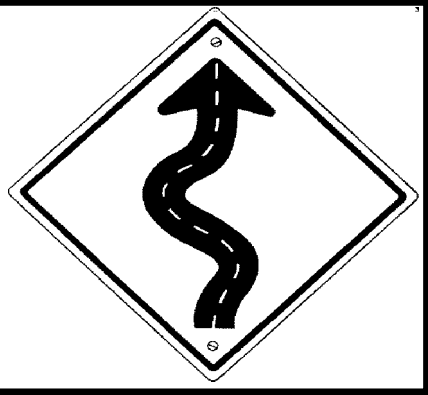


# Guardianship and the Disability Rights Movement

BY DIANE COLEMAN and TOM NERNEY



## Introduction

The disability rights movement has never been monolithic, but it has experienced an increasing consensus about the importance of limiting the legal authority granted to guardians, especially in life and death health care decision-making. Twenty-six national disability rights groups asked the courts not to allow Terri Schiavo's guardian to bring on her death. But the arguments advanced by the disability rights perspective were long dismissed by a burgeoning and now fully developed movement.

The self-determination movement is far ahead of courts, legislatures, media and society at large when it comes to the theory, importance and practical aspects of determining the preferences of people with significant intellectual disabilities. While many states have added due process protections to guardianship laws, and many have adopted reforms favoring guardianships limited to specific types of decisions rather than all decisions affecting a person's life, implementation of these reforms has been woefully inadequate.

## Bioethics – The Single Greatest Threat

It can be argued that the convergence of the fields of ethics, medicine and law into a powerful field of bioethics represents the single greatest threat to the welfare of those with significant disabilities in this country. Under the rubric of utilitarian ethics and the language of rights, discrimination against people with disabilities has become enshrined in law and popular imagination. And this new right to die is

relentlessly moving to the duty to die. What was once hidden medical practice has moved to publication in prestigious journals and, finally and very quickly, into contemporary case law. Some milestones in this recent history are compelling.

In 1973 two doctors (Duff and Campbell, 1973) published an article in the *New England Journal of Medicine* advocating for the withdrawal of treatment from newborn infants with disabilities.<sup>1</sup> They argued that this was, in fact, now accepted practice and prevented a life of "suffering." There was some outrage expressed and even a congressional hearing but, by 1983, when the starvation death of the Indiana "Baby Doe" case reached the public, the issue had largely been settled within the medical community.

Both the Indiana case and the 1983 Oklahoma Children's Memorial Hospital case, where infants with spina bifida went untreated, produced extensive media coverage and, for the first time, introduced public discussions of the cost of life-long treatment for these children. The Oklahoma medical protocol (Gross, Cox, Tatyrek, Pollay & Barnes, 1983) specifically factored in the relative poverty of parents in the selection process for what was called a treatment protocol.<sup>2</sup> For the first time non-treatment became a form of treatment. Starvation and dehydration were soon to become painless, and persistent vegetative state as a medical description would soon enter the vocabulary as a way to depersonalize the individuals with disabilities.

In 1984, doctors at the Brown University Medical School (Walker, Feldman, Vohr & Oh, 1984) argued in *Pediatrics*, the journal of the American Academy of Pediatrics, that even though only 16% of premature babies born at very low birth weights in a study they conducted had significant life-long disabilities, all of the low birth weight children should not be treated.<sup>3</sup>

There were still some debates going on within this field of bioethics. Daniel Callahan, a pioneer in the field and once a voice for reason and compassion wrote in the *Hastings Report* in 1983 that the feeding of hungry or disabled individuals was "...the perfect symbol of the fact that human life is inescapably social and communal." (Callahan, 1983)<sup>4</sup> Less than four years later, Callahan changed his mind under pressure and, in a review of his book, the American philosopher Sidney Hook took him to task for not going far enough. (Hook, 1988).<sup>5</sup> Callahan had also proposed at this time that we consider certain aging individuals with disabilities as "biologically tenuous" in order to further advance the rationing of medical care.<sup>6</sup>

Is there now, given the severe fiscal constraints that all states are experiencing, especially in their Medicaid programs, an emerging "duty to die?" In the 1997 edition of the *Hastings Report*, John Hardwig wrote that that time had come. (Hardwig, 1997)<sup>7</sup> In that article, he defended the former governor of Colorado, Richard Lamm, (who acerbically asked elderly people with disabilities to step aside and make way for the young) and explicitly called for our personal obligation to die should we become unable to care for ourselves. How close are we to witnessing this new duty to die by surrogate means? How many guardians would dutifully embrace their new responsibility?

## Case History from Quinlan to Schiavo

Prior to the 1970's, the right to refuse treatment was not a major source of social concern. Unwanted medical treatment was not a big issue. After all, the federal government did not enter the health

insurance field until 1965. There were court disputes over the right of an individual to refuse life-sustaining treatment, but these tended to focus on situations in which the individual had an additional basis for refusing treatment beyond that of privacy, such as religious convictions against certain types of medical intervention.

Beginning in the 1970's, several high profile court cases defined and expanded the right to refuse treatment. Five of the leading cases involved the right of a substitute decision maker to refuse life-sustaining treatment for a person deemed "incompetent."

The first of these involved Karen Quinlan, a New Jersey woman stated to be in a coma or persistent vegetative state. Ms. Quinlan's family sought to remove her ventilator. When the state Supreme Court granted them that right in 1973,<sup>8</sup> it turned out that she could breathe without the ventilator. The family did not propose to remove her food and fluids, and she lived ten more years. To the best of the authors' knowledge, no segment of the disability community expressed opinions about this case through articles or friend-of-the-court (amicus) briefs.

Throughout the 1980's, courts found an individual's right to refuse treatment in several cases involving male quadriplegic ventilator users who demanded liberty from nursing homes or, in the alternative, death through "pulling the plug." Again and again, courts reviewed the legally relevant state interests – preserving life, preventing suicide, protecting third parties, and protecting the "integrity of the medical profession" – and found them insufficient to overcome the individual's so-called "right to die."<sup>9</sup> Society was more ready to grant death than liberty from a nursing home. At this point, the disability rights group, ADAPT, began filing amicus briefs in these cases, finding that a choice between a nursing home and death is no choice at all.

Against this backdrop, in the late 1980's, the Michael Martin case arose, in which a mother disputed a wife's decision to remove a feeding tube from a brain-injured man. The Michigan courts refused to substitute the mother as guardian, but would not allow the wife to withhold Mr. Martin's food and water.<sup>10</sup> There was no unified disability community response to this case, but it was a subject in articles and conference presentations in the physical disability community.

In 1990, the U.S. Supreme Court issued its first and still only ruling on the substantive power of guardians to withhold life-sustaining treatment in the Cruzan case. The developmental disability community, notably The Arc, filed an amicus brief in the case, but the physical disability community did not. In this pivotal case, the highest court in the land found that providing food and fluids by tube is medical treatment, that "competent" individuals have a right to refuse treatment, that this right survives "incompetence" and may be exercised by a substitute decision-maker, and that a state may require "clear and convincing evidence" of an individual's wishes before allowing a guardian to withhold life-sustaining treatment.<sup>11</sup> The Court pointed out that a high evidentiary standard was appropriate because even a well meaning guardian may have conflicts of interest or other competing motives. The Court did not rule on whether a lower standard could be allowed if adopted by a state. While many states have, in fact, adopted lower standards, this crucial issue has not yet been revisited by the U.S. Supreme Court.

Several years later, the problem of non-voluntary and involuntary withdrawal of food and water moved onto the broader disability community's radar screen. Before Terri Schiavo, there was Robert Wendland in California. Both his wife and mother agreed that Mr. Wendland 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 against the general presumption that no one would want to live with his disabilities, being used to justify lowering constitutional protections of his life.<sup>12</sup> Ultimately, the California Supreme Court agreed with disability groups that his life could not be taken without clear and convincing evidence of his wishes.<sup>13</sup>

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.<sup>14</sup> Disability organizations were deeply disturbed to see court after court uphold questionable lower court rulings. This time, 55 bioethicists supported the removal of food and water. Disturbing, too, was 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, swallowing therapy, the potential for oral feeding, speech therapy, and the freedom to leave the hospice with her parents, even temporarily. Disability advocates were concerned that adult protective services did not intervene, 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, at worst as though she was already dead.

It only takes common sense to recognize the potential for conflicts of interest in a guardian, even conflicts of which they may be unaware. A recent Alzheimer's study confirmed previous studies that caregivers have a lower opinion of their relative's quality of life with Alzheimer's than the individuals themselves have, and found an explanation for the discrepancy. It seems

that the caregivers project their own feelings of the burden of care-giving onto the people for whom they provide care.<sup>15</sup> And what of state guardians? In an ominous ruling, the Kentucky Supreme Court declared 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.<sup>16</sup>

### The growing disability consensus

While it is clear that most people, in and out of the disability movement, want to have the right to refuse unwanted medical treatment, the alliance of developmental and physical disability groups and their consensus around the Wendland and Schiavo cases demonstrates a growing concern about non-voluntary and outright involuntary medical killing through withholding of treatment, even food and water. People with disabilities and allies are feeling the pressures toward death from several directions.

First, increasingly throughout the last decade or more (since the fiscal incentives of managed care overtook the health care system), people with disabilities and medical treatment consumers in general experience the need to be knowledgeable advocates to ensure proper health care is provided.

Second, while the Patient Self-Determination Act of 1991 purported to help people effectuate their right to make their own health care decisions, whenever people with disabilities are admitted to a facility, the boilerplate forms they are given are not balanced and objective, but exclusively oriented toward refusal of treatment. The community is full of anecdotes of people with disabilities pressured by social workers to sign do-notresuscitate orders.

One of the leaders of the end-of-life care movement, Dr. Ira Byock, was interviewed

by Ragged Edge Magazine, a leading disability rights publication.<sup>17</sup> He stated that Partnership for Caring and Last Acts, national leaders in the movement until they disappeared under a cloud late last year, had excluded the disability perspective, and that this exclusion was “deliberate and irresponsible.” What’s especially disturbing is that they had fifteen years and hundreds of millions of dollars in funding from prominent foundations, and set up surrogate decision-making protocols to end the lives of people with intellectual disabilities, without seeking the input of such individuals and the established organizations that address issues of self-determination for people who have less typical ways of receiving, processing and communicating information.

### Barriers to consensus

A commonly stated reason within the disability community for hesitation or refusal to join the campaign to save Terri Schiavo was the problem of association with religious, pro-life and right-wing advocates. While disability advocates were covered in over 100 national and local television news broadcasts and talk shows on Schiavo, that was a mere drop in the proverbial bucket of Schiavo coverage overall.

When we analyze why the pro-life and religious advocates received such disproportionate attention, one factor is that disability advocates did not have the financial or personnel resources to carry out a large, prolonged vigil in Florida. But long before the last few weeks of Terri Schiavo’s life, the disability perspective was ignored. For the last three decades, certain bioethicists have told the press and the public that euthanasia is about compassionate progressives versus the religious right. Concerned disability groups don’t fit the long-settled script and so disability advocates have been marginalized or ignored entirely.

It is a long-term fight for disability advocates to be heard through the barrier of the established script. The organizations that supported Terri Schiavo’s right to food and water held their position as one consistent

with disability rights, and not necessarily identified with either the right or the left. In fact, advocates worked to hold policymakers from both sides of the political aisle accountable. But so many reporters were suspicious that disability groups were secretly puppets of the right wing, that Not Dead Yet often added the following statement to Schiavo interviews: “The far right wants to kill us slowly and painfully by cutting the things we need to live, health care, public housing and transportation, etc. The far left wants to kill us quickly and call it compassion.”

Apart from the right-left tension, also known as “strange bedfellows,” there are some individuals with disabilities who substantively disagree with the positions taken by national disability advocacy organizations. Some view these positions as paternalistic and over-protective, contrary to the principles of self-determination. Some individuals with disabilities favor legalization of assisted suicide. Some object to identifying Terri Schiavo as a person with a disability.<sup>18</sup> The disability rights movement is not sufficiently strongspoken and recognized in the mainstream community to escape the neutralizing effect that a few individual dissenters can have on the message of groups representing millions.

In hindsight, the facts in the Schiavo case also suggest that an Olmstead challenge could have been raised. Using self-determination oriented, person-centered planning approaches, the claim could have been made that Terri Schiavo’s Olmstead rights were violated by her guardian when he incarcerated her in a hospice facility, rather than allowing her to receive long term care services at home with her mother and family. Her ability to live at home and her preference to be with her mother could have been tried in federal court under the Americans With Disabilities Act, using experts from the disability rights and self-determination movements.

Futility is proof that more unity is needed

Unfortunately, the anecdotal evidence suggests that Terri Schiavo’s case may be

the tip of a very large and almost fully submerged iceberg. It appears that bioethics has pretty much dominated end-of-life care movement work in policymaking, imposing a “lifeboat” approach, deciding who gets thrown out.

In fact, if neither the patient nor guardian are willing to refuse life-sustaining treatment that the physician does not want to provide, futility policies have been developed through which doctors simply over-rule the patient or guardian. This is involuntary euthanasia. The AMA recommends procedurally based futility policies, which take the family through a series of steps, including ethics committee reviews, to persuade them that the doctor’s decision not to treat is best.<sup>19</sup> Increasingly, the only “good” decision is a “death” decision.

## Conclusion

As we watch state Medicaid programs cut people and services, knowing that many disabled and non-disabled will die as a result, the importance of unity within the disability community has never been more clear. If we know that we are not better off dead, and we know that society is not better off without us, we had better say so very strongly. We must not only build our alliances within the movement, but reach out to other health care advocates and help them understand that our lives are not a waste of society’s resources.

For these reasons the authors believe that it is long past time to create an emergency summit on these issues, raise dollars to advance a disability rights agenda and create several parallel strategies within academia, the media and our social and cultural organizations. There is no longer time to wait on the sidelines.

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<sup>12</sup> <http://www.notdeadyet.org/docs/wendbrief.html>

<sup>13</sup> Conservatorship of Wendland, 28 P.3d 151 (Cal. 2001)

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<sup>15</sup> See, e.g., Psychiatric News July 16, 2004, Volume 39 Number 14 © 2004 American Psychiatric Association p. 32.

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