



Bioethics Review

The Scholl Institute is a nonprofit, Judeo-Christian organization that addresses bioethical issues including euthanasia, (physician-assisted-suicide) the withholding or withdrawing of food and water from non-dying patients, brain death, organ transplantation, genetic engineering, and rights of disabled or mentally ill persons.

ASSISTED SUICIDE: A DISABILITY PERSPECTIVE

The public debate over assisted suicide, both globally and locally in California, has caused many groups to come together in opposition to such an injustice. Scholl Institute has been privileged recently to work closely with some disability rights organizations, whose perspective and insight into this issue has proved invaluable. Scholl would like to share with its readers this essential viewpoint of the disability community.

Why are all major disability organizations opposed to the legalization of assisted suicide?

Laura Remson Mitchell, who has MS and is an executive member of the California Disability Alliance says, "We share the author's [of AB 654] belief in the importance of autonomy; indeed, that is a hallmark of disability rights. However...people with disabilities are particularly at risk when this [legalization of assisted suicide] happens because of deeply ingrained fears and stereotypes, and because of certain legal decisions that have already equated severe disability with terminal illness."¹



Left: Rick Franz - one of over 100 individuals who picketed Assembly man Nunez's office in Los Angeles against assisted suicide.

What is the link between disability and assisted suicide?

"The point of assisted suicide is purported to be relief from untreatable pain at the end of life. However, all but one of the people in Oregon who were reported to have used that state's assisted suicide law during its first year wanted suicide not because of pain, but for fear of losing functional ability, autonomy, or control of bodily functions. Oregon's subsequent reports have had similar results... But as many thousands of people with disabilities who rely on personal assistance have

learned, needing help is not undignified, and death is not better than reliance on assistance. Have we gotten to the point that we will abet suicides because people need help using the toilet?"² -Marilyn Golden, paraplegic and policy analyst for DREDF.

Is there a personal reason you are opposed to assisted suicide?

MS patient, CDA member, and Scholl President, Molly Israel responds, "As a person with a disability and as a nurse, I know first hand what it is like to be depressed from receiving a life threatening or life changing diagnosis. If assisted suicide had been available when I was diagnosed 20 years ago, I might have chosen the easier or at least cheaper way out, especially when I lost my health insurance and had to wait several years before receiving disability payments and then another 2 years before being eligible for Medicare."³

World renowned speaker and quadriplegic, Joni Erickson Tada recalls, "My mind again raced back to 1967 when I was one of those severely disabled people confined to a hospital room and surrounded by machines and tubes. I know now that my funereal despair was clouded by severe depression. And I know that I, or my friends and family, might have been open to listening to aid-in-dying suggestions had we been conditioned by pleasant-sounding persuasion.

'Such a shame, so unfortunate. She'd be better off if she'd never made it,' one of my distant relatives had sighed. And it almost sounded not half-bad. When you can't think beyond four bleak hospital walls, the words of experts and professionals, even distant relatives, can sound plausible."⁴

What about the idea that this is about people being able to die with dignity?

"No matter what you call it, suicide, either through a bottle of pills or from pulling a trigger, is never death with dignity."⁵ - Molly Israel

Sanda Allyson, of the Christian Disability group Joni and Friends, says "...no one should be made to feel that death is the only choice of dignity. Easier paths are rarely the correct paths. Life is not just about what's easy; it is also about hardships. And, as human nature dictates, we learn the most from the most difficult experiences. Those difficult experiences are part of the

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journey. They should be learned from, experienced fully, not eliminated. It is in the fires of our own suffering that we learn the greatest empathy, compassion, and the art of caring for others. **If it is suggested that dignity is only found in ending my life prematurely, that also says that to choose to persevere is weakness.** This could not be farther from the truth. And, if my life changes someone for the better in my persevering, even if it's only one, then I am better for it, and so is the world.⁶

What have you learned working with the disability community to fight assisted suicide?

"When I first started working with the issue, I did not see myself as disabled and did not feel connected to their movement. Now, I am much more aware of issues related to health care coverage and disability rights and how they put many people in a vulnerable position especially if physician assisted suicide would be legalized."⁷ – Molly Israel

Why do those in the disability community feel so passionately about this issue?

"...it is the minds of the able bodied that view the challenged life as less than able, not as valuable, not able to contribute, not able to love or be loved in any worthwhile sense. Ask any person with a visible physical disability about discrimination. It is the worst discrimination statistically in the nation. It is usually not those with disabilities who struggle with knowing they can contribute, but rather convincing the able-bodied that it is so. Ironically, those who have survived serious injury or illness often receive the gift of empowerment from having survived something important, and the gift of clearer understanding of what really matters in this precious life."⁸ - Sanda Allyson

What about the Oregon law? Not many people have used it.

"This isn't a bill that will just affect 3 in 1000 terminally ill people as it does in Oregon," said Lillibeth Navarro, quadriplegic and member of Not Dead Yet. "If assisted suicide becomes legal, it will impact many Californians, a prescription for poison is cheaper than medical care."

The official Oregon statistics state that in 2003, 87% of those who made the request for a lethal prescription did so because of fear of disability and 63% for fear of being a burden on family, friends and caregivers.

Says Sanda Allyson, "That's not a choice. That's feeling like you have no choice."⁹

Joni Erickson Tada's work and words are a testament to the importance of the disability voice in the Assisted Suicide debate:

"Funding cutbacks for disability services, bureaucratic tangles in Medicaid regulations, right-to-die legislation—she [Tada] knows the details. 'It's a schizophrenic society we live in,' she says. 'It's like, let's pass the Americans with Disabilities Act, let's create equal access, let's reauthorize the Individuals with Disabilities Education Act, and then let's also pass a state initiative that allows physicians to give someone with a disability three grams of Phenobarbital if that's his wish. There are too many Jack Kevorkians out there rubbing their hands and wanting to assist you with your death wish... **There's such a huge premise in this society that you're better off dead than disabled. People have such huge fundamental fears of disability.**'"¹⁰

California Disability Alliance Hails Defeat of Doctor-Assisted Suicide; LA Times Called Support, 'so weak in the Assembly'

SACRAMENTO, Calif., June 2 /U.S. Newswire/ -- Californians with disabilities and many others opposing AB 654, the bill to sanction doctor-assisted suicide in California, hailed its defeat on Thursday. The action by the bill's authors all but ends the imminent threat of doctor-assisted suicide in California.

Although the bill is now dead, proponents announced they will amend the assisted suicide language into an Assembly bill already in the State Senate. The amended bill is expected to die in the Senate.

"At the end of the day proponents couldn't find 20 votes to publicly support this bill," noted Laura Remson Mitchell of the California Disability Alliance. "When legislators realized this bill was not about the right to die, but was in fact about undermining our healthcare system and doctors assisting in their patients' suicide, support evaporated as it always has."

Update on California attempt to legalize assisted suicide (6/08/05):

Author Amends Bill: Replaces Health Care for Chronically Ill Poor with Assisted Suicide

AB 651 passed the Assembly as a health care bill for the chronically ill poor. Then the authors Levine and Berg, gutted and amended the bill, i.e. substituted entirely new language so that it would permit doctors to assist their patients to kill themselves.

"Health care advocates are appalled at how utterly callous this appears," said Tim Rosales, a spokesperson for the anti-suicide coalition.

Scholl Institute of Bioethics will continue to work with the disability community to fight against the legalization of assisted suicide in any form.

¹ Letter to California State Assembly by Laura Remson Mitchell, Member of the Executive Committee of the California Disability Alliance.)

² Marilyn Golden, "Why Assisted Suicide Must Not Be Legalized." <http://www.dredf.org/assistedsuicide.html>

³ Letter to the California State Assembly by Molly Israel, California Disability Alliance member

⁴ Joni Erickson Tada, *When is it Right to Die?* Zondervan, Grand Rapids, MI: 1992.

⁵ Molly Israel, President of Scholl Institute of Bioethics

⁶ Sanda Allyson, "Million Dollar Baby' Cost Too High", February 4, 2005 [emphasis added]

<http://www.joniandfriends.org/apcm/APCMviewer.asp?a=93&z=4>

⁷ Molly Israel, President of Scholl Institute of Bioethics and member of California Disability Alliance

⁸ Sanda Allyson, "Million Dollar Baby' Cost Too High", February 4, 2005 <http://www.joniandfriends.org/apcm/APCMviewer.asp?a=93&z=4>

⁹ Sanda Allyson, "Million Dollar Baby' Cost Too High", February 4, 2005 <http://www.joniandfriends.org/apcm/APCMviewer.asp?a=93&z=4>

¹⁰ Tim Stafford, "A Heaven-made Activist," Christianity Today 1/9/04. <http://www.christianitytoday.com/ct/2004/001/3.46.html>