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Terri Schiavo and the Disability Rights Community: A Cause for Concern

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Many disability rights organizations saw Terri Schiavo as one of their own. They compared her condition, a “permanent vegetative state,” to autism, Down syndrome, and cerebral palsy, and denounced the removal of her feeding tube as “death

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1 D'Alemberte Professor of Law, Florida State University College of Law. I wish to thank the University of Chicago Legal Forum for inviting me to the conference where I presented this paper and for its editorial assistance. I am also grateful for the research support of the FSU College of Law and the assistance of the College of Law's library staff.

1 See ADA Watch, et al, Issues Surrounding Terri Schindler-Schiavo Are Disability Rights Issues, Say National Disability Organizations, Ragged Edge Online (Oct 27, 2003), available at <http://www.raggededgemagazine.com/schiavostatement.html> (last visited Feb 27, 2006) (signed by the following twenty-three national disability rights groups: ADA Watch, ADAPT, AIMMM-Advancing Independence, Center for Self Determination, Center on Human Policy, Citizens United Resisting Euthanasia (“CURE”), Disability Rights Center, Disability Rights Education & Defense Fund, Disability Rights Project of the Public Interest Law Center of Philadelphia, Hospice Patients Alliance, National Catholic Partnership on Disability, National Coalition for Disability Rights, National Coalition on Self-Determination, National Council on Independent Living, National Disabled Students Union, National Down Syndrome Congress, National Organization on Disability, National Spinal Cord Injury Association, Not Dead Yet, Self Advocates Becoming Empowered (“SABE”), TASH (formerly The Association of Persons with Severe Handicaps), World Association of Persons with Disabilities, World Institute on Disability). The case of Terri Schiavo is widely regarded as our nation’s most prominent and most litigated “right to die” case to date. For a description of the facts of the case, see Lois Shepherd, Terri Schiavo: Unsettling the Settled, 37 Loy U Chi L J 297 (2006). Most relevant here is the fact that she lived in a permanent vegetative state for fifteen years before her feeding tube was removed upon a court order sought by her husband.

2 The term “permanent vegetative state” describes the condition of a person who has entered a permanent, continuing state of unconsciousness marked by periods of wakefulness. Bryan Jennett, The Vegetative State: Medical Facts, Ethical and Legal Dilemmas 4-5 (Cambridge 2002). A number of commentators have protested that the term “vegetative” is demeaning because it suggests that the patient is something less than a person, a mere “vegetable.” Id at 5. See also Raphael Cohen-Almagor, Some Observations on Post-Coma Unawareness Patients and On Other Forms of Unconscious Patients: Policy Proposals, 16 Med & L 451, 461 (1996) (arguing that the term ‘vegetative’ dehumanizes the patients, suggesting that we speak of some form of sub-human life); Adam J. Hildebrand, Masked Intentions: The Masquerade of Killing Thoughts Used to Justify Dehydrating and Starving People in a “Persistent Vegetative State” and People With Other Profound Neurological Impairments, 16 Issues L & Med 143, 148-49 (2000) (arguing that the term “vegetative” is “an insult to the inherent dignity of the human person”). While I am sympathetic to this argument, the terminology has become so widespread, with no alternative yet achieving any significant use, that to use a different term may cause confusion.
by starvation."³ In an amicus brief,⁴ they claimed that because perceptions about her "quality of life" drove the decision to discontinue her nutrition and hydration, she could not be "distinguish[ed] from anyone else who is 'incompetent,' including thousands who cannot speak due to developmental or physical disabilities."⁵ The brief continued, "It is naïve to believe such attitudes would not be used to justify the death of people with severe disabilities if the opportunity arose."⁶ Twenty-three national disability groups adopted a statement that argued that the fate of Terri Schiavo was "entwined with all disabled people who rely on surrogates [to make their medical decisions]."³⁷

Although Ms. Schiavo died in March 2005 when her feeding tube was removed for a third and final time, the advocacy her case spurred continues. A number of disability rights groups have urged lawmakers to severely restrict the withholding or withdrawal of artificial nutrition and hydration from "people with cognitive disabilities."⁸ Under one proposal, artificial nutrition and hydration could not be removed from those who have never been competent unless their bodies are unable to digest or absorb the nutrition and hydration.⁹ Several states have consid-

⁴ The brief was filed in support of Florida legislation, passed in October 2003, that gave the state's Governor Jeb Bush the power to order the reinsertion of Ms. Schiavo's feeding tube after it was removed upon a court order. The law, commonly referred to as "Terri's Law," was declared unconstitutional by the Florida Supreme Court in Bush v Schiavo, 885 S2d 321 (Fla 2004).
⁵ Brief of Amici Curiae Not Dead Yet et al in Support of Appellant and Requesting Reversal, Bush v Schiavo, *2 (Fla filed July 12, 2004) (available on Westlaw at 2004 WL 1713757) ("Not Dead Yet Brief"). The organizations joining as Amici Curiae in this brief were: Not Dead Yet, ADAPT, The ARC of the United States (formerly the Association for Retarded Citizens), Center on Human Policy (Syracuse University), Center on Self Determination, Disability Rights Center, Freedom Clearinghouse, Hospice Patients' Alliance, Mouth Magazine, National Council on Independent Living, National Disabled Students Union, National Spinal Cord Injury Association, Self-Advocates Becoming Empowered, Society for Disability Studies, TASH, World Association of Persons with Disabilities, and World Institute on Disability. Id at inside cover.
⁶ Id.
⁹ See id:

NCIL supports legislation that restores and maintains restrictions on surrogate decisions for withholding of food and water via tube. Specifically, legislation should
erred legislation, based on a model act drafted by the National Right to Life Committee ("NRLC"), which proposes just such changes—an act significantly titled “Starvation and Dehydration of Persons with Disabilities Prevention Act.”

I have long shared these groups’ concern that evaluations about “quality of life” can harm people with disabilities. But I think the response of the disability rights community to the Terri Schiavo controversy is misguided and wrong. In particular, the

only allow for withholding of food and water in the presence of ‘clear and convincing evidence’ of the person’s wishes or when the person’s medical condition renders them incapable of digesting or absorbing the nutrition and hydration so that its provision would not contribute to sustaining the person’s life.

Id. By requiring evidence of an individual’s wishes before the withholding of artificial nutrition and hydration, the legislation supported by the NCIL excludes the never-competent individual except when the nutrition and hydration cannot be digested or absorbed.

10 National Right to Life Committee (“NRLC”), Model Starvation and Dehydration of Persons with Disabilities Prevention Act (NRLC Jan 2006), available at <http://www.nrlc.org/euthanasia/modelstatelaw.html> (last visited Feb 27, 2006). This model act applies to any individual who is legally incapable of making health care decisions and prohibits any “guardian, surrogate, public or private agency, court, or any other person” from authorizing the withholding or withdrawal of nutrition and hydration from such individual except in certain narrowly defined circumstances. Id at §3A. Nutrition and hydration can be withheld or withdrawn when its provision would be medically inappropriate because it (a) would not be medically possible, (b) would hasten death, or (c) would not sustain life because the person is incapable of digesting or absorbing nutrition and hydration. Id at §4A. In addition, nutrition and hydration can be withheld or withdrawn when the individual has executed a written directive so authorizing or when “there is clear and convincing evidence that the person, when legally capable of making health care decisions, gave express and informed consent to withdrawing or withholding hydration and nutrition in the applicable circumstances.” Id at §§4B, 4C. For individuals who have never been competent, the written directive or “express and informed consent” exceptions would not apply.


effect of lumping Ms. Schiavo in with people who are “profoundly developmentally disabled”\(^4\) (who are and always have been incompetent) could lead to an unintended erosion of the rights disability groups have worked hard to secure.

Our instinct is—and should be—to safeguard any advances in the protection of the lives and well-being of all disabled people. History is too heavy with the horrors of forced sterilizations, eugenics experiments, and medical neglect and abuse for us not to think very carefully about making “quality of life” decisions for those we judge to be incompetent.\(^5\) Even today, in every society and in virtually every realm of life, the discrimination against people with disabilities in employment, access, education, and health care is so constant\(^6\) that we’re tempted to see the struggle for disability rights as one straightforward push in one invariable direction: more rights protecting life, equal treatment, and inclusion. The idea that distinctions might be made between different disabilities adds complications that are simpler to avoid.

But I believe it is fundamentally disrespectful to a person who is profoundly disabled to equate her condition with that of someone in a permanent vegetative state, as if these conditions are part of a continuum. The view that the permanent vegetative state is merely at one end of a continuum of disabilities seems to serve neither the profoundly disabled person who has entered a permanent vegetative state, nor profoundly disabled people in general. It fails the first group of individuals and their families because it denies the loss they have suffered when such individuals enter a permanent vegetative state; furthermore, it may lead to policies that inhibit reasonable decisions to terminate treatment and allow such individuals to die. The failure to recognize a deep divide between the condition of permanent vegeta-

\(^{14}\) By the term “profoundly developmentally disabled” or simply, “profoundly disabled,” I mean individuals who are cognitively disabled from birth or childhood to such a degree that they are and always have been unable to make important decisions affecting their lives. See Norman L. Cantor, *Making Medical Decisions for the Profoundly Mentally Disabled* 1 (MIT 2005). Like Cantor, I will use the term “profoundly disabled” as shorthand in referring to this population, by which I do not mean to refer to individuals with physical disabilities, but only to those with mental disabilities. Id at 215 n 2.


\(^{16}\) Longmore, 3 Issues L & Med at 147-50 (cited in note 15).
tive state and other disabilities also does a disservice to the second group of individuals—the profoundly disabled—as it ignores and discounts their abilities to interact meaningfully with other people and with their environment. Contrary to the apparent aims of the disability rights groups, this view could lead to less, rather than more, protection from inappropriate decisions regarding their care and treatment. These concerns, explained more fully below, lead me to conclude that if disability groups wish to promote respect and care for the profoundly disabled, they should support a moral and legal distinction between a permanent vegetative state and other disabilities.

I. THE PROBLEM OF THE PROFOUNDLY DISABLED INDIVIDUAL WHO ENTERS A PERMANENT VEGETATIVE STATE

Disability groups have described the Terri Schiavo controversy as a conflict between the right to life (without discriminatory assessments about the quality of that life) and the right to refuse medical treatment.\(^{17}\) The right to refuse treatment, which derives primarily from common law and constitutional rights in bodily integrity,\(^{18}\) is generally understood as a right to refuse unwanted treatment.\(^{19}\) It is largely an autonomy-driven right, requiring that we respect what the competent patient presently chooses or what the incompetent patient formerly chose when still competent or what we believe she would choose today if still competent to do so.\(^{20}\) The autonomy rationale carries less weight

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\(^{17}\) See Not Dead Yet Brief at *13 (cited in note 5) (asserting that "[c]ases like Ms. Schiavo's raise competing individual interests under the Due Process Clause—the right to refuse treatment *as well as* the right to life" and indicating that Florida courts have "de-

cline[d] to 'make judgments about the "quality" of life that a particular individual may enjoy'"). The Brief also argues that the Florida legislature's enactment of "Terri's Law" (which permitted the Governor to order the reinsertion of Ms. Schiavo's feeding tube) "must be seen in the context of the denial of medical treatment based on disability." Id at *16. In later proceedings Ms. Schiavo's parents argued that the decision to terminate her nutrition and hydration violated the Americans with Disabilities Act. See Verified Amended Complaint, Schindler v Schiavo, No 8:03-CV-1860-T-26-TGW, ¶ 75 (M D Fla filed Aug 30, 2003) (available on Westlaw at 2003 WL 23774093).

\(^{18}\) Cruzan v Director, Mo Dept of Health, 497 US 261, 278 (1990) ("The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions."); Washington v Glucksberg, 521 US 702, 725 (1997) (explaining that the assumption in Cruzan that there was a constitutionally protected right for a competent person to refuse lifesaving nutrition and hydration was based in "the common-law rule that forced medication was a battery, and the long legal tradition protecting the decision to refuse unwanted medical treatment").

\(^{19}\) Glucksberg, 521 US at 725.

\(^{20}\) Consider Norman Cantor, Discarding Substituted Judgment and Best Interests: Toward a Constructive Preference Standard for Dying, Previously Competent Patients Without Advance Instructions, 48 Rutgers L Rev 1193, 1199-1241 (1996) (explaining the
when we are dealing with the profoundly disabled because such individuals could not at any time make choices about treatment refusal or even indicate an implied preference in one direction or another.\textsuperscript{21} If the right to refuse treatment can only be accessed through autonomous choices, then for individuals who have never been competent to make important decisions the right to life and nondiscriminatory treatment will always prevail over the right to refuse treatment. The question of whether artificial nutrition and hydration can be withdrawn from such individuals, even when they have entered a permanent vegetative state, would have to be answered “no.”

But the right to refuse treatment has also been understood, in some instances, as extending beyond respect for a person’s autonomy in making choices about what treatment is wanted or unwanted. Instead, as a number of courts have recognized, there may be instances in which it is appropriate to engage in a so-called “best interests” analysis, objectively weighing the burdens and benefits of treatment for people who have never been competent.\textsuperscript{22} Disability rights groups have generally rejected such a best interests analysis as inviting inappropriate evaluations of the quality of the continued life of the individual.\textsuperscript{23}

Even with a best interests analysis, however, the problem posed by the profoundly disabled individual who has entered a permanent vegetative state is not readily solved. What are the burdens of continued treatment? We cannot say that the person who is in a permanent vegetative state suffers.\textsuperscript{24} She is perma-

\textsuperscript{21} See, for example, Superintendent of Belchertown State School v Saikewicz, 370 NE2d 417 (Mass 1977), a case often cited for revealing the difficulty or even impossibility of recognizing autonomy-based rights to refuse medical treatment for the profoundly disabled. In this case, the court describes itself as applying the substituted judgment approach to a question of treatment refusal by a profoundly disabled adult, an approach that requires discerning what the patient himself would choose if able to do so. But because the patient could never have made any choices of this kind, the case is widely acknowledged as adopting the best interests approach. Mark A. Hall, Mary A. Bobinski, and David Orentlicher, Health Care Law and Ethics 543 (Aspen 6th ed 2003) (“Indeed, inasmuch as Mr. Saikewicz had never been competent, it made no sense to employ a substituted judgment.”).

\textsuperscript{22} See, for example, Woods v Commonwealth of Kentucky, 142 SW3d 24, 50 (Ky 2004) (reading Kentucky state law as “permit[ting] a surrogate [to] withhold[] or withdraw[] life-prolonging treatment from a patient who is permanently unconscious or in a persistent vegetative state” based on a good faith best interests analysis).

\textsuperscript{23} See Not Dead Yet Brief at *20 (cited in note 5) (commending Florida law for “focusing on the wishes and desires of Terri Schiavo rather than the subjective views of others concerning her ‘quality of life’”).

\textsuperscript{24} Jennett, The Vegetative State at 15, 18-19 (cited in note 2) (“It is widely held that
nently unconscious. She cannot feel pain or discomfort. Because such individuals can no longer experience any burdens, one cannot say, under a traditional best interests analysis, that the burdens of continued treatment or continued life outweigh its benefits. How, then, if neither test is workable, do we answer the question whether such a person must be fed by tube for twenty or thirty years with essentially no possibility of recovery? Some would argue that continued provision of artificial nutrition and hydration is necessary in these circumstances under both a pure autonomy model of surrogate decision-making (because the autonomous wishes of the profoundly disabled individual cannot be determined) and also under a best interests model of surrogate decisionmaking (because there are no concrete burdens to weigh against the “benefit” of continued life).

The vast majority of competent individuals say they would not want to receive artificial nutrition and hydration if they entered a permanent vegetative state, but our current methods of analysis make it difficult to allow the profoundly disabled the same right to refuse treatment as is given to once-competent individuals. Some argue that the permanent vegetative state is simply an intolerable condition for everyone, garnering some support for this conclusion from the consensus view of competent individuals. But it is difficult to see why the opinions of competent individuals should carry much weight here, since they frequently reject the idea of continuing life in a variety of disabling conditions. If we accept the position that the profoundly dis-

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vegetative patients are unaware of their surroundings or of themselves, implying loss of the capacity to experience pain or suffering.”)

25 Id at 2, 10.
26 Id at 15, 18-19.
27 See id at 64-69.
28 Cruzan, 497 US at 312 n 11 (Brennan dissenting) (citing “[a] 1988 poll conducted by the Colorado University Graduate School of Public Affairs[, which] showed that 85 percent of those questioned would not want to have their own lives maintained with artificial nutrition and hydration if they became permanently unconscious”); Schulman, Ronca, & Bucuvalas, Inc, SRBI/Time Magazine Poll # 2005-3500: Terri Schiavo, question 11 (Roper Center for Public Opinion Research Mar 22-24, 2005), available at <http://roperweb.ropercenter.uconn.edu/cgi-bin/hsrun.exe/Roperweb/Catalog40/Catalog40.htx;start= summary_link?archivo=USSRBI2005-3500> (last visited Feb 27, 2006) (indicating that 69 percent of Americans “would . . . want [their] guardian to remove [their] feeding tube”).
29 Cantor, Making Medical Decisions at 124-45 (cited in note 14).
30 In one study, individuals were asked whether they would want life support systems, including artificial nutrition and hydration, withdrawn if they had “an illness that made [them] totally dependent on a family member or other person for all of [their] care?” Fifty-one percent said that they would want treatment
abled should not be allowed to die simply because a number of competent individuals imagine (in the abstract) that they would wish to die in such circumstances, then it seems odd to turn to popular opinion surveys to determine whether life for the profoundly disabled becomes intolerable once a permanent vegetative state has been entered. If competent individuals find the starting point of profound disability intolerable, they will no doubt find the vegetative state intolerable.

The difficulty posed by this situation, however, cannot simply be avoided as the disability rights groups have tried—by sweeping the permanently vegetative person into the same category as the person with autism, or Down syndrome, or cerebral palsy. The disability groups' adoption of the "fight for Terri's life" has been most troubling in its failure to recognize a deep divide between the condition of permanent vegetative state and other disabilities.

Sometimes a simple remark from the wrong person at the wrong time can bring things into focus. I found this to be true of a televised statement made in October 2003 by Johnnie Byrd, then the speaker of the Florida House of Representatives and a supporter of Florida legislation to allow the Governor to reinsert Ms. Schiavo's feeding tube. In a broadcast of the NewsHour with Jim Lehrer, Byrd referred to Terri Schiavo as a "beautiful lady." He said that the legislature and citizens of Florida had lost confidence in the legal process because of the "conflicts of interest between the husband and the best interest of this beautiful lady." He said that the legislature and citizens of Florida had lost confidence in the legal process because of the "conflicts of interest between the husband and the best interest of this beau-

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James Lindgren, Death by Default, 56 L & Contemp Probs 185, 198-99 (Summer 1993).

A study of health professionals' attitudes revealed that of a group of 153 emergency care providers, only 18 percent imagined they would be glad to be alive with a severe spinal cord injury. A comparison group of 128 persons with high-level spinal cord injuries provided vastly different results. Ninety-two percent of that group said they were glad to be alive. Another study found a similarly high number (82 percent) of emergency care providers indicating that they preferred death to severe disability. Carol J. Gill, Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia, 6 Psychol Pub Pol'y & L 526, 530 (2000) (citing Gerhart, et al, Quality of life following spinal cord injury: Knowledge and attitudes of emergency care providers, 23 Annals of Emergency Medicine, 807-12 (1994); C.A. Bach and R.W. McDaniel, Quality of life in quadriplegic adults: A focus group study, Rehabilitation Nursing, 18(6), 364-67 (1993)).


32 Id.
tiful lady.\textsuperscript{33} Clips of videotaped footage of Ms. Schiavo had already been and would continue until her death in 2005 to be repeatedly broadcast on television and widely available on the internet. In those clips, her face is puffy, her mouth slack, her limbs contorted; at most the footage indicated a very minimal response to her surroundings\textsuperscript{34} (in fact, the videotape is widely regarded as misleading, consisting of only seconds culled from hours of taping in which her parents and others tried, unsuccessfully, to elicit some response from her\textsuperscript{35}). When I heard Johnnie Byrd refer to Terri Schiavo as a “beautiful lady,” the description seemed patronizing and insulting. But why? Was he merely saying that all people are beautiful? And if so, what could be offensive about that?

Terri Schiavo had been a beautiful woman in the way we normally talk about beauty—a vivacious young woman struck down in her prime. But a politician calling her that now, clearly to advance his own political agenda, seemed to deny the tragedy she had endured.

And this, I think, is the key point. If someone profoundly disabled from birth suffered an injury that caused her to enter a permanent vegetative state, she would have lost as much as any competent person who entered a permanent vegetative state has lost. They each would have lost all they had. They would have lost all cognition, all emotion, all sensation they otherwise had. It would be just as tragic for a person with a profound developmen-

\textsuperscript{33} Id.

\textsuperscript{34} For an analysis of the media use of the videos (and also to view two of the videos), see Diane Waldman, \textit{Timely Triage: Schiavo Videos—Context and Reception}, \textit{Jumpcut}, available at <http://www.ejumpcut.org/currentissue/SchiavoWaldman/index.html> (last visited April 26, 2006). See also Terri Schindler Schiavo Foundation, available at <http://www.terrisfight.org> (last visited Mar. 3, 2006), the website established by Ms. Schiavo’s parents. During the controversy surrounding the removal of Ms. Schiavo’s feeding tube, this website published several photographs and also videoclips of Terri Schiavo in the condition in which she existed for many years, which the Florida circuit court determined, upon the evidence submitted by numerous doctors, was a permanent vegetative state. Id. There are also photographs of what Terri looked like before the heart attack that led to her vegetative condition. Id. Videoclips of Terri are no longer available on this website.

\textsuperscript{35} Colleen McCain Nelson, \textit{Video Clip Misleading, Experts Say; Schiavo’s Changing Expressions Subject of Debate}, Herald News (Passaic County, NJ) A17 (Mar 23, 2005); see also \textit{Schindler v Schiavo}, 851 So2d 182, 186 (stating that, after “repeatedly examining the videotapes, not merely watching short segments but carefully observing the tapes in their entirety,” the court would uphold the guardianship court’s decision even under de novo review); Judith Graham, \textit{Seeking Meaning in a Hint of a Smile; Terri Schiavo’s Parents Make a Powerful Video Appeal to the Public, but Experts Say that the Images they Show are Misleading}, Chi Trib C1 (Mar 23, 2005) (“What appears on the surface to be intelligent, intelligible behavior on Schiavo’s part is anything but, most physicians say.”).
tal disability to enter a permanent vegetative state as it would be for a scientific genius on the order of Einstein or any single one of us. For each individual, all sentient humanity is lost—it is as if the person has for all purposes died but simply failed to take her body along.

Those in the disability community who have jumped on the “Right to Life” bandwagon argue that we cannot draw a line between a person in a permanent vegetative state and people with other profound disabilities. Many people with disabilities, they argue, are unable to communicate, at least temporarily. Many people with disabilities have been falsely or mistakenly told that their conditions are incurable, or judged to have lower levels of abilities than they actually do possess. Misjudgments about the capabilities of people with disabilities abound.

Let’s assume, for the sake of argument, that adults who have been in a vegetative state for over one year are permanently so, that there is remarkably little chance of recovery of any consciousness—so little that it is actually more accurate to say there is none, and that there is absolutely no consciousness present (there is, of course, very strong medical evidence which supports this, but it is not my point to defend it). On this assumption, is it really convincing to say that there is no difference between zero consciousness and some consciousness, however small? Doesn’t saying so fail to appreciate the interests that even the profoundly disabled person does have—interests in experiencing care, human relationships, sensory stimulation of some kind or degree?


37 Consider Mary Johnson, After Terri Schiavo: Why the disability rights movement spoke out, why some of us worried, and where do we go from here, Ragged Edge Online (Apr 2, 2005), available at <http://www.raggededgemagazine.com/focus/post-schiavo0405.html> (last visited Feb 27, 2006) (citing a recent study by doctors at Columbia Medical Center which found that “patients ‘who are treated as if they are almost completely unaware may in fact hear and register what is going on around them but be unable to respond’”).


39 Consider id (noting that “[h]istorically, many people with disabilities such as autism, Down syndrome and cerebral palsy have been thought to be incapable of communication”).

The bodies of people in a permanent vegetative state are in a sense no longer a part of an embodied self, because they are empty of the self. We do not owe responsibilities to that empty body. It is true that we owe some duties to the person who used to inhabit the body and to her family and friends—to treat the body with respect for example. In addition, if that person had previously expressed her wish to be kept alive, whatever her reasons, we should probably honor that desire.\textsuperscript{41} The profoundly disabled, by definition, have never expressed such desires. The permanent vegetative state offers them no more beneficial life than it offers to the rest of us.

In order to understand this distinction more clearly, we must recognize the distinction between “experiential” interests and “critical” or “future oriented” interests.\textsuperscript{42} People demonstrate their experiential interests when they “do things because [they] like the experience of doing them.”\textsuperscript{43} People also have critical interests: interests of a more normative nature, interests that their lives as a whole be successful according to certain critical judgments that they as individuals at one time possessed.\textsuperscript{44} For example, a person may believe that to have a successful life includes being respected as an independent, alert, dignified person. Forgoing life-sustaining treatments in a permanent vegetative state may be in keeping with that earlier judgment. Another person may believe that a successful life would entail staying alive in defiance of death or because of religious values.\textsuperscript{45} The critical interests of the latter person may be respected by continuing, rather than forgoing, life-sustaining treatment.\textsuperscript{46}

\textsuperscript{41} I say “probably” because I can imagine a set of circumstances in which we would not honor it, for example, because of decisions to allocate scarce resources elsewhere.

\textsuperscript{42} Ronald Dworkin, \textit{Life’s Dominion: An Argument About Abortion, Euthenasia, and Individual Freedom} 199-213 (Vintage Books 1994). See also Allen E. Buchanan and Dan W. Brock, \textit{Deciding for Others: The Ethics Of Surrogate Decision Making} 128-29 (Cambridge 1989) (arguing that some people, prior to entering a vegetative state, may have “had certain future-oriented interests which will be satisfied or thwarted depending on what happens to him or her after becoming permanently unconscious”). Consider Lois Shepherd, \textit{In Respect of People Living in a Permanent Vegetative State—And Allowing Them to Die}, Health Matrix (2006) (forthcoming) (discussing experiential and critical interests of people in a permanent vegetative state).

\textsuperscript{43} Dworkin, \textit{Life’s Dominion} at 201 (cited in note 42).

\textsuperscript{44} Id at 201-213.

\textsuperscript{45} Id at 213 (discussing how an individual’s virtues, character traits, and intimate personal knowledge might be factors in one’s decision to remain in a vegetative state). See also Buchanan and Brock, \textit{Deciding for Others} at 128-29 (cited in note 42) (discussing the interests and values of a pre-vegetative individual, including religious and moral values, as factors in determining whether one should stay alive).

\textsuperscript{46} Dworkin, \textit{Life’s Dominion} at 213 (cited in note 42).
People in a permanent vegetative state clearly do not have experiential interests. And, while the previously-competent may have formed critical interests regarding life-death preferences upon entering a permanent vegetative state, the profoundly disabled cannot form any such interests. Therefore, the profoundly disabled person who has become permanently vegetative has no interests to be protected by the right to life, and any decision to keep them alive must be based on the preferences and interests of other people. This violates the principle that we must treat people as ends in themselves, an idea I explore in more depth elsewhere. Why should the profoundly disabled be placed at greater risk of such objectification and instrumental use than people who were once competent? Why should their families be made to suffer a longer period of distress while their loved ones are permanently nonresponsive?

Norman Cantor has similarly urged that profoundly disabled individuals should not be forced to continue living in a permanent vegetative state, but he does so for different reasons. Professor Cantor argues that permanent unconsciousness is an inherently undignified condition in which no one should be forced to live. “[A]rtificial preservation of life support” in these circumstances, he writes, is “an inhumane, intrinsically demeaning practice” that surrogates should not be permitted to choose for the profoundly disabled.

I think the concept of dignity is useless in this context. It means too many things to too many people and too often is used to refer to conditions that disabled individuals live with every day as they lead successful and meaningful lives. For example, the loss of dignity has been found in incontinence or dependency for “intimate care” or in helplessness or a “degraded” appearance. It is not uncommon for courts, in analyzing the claims of disabled individuals to a “right to die,” to place substantial emphasis on

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47 Shepherd, In Respect of People Living in a Permanent Vegetative State—And Allowing Them to Die (forthcoming) (cited in note 42) (discussing the actual or perceived interests of others in the prolongation of Terri Schiavo’s life and how, generally, the interests of others in continuing a person’s life are permitted to prevail in a legal system for end-of-life decisionmaking that is based upon a blanket presumption in favor of life).
46 For a general discussion, see Cantor, Making Medical Decisions at 122-27 (cited in note 14).
49 Id at 122.
50 Id at 127.
51 See Shepherd, 7 Cornell J L U Pub Pol’y at 448-52 (cited in note 13) (arguing that the “death with dignity” movement has advanced an understanding of “dignity” with strong normative content, threatening autonomy and respect for the individual person).
such "indignities." For example, one court has suggested that
dignity is incompatible with existence in "a childlike state of
helplessness, diapered, sedated, incontinent."\(^{52}\) Similarly, an-
other court suggested that one disabled individual necessarily
lacked dignity because she had "to be fed, cleaned, turned, bed-
ded, [and] toileted by others" and had to "lie physically helpless
subject to the ignominy, embarrassment, humiliation and dehu-
manizing aspects created by her helplessness."\(^{53}\) These objective-
seeming criteria for dignity are actually quite subjective—coming
from the subjective view of the competent individual who does
not have these characteristics. These are the kinds of characteri-
zations that offend disability groups, and with good reason.\(^{54}\)

Instead of focusing on whether someone possesses dignity,
and what that dignity entitles him to, or what the loss of that
dignity signifies in terms of life-sustaining treatment, I suggest
that we focus instead on determining how best to respect and
care for the individual. Respect and care for individual human
beings protects us from being experimented upon without our
consent, or having our organs removed, or being subjected to
other instrumental uses. Respect and care for Terri Schiavo, for
example, should have protected her from the public display to
which her body was subjected.

Disability rights groups failed, in my opinion, to respect and
care for Terri Schiavo when they essentially used her as a
"poster child" to protect other disabled individuals from what
they believe are inappropriate treatment refusals.\(^{55}\) These groups
contributed to the prolongation of her life against her apparent
(indeed, proven) wishes,\(^{56}\) and when she could not experience any

\(^{52}\) Compassion in Dying v Washington, 79 F3d 790, 814 (9th Cir 1996) revd as Wash-
ington v Glucksberg, 521 US at 704.

\(^{53}\) Bouvia v Superior Court, 179 Cal App 3d 1127, 1143 (1986).

\(^{54}\) Consider Johnson, After Terri Schiavo, Ragged Edge Online (Apr 2, 2005), avail-
able at <http://www.raggededgemagazine.com/focus/postchiavo0405.html> (last visited
Feb 27, 2006) (cited in note 37) ("[P]eople who are not disabled, despite what they think
they understand and would want, have no real clue as to what it is like to live as a dis-
abled person. And there is no way . . . . that they can know now what they would really
want once they became disabled.").

\(^{55}\) As I have written elsewhere, "Keeping Terri Schiavo alive for the benefit of other
people with severe disabilities is no more morally acceptable than keeping her alive for
her parents or for doctors or for the Governor of Florida. It is especially disconcerting to
witness groups who purport to stand up for the vulnerable in our society to use one of
those vulnerable people for their cause." Lois Shepherd, In Respect of People Living in a

\(^{56}\) In re Guardianship of Schiavo, 2000 WL 34546715, *4 (Fla Cir Ct), affd, 780 S2d
176, 180 (Fla App 2001) (finding that Terri Schiavo had expressed sentiments to several
people from which it could infer a desire to be allowed to die if she ever entered a persis-
benefit from living. They did this not, therefore, for her benefit, but for the benefit of other disabled individuals. Likewise, when these groups insist that the profoundly disabled who enter a vegetative state receive perpetual artificial nutrition, they lose sight of the individual they claim to protect.

The distance between Cantor’s position and the one expressed here may be both closer together and further apart than is readily apparent. Our positions are closer in the sense that while Cantor is willing to say that permanent vegetativeness is an intrinsically undignified state and I am not, we are both concerned that people not remain in vegetative limbo to satisfy others’ interests.\footnote{Consider Cantor, \textit{Making Medical Decisions} at 124 (cited in note 14) (“[R]espect for human dignity is what insulates the never competent patient from regularly being subjected to bodily invasions such as tissue harvesting or hazardous medical experimentation that would benefit others.”).} In addition, Cantor states that contemporary norms would consider only a few, narrow conditions as intrinsically undignified, including “permanent unconsciousness, mental decline to a semiconscious state where the person can no longer recognize and relate to others, and serious irremediable suffering.”\footnote{Id at 126-27.} But at the same time Cantor readily recognizes that norms of dignity change over time and appears willing to let those changing norms of the vague notion of dignity determine when artificial nutrition and hydration may or should be removed.\footnote{Consider id (noting that “[t]he concept of intrinsic human dignity is ‘neither static nor universal’ and evolves according to cultural conditions . . . ”).} Moreover, he advocates a narrower set of intrinsically undignified conditions for those who were previously profoundly disabled than he would for those who were previously competent.\footnote{Id at 126.} He argues that “a possibly degrading condition—like extreme dementia or total helplessness—is more likely to be deemed intolerably undignified when the actual values of a previously competent patient are known . . . than when notions of intrinsic indignity come into play.”\footnote{Cantor, \textit{Making Medical Decisions} at 124 (cited in note 14).} Here, our positions diverge, because for me both the willingness to call various conditions “undignified” according to social norms and the willingness to ascribe certain conditions as undignified for some people but not for others remain unacceptable because of the reduced respect this evidences toward people with profound disabilities.

\footnote{tent vegetative state; determining that evidence of Ms. Schiavo’s desire to be allowed to die met Florida's standard of “clear and convincing”).}
11. **POSSIBLE EFFECTS OF THE DISABILITY RIGHTS' PERSPECTIVE ON THE PROFOUNDLY DISABLED**

Thus far, I have focused primarily on how the disability groups' position on Terri Schiavo may result in inadequate respect and care for the profoundly disabled individual who enters a permanent vegetative state. But I also have concerns about the potential effects of this position on the profoundly disabled generally. First, the blurring of the line between the permanently vegetative and the profoundly disabled that was an essential part of the disability groups' strategy on Terri Schiavo may backfire. Instead of leading to continued life support for those in a permanent vegetative state, it may lead to less appreciation of the abilities of those who are merely profoundly disabled and less protection of their distinct interests. Second, disability groups have supported proposed legislation to allow artificial nutrition and hydration to be withheld only for those patients who have once been competent. Such legislation, if adopted, would require the administration of artificial nutrition and hydration even when it would cause suffering for such patients and no corresponding benefit.

A. **Blurring the Line Between the Permanently Vegetative and the Profoundly Disabled**

Presumably, one primary objective of disability groups in joining the fight against removing Ms. Schiavo's feeding tube was to protect against "slippery slope" concerns.\(^6\) The view is something like this: If the law allows artificial nutrition and hydration to be removed from people in a permanent vegetative state on the basis of somewhat casual remarks by the individual when competent, then won't it also be pushed to allow nutrition and hydration or other life support to be removed from people with profound disabilities? If, as under Florida law, casual remarks and evidence of "personality and values" can be used to determine a formerly competent patient's preferences, isn't it fair to say that a certain amount of projection by the surrogate decisionmaker, the courts, and society in general is taking place? And if that is allowed—if societal views about which lives are worth living determine who lives and dies—then shouldn't the disability groups try to put a stop to it here and now?

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\(^6\) Consider Not Dead Yet Brief at *16-20 (cited in note 5).
As a practical matter, courts and statutes do treat the permanently vegetative differently than they treat people with profound disabilities. In Florida, for example, decisions by surrogates to remove life support from incompetent patients receive statutory protection only in narrowly defined conditions. The relevant Florida statutes set out procedures to allow the removal of life support from incompetent individuals who are terminally ill, in a permanent vegetative state, or in an end-stage condition. They do not sanction the withholding or withdrawing of nonburdensome life support from individuals simply because they are profoundly disabled.

These distinctions indicate that the permanently vegetative are different and that decisions to remove life support from them will be governed by a set of standards not applicable to people with profound disabilities. And, as I have argued above, this differential treatment is justified because of the permanent and complete loss of consciousness by the individual in a permanent vegetative state.

By blurring the line between the permanently vegetative and the profoundly disabled, disability groups may be jeopardizing existing protection for the profoundly disabled. Once the line is blurred, it is not obvious that societal views and changes in the law that might develop from those views would gravitate toward tighter restrictions on treatment refusals for the permanently vegetative. The American public might instead prefer a loosening of restrictions on the removal of life support from the profoundly disabled. Certain in their belief that the permanent vegetative state is intolerable, and told that the permanently vegetative are not very different from the profoundly disabled, the general pub-

64 Id. An "end-stage condition" is defined as "an irreversible condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration and which, to a reasonable degree of medical probability, treatment of the condition would be ineffective." Id. This term is commonly understood to embrace advanced dementia, such as that caused by Alzheimer's disease, which is "steadily progressive, incurable and ultimately fatal." See Opinion No. 00-02 of the Maryland Attorney General (Nov. 16, 2000) (interpreting a statute similar to Florida's).
65 In this regard, note the California case, Conservator of Wendland, 28 P3d 151 (Cal 2001) (finding that the conservator failed to prove by clear and convincing evidence that the conservatee—who was severely brain damaged but not permanently vegetative—wished to refuse life-sustaining treatment or that to withhold such treatment would have been in his best interest). In that case, the court noted that "[i]t is . . . worth mentioning that no decision of which we are aware has approved a conservator's or guardian's proposal to withdraw artificial nutrition and hydration from a conscious conservatee or ward." Id at 170.
lic might, for example, wish to add to the categories of conditions receiving legal sanction for treatment refusals. One possibility would be to add the "minimally conscious condition" to the types of conditions identified by state statutes as those in which treatment withdrawal may occur by surrogate decisionmaking. This is the condition that Terri Schiavo's parents claimed their daughter was in during the later years of their fight to prevent removal of her feeding tube. The evidence presented in court was clearly otherwise, but for some Americans the specificity of the diagnosis may not have mattered much—what they saw was a condition for which they approved removal of the feeding tube.

In my view, if disability groups wish to protect the profoundly disabled from the withdrawal or withholding of life sup-

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66 For a general discussion of the "minimally conscious condition," see Jennett, The Vegetative State at 24 (cited in note 2). The criteria for diagnosing the minimally conscious state, as recently developed by a group of experts, are as follows:

Evidence of limited but clearly discernible self or environmental awareness on a reproducible or sustained basis, by one or more of these behaviours:

1. Simple command following
2. Gestural or verbal 'yes/no' responses (regardless of accuracy)
3. Intelligible verbalization
4. Purposeful behaviour including movements or affective behaviours in contingent relation to relevant stimuli; examples include:
   (a) appropriate smiling or crying to relevant visual or linguistic stimuli
   (b) response to linguistic content of questions by vocalization or gesture
   (c) reaching for objects in appropriate direction and location
   (d) touching or holding objects by accommodating to size and shape
   (e) sustained visual fixation or tracking as response to moving stimuli.

Id at 24.


68 In re Guardianship of Schiavo, No 90-2908-GB-003, 2002 WL 31817960, *3 (Fla Cir Ct Nov 22, 2002). See generally, Shepherd, 37 Loy U Chi L J 297 (cited in note 1) (including a factual history of the Terri Schiavo case). The medical evidence is also described in In re Guardianship of Schiavo, 792 So2d 551, 554, 560 (Fla Dist Ct App 2001) and In re Guardianship of Schiavo, 851 So2d 182, 185 (Fla Dist Ct App 2003).

69 According to one survey in which respondents were asked "If you were in Terri Schiavo's place, would you want your guardian to remove your feeding tube or not?," 69 percent responded "Yes." Schulman, Ronca, & Bucuvalas, Inc, SRBI/J'me Magazine Poll # 2005-3500: Terri Schiavo, question 11 (Roper Center for Public Opinion Research Mar 22-24, 2005), available at <http://roperweb.ropercenter.uconn.edu/cgi-bin/hrun.exe/Roperweb/Catalog4/Catalog4.htx;start=summary_link?archno=USSRB12005-3500> (last visited Feb 24, 2006) (cited in note 28).
port, then they should seek to preserve and emphasize the distinction between no capacity to experience life and some capacity to do so. They should highlight the fact that for people with profound disabilities who are not permanently unconscious, there are benefits to continued living—rich and meaningful benefits.

Moreover, the capacity of the profoundly disabled to, in the main, experience and benefit from human relationships means that disability groups should educate the public about the importance of and value in establishing relationships with people with profound disabilities. Despite the campaign of misinformation feeding the media about her condition—such as the few-second videotape that appeared to show Terri Schiavo responding to her mother’s presence—the American public appeared to understand Ms. Schiavo’s true condition.70 Sadly, Ms. Schiavo no longer experienced a relationship with her mother. But for people with profound disabilities, the care and concern that others show for them is experienced and should be encouraged. Confusing their condition with a permanent vegetative state might diminish efforts at establishing and maintaining relationships that are beneficial to the profoundly disabled.

B. Proposed Legislation Restricting the Removal of Artificial Nutrition and Hydration

There is also another way in which the position taken by the disability rights groups in response to the Schiavo controversy may negatively affect people with profound disabilities. As noted above, a number of these groups have lent their support to state legislative proposals that would prevent the removal of artificial nutrition and hydration from individuals who have never expressed a desire to terminate treatment. This would mean that, except in narrow circumstances, the profoundly disabled who are terminally ill would be forced to receive nutrition and hydration, even if the imposition of such treatment caused suffering and even if the burdens of treatment to them far outweighed the benefits of a brief extension of life.

Consider the case of Sheila Pouliot, a terminally ill, profoundly disabled woman whose life was inappropriately extended by the provision of artificial nutrition and hydration because

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70 Robert J. Blendon, et al, The American Public and the Terri Schiavo Case, 165 Arch Int Med 2580, 2582 (2005) (“A majority of Americans (54%) said there was no chance whatsoever that Schiavo would eventually show significant improvement in brain activity if the feeding tube were reinserted permanently.”).
New York law appeared to require it. Because Ms. Pouliot's body was unable to tolerate a gastronomy tube that might provide adequate nutrition, she was instead intravenously fed a glucose-only formula that did not prevent her body from being starved of protein. One of her physicians stated that the IV nutrition and hydration she was forced to undergo allowed "the patient [to be] kept alive for her own body to consume/eat itself." Despite substantial pain relief medications, Ms. Pouliot clearly suffered in the last two months of her life—as evidenced by her crying, moaning, and grimacing—from the forced administration of half measures of nutrition and hydration.

The NLRC has proposed a model act that would prohibit the withholding or withdrawal of artificial nutrition and hydration from individuals without a written directive or a very precise oral directive, which Sheila Pouliot did not and could not have. There is an exception for when the provision of artificial nutrition and hydration would be medically inappropriate, as it was in Pouliot's case, but that exception is likely too narrow to have applied. The exception applies when the provision of nutrition and hydration could not be absorbed and therefore would not contribute to sustaining the person's life. In Pouliot's case, the intravenous feeding did sustain and extend Pouliot's life, although at the cost of great suffering.

Some disability rights groups appear to support legislation like the NRLC's model act. Other disability rights groups have

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71 Alicia Ouellette, When Vitalism is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment, 79 Ind L J 1, 13-18 (2004).
72 Id at 16.
73 Id at 17.
74 Cantor, Making Medical Decisions at 40 (cited in note 14).
76 Consider Ouellette, 79 Ind L J at 17 (cited in note 71) ("New York law prohibited a third party . . . from making the decision to terminate life-sustaining treatment for another.").
77 See NCIL, Rights of People with Disabilities to Food and Water Resolution (Not Dead Yet July 14, 2005), available at <http://www.notdeadyet.org/docs/ncilres0705.html> (last visited Feb 27 2006) (cited in note 8) ("[L]egislation should only allow for withholding of food and water in the presence of 'clear and convincing evidence' of the person's wishes or when the person's medical condition renders them incapable of digesting or absorbing the nutrition and hydration so that its provision would not contribute to sustaining the person's life.").
adopted different statements that may or may not have approved the use of intravenous feeding to sustain Pouliot's life.  

Yet Sheila Pouliot's suffering was real. It was not the projected or imagined suffering that is sometimes used to justify the avoidance of the births of people with developmental disabilities. Nor was it the suffering imagined or at least rhetorically recognized by Nazi doctors who euthanized children with disabilities and the elderly. Concerned with protecting the disabled as a group from such prejudices, disability groups have sometimes advocated policies that fail to adequately protect individuals from actual suffering. They appear to be following that course again with regard to proposed changes to state end-of-life laws, which would not allow artificial nutrition and hydration to be withheld even when the burdens of its provision far outweigh the benefits. This may simply be an oversight or a misunderstanding of how the proposed legislation would actually work, rather than an actual indifference to the potential harm that such policies and practices could have. But even if well-intentioned, these groups' position on artificial nutrition and hydration needs to be clarified or corrected to protect the interests of the profoundly disabled.

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For the limited number of people who have lifelong cognitive disabilities and who have never had the ability to exercise self-determination regarding life-sustaining care and treatment, such care and treatment should not be withheld or withdrawn unless death is genuinely imminent and the care or treatment is objectively futile and would only prolong the dying process. When doubt exists as to whether to provide life-sustaining care and treatment a presumption must always be made in favor of providing such care and treatment.

Id.

79 Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 F S U L Rev 315 (2003). See also Mary Crossley & Lois Shepherd, *Genes and Disability: Questions at the Crossroads*, 30 F S U L Rev xi, xiv-xv (2003): To the extent such [historical eugenic] selection practices may appear to be based upon more laudable impulses to avoid suffering (rather than, for example, to relieve society of the economic burdens of caring for people with mental retardation), assumptions about the suffering of children with mental retardation should more honestly be understood as involving concerns about the ability to live independently.

Id.

CONCLUSION

The reaction of disability rights groups to the Schiavo controversy has the potential to strengthen the right to life for the profoundly disabled, but it also has the potential to diminish their protection from being treated as mere objects rather than as people. With respect to the profoundly disabled individual who enters a permanent vegetative state, the disability rights groups’ reaction may lead to policies that require such individuals to be kept alive although they will never experience or benefit from continued existence. The families of these individuals may suffer harm as a result of such policies, by being refused the opportunity—generally available to family members of other vegetative patients—to let their loved ones die.

In addition, when disability rights groups refuse to acknowledge that a permanent lack of consciousness is a condition very different from profound disability, they contribute to confusion about the abilities of people who are profoundly disabled to experience life and human relationships. The consequences of expressions of this viewpoint are only speculative—perhaps the position of disability rights groups on Terri Schiavo will lead to more respect and care for all people, as presumably is intended. But it seems just as likely that for people who are convinced that someone like Terri Schiavo should not be kept alive, their minds will be unchanged on that subject, yet having been told that her condition is not very different from others, may be open to expanding rather than contracting the conditions in which life support can be removed.

Finally, if state legislatures, hospitals, and physicians answer the calls to make the removal of nutrition and hydration more dependent on expressions of autonomous decisionmaking and remove this option from the profoundly disabled, these individuals will be at greater risk of non-beneficial administrations of nutrition and hydration that actually cause them harm.