

COVER MEMORANDUM UPON THE REISSUANCE OF THE NCD STATEMENT OPPOSING LEGALIZATION OF ASSISTED SUICIDE

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Introduction

On March 24, 1997, the National Council on Disability (NCD) issued “Assisted Suicide: A Disability Perspective,” <http://www.ncd.gov/newsroom/publications/1997/suicide.htm> as part of its role 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. 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, concluding that:

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 has 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.

The U.S. Supreme Court has agreed to hear a case this year about the Oregon “Death with Dignity Act.” Congress has also begun taking a look at federal legislation to address laws governing surrogate decisions to withhold life-sustaining treatment in the aftermath of the *Schiavo* case. Accordingly, in the context of the current public debate, NCD reaffirms its position opposing the legalization of assisted suicide by reissuing its 1997 position paper along with this statement of its reasons for doing so.

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. 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.

At the same time, bills to legalize assisted suicide have been introduced this year in a number of states (Hawaii, California, Vermont), as have bills to de-criminalize 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 is terminal, acting voluntarily, and that other statutory criteria are 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.¹ 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 report for issuing lethal prescriptions are the patient's “loss of autonomy” (87%), “loss of dignity” (80%), and “feelings of being a burden”

(36%).² People with disabilities are concerned that these psycho-social factors leading to assisted suicide are being widely accepted as sufficient justification for assisted suicide. In 2004, only 5% of patients requesting a lethal prescription were referred for a psychiatric evaluation by a physician. For all the reported years (1998-2004) the figure is only 16%.³

The Oregon Death with Dignity Act authorizes physicians to make “end of life” decisions 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 person considering suicide would be treated. This different treatment is inconsistent with the principles embodied in 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. Competent individuals 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.⁴ 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. In 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 withhold sustenance to him, and forty-three bioethicists filed a friend of the court brief in agreement. Ten disability rights organizations filed briefs arguing against lowering constitutional protections of his life and the presumption that people would not want to live with his disabilities. Ultimately, the California Supreme Court agreed that Mr. Wendland’s life could not be taken without clear and convincing evidence of his wishes.⁵ Unfortunately, this ruling was issued three weeks after he died from pneumonia and lack of antibiotics.

People who are labeled "terminal," based on a medical prediction that they will die within six months, are — or almost inevitably will become — disabled. 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 also been disability rights issues for decades. Nevertheless, the perspectives of disability consumer organizations were consistently beneath the radar of the media giving prominent attention to Ms. Schiavo.

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.⁶ Many of these groups also joined in one or more of three amicus briefs⁷ 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.

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 fluids or food, yet the courts, and most of the media, failed to make this distinction in Ms. Schiavo’s case. The view that no one would want to live like Terri Schiavo, regardless of her precise level of consciousness, led many in the public to view the guardian’s actions as delivering her from the suffering of her disabled life.

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.⁸ 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.⁹ 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. The explanation for the discrepancy was that the caregivers projected their own feelings about the burden of care-giving onto the person they cared for.¹⁰ 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.¹¹

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 as having an intellectual disability, despite the financial conflict of interest for a state guardian of a ward on Medicaid.¹²

Conclusion

The Council's position paper carefully examined the many forms of discrimination and devaluation 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.¹³

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 individuals with disabilities feel 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 to live independently in the community. Legalized medical killing solely based on disability should be rejected. People with disabilities are not better off dead, and society is not better off without us.

Acknowledgment

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¹ 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.

² Id. at page 24.

³ Id.

⁴ 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.

⁵ Wendland v. Wendland, 28 P.3d 151, 172 (2001).

⁶ Issues Surrounding Terri Schindler-Schiavo Are Disability Rights Issues, Say National Disability Organizations, Oct. 27, 2003, Rugged Edge Online,

<http://www.raggededgemagazine.com/schiavostatement.html>

⁷ 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>.

⁸ 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>

⁹ 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.

¹⁰ 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>

¹¹ 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.

¹² State can end life support of wards, Lexington (KY) Herald-Leader, Aug. 27, 2004

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

¹³ 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