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Disability and the End of Life

The message from the disability rights community¹ in the debate over end-of-life decisionmaking is simple and compelling: the disabled are better off alive than dead.² Any effort to terminate life-sustaining treatment for a person who finds him- or herself disabled is not only demeaning to all people with disabilities, it also constitutes legal discrimination.³ Thus, courts and legislatures must prevent the termination of medical treatment, especially nutrition and hydration, in cases in which the patient

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¹ I use the term “disability rights community” throughout this paper to refer to the large number of disability rights activists and scholars that have come together in opposition to laws that allow choice in dying. See, e.g., Not Dead Yet, Articles and Issues, Terri Schiavo, <http://www.notdeadyet.org/docs/articles.html#schiavo> (last visited Sept. 23, 2006) (collating the collective responses of the disability rights community to the *Schiavo* case). These groups cannot, of course, speak for every person with a disability, and there has been discussion and dissent within the community. See, e.g., Andrew I. Batavia, *Ideology and Independent Living: Will Conservatism Harm People with Disabilities?*, 549 ANNALS AM. ACAD. POL. & SOC. SCI. 10, 11 (1997). Nonetheless, the unanimity of the major disability rights groups in opposition to laws allowing a family member or other surrogate to terminate life-sustaining nutrition and hydration is remarkable. See Lois L. Shepherd, *Terri Schiavo and the Disability Rights Community*, 2006 U. CHI. LEGAL F. (forthcoming 2006), available at <http://ssrn.com/abstract=882480>.

² See Adrienne Asch, *Disability, Bioethics, and Human Rights*, in HANDBOOK OF DISABILITY STUDIES 297-301 (Gary L. Albrecht et al. eds., 2001) (stating that “the first right of people with disabilities is a claim to life itself, along with the social recognition of the value and validity of the life of someone with a disability”); *Issues Surrounding Terri Schindler-Schiavo Are Disability Rights Issues, Say National Disability Organizations*, RAGGED EDGE MAG., Oct. 27, 2003, available at <http://www.ragged-edge-mag.com/schiavostatement.html> (setting forth a statement signed by twenty-four disability rights groups).

³ Brief for Not Dead Yet et al. as Amici Curiae Supporting Appellants at 4, *In re Schiavo*, 851 So. 2d 182 (Fla. Dist. Ct. App. 2004) (No. 2D02-5394), available at <http://www.notdeadyet.org/docs/schavobrief.html> [sic] [hereinafter *Schiavo I Amici Brief*].

has no written living will.⁴ The message has traction. By engaging in major lobbying efforts and court cases to press their cause, disability groups like Not Dead Yet and activists like lawyer Harriet McBryde Johnson have shaken foundational principles of law and bioethics that have for at least thirty years made it permissible for individuals to choose to forgo life-sustaining treatment.⁵

To some degree, the success of the disability rights movement in spreading its message is attributable to an unspoken rule that the disability rights community is untouchable. People outside the community who have not experienced the life of a person with disabilities⁶ dare not disagree with the disabled. The reluctance is somewhat justified: the able-bodied have not experienced the condescension and discrimination regularly inflicted on the disabled.⁷

⁴ See, e.g., Position Statement, Nat'l Council on Indep. Living, Rights of People with Disabilities to Food and Water (July 14, 2005), <http://www.notdeadyet.org/docs/ncilres0705.html> [hereinafter NCIL Position Statement] (supporting "legislation that restores and maintains restrictions on surrogate decisions for withholding of food and water via tube"); Position Statement, Ctr. on Human Policy, A Statement of Common Principles on Life-Sustaining Care and Treatment of People with Disabilities, <http://thechp.syr.edu/endorse> (last visited Aug. 26, 2006) [hereinafter CHP Position Statement] (noting principles endorsed by thirty-five disability rights organizations).

⁵ See Kathy L. Cerminara, *Tracking the Storm: The Far-Reaching Power of the Forces Propelling the Schiavo Cases*, 35 STETSON L. REV. 147, 159-76 (2005) (tracking procedural and substantive effects post-Schiavo); Lois Shepherd, *Terri Schiavo: Unsettling the Settled*, 37 LOY. U. CHI. L.J. 297, 300 (2006) (contemplating potential shift in decisionmaking by health care and judicial entities irrespective of statutory modifications); Tom Mayo, *Living and Dying in a Post-Schiavo World*, JURIST, Dec. 3, 2005, <http://jurist.law.pitt.edu/forumy/2005/12/living-and-dying-in-post-schiavo-world.php> (discussing unsettling changes concerning the medical treatment); NCIL Position Statement, *supra* note 4.

⁶ Disability scholars point out a simple truth: except for the few people who die suddenly, all people will experience disability. Thus, some people suggest that those without disabilities should be called the "temporarily abled." See, e.g., Carrie Menkel-Meadow, Commentary, *And Now a Word About Secular Humanism, Spirituality, and the Practice of Justice and Conflict Resolution*, 28 FORDHAM URB. L.J. 1073, 1082 (2001).

⁷ Harriet McBryde Johnson describes the reaction she receives from most people as "decidedly negative." Harriet McBryde Johnson, *Unspeakable Conversations*, N.Y. TIMES, Feb. 16, 2003, § 6 (Magazine). She talks about strangers commenting to her that they "admire you for being out" because "most people would give up," or kill themselves if they had to live like she does. *Id.*; see also JOSEPH P. SHAPIRO, NO PITY 12-40 (1993) (classifying the treatment received by people with disabilities as either "Tiny Tims" or "Supercrrips"). Shapiro explains that:

[o]ften the discrimination is crude bigotry, such as that of a private New Jersey zoo owner who refused to admit children with retardation to the

But to a very real degree, the lack of serious scholarly challenge to the position of the community is itself patronizing.⁸ Indeed, the “reflexive scorn”⁹ to the activists’ message and the near silence¹⁰ in the legal literature in response to the avalanche of disability scholarship against the termination of end-of-life treatment¹¹ is astounding. This silence further marginalizes the very

Monkey House, claiming they scared his chimpanzees. It may be intolerance that permitted a New Jersey restaurant owner to ask a woman with cerebral palsy to leave because her appearance was disturbing other diners. . . . In other cases, however, the discrimination at issue is more subtle because it is based on the paternalistic assumption that disabled people are not entitled to make their own decisions and lead the lives they choose.

Id. at 25-26. See generally HANDBOOK OF DISABILITY STUDIES, *supra* note 2, at 351-512 (documenting the experience of disability).

⁸ The lack of serious discourse appears to be a major source of frustration for both activists and scholars. See, e.g., Asch, *supra* note 2, at 320 (quoting the demand: “[n]othing about us without us . . . [w]e demand that we are included in all debates and policy-making regarding bioethical issues”); Adrienne Asch, *Recognizing Death While Affirming Life: Can End of Life Reform Uphold a Disabled Person’s Interest in Continued Life?*, in IMPROVING END OF LIFE CARE: HASTINGS CTR. SPECIAL REP., Mar.-Apr. 2003, at S31, S36 (Bruce Jennings et al. eds.) (noting that the “largely absent disability perspective could profitably enliven the world of end of life reform”); Not Dead Yet, What the Disability Rights Movement Wants, <http://www.notdeadyet.org/docs/drmwants0305.html> (last visited Oct. 5, 2006) (demanding “equal time in an open public discussion”).

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⁹ Carl Schneider used the term “reflexive scorn” to describe the left’s reaction to disability activists’ arguments against the removal of Terri Schiavo’s feeding tube. Carl E. Schneider, *Hard Cases and the Politics of Righteousness*, 35 HASTINGS CTR. REP., May-June 2005, at 24, 26.

¹⁰ To be sure, the bioethics literature contains acknowledgments of the importance of incorporating disability studies into bioethics. See Mark G. Kuczewski, *Disability: An Agenda for Bioethics*, AM. J. BIOETHICS, Summer 2001, at 36. However, there has been little express challenge to the disability perspective. A short article by Art Caplan addresses the issues of disability at the end of life head-on. See Arthur Caplan, *Movie Asks the “Million Dollar” Question*, MSNBC, Feb. 17, 2005, <http://www.msnbc.msn.com/id/6970787>. And Professor Kathy Cerminara argues the fear driving the movement is unfounded. Kathy L. Cerminara, *Critical Essay: Musings on the Need to Convince Some People with Disabilities that End-of-Life Decision-Making Advocates Are Not Out to Get Them*, 37 LOY. U. CHI. L.J. 343, 378-84 (2006); see also Norman L. Cantor, *Déjà Vu All Over Again: The False Dichotomy Between Sanctity of Life and Quality of Life*, 35 STETSON L. REV. 81, 82-83 (2005) (acknowledging the disability argument against quality of life considerations in end-of-life cases); Cerminara, *supra* note 5, at 159-77; Bonnie Steinbock, *Disability, Prenatal Testing, and Selective Abortion*, in PRENATAL TESTING AND DISABILITY RIGHTS 108 (Erik Parens & Adrienne Asch eds., 2000) (arguing against the disability rights position on prenatal testing).

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¹¹ See SHAPIRO, *supra* note 7, at 237-88; Adrienne Asch, *Disability: Attitudes and Sociological Perspectives*, 2 ENCYCLOPEDIA OF BIOETHICS 602 (rev. ed. 1995); Andrew I. Batavia, *Disability and Physician-Assisted Suicide*, 336 NEW ENG. J. MED. 1671 (1997); Andrew I. Batavia, *Disability Rights in the Third Stage of the Independent Living Movement: Disability Community Consensus, Dissent, and the Future*

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group whose marginalization moved it to action in the first place, and leaves unanswered the very real charge of disability discrimination made by those suffering the discrimination.¹² Equally troubling, the apparent deference to the community's message gives the activists legitimacy in their lobbying despite theoretical and practical flaws in their argument.¹³

This Article seeks to answer the call from the disability rights community for a real debate on the role of disability in end-of-life decisionmaking.¹⁴ In the Article, I question whether the crusade by disability rights activists against freedom in medical decisionmaking is in fact in the best interest of people living with physical and mental challenges, and I conclude that it is not. I argue that in seeking to protect members of the disability community from perceived and real threats, the activists would limit options for all of us by declaring how we must, or, more correctly, how we must not die. In this way, Not Dead Yet, Harriet

of Disability Policy, 14 STAN. L. & POL'Y REV. 347 (2003); Cerminara, *supra* note 5, at 159-76; Diane Coleman, *Assisted Suicide and Disability: Another Perspective*, HUM. RTS. MAG., Winter 2000, at 6; Pamela Fadem et al., *Attitudes of People with Disabilities Toward Physician-Assisted Suicide Legislation: Broadening the Dialogue*, 28 J. HEALTH POL. POL'Y & L. 977 (2003); Carol J. Gill, *Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia* (2000), 6 PSYCHOL. PUB. POL'Y & L. 526 (2000); Stanley S. Herr et al., *No Place to Go: Refusal of Life-Sustaining Treatment by Competent Persons with Physical Disabilities*, 8 ISSUES L. & MED. 3 (1992); Paul K. Longmore, *Elizabeth Bouvia, Assisted Suicide and Social Prejudice*, 3 ISSUES L. & MED. 141 (1987); Paul Steven Miller, *The Impact of Assisted Suicide on Persons with Disabilities—Is It a Right Without Freedom?*, 9 ISSUES L. & MED. 47 (1993); Nat'l Legal Ctr. Staff, *Medical Treatment for Older Persons and Persons with Disabilities: 1990 Developments*, 6 ISSUES L. & MED. 341 (1991); Mark Schlesinger, *In the Marketplace for Ideas Affecting Public Policy*, 28 J. HEALTH POL. POL'Y & L. 965, 970-72 (2003); Lois Shepherd, *Face to Face: A Call for Radical Responsibility in Place of Compassion*, 77 ST. JOHN'S L. REV. 445 (2003); Walter Wright, *Historical Analogies, Slippery Slopes, and the Question of Euthanasia*, 28 J.L. MED. & ETHICS 176 (2000); Teresa Harvey Paredes, Comment, *The Killing Words? How the New Quality-of-Life Ethic Affects People with Severe Disabilities*, 46 SMU L. REV. 805 (1993); Jennifer A. Zima, Note, *Assisted Suicide: Society's Response to a Plea for Relief or a Simple Solution to the Cries of the Needy*, 23 RUTGERS L.J. 387 (1992).

¹² I have been struck by the literal marginalization of disability scholars in health law and bioethics meetings that focus on end-of-life issues as well. I cannot claim to have attended all or even most of the meetings, but in those I have attended, sessions featuring disabilities scholars are often held at the end of a conference and attended primarily by members of the community.

¹³ Lennard Davis argues that the lack of nuance in disability studies is attributable to the community's lack of cultural literacy. See Lennard J. Davis, *Life, Death, and Biocultural Literacy*, CHRON. OF HIGHER EDUC. (Wash., D.C.), Jan. 6, 2006, at 9.

¹⁴ See, e.g., Not Dead Yet, *supra* note 8 (demanding "equal time in open public discussion").

McBryde Johnson, and other disability rights activists pose a direct and immediate threat to the laws that give families choices in decisionmaking at the end of life. Their advocacy may well lead to perniciously paternalistic legal action that will disable all of us—people with and without disabilities—by eliminating medically appropriate and morally acceptable options for medical decisionmaking at the end of life.

I argue further that although the theory underlying the activist agenda has its roots in disability studies, it does not withstand scrutiny. The theory that laws allowing choice in dying perpetuate disability discrimination is flawed by conflation, inflation, misidentification, and a misplaced operational definition of disability. Specifically, the theory conflates dying with disability and misidentifies a persistent vegetative state as a disability that permits meaningful life. The conflation derives from a misplaced operational definition of disability that insists that all people fed by feeding tubes are the same. The conflation and misidentification allow the community to cast decisions to withhold or withdraw feeding tubes as disability prejudice, when such decisions are, in fact, an affirmation of autonomy and a showing of respect for individual values.

By disproving the underlying theory and exposing the negative practical implications of the disability agenda, I hope to derail the community's effort to turn back thirty years of progress in protecting patients and their families at the end of life. That said, my conclusion is not that the disability rights community has nothing of value to add to policy surrounding end-of-life decisionmaking. To the contrary, while I disagree with the extreme position of what I call the new activists,¹⁵ I argue that much of the community's message has merit. Judges, bioethicists, lawyers, legislatures, and health care providers should take concrete steps to stop the palpable discrimination that triggered the political movement in the first place and to alleviate the fear and hurt that has driven scholars and activists to extreme positions. I argue that two steps are necessary to achieve this goal. First, courts, bioethicists, and lawyers must stop justifying autonomous decisions to refuse treatment as reasonable by devaluing life with disability. Second, health care providers and policymakers, in-

¹⁵ I use the term "new activists" to distinguish the new breed of disability rights advocates, like those involved with Not Dead Yet, from the less militant activists who worked for passage of the Americans with Disabilities Act.

cluding institutional ethics boards, should reevaluate the notion of informed consent in cases of sudden disability to incorporate the evidence from empirical studies by disability scholars.

Part I of this paper introduces the activists and scholars who make up the disability rights community, explores the history of the disability rights movement, and sets forth the message, theory, and demands of the activists with respect to end-of-life decisionmaking. Part II discusses how the community has effectively changed public discourse about choices in dying. Part III exposes the danger posed by the community’s demands, and identifies the conflation, inflation, and misidentification that undermine the theory that choice in dying is disability discrimination. Part IV argues that although they should not erode laws that allow the disabled and their families’ choice in dying, policy-makers, scholars, judges, lawyers, and health care providers should heed much of the message coming from the community. In particular, judges should avoid perpetuating the tragic myth of life with disability and focus instead on autonomy and the process of informed consent. At the same time, scholars, policymakers, and providers should rethink what it means to obtain informed consent in cases of sudden disability in light of evidence generated by disability scholars. Part V concludes by issuing a challenge to both sides of the debate.

I

THE MESSENGERS AND THE MESSAGE

The disability rights community consists of both activists and scholars. Neither faction purports to speak for every person with a disability,¹⁶ but, as the following discussion shows, both groups present a remarkably coherent message.¹⁷ Moreover, the activ-

¹⁶ See Adrienne Asch, *Distracted by Disability*, CAMBRIDGE Q. HEALTHCARE ETHICS, Jan. 1998, at 77, 81. Asch explains the difficulties with defining a disability rights community, but asserts that:

what people with disabilities share is the experience that their departure from what is species typical makes them the objects of unequal treatment such as denial of employment or education for which they qualify. . . . [M]ore than half of the respondents [to a 1994 survey] perceived themselves to be a member of a minority and accepted the notion that they were indeed members of a disability community.

Id.

¹⁷ The loudest dissenting voice from within the disability rights community is Andrew Batavia’s. Batavia started an organization called Autonomy that “represents the interests of people with disabilities who wish to exercise choice in all aspects of

ists speak for what they have defined as the disability rights community.¹⁸

It is not clear whether the activism around disability rights led to the field of disability studies or if the early disability scholars triggered activism among the ranks.¹⁹ In either case, the scholarship in the field nourishes the activist agenda, and the activism generates scholarly discussion.²⁰

A. Disability Studies: The Brain Behind the Machine

Disability studies deconstructs the myth of the tragic life of the person with disabilities. The field is rich and varied;²¹ it incorporates Marxism, feminist postmodernism, and poststructuralism. It emphasizes, among other things, the social oppression of the disabled and the cultural perception of life with disability.²²

[their] lives, including choice at the end of life.” See *Autonomy, Mission & Principles*, www.autonomynow.org/mission.html (last visited Sept. 21, 2006).

¹⁸ See, e.g., Press Release, Not Dead Yet, Schiavo Case Is About Disability Rights (Mar. 20, 2005), <http://www.notdeadyet.org/docs/schiavostatement032005.html> (referring to the “disability rights community”).

¹⁹ For a more thorough overview of the growth of the disability rights movement and its impact on federal law, see SHAPIRO, *supra* note 7, and Jonathan C. Drimmer, Comment, *Cripples, Overcomers, and Civil Rights: Tracing the Evolution of Federal Legislation and Social Policy for People with Disabilities*, 40 UCLA L. REV. 1341 (1993). See also David L. Braddock & Susan L. Parish, *An Institutional History of Disability*, in HANDBOOK OF DISABILITY STUDIES, *supra* note 2, at 44 (citing to writings of blind Americans in the 1950s as introducing the theoretical basis for the social construction of disability).

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²⁰ See, e.g., MARY JOHNSON, *MAKE THEM GO AWAY: CLINT EASTWOOD, CHRISTOPHER REEVE AND THE CASE AGAINST DISABILITY RIGHTS* (2003) (marrying the activist agenda of Not Dead Yet, of which Johnson is the founder, to disability theory).

²¹ For example, James I. Charlton analyzes disability oppression and activism from an international perspective. JAMES I. CHARLTON, *NOTHING ABOUT US WITHOUT US: DISABILITY OPPRESSION AND EMPOWERMENT* (1998). Joseph Shapiro traces the history of the movement in his book, *No Pity*. SHAPIRO, *supra* note 7. Michelle Fine and Adrienne Asch explore disability from a feminist perspective. WOMEN WITH DISABILITIES: ESSAYS IN PSYCHOLOGY, CULTURE, AND POLITICS (Michelle Fine & Adrienne Asch eds., 1988). Nancy L. Eiesland applies disability theory to liberation theology in *The Disabled God*. NANCY L. EIESLAND, *THE DISABLED GOD: TOWARD A LIBERATORY THEOLOGY OF DISABILITY* (1994). See also *DISABILITY STUDIES: ENABLING THE HUMANITIES* (Sharon L. Snyder et al. eds., 2002) (integrating disability studies into humanities teaching and scholarship); *THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES: DIFFERENT BUT EQUAL* (Stanley Herr et al. eds., 2003) (exploring human rights issues); JULIE SMART, *DISABILITY, SOCIETY, AND THE INDIVIDUAL* (2001) (discussing the disability experience from the perspective of disabled individuals).

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²² Gareth Williams, *Theorizing Disability*, in HANDBOOK OF DISABILITY STUDIES, *supra* note 2, at 124.

From all perspectives, the central tenet of disability studies is the rejection of the medical model of disability as a foundation for effective understanding of impairment or disability.²³ “The medical view of disability . . . treats the individual as deficient and inherently inferior because she falls below an arbitrary physiological standard that delineates social acceptance and that can only be ‘normalized’ and incorporated into society through a medical cure.”²⁴ Falling below the physiologic standard is problematic, in the medical view of disability, because “impairments of normal species functioning reduce the range of opportunity open to the individual . . . [to] construct a ‘plan of life’ or ‘conception of the good.’”²⁵ Thus, the medical view of disability essentially locates the problems caused by disability in the disabled individual.

Historic events provide vivid examples of how the medicalization of disability harms people with disabilities. The eugenics program in Nazi Germany may be the most obvious example—Nazi medical centers killed a quarter of a million disabled people because they were considered “useless eaters”²⁶—but the United States has also engaged in outright disability discrimination through forced institutionalization, sterilization, and eugenics.²⁷ Notably, Justice Marshall compared this country’s treatment of

²³ *Id.*

²⁴ Drimmer, *supra* note 19, at 1348; *see also* Asch, *supra* note 2, at 300 (noting that some define a person as “healthy if the person’s organism performs species-typical functions with statistically typical efficiency”).

²⁵ NORMAN DANIELS, *JUST HEALTH CARE: STUDIES IN PHILOSOPHY AND HEALTH POLICY* 27 (1985).

²⁶ Stephen L. Mikochik, *Assisted Suicide and Disabled People*, 46 *DEPAUL L. REV.* 987, 999 (1987). Mikochik points to a quote from Leo Alexander, chief medical consultant at Nuremberg, who observed the Nazi atrocities:

Whatever proportions these crimes finally assumed, it became evident to all who investigated them that they had started from small beginnings, . . . at first merely a subtle shift in emphasis in the basic attitude of physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as a life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually, the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Aryans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude toward the non-rehabilitable sick.

Id. at 999 n.82 (citing Joan R. Bullock, *Abortion Rights in America*, 1994 *BYU L. REV.* 63, 69 n.30).

²⁷ The American experience, at least as to sterilization, preceded World War I.

the disabled to the Jim Crow regime.²⁸

Similarly, Justice Holmes famously confirmed that the United States viewed people with disabilities as the problem when he sanctioned the forced sterilization of Carrie Buck:

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough.²⁹

The “Baby Doe” cases provide another example of the problematic results of the medical view of disability. “Baby John Doe” was born in 1982 in Bloomington, Indiana. He had Down syndrome and an esophageal blockage. The blockage was treatable with a relatively minor surgical correction, but his parents opted against the surgery because of advice given to them by their physician about the dismal prospects for a person living with Down syndrome. The baby died of starvation at six days old.³⁰ In a similar case, the parents of “Baby Jane Doe” declined surgery for their daughter, who had been born with spina bifida and hydrocephalus, based on the advice of their physicians.³¹ Both babies were denied treatment that could have alleviated certain of their medical problems because they had permanent disabilities that no medical treatment could cure. To disability

See Philip R. Reilly, *THE SURGICAL SOLUTION: A HISTORY OF INVOLUNTARY STERILIZATION IN THE UNITED STATES* 30-40 (1991).

²⁸ Mikochik, *supra* note 26, at 1000 (citing *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 461-62 (1985) (Marshall, J., concurring in part and dissenting in part)).

²⁹ *Buck v. Bell*, 274 U.S. 200, 207 (1927) (citation omitted).

³⁰ See Angie L. Guevara, Note, *In re K.I.: An Urgent Need for a Uniform System in the Treatment of the Critically Ill Infant—Recognizing the Sanctity of Life of the Child*, 36 U.S.F. L. REV. 237, 238-39 (2001), for an account of the “Baby Doe” litigation. Ultimately, certiorari was denied by the U.S. Supreme Court in 1983. *Infant Doe v. Bloomington Hosp.*, 464 U.S. 961 (1983).

³¹ *Weber v. Stony Brook Hosp.*, 467 N.Y.S.2d 685, 686 (App. Div. 1983). This case led to a 1983 President’s Commission report that would disallow denial of surgery to “an otherwise healthy Down [s]ndrome child whose life is threatened by a surgically correctable complication.” Asch, *supra* note 2, at 303; see Guevara, *supra* note 30, at 240-41.

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rights scholars, the denial of treatment in the Baby Doe cases “represented a kind of discrimination against people with disabilities by the medical profession and frightened parents who were unable to imagine having a child with a disability as anything but a tragedy and disaster”³²

Instead of a medical view of disability, disability scholars view disability as “a socially constructed condition, through which the ‘problem’ is defined as ‘a dominating attitude by professionals and others, inadequate support services when compared with society generally, as well as attitudinal, architectural, sensory, cognitive and economic barriers.’”³³ As stated by one scholar:

[T]he “socio-political” model of disability views disability as “a product of interaction between health status and the demands of one’s physical and social environment,” and “locates” disability in the interface between the individual and her environment. In doing so, the socio-political model of disability (and a related construct—the minority model) stand in stark contrast to the medical model of disability, “which regards disability as a defect or sickness which must be cured through medical intervention,” and which expressly locates the “problem” in the disabled person.³⁴

Under a social view of disability, a paralyzed person who cannot get into a building because the entrance is at the top of the stairs is not “disabled” by his or her physical impairments. The disability results from the social failure to provide wheelchair accessible ramps. Thus, “the culprit is not biological, psychic, or cognitive equipment but the social, institutional, and physical world in which people with impairments must function—a world designed with the characteristics and needs of the nondisabled majority in mind” in which “[a]n impaired arm becomes a manual disability or social handicap only because of the interaction of a particular physiology with a specific social, legal, and attitudinal environment.”³⁵

The prevailing message in the scholarship is that life with disa-

³² Asch, *supra* note 2, at 304.

³³ Laura L. Rovner, *Disability, Equality, and Identity*, 55 ALA. L. REV. 1043, 1043-44 (2004) (citing Deborah Kaplan, *The Definition of Disability: Perspective of the Disability Community*, 3 J. HEALTH CARE L. & POL’Y 352, 352-53 (2000)). See, e.g., Michelle Fine & Adrienne Asch, *Disability Beyond Stigma: Social Interaction, Discrimination, and Activism*, 44 J. SOC. ISSUES 3, 8-15 (1988) (challenging social psychology’s assumptions of disability).

³⁴ Rovner, *supra* note 33, at 1044 (footnotes omitted).

³⁵ Asch, *supra* note 2, at 300.

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bility is not tragedy.³⁶ Rather, the tragedy is the failure of social institutions to help people with physical impairments to lead productive lives. Thus, disability scholars argue that “rules, laws, means of communication, characteristics of buildings and transit systems, the typical eight-hour work day, and aesthetic preferences all exclude some people from participating in school, work, civic, or social life.”³⁷ Given appropriate accommodation by society, a disabled person can have a rewarding life.³⁸

Disability scholars have proved their point in part through empirical studies that reveal that “people who experience disability—whether it be congenital or acquired, whether sensory, cognitive, motor, or other—can find considerable reward and satisfaction in their lives.”³⁹ Indeed, studies have consistently shown that the number of people with disabilities who found satisfaction in their lives far exceeds predictions by health professionals.⁴⁰

Disability scholars view court cases involving medical decision-making as statements about the tragedy of life with disability. According to the literature, courts have accepted and perpetuated two incorrect assumptions in allowing people to forgo medical treatment and choose death over life with disability: “First, the life of someone with a chronic illness or disability . . . is forever disrupted Second, if a disabled person experiences iso-

³⁶ *Id.*

³⁷ *Id.* Adrienne Asch criticizes bioethics thus:

[B]ioethics insists that individuals should be able to determine the situations under which they find life intolerable but has never challenged them to ask themselves what they found intolerable. Nor has bioethics suggested that what was unacceptable might not be inherent in quadriplegia, stroke, or a degenerative neurological disorder but instead could result from the social arrangements facing people living with such conditions.

Asch, *supra* note 2, at 299.

³⁸ *Id.* The Americans with Disabilities Act was a major victory for disability scholars and activists. 42 U.S.C. § 12101-12213 (2000). It adopted as law the rule that society had the obligation to offer people with disabilities a better quality of life and the opportunity to contribute meaningfully to society.

³⁹ Asch, *supra* note 2, at 301. The evidence shows that “even those who work most closely with the disabled underestimate their quality of life.” Kuczewski, *supra* note 10, at 39.

⁴⁰ See Asch, *supra* note 2, at 301 (citing eleven such studies); see also NATIONAL ORGANIZATION ON DISABILITY, N.O.D./HARRIS SURVEY OF AMERICANS WITH DISABILITIES 85-90 (1994) (comparing life satisfaction of people with and without disabilities); Saroj Saigal et al., *Self-Perceived Health Status and Health-Related Quality of Life of Extremely Low-Birth-Weight Infants at Adolescence*, 276 J. AM. MED. ASS’N 453, 455-57 (1996) (evaluating self-assessed quality of life of adolescents who were extremely low-birth-weight infants).

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lation, powerlessness, poverty, unemployment, or low social status, these are inevitable consequences of biological limitation.”⁴¹

The case of Elizabeth Bouvia tells the story.⁴² Elizabeth Bouvia, a twenty-eight-year-old woman who had cerebral palsy and arthritis, asked a California court to remove a nasogastric tube and allow her to die of starvation. Bouvia was not terminally ill but the court granted her wish.⁴³ Lawyers and scholars pressing autonomy as the gold standard in medical decisionmaking hailed the *Bouvia* case as a landmark victory because it affirmed that even those who are not terminally ill can decline treatment, and that artificial nutrition and hydration is medical treatment.⁴⁴ Disability scholars read *Bouvia* very differently. They saw Elizabeth Bouvia as a person with disabilities who lacked the social support necessary to allow her life to have meaning.⁴⁵ They pointed out that she demanded the right to starve herself only after she had a miscarriage, her husband left her, her family abandoned her, the county failed to find a suitable place to house her, and she was forced to withdraw from graduate school because the dean believed her disability made her an inappropriate student.⁴⁶

⁴¹ Asch, *supra* note 2, at 300.

⁴² *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Ct. App. 1986). Disabilities scholars frequently cite to two other cases to make the same point: *Georgia v. Mc-Afee*, 385 S.E.2d 651 (Ga. 1989), and *McKay v. Bergstedt*, 801 P.2d 617 (Nev. 1990).

⁴³ Elizabeth Bouvia chose not to end her life after the court granted her wish to die. On a 1997 *60 Minutes* broadcast, she explained her decision:

Mike Wallace: (*voiceover*) After several attempts at starvation, Elizabeth told us, it just became physically too difficult to do. She didn't want to die a slow, agonizing death, nor to do it in the spotlight of public scrutiny. And she told us, with great regret, she quietly chose to live.

Ms. Bouvia: Starvation is not an easy way to go.

Wallace: Oh, no.

Ms. Bouvia: You can't just keep doing it and keep doing it. It really messes up your body. And my body was already messed up.

JERRY MENIKOFF, *LAW AND BIOETHICS: AN INTRODUCTION* 262 (2001).

⁴⁴ See, e.g., S. Elizabeth Wilborn Malloy, *Beyond Misguided Paternalism: Resuscitating the Right to Refuse Medical Treatment*, 33 WAKE FOREST L. REV. 1035, 1084-85 (1998) (“The approach provided in the . . . *Bouvia* case[] reflect[s] respect for the rights of patient autonomy.”); Jerry Menikoff, *Demanded Medical Care*, 30 ARIZ. ST. L.J. 1091, 1091 (1998) (noting that “[p]atient autonomy’ is now accepted as the gold standard for ethical decision-making when recommended care conflicts with a patient’s wishes”).

⁴⁵ See, e.g., Longmore, *supra* note 11, at 157.

⁴⁶ Asch, *supra* note 2, at 311.

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Disability scholars saw Bouvia's plight as a classic case of society failing a person with disability. The appropriate answer to Bouvia's situation, argued disability scholars, was social support and intervention, not acquiescence to her demand for death.⁴⁷ The community saw the court's decision to allow Bouvia to starve herself as judicial confirmation that lives with disability are not worth living.

The judge who authored *Bouvia* gave disability scholars many reasons to believe that the decision was not about autonomy, but about disability discrimination.⁴⁸ The court went to great lengths to describe in painstaking detail the physical elements of Bouvia's disability. It then explained that her decision that her life had no meaning was reasonable: "Her mind and spirit may be free to take great flights but she herself is imprisoned, and must lie physically helpless subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness."⁴⁹ Thus, the judge asserted that disability had ruined Bouvia's life, that "such life has been physically destroyed and its quality, dignity and purpose [are] gone."⁵⁰ Without exploring the implications of the social changes in Bouvia's life, the judge characterized extending her life as "monstrous."⁵¹

The functional limitations faced by Bouvia mirrored those of many disability rights leaders who could live for decades with the assistance of medical treatment and technology.⁵² Thus, unlike the earlier cases that involved decisionmaking for people who were permanently unconscious or terminally ill,⁵³ the case got the

⁴⁷ See, e.g., Longmore, *supra* note 11, at 144.

⁴⁸ The 1996 decision in *Compassion in Dying v. Washington* that supported physician-assisted suicide also portrayed life with disabilities as hopeless. The court referred to people with physical impairments as existing in "a childlike state of helplessness" exemplified by physical immobility or by their use of diapers to deal with incontinence. 79 F.3d 790, 814 (9th Cir. 1996), *rev'd sub nom.* *Washington v. Glucksberg*, 521 U.S. 702 (1997). Similarly, in *Georgia v. McAfee*, the court described the plaintiff, a ventilator-dependent man who been needlessly housed in a hospital ICU for months as being "incapable of spontaneous respiration, and . . . dependent upon a ventilator to breathe. According to the record there is no hope that Mr. McAfee's condition will improve with time, nor is there any known medical treatment which can improve his condition." 385 S.E.2d 651, 651 (Ga. 1989).

⁴⁹ *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 305 (Ct. App. 1986).

⁵⁰ *Id.* The "monstrous" language used in *Bouvia* was quoted by the court in *McKay v. Bergstedt*. 801 P.2d 617, 624 (Nev. 1990).

⁵¹ *Bouvia*, 225 Cal. Rptr. at 305.

⁵² Asch, *supra* note 2, at 312.

⁵³ See, e.g., *Satz v. Perlmutter*, 362 So. 2d 160, 164 (Fla. Dist. Ct. App. 1978) (allowing terminally ill patient to refuse life-sustaining treatment); *In re Quinlan*, 355

attention of disability scholars. They read *Bouvia* as confirmation that laws that provided patients choice in medical decision-making were really a legal judgment that their lives were not worth living.⁵⁴

Following *Bouvia*, disability scholars started to question whether such cases were really about autonomy, a principle cherished by the community, or about a new eugenics.⁵⁵ They argued that “[the nondisabled public] readily conclude[s] that the disabled person’s wish to die is reasonable because it agrees with [the] preconception that the primary problem for such individuals is the unbearable experience of a permanent disability. . . . If permanent disability is the problem, death is the solution.”⁵⁶ Disability scholars further observed that “[w]hen the nondisabled say they want to die, they are labelled [sic] as suicidal; if they are disabled, it is treated as ‘natural’ or ‘reasonable.’”⁵⁷

To disability scholars, the willingness of courts and the public to accept as reasonable the wish to die exemplified a lack of social recognition for the value and validity of a disabled life.⁵⁸ From a disability perspective, courts failed by focusing on limitations created by physical impairment, instead of focusing on the ways “in which law, medicine, bioethics, and government programs failed to help traumatically disabled patients discover the financial, technological, social, and psychological resources that could sustain them and provide the opportunity for rewarding life.”⁵⁹

Thus the first right of people with disabilities became “a claim to life itself.”⁶⁰ Laws that allow the refusal of treatment became suspect. Disability scholarship came to question the emphasis in current law on autonomy as the paramount concern in end-of-life cases.⁶¹ The skepticism became especially pronounced when the

A.2d 647, 672 (N.J. 1976) (allowing family to terminate treatment for permanently unconscious patient).

⁵⁴ See, e.g., Longmore, *supra* note 11, at 144.

⁵⁵ See Herr et al., *supra* note 11, at 36.

⁵⁶ Carol J. Gill, *Suicide Intervention for People with Disabilities: A Lesson in Inequality*, 8 ISSUES L. & MED. 37, 39 (1992).

⁵⁷ *Compassion in Dying v. Washington*, 49 F.3d 586, 593 (9th Cir. 1995) (citing Gill, *supra* note 56, at 38-39), *aff'd en banc*, 79 F.3d 790 (9th Cir. 1996), *rev'd sub nom.* *Washington v. Glucksberg*, 521 U.S. 702 (1997).

⁵⁸ See Asch, *supra* note 2, at 301.

⁵⁹ Asch, *supra* note 8, at S34.

⁶⁰ Asch, *supra* note 2, at 301.

⁶¹ Asch, *supra* note 8, at S33 (pointing to the “danger of relying on a simple notion of patient autonomy when deciding to withdraw life-sustaining treatment”).

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nation turned its attention to the question of physician-assisted suicide.⁶² Disability scholars strongly opposed physician-assisted suicide, arguing expressly that right-to-die cases “reflect a societal prejudice that devalues the worth of disabled persons’ lives.”⁶³ As a result, scholars urged “clinicians and policy-makers to question how truly autonomous is anyone’s wish to die when living with changed, feared, and uncertain physical impairments.”⁶⁴

In time, scholars criticized laws that allow family members to withhold treatment.⁶⁵ As one scholar noted, “Even a demonstrably loving and involved family may be unable to put aside its own view of how limited life with disability is to imagine such a life from the vantage point of someone with the impairment.”⁶⁶ In keeping with its position, disability scholars applauded the New York Court of Appeals when it refused to allow the mother of a man with profound mental retardation the option of declining treatment for her son’s cancer.⁶⁷ The mother had provided good care to her son throughout his life, but was concerned that the treatments were unduly upsetting to him. The court held that no one, not even a loving family member, could decline life-saving treatment for someone who has not expressed his or her own wish to refuse treatment.⁶⁸

⁶² See Conference Transcript, *Socially-Assisted Dying: Media, Money & Meaning*, 7 CORNELL J.L. & PUB. POL’Y 267, 270-94 (1998) (illustrating views of “proponents and opponents from the disability community” concerning assisted death); Yale Kamisar, *Against Assisted Suicide—Even a Very Limited Form*, 72 U. DET. MERCY L. REV. 735, 740-43 (1995); M. Cathleen Kaveny, *Managed Care, Assisted Suicide, and Vulnerable Populations*, 73 NOTRE DAME L. REV. 1275, 1299-1307 (1998) (discussing the dangers of physician-assisted suicide in American health care institutions and its repercussions on vulnerable populations); Mikochik, *supra* note 26, at 995-1002.

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⁶³ Adam A. Milani, *Better Off Dead than Disabled?: Should Courts Recognize a “Wrongful Living” Cause of Action When Doctors Fail to Honor Patients’ Advance Directives?*, 54 WASH. & LEE L. REV. 149, 198 (1997); accord Coleman, *supra* note 11, at 6; Fadem, *supra* note 11, at 987-88; Gill, *supra* note 11, at 528-32; Longmore, *supra* note 11, at 152, 166-68.

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⁶⁴ Asch, *supra* note 8, at S33.

⁶⁵ Asch, *supra* note 2, at 310.

⁶⁶ *Id.* at 309.

⁶⁷ *In re Storar*, 420 N.E.2d 64, 73 (N.Y. 1981).

⁶⁸ *Id.*; see also *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 613 (N.Y. 1988) (“[N]o person or court should substitute its judgment as to what would be an acceptable quality of life for another.”). The *Storar* and *Westchester* decisions have been roundly criticized by people who advocate for self-determination as the paramount concern. *E.g.*, Hon. Stewart F. Hancock, Jr., *The Role of the Judge in Medical Treatment Decisions*, 57 ALB. L. REV. 647, 652-53 & n.25 (1994). Obviously,

In addition to questioning the ability of family members to make decisions for their disabled loved ones, some disability scholars question the notion of precedent autonomy. Precedent autonomy is the concept that supports living wills.⁶⁹ It allows people to decide in advance what medical decisions should be implemented if they later become unable to express their wishes, and requires health care providers to act on those decisions. Disability scholars are suspicious of such directives, believing that people who are not disabled cannot imagine that life with a disability would be rewarding.⁷⁰ According to the scholars, rather than blindly following advance directives, treatment should be evaluated from the viewpoint of the recently disabled individual.⁷¹ If a person appears to take pleasure in her current state of disability, that current state should be maintained despite previously expressed wishes to avoid life in a disabled state.

Thus, disability scholarship calls into question the role of autonomy, families, and advance directives in end-of-life decision-making. The bottom line, argues scholar Adrienne Asch, is that “[i]t is crucial for anyone seeking to advance the dignity and worth of people with all disabilities to promote their participation in life-and-death decisions and to circumscribe family decisionmaking on behalf of those who have less than full legal authority to make their own decisions.”⁷²

B. *The Birth of a New Advocacy*

Disability studies is inextricably linked with disability rights activism. The thoughtful analysis of legal-medical issues by disability theorists has given rise to a political force. The early political activism of the disability movement, as supported by the developing scholarship, led to legislation like the Rehabilitation Act and eventually to the Americans with Disabilities Act.⁷³

The disabilities movement took on a different form—what I call a new activism—in the late 1980s and early 1990s. The original focus of the new activists was not medical cases; it was the

someone who has never been competent to express his wishes could never refuse medical care.

⁶⁹ Leslie Pickering Francis, *Decisionmaking at the End of Life: Patients with Alzheimer's or Other Dementias*, 35 GA. L. REV. 539, 551, 569-76 (2001).

⁷⁰ Asch, *supra* note 2, at 310.

⁷¹ *Id.*

⁷² *Id.* at 311.

⁷³ Rovner, *supra* note 33, at 1059-62.

Jerry Lewis Muscular Dystrophy Association Telethon. Disability activists consider telethons that trot out disabled children as mascots “demeaning and exploitative of disability as tragic and catastrophic.”⁷⁴ Evan Kemp, Jr., former chair of the federal Equal Employment Opportunity Commission, presented the earliest public critique of telethons in a 1981 *New York Times* editorial, in which he stated that “[b]y arousing the public’s fear of the handicap itself, the telethon makes viewers more afraid of handicapped people. . . . The telethon’s critical stress on the need to find cures supports the damaging and common prejudice that handicapped people are ‘sick.’”⁷⁵ A decade after Kemp’s critique was published, the early activists began to demonstrate against the telethons.⁷⁶ The activists’ message was angrier than Kemp’s.⁷⁷ One activist protested, “It’s all about stirring up pity, when we don’t want pity. And Jerry Lewis ought to be fired. He actually called people in wheelchairs ‘half persons.’”⁷⁸

Having organized against telethons, the new activists turned their attention to court actions involving medical decisionmaking, where they participated with limited attention for many years.⁷⁹ The organized activity culminated, of course, in the case of Terri Schiavo. One of the most powerful voices in the *Schiavo* case was Harriet McBryde Johnson’s. McBryde Johnson is a disability rights lawyer and activist who lives with a neuromuscular

⁷⁴ Sharon Barnartt et al., *Advocacy and Political Action*, in HANDBOOK OF DISABILITY STUDIES, *supra* note 2, at 441 (referring to eighteen protests against telethons in 1992 and ten protests in 1993).

⁷⁵ Evan J. Kemp, Jr., Op-Ed., *Aiding the Disabled: No Pity, Please*, N.Y. TIMES, Sept. 3, 1981, at A19; *see also* SHAPIRO, *supra* note 7, at 23-24 (quoting *id.*).

⁷⁶ *See* SHAPIRO, *supra* note 7, at 24-26.

⁷⁷ *See* HARRIET MCBRYDE JOHNSON, TOO LATE TO DIE YOUNG: NEARLY TRUE TALES FROM A LIFE 50 (2005). McBryde Johnson explains her reaction to telethons:

Together in the cripple ghetto, my friends and I watched the annual parade of our little doppelgängers being publicly sentenced to death. . . . Later, having moved on to the mainstream world, I wanted to go to law school, qualify for scholarships, get a job and a car loan, start a business. But dying children aren’t allowed to do such things; they can’t be trusted to fulfill their obligations.

Id.

⁷⁸ *Id.* at 48.

⁷⁹ Milani, *supra* note 63, at 209-12 (describing intervention by activists on behalf of Kenneth Bergstedt, a Nevada man who became quadriplegic and dependent on a ventilator as a result of a swimming accident at age ten). At age thirty-one, faced with the imminent death of his ill father, Kenneth petitioned the court to allow his father to turn off his respirator. *See* McKay v. Bergstedt, 801 P.2d 617, 624-25 (Nev. 1990).

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degenerative disease that has left her, in her words, “a jumble of bones in a floppy bag of skin.”⁸⁰ She is not able to walk, stand, lift heavy objects, or swallow solid foods.⁸¹ To keep herself upright in her chair, she leans forward, rests her rib cage on her lap and plants her elbows beside her knees.⁸² She eats puréed food, lacks the physical strength to get out of bed on her own, and will someday soon need to eat through a feeding tube.

McBryde Johnson is anything but weak. Her mind has the strength and agility her body lacks.⁸³ Her writing is wicked, sharp, insightful, and funny.⁸⁴ Her oral presentations are equally compelling. She uses personal stories and insights strengthened by her physical weakness to advocate her positions on issues involving life and death.⁸⁵ Specifically, she uses the strongest sort of identity politics, legal acumen, and powerful straight talk to argue against choice in medical decisionmaking. Her message resonates.

Harriet McBryde Johnson came to national prominence when she published a cover story in the *New York Times Magazine*.⁸⁶ In the article, McBryde Johnson described her experience at Princeton University in which she confronted ethicist Peter Singer. She saw the debate with Singer as personal, stating:

[Peter Singer] doesn’t want to kill me. He simply thinks it would have been better, all things considered, to have given my parents the option of killing the baby I once was, and to let other parents kill similar babies as they come along and thereby avoid the suffering that comes with lives like mine and satisfy the reasonable preferences of parents for a different kind of child.⁸⁷

⁸⁰ McBryde Johnson, *supra* note 7.

⁸¹ *Id.*

⁸² *Id.*

⁸³ She has a B.S. in history from Charleston Southern University, a Master’s in Public Administration from the College of Charleston, and a J.D. from the University of South Carolina. Biography of Harriet McBryde Johnson, <http://www.nd.edu/~ndr/issues/ndr8/johnson/bio.html> (last visited Sept. 6, 2006).

⁸⁴ See generally MCBRYDE JOHNSON, *supra* note 77.

⁸⁵ *Id.*

⁸⁶ McBryde Johnson, *supra* note 7.

⁸⁷ *Id.* McBryde Johnson’s description of Singer’s position is accurate. See generally HELGA KUHSE & PETER SINGER, SHOULD THE BABY LIVE? THE PROBLEM OF HANDICAPPED INFANTS iii (1985) (“This book contains conclusions which some readers will find disturbing. We think that some infants with severe disabilities should be killed.”); PETER SINGER, RETHINKING LIFE AND DEATH: THE COLLAPSE OF OUR TRADITIONAL ETHICS 128-31 (1994); Helga Kuhse & Peter Singer, *Ethics and the Handicapped Newborn Infant*, 52 SOC. RES. 505, 527-34 (1985) (advancing

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McBryde Johnson first met Singer when she attended a lecture entitled “Rethinking Life and Death” in the spring of 2001 at the College of Charleston.⁸⁸ She confronted him during the question and answer session, and their dialogue continued by e-mail over the next year. Eventually, Singer invited McBryde Johnson to debate him at Princeton. They worked out an arrangement for two presentations by McBryde Johnson. She detailed and reflected upon her talks in an article titled “Unspeakable Conversations,” in which she challenged Singer’s abstract philosophical thinking with her lived experience.⁸⁹ The article became regular reading in bioethics, philosophy, and disabilities law classes across the country.

McBryde Johnson continued to argue against Singer’s radical position in the years that followed. She presented numerous lectures and continued her work as a disability rights lawyer. She showed up on the national stage again during the *Schiavo* debacle.

Perhaps more than any other statement on the case, McBryde Johnson’s short commentary titled “Not Dead at All: Why Congress Was Right to Stick Up for Terri Schiavo” succinctly and powerfully argued against the withdrawal of Terri Schiavo’s feeding tube.⁹⁰ In the commentary, she made ten points which can be summarized as follows: Schiavo was not terminally ill; artificial nutrition and hydration are not life support and are not treatment; since Schiavo was not suffering, her death could not be justified as relieving suffering; no one could determine what Schiavo’s wishes were at the time the decision to terminate treatment was made; Schiavo had a federal constitutional right not to be deprived of her life without due process; terminating nutrition and hydration for Schiavo would violate the Americans with Disabilities Act; fear of feeding tubes is a form of disability prejudice; and the federal government did not take sides by passing a law to allow the federal courts to step into the Schiavo case after it had been resolved in the state courts.⁹¹

theory that infanticide “before the onset of self-awareness” poses no threat); Peter Singer, *Which Babies Are Too Expensive to Treat?*, 1 *BIOETHICS* 275 (1987).

⁸⁸ McBryde Johnson, *supra* note 7.

⁸⁹ *Id.*

⁹⁰ Harriet McBryde Johnson, *Not Dead at All: Why Congress Was Right to Stick Up for Terri Schiavo*, *SLATE*, Mar. 23, 2005, <http://www.slate.com/id/2115208>, reprinted in Editorial, *Overlooked in the Shadows*, *WASH. POST*, Mar. 25, 2005, at A19.

⁹¹ *See id.*

McBryde Johnson's arguments paralleled those made in briefs to the court and in position papers by the disability rights group Not Dead Yet. Not Dead Yet is a national disability rights group that has taken the lead in opposing the legalization of assisted suicide, euthanasia, and the termination of life-sustaining treatment.⁹² The group stages noisy demonstrations with its members arriving at courtrooms, lecture halls, and rallies in a mass of wheelchairs. Members carry signs that say "Health Care Not Death Care" and "Medical Ethicists Are Not Ethical."⁹³ Further, they submit briefs in court cases⁹⁴ and lobby heavily in state legislatures.⁹⁵

Not Dead Yet showed up well before the media, President Bush, or Senator Bill Frist noticed Terri Schiavo. In fact, members of Not Dead Yet have actively opposed laws that permit people or their surrogates to terminate life sustaining treatment since 1983, when Elizabeth Bouvia obtained the court order that required the hospital to remove the nasogastric tube.⁹⁶

The group began its public activities in 1996 when Jack Kevorkian started providing assisted suicide to the public.⁹⁷ In a 1997 rally, 500 people with disabilities gathered to chant "Not Dead

⁹² See generally Not Dead Yet, About Not Dead Yet, <http://www.notdeadyet.org/docs/about.html> (last visited Sept. 23, 2006) (explaining who the group is and why it exists).

⁹³ Diane Coleman, *Not Dead Yet, The Resistance Meets Success*, MEMPHIS CTR. FOR INDEP. LIVING, <http://www.mcil.org/mcil/mcil/ndy.htm> (last visited Sept. 9, 2006).

⁹⁴ See, e.g., Brief for Not Dead Yet et al. as Amici Curiae Supporting Petitioners, *Gonzales v. Oregon*, 126 S. Ct. 904 (2006) (No. 04-623) [hereinafter *Gonzales* Amici Brief]; Brief for Not Dead Yet et al. as Amici Curiae Supporting Appellants, *Oregon v. Ashcroft*, 368 F.3d 1118 (9th Cir. 2004) (No. 02-35587) [hereinafter *Ashcroft* Amici Brief]; Brief for Not Dead Yet et al. as Amici Curiae Supporting Respondents, *Wendland v. Wendland*, 28 P.3d 151 (Cal. 2001) (No. S087265) [hereinafter *Wendland* Amici Brief]; *Schiavo I* Amici Brief, *supra* note 3.

⁹⁵ See, e.g., Disability Rights Education & Defense Fund, <http://www.dredf.org/> (last visited Sept. 14, 2006) (describing various state initiatives and explaining the organization's mission as "dedicated to protecting and advancing the civil rights of people with disabilities through legislation, litigation, advocacy, technical assistance, and education and training of attorneys, advocates, persons with disabilities, and parents of children with disabilities"). *But cf.* Press Release, Not Dead Yet, Disability Advocates: Texas "Futile Care" Law Should Be Euthanized, <http://www.notdeadyet.org/docs/TXfutilecarelawPR0506.html> (last visited Sept. 14, 2006) (calling for a "halt to the backroom lobbying by special interest groups" related to Texas' "futile care" statute).

⁹⁶ *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 298 (Ct. App. 1986); see *supra* text accompanying notes 42-51.

⁹⁷ Not Dead Yet, *supra* note 92.

Yet” in protest of Kevorkian’s acquittal on criminal charges.⁹⁸ The group’s purpose is to prevent disability discrimination in end-of-life cases.⁹⁹ It frames the issue of assisted suicide as follows:

Though often described as compassionate, legalized medical killing is really about a deadly double standard for people with severe disabilities, including both conditions that are labeled terminal and those that are not. . . . [C]ountless people with disabilities have already died before their time. For some, a disabled person’s suicidal cry for help was ignored, misinterpreted, or even exploited by the right-to-die movement. For others, death came at the request of a family member or other health care surrogate. This is not compassion, it’s contempt.¹⁰⁰

Working together with twenty-five national disability groups, Not Dead Yet took on a prominent and public role during the *Schiavo* case.¹⁰¹ The activists claimed Terri Schiavo as one of their own. As the group wrote in an amicus brief:

Ms. Schiavo’s fate is intertwined with that of many people with disabilities who must rely on surrogates. If . . . Ms. Schiavo’s “quality of life”—as determined by others—justifies her death, then one cannot distinguish Ms. Schiavo from anyone else who is “incompetent,” including thousands who cannot speak due to developmental or physical disabilities.¹⁰²

Not Dead Yet filed several amicus briefs during the course of the *Schiavo* case, all of which raised three principal arguments: first, that the trial court had failed in its fact-finding role; second, that Terri Schiavo had a substantive due process right to receive treatment; and third, that the denial of medical care because of cognitive disability constituted illegal differential treatment under the Americans with Disabilities Act.¹⁰³ The *Schiavo* briefs reiterated arguments made for years by the activists, but it was during *Schiavo* that they got the most attention.¹⁰⁴

In addition to making the legal arguments in courts, Not Dead

⁹⁸ See *id.*

⁹⁹ *Id.*

¹⁰⁰ *Id.*

¹⁰¹ See Cerminara, *supra* note 5, at 154-55 (noting several public interest groups took part in the *Schiavo* appeal).

¹⁰² *Schavo I* Amici Brief, *supra* note 3, at 4.

¹⁰³ *Id.* See *infra* Part III.A for a response to these arguments.

¹⁰⁴ See, e.g., Diana Penner, *Indiana Tackled Right-to-Die Issue in '91: In Schiavo-Like Case, Parents Agonized, then Chose to Remove Tube; A Legal Battle Followed*, INDIANAPOLIS STAR, Mar. 27, 2005, at 1A.

Yet actively lobbied the Florida legislature, Florida Governor Bush, Congress, and the President on behalf of their cause. The results were stunning. The lobbying effort helped to achieve state legislation, federal and state court litigation, federal legislation, executive action, and twenty-four-hour media coverage for weeks on end.¹⁰⁵ Through its involvement in the case, Not Dead Yet raised the profile of the disability rights movement and its message to a national stage in a very real way.¹⁰⁶ Suddenly, the public was engaged in debates about persistent vegetative states, advance directives, and artificial nutrition and hydration. After the immediate furor over *Schiavo* subsided, Not Dead Yet began supporting a Model Starvation and Dehydration of Persons with Disabilities Prevention Act (Model Act). The Model Act would effectively take away the power of surrogate decisionmakers to withhold life-sustaining treatment, especially nutrition and hydration, in the absence of a written living will.¹⁰⁷

Thus, the agenda of many disability scholars and activists is very much the same with respect to end-of-life cases. The two groups appear united in their desire to prevent surrogates from withholding treatment, especially nutrition and hydration, at the end of a person's life. The community opposes such decisions because, in its view, they are based on and perpetuate the notion that a disabled person's life is not worth living. The acceptable alternative is to educate patients and their families about the potential value of life with disability, and to provide patients and their families the support, accommodation, and tools needed to maximize the value of that life.

After Terri Schiavo died, the new activists brought their agenda to state legislatures across the country. The following Part discusses the impact of their actions.

II

HEARING THE MESSAGE: HOW THE DISABILITY LOBBY HAS SUCCEEDED IN CHANGING PUBLIC DISCOURSE

For at least twenty years, certain principles have been settled as matters of law and ethics. First, every competent person of

¹⁰⁵ George J. Annas, "Culture of Life" Politics at the Bedside—The Case of Terri Schiavo, 352 NEW ENG. J. MED. 1710, 1711-14 (2005).

¹⁰⁶ See Cerminara, *supra* note 10, at 346, 348.

¹⁰⁷ See *infra* Part III.B (discussing the Model Act in detail).

adult years has a qualified right to decide what to do with her own body.¹⁰⁸ That right, which is rooted in both constitutional and common law, includes the right to refuse medical treatment.¹⁰⁹ Second, if a person lacks capacity to make medical decisions, someone else may make medical decisions for her.¹¹⁰

¹⁰⁸ See, e.g., *Lawrence v. Texas*, 539 U.S. 558, 578 (2003) (holding that the Constitution protects the right of an individual to engage in intimate sexual conduct); *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 278 (1990) (stating that a constitutional right to refuse life-sustaining medical treatment could be inferred from the Court's prior decisions); *Roe v. Wade*, 410 U.S. 113, 154 (1973) (finding that the ability of a woman to have an abortion was within the realm of personal liberty protected by the constitution); *In re Browning*, 568 So. 2d 4, 10 (Fla. 1990) (citing *Cruzan* for the proposition that "[a] competent individual has the constitutional right to refuse medical treatment regardless of his or her medical condition"); *In re Quinlan*, 355 A.2d 647 (N.J. 1976) (holding that Karen Quinlan had a federal constitutional right to privacy to terminate life-sustaining treatment and that Quinlan's father could act on his daughter's behalf to order removal of the ventilator that aided her respiration).

¹⁰⁹ See *Vacco v. Quill*, 521 U.S. 793, 807-08 (1997) (declaring that everyone, regardless of physical condition, is entitled, if competent, to refuse unwanted life-saving treatment); *Washington v. Glucksberg*, 521 U.S. 702, 724 (1997) (same); *Blouin v. Spitzer*, 356 F.3d 348, 360 (2d Cir. 2004) (same). The importance of the right to decline medical treatment was recently affirmed and invigorated in *Sell v. United States*, 539 U.S. 166, 185-86 (2003).

¹¹⁰ *Cruzan*, 497 U.S. at 284 (noting that while a state may impose evidentiary requirements for a guardian to make certain medical decisions, someone other than the patient may make medical decisions for a patient); *Rasmussen v. Fleming*, 741 P.2d 674, 682 (Ariz. 1987) (finding the right to refuse medical treatment, including artificial nutrition and hydration, is protected under United States Constitution, Arizona Constitution, and common law right to be free from bodily invasion); *Barber v. Superior Court*, 195 Cal. Rptr. 484, 486 (Ct. App. 1983) (allowing, in the first reported case, withdrawal of nutrition and hydration, and holding that doctors not criminally liable for following family's wishes to discontinue artificial nutrition and hydration from man in "a deeply comatose state from which he was not likely to recover"); *In re Browning*, 568 So. 2d at 11 (holding that the constitutional right of privacy embraces the right to refuse all artificial means of life support). States have adopted differing mechanisms to give voices to surrogates. See generally Alicia R. Ouellette, *When Vitalism Is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 IND. L.J. 1, 3 n.7 (2004) (detailing the statutory provisions in each state that cover living wills, proxies, and surrogacy). Most states will enforce advance directives or the appointment of a health care agent. *Id.* Some states automatically appoint a surrogate. E.g., 755 ILL. COMP. STAT. ANN. 40/1-40/65 (West 1992 & Supp. 2006). Some states require a surrogate decisionmaker to make decisions for the patient considering only what is in the best interest of the patient. E.g., CAL. PROB. CODE §§ 4711, 4714-4716 (West 1991 & Supp. 2006). Other states ask the surrogate to exercise "substituted judgment," that is, to decide what the patient would want if she could speak for herself. E.g., MD. CODE ANN. HEALTH-GEN. § 5-605 (West 2002 & Supp. 2006); *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 431 (Mass. 1977). Some states have a hybrid model that allows for substituted judgment when the patient's wishes are known, but require a decision based on the patient's best

Third, the provision of nutrition and hydration to someone who cannot eat or drink on his or her own is medical treatment, just as the provision of air to someone who cannot breathe or insulin to a diabetic is a medical treatment.¹¹¹ Fourth, a competent individual may voluntarily forgo life-sustaining nutrition and hydration in any state in the country.¹¹² Fifth, the right to decline treatment is protected in all fifty states by statutes that ensure that a person’s wish to forgo life-sustaining treatment can be carried out by a surrogate if the person loses competency.¹¹³

The *Schiavo* case called all these principles into question.¹¹⁴ To be sure, the case did not itself result in a change in the law, but the activism of the disability rights community and the publicity the community created through *Schiavo* has had “lingering effects.”¹¹⁵ The most vulnerable principles concern the provision of nutrition and hydration as medical treatment, and the ability of a surrogate to withhold such nutrition and hydration for a person who cannot speak on his or her own behalf.¹¹⁶ The activism resulting from the *Schiavo* case further weakened the resilience of these principles.

Professor Tom Mayo explained, “[I]t apparently came as a surprise to a lot of members of Congress and the public that ‘artificial nutrition and hydration’ (‘ANH’) is deemed to be ‘life-sustaining treatment’ and therefore is an intervention that may be refused on behalf of an incompetent patient”¹¹⁷ During *Schiavo*, disability activists pressed the notion that ANH is not a medical treatment but a fundamental human right, and legislators became open to the disability rights argument. The disabil-

interests where the wishes are not known or knowable. *E.g.*, DEL. CODE ANN. tit. 16, § 2507 (2003 & Supp. 2004).

¹¹¹ See *Cruzan*, 497 U.S. at 261; ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* § 6.03[G] tbl.6-2 (3d ed. 2004 & Supp. 2006) (providing a state-by-state list of medically supplied nutrition and hydration cases and attorney general opinions).

¹¹² See *Vacco*, 521 U.S. at 800 (declaring that “everyone, regardless of physical condition, is entitled, if competent, to refuse unwanted lifesaving medical treatment”); *Cruzan*, 497 U.S. at 277 (indicating that competent persons have a constitutionally protected liberty interest in refusing unwanted medical treatment); see also *Sell*, 539 U.S. at 178 (recognizing a “‘significant’ constitutionally protected ‘liberty interest’” in avoiding forced medical treatment).

¹¹³ See Ouellette, *supra* note 110, at 3 n.7 (citing living will statutes, surrogacy statutes, and health care proxy laws in all fifty states).

¹¹⁴ See Shepherd, *supra* note 5, at 297-301.

¹¹⁵ Cerminara, *supra* note 5, at 158-59.

¹¹⁶ See Shepherd, *supra* note 5, at 301.

¹¹⁷ Mayo, *supra* note 5.

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ity rights community got additional support from the Vatican, which came out against the removal of Terri Schiavo’s feeding tube.¹¹⁸ Pope John Paul II wrote in 2004 that “[t]he administration of water and food, even when provided by artificial means, always represents a natural way of preserving life . . . not a medical procedure.”¹¹⁹ Because Schiavo was brain damaged but not brain dead, Vatican officials said she must be kept alive.

Building on the momentum of the *Schiavo* case, disability activists, together with unlikely bedfellows in the right-to-life lobby, began pressing the Model Starvation and Dehydration of Persons with Disabilities Prevention Act¹²⁰ in state legislatures across the country.¹²¹ The Model Act would create a presumption that all people who lack the legal capacity to make their own “health care decisions [have] directed [their] health care providers to provide . . . nutrition and hydration to a degree that is sufficient to sustain life.”¹²² The presumption may be overcome only if withholding artificial hydration and nutrition is explicitly contemplated in the patient’s living will or if there is “clear and convincing evidence that the person . . . gave express and informed consent to [reject] nutrition or hydration in the applicable circumstances.”¹²³ Various versions of the Model Act have been introduced as bills around the country.¹²⁴

For example, a bill introduced in Kansas would make it more difficult for guardians of the disabled to withhold nutrition and hydration from people under their care.¹²⁵ The bill, supported expressly by Not Dead Yet President Diane Coleman, would require “legal guardians for people who are incapacitated, disabled

¹¹⁸ Alessio Vinci, *Vatican Weighs In on Schiavo Case*, CNN.COM, Mar. 23, 2005, <http://edition.cnn.com/2005/LAW/03/22/schiavo.vatican/>.

¹¹⁹ *Id.* (omission in original).

¹²⁰ MODEL STARVATION AND DEHYDRATION OF PERSONS WITH DISABILITIES PREVENTION ACT (Nat’l Right to Life Comm. 2006), <http://www.nrlc.org/euthanasia/modeln&hstatelaw.pdf> [hereinafter MODEL ACT].

¹²¹ Shepherd, *supra* note 5, 327-28 n.155.

¹²² MODEL ACT, *supra* note 120, § 3(A).

¹²³ *Id.* § 5(A).

¹²⁴ For example, versions of the Act have been proposed in Iowa, Florida, and, according to news reports, Alabama, Hawaii, Louisiana, Mississippi, and South Dakota. Mayo, *supra* note 5; see also Robert Tanner, *Schiavo Case Spurring Statehouse Debate*, ABC NEWS, Apr. 3, 2005, <http://abcnews.go.com/Politics/print?id=637522>. Some of the bills introduced are: H.R. 701, 2005 Leg., 107th Sess. (Fla. 2005) and H.R. 4752, 2005 Leg., 93d Sess. (Mich. 2005).

¹²⁵ See John Hanna, *Schiavo Case Spurs Kansans to Action*, LAWRENCE J.-WORLD, Mar. 26, 2005, available at http://www2.ljworld.com/news/2005/mar/26/schiavo_case_spurs/.

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or unable to make some decisions for themselves . . . [to] obtain permission from a judge or jury to withhold food and water if the people in their care had no living wills”¹²⁶

The disability rights community’s success in bringing attention to its message during the *Schiavo* case may affect more than the legal treatment of nutrition and hydration. Professor Kathy Cerminara points to four other ways in which the *Schiavo* case may yet change laws around disability at the end of life.¹²⁷ First, legislatures may consider whether to “prevent persons who might inherit from a patient upon that patient’s death from making decisions regarding withholding or withdrawal of life-sustaining treatment.”¹²⁸ This particular reform, if enacted, will affect close family members who, many would argue, are the most appropriate people to make health care decisions for incompetent patients.¹²⁹

Second, legislatures may consider whether courts must approve decisions regarding withdrawal of life-sustaining treatment,¹³⁰ or whether courts must appoint a guardian ad litem for all patients who are subject to a decision to withdraw treatment. According to Professor Cerminara, such an option, “would force . . . families, who are already facing gut-wrenching situations, to stake out contentious positions even more strongly than any of them may wish; these families should instead be focusing on what the patient would have wanted.”¹³¹

Third, legislatures might reconsider the appropriateness of the substituted judgment standard and the use of what Norman Cantor calls “constructive preference” for the patient whose wishes are not known.¹³² Most states allow surrogate decisionmakers to use substituted judgment—that is, the surrogate is permitted to

¹²⁶ *Id.*

¹²⁷ Cerminara, *supra* note 5, at 159-76.

¹²⁸ *Id.* at 160.

¹²⁹ See Kathleen M. Boozang, *An Intimate Passing: Restoring the Role of Family and Religion in Dying*, 58 U. PITT. L. REV. 549, 585 (1997).

¹³⁰ Hanna, *supra* note 125.

¹³¹ Cerminara, *supra* note 5, at 164.

¹³² *Id.* at 165; see also Allen E. Buchanan, *The Limits of Proxy Decisionmaking for Incompetents*, 29 UCLA L. REV. 386, 407-08 (1981) (arguing that in substituted judgment cases, the court should act in the incompetent’s best interests); Norman L. Cantor, *The Relation Between Autonomy-Based Rights and Profoundly Mentally Disabled Persons*, 13 ANNALS HEALTH L. 37, 40 (2004) [hereinafter Cantor, *Autonomy-Based Rights*]; Norman L. Cantor, *Twenty-Five Years After Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 J.L. MED. & ETHICS 182, 192-93 (2001) (discussing the “constructive preference” surrogate decisionmaking standard).

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determine what the patient would have wanted had she been able to decide for herself.¹³³ The standard does not require written evidence of the patient’s wishes.¹³⁴ Rather, the surrogate can make the determination based upon the patient’s values, beliefs, and past choices.¹³⁵ In some cases, the patient has never had the ability to express wishes for end-of-life medical care, or to form values or beliefs that would have shaped the decision. In such cases, surrogates are “actually determining a ‘constructive preference’ for the patient—‘imputing choices to a formerly competent patient based on what the vast majority of competent persons would want done for themselves in the circumstances at hand.’”¹³⁶ Because most people favor termination of treatment in cases where they must “exist in a non-communicative state or a state in which they manifest little or no control over their surroundings or recognition or enjoyment of loved ones,”¹³⁷ a scheme allowing a decisionmaker to act on constructive preference will allow the termination of treatment in more cases than not. The mid-level appellate court in *Schiavo* expressly stated that use of the majority view was inappropriate in conducting a substituted judgment analysis.¹³⁸ The Model Act shopped in *Schiavo*’s wake would prohibit the use of constructive preference and substituted judgment altogether.

Finally, the case may trigger change in the way legislatures treat people in persistent vegetative states (PVS). Because *Schiavo* drew attention to the somewhat incongruous fact that someone in a PVS can appear awake and able to react to certain stimuli, legislatures could decide to revisit statutory definitions of a PVS, or, more alarmingly, revisit laws that allow the termination of treatment for a person in a PVS.¹³⁹ For example, Lois Shepherd describes a bill that is pending in Ohio as making it “even more likely that the preferences for treatment withdrawal

¹³³ See Ouellette, *supra* note 110, 48-55 app. (charting laws in all fifty states and revealing that substituted judgment is the majority model).

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¹³⁴ “The substituted judgment standard has subjective and objective components. Through this standard, the surrogate attempts to ascertain, with as much specificity as possible, the decision the incompetent patient would make if he were competent to do so.” *Martin v. Martin (In re Martin)*, 538 N.W.2d 399, 407 (Mich. 1995).

¹³⁵ See MEISEL & CERMINARA, *supra* note 111, § 4.02.

¹³⁶ Cerminara, *supra* note 5, at 165.

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¹³⁷ *Id.* at 166 (citing Robert A. Pearlman, *Insights Pertaining to Patient Assessments of States Worse than Death*, 4 J. CLINICAL ETHICS 33 (1993)).

¹³⁸ Cerminara, *supra* note 5, at 166.

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¹³⁹ *Id.* at 176-77.

of a person in a permanent vegetative state would be ignored.”¹⁴⁰ The law would make the surrogacy process that ordinarily applies to patients who lack decisionmaking capacity inapplicable for patients in persistent vegetative states if someone who could potentially serve as a surrogate agreed in writing not to withdraw artificial nutrition and hydration. That person would be given the power over the patient regardless of what the patient might have wanted. The bill’s effect would be “to nullify a patient’s wishes to discontinue tube feeding by deferring to a surrogate who determined otherwise.”¹⁴¹

The impact of the new advocacy will not be known for some time. In the meantime, a critical examination of both the agenda and its underlying theory is in order.

III

DANGER, CONFLATION, MISIDENTIFICATION, AND PERNICIOUS PATERNALISM

The new advocacy by the disability rights community on end-of-life cases is theoretically flawed and dangerous. The community advocates laws that would make it virtually impossible for surrogates to terminate life-sustaining treatment for people who lack capacity and have no living will.¹⁴² The community argues that such legislation is necessary to protect the disabled from discrimination that will force early death because of the judgment that disabled lives are not worth living.¹⁴³

Before the new advocacy took center stage in the disability rights movement, paternalism was the enemy of the community. Disability rights activist James Charlton explained,

¹⁴⁰ Shepherd, *supra* note 5, at 318-19 & n.11 (citing H.R. 201, 126th Gen. Assem., Reg. Sess. (Ohio 2005), and noting that as of January 7, 2006, the Bill remained in committee).

¹⁴¹ *Id.*

¹⁴² See, e.g., NCIL Position Statement, *supra* note 4 (supporting legislation “that restores and maintains restrictions on surrogate decisions for withholding of food and water via tube”); CHP Position Statement, *supra* note 4 (stating that for those lacking capacity and a directive, “treatment should not be withheld or withdrawn unless death is genuinely imminent” or continued care “is objectively futile”). The exception that would allow termination of treatment if so requested in a living will reflects one of two things: respect for unambiguous statements of precedent autonomy, or, more cynically, a resigned acceptance that contesting the use of living wills is a losing cause. I suspect the latter. The theory behind the community’s message against termination of treatment for people without living wills applies with the same force to living wills as it does to other methods of medical decisionmaking.

¹⁴³ See *supra* Part II.

“[p]aternalism lies at the center of the oppression of people with disabilities. Paternalism starts with the notion of superiority: We must and can control these ‘subjects’ in spite of themselves, in spite of their individual will, or culture and tradition.”¹⁴⁴ The new activists have focused on a new enemy—people who favor autonomy as the paramount concern in medical decisionmaking. Thus, a new activist charged, “If I were listing the most dangerous people in the U.S. today, bioethicists, aka medical ethicists, would top my list—way above skinheads, whose beliefs they appear to share.”¹⁴⁵

How did the new activists stray so far from their roots in disability studies that they began pushing paternalistic laws that would disable individuals already facing disability? Kathy Cerminara argues that right-to-life advocates have co-opted the disability agenda.¹⁴⁶ I disagree, at least in part. While the interests and activism of the two groups converged as early as 1983¹⁴⁷ with respect to the Baby Doe cases,¹⁴⁸ the new agenda is the natural outgrowth of disability studies and identity politics.

Disability studies reframed common problems faced by people with physical and cognitive impairments as disability issues and brought together a diverse group that rallied together to become a political force. The activists, consisting of people with a wide array of physical impairments, joined together in a struggle based on the shared experience of injustice. The larger the group, the greater its power. The more universalized its agenda, the greater its impact. Thus, while the activists’ purported goal, like that of their scholarly counterparts, is greater self-determination and the elimination of social obstacles to success for their constituents, their agenda relies on the recognition of disability as a political force. The cohesion of the group paid off, in a classic example of the power of identity politics, with the passage of the Americans with Disabilities Act (ADA).

The group’s focus on a universal answer to end-of-life decisionmaking, however, is not a victory for its members. The new

¹⁴⁴ CHARLTON, *supra* note 21, at 54-55.

¹⁴⁵ Kuczewski, *supra* note 10, at 36 (quoting Alice Mailhot, *Bioethics: Introduction to Theories from Hell*, MOUTH MAG., 1994, available at www.notdeadyet.org/bioethic.html).

¹⁴⁶ Cerminara, *supra* note 10, at 370-84.

¹⁴⁷ See Asch, *supra* note 2, at 303.

¹⁴⁸ *E.g.*, *Infant Doe v. Bloomington Hosp.*, 464 U.S. 961 (1983) (denying certiorari).

activists' agenda around end-of-life decisionmaking is plagued by paternalism that marks a departure from the scholarly focus on the importance of self-determination for people with disabilities.

In this Part, I argue that the disability activists' flawed agenda with respect to end-of-life decisionmaking is the result of the misuse of identity politics.¹⁴⁹ That is, the activists' single-minded focus on disability, their need to claim all impaired persons as disabled, their effort to reframe all end-of-life cases as disability issues, and their claim of self determination for the community regardless of its impact on individual members have led the group to its current posture—that of asserting that there is one single answer to disability.

The position taken by the disability activists is not only analytically flawed, it is also dangerous. If adopted, the laws they advocate would themselves discriminate against the disabled by making it impossible for anyone who lacks capacity—itsself a kind of disability—from having access to a medically appropriate treatment. The result would not only physically hurt people, it would have the ironic effect of disabling the disabled.

I start by dispensing with the legal arguments advanced by Not Dead Yet and others that laws that allow surrogates to choose to withdraw life-sustaining treatment legally discriminate against the disabled. I then address the advocate's proposed legislation, and show how adoption of laws based on their model legislation would hurt all of us, especially those with disabilities. Finally, I explore the theoretical flaws—conflation, misidentification, social kinship, and assumption—that led the activists to their extreme positions.

A. *Legal Flaws, Medical Errors, and Discriminatory Effect*

The legal arguments pressed by the new activists in cases like *Schiavo* are easily dismissed. The principle underlying the arguments is that laws that allow surrogates to choose to withdraw or withhold treatment at the end of life violate the ADA and the due process rights of persons with disabilities.¹⁵⁰

¹⁴⁹ Identity politics is “the mobilization around gender, racial, and similar group-based categories in order to shape or alter the exercise of power to benefit group members.” Martha Minow, *Not Only for Myself: Identity, Politics, and Law*, 75 OR. L. REV. 647, 648 (1996).

¹⁵⁰ See *Gonzales* Amici Brief, *supra* note 94, at 10; *Ashcroft* Amici Brief, *supra* note 94; *Wendland* Amici Brief, *supra* note 94; *Schiavo I* Amici Brief, *supra* note 3. To be sure, the activists also challenged factual determinations in the individual

1. *Americans with Disabilities Act*

The new activists argue that allowing a surrogate like Michael Schiavo to deny food and water to someone who is too disabled to make her own health care decisions is disability discrimination that violates the ADA.¹⁵¹

The purpose of the ADA was to “provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”¹⁵² The ADA offers broader protection against disability discrimination than the protection provided by other federal laws.¹⁵³ The ADA provides that “[n]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation”¹⁵⁴ The ADA also forbids “utilizing standards, criteria, or methods of administration that have the effect of discrimination on the basis of disability.”¹⁵⁵ Medical care clearly falls under the ADA’s operation.¹⁵⁶

Families of people with disabilities and disability rights activists have successfully turned to the ADA to force health care providers to treat people with disabilities.¹⁵⁷ They have con-

cases, such as the finding that Terri Schiavo was in a persistent vegetative state and that there was clear and convincing evidence of her wishes. *See Schiavo I* Amici Brief, *supra* note 3. Those case-specific challenges are less important than the broader claims of disability discrimination that, if successful, would undermine basic legal principles of medical decisionmaking in future cases.

¹⁵¹ *See Schiavo I* Amici Brief, *supra* note 3.

¹⁵² 42 U.S.C. § 12101(b)(1) (2000).

¹⁵³ Two federal statutes protect people with disabilities from improper discrimination. Section 504 of the Rehabilitation Act of 1973 provides that “[n]o otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance” 29 U.S.C. § 794(a). The ADA’s coverage is broader, applying to disability-based discrimination by employers and public accommodations such as doctor’s offices and hospitals. 42 U.S.C. §§ 12112, 12181(7), 12182.

¹⁵⁴ 42 U.S.C. § 12182.

¹⁵⁵ *Id.* § 12112(b)(3)(A).

¹⁵⁶ *See, e.g.,* *Bragdon v. Abbott*, 524 U.S. 624 (1998) (applying ADA in medical treatment case involving a dentist).

¹⁵⁷ The most significant victory came not from the courts, but from a decision by the Health and Human Services Secretary to block the Oregon health care rationing plan on grounds it would violate the antidiscrimination laws. Letter from Louis W. Sullivan, Sec’y of Health and Human Servs., to Barbara Roberts, Governor of Or. (August 3, 1992) (with accompanying three-page “Analysis Under the Americans with Disabilities Act (ADA) of the Oregon Reform Demonstration”), *reprinted in ADA Analyses of the Oregon Health Care Plan*, 9 ISSUES L. & MED. 397, 409-12

vinced courts that when the family or the patient's surrogate has consented to the care, a disabled person is entitled to all the medical care that would be provided to a nondisabled person.¹⁵⁸ A refusal by a medical provider to honor a request for treatment can constitute discrimination under the ADA.¹⁵⁹ Thus, an HIV-infected woman successfully sued under the ADA to force a dentist to fill her cavity in his office instead of in the hospital,¹⁶⁰ and the mother of an anencephalic infant was able to use the ADA to

(1994). The advocates have also had some court victories. *See, e.g.*, *Henderson v. Bodine Aluminum, Inc.*, 70 F.3d 958, 960 (8th Cir. 1995) (finding in a case of an insurance denial for a bone marrow treatment that "if the evidence shows that a given treatment is non-experimental—that is, if it is widespread, safe, and a significant improvement on traditional therapies—and the plan provides the treatment for other conditions directly comparable to the one at issue, the denial of that treatment arguably violates the ADA"); *Carparts Distrib. Ctr., Inc. v. Auto. Wholesaler's Ass'n of New Eng., Inc.*, 37 F.3d 1216 (1st Cir. 1994) (applying ADA to denial of health coverage by employer health plan); *In re Baby "K,"* 832 F. Supp. 1022, 1028-29 (E.D. Va. 1993) (requiring hospital to provide life support to anencephalic infant).

¹⁵⁸ *E.g.*, *In re Baby "K,"* 832 F. Supp. at 1028-29.

¹⁵⁹ The refusal by a medical provider to give treatment demanded by a patient or a patient's surrogate raises tough questions under the ADA that are not addressed in this Article. This Article focuses on the specific issue of disability activists' crusade to limit the ability of a patient's surrogate to forgo treatment. For further discussion of the role of the ADA in cases where demanded care is refused, see Mary Crossley, *Becoming Visible: The ADA's Impact on Health Care for Persons with Disabilities*, 52 ALA. L. REV. 51, 57-68 (2000) (recognizing the ADA's possible application in cases in which an individual is denied care that she sought, and discussing the limits of a statute's applicability in rationing schemes) and Maxwell J. Mehlman et al., *When Do Health Care Decisions Discriminate Against Persons with Disabilities?*, 22 J. HEALTH POL. POL'Y & L. 1385 (1997) (distinguishing the difficult question of the ADA's application to medical treatment decisions made by providers when a patient or patient's legally authorized representative declines treatment). The application of the ADA in cases when providers refuse care due to futility, or where rationing schemes make care inaccessible, are legally distinct from the one posed by the new activists in *Schiavo*. *See* Crossley, *supra*, at 75-77 (discussing Oregon's rationing scheme); Mary A. Crossley, *Medical Futility and Disability Discrimination*, 81 IOWA L. REV. 179, 202-50 (1995) (arguing that the ADA is an inadequate tool for analyzing the merits of futility policies); Mehlman et al., *supra*, at 1389-92 (1997) (discussing futility disputes); David Orentlicher, *Rationing and the Americans with Disabilities Act*, 271 J. AM. MED. ASS'N 308 (1994); Philip G. Peters, Jr., *Health Care Rationing and Disability Rights*, 70 IND. L.J. 491, 492 (1995) (considering how rationing "can be legally and ethically defended by proof that the excluded treatments are less effective than those which are provided"); Philip G. Peters, Jr., *When Physicians Balk at Futile Care: Implications of the Disability Rights Laws*, 91 NW. U. L. REV. 798, 810-19 (1997) (discussing futility disputes); James V. Garvey, Note, *Health Care Rationing and the Americans with Disabilities Act of 1990: What Protection Should the Disabled Be Afforded?*, 68 NOTRE DAME L. REV. 581, 601-02, 613-16 (1993) (evaluating the Oregon Health Plan's compatibility with the ADA).

¹⁶⁰ *Bragdon*, 524 U.S. at 648-54.

force a hospital to keep her baby alive through ventilation.¹⁶¹ The courts in these cases reasoned that treatment available to the nondisabled must be available to the disabled.¹⁶²

Applying this reasoning in the case of Terri Schiavo, Not Dead Yet argued that removing Terri Schiavo's feeding tube would deny Schiavo the care that would be provided to people without disabilities because people without her disability would be provided nutrition and hydration.¹⁶³ Specifically, the group's amicus brief to the Florida District Court of Appeal in *In re Schiavo* argues:

Treating people differently based on health or disability status violates the rights of people with disabilities under the ADA. Absent proof that it is truly the person's decision, withholding medical care based on the belief that he or she would rationally want to die because of a disability is discriminatory. . . . When health care providers deny people with severe cognitive disabilities the health care they need to live, but do not do so for others, they violate Title III of the ADA, governing health care providers and other "public accommodations." When state and local governments establish laws and policies that deprive people with cognitive disabilities of the care granted to "competent" persons, they violate Title II of the ADA.¹⁶⁴

The argument fails for several reasons. First, it wrongly assumes that Terri Schiavo was denied care that she would otherwise have received because of her disability. She was not. Terri Schiavo could not receive the care because no one with authority to authorize the continuation of artificial nutrition and hydration had consented to it. The United States Supreme Court decided the issue in *Bowen v. American Hospital Association*.¹⁶⁵ There, the Court was asked whether the Rehabilitation Act prohibited the withholding of medical treatment to handicapped infants.¹⁶⁶ The Supreme Court found no evidence that the hospitals had denied treatment on the basis of handicap.¹⁶⁷ Rather, treatment was denied because of the absence of parental consent.¹⁶⁸ Accordingly, the Supreme Court concluded, "A hospital's withholding of treatment [from a handicapped infant] when no parental

¹⁶¹ *In re Baby "K,"* 832 F. Supp. at 1028-29.

¹⁶² *See id.* at 1029.

¹⁶³ *Schiavo I* Amici Brief, *supra* note 3.

¹⁶⁴ *Id.* at 19.

¹⁶⁵ 476 U.S. 610 (1986).

¹⁶⁶ *Id.* at 612.

¹⁶⁷ *See id.* at 630.

¹⁶⁸ *Id.* at 630-31.

consent has been given cannot violate [the Rehabilitation Act], for without the consent of the parents . . . the infant is neither 'otherwise qualified' for treatment nor has he been denied care 'solely by reason of his handicap.'"¹⁶⁹

The Court's reasoning in *Bowen* applies equally in the case of Terri Schiavo. The case had nothing to do with disability discrimination. A hospital cannot administer medical treatment in the absence of a patient's consent or consent by a legal surrogate because without consent, the patient is not qualified to receive treatment. Under Florida law, Michael Schiavo was Terri Schiavo's legal surrogate. His refusal to consent to treatment on Terri Schiavo's behalf disqualified her for treatment and provided her physicians a reason to withdraw her treatment other than her disability.¹⁷⁰ Thus, *Schiavo* was not a case about treatment refusal based on disability.

Secondly, the laws that gave Michael Schiavo the power to refuse treatment for his wife do not discriminate against people with disabilities; those laws give people with disabilities, like Terri Schiavo, a voice in their medical decisionmaking. Laws that give surrogates the power to make medical decisions are not analogous to a dentist's refusal to fill a cavity for an AIDS patient in a dentist's office.¹⁷¹ Whereas the dentist's refusal to fill a cavity constituted denial of access to appropriate medical care,¹⁷² the Florida surrogacy laws provided Terri Schiavo with access to medically appropriate options, including the option to refuse treatment.¹⁷³

¹⁶⁹ *Id.* at 630; see also *United States v. Univ. Hosp. State Univ. of N.Y. at Stony Brook*, 729 F.2d 144, 161 (2d Cir. 1984) (holding that the Rehabilitation Act did not authorize government intervention overriding the private decision of parents to refuse consent to corrective surgery for a child born with spina bifida and hydrocephalus). Title III of the ADA does not contain the "otherwise qualified" language in section 504 of the Rehabilitation Act.

¹⁷⁰ The real issues in the case were whether Michael Schiavo should be disqualified as a guardian and, if not, whether he had proved what Terri's wishes were by clear and convincing evidence.

¹⁷¹ See *Bragdon v. Abbott*, 524 U.S. 624 (1998).

¹⁷² See *id.* at 641. The dentist did not argue that his desire to treat the patient in a hospital rather than a dentist's office was medically appropriate for the patient. The dentist argued that the option was permissible under the harm exception to the ADA. See *id.* at 648.

¹⁷³ Obviously, the ADA does not prohibit medical treatment that is appropriate because of a patient's disability. As the First Circuit Court of Appeals noted:

[S]uch a prohibition would not only be nonsensical; it would be unethical. . . . "Ethical medical decisionmaking should take into account all medical factors—disability-related or not—affecting a patient's condition and prog-

Terminating treatment is part of good palliative care practice.¹⁷⁴ Like a decision to provide pain-relieving drugs despite the fact that they might hasten death, a decision to terminate treatment may be made to increase patient comfort, to eliminate pain, or to stop bodily deterioration.¹⁷⁵ The decision might also be made to implement the patient’s own judgment about life in her current state. In any of these cases, standard medical care offers all adults the option to choose whether to terminate treatment.

Furthermore, people choose to terminate treatment in hospitals every day. Jehovah’s Witnesses refuse blood transfusions. Cancer patients refuse chemotherapy. People in persistent vegetative states refuse nutrition and hydration through advance directives. Since Terri Schiavo had no advance directive and could not make her own health care decisions, she could access treatment options solely through her surrogate. Thus, the law that gave Michael Schiavo power to make medical decisions in Terri’s stead gave Terri access to appropriate medical care.

Not Dead Yet’s argument turns the ADA on its head. Laws that give people with disabilities access to choice between medically acceptable treatments protect the rights of people with disabilities—even if one of the choices is the termination of treatment. It is the denial of access to all available options that

nosis. Thus, to read the ADA as prohibiting a medical decision-maker from considering medical factors flowing from a disability would put the disabled patient . . . in a different, arguably worse, position than the nondisabled patient.”

Lesley v. Chie, 250 F.3d 47, 53 n.6 (1st Cir. 2001) (quoting Mary A. Crossley, *Of Diagnoses and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection*, 93 COLUM. L. REV. 1581, 1655 (1993)).

¹⁷⁴ See BRITISH MEDICAL ASSOCIATION, WITHHOLDING AND WITHDRAWING LIFE-PROLONGING MEDICAL TREATMENT: GUIDANCE FOR DECISION MAKING (2001); Frank D. Ferris et al., *Ensuring Competency in End-of-Life Care: Controlling Symptoms*, BMC PALLIATIVE CARE, July 30, 2002, at 10, <http://www.biomedcentral.com/content/pdf/1472-684X-1-5.pdf> (“[M]ost experts feel that dehydration in the last hours of living does not cause distress and may stimulate the release of endorphins”); Robert M. McCann et al., *Comfort Care for Terminally Ill Patients: The Appropriate Use of Nutrition and Hydration*, 272 J. AM. MED. ASS’N 1263, 1265-66 (1994) (recognizing that providing nutrition and hydration to terminally ill patients can cause unwanted and painful side effects and finding that terminating the treatment increases patient comfort); Robert J. Sullivan, Jr., *Accepting Death Without Artificial Nutrition or Hydration*, 8 J. GEN. INTERNAL MED. 220, 222 (1993) (“[I]t is likely that prolonged dehydration and starvation induce no pain and only limited discomfort”).

¹⁷⁵ See Ouellette, *supra* note 110, at 34, for further discussion on how the option to terminate treatment is essential to palliative care.

would violate the ADA. In fact, surrogacy laws ensure that the ADA's demand for access is fulfilled. Substituted-judgment and best-interests based statutes are reasonable accommodations. They give the people who lack competence to make their own health care decisions access to the same options available to those who have competence. In this way, surrogacy statutes can be compared to access ramps installed by building owners after the passage of the ADA. Just as ramps were not the equivalent to stairs (e.g., they might be located in the back of the building and take longer to traverse than stairs), surrogacy laws are not the equivalent to an actual exercise of medical decisionmaking by the disabled person. However, just like ramps allow the person with the disability to get into a building, surrogacy laws allow the patient access to all appropriate treatment decisions, including no treatment at all.

So long as a surrogate is choosing between medically acceptable options, the ADA has no role in a medical decisionmaking case. Palliative care medicine views the termination of treatment, including the withholding of nutrition and hydration, as medically appropriate when a person is terminally ill or permanently unconscious. Like dental treatment, palliative care is a public accommodation available to the general public. The activists' position would limit options for surrogates and thereby deny people who lack the capacity access to an acceptable option in palliative care, thus denying the disabled a public accommodation. The denial of access would be based on the patient's disability: the inability to form or express intent.

If the disability activists are right, and the ADA prohibits decisions to terminate treatment for people who cannot speak for themselves, then the ADA would prohibit the disabled from receiving appropriate palliative care.¹⁷⁶ The ADA should not be used to keep people with disabilities from accessing any medical choice. If it is applicable to end-of-life decisions at all, the ADA should ensure that people with disabilities have the same access to palliative care as all other patients.¹⁷⁷

2. *Due Process*

Not Dead Yet's argument that laws that allow the termination of treatment violate patients' due process rights is even less com-

¹⁷⁶ See *id.* at 43.

¹⁷⁷ *Id.*

elling than its discrimination argument. Not Dead Yet argues that the Supreme Court in *Cruzan v. Director, Missouri Department of Health*¹⁷⁸ specifically held that a patient's due process right to life is violated by allowing surrogates to make decisions to withhold treatment on anything less than "clear and convincing" evidence that the patient expressed the wish to terminate treatment.¹⁷⁹ The argument misconstrues the Supreme Court's *Cruzan* decision.

Nancy Cruzan was in a persistent vegetative state because of injuries she sustained during an automobile accident.¹⁸⁰ Her parents sought a court order directing the withdrawal of life-sustaining nutrition and hydration. The Supreme Court of Missouri held that her parents lacked the authority to make the decision because they could not produce clear and convincing evidence that Cruzan would have wanted to terminate treatment.¹⁸¹ The Supreme Court "granted certiorari to consider the question whether Cruzan has a right under the United States Constitution that would require the hospital to withdraw life-sustaining treatment from her under these circumstances."¹⁸²

The Court carefully and narrowly defined the issue as whether Missouri's clear and convincing evidence standard infringed upon Nancy Cruzan's due process rights to refuse life-saving treatment.¹⁸³ The Court upheld the Missouri statute, explaining that when a patient is incompetent to assert her own wishes, "a State may properly decline to make judgments about the 'quality' of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life."¹⁸⁴ Thus, the Court held that the Due Process Clause does not require the state to repose judgment with anyone but the patient herself on what is an acceptable quality of life.¹⁸⁵

Contrary to Not Dead Yet's interpretation of *Cruzan*, nothing

¹⁷⁸ *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990).

¹⁷⁹ See Brief of Amici Curiae Not Dead Yet et al. Supporting Appellant, *Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2004) (No. SC04-925), reprinted in 20 ISSUES L. & MED. 171, 176-79 (2004). The group pressed this argument in the context of the *Schiavo* case, despite the fact that Florida's law required proof by clear and convincing evidence. *Bush*, 885 So. 2d at 335 & n.4.

¹⁸⁰ *Cruzan*, 497 U.S. at 265.

¹⁸¹ *Id.*

¹⁸² *Id.* at 269.

¹⁸³ See *id.* at 280 (majority opinion); *id.* at 292 (O'Connor, J., concurring).

¹⁸⁴ *Id.* at 282 (majority opinion).

¹⁸⁵ *Id.* at 285-86.

in the decision remotely suggests that Missouri’s high evidentiary standard is constitutionally required. The Court simply upheld Missouri’s law as one acceptable state alternative.¹⁸⁶ In fact, Justice O’Connor explained in her concurrence that the Court’s decision was “only that one State’s practice does not violate the Constitution; the more challenging task of crafting appropriate procedures for safeguarding incompetents’ liberty interests is entrusted to the ‘laboratory’ of the States, in the first instance.”¹⁸⁷ Thus, other states have latitude to adopt schemes that differ from Missouri’s, including ones that allow surrogates to make decisions on less than clear and convincing evidence.¹⁸⁸

To be sure, *Cruzan* would permit the limitations on surrogate decisionmaking that Not Dead Yet and its fellow amici (several disability rights groups joined the brief) sought in the *Schiavo* case.¹⁸⁹ What is curious, however, is that the activists oppose more generous surrogacy statutes that actually protect the due process rights of people with severe disabilities. Like all citizens, people with severe disabilities have the due process right to refuse medical treatment. Norman Cantor identifies three components of that right: “(1) an interest in self-determination (i.e., in making a choice about treatment); (2) an interest in well-being (i.e., in having net interests advanced by a decision about treatment); and (3) an interest in maintenance of bodily integrity (i.e., freedom from unnecessary bodily invasion).”¹⁹⁰ A well-intended surrogate is the best person to exercise the disabled patient’s right to well-being and maintenance of bodily integrity. Although a surrogate cannot exercise a profoundly disabled person’s right to self determination, “[a] conscientious surrogate can determine whether medical intervention will promote the well-being or net interests of a profoundly disabled patient and whether the patient’s bodily integrity or dignity will be needlessly compromised by the contemplated medical procedure.”¹⁹¹

¹⁸⁶ See *id.* at 286-87.

¹⁸⁷ *Id.* at 292 (O’Connor, J., concurring) (quoting *New State Ice Co. v. Liebmann*, 285 U.S. 262, 311 (1932) (Brandeis, J., dissenting)).

¹⁸⁸ See Ouellette, *supra* note 110, at 48-55 app. (charting laws in every state and revealing that more than half use a substituted judgment approach). R

¹⁸⁹ It is worth noting, moreover, that Florida law provided Schiavo the protection of the clear and convincing evidence standard. *Id.* at 49 app. (citing FLA. STAT. ANN. § 765.401(3) (West 1997 & Supp. 2003)).

¹⁹⁰ Cantor, *Autonomy-Based Rights*, *supra* note 132, at 43-44. R

¹⁹¹ *Id.* at 44. It is possible, moreover, that the Constitution provides a right to pain control, and the avoidance of medically inappropriate care. See Ouellette,

Disability activists fear that no surrogate is conscientious, and that no surrogate can be trusted to make a decision to refuse treatment for reasons other than fear of disability. Thus, out of fear that surrogate decisionmaking could be abused, disability activists would create a right to life that would prevent surrogates from exercising an independent judgment for an individual patient about a particular person's well-being and bodily integrity. If adopted, the position could have serious negative consequences for anyone who has not issued an advance directive.

B. Danger: Substituted Judgment for Everyone

The legislative agenda being pushed by the new activists is blatantly paternalistic. Its purpose is to protect disabled patients. In effect, the activists are saying that individuals, their families, and their physicians cannot be allowed to make their own decisions, because people without disabilities cannot and do not understand and accept that life with disability can be a life with quality. Therefore, to protect people with disabilities, the new activists would take certain choices out of the hands of people without disabilities. This Part argues that adopting the agenda would not protect the disabled—it would harm them.

Major disability rights groups have adopted common resolutions that set forth the new activists' agenda. That agenda focuses on the power of surrogates to withhold nutrition and hydration, and could easily apply to any life-sustaining treatment. The legislation the new activists are proposing would essentially eliminate the ability of surrogates to use substituted judgment as a model for decisionmaking and impose, instead, the activists' judgment that continued life is the appropriate course. For example, the National Council for Independent Living has resolved to advocate for legislation that would "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

supra note 110 at 32-36 & nn.203-04 (citing Robert A. Burt, *The Supreme Court Speaks: Not Assisted Suicide but a Constitutional Right to Palliative Care*, 337 NEW ENG. J. MED. 1234, 1234 (1997), and Alan Meisel, *Pharmacists, Physician-Assisted Suicide, and Pain Control*, 2 J. HEALTH CARE L. & POL'Y 211, 214-15 (1999)). Neither the right to pain control nor the avoidance of medically inappropriate care was at issue in *Schiavo*. Schiavo could feel no pain, and providing treatment was not inappropriate.

to sustaining the person's life."¹⁹²

The Model Starvation and Dehydration of Persons with Disabilities Prevention Act specifically imposes a presumption "that every person legally incapable of making health care decisions has directed his or her health care providers to provide him or her with nutrition and hydration to a degree that is sufficient to sustain life."¹⁹³ Thus, the Model Act expressly imposes a substituted judgment about what the person would want, regardless of the individual's values. The presumption could be overcome in very limited circumstances. "No guardian, surrogate, public or private agency, court, or any other person" would have the authority to terminate nutrition and hydration except if expressly provided for in a living will, or if the surrogate could produce "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 or nutrition in the applicable circumstances," or if the nutrition and hydration is not medically possible, would hasten death, or would not contribute to sustaining the person's life.¹⁹⁴

The Model Act and the resolutions of various disabilities groups would impose laws very much like New York's.¹⁹⁵ New York is one of three states that severely limits the ability of family members to refuse life-sustaining treatment for patients who lack competence to make their own decisions in the absence of an advance directive.¹⁹⁶

New York law, much like the law proposed by the Model Act,

¹⁹² NCIL Position Statement, *supra* note 4 (emphasis added). See also CHP Position Statement, *supra* note 4 ("Absent clear and convincing evidence of the desires of people with disabilities to decline life-sustaining care or treatment, such care or 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.").

¹⁹³ MODEL ACT, *supra* note 120, § 3(A).

¹⁹⁴ *Id.* §§ 3(B), 5(A).

¹⁹⁵ New York has carved out a small exception to its vitalist laws because of the tragic case of Sheila Pouliot. See *Blouin v. Spitzer*, 356 F.3d 348 (2d Cir. 2004). The Health Care Act for Persons with Mental Retardation sets up the only available mechanism to terminate life-sustaining treatment for a person who has never had decisionmaking capacity. See N.Y. SURR. CT. PROC. ACT LAW § 1750-b (McKinney Supp. 2003) (allowing surrogate of person with mental retardation to terminate treatment). This statutory exception, by definition, does not apply to people incapacitated by brain injury, mental illness, minority, or other physical illness. *Id.*

¹⁹⁶ Along with New York, Michigan and Missouri also severely limit family members' ability to refuse life-sustaining treatment for people who lack decisionmaking capacity and have no living will. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S.

makes it nearly impossible for the family of a person who lacks decisionmaking capacity to forgo life-sustaining treatment in the absence of a living will.¹⁹⁷ Under New York common law, a “patient alone had the right to decide on terminating life support systems.”¹⁹⁸ Consistent with the personal nature of this right, the New York Court of Appeals took note of the “fundamental commitment to the notion that no person or court should substitute its judgment as to what would be an acceptable quality of life for another.”¹⁹⁹ New York does not allow a third party to terminate life-sustaining sustenance for a person who has not stated a “specific subjective intent”²⁰⁰ to forgo such treatment under the specific circumstances presented, a requirement that is so strict that it is almost never satisfied absent a written directive.²⁰¹ The rule applies with particular force to nutrition and hydration by prohibiting parents and guardians from making a “decision that would result in [the incompetent patient] starving to death, if such could be medically avoided, regardless of how soon he may or may not succumb from other causes.”²⁰²

261, 285-86 (1990); *Martin v. Martin (In re Martin)*, 538 N.W.2d 399, 413 (Mich. 1995).

¹⁹⁷ See *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 193 (N.D.N.Y. 2002) (“New York law does not allow a third party to decide that the quality of life of another has declined to a point where treatment should be withheld and the patient should be allowed to die.”), *aff’d*, 356 F.3d 348 (2d Cir. 2004); *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 613 (N.Y. 1988). New York’s protection of life yields to the express exercise of autonomy, except in cases involving cardiopulmonary resuscitation and for people with mental retardation. In all other cases, the general rule requiring treatment applies. See § 1750-b.

¹⁹⁸ *Grace Plaza of Great Neck, Inc. v. Elbaum*, 623 N.E.2d 513, 515 (N.Y. 1993).

¹⁹⁹ *In re Westchester County Med. Ctr.*, 531 N.E.2d at 613.

²⁰⁰ *Hancock*, *supra* note 68, at 652 (citing *In re Westchester County Med. Ctr.*, 531 N.E.2d at 613).

²⁰¹ *In re Westchester County Med. Ctr.*, 531 N.E.2d at 608 (rejecting patient’s statements that she would not like to live like a vegetable or be a burden on her family as insufficient to show clear and convincing evidence of her wishes).

²⁰² *In re Matthews*, 650 N.Y.S.2d 373, 377 (App. Div. 1996). As I have noted in a previous article:

New York’s policy prohibiting third-party decisions to withhold life-sustaining treatment where the patient’s wishes are not known or knowable is reflected in statute. In 1985, the legislature enacted Mental Hygiene Law Article 80, providing for “surrogate decision-making committees” to make health care decisions for incompetent residents of mental hygiene facilities who need “major medical treatment” and do not have family members, guardians, committees or conservators available to make those decisions. The types of “major medical treatment” within a committee’s purview were explicitly defined to exclude “nutrition or . . . the withdrawal or discontinuance of medical treatment which is sustaining life functions.”

Some patients, such as the profoundly retarded, the mentally ill, and those born with brain injuries, have never had the ability to express a specific subjective intention. Others simply did not express a specific subjective intention prior to becoming incapacitated. As to both groups, the Model Act and the resolutions similar to New York’s law²⁰³ would require that life-sustaining treatment be provided.

The so-called protection afforded the disabled by the New York law and in the law sought by the new activists is dangerous. As discussed in Part II, eliminating choices available to surrogates will prevent people with profound disabilities from gaining full access to palliative care. Such limitations may very well violate the ADA. The limitations will, moreover, remove from the equation the disabled patient’s right to bodily integrity and freedom from restraint. The experiences with such laws by disabled people in New York stand as cautionary tales to those who would spread them throughout the country.

1. *Two Cautionary Tales*

Two cases exemplify the problem with paternalistic laws like those being advocated by Not Dead Yet. Both cases arise in New York. The use of New York cases is appropriate because the new activists and disability scholars look to New York law as appropriately protecting the rights of the disabled through their strict limitations on surrogate decisionmaking.²⁰⁴

Sheila Pouliot lived almost her entire life with severe disabilities and died after being subjected to New York’s laws at age forty-two.²⁰⁵ Her story, which I have written about before, bears repeating because it stands as a terrible lesson about the cost to people with disabilities exacted by paternalistic laws. Contrasted to her story is that of Scott Matthews, another person at the center of a controversy over the imposition of a feeding tube. The two stories demonstrate persuasively the danger of paternal-

Ouellette, *supra* note 110, at 23 (footnotes omitted).

²⁰³ See *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 193 (N.D.N.Y. 2002), *aff’d*, 356 F.3d 348 (2d Cir. 2004); *In re Westchester County Med. Ctr.*, 531 N.E.2d at 613.

²⁰⁴ See *supra* Part II.B.

²⁰⁵ For more information on the case of Shelia Pouliot, see *Blouin v. Spitzer*, 356 F.3d 348, 354-56 (2d Cir. 2004); Michael P. Allen, *The Constitution at the Threshold of Life and Death: A Suggested Approach to Accommodate an Interest in Life and a Right to Die*, 53 AM. U. L. REV. 971, 984 (2004); Cantor, *supra* note 10, at 88 n.45; Cantor, *Autonomy-Based Rights*, *supra* note 132, at 46; Cerminara, *supra* note 10, at 375; and Ouellette, *supra* note 110, at 13-18.

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istic laws, the value of autonomy, and the need to allow people with disabilities mechanisms to avoid pain, degradation, and restraint.

Sheila Pouliot was admitted to a state-run hospital in upstate New York with bleeding in her gastrointestinal tract and what was initially diagnosed as aspiration pneumonia.²⁰⁶ For years, she had been fed through a gastrostomy tube, but because of her bleeding, Pouliot could no longer tolerate tube feeding.²⁰⁷ Physicians advised Pouliot's family "that she was suffering from what was likely to be her terminal illness, that she was in pain, and that further treatment would likely prolong the suffering."²⁰⁸

Initially, her physicians complied with the family's request to withhold all treatment and provide only pain relief.²⁰⁹ Six days after her admission to the hospital, however, a state agency informed the hospital that New York law did not allow her family to make the decision to terminate the provision of nutrition and hydration, and the hospital ordered the physicians to resume treatment.²¹⁰

The dispute ended up in court. Pouliot's family, physicians, and guardian sought permission to terminate treatment.²¹¹ The state attorney general argued in favor of continued treatment.²¹² The trial judge ordered the continuing provision of artificial nutrition and hydration based on a straightforward application of New York law and the consent of the family.²¹³

²⁰⁶ *Blouin*, 356 F.3d at 352.

²⁰⁷ She had an acute abdomen, manifested by generalized, "severe abdominal pain and a nonfunctioning intestine." Ouellette, *supra* note 110, at 14.

²⁰⁸ *Id.*

²⁰⁹ *Id.*

²¹⁰ *Id.* at 15.

²¹¹ As the New York District Court explained:

During the hearing, the treating physicians informed the court that there is a 14-day period during which is it [sic] medically appropriate to withhold nutrition and that it was their intention to do so while continually assessing Ms. Pouliot's readiness to receive nutrition. The treating physicians also testified that further treatment to provide nutrition to Ms. Pouliot would result in prolonging her agony without any significant health or medical benefits.

Blouin v. Spitzer, 213 F. Supp. 2d 184, 187 (N.D.N.Y. 2002), *aff'd*, 356 F.3d 348 (2d Cir. 2004).

²¹² *See id.* at 186.

²¹³ On January 3, 2000, the trial judge issued an order that all medical treatment for Pouliot be terminated, except for nutrition, as tolerated, and hydration care. *Id.* at 187. The next day, "the guardian *ad litem* and plaintiff commenced an Article 78 proceeding and petitioned the Supreme Court of New York to enjoin permanently

The treatment successfully sustained life functions, but Pouliot's condition deteriorated. Doctors provided Pouliot with as much nutrition and hydration as was possible over the course of two months.²¹⁴ They were limited to providing what they could through intravenous lines because gastrointestinal bleeding prevented use of the feeding tube.²¹⁵ The calories that sustained Pouliot's life caused her significant pain. As I describe in a previous article:

During that time, Ms. Pouliot's body began to catabolize her own tissue. The hydration provided through the [intravenous] tubes damaged her organs and caused her severe pain. Further, it caused her severe edema, which stretched [Ms. Pouliot's] skin to the point where it fell off and left raw painful areas. She was in agony [and] spent the next two months moaning and curled in the fetal position.²¹⁶

Efforts to control Pouliot's pain were unsuccessful. After two months, one of her physicians stated in a consultation note that the continuation of ANH was "inhumane and . . . causing suffering. From a medical standpoint, it [was] outside the bounds of . . . medically indicated care."²¹⁷

Pouliot's guardian returned to court, this time arguing, with the agreement of the doctors and ethicists who had examined Pouliot, that terminating nutrition and hydration would lessen her pain.²¹⁸ The problem, said the attorney general, was that the treatment that was harming Pouliot was technically life sustaining, and New York law prohibited a third party, even a court-appointed guardian or loving family member, from making the decision to terminate life-sustaining treatment for another person.²¹⁹ The trial judge eventually issued an order permitting the

the State of New York, its agents, officers and/or employees from further medical intervention, nutritional sustenance, or other life-sustaining treatment for Ms. Pouliot." *Id.* At the conclusion of the hearing, the trial judge "temporarily enjoined the named respondents from providing any medical intervention with regard to nutritional sustenance." *Id.* Pouliot received hydration only until January 7. *See id.* Then, after the trial judge was made aware of the limitations in New York law, the family, guardian, and hospital attorneys agreed to provide Pouliot hydration and to attempt to provide 900 calories of nutrition, which was an amount sufficient to maintain life. *See id.* at 186-87.

²¹⁴ *See Blouin v. Spitzer*, 356 F.3d 348, 354 (2d Cir. 2004).

²¹⁵ *Id.* at 355 n.5.

²¹⁶ Ouellette, *supra* note 110, at 16 (footnote omitted).

²¹⁷ *Blouin*, 356 F.3d at 355 n.4; *see also* Ouellette, *supra* note 110, at 17.

²¹⁸ *Blouin*, 356 F.3d at 355.

²¹⁹ *See id.*

withdrawal of treatment, despite his acknowledgment that New York law did not clearly allow such an order.²²⁰ Pouliot died on March 6, 2000, days after the trial court issued its order.²²¹

The case of Scott Matthews had a happier ending.²²² Scott was a twenty-eight-year-old man with profound cognitive and physical disabilities.²²³ At the time of the court case, Scott was described as “severely malnourished.”²²⁴ His disabilities, which included a swallowing disorder, made it very difficult for him to be fed orally.²²⁵ He had been repeatedly hospitalized for dehydration, malnutrition, and aspiration pneumonia.²²⁶ His physician opined that “Scott’s malnutrition was life threatening and Scott ‘does not and can not’ get adequate nutrition and hydration from oral feeding.”²²⁷

Scott’s parents went to court to fight an effort by his care providers and a state agency to surgically place a feeding tube in Scott.²²⁸ Scott’s parents objected to the placement of the feeding tube because of the possible medical complications of the procedure, and “the effect on Scott’s emotional well-being if he was denied the social contact that feeding with others [has] provided.”²²⁹ Specifically, his mother explained “that Scott, who is quadriplegic, nonverbal and incontinent, makes no other purely voluntary decision than his choice to eat.”²³⁰ Replacing oral feeding with tube feeding would have taken away Scott’s greatest pleasure.

The mother was supported by a second physician, who came to know Scott because of a fortuitous visit that occurred when Scott’s regular physician was on vacation.²³¹ The second physician testified that it was reasonable to allow Scott to continue oral feedings given his parents’ concerns.²³²

²²⁰ *See id.*

²²¹ *Id.* at 356.

²²² *In re Matthews*, 650 N.Y.S.2d 373 (App. Div. 1996).

²²³ *Id.* at 374.

²²⁴ *Id.* (stating that his weight fluctuated between forty-three and forty-seven pounds).

²²⁵ *Id.*

²²⁶ *See id.* at 374-75.

²²⁷ *Id.* at 375.

²²⁸ *Id.* at 375-76.

²²⁹ *Id.* at 374-75.

²³⁰ *Id.* at 376 n.7.

²³¹ *Id.* at 375.

²³² *See id.*

The trial court found that Scott suffered from “profound life-threatening malnutrition.”²³³ Because Scott had never been competent to form and express an opinion about the use of a feeding tube under the clear and convincing evidence standard, the trial court ordered the use of a feeding tube.²³⁴

The New York Appellate Division reversed, finding that the appropriate standard was not the clear and convincing evidence standard, but the best interest standard.²³⁵ The court emphasized that even under this standard, New York law does not permit a parent to “deprive a child of life-saving treatment, however well intentioned.”²³⁶ It went on, however, to interpret the second doctor’s testimony to support the conclusion that Scott’s life could be maintained with oral feedings.²³⁷ The court concluded that as long as Scott could sufficiently maintain his life through oral feedings, a more invasive feeding procedure would be premature.²³⁸ The court cautioned, however, that had evidence been presented that Scott was being deprived life-sustaining treatment, it would have granted the request for the tube.²³⁹

2. *Lessons Learned*

The stories of Sheila Pouliot and Scott Matthews teach several lessons. First, they show that paternalism can hurt. Pouliot’s case is paradigmatic on this point. The paternalistic laws that protected her from unscrupulous guardians and hidden eugenics caused her pain, bodily degradation, and an agonizing death. By focusing on protecting her life and her inability to express her own wishes, the laws took Pouliot’s right to be free from invasions upon her bodily integrity and restraint out of the equation.

²³³ *Id.*

²³⁴ *Id.* at 375-76.

²³⁵ As the court explained:

[I]n situations where an individual has always been incompetent to make his or her own decisions, resolution of consent to treatment issues would be guided by different principles than those in a situation where a formerly competent patient subsequently becomes incapable of rendering his or her own treatment decisions. Thus, in the case at hand . . . the law relating to decisions as to life-sustaining treatment for infants is the only fair method by which Scott’s rights can be assessed.

Id. at 376-77 (citations omitted).

²³⁶ *Id.* at 377.

²³⁷ *Id.* at 378.

²³⁸ *Id.* at 379.

²³⁹ *Id.*

Thus, she was forced to receive treatment that “sustained her life,” but broke her body down at the same time.

Application of the Model Act to Pouliot would have generated the same result. Because Pouliot was not competent to make her own health care decisions, the Model Act would have created the presumption that Pouliot had “directed . . . her health care providers to provide . . . nutrition and hydration . . . sufficient to sustain life.”²⁴⁰ None of the exceptions in the Model Act would have helped Pouliot. She had no advance directive, could not give express informed consent, and was not receiving treatment that was medically impossible, hastening death, or unnecessary to sustaining her life.²⁴¹

Pouliot’s case is an extreme example, but other cases involving judgments about whether or how to treat the dying or the profoundly disabled also raise questions about the right to bodily integrity and freedom from restraint. The new activists’ approach would eliminate individual choice about those values for people who lack decisionmaking capacity.²⁴²

Applying the new activists’ approach to Scott Matthews’s case demonstrates the problem. He too would be subject to the presumption that he directed “his . . . health care providers to provide him . . . with nutrition and hydration to a degree that is sufficient to sustain life.”²⁴³ The Model Act would prevent his parents or any public agency or court from withholding nutrition and hydration. None of the Model Act’s exceptions would apply. Thus, the Model Act would appear to require the implementation of the feeding tube based on the testimony that he was facing “profound life-threatening malnutrition.”²⁴⁴

Placement of the feeding tube in Scott would have required surgery that intruded on his bodily integrity. The surgery carried the risks of anesthesia, aspiration of vomit, skin irritation from the tube, ulceration and bleeding into the stomach lining, tube blockage over time, osmotic diarrhea, and that the feeding tube might migrate.²⁴⁵ The statute takes into account none of these

²⁴⁰ MODEL ACT, *supra* note 120, § 3(A).

²⁴¹ *Id.* at § 4(A)-(B).

²⁴² “In short, a policy demanding clear prior expressions as a prerequisite to withdrawal of life support is inhumane in disregarding the possible harm and degradation to the now-incompetent patient.” Cantor, *supra* note 10, at 93.

²⁴³ See MODEL ACT, *supra* note 120, at § 3(A).

²⁴⁴ *In re Matthews*, 650 N.Y.S.2d at 375.

²⁴⁵ *Id.* at 375 n.3.

bodily invasions.

Even more troubling than the physical intrusion, the feeding tube would have restricted Scott's freedom to choose to eat,²⁴⁶ and to enjoy the social companionship oral feedings allowed. With it, Scott would have been deprived of the one activity that brought him the most pleasure—oral feedings. Surely, at least some members of the disability rights community would support his family's effort to allow him continued access to that activity, even if pursuing that course shortened his life. Ironically, the law the new activists are pushing to combat a different problem would have deprived Scott of the pleasure of eating.

To be sure, a judge applying the Model Act to the *Matthews* case might have worked the evidence to find that the feeding tube was not needed to sustain life, like the New York Appellate Division did. However, one can easily imagine another case raising the same issue in which a family does not have the good fortune to find a doctor who would support its efforts to continue oral feeding. The result in such a case would necessarily be the imposition of the tube and the concomitant bodily intrusion and restraint.

The second lesson these cases teach is that family members and well-intentioned surrogates can be trusted. In both cases, the family members acted compassionately to protect the well-being of their disabled relative. The new activists would cut family members out of the medical decisionmaking process. Thus, like Pouliot's sister, family members would have to sit by helplessly and lose what is often a lifelong role as a patient's advocate.

Does the family's role deserve mentioning? The activists would surely argue it does not. From the perspective of the scholars and activists who believe that nondisabled caregivers cannot be trusted because they might believe the myth of the tragic life with disability, it is inappropriate to express concern for the impact of laws on family members. Under the approach adopted by the disability scholars and new activists, the central driving concerns should be empowerment and protection of the disabled.

I believe, however, that families and caregivers are central positive driving forces for empowering the people under their care.

²⁴⁶ See *id.* at 376 n.7.

Scott Matthews's parents and Sheila Pouliot's family are but two examples. Many people with disabilities have loving families and caregivers who share the community's passion for protecting and enabling people with disabilities, particularly the disabled under their care.²⁴⁷ The new agenda does not even allow for the possibility that a family member might understand and know a loved one's wishes, values, strengths, or pain tolerance, and may actually be working in the individual's best interest.

The activists prefer to leave decisions to the courts. Thus, Not Dead Yet's Mary Johnson is supporting the Kansas bill that would require court review of any decision made by a third party to terminate treatment.²⁴⁸ Her support, I suppose, is based on the premise that judges are educable in a way that family members are not.

Again, the negative effects of this paternalistic bill would hurt the very people it is intended to help. The bill would have social and financial costs. Requiring court review of medical decisions would make public otherwise private decisions about health care, turn caregivers into adversaries, and divert financial resources from the patient at the center of the controversy to pay for lawyers. Such a system would cost the impaired person an unacceptable amount.

The third lesson these cases teach is that a right to choose no treatment can affirm a life well-lived. While laws such as New York's are designed to protect the disabled from bad choices made by their caretakers, the laws limit the choices available to people with disabilities. In Scott Matthews's case, his parents' choice empowered him: it gave him socialization and pleasure.

More importantly, perhaps, choice is power. Giving people with disabilities choice, even if that choice must be exercised through a surrogate, affirms the intrinsic worth of each individual. By contrast, paternalistic laws view the disabled as so weak and vulnerable that they need special protection. As disability scholar Anita Silvers states, "Characterizing a group as vulnerable further isolates its members from others in society. Doing so emphasizes their supposed fragility, which becomes a reason to

²⁴⁷ For a compelling argument in favor of an increased role of families in medical decisionmaking cases, see Boozang, *supra* note 129.

²⁴⁸ See Hanna, *supra* note 125.

deny that they are capable, and therefore deserving, of full social participation.”²⁴⁹

The power of choice becomes evident from other cases as well. There are several documented cases of people who desperately sought the right to die, only to choose to live after winning the right to choose to refuse treatment. For example, Elizabeth Bouvia chose to live after she won her court battle.²⁵⁰ So too did Larry McAfee, another disabled plaintiff who sought a court order to remove life-sustaining treatment.²⁵¹ Likewise, only 246 of the 390 people who went through the lengthy process to obtain a legal prescription for suicide between 1998 and 2005 under Oregon’s assisted suicide bill ended up using the medication.²⁵² In such cases, it is possible that once a person knows she can choose death if life truly does become unbearable, life may feel more valuable. Given options and control, people may become reluctant to give up that life, or at least less desperate to leave it.²⁵³ By contrast, limiting options for people with disabilities might actually lead to more deaths by more desperate people who feel cornered by life with a disability. In this way, laws protecting choice in dying may actually affirm life.²⁵⁴

Like the telethons of old, the new activists portray people with disabilities as victims in need of saving.²⁵⁵ To the extent that the

²⁴⁹ Anita Silvers, *Protecting the Innocents from Physician-Assisted Suicide: Disability Discrimination and the Duty to Protect Otherwise Vulnerable Groups*, in *PHYSICIAN ASSISTED SUICIDE: EXPANDING THE DEBATE* 133, 135 (Margaret P. Battin et al. eds., 1998).

²⁵⁰ Milani, *supra* note 63, at 207-09.

²⁵¹ *State v. McAfee*, 385 S.E.2d 651, 651 (Ga. 1989).

²⁵² Int’l Task Force on Euthanasia and Assisted Suicide, 8 Years Under Oregon’s Assisted Suicide Law, *available at* <http://www.internationaltaskforce.org/orstats.htm>. The annual reports on which the chart is based do not disclose why the patients did not ultimately use the prescription.

²⁵³ *See generally id.* (cataloging patients’ reasons for requesting assisted suicide).

²⁵⁴ Kathy L. Cerminara, *Therapeutic Death: A Look at Oregon’s Law*, 6 *PSYCHOL. PUB. POL’Y & L.* 503, 514 (2000) (discussing empirical research that shows “[t]he more choices we give individuals, the more they will act as mature, self-determining adults. If the physician presents choices to the patient and explains the benefits and consequences of each one of them, there is greater possibility that the patient will make a rational decision, thus decreasing the probability of ‘irrational suicide’ occurring out of fear or lack of information”).

²⁵⁵ Anita Silvers has likened the paternalistic views of disabled people to the historically paternalistic views of women. Portraying disabled people as especially vulnerable stereotypes the disabled as a definitively weak class similar to the historical view of women that kept them from high-stress jobs because they needed “special protection.” *See Silvers, supra* note 249, at 135. Characterizing people with disabilities as incompetent, easily coerced, and inclined to end their lives places them in the

activists may be right, their proposed cure is worse even than the problem. Eliminating choice, infantilizing people by disempowering their families, and imposing destructive solutions by destroying choice, are not effective means of protecting people with disabilities.²⁵⁶

C. Flawed Reasoning

Identity politics allows the new activists to see every problem, and to craft every solution through a single lens that focuses exclusively on disability. As to end-of-life cases, the new activists see every decision as a judgment about disability: a decision to live affirms life with disability as valuable, whereas a decision to refuse treatment, and thus die, devalues and harms people with disabilities.

The attempt to explain end-of-life decisionmaking through the single lens of disability fails. End-of-life decisionmaking is anything but one-dimensional. What might work for the community might be wrong for the individual. For the new activists' position to be correct, each individual's choice (or that of a surrogate) must be about life with disability. Any rejection of medical treatment must be about rejection of life with disability. Every person at the center of an end-of-life case must be thought of first as a person with disability.²⁵⁷ All of these assumptions have analytical flaws.

The arguments offered by the new activists conflate dying with disability, misidentify persistent vegetative states with other forms of disability that allow the real possibility of a sapient life, and insist on a social kinship of every person who uses a feeding tube. More importantly, they insist that the patient's status as a person with disability takes precedence over all other aspects of that person's life, and that perseverance is the only acceptable

roles to which they have been confined by disability discrimination. "Doing so emphasizes their supposed fragility, which becomes a reason to deny that they are capable." *See id.*

²⁵⁶ Better options include improving the provision of services to people with disabilities during their lives, educating the public about the positive potential for life with disability, enacting safeguards to protect against unscrupulous surrogates, and perhaps revising our thinking about informed consent in future cases involving disability. *See infra* Part IV.

²⁵⁷ Carol Gill expressly argues that "in order for people with disabilities to function well in this oppressive society, disability should be a 'positive and central' part of their identity." Adrienne Asch, *Critical Race Theory, Feminism, and Disability: Reflections on Social Justice and Personal Identity*, 62 OHIO ST. L.J. 391, 415 (2001).

response to disability. The following discussion examines more deeply the analytical flaws behind the new agenda.

1. *I See Disabled People Everywhere: The Problem of Conflation and Inflation*

At the heart of the new activists' agenda, inextricably linked with the fear of eugenics and the social critique of society's response to disability, is the problem of the insult. When a person chooses death over life with disability, or when a person's surrogate makes that decision for a patient who lacks competence to make her own decisions, members of the disability rights community perceive an insult—a judgment that disabled lives are valued less than other lives.²⁵⁸ The message received is that people would rather die than live as disabled persons.

The insult results in part from the conflation that plagues the agenda. Specifically, the activists conflate all potential forms of physical and cognitive impairment under the big tent of “disability.” Their agenda applies equally to people with physical impairments like paralysis as it does to people who are in persistent vegetative states or who are terminally ill.

The problem is that physical impairments, PVSs, and terminal illnesses are not the same. Physical impairments that allow sapient life are fundamentally different from PVSs, and paralysis and blindness are fundamentally different from terminal cancer.

Disability scholars recognize the differences between disability and terminal illness. Indeed, the scholarship is built around the notion that disability is not all illness. One scholar noted, “The social model of disability disconnects our conceptualization of disability from illness and pain so as to ensure that no judgment

²⁵⁸ *E.g.*, Cerminara, *supra* note 10, at 343 (describing a woman's response to the Schiavo case: “I am not a cabbage, an onion, nor a cob of corn”); Laura Hershey, *Killed by Prejudice*, THE NATION, May 2, 2005, available at <http://thenation.com/doc/20050502/hershey> (claiming that describing feeding tubes and ventilators as “life support,” disabled people get put in a different legal category “with less reason to live”); 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 MAG., Apr. 2, 2005, at 4, available at <http://www.ragged-edge-mag.com/focus/postschiavo0405.html> (describing the bigotry of the “better dead than disabled” school); Jenny Morris, *Tyrannies of Perfection*, NEW INTERNATIONALIST, July 1992, at 16, available at <http://live.newint.org/issue233/tyrannies.htm> (arguing that the explicit motivation for court rulings that allow a severely disabled person to choose death over life with disability “is the notion that physical and intellectual impairment inevitably means a life which is not worth living”).

about the lives of people with disabilities is distorted by uncritical assumptions about their suffering.”²⁵⁹ To be sure, terminal illness can disable a person. But dying people face different questions than people with other physical impairments do.

Likewise, people in PVSs need much of the same care required by quadriplegics. But the conditions are fundamentally different. Unlike other impairments, a PVS is the actualization of myth of the tragic life with disability. That myth says the person with disability can experience no joy or pleasure in life. For the PVS patient, the myth is reality. A person in a PVS cannot experience pleasure or pain, because the part of the brain that processes those functions is destroyed. The PVS patient is beyond disability.

This is not to say that a person in a PVS does not deserve respect or care. The decisions about their care should be made according to the wishes expressed by the patients in their advance directives or as interpreted by their surrogates. My point is merely that the condition of a PVS is different, and individual decisions about a PVS do not reflect on the value of life with disability.

The activists’ conflation of PVS, terminal illness, and physical impairment artificially inflates the “insult” problem. Society has distinctly different views of life in vegetative states or with terminal illness than life with other physical impairments. Over ninety percent of people would not want to be kept alive in a PVS,²⁶⁰ but no similar attitudes exist with respect to life with blindness or paralysis. The different attitudes do not reflect disability prejudice, but the reality that not all “disabilities” are the same.

2. *A Choice to Refuse Treatment Is Not a Value Judgment About Life with Disability.*

The new activists’ agenda is not only overbroad, it also inflates

²⁵⁹ ANITA SILVERS ET AL., *DISABILITY, DIFFERENCE, DISCRIMINATION: PERSPECTIVES ON JUSTICE IN BIOETHICS AND PUBLIC POLICY* 76 (1998).

²⁶⁰ As Norman Cantor wrote:

A permanently unconscious state is the principal example of an intolerably undignified status. Over ninety percent of people consistently say that they would not want to be preserved in this condition devoid of emotion or interaction with a human environment. In other words, an overwhelming majority of people would rather die than live “in such a physically, emotionally, and socially impoverished state.”

Cantor, *supra* note 10, at 98 (footnote omitted).

the role of disability prejudice in individual end-of-life cases. Its insistence on continued life as the only answer to disability ignores the complexity of medical decisionmaking. It also ignores the reality that while life with disability (if properly defined to exclude PVSs) can and should be meaningful, physical impairments necessarily involve certain restraints and bodily degradation. Decisions to avoid restraint and protect bodily integrity are not in any way judgments about the value of people with disabilities.

The following examples demonstrate this disconnect. I enjoy driving. My act and enjoyment of driving in no way reflect a judgment about people who cannot or do not drive. I wear a seatbelt to avoid physical harm in the event of an accident. My safety precautions in no way reflect a judgment about those who have been harmed in car wrecks. I avoid seeing doctors. My aversion to going to the doctor's office in no way reflects a judgment about people who require constant medical care. My actions and preferences simply reflect personal choice; they do not reflect a judgment about others who live life differently.

End-of-life decisionmaking works in the same way. A decision to forgo medical treatment, even life-sustaining medical treatment, may involve decisions to avoid certain conditions that are part of the daily lives of many individuals with disabilities. But "[b]ecause life-sustaining medical intervention constitutes both a bodily invasion and a personal choice regarding the appropriate response to an affliction," every person should have the right to reach his or her own decision about the medical choices.²⁶¹ A personal assessment about pain, bodily intrusions, physical limitations, bodily integrity, and freedom from restraint is no more a judgment about the value of people who live with disability than is the decision to wear a seatbelt. Those choices are personal and unrelated to the value of other people who live with the impairments.

3. *The Rejection of Feeding Tubes Is Not Disability Prejudice*

Feeding tubes deserve special attention. First, the attempt to remove Terri Schiavo's feeding tube triggered unprecedented attention and second-guessing of settled principles of law. Second, the activists have focused their immediate attention on feeding tubes.

²⁶¹ *Id.* at 85.

Harriet McBryde Johnson explained the social kinship she, and others in the movement, feel with people fed with feeding tubes:

I watch nourishment flowing into a slim tube that runs through a neat, round, surgically created orifice in Ms. Schiavo's abdomen, and I'm almost envious. What effortless intake! Due to a congenital neuromuscular disease, I am having trouble swallowing, and it's a constant struggle to get by mouth the calories my skinny body needs. For whatever reason, I'm still trying, but I know a tube is in my future.²⁶²

Because she may need a feeding tube someday, McBryde Johnson feels that no one should be denied one. Instead, she believes it is a piece of equipment, like a wheelchair, which should never be denied.²⁶³

I agree that no one should be denied a feeding tube, but no one should be denied the choice to refuse a feeding tube either. In the first place, feeding tubes are not like wheelchairs. They cannot be used without surgical intervention and the accompanying risk of infection.²⁶⁴ The tubes themselves have an impact on a person's bodily integrity that must be balanced against their benefits. Moreover, feeding tubes limit a person's ability to take food orally, whereas wheelchairs do not limit a person's ability to walk.²⁶⁵ For this reason, an individual's objection to a feeding tube might have nothing at all to do with disability.

Consider Scott Matthews. Scott's family asserted the desire to avoid a feeding tube so that he could continue the activity he enjoyed most in his life. The desire to eat, the social enjoyment of a shared meal, and the taste of food are to some so valuable an experience that losing those abilities would be devastating. Scott's parents' decision to avoid the feeding tube reflected values that were inherently personal to Scott; the decision had nothing to do with disability prejudice. The new activists' legislation would deny all of us the ability to decide that the social benefits of eating outweigh the risk of a premature death.

The argument that fear of feeding tubes is a form of disability prejudice focuses on the physical aspect of disability: the inability

²⁶² McBryde Johnson, *supra* note 90.

²⁶³ *Id.*

²⁶⁴ See *In re Matthews*, 650 N.Y.S.2d 373, 375 nn.2-3 (App. Div. 1996) (describing the surgical procedure and risks involved in inserting a feeding tube).

²⁶⁵ In this way, feeding tubes are distinctly different from wheelchairs that enable mobility.

to eat. Disability scholars argue that the focus on the physical is misplaced, one stating, “[I]ndependence need not be viewed in physical terms; rather, self-direction, self-determination, and participation in decisionmaking about one’s life are more . . . authentic measures of desirable independence, or better, interdependence.”²⁶⁶ The focus on the physical aspect of the inability to eat improperly displaces the importance of self-determination in the decision to use or not use a feeding tube. Like with other decisions, an individual’s decision to accept or reject a feeding tube should belong to the individual.

IV

CONVERSATIONS GO TWO WAYS

On the one hand, I am critical of the new activists’ agenda, and I firmly believe it should be rejected. On the other hand, I take no issue with much of the message propounded by the disability rights community. Indeed, I agree that society fails itself when it devalues the worth of people with disabilities by its collective attitude and actions. I also agree that the history and threat of eugenics and forced sterilization are too recent to suggest that the activists’ fear of these things is outdated or unnecessary.²⁶⁷ I do take issue, however, with the way the disability rights community has applied its theory to end-of-life decisionmaking and to the legal and advocacy positions that result.

I would argue, moreover, that the extreme positions that the new activists are taking in end-of-life cases give policymakers, bioethicists, health care providers, and scholars who favor autonomy rights a reason to dismiss the entire field of disability studies as fringe. Dismissing the field would be a mistake.²⁶⁸ Disability theory has much to offer health policy.

First, disability theory identifies systematic failures with health care and health policy. Some of those failures come to light in end-of-life cases. The much-discussed case of Elizabeth Bouvia is a good example of systematic failures. Bouvia was socially iso-

²⁶⁶ Asch, *supra* note 2, at 313.

²⁶⁷ Lightning rods like Princeton’s Peter Singer, who advocate that in some situations parents should be allowed to euthanize their severely disabled newborns, *see supra* note 87, eliminate the contention that fear of eugenics is unfounded.

²⁶⁸ In fact, noted scholar and ethicist Howard Brody admitted to making that very mistake. Howard Brody, *A Bioethicist Offers an Apology*, CITY PULSE (Lansing, Mich.), Oct. 6, 2004, available at <http://archives.lansingcitypulse.com/041006/features/health.asp>.

lated in a hospital by a system that dealt only with the medical aspects of disability. A system that focuses exclusively on cure has little to offer the permanently disabled. A greater focus on long-term and rehabilitative care could change the reality of existence for people with permanent physical impairments so they are not left alone in hospitals without any means of achieving their full potential.

Second, disability scholars call attention to the way in which judges and lawyers needlessly devalue the lives of people with physical impairments and perpetuate the myth of the tragedy of life with disability. The criticism of the *Bouvia* decision and ones like it is spot on. *Bouvia*'s request to avoid medical treatment should not have been granted because her physical condition devalued her life. Her request should have been granted because it was her decision.

The cases involving treatment refusals by Jehovah's Witnesses provide a better model than the *Bouvia* decision for judicial opinions in treatment refusal cases involving people with disabilities.²⁶⁹ In affirming the right of members of the Jehovah's Witnesses to refuse blood transfusions, the courts do not assess the reasonableness of the religious belief that one should not take blood. The courts ask only if the person is competent to make that choice. Similarly, when asked to review treatment refusal cases involving disabilities, the courts need not justify the decision itself as reasonable by talking about the alleged hopelessness of life with disability. Courts need simply assess the competency of the decisionmaker to make an informed choice.

Third, and perhaps most important, disability scholars correctly note that there is a genuine need to question whether society is too quick to accept as reasonable the decision of a newly disabled person to die rather than to continue to live with a disability. I call this the *Million Dollar Baby* problem. In the film *Million Dollar Baby*, the character played by Hilary Swank

²⁶⁹ See, e.g., *Stamford Hosp. v. Vega*, 674 A.2d 821, 824-25 (Conn. 1996) (involving refusal of blood transfusion by Jehovah's Witness who had bled heavily after delivering child); *Fosmire v. Nicoleau*, 551 N.E.2d 77, 78-79 (N.Y. 1990) (involving the refusal of blood transfusion by thirty-six-year-old Jehovah's Witness following cesarean section); cf. *Thor v. Superior Court of Solano County*, 855 P.2d 375, 382 (Cal. 1993) (affirming right of competent quadriplegic prisoner to refuse food, necessary medical care, and treatment). Norman Cantor points to these latter two cases as ones in which a court's acceptance of a treatment refusal decision is not a value judgment about the reason for the refusal but rather is a personal self determination for the patient. See Cantor, *supra* note 10, at 85 & nn.21 & 23.

asked for and received euthanasia shortly after suffering a catastrophic disability.²⁷⁰ The disability rights community condemned the movie as perpetuating disability prejudice.²⁷¹ As is clear from the rest of this paper, I am not concerned with the character’s ultimate decision. The problem, as I see it, is that the decision was precipitous.

Disability scholarship has produced hard evidence that people who face sudden catastrophic injury might not be able to give informed consent as quickly as previously thought.²⁷² The studies show that when people are in a “liminal state,” that is, after they have lost their old identity as fully functioning but before they’ve accepted their new identity as a person with a disability, they may be unable to process information or recognize the potential for a quality life with disability.²⁷³ Thus, they may be inclined to refuse treatment early after the change.

The scholarship suggests that the notion of what it takes to give informed consent should be revisited in cases of sudden disability. If individuals are truly unable to process information, how can they make informed decisions? Proposals for reforming the informed consent process²⁷⁴ deserve further study, as does

²⁷⁰ MILLION DOLLAR BABY (Warner Bros. 2004).

²⁷¹ See, e.g., Daniel Costello, *Assisted Suicide at Center Stage Once Again: Award-Winning Movies and Upcoming Legislation Give New Urgency to the Contentious Issue*, L.A. TIMES, Mar. 7, 2005, at F1 (noting that disability advocates expressed concerns that the film stigmatizes those with recent disabilities); John Hockenberry, *And the Loser Is . . .*, MILLION DOLLAR BIGOT, <http://www.milliondollarbigot.org/loser.html> (last visited Oct. 12, 2006) (criticizing the film).

²⁷² See, e.g., Gary L. Albrecht & Patrick J. Devlieger, *The Disability Paradox: High Quality of Life Against All Odds*, 48 SOC. SCI. & MED. 977, 980 (1999) (“Individuals, families, and communities are unprepared to recognize and seldom ready to accept disability.”); Asch, *supra* note 2, at 312-13 (quoting a 1987 report indicating that the onset of impairment may delay adaptation and comprehension); David R. Patterson et al., *When Life Support Is Questioned Early in the Care of Patients with Cervical-Level Quadriplegia*, 328 NEW ENG. J. MED. 506, 506 (“Patients frequently have a diminished capacity to make important decisions during the first several months after an injury . . .”).

²⁷³ Susan Merrill Squier uses this term to characterize unsettled stages of human existence. SUSAN MERRILL SQUIER, LIMINAL LIVES: IMAGINING THE HUMAN AT THE FRONTIERS OF BIOMEDICINE 3-4 (2004). For a very personal and sensitive description of one family’s experience with life in a liminal state, see RICHARD GALLI, RESCUING JEFFREY (2000).

²⁷⁴ Arthur Caplan and others argue for an educational model of informed consent that stresses that a patient needs an opportunity to experience the post-traumatic phase of care. The educational model of informed consent allows the treatment team to insist paternalistically on treatment during the initial period following a sudden-onset disability because the patient is not yet fully informed about the potential for quality life with disability. Arthur L. Caplan et al., *Ethical & Policy Issues*

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the suggestion for “disability consults” as a regular part of medical treatment.²⁷⁵

The passion with which the new activists argue that medical decisionmaking at the end of life must be limited to protect the disabled from discrimination demonstrates the depth of the fear and distrust the community has in its own members, lawmakers, health care providers, and society itself. Some of that fear is provoked by individuals like Peter Singer who argue for the right of parents to kill severely “damaged” newborns.²⁷⁶ But most of that fear and distrust can be linked to lived experiences of people with disabilities.²⁷⁷ Attention to disability scholarship can only enrich end-of-life policy.

CONCLUSION

Arguing against the disability rights community on issues that concern disability rights is problematic. Community members speak with a power and authority born of experience. But the power the collective voice carries is the very reason the message must be examined critically. It would be a perverse irony if the legacy of the same community that established civil rights for persons with disabilities were the imposition of an absolute limitation on the liberty rights of all of us as we experience the dying process with our family members.

The purpose of this Article is not to suggest that disability is reason to kill. Nor is it to suggest that the disability rights community is wrong to express that it is dangerous and insulting to people living with disabilities to allow people to terminate their own or other people’s lives because of a physical disability. To the contrary, ethicists, judges, and lawmakers should be very cognizant of those concerns. The purpose of this Article is to suggest that the solution proposed by the new activists is even more dangerous than the danger being fought against.

Taking away options and power in medical decisionmaking for people too disabled to run their own care is demeaning. By contrast, permitting people with disabilities, their family members, or other surrogates to make reasonable choices about medical

in *Rehabilitative Medicine*, 17 HASTINGS CTR. REP. SPECIAL SUPP., Aug. 1987, at S1, S11-14.

²⁷⁵ Asch, *supra* note 8, at S31.

²⁷⁶ See *supra* note 87 and accompanying text.

²⁷⁷ See, e.g., JOHNSON, *supra* note 20; MCBRYDE JOHNSON, *supra* note 77.

care, including artificial nutrition and hydration, is a statement of profound respect for personhood. Giving all people a voice in their medical care respects and recognizes that all people bring to decisionmaking a lifetime of experience, pain thresholds, tolerance for intrusions of the body, the wish to sleep, the ability to sit still, prior relationships with doctors and hospitals, the depth of attachment to particular freedoms or abilities, and the other realities of the human condition. In some cases, the only way to give a person a voice is to give that person a voice through a surrogate. In a real way, a surrogate decisionmaker for a mentally incapacitated patient is like a wheelchair for a person who cannot walk. It is not a perfect substitute, but it is the best possible accommodation. One person's preference to terminate treatment is not a judgment about the value of another person's life. It is a statement about that individual only: that for this person, with this history, this experience, and this existence, the treatment is not wanted. That said, judges, ethicists, and physicians have, for the most part, accepted as true the myth of the tragedy of life with disability. That myth should play no role in law or medicine.

I will conclude by issuing challenges to both sides of the debate. To disability rights activists, consider the possibility that medical decisionmaking is about more than disability, and that limiting options hurts all of us. Also, reconsider the practice of bundling terminal illness and persistent vegetative states into the scope of disability. The social model of disability hinges on the possibility of meaningful sapient life when adequate social support is available. The argument loses credibility in the case of the dying and permanently unconscious. And to scholars, judges, and policymakers who argue in favor of autonomy, listen to the disability movement. Consider how negative characterizations of life with disability such as the description presented in *Bouvia* demean the existence of millions of people who live and even thrive with similar conditions. Moreover, listen to calls for the incorporation of patient, family, and provider education about the real possibility for a quality life in all cases involving disability. That educational process will help all of us become informed about the realities of life with disability so that when we consent to treatment, the consent is based on real information, not fear and prejudice.