Assisted Suicide: A Disability Perspective

Position Paper

National Council on Disability

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Executive Summary

Physician-assisted suicide and related issues have garnered much judicial, media, and scholarly attention in recent months. Two cases presently pending before the United States Supreme Court raise the issue of the legality of state laws prohibiting physician-assisted suicide. As the principal agency within the federal government charged with the responsibility of providing cross-disability policy analysis and recommendations regarding government programs and policies that affect people with disabilities, the National Council on Disability is issuing this position paper in the hope of presenting a coherent and principled stance on these issues drawn from the input and viewpoints of individuals with disabilities.

In the body of this position paper, the Council examines a number of insights derived from the experiences of people with disabilities focusing on the following topics:

1. The Paramount Issue -- Rights, Services, and Options
2. The Reality and Prevalence of Discrimination
3. Deprivation of Choices and the Importance of Self-Determination
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Based upon these insights from those who have experienced disabilities and upon the existing legal framework, the National Council on Disability has formulated its position on the issue of physician-assisted suicide for persons with imminently terminal conditions as follows:

The benefits of permitting physician-assisted suicide are substantial and should not be discounted; they include respect for individual autonomy, liberty, and the right to make one's own choices about matters concerning one's intimate personal welfare; affording the dignity of control and choice for a patient who otherwise has little control of her or his situation; allowing the patient to select the time and circumstances of death rather than being totally at the mercy of the terminal medical condition; safeguarding the doctor/patient relationship in making this final medical decision; giving the patient the option of dying in an alert condition rather than in a medicated haze during the last hours of life; and, most importantly, giving the patient the ability to avoid severe pain and suffering.

The Council finds, however, that at the present time such considerations are outweighed by other weighty countervailing realities. The benefits of physician-assisted suicide only apply to the small number of people who actually have an imminently terminal condition, are in severe,

untreatable pain, wish to commit suicide, and are unable to do so without a doctor's involvement.

The dangers of permitting physician-assisted suicide are immense. The pressures upon people with disabilities to choose to end their lives, and the insidious appropriation by others of the right to make that choice for them are already prevalent and will continue to increase as managed health care and limitations upon health care resources precipitate increased "rationing" of health care services and health care financing.

People with disabilities are among society's most likely candidates for ending their lives, as society has frequently made it clear that it believes they would be better off dead, or better that they had not been born. The experience in the Netherlands demonstrates that legalizing assisted suicide generates strong pressures upon individuals and families to utilize that option, and leads very quickly to coercion and involuntary euthanasia. If assisted suicide were to become legal, the lives of people with any disability deemed too difficult to live with would be at risk, and persons with disabilities who are poor or members of racial minorities would likely be in the most jeopardy of all.

If assisted suicide were to be legalized, the only way to ward off the most dire ramifications for people with disabilities would be to create stringent procedural prerequisites. But, to be effective, such procedural safeguards would necessarily sacrifice individual autonomy to the supervision of medical and legal overlords to an unacceptable degree -- the cure being as bad as the disease.

For many people with disabilities, it is more often the discrimination, prejudice, and barriers that they encounter, and the restrictions and lack of options that this society has imposed, rather than their disabilities or their physical pain, that cause people with disabilities' lives to be unsatisfactory and painful. The notion that a decision to choose assisted suicide must be preceded by a full explanation of the programs, resources, and options available to assist the patient if he or she does not decide to pursue suicide strikes <u>many</u> people with disabilities as a very shallow promise when they know that all too often the programs are too few, the resources are too limited, and the options are nonexistent. Society should not be ready to give up on the lives of its citizens with disabilities until it has made real and persistent efforts to give these citizens a fair and equal chance to achieve a meaningful life.

For these reasons, the Council has decided that at this time in the history of American society it opposes the legalization of assisted suicide. Current evidence indicates clearly that the interests of the few people who would benefit from legalizing physician-assisted suicide are heavily outweighed by the probability that any law, procedures, and standards that can be imposed to regulate physician-assisted suicide will be misapplied to unnecessarily end the lives of people with disabilities and entail an intolerable degree of intervention by legal and medical officials in such decisions. On balance, the current illegality of physician-assisted suicide is preferable to the limited benefits to be gained by its legalization. At least until such time as our society provides a comprehensive, fully-funded, and operational system of assistive living services for people with disabilities, this is the only position that the National Council on Disability can, in good conscience, support.

I. INTRODUCTION

Physician-assisted suicide and related issues have garnered much judicial, media, and scholarly attention in recent months. Well-publicized instances of legal prosecutions of medical practitioners, such as Dr. Jack Kevorkian, for engaging in acts of assisted suicide, and recent consideration by the United States Supreme Court of a pair of cases in which the legality of state laws prohibiting physicians from assisting suicides by their patients has been contested have generated considerable debate, controversy, and pontificating by various individuals and organizations.

As the principal agency within the federal government charged with the responsibility of providing cross-disability policy analysis and recommendations regarding government programs and policies that affect people with disabilities, the National Council on Disability is issuing this position paper in the hope of presenting a coherent and principled stance on these issues drawn from the input and sometimes conflicting viewpoints of individuals with disabilities. This position paper was drafted for the National Council on Disability by Professor Robert L. Burgdorf Jr. of the University of the District of Columbia School of Law.

II. COMPLEXITY OF THE ISSUES

Discussions of the issues surrounding the question of physician-assisted suicide should not oversimplify the subject. While various individuals and organizations have sometimes formulated their positions in ways that make the issues seem simple and straightforward, consideration of the legal, medical, and societal implications of assisted suicide are inherently thorny and multifaceted. If one limits consideration only to matters of legality, the question whether or not physician-assisted suicide should be legal involves a number of component questions: Is there or should there be a legal right to commit suicide? Should it ever be legal for some other person to assist in a suicide? Should a physician ever be permitted to assist in a suicide? Should any right to commit suicide or to assist in someone else's suicide be limited to situations where a person is terminally ill? If so, how imminent must the person's death be? Should any right to commit suicide or to assist in someone else's suicide be limited to situations where a person is in severe pain? If so, how much pain suffices? Sporadic or constant pain? What if the pain is partially or fully treatable? Is it assisting suicide to treat pain with medication or other techniques that will shorten life? Should a person's age and life expectancy ever be considered? Is there a difference in the criteria that should be applied to determinations whether or not to provide ordinary medical treatment; to provide, refuse to

provide, or to terminate "extraordinary measures;" or to assist the termination or shortening of life? Should there be a difference in the requirements and standards applied to decisions to administer medical procedures that will save a person's life versus those that will merely extend it somewhat? Who should make such determinations -- the patient, the doctor, the family, medical review boards, the courts? Do the same or different considerations apply regarding individuals who are not capable of making the decisions about their treatment themselves? What types of procedural safeguards should be imposed to ensure the integrity of the decision-making process? Can such procedural prerequisites be workable and effective in application?

Even the more straightforward situation where an individual is able to take her or his own life without direct assistance involves its own legal complications. If a physician prescribes medication that is used in the suicide, the doctor may risk legal liability to the extent that it appears that the doctor intentionally prescribed the medication for that purpose. And the individual who decides to take his or her life may endanger family members or others who are present when the deed is done, because they may risk liability for aiding or abetting the suicide, a circumstance that at the very least adds stress, guilt, or isolation and loneliness for all of those involved in the scenario.

This position paper does not aim to unravel all such complexities and answer all of the foregoing questions. It

seeks, rather, to delineate some criteria and principles derived from the experiences and deliberations of people with disabilities that will hopefully enlighten future initiatives undertaken by the federal government and the states to refine the law in this area. There can be little question that current laws and legal principles regarding treatment, nontreatment, and assisted suicide need refinement. One of the ironies of the law as it currently stands has been described by a physician in an article in the New England Journal of Medicine in which he cited two hypothetical patients:

> One is 28 years old, despondent over the recent breakup of a romantic relationship, and because of an acute asthma attack, temporarily dependent on a ventilator. Apart from asthma, this person is in good health. The other patient is 82 years old, is wracked with pain from extensive metastic cancer, and has only a few weeks to live. Assume that both persons want to end their lives, the 28-year-old by refusing the ventilator and the 82-year-old by suicide. Under current law, the 28-year-old has the right to refuse the ventilator, whereas the 82-year-old generally lacks the right to assistance with suicide.[1]

People with disabilities report numerous other problems with the law as it currently stands, including unconsented denials of treatment, pressure to refuse or discontinue treatments, disregard of requests for relief from pain, "Do Not Resuscitate" consent forms hidden within a stack of admission and consent papers, and involuntary assisted-"suicide."

[1] David Orentlicher, M.D., J.D., "The Legalization of Physician Assisted Suicide," New England Journal of Medicine 335: 663, 665 (Aug. 29, 1996).

III. THE CASES UNDER CONSIDERATION BY THE SUPREME COURT

The United States Supreme Court has before it this term two cases that raise the question of the legality of physician suicide and the permissibility of state laws that prohibit it -- Vacco v. Quill[2] and State of Washington v. Glucksberg[3]. This section provides a brief summary of those two cases. As a precedential backdrop, however, it is important to be aware of a prior decision of the Court -- Cruzan v. Director, Mo. Dept. of Health[4].

In Cruzan, the Court considered the challenge by the parents of a woman who had been in a coma for seven years following an automobile accident to the refusal by state hospital officials and the Missouri Supreme Court to authorize the removal of a feeding tube keeping Nancy Cruzan alive. The Supreme Court of the United States upheld Missouri's legal standard for such cases, which required "clear and convincing evidence" of the patient's wishes before life support could be removed. In doing so, the Court recognized that "a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment," and assumed for the purposes of the case that the Constitution "would grant a competent person a constitutionally protected right to refuse lifesaving hydration

[2] No. 95-1858, October Term, 1996.

[3] No. 96-110, October Term, 1996.

[4] 497 U.S. 261 (1990).

and nutrition."

In its reasoning upholding the Missouri legal framework restricting the removal of life support for persons not able to make the decision themselves, the Cruzan Court recognized Missouri's interests in the protection and preservation of life and in avoiding erroneous decisions to withdraw life-sustaining treatment. It noted in passing that "the majority of States in this country have laws imposing criminal penalties on one who assists another to commit suicide."

The current cases examine the legality of such state laws. The Vacco and Glucksberg cases present the Court with two different legal theories under which physician-assisted suicide laws have been challenged -- in Vacco, equal protection, and in Glucksberg, due process.

In Vacco v. Quill,[5] three terminally ill patients and three physicians who treat terminally ill patients challenged the constitutionality of New York statutes that made it a crime (manslaughter) for any person to intentionally cause or aid another to commit suicide. The plaintiffs challenged the laws as violating both the due process and equal protection guarantees of the U.S. Constitution. The trial court dismissed both claims. On appeal, the United States Court of Appeals for the Second Circuit ruled that the N.Y. assisted-suicide laws violated the Equal Protection Clause because they are not rationally related

[5] No. 95-1858, October Term, 1996.

to any legitimate state interest.[6] In reaching this conclusion, the Second Circuit reasoned as follows:

> New York does not treat similarly circumstanced persons alike: those in the final stages of terminal illness who are on life-support systems are allowed to hasten their deaths by directing the removal of such systems; but those who are similarly situated, except for the previous attachment of life-sustaining equipment, are not allowed to hasten death by self-administering prescribed drugs.[7]

The Second Circuit found that there was no legitimate state interest to support the difference in treatment between terminally ill patients on life-support and those seeking assistance in directly ending their lives. The Supreme Court agreed to review the Second Circuit's equal protection ruling in Vacco.

State of Washington v. Glucksberg[8] involves a similar challenge, by four physicians who treat terminally ill patients, three terminally ill persons, and an organization that provides assistance to terminally ill persons, to the constitutionality of a Washington law that makes it a crime for any person who knowingly causes or aids another person to attempt suicide. The plaintiffs had challenged the Washington statute under the Equal Protection and Due Process clauses of the U.S. Constitution. The district court granted summary judgment in favor of the plaintiffs on both claims.

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[6] Quill v. Vacco, 80 F.3d 716 (2d Cir. 1996).

[7] Id. at 729.

[8] No. 96-110, October Term, 1996.

A panel of the United States Court of Appeals for the Ninth Circuit initially reversed the decision on both grounds, but on rehearing en banc, the Ninth Circuit ruled that the Washington statute violates due process. It began its analysis by finding that there is a constitutionally protected liberty interest "in choosing the time and manner of one's death," and more particularly that "[a] competent terminally ill adult, having lived nearly the full measure of his life, has a strong liberty interest in choosing a dignified and humane death rather than being reduced at the end of his existence to a childlike state of helplessness, diapered, sedated, incontinent."

The Ninth Circuit then weighed these liberty interests of the terminally ill patient against the state's interests in preserving life, preventing suicide, in avoiding the taking of life due to "a fit of desperation, depression, or loneliness or as a result of any other problem, physical or psychological, which can be significantly ameliorated," and in avoiding deaths result from undue influence by family members and physicians. The Ninth Circuit ruled that some of these interests were diminished because the patient's life was going to end anyway, and that the others could be better served "through procedural safeguards, rather than through a complete ban on assisted suicide."

The Supreme Court agreed to review the Second Circuit's due process ruling in Glucksberg. The Court heard oral arguments on the Vacco and Glucksberg cases on January 8, 1997.

IV. PERSPECTIVES OF INDIVIDUALS WITH DISABILITIES

Many people are interested in the subject of assisted suicide. Many in the medical profession, including physicians, nurses, and hospital administrators have spoken out about their views on these matters, and the American Medical Association has taken a position. Ethicists and religious officials have articulated their analyses. Organizations for and against assisted suicide have advocated for their respective positions. Family members of persons with terminal illnesses have had strong feelings on these issues. The courts, including the Supreme Court of the United States, have increasingly been asked to address these types of issues.

Another group whose constituents often have strong views about assisted suicide is people with disabilities. Given that persons suffering from terminal illnesses and those experiencing severe pain almost always meet the definition of individuals with disabilities, and that people with disabilities run the risk of being subject to life-shortening measures even when they may not in fact have life-threatening conditions, the views and insights of people with disabilities would seem to be very significant to the debate on this issue. And yet the viewpoints of individuals with disabilities have been, if not ignored, at least not a major piece of the public and judicial debate on this issue.

In submitting amicus curiae briefs in the two Supreme Court cases addressing physician-assisted suicide cases, the Solicitor

General and Department of Justice Attorneys were required to identify the interests of the United States in the litigation that justified its involvement in the cases. In its briefs, the United States pointed to two such interests -- the fact that the United States owns and operates health care facilities (such as V.A. hospitals and nursing homes), and the fact that federal law requires health care providers receiving Medicaid and Medicare funds to inform patients that they have a right to refuse life-sustaining treatment and to record any directives in this regard they may have. Seemingly much more directly relevant, but not mentioned in the briefs, is the fact that under the federal Rehabilitation Act and the Americans with Disabilities Act the United States, through the Department of Justice, is responsible for enforcement of requirements that people with disabilities not be discriminated against by federal, state, and private hospitals and other health care providers. This duty of ensuring that people with disabilities are treated equally in regard to medical treatment is not relied upon, nor even mentioned, in the Department of Justice briefs.

A. A Split of Opinion?

Within the disability community, divergent opinions about assisted suicide have given rise to heated debates; advocates for the differing positions articulate strong arguments that theirs is the more informed position or is more representative of a majority of individuals with disabilities. The absence of a

single consensus viewpoint within the group does not mean, however, that the opposing views cancel one another out; each of the viewpoints is significant. The two separate points of view in the disability community are each voicing a legitimate and weighty concern that is rooted in the disability experience.

On the one hand, those individuals with disabilities and organizations who favor assisted suicide help to point out that people with disabilities are entitled to, and in the past have often been deprived of, the opportunity to make full choices for themselves. Individuals with disabilities should be entitled, says this view, to make their own life choices without interference from medical personnel and society at large, particularly when the choice is one to avoid unbearable pain by foregoing a few days, weeks, or months of additional life. Other members of the disability community and organizations representing them argue that assisted suicide has and will be used to cut short the lives of people with disabilities whose quality of life and worth as human beings have long been egregiously undervalued by society. Each of these viewpoints has considerable basis in truth. And both of them are motivated by an underlying desire that people with disabilities be accorded a position of dignity and equality in American society. The National Council on Disability believes that articulating with more particularity the various insights of people with disabilities that bear upon the decisions whether or not to prolong and whether or not to abet the shortening of life of

individuals with serious medical conditions will provide considerable guidance and enlightenment as to how these issues should be resolved and the way laws ought to address such matters in the future.

B. Insights from the Disability Experience

1. The Paramount Issue -- Rights, Services, and Options

Arguments for or against assisted suicide in particular situations are often framed in terms of future quality of life of the affected individual. These appraisals of life quality of people with disabilities occur in a context -- the opportunities, impediments, services, burdens, rights, responsibilities, pleasures, suffering, assistance, and obstacles that the individual can expect in her or his situation in our society. In large part, this context is defined by society's treatment of people with disabilities -- the barriers it has erected or tolerated, or prohibited and removed; the rights it has recognized and enforced, or denied, ignored, or not implemented; the services it has provided or fostered, or refused or neglected to provide; the independence and options it has conferred and promoted, or the dependence it has accepted and perpetuated; the suffering it has allowed or condoned, or addressed and ameliorated; the isolation and invisibility it has imposed or accepted, or the integration and participation it has instilled; the choices it has enabled and respected, or its withdrawal of

the very liberty to make choices or acquiescence to the absence of any real choices.

The National Council believes that the issue of assisted suicide should be viewed as interrelated with more basic, general issues of the rights, opportunities, and status of people with disabilities in our nation and of the services, programs, policies, options, and choices our society makes available for people with disabilities. In its July 1996 report to the President and the Congress, Achieving Independence: The Challenge for the 21st Century, the Council presented over 120 recommendations addressing 11 broad topic areas for improving laws, policies, programs, and services for people with disabilities. Implementing the recommendations in Achieving Independence would go a long way toward assuring that any self-assessment or decision about the quality of life of an individual with a disability would be made in an optimal context of independence, equality of opportunity, full participation, and empowerment.

In addition, people with terminal illnesses would benefit greatly from expanded availability of hospice services. These programs provide a team-oriented program of care that seeks to treat and comfort persons with terminal conditions in their homes or in home-like settings, with an emphasis on pain management and control of symptoms.[9] They seek to ameliorate the psychological,

[9] National Hospice Association, "Hospice in Brief" at p. 1.

spiritual, and physical pain that may be associated with the process of dying, and they provide support for family members and friends while their loved one is dying, and bereavement care after the person has died.[10] More than 90% of hospice care hours are provided in patients' homes, thus substituting for more expensive and more disorienting hospitalization.[11] Studies indicate great savings in hospice costs versus alternative forms of treatment.[12] And yet such programs are not yet as widely available as they need to be.[13]

People with disabilities have long tried to convince the rest of society that the most serious problems facing those who have disabilities often arise, not from the disability itself, but from societal attitudes toward and treatment of individuals with disabilities. In 1975, a United Nations Expert Group declared that

> despite everything we can do, or hope to do, to assist each physically or mentally disabled person achieve his or her maximum potential in life, our efforts will not succeed until we have found the way to remove the obstacles to this goal directed by human society -- the physical barriers we have created in public buildings, housing, transportation, houses of worship, centers of social life, and other community facilities -- the social barriers we have evolved and accepted against those who vary more than a certain

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[10] Id.

[11] National Hospice Association, "Hospice Fact Sheet" at p. 1 (Jan. 1, 1997).

[12] Id. at p. 2, citing a 1995 study by Lewin-VHI and a 1988 study conducted by the Health Care Financing Administration (HCFA).

[13] For a good overview and additional information about hospice programs, see, e.g., Larry Beresford, The Hospice Handbook (1993).

> degree from what we have been conditioned to regard as normal. More people are forced into limited lives and made to suffer by these man-made obstacles than by any specific physical or mental disability.[14]

This idea that external factors are more damaging than the characteristics of disability itself is an important insight in trying to evaluate options for dealing with the impact of medical conditions and living with impairments. It suggests that people are likely to have much more success in dealing with their disabilities if they are informed about accommodations and services they may be able to use, and if there are sufficient support services and resources in place to assist in the individual's efforts to cope with the situation. In one dramatic example, Larry McAfee, a Georgia man who was involved in a motorcycle accident that left him quadriplegic and dependent on a ventilator, went to court to establish his right to discontinue the ventilator with the expectation that he would die.[15] Publicity about the case led, however, to communications with disability advocates and an outpouring of community support. Buoyed by this information and support, McAfee refused to exercise his court-recognized "right to die," fought to be released from a nursing home, and got himself a job.

The McAfee outcome is in stark contrast with the situation of Kenneth Bergstedt who, with disabilities similar to McAfee's,

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[14] Report of the United Nations Expert Group Meeting on Barrier-Free Design, 26 Int. Rehab. Review 3 (1975).

[15] State v. McAfee, 385 S.E.2d 651 (Ga. 1989).

had his ventilator discontinued and died, principally because he feared being forced to live in a nursing home after the death of his father. The Nevada Supreme Court, ruling after Bergstedt's death, concluded that his "suffering resulted more from his fear of the unknown than any source of physical pain," and noted that he did not have a realistic understanding of his options sufficient to make an intelligent life-or-death decision.[16] Reviewing the limited assistance afforded Bergstedt before his death, a dissenting judge commented: "With this kind of support it is no wonder that he decided to do himself in."[17] If he were still alive, said the court, "it would have been necessary to fully inform him of the care alternatives that would have been available to him after his father's death or incapacity."[18]

The Bergstedt situation focuses on patients' being provided accurate information about services, support, and other resources. Equally or more important, however, is that adequate support systems and options be in place and available. People with disabilities facing medical treatment decisions need both information about options and the availability of the options themselves. Such community support services may take a variety of forms -- counseling, independent living services, vocational rehabilitation, treatment of depression, contact with disability

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[16] McKay v. Bergstedt, 801 P.2d 617, 624-35 (Nev. 1990).

[17] Id. at 637.

[18] Id. at 628.

peers and organizations, clear and understandable medical information, financial resources, housing options, transportation options, assistive devices, interpreters and personal care assistance, various types of therapy, job training, and others.

Clearly the elimination of discriminatory barriers and the availability of support services and financial resources, including adequate health insurance, will greatly impact the chances that a person will successfully deal with a disability. In the final analysis, most people with disabilities would welcome the same amount of attention for community support services and resources, and the kinds of efforts recommended in Achieving Independence as is currently being focused on the issue of assisted suicide.

2. The Reality and Prevalence of Discrimination

The opposing views within the disability community on the issue of assisted suicide share a common ground -- a recognition of the danger of discrimination to the interests and fair treatment of people with disabilities. Those opposed to assisted suicide fear that deeply ingrained prejudice and patterns of undervaluing the worth of individuals having disabilities have led and will predictably continue to lead to the unnecessary deaths of persons with disabilities. Those who believe that people with disabilities should have access to physician-assisted suicide point out that one of the principle dynamics that have prevented people with disabilities from occupying a position of

equality and dignity in society has been the denial of the right of people with disabilities to make their own choices, and that other people have often imposed undesired life choices upon people with disabilities. Neither point of view doubts the existence of discrimination against people with disabilities.

On many previous occasions, the Council has discussed and documented the existence of widespread and virulent discrimination on the basis of disability. The existence of such discrimination and the deleterious effect that it has upon citizens with disabilities and our Nation were primary reasons that in 1986 the Council proposed the enactment of the Americans with Disabilities Act (ADA). In enacting the ADA, Congress expressly found that "historically, society has tended to isolate and segregate individuals with disabilities, and despite some improvements, such forms of discrimination continue to be a serious and pervasive social problem."[19] Further, it declared that individuals with disabilities "have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society.[20] Congress also made findings that such discrimination persists in the critical areas of "health services ... and access to public services."[21]

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42 U.S.C. §12101(a)(2).

[20] *Id.* §12101(a)(7).

[21] Id. at §12101(a)(2).

Discrimination against people with disabilities in regard to medical treatment had previously examined by the U.S. Commission on Civil Rights which concluded that people with disabilities "face discrimination in the availability and delivery of medical services" including the "withholding of lifesaving medical treatment."[22] The deep-seated nature of discrimination on the basis of disability has been widely acknowledged and documented by numerous other authorities.[23]

Discrimination against them because of their disabilities is a daily experience of many individuals with disabilities.

3. Deprivation of Choices and the Importance of Self-Determination

Many people with disabilities subscribe to an approach to

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[22] U.S. Comm'n on Civil Rights, Accommodating the Spectrum of Individual Abilities 35-36 (1983).

[23] See, e.g., Accommodating the Spectrum of Individual Abilities 17-42, 159; Alexander v. Choate, 469 U.S. 287, 295-96, 286 (quoting 117 Cong. Rec. 45,974 (1971) (statement of Rep. Vanik); 118 Cong. Rec. 526 (1972) (statement of Sen. Percy)) (1985); S. Rep. No. 116, 101st Cong., 1st Sess. 9 (1989); H.R. Rep. No. 485, 101st Cong., 2d Sess. pt. 2, at 32 (1990) (Education and Labor Committee) [hereinafter Education & Labor Committee Report]; Task Force on the Rights & Empowerment of Americans with Disabilities, Equality for 43 Million Americans with Disabilities: A Moral and Economic Imperative 8 (1990), quoted in Education & Labor Committee Report, at 31-32; Louis Harris & Assocs., The ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream 70, 75 (1986); Louis Harris & Assocs., The ICD Survey II: Employing Disabled Americans 12 (1987); City of Cleburne v. Cleburne Living Center, 473 U.S. 432, 454 (Stevens, J., joined by Burger, C.J., concurring) (1985); id. at 461, 462 (Marshall, J., joined by Brennan & Blackmun, JJ., concurring in part and dissenting in part).

living with disabilities that is termed "independent living." The Council has endorsed the independent living philosophy and it has been embraced in various federal statutes.[24] The U.S. Commission on Civil Rights has observed that a key element of independent living is self-determination for individuals with disabilities: "Independent living programs insist on `client self-choice rather than incorporation of the client into a set of goals established by program managers, service professionals, or funding mechanisms . . . .'"[25] At the core of the independent living philosophy is a conviction that people with disabilities "desire to lead the fullest lives possible, outside of institutions, integrated into the community, exercising full freedom of choice."[26] One disability advocate has elaborated:

> Independent living is . . . to live where and how one chooses and can afford. It is living within the community in the neighborhood one chooses. It is living alone or with a roommate of one's choice. It is deciding one's own pattern of life-schedule, food, entertainment, vices, virtues, leisure, and friends. It is freedom to take risks and freedom to make mistakes.[27]

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[24] See, e.g., 29 U.S.C. §§ 701(a)&(b), 706(20), 706(30), 796a(1), 796d(a), 796c(a)(2); 42 U.S.C. §§ 8013(4), 12101(a)(8).

[25] Accommodating the Spectrum, supra n. 17, at 83-84, (quoting Timothy M. Cole, "What's New About Independent Living?," 60 Archives Physical Med. & Rehabilitation 458-62 (1979)).

[26] Center for Independent Living, "Independent Living: The Right to Choose," in Disabled People as Second-Class Citizens 248 (Eisenberg, Griggins, & Duval eds., 1982) (quoted in Accommodating the Spectrum, supra n. 17, at 84).

[27] Gini Laurie, "Independent Living Programs," 22 Rehabilitation Gazette 9-11 (1979) (quoted in Accommodating the Spectrum, supra n. 17, at 83).

Regarding the latter point, some authorities have described the "dignity of risk," a concept that counters overprotection of people with disabilities by advocating a right of such people to take normal risks.[28] One commentator has observed: "The dignity of risk is what the independent living movement is all about. Without the possibility of failure, the disabled person is said to lack true independence and the mark of one's humanity -- the right to choose for good or evil."[29]

1992 amendments to the Rehabilitation Act increased the focus on independent living and spelled out in more detail the approach that Congress understood to be represented by that phrase. Congress found that

> disability is a normal part of the human experience and in no way diminishes the right of individuals to -- (A) live independently; (B) enjoy self-determination; (C) make choices; (D) contribute to society; (E) pursue meaningful careers; and (F) enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society.[30]

Congress also declared that "the goals of the Nation properly include the goal of providing individuals with disabilities with the tools necessary to -- (A) make informed choices and decisions; and (B) achieve . . . independent living . . . for

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[28] See, e.g., Accommodating the Spectrum, supra n. 17, at 85, and authorities cited therein.

[29] Gerben DeJong, "Independent Living: From Social Movement to Analytic Paradigm," 60 Archives Physical Med. & Rehabilitation 435-46 (1979) (quoted in Accommodating the Spectrum, supra n. 17, at 85).

[30] *Id.* §701(a)(3), *as amended by* Pub. L. No. 102-569, tit. I, §101, 106 Stat. 4346 (1992).

such individuals."[31]

However phrased, it is clear that equality and dignity for people with disabilities are strongly connected to the ability to of individuals with disabilities to make important life choices for themselves.

4. Others' Underestimation of Life Quality

One of the hallmarks of societal attitudes toward disabilities has been a tendency of people without disabilities to overestimate the negative aspects and underestimate the positive features of the lives of those who have disabilities. The attitude of "I don't see how you can live with that" -- sometimes expressed more dramatically as "I'd rather be dead than have [X disability]" -- is one that people often exhibit in their encounters with people with disabilities.

The U.S. Commission on Civil Rights has described the "extremely extensive" negative connotations of disability: "To the fact that a [person with a disability] differs from the norm physically or mentally, people often add a value judgment that such a difference is a big and very negative one."[32] The United States Supreme Court has acknowledged that "society's accumulated myths and fears about disability are as handicapping as are the

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[31] *Id.* §701(a)(6), *as amended by* Pub. L. No. 102-569, tit. I, §101, 106 Stat. 4346 (1992).

[32] U.S. Comm'n on Civil Rights, Accommodating the Spectrum of Individual Abilities 26 (1983)

physical limitations that flow from actual impairment."[33] Regulations and courts addressing job discrimination based on disability under the ADA and other laws have expressly identified the discrimination that results from misperceptions and unrealistically low expectations of what people with disabilities are able to do.[34] One legal commentator has written that "[t]he image of a [person with a disability] as one who is not able to do many things, who is unable to fill a proper role in society, and who is not a success in terms of achievements or happiness is widespread and deep-seated."[35]

In reality, such attitudes and negative predictions of life quality have little to do with the actual life experiences of

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[33] School Board of Nassau County v. Arline, 480 U.S. 273, 284-85 (1987).

[34] 29 C.F.R. 406 (app. to pt. 1630) (commentary on §1630.2(l)) (1993) (can prove discrimination "by demonstrating that the exclusion was caused by one of the `common attitudinal barriers' toward individuals with disabilities such as an employer's concern about productivity, safety, insurance, liability, attendance, cost of accommodation and accessibility, workers' compensation costs, and acceptance by coworkers and customers"); Wooten v. Farmland Foods, 58 F.3d 382, 385 (8th Cir. 1995) (the "regarded as" prong of the definition of disability encompasses "archaic attitudes, erroneous perceptions, and myths"). Several ADA decisions have recognized employers' "myths, fears and stereotypes associated with disabilities." See, e.g., Freund v. Lockheed Missiles and Space Co., 930 F.Supp. 613, 618 (S.D.Ga. 1996); EEOC v. Texas Bus Lines, 923 F.Supp. 965, 975 (S.D.Tex. 1996); Howard v. Navistar Internat'l Transp. Corp., 904 F.Supp. 922, 929-30 (E.D.Wis. 1995); Pritchard v. Southern Company Services, 1995 WL 338662, 4 AD Cases 465, 473 (N.D.Ala. 1995); Lussier v. Runyon, 1994 WL 129776, 3 AD Cases 223, 231 (D.Me. 1994); Scharff v. Frank, 791 F.Supp. 182, 187 (S.D.Oh. 1991) ("stereotypical treatment").

[35] Robert L. Burgdorf Jr., The Legal Rights of Handicapped Persons: Cases, Materials, and Text 8 (1980).

people with disabilities. People with disabilities commonly report more satisfaction with their lives than others might have expected. Though they commonly encounter obstacles, prejudice, and discrimination, most people with disabilities manage to derive satisfaction and pleasure from their lives. After conducting a nationwide poll of people with disabilities, Louis Harris and Associates reported that "[d]espite their disadvantaged status and frequent exclusion from activities enjoyed by most Americans, a large majority of disabled Americans are satisfied with their lives"; the Harris organization described this as "a remarkable finding in light of the portrait of hardships revealed in these survey findings."[36] Even individuals who identified themselves as having very severe disabilities tended to report that they were very or somewhat satisfied with their lives.[37]

Nor do disabilities generally have the devastating effect upon the social milestones of marriage and having children that some might expect. There is virtually no difference between the proportion of Americans with disabilities and those without who are married,[38] and most people with disabilities do not consider their disability to have much impact on their ability to have

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[36] Louis Harris & Assocs., The ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream 55 (1986).

[37] Id. at 46, Table 19.

[38] Id. at 42.

children or their interest in doing so.[39] Even people with severe pain and highly invasive medical treatments report higher life satisfaction than others expect.[40]

The realities of quality of the lives of Americans with disabilities is obscured by the misguided projections and low expectations of others, for as one disability authority has observed, "when society opts to judge the quality of life for an individual with a disability, it does so from the perspective of a fear of disability and historical prejudice and discrimination."[41]

5. Fallibility of Medical Predictions

Many people with disabilities have been great beneficiaries of the miracles of modern medicine. Some owe their very lives and others much of their ability to function to the medical profession. Lifesaving treatments, rehabilitative surgical techniques, new medications, and numerous other medical advances have greatly improved chances for survival, the amelioration of limitations, and options for accommodating disabilities. And yet

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[39] Id. at 42 (only 7% of persons with disabilities say that their disability has a negative effect on their ability to, or interest in, having children).

[40] See, e.g., J.R. Bach & M.C. Tilton, "Life Satisfaction and Well Being Measures in Ventilator Assisted Individuals with Traumatic Tetraplegia," 75 Arch. of Physical Med. & Rehab. 626 (1994).

[41] Paul Steven Miller, The Impact of Assisted Suicide on Persons with Disabilities -- Is It A Right Without Freedom?, Issues in Law & Medicine 9:47, 54 (1993).

people with disabilities have also frequently seen firsthand evidence that medicine is not totally a science but still something of an art, particularly in regard to the imperfections of medical prognosticating. Individuals with disabilities and parents of children with disabilities have encountered numerous kinds of fervently pronounced, but inaccurate predictions by members of the medical professional. Some have been told that they or their children would not survive, or would not regain consciousness, or would not walk, or would not read, or would not be toilet-trained, or could not live independently, or could not perform particular activities, and yet ultimately found these predictions to be wildly inaccurate. Other people have been confined and subjected to involuntary treatment regimes based upon notoriously unreliable predictions about their supposed proclivities, ability to cope, or even dangerousness, based upon the application of psychiatric labels.

Predictions of patients' life expectancy are particularly difficult and unreliable.[42] Indeed, "[a] surprising number of people have had the experience of being misinformed that they had a terminal illness."[43] Evan Kemp, former chairman of the Equal Employment Opportunity Commission, who was diagnosed with a progressive neuromuscular disease at age 12, has written:

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[42] See, e.g., Joanne Lynn, et al., Accurate Prognostications of Death: Opportunities and Challenges for Clinicians, 163 W.J.Med. 250, 251 (1995).

[43] Richard A. Posner, Aging and Old Age 245 (1995).

> Upon diagnosis, my parents were informed by the physicians treating me that I would die within two years. Later, another group of physicians was certain that I would live only to the age of 18. Yet here I am at age 59, continuing to have an extraordinarily high quality of life.
>
> And my case is by no means unique. The majority of families I have encountered in my lifetime, and who have been close enough to share details of their extended family life, have had at least one member who defied the medical establishment by living a far longer and more productive life than expected.[44]

One noteworthy example of erroneous medical predicting grew out of an early, widely publicized court case[45] in which permission was sought to discontinue a ventilator for a comatose young woman named Karen Quinlan. There was no dispute among the medical experts that without the assistance of the ventilator Ms. Quinlan would die in a matter of days or weeks, if not hours. After the New Jersey courts approved discontinuance of the ventilator, it was removed, but Karen Quinlan stayed alive, breathing on her own, for almost ten years. However one feels about the court's decision in the Quinlan matter, it is clear that the medical forecasting was substantially erroneous in this highly visible, carefully considered, fully-litigated situation.

This is not to suggest that most or even a substantial portion of medical forecasting is erroneous, but people with disabilities are aware of enough instances of dramatic mistakes that many of them have a healthy skepticism of medical

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[44] Evan J. Kemp Jr., "Could You Please Die Now?: Disabled People Like Me Have Good Reason to Fear the Push for Assisted Suicide," The Washington Post C1 (Jan. 5, 1997).

In re Quinlan, 355 A.2d 647 (N.J. 1976).

predictions, particularly as it relates to future life quality. Medical personnel are generally not very knowledgeable of special education and rehabilitation techniques, specialized accommodations, independent living philosophy, and other factors that may spell the difference between a direly limited or a satisfying and fulfilling future for an individual with a disability.

6. Eschewing the Medical Model of Disabilities

In its Achieving Independence report, the Council observed that a "disability rights perspective ... stands in contrast to a medical model, which views people with disabilities as needing to be cured.'"[46] The medical model imposes certain expectations upon both the medical personnel and the "patient."[47] It places primary responsibility for diagnosis and treatment in the hands of medical practitioners. Physicians are deemed to be the technically competent experts for addressing the patient's needs through an established chain of command to other medical personnel. The patients, for their part, are expected to play the roles of "sick" or "impaired" persons; this entails an exemption from some ordinary social activities and responsibilities, and an expectation that they will cooperate

[46] National Council on Disability, Achieving Independence: The Challenge for the 21st Century 19 (1996).

[47] See, e.g., Gerben DeJong, Independent Living: From Social Movement to Analytic Paradigm, 39, 50-51 (Robert P. Marinelli & Arthur E. Dell Orto, eds., 1984).

with the attending medical practitioners in "getting well."[48] The medical model views people with disabilities as "victims" of a medical problem in need of treatment, not as responsible adults in need of rights and respect.[49]

People with disabilities have first-hand experience with the medical model in various service delivery systems including hospitals and some rehabilitation facilities, and sometimes, often in its most egregious form, in mental health treatment facilities. The application of the medical model in the mental health context has been widely described and vehemently criticized by various commentators.[50] Frequently, it has involved the involuntary institutionalization of individuals based upon a dubious psychiatric diagnosis, enforced confinement on locked wards in a control-oriented regime with limited

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[48] Id. at 52-53.

[49] Douglas Biklen, The Myth of Clinical Judgment, Journal of Social Issues Vol. 44: 127, 128 (1988).

[50] See, e.g., Erving Goffman. Asylums: Essays on the Social Situation of Mental Patients and Other Inmates. Garden City, N.J.: Anchor Books; Thomas S. Szasz. 1961. The Myth of Mental Illness. New York: Harper and Row; Thomas S. Szasz. 1970. The Manufacture of Madness: A Comparative Study of the Inquisition and the Mental Health Movement. New York: Dell; R.D. Laing. 1967. The Politics of Experience. New York: Pantheon Press; Ethan Fromm. 1970. The Crisis of Psychoanalysis. New York: Holt, Rinehart and Winston; E. Fuller Torrey. 1975. The Death of Psychiatry. New York: Penguin Books; John Gliedman & William Roth. 1980. The Unexpected Minority: Handicapped Children in America. New York: Harcourt Brace Jovanovich; Bonnie Milstein & Steven Hitov. 1993. Housing and the ADA. In Lawrence O. Gostin & Henry A. Beyer, eds. Implementing the Americans with Disabilities Act: Rights and Responsibilities of All Americans, 137, 144-47. Baltimore, MD: Paul H. Brookes Publishing Co.

freedoms conditioned upon compliance with the rules of the facility, as well as "treatment" which may be unwanted, most frequently the administration of powerful psychotropic drugs or controversial electroshock "therapy." As commentators have noted: "First and foremost, programs reflect the medical model mentality that perceives people with mental disabilities as perpetual patients, with the resultant infantilization that so often accompanies that status."[51]

Many people with disabilities reject the behavioral expectations imposed upon them by such roles, and "do not want to be relieved of their familial, occupational, and civic responsibilities in exchange for a childlike dependency."[52] Clearly the medical model is contrary to the notions of independent living, consumer self-direction, and freedom of choice discussed in section 3 above. From an independent living perspective,

> the pathology is not in the individual, as the medical model would suggest, but rather in the physical, social, political and economic environment that has up to now limited the choices available to people with disabilities. The solution to these problems is not more professional intervention but more self-help initiatives leading to the removal of barriers and to the full participation of disabled people in

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[51] Bonnie Milstein & Steven Hitov. 1993. Housing and the ADA. In Lawrence O. Gostin & Henry A. Beyer, eds. Implementing the Americans with Disabilities Act: Rights and Responsibilities of All Americans, 137, 145-46. Baltimore, MD: Paul H. Brookes Publishing Co.

[52] DeJong, supra, at 52.

society.[53]

Again, this is not to suggest that people with disabilities have not received great benefits from various medical interventions, assuming truly informed consent has been obtained -- from treatments and therapies provided by medical personnel and from the treatment techniques, devices, and medications available at modern medical facilities. Nonetheless, many people with disabilities view the medical model as a poor prism, for themselves and our society, through which to view the reality of their lives with disabilities.

7. The Impact of Onset of Disability Upon Emotional State and Decision-Making

When a person is not born with a disability, the onset of a substantially impairing condition and the awareness of one's new physical or mental limitations usually come as a blow to a person's self-image and psychological balance. Disabilities that are the result of violence, accident, or illness usually are accompanied by additional emotional repercussions. The inception of disabilities is often associated with a period of hospitalization or other intense medical intervention that adds additional disorientation. Pain and medication may take an additional toll on emotional equilibrium. Family members and friends may be devastated by what has happened and find it hard

[53] Gerben DeJong and Raymond Lifchez, Physical Disability and Public Policy, The Scientific American 248: 41, 45 (1983).

to relate to the individual in ways they normally did in the past. Neither the individual with the new disability nor friends and family members may have any idea how people adapt to such a condition, any concept of rehabilitation possibilities, nor a clue that many people are living fulfilling and joyful lives with the same or even more severe conditions. To a person newly confronted with the realization that he or she has a disability, it may appear that the "whole world has been turned upside down." Strong feelings of fear, helplessness, anger, sadness, shame, and confusion are common.

It is typical, therefore, for people who have recently been confronted with a disability to experience a period of disorientation and depression. With proper assistance and information, such disorientation and depression usually abate over time. It may follow a pattern of denial, anger, hopelessness, adjustment that characterize the grieving process for various kinds of serious losses. Sometimes medication, psychotherapy, or other treatment may be necessary to help deal with lingering depression. Most people with disabilities gradually come to accept and live constructively with their disabilities. They may undergo rehabilitation and learn techniques for adapting to and surmounting limitations; they may discover that there are devices and accommodations that will make them more independent, productive, and comfortable; they may find that many other people have similar conditions and managing to do quite well anyway. Generally the feelings of helplessness and

sadness fade away to a manageable level over time.

The existence of a normal period of disorientation and depression following the acquisition of a disability makes it imperative that people in such a situation not try to make long-term or irreversible decisions that may be colored by the temporary depression and disorientation rather than by an exercise of sound judgment. Medical personnel cannot be counted on to distinguish between the two situations, for "physicians responding to requests for assistance are often inadequately trained to distinguish rational requests from those driven by depression."[54] The experience of numerous people with disabilities is that they would have been unable to make truly rational decisions while still in the throes of the unsettled state of mind that commonly accompanies the onset of a disabling condition. Moreover, during such a period of confusion and emotional instability, people are particularly vulnerable to duress, intimidation, and coercion by those around them.

In addition, people newly confronted with a disability "may have internalized society's prejudices against persons with disabilities or developed fears about living with a disability. With counseling and time, however, such notions or feelings can

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[54] David Orentlicher, M.D., J.D., "The Legalization of Physician Assisted Suicide," New England Journal of Medicine 335: 663, 664 (Aug. 29, 1996), citing Y. Conwell & E.D. Caine, "Rational Suicide and the Right to Die -- Reality and Myth," New England Journal of Medicine 325: 1100-03 (1991).

dissipate."[55] With proper information, support, and care, the depths of disorientation and overwhelming sadness will usually ease with the passage of time and the person with a new disability will have a chance to integrate the idea of having a disability, to learn ways to manage it and its consequences, and to return to the quest confronting all human beings of trying to wrest a reasonable degree of happiness and fulfillment from our existence.

8. The Reality of Living with Pain and Bodily Malfunction

Some individuals with disabilities have had to confront severe pain, sometimes chronic pain, and have experienced the two-edged reality of living with such pain. On the one hand, they have encountered the truly debilitating effects of chronic pain that saps one's strength and drains one's psyche. Only persons who have experienced significant, long-term pain fully understand its crushing impact. On the other hand, many people have learned firsthand that there are a variety of techniques for treating pain, including various medications, biofeedback, nerve treatments, hypnosis, and other nonobtrusive alternative medical treatments. Moreover, even in the rarer situations where pain is essentially untreatable, some individuals have learned to

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[55] Paul Steven Miller, "The Impact of Assisted Suicide on Persons with Disabilities -- Is It A Right Without Freedom?," Issues in Law & Medicine 9:47, 58 (1993).

successfully live with their pain, and report life satisfaction and desire to continue living despite their pain.[56]

From these varying experiences, one learns that some people's pain can be treated and ameliorated, others can learn to manage and live with their pain, and still others experience pain that cannot be eased and that they find themselves unable to endure. The very real impact of chronic, severe, untreatable pain should not be underestimated.

People with disabilities also have considerable experience in dealing with the malfunctioning, breakdown, or absence of normal body parts or mental processes. Having learned to deal with such imperfect functioning as part of their ongoing day-to-day existence, people with disabilities are much less likely to be horrified by such physical or mental dysfunction. Consequently, people with disabilities tend to be much more aware than the general public that one can lead a valid, happy life even though one's legs or eyes or arms or memory or bladder or ears or mouth or brain or genitals or sensory processing or hands or whatever other parts of the body or mind are not working properly.

A key implication of people with disabilities' experience

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[56] See, e.g., J.R. Bach & M.C. Tilton, "Life Satisfaction and Well Being Measures in Ventilator Assisted Individuals with Traumatic Tetraplegia," 75 Arch. of Physical Med. & Rehab. 626 (1994); Ezekiel J. Emmanuel, Diane L. Fairclough, Elisabeth R. Daniel, & Brian R. Clarridge, "Euthanasia: Physician Assisted Suicide: Attitude and Experiences of Oncology Patients, Oncologists, and the Public," Lancet 347: 1805-10 (1996).

with pain and dysfunction is the need for more frequent and informed use of pain relief medication. The American Medical Association (AMA) and the United States Government have both acknowledged that physicians have not done an adequate job in treating pain.[57] To address this problem, the AMA, the American Board of Internal Medicine, the American Academy of Hospice and Palliative Medicine, and other medical organization have undertaken various initiatives to improve the training and continuing education of doctors in pain relief measures for persons with terminal medical conditions.[58] According to medical authorities, many physicians are not sufficiently familiar with the use of various treatments, including heavy doses of morphine, to control pain in dying patients.[59] Medical ethics standards permit doctors to prescribe medication to relieve pain even if the necessary dose will hasten death.[60] Better training of

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[57] Knight Ridder/Tribune, "AMA to Teach Doctors to Aid the Dying," Chicago Tribune p. 1A10 (Dec. 13, 1996); Brief for the United States as Amicus Curiae Supporting Petitioners in Vacco v. Quill, No. 95-1858, October Term, 1996 at p. 9 (referring to "health care system that often undertreats patients' pain"); Brief for the United States as Amicus Curiae Supporting Petitioners in State of Washington v. Glucksberg, No. 96-110, October Term, 1996, at p. 19 ("inadequately treated pain").

[58] Knight Ridder/Tribune, "AMA to Teach Doctors to Aid the Dying" Chicago Tribune p. 1A10 (Dec. 13, 1996).

[59] Id.

[60] AMA Council on Ethical and Judicial Affairs, Code of Medical Ethics: Current Opinions § 2.20 (1989), cited in Brief for the United States as Amicus Curiae Supporting Petitioners in State of Washington v. Glucksberg, No. 96-110, October Term, 1996, at p. 17.

physicians in techniques and standards for treatment of pain should be a primary goal, so that all individuals who are confronted with serious pain can have maximum relief. Moreover, hospice and other programs and treatments to make the process of dying more comfortable and peaceful should be made widely available.

9. Divergent Interests of Those Involved in Assisted Suicide Decisions

As they have undertaken to attain independence and self-determination in their lives -- to make the kinds of choices regarding their own activities, living arrangements, and means for pursuing happiness that other Americans take for granted -- citizens with disabilities have become sharply aware of the fact that their interests often diverge from those of others who would seek to act "in their best interest." Medical personnel, officials of residential and other care-giving facilities, religious officials, social workers, rehabilitation professionals, and even family members often have views as to what would be best for an individual with a disability that are drastically different from what she or he actually wants. This becomes particularly true when there may be other interests or agendas being pursued by these other parties.

Decisions about medical care are particularly subject to such separate, and often conflicting, interests in the outcome. Physicians may have concerns about prolonging treatment of

patients whom they are unable to "cure," and psychological pain about continuing to see patients for whom they have "failed." Or they may have pressures from too heavy a patient load. Overcrowded medical facilities may need "the bed" that the patient is occupying. The doctor and the medical facility may be concerned about insurance limits on extended treatment or the exhaustion of financial resources of the patient or the patient's family, and fear that the bill for continued care will never be paid. Conferring medical peers may have various motivations including mutual backscratching, professional deference, or career goals that render peer review a mere rubberstamping. Other medical personnel and related professionals may have their own personal or philosophical axes to grind.

Family members may have any number of tensions, disputes, agendas, and pressures, not the least of which may be financial concerns, or emotional strain or exhaustion from the ordeal of extended medical treatment of a family member or of having a close relative diagnosed with a terminal condition. In what hopefully are rarer cases, a close relative may have actual animosity toward the person who is undergoing treatment or may be involved in a love triangle or some other conflict-filled situation.

People with disabilities would generally be unwilling to let doctors, nurses, medical review panels, or their own families make judgments in their place concerning something as important as their health and very life.

V. CONCLUSIONS

Based upon the foregoing insights derived from the experience of people with disabilities and the existing legal framework, the National Council on Disability has grappled to arrive at a constructive, principled position on the issue of physician-assisted suicide for persons with imminently terminal conditions. To some degree this effort has appeared to be like the plight of the mythical Jason whose ship, the Argo, had to sail between the two monsters Charybdis and Scylla -- neither choice is very appealing.

Opposing the legalization of assisted suicide seemingly deprives people with disabilities faced with imminent death and severe pain the only power they can have to decide when and how they will die, an ability to choose that might offer them some control, dignity, and measure of self-determination in an otherwise bleak situation; such control of one's own destiny, freedom of choice, and self-determination are key principles of the disability rights and independent living philosophies and cornerstones of the initiatives which the Council has advocated.

On the other hand, legalizing assisted suicide seems to risk its likely use, the ultimate manifestation of prejudice against people with disabilities in our society, as a means to unnecessarily end or to coerce the end of people with disabilities' lives; persons with disabilities know that many in society believe that they would be better off dead, and legalized assisted suicide offers a subtle and sometimes-not-so-subtle way

to make that judgment a reality.

To resolve this dilemma, the Council has weighed the pros-and-cons very carefully. Among other considerations, it has found the following to weigh very heavily in its deliberations:

The Current Situation

Under current law, most people who choose to commit suicide can do so without the assistance of a physician. Only a small number of people having disabilities are unable to terminate their lives if they choose to do so. Patients have the right to refuse medical treatments, even lifesaving or life-prolonging measures; informed consent of the patient is a legal prerequisite for the initiation or continuation of medical treatment. Physicians are permitted under current medical standards to prescribe medication as necessary to control pain, even if the necessary dosage will result in hastening the patient's death. Most, though not all, pain, even if severe, can be controlled by the proper administration of medication; better training of physicians would improve effective treatment of pain. Many individuals learn to live satisfying lives in spite of experiencing severe pain.

People with disabilities' lives are frequently viewed as valueless by others, including members of the medical profession. People with disabilities are often harassed and coerced to end their lives when faced with life-threatening conditions, even if the conditions are imminently treatable; others have had their

lives involuntarily terminated by medical personnel. These practices manifest blatant prejudice and are a virulent form of the discrimination that the Americans with Disabilities Act and other laws condemn. Legal and medical authorities should denounce and prohibit any attempt to pressure, harass, or coerce any individual to shorten her or his life; they should certainly proscribe any action to terminate an individual's life taken without that person's full, voluntary, and informed consent, whether it be called "suicide," "mercy killing," "letting nature take its course," or some other euphemistic term. And certainly there should be official condemnation and cessation of practices by which people with disabilities are pressured to sign "Do Not Resuscitate" consent forms, or such forms are hidden within a stack of admission and consent papers in the hope that the individual with a disability will sign them without paying attention to what is being signed.

Procedural Protections

As a potential escape hatch from the dilemma described above, the Council considered the possibility that a properly devised set of procedural protections could permit physician-assisted suicide to occur in limited circumstances while preventing it from being abused or applied improperly to the disadvantage of people with disabilities. There have been various proposals of such procedural safeguards or the elements

they should contain.[61] An article in the New England Journal of Medicine proposed a system in which treating physicians would be prohibited from complying with a patient's request for assisted suicide unless the request was approved by a physician "palliative care specialist" and by a "regional palliative care committee" with both lay and professional members.[62] In the Netherlands, assisted suicides (and active euthanasia) are permitted by the courts if they satisfy nine criteria that impose a combination of substantive platitudes and procedural standards:

> (1) The patient must be suffering unbearably; (2) the patient must be conscious when he expresses the desire to die; (3) the request for euthanasia must be voluntary; (4) the patient must have been given alternatives with time to consider them; (5) there must be viable solutions for the patient; (6) the death must not inflict unnecessary suffering on others; the decision must involve more than one person; (8) only a physician may perform the euthanasia; and (9) the physician must exercise great care in making the decision.[63]

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[61] In the related context of discontinuance of life-prolonging treatment for patients totally unable to make the decisions themselves, some courts have required various procedural safeguards. See Superintendent of Belchertown v. Saikewicz, 370 N.E.2d 417 (Mass. 1977) (required approval in court proceeding with appointment of a guardian ad litem to represent the interests of the patient); In re Quinlan, 355 A.2d 647 (N.J. 1976) (required combined agreement of the attending doctors, the family, and hospital review panel).

[62] Franklin G. Miller, Timothy E. Quill, Howard Brody, John G. Fletcher, Lawrence O. Gostin, & Diane E. Meier, "Regulating Physician Assisted Death," The New England Journal of Medicine 331: 119-122 (July 14, 1994).

[63] Report of Chairman Charles T. Canady to the Subcommittee on the Constitution of the Committee on the Judiciary of the House of Representatives 104 Cong., 2d Sess., p. 6 (September 1996). In 1986, the Royal Dutch Medical Association published "Guidelines for Euthanasia," that establish five criteria: "voluntariness," "a well considered request," "persistent desire

These limited procedural protections have certainly not worked. As Representative Charles Canady, Chair of the Subcommittee on the Constitution of the U.S. House of Representatives has reported, the Netherlands procedures "give an enormous amount of discretion to doctors, and, consequently, give very little protection to patients."[64] As a result, non-voluntary euthanasia is being widely performed in the Netherlands.[65]

One of the briefs filed in favor of legalizing physician-assisted suicide in the pending Supreme Court cases suggested that states might impose the following safeguards:

- requiring the individual to repeat the request on more than one occasion;
- requiring the request to be made to more than one doctor;
- requiring the individual to be provided an opportunity to discuss the problem with a mental health professional;
- requiring the individual to be informed of programs and resources that are available to improve the quality of his or her remaining life; and
- requiring the individual to be informed on several occasions that he or she may, and is encouraged to,

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for death," "unacceptable suffering," and "collegial consultation." Id. at 8, quoting Jürgen Wöretshofer & Matthias Borgers, "The Dutch Procedure for Mercy Killing and Assisted Suicide by Physicians in a National and International Perspective," Maastricht Journal of European and Comparative Law 2:2, 7 (1996).

[64] Report of Chairman Charles T. Canady to the Subcommittee on the Constitution of the Committee on the Judiciary of the House of Representatives 104 Cong., 2d Sess., p. 11 (September 1996).

[65] Id. at p. 1.

change his/her mind at any time.[66]

The vigorous implementation of these various proposals would still fall far short of protecting the rights and interests of people with disabilities. To effectively limit assisted suicides to appropriate situations and make certain that they do not become a vehicle for fatal discrimination against people with disabilities, such procedures would, at a minimum, have to ensure: that the patient's diagnosis is completely accurate; that the condition of the patient is definitely terminal; that the patient's death is imminent; that there are no available treatments that can save or significantly prolong the patient's life; that the patient is suffering unendurable pain and this pain cannot be controlled by medication or alternative treatments or therapies; that the patient wishes to commit suicide; that the patient's decision is based upon full information about the patient's diagnosis, prognosis, and options and the patient has understood this information; that the patient's desire to die is not a result of temporary dejection resulting from disorientation, adjusting to new limitations, or other causes; that the patient's desire to die is not a result of prejudice, stereotypes, and misinformation about people with disabilities and living with a disability; that the patient's decision to seek suicide is reached only after the patient has received, from

[66] Brief for Amici Curiae, Gay Men's Health Crisis et al. in Vacco v. Quill, No. 95-1858, and State of Washington v. Glucksberg, No. 96-110, October Term, 1996, at p. 15.

knowledgeable disinterested sources, a thorough exploration and explanation of treatment options, rehabilitative techniques, assistive devices, accommodations, etc., for living successfully with the patient's disabilities; that the patient has had the opportunity to meet and talk at length with people living with similar disabilities; that the patient has made the decision to choose suicide freely without being influenced by coercion, harassment, intimidation, or duress; that the patient has requested physician assisted suicide repeatedly over a sufficiently long period of time to ensure that it represents a determined steady conviction to end his or her life; that the patient is unable to commit suicide without the assistance of a physician; and that there is oversight by responsible, objective, disinterested, and impartial authorities who can verify whether or not the foregoing prerequisites to a patient's decision to choose suicide have been satisfied.

It may be possible to construct procedural safeguards to ensure that some of these elements are fulfilled in particular circumstances. Given the current state of medical science and human institutions, however, it may be nearly impossible for some of these prerequisites to be satisfied. The diagnosis that conditions are terminal and that death is imminent are not totally reliable. Relative assessments of pain and the state of mind or motivation of patients are not objectively measurable and thus are hard to verify. Medical personnel with an agenda of promoting assisted suicide may influence patients and manipulate

the procedural safeguards. Individuals who are hospitalized, medicated, and faced with a serious health problem are very vulnerable to subtle psychological pressures from their care providers and loved ones. Medical reviews and second opinions are subject to professional deference and conflicts of interest. Can medical authorities realistically attest that the patient has received adequate information about resources, accommodations, assistive devices, and other matters enhancing one's option in living with a disability?

More importantly, however, the more stringent and encompassing one seeks to make procedural safeguards in this context, the more intrusive they become, and the greater the extent to which doctors and psychiatrists become the gatekeepers. Putting the procedures in a judicial or quasi-judicial setting would not avoid this problem, because most of the testimony and opinions would still have to come from medical practitioners, consultants, and experts; the medical profession would still serve as gatekeepers, but now there would be lawyers and judges involved too as overseers. Establishing with certainty that a particular patient has the mental competence and emotional balance for making the decision to die will inevitably involve psychiatric evaluations. As the procedural noose tightens to prevent erroneous and inappropriate assisted suicides, the individual's privacy and control of the situation fly out the window, and the medical model runs rampant. Ironically, the pursuit of assisted suicide in the name of individual liberty

would wind up necessitating egregious restrictions and highly invasive participation by members of the medical and legal professions.

Weighing the Dangers of Physician-Assisted Suicide Against its Benefits

The benefits of permitting physician-assisted suicide have been ably argued by advocates of its legalization. They include respect for individual autonomy, liberty, and the right to make one's own choices about matters concerning one's intimate personal welfare; affording the dignity of control and choice for a patient who otherwise has little control of her or his situation; allowing the patient to select the time and circumstances of death rather than being totally at the mercy of the terminal medical condition; safeguarding the doctor/patient relationship in making this final medical decision; giving the patient the option of dying in an alert condition rather than in a medicated haze during the last hours of life; and, most importantly, giving the patient the ability to avoid severe pain and suffering. Some of these benefits for the individuals involved are substantial and should not be discounted.

Whatever beneficial consequences of physician-assisted suicide there may be, however, the benefits only apply to the small number of people who actually have an imminently terminal condition, are in severe, untreatable pain, wish to commit suicide, and are unable to do so by themselves. Many terminal

patients enduring pain do not wish to terminate their lives.[67] Most of those who do can do so without a doctor's involvement.

The dangers of permitting physician-assisted suicide are large indeed. The pressures upon people with disabilities to choose to end their lives, and the insidious appropriation by others of the right to make that choice for them are already way too common in our society. These pressures are increasing and will continue to grow as managed health care and limitations upon health care resources precipitate increased "rationing" of health care services and health care financing.[68]

There is no doubt that people with disabilities are among society's most likely candidates for ending their lives. As the experience in the Netherlands demonstrates,[69] there is also little doubt that legalizing assisted suicide generates strong pressures upon individuals and families to utilize that option,

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[67] See, e.g., Ezekiel J. Emmanuel, Diane L. Fairclough, Elisabeth R. Daniel, & Brian R. Clarridge, "Euthanasia: Physician Assisted Suicide: Attitude and Experiences of Oncology Patients, Oncologists, and the Public," Lancet 347: 1805-10 (1996) (cancer patients enduring pain not inclined to want euthanasia or assisted suicide).

[68] One author has observed that, as health cares costs increase, while funding for health care and supportive programs is restricted, "assisted suicide becomes a more cost-effective, expedient, and ultimately socially acceptable option. Paul Steven Miller, "The Impact of Assisted Suicide on Persons with Disabilities -- Is It A Right Without Freedom?," Issues in Law & Medicine 9:47, 54, 56 n. 33 (1993).

[69] See generally Report of Chairman Charles T. Canady to the Subcommittee on the Constitution of the Committee on the Judiciary of the House of Representatives 104 Cong., 2d Sess., (September 1996).

and leads very quickly to coercion and involuntary euthanasia. The so-called "slippery slope" already operates in regard to individuals with disabilities and decisions to discontinue life-support systems and "Do Not Resuscitate" orders; it would expand dramatically if physician-assisted suicide were to become legal. Moreover, not only would the lives of people with any disability deemed too difficult to live with be at risk, but persons with disabilities who are poor or members of racial minorities are likely to be in the most jeopardy of all.

If assisted suicide were to be legalized, the most dire ramifications for people with disabilities would ensue unless stringent procedural prerequisites were established to prevent its misuse, abuse, improper application, and creeping expansion. But, to be effective, such procedural safeguards would necessarily sacrifice individual autonomy to the supervision of medical and legal overlords to an unacceptable degree -- the cure in this case being as bad as the disease.

At its core, legalization of physician-assisted suicide would represent a recognition by society that some particular individuals have gotten all the substantial positive benefits they are going to get from their lives, and, in the face of serious pain and suffering they would endure if they continue to live, the few more hours or days they can wring out of existence are not worth it; for such individuals society would be saying that death is preferable to life, and physicians would be empowered to help them terminate their lives. For many people

with disabilities, society has frequently made it clear that it believes they would be better off dead, or better that they had not been born. But it is more often the discrimination, prejudice, and barriers that they encounter, and the restrictions and lack of options that this society has imposed, rather than their disabilities or their physical pain, that cause people with disabilities' lives to be unsatisfactory and painful.

In proposals to legalize assisted suicide, proponents are sometimes willing to agree that a decision to choose suicide must be preceded by a full explanation of the programs, resources, and options available to assist the patient if he or she does not decide to pursue suicide.[70] Many people with disabilities find this to be a very shallow promise when they know that all too often the programs are too few, the resources are too limited, and the options, very often, are nonexistent. Society should not be ready to give up on the lives of its citizens with disabilities until it has made real and persistent efforts to give these citizens a fair and equal chance to achieve a meaningful life.[71] Some of the energy being devoted to promoting assisted suicide might be put to better use in helping to improve

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[70] See, e.g., Brief for Amici Curiae, Gay Men's Health Crisis et al. in Vacco v. Quill, No. 95-1858, and State of Washington v. Glucksberg, No. 96-110, October Term, 1996, at p. 15.

[71] For the Council's proposals as to how America might better afford people with disabilities opportunities for independence, dignity, self-sufficiency, and full participation, see National Council on Disability, Achieving Independence: The Challenge for the 21st Century (1996).

the lives of people with disabilities.

For all of these reasons, the Council has decided that at this time in the history of American society it opposes the legalization of assisted suicide. Current evidence indicates clearly that the interests of the few people who would benefit from legalizing physician-assisted suicide are heavily outweighed by the probability that any law, procedures, and standards that can be imposed to regulate physician-assisted suicide will be misapplied to unnecessarily end the lives of people with disabilities and entail an intolerable degree of intervention by legal and medical officials in such decisions. On balance, the current illegality of physician-assisted suicide is preferable to the limited benefits to be gained by its legalization. At least until such time as our society provides a comprehensive, fully-funded, and operational system of assistive living services for people with disabilities, this is the only position that the National Council on Disability can, in good conscience, support.