile, neither the public nor health professionals endorse this so-called "autonomous" decision for young, healthy Americans. If there is a constitutional right to control one's death through assistance, it should apply to all citizens, not just those judged (or misjudged) to have a deficient life.

12) Assisted suicide is classist. Those who are used to privilege, and the control over one's life that privilege affords, will benefit from having one more choice--the choice to die by their own schedule. Such individuals expect to control all aspects of their lives. Either they cannot truly fathom the experience of disenfranchised groups, or they are willing to risk the safety of many (society's poor and oppressed) to ensure their personal access to more options. On the other hand, those who lack privilege, who are socially devalued and feared, those who are denied meaningful options to **live**, will be endangered by legalization of assisted suicide. The historical reality of disabled people's experience is that society does not adequately support our lives unless pressured by strong legal sanctions. The Congress of the United :States acknowledged that disabled people are a discrete and insular minority in its passage of the Americans with Disabilities Act in 1990. We are entitled to the equal protection of the laws under the 14th Amendment of the U.S. Constitution. The laws that protect our lives have often been the only buffer between us and annihilation. Now, under the guise of a 14th Amendment protection of an alleged liberty interest in assisted suicide, a certain class of

people will be denied the 14th Amendment's equal protection of laws providing for suicide prevention when one poses a danger to oneself.

13) There is virtually no research on suicide and suicidal wishes in people with disabilities. This is a direct reflection of how little our lives are valued. Physicians, such as Timothy Quill, who propose guidelines for "safe" assisted death admit that the social consequences of assisted suicide are unknown. Yet they argue that legalizing physician assisted suicide will open up this area for investigation. At what cost to whom? It is hard to imagine a physician defending this kind of research design for any other group of people. Why are ill and disabled persons dispensible?

14) People with disabilities and incurable illnesses deserve the same social supports and commitment to suicide intervention as any other citizen. Although proponents of assisted suicide often emphasize its rationality, suicidologists tell us there is always a powerful emotional force and the pain of unmet needs underlying the desire to die. Most death requests, even in terminally ill people, are propelled by despair and treatable depression. As two such experts stated recently (Herbert Hendin and Gerald Klermand in ***Amer J. of Psychiatry*** Jan. 1993):

> *Advocates of physician-assisted suicide try to convey the impression that in terminally ill patients the wish to die is totally different from suicidal intent in those without terminal illness. However, like other suicidal individuals, patients who desire an early death during a terminal illness are usually suffering from a treatable mental illness, most commonly a depressive condition. Strikingly, the overwhelming majority of the terminally ill fight for life to the end. Some may voice suicidal thoughts in response to transient depression or severe pain, but these patients usually respond well to treatment for depressive illness and pain medication and are grateful to be alive.*

In fact, periods of depression are common in people adjusting to new or progressive disabilities. Such depression and concommitant suicidal feelings can persist for months or even years if not addressed with support and treatment from those experienced in working with people with disabilities.

15) Women with disabilities will be particularly endangered by the legalization of assisted suicide. Research indicates that women with disabilities are even more socially devalued then disabled men. We are also more likely to bear the stresses of poverty and social isolation. As women, we are twice as likely as men to suffer from depression. A study by DisAbled Women's Network (DAWN) in Canada indicates that rates of depression and suicide may be even higher for women with disabilities than other women due to our multiple stresses, our high incidence of abuse, and our internalization of society's message that we are useless and inferior as women. If anyone doubts that women will be exploited

and endangered by assisted suicide, that doubter should study Kevorkian's "clients." The first eight were all middle aged or elderly women with chronic illnesses and disabilities. Many said they feared being a burden on others. An autopsy on one of them revealed no evidence of any physical illness. Women with disabilities are going to be the first to feel a "duty to die."

16) People with disabilities in our country are increasingly caught in a perilous bind. On one side, recent assaults on the Americans with Disabilities Act and the Individuals with Disabilities Education Act threaten our hope of equal opportunity, and managed care threatens our access to basic healthcare and long-term services. On the other side, sanctioned assisted suicide allows our healthcare professionals to offer the final solution.

## *Conclusion*

People have always been afraid to face the practical difficulties and losses associated with aging, illness and disability. In today's society, with cutbacks in health care and the human service "safety net," and with growing isolation from the supports our families could once more easily provide, people's fears are understandably growing. As a culture, we must address these very real human needs and fears.

But, particularly in the absence of a constitutional right to physician care, a right to physician-assisted suicide is not the answer. While a few may have all the options that money can buy and choose the final solution with complete understanding and freedom, the majority who are offered this option are people that society is all too ready to abandon as too costly and unproductive- -people who can only depend on the protection of the law. The depth and breadth of this abandonment is only understood by those who live it everyday.

We ask all who care about social injustice to believe us when we state that disability-based discrimination in this culture is deep-seated, virtually unconscious, pervasive and overwelming. This discrimination against millions of Americans must be understood and reversed, in ways that few can even envision, long before we discuss expanding the ways in which society's unwanted can be killed.

But if, in the prevailing confusion and despair of our culture, physician-assisted suicide will become a constitutional right for some, then it must be a constitutional right for all, nondisabled as well as disabled. The same safeguards, or lack of safeguards, that apply to some must apply to all. Those who have asserted the 14th Amendment's right to liberty as the legal foundation for a steady expansion of the right to die in the last decade cannot be allowed to continue to ignore the 14th Amendment's Equal Protection clause.

The assertion that people with disabilities are not threatened by physician-assisted suicide is false, based on virtually every court precedent to date, as well as actual practice in our culture today. The fact that its proponents continue to dismiss and marginalize the input of the disability community on this topic leads us to believe that they may actually feel that our untimely deaths are ultimately acceptable in the interest of the "greater good."

Then we can only call upon this Congress and the good people of our nation to resist our being singled out, to resist this form of discrimination. We are the proverbial "canaries in the coal-mine", the barometers of our value system. If we are declared expendable, who will be next?