

DRAFT COVER MEMO UPON THE REISSUANCE OF THE NCD STATEMENT OPPOSING LEGALIZATION OF ASSISTED SUICIDE – DIANE COLEMAN, J.D.

Introduction

On March 24, 1997, the National Council on Disability issued “Assisted Suicide: A Disability Perspective,” becoming one of the first prominent national disability organizations to address the controversial topic. At the time the Position Paper was issued, the U.S. Supreme Court was preparing to rule on appeals from the Second and Ninth Circuit Courts, each of which had declared assisted suicide a constitutional right.

After a thorough review of the forms of discrimination people with disabilities experience in American society, the Council decided to oppose 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 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.

In the eight years since the Position Paper was issued, the U.S. Supreme Court overturned the Second and Ninth Circuits and ruled that there was no constitutional right to assisted suicide, but that the states could experiment with state laws allowing it. There has been an opportunity to observe the implementation of the Oregon assisted suicide law, and the evolution of cultural attitudes toward so-called “mercy killing,” of both the medical and non-medical variety. Jack Kevorkian was convicted of second degree murder for committing active euthanasia of a man with ALS, utilitarian euthanasia advocate Professor Peter Singer was hired for a prestigious bioethics chair at Princeton University, two movies favorably depicting euthanasia of people with quadriplegia won Oscars, and numerous courts upheld the right of a guardian to starve and dehydrate a severely brain injured but healthy woman in Florida.

Also during the intervening years, additional national disability rights organizations have adopted formal positions opposing legalization of assisted suicide, including but not limited to the American Association of People With Disabilities, the National Council on Independent Living, the National Spinal Cord Injury Association and the Disability Rights Education and Defense Fund. The National Council on Disability shares their interest in working to ensure that all branches of government respect and uphold the civil and constitutional rights of people with disabilities.

Accordingly, the Council is now re-issuing and reaffirming its Position Paper opposing the legalization of assisted suicide.

What Does Disability Have to Do With Assisted Suicide?

Many people who favor legalization of assisted suicide object to the involvement of disability rights organizations in the public debate. After all, they say, assisted suicide is about terminal illness, not disability.

Most people realize that they have a strong likelihood of becoming terminally ill before their life is over. But many do not realize that they have an almost equal likelihood of passing through stages of chronic illness and disability before they are judged "terminal."

The disability experience is that people who are labeled "terminal," based on a medical prediction that they will die within six months, are — or almost inevitably will become — disabled. Furthermore, virtually all "end-of-life care" issues — access to competent health care, adequate pain relief, in-home personal care and flexible, consumer-responsive supports, peer counseling, family support — have been disability rights issues for decades.

In fact, although intractable pain has often been given as the primary reason for enacting assisted suicide laws, the reasons doctors actually report for issuing lethal prescriptions are the patient's "loss of autonomy" and "feelings of being a burden." These feelings arise when a person acquires physical impairments that necessitate relying on other people for help in tasks and activities formerly carried out alone. Studies of patient attitudes toward assisted suicide and euthanasia confirm that "[p]atients' interest in physician-assisted suicide appeared to be more a function of psychological distress and social factors than physical factors."¹ "When patients ask for death to be hastened," another study concluded, "the following areas should be explored: the adequacy of symptom control; difficulties in the patient's relationships with family, friends, and health workers; psychological disturbances, especially grief, depression, anxiety, . . ."² And another study exploring psycho-social factors provided the following analysis:

The desire for euthanasia or assisted suicide resulted from fear and experience of two main factors: disintegration and loss of community. These factors combined to give participants a perception of loss of self. . . . Symptoms and loss of function can give rise to dependency on others, a situation that was widely perceived as intolerable for participants: "I'm inconveniencing, I'm still inconveniencing other people who look after me and stuff like that. I don't want to be like that. I wouldn't enjoy it, I wouldn't, I wouldn't. No, I'd rather die."

Participants frequently used the notion of dignity to describe the experiences associated with disintegration: . . . "You've become a bag of potatoes to be moved from spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors' appointments or wheeled in a wheelchair, and it really does take away any self-worth, any dignity, or any will to continue to live."

. . . Loss of community entailed the progressive diminishment of desire and opportunities to initiate and maintain close personal relationships, owing to loss of mobility, exclusion and alienation by others, and self-isolating actions by participants. . .

Participant: "I think we should all be allowed to die with our dignity intact."

Interviewer: "OK and what do you mean by dignity?"

Participant: "Um, the ability to perform simple things like, you know, going to the bathroom on your own and not through a bag, um, breathing with your own lungs, . . . I used to be somebody, but now, like I mean, you know, I'm no better than like a doll, somebody has to dress me and feed me and I guess it's uh, I don't know how to explain it, really."³

These are quintessential disability issues.

The Oregon Assisted Suicide Law

The Oregon "Death With Dignity Act" has been challenged by the U.S. Department of Justice under the Controlled Substances Act, asserting that federal law prohibits physicians from prescribing controlled substances for assisted suicide, on the grounds that it is not a "legitimate medical purpose" for their usage. The District and Circuit Courts have upheld the Oregon law, and the U.S. Supreme Court has agreed to hear the case in 2005. The legal issues pertain to the respective roles of federal and state government. The Council does not expect the Supreme Court to rule on the assisted suicide question, *per se*.

Nevertheless, at the same time, bills to legalize assisted suicide have been introduced this year in a number of states (Hawaii, California, Vermont), as well as bills to decriminalize or reduce penalties under state laws prohibiting assisted suicide (Connecticut).

It should be noted that suicide, as a solitary act, is not illegal in any state. Disability concerns are focused on the systemic implications of adding *assisted* suicide to the list of "medical treatment options" available to seriously ill and disabled people. The Oregon Law grants civil and criminal immunity to physicians providing lethal prescriptions based on a stated claim of "good faith" belief that the person was terminal, acting voluntarily, and that other statutory criteria were met. This is the lowest culpability standard possible, even below that of "negligence," which is the minimum standard governing other physician duties.

As the Oregon Reports on physician-assisted suicide make clear, the state has not been able to assess the extent of non-reporting or noncompliance with the law's purported safeguards, but only obtains brief interviews with physicians who file their paperwork. There are no enforcement provisions in the law, and the reports themselves demonstrate

that non-terminal people are receiving lethal prescriptions.⁴ As the *Oregonian* newspaper stated on March 8, 2005 in "Living with the dying 'experiment,'" examining the case of David E. Prueitt who woke from his assisted suicide after two weeks and did not try again, "The rest of us . . . still need an answer from a system that seems rigged to avoid finding one."

Increasingly, the reasons doctors actually report for issuing lethal prescriptions are the patient's "loss of autonomy" (87%), "loss of dignity" (80%), and "feelings of being a burden" (36%).⁵ People with disabilities are concerned that these psycho-social factors leading to assisted suicide are being widely accepted as sufficient justification for assisted suicide, with most physicians not even asking for a psychological consultation (5% in 2004, 16% overall)⁶ or the intervention of a social worker familiar with home and community based services that might alleviate these feelings. The societal message is "so what?" or "who cares?"

The Oregon Death With Dignity Act authorizes and empowers physicians to discriminate in their response to a patient's expression of the wish to die based on the patient's disability. The underlying practical basis for the physician's determination that the individual is eligible for assisted suicide is the individual's physical dependence on others for everyday needs, which is viewed as depriving them of what non-disabled people often associate with "autonomy" and "dignity," and may also lead them to feel like a "burden." This establishes grounds for physicians to treat these individuals completely differently than a physically able-bodied suicidal person would be treated.

The individual's request for assisted suicide is necessary, but not sufficient, to get it. In effect, the Oregon Law gives physicians the power to judge whether a particular suicide is "rational" or not based on his or her prejudicial devaluation of the individual's quality of life, and then to actively assist certain suicides based on that judgment. This should be viewed as a violation of the Americans with Disabilities Act, which prohibits discrimination based on disability.

The Erosion of Protections for People in Guardianship

Assisted suicide laws and practices do not stand in isolation, but arise in the context of a larger health care system that also includes substitute decision-making affecting the lives of people who are deemed "incompetent" or not capable of making and communicating their own decisions. Determinations of "incompetence" are made both formally through the courts, and informally, depending on state laws and health care provider policies. A competent individual may direct their future medical care during a potential period of incompetence through the use of an advance directive. An advance directive can specify the medical treatments that an individual would accept or refuse in various circumstances.⁷ In addition or in the alternative, an advance directive can designate a substitute or proxy whom the individual trusts to weigh the complex information and factors that may be involved in a specific health care decision.

Health care decisions for people deemed incompetent are generally governed by state laws. Substitute decision-makers may be proxies chosen by the individual while competent, surrogates appointed according to a priority list established in state law (the list usually beginning with the spouse and ending with the public guardian), or health care providers with whom the individual or family may not agree. Surrogate decisions are supposed to be based on what the individual's wishes would have been, if competent. However, most states have laws permitting health care providers to avoid compliance with advance directives. When the provider refuses to withhold or withdraw treatment, these provisions are referred to as "conscience clauses" and usually require some effort to transfer the patient to another provider. When the provider refuses to provide desired care, these provisions are called "futile care" policies.

Several court cases have arisen from family disputes involving people who became incompetent without executing an advance directive. Before the well-known case of Terri Schiavo in Florida, there was the case of Robert Wendland in California. Both Mr. Wendland's wife and mother agreed that he was not in a "persistent vegetative state," and that he had not left clear and convincing evidence of his wishes. Nevertheless, his wife argued that she should be able to remove his tube feeding anyway. A state statute, based on a national model health care decisions code, gave her the right to starve and dehydrate him, and forty-three bioethicists filed a friend of the court brief in agreement. Ten disability rights organizations filed in support of the mother's view, and against the general presumption that no one would want to live with his disabilities, which was being used to justify lowering constitutional protections of his life. Ultimately, the California Supreme Court agreed that Mr. Wendland's life could not be taken without clear and convincing evidence of his wishes.⁸ Unfortunately, this ruling was issued three weeks after he died from pneumonia and lack of antibiotics.

By the time the Schiavo case reached major national attention in 2003, twenty-six national disability organizations had taken a position that Terri Schiavo should receive food and water, due to the highly conflicting evidence of her wishes and the fact that she had not chosen her own guardian.⁹ Many of these groups also joined in one or more of three amicus briefs¹⁰ filed at various stages of the proceedings by Not Dead Yet, a national disability rights group that advocates against legalizing assisted suicide and non-voluntary euthanasia.

Many people with disabilities were deeply disturbed to see court after court uphold questionable lower court rulings. In *Schiavo*, fifty-five bioethicists supported the removal of food and water. Many disability groups were also disturbed that the court allowed most of Terri Schiavo's rehabilitation funds to be spent on her husband's lawyers, that she was denied a properly fitted wheelchair, a swallowing test (though she swallowed her own saliva), swallowing therapy, the potential for oral feeding, speech therapy, and the freedom to leave the hospice with her parents, even temporarily. There was also concern that adult protective services did not intervene (until too late), and the state protection and advocacy agency tried but proved powerless. It would appear that the prevalent prejudice that no one would want to live like Terri Schiavo translated into

her guardian's unfettered right to treat her at best as a prisoner, and at worst as though she was already dead.

The guardian's and courts' refusal to allow any attempts at providing oral fluids or food is perhaps most significant. The guardian has the right to refuse medical treatment, which has been defined by courts and state statutes to include tube feeding. This is not the same as a guardian refusing oral food and fluids, yet the courts, and most of the media and the public, made no distinction. The prevalent view that no one would want to live like Terri Schiavo, regardless of her precise level of consciousness, which was highly disputed, led most to view the guardian's actions as delivering her from the suffering of her disabled life. The public was not permitted to see her current reactions, and those who visited her, and claimed that she responded to them and demonstrated a will to live, had no power against the absolute authority given to the guardian.

Nevertheless, the perspectives of such prominent national groups as The Arc of the United States, the National Spinal Cord Injury Association, the National Council on Independent Living, the Disability Rights Education and Defense Fund and many others were consistently ignored by most of the press, as well as the courts.

Unfortunately, the anecdotal evidence suggests that Terri Schiavo's case may be the tip of a very large and almost fully submerged iceberg. One mission of the end-of-life care movement has been to educate health care providers about how to provide good palliative care, but another mission has been to shape public policy on health care. It appears that a certain line of thought in bioethics has taken over the policy-making work. This line of thought involves a "lifeboat" approach, deciding who gets thrown out.

For the last three decades, mainstream bioethicists have told the press and the public that euthanasia is about "compassionate progressives" versus the "religious right." It appears that disability rights advocates do not fit that script and have therefore been ignored. Nevertheless, these bioethicists are actually talking about the legal parameters for statutory guardians and health care providers to medically end the lives of people with disabilities, especially cognitive disabilities, on a discriminatory, non-voluntary or involuntary basis. Based on their well-funded policy work, it often takes more documentation to dispose of our property than to dispose of our lives.

Why make it easier for guardians to refuse food and water on behalf of persons who cannot speak for themselves? In a 1983 article, over two decades ago, reflecting on the possible outcome of this food and water debate, Daniel Callahan, then director of the prestigious Hastings Center, wrote that "...a denial of nutrition, may, in the long run, become the only effective way to make certain that a large number of biologically tenacious patients actually die." He further predicted, "Given the increasingly large pool of superannuated, chronically ill, physically marginal elderly, it could well become the *nontreatment* of choice."¹¹

Policies on removal of food and water have serious and far-reaching implications. Many people in nursing homes are on feeding tubes not because they cannot eat orally, but

because there are not enough staff to help them eat.¹² One study also found that in for-profit nursing homes, African-Americans with dementia are taken off hand feeding and put on a feeding tube sooner in the disease process than their white counterparts.¹³ As a result, the individual is then on “life support,” the kind that can be removed by a third party decision-maker.

A new Alzheimer's study last year confirmed previous studies that caregivers have a lower opinion of their relative's quality of life with Alzheimer's than the persons themselves have, and found an explanation for the discrepancy. The caregivers project their own feelings about the burden of care-giving onto the person they care for.¹⁴ These are the very caregivers who may make life-ending decisions.

Similarly, studies consistently demonstrate that physicians and other health care providers rate the quality of life of people with significant disabilities and illnesses significantly below the individual's rating of their own quality of life.¹⁵ These are the very health care providers who make “futile care” decisions based on quality of life judgments.

Another conflict of interest arises in the context of a public guardian, appointed if no family member or qualified friend will serve. The Kentucky Supreme Court ruled in 2004 that a public guardian may deprive life sustaining treatment from a man labeled mentally retarded, despite the financial conflict of interest for a state guardian of a ward on Medicaid.¹⁶

In the absence of an open public dialogue, under the public “radar” until *Schiavo*, the bioethicists have distorted the palliative care movement into a life-ending movement. This affects more than the disability community of today, it affects everyone, directly or through family, sooner or later. Rules are being made for who lives and who dies, but the rule-making and the withholding of life-sustaining treatment are happening behind closed doors and without any form of accountability. This is the context in which assisted suicide laws continue to be proposed, and should continue to be resisted.

Conclusion

The Council's Position Paper carefully examined the many forms of discrimination and devaluation that people with disabilities experience in today's society. The struggle to implement the social vision embodied in the Americans With Disabilities Act (ADA) continues. In view of the aging of our population, policy-makers should turn to the disability rights movement for its expertise in cost-effective services to enhance self-determination and independence. While study and consensus building continue with respect to the formulation of public policies in the aftermath of *Schiavo*, some principles recently expressed to a Congressional subcommittee by attorney, parent and advocate Rud Turnbull seem clear:

- Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society.
- The nation's policy for people with disabilities is to assure their equal protection under the law, advance their self-determination, and promote their independent living.
- Discrimination against any person with a disability, regardless of the nature or severity of the disability, is morally and legally indefensible.
- When medical care is clearly beneficial, it must be provided.
- It is impermissible to take into account any anticipated or actual limited potential of a person or lack of resources.
- The person's disability itself must never be the basis for a decision to withhold treatment.¹⁷

It is critical that the rights of people with disabilities, old and young, to choose home and community based long term care services be fully implemented, consistent with Title II of the ADA and the U.S. Supreme Court decision in *Olmstead*. If an individual with disabilities feels that they have lost control in their lives, been devalued because of their impairments, and become a burden to others, the appropriate response from society is to support him or her, not to kill. Legalized medical killing based on disability should be rejected. People with disabilities are not better off dead, and society is not better off without us.

¹ Breitbart, William MD; Rosenfeld, Barry D. PhD; Passik, Steven D. PhD, Interest in Physician-Assisted Suicide Among Ambulatory HIV-Infected Patients, *Am J Psychiatry* 1996; 153:238-242.

² Block SD; Billings JA, Patient requests to hasten death. Evaluation and management in terminal care. *Archives of Internal Medicine*. 154(18):2039-47, 1994 Sep 26.

³ Lavery, J.M., Boyle, J., Dickens, B.M., Maclean, H., & Singer, P.A. (2001). Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: A qualitative study. *Lancet*, 358 (9279), 362-7.

⁴ Seventh Annual Report on Oregon's Death With Dignity Act, Department of Human Services, Office of Disease Prevention and Epidemiology, March 10, 2005, <http://egov.oregon.gov/DHS/ph/pas/docs/year7.pdf>, pages 16, 25.

⁵ Seventh Annual Report on Oregon's Death With Dignity Act, page 24 (see Note 4).

⁶ Id.

⁷ But for a comprehensive review of relevant research, see, Fangerlin & C.E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report* 34, no. 2 (2004): 30-42.

⁸ *Wendland v. Wendland*, 28 P.3d 151, 172 (2001).

⁹ Issues Surrounding Terri Schindler-Schiavo Are Disability Rights Issues, Say National Disability Organizations, Oct. 27, 2003, *Ragged Edge Online*, <http://www.raggededgemagazine.com/schiavostatement.html>

¹⁰ See, e.g., BRIEF OF AMICI CURIAE NOT DEAD YET ET AL. IN SUPPORT OF APPELLANTS AND REQUESTING REVERSAL, Filed In re GUARDIANSHIP OF THERESA MARIE SCHIAVO (2nd District Court of Appeal, Florida, February 21, 2003) <http://www.notdeadyet.org/docs/schavobrief.html>.

¹¹ Daniel Callahan, "On Feeding the Dying," *Hastings Center Report*, October 1983, p. 22.

¹² Brad Heath, Nurse, aide shortage imperils patients: One-fifth of residents live in nursing homes where staffing levels could affect nutrition, *The Detroit News* November 28, 2004

<http://www.detnews.com/2004/specialreport/0411/28/A15-17471.htm>

¹³ Mitchell SL, Teno JM, et al., Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment, *JAMA*, July 2, 2003; 290(1), 73-80.

¹⁴ Joan Arehart-Treichel, For Alzheimer's Patients, Life May Be Better Than Caretakers Think, *Psychiatric News* July 16, 2004, Volume 39 Number 14, © 2004 American Psychiatric Association p. 32, <http://pn.psychiatryonline.org/cgi/content/full/39/14/32-a>

¹⁵ Gerhart, K. A., Kozoil-McLain, J., Lowenstein, S.R., & Whiteneck, G.G. (1994). Quality of life following spinal cord injury: knowledge and attitudes of emergency care providers. *Annals of Emergency Medicine*, 23, 807-812; Cushman, L.A & Dijkers, M.P. (1990). Depressed mood in spinal cord injured patients: staff perceptions and patient realities, *Archives of Physical Medicine and Rehabilitation*, 1990, vol. 71, 191-196.

¹⁶ State can end life support of wards, *Lexington (KY) Herald-Leader*, Aug. 27, 2004

<http://www.kentucky.com/mld/kentucky/news/9509486.htm>

¹⁷ Testimony before the U.S. Senate Health, Education, Labor and Pensions, Health Care Provided to Non-ambulatory Persons, Hearing Date: April 6, 2005, http://help.senate.gov/testimony/t231_tes.html