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The Relation Between Autonomy-Based Rights and Profoundly Mentally Disabled Persons

*Norman L. Cantor**

I. ATTRIBUTING THE “SAME RIGHTS” TO THE PROFOUNDLY DISABLED

People have a Fourteenth Amendment liberty right to make important medical choices like termination of pregnancy, use of contraception, and rejection of life-sustaining treatment. Profoundly mentally disabled persons, however, are so cognitively impaired that they cannot make their own important medical decisions. Some courts suggest that the mentally impaired are still entitled to “the same right” as competent persons to make critical medical decisions. Can autonomy-based rights—rights involving a considered weighing of options—extend to never-competent persons? Can a profoundly disabled person have the same constitutional right to reject end-of-life medical treatment as a competent person?

The notion of a constitutional right to make important medical decisions dates to the middle of the twentieth century. In 1965, the United States Supreme Court in *Griswold v. Connecticut* indicated that certain unenumerated but fundamental elements of liberty, including the right to make certain personal choices, are protected by the federal Constitution.¹ In *Griswold*, the Court struck down a Connecticut statute that banned the use of contraceptives by married couples. The Court held that access to contraception is part of a fundamental liberty interest within marital privacy.² After the *Griswold* opinion, cases and commentators applied the “liberty” rationale to a competent patient’s right to reject life-sustaining medical treatment.³ A patient’s right to freely make personal medical

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1. 381 U.S. 479, 481-84 (1965).

2. *Id.* at 485.

3. See, e.g., *Aste v. Brooks (In re Estate of Brooks)*, 205 N.E.2d 435, 442 (Ill. 1965); Norman L. Cantor, *A Patient’s Decision to Decline Life-Saving Medical Treatment: Bodily Integrity Versus the Preservation of Life*, 26 RUTGERS L. REV. 228, 240-41 (1973); William

decisions was further promoted by the United States Supreme Court's 1973 opinion in *Roe v. Wade*, where the court reinforced the constitutional protection of intimate personal decisions, including a joint patient-physician decision to terminate a pregnancy.⁴

In the landmark *Quinlan* case in 1976, the New Jersey Supreme Court held that a competent patient has a constitutionally protected right to decline or accept life-sustaining medical intervention.⁵ This liberty right applied even in the context of a patient mired in a permanently unconscious state.⁶ According to Chief Justice Hughes' opinion, "the only practical way to prevent destruction of the [now-incompetent patient's right to decline treatment]"⁷ was to permit a conscientious guardian to determine how the patient would exercise the right in the circumstances at hand. The conscientious guardian in *Quinlan* was the patient's father, who was deemed to be entitled to decide whether to withdraw respiratory support for his unconscious daughter.⁸

A number of other courts followed suit and adopted the position that a surrogate should be able to exercise choice on behalf of a now-incompetent patient in order to preserve the patient's constitutional right to decline treatment.⁹ The exercise of substituted judgment by a surrogate, seeking to replicate what the now-incompetent person would decide, was seen as a necessary means to preserve the patient's fundamental liberties and constitutional rights.¹⁰ In the context of making medical decisions, some courts even declared that incompetent persons enjoy the *same* rights to decide a medical course as competent persons.¹¹ Analogous lines of cases

P. Cannon, *The Right to Die*, 7 HOUS. L. REV. 654, 662 (1970); David J. Sharpe & Robert F. Hargest, *Lifesaving Treatment for Unwilling Patients*, 36 FORD. L. REV. 695, 695 (1968).

4. *Roe v. Wade*, 410 U.S. 113 (1973). See also *Lawrence v. Texas*, 123 Sup. Ct. 2472, 2477 (2003) (confirming the principle that certain intimate personal choices are entitled to special constitutional protection).

5. *In re Quinlan*, 355 A.2d 647, 670 (N.J. 1976).

6. *Id.* at 664.

7. *Id.* See also Donald Beschle, *Autonomous Decisionmaking and Social Choice: Examining the Right to Die*, 77 KY. L.J. 319, 327 (1988-89).

8. *Quinlan*, 355 A.2d at 671.

9. See *Rasmussen v. Fleming*, 741 P.2d 674, 686 (Ariz. 1987); *John F. Kennedy Mem'l Hosp. v. Blutworth*, 452 So. 2d 921, 926 (Fla. 1984); *Foody v. Manchester Mem'l Hosp.*, 482 A.2d 713, 718 (Conn. Super. Ct. 1984); *In re Welfare of Colyer*, 660 P.2d 738, 746 (Wash. 1983); *Severns v. Wilmington Med. Ctr., Inc.*, 421 A.2d 1334, 1347 (Del. 1980); *In re Guardianship of Ingram*, 689 P.2d 1363, 1372 (Wash. 1984).

10. *In re R.H.*, 622 N.E.2d 1071, 1075 (Mass. App. Ct. 1993) ("The right of incompetent individuals to refuse medical treatment is effectuated through the doctrine of substituted judgment."). See also *Brophy v. New Eng. Sinai Hosp.*, 497 N.E.2d 626, 634-35 (Mass. 1986); *In re Ingram*, 689 P.2d at 1369; *In re Moe*, 432 N.E.2d 712, 720 (Mass. 1982); *Blutworth*, 452 So. 2d at 926.

11. See *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 423

preserved a mentally incapacitated person's right of medical choice in the contexts of contraception and sterilization.¹² These courts authorized surrogate choice so long as the guardian's decision would promote the patient's interests.¹³

Other commentators question whether the right to reject medical treatment should be extended to incapacitated patients.¹⁴ For them, the patient's constitutional right is grounded in autonomous choice—a personalized weighing of options reflecting the patient's own values and preferences. An incompetent patient by definition could not have the capacity to understand the alternatives and to exercise informed choice. Commentators ask, “[w]hatever rights an incompetent person may be said to possess, how can autonomous choice be one of them when incompetency means precisely the inability to exercise choice?”¹⁵ For these commentators, personal freedom to make decisions cannot extend to incompetent patients. For them, the “proxy exercise of the right of self-determination is simply not possible.”¹⁶

The criticism of applying “self-determination” and “substituted judgment” to incapacitated persons is unconvincing in the context of previously competent patients. If a competent person made a prospective choice (e.g., an advance medical directive), or articulated values and preferences that would sufficiently dictate medical decisions post-competency, the concept of self-determination is being respected.¹⁷ Although a person's prospective choice may not be as informed as contemporaneous choice, a person anticipating future medical situations

(Mass. 1977); *Bludworth*, 452 So. 2d at 926; *Colyer*, 660 P.2d at 744.

12. See *Wentzel v. Montgomery Gen. Hosp.*, 447 A.2d 1244, 1258 (Md. App. 1982); *In re Grady*, 426 A.2d 467 (N.J. 1981); *In re Guardianship of Hayes*, 608 P.2d 635, 637 (Wash. 1980).

13. *Hayes*, 608 P.2d at 637; *In re C.D.M.*, 627 P.2d 607, 612 (Alaska 1981); *Grady*, 426 A.2d at 482; *In re Welfare of Hilstrom*, 363 N.W.2d 871, 874 (Minn. Ct. App. 1985).

14. John A. Robertson, *Cruzan and the Constitutional Status of Nontreatment Decisions for Incompetent Patients*, 25 GA. L. REV. 1139, 1160 (1991); Daniel B. Griffith, *The Best Interests Standard: A Comparison of the State's Parens Patriae Authority and Judicial Oversight in Best Interests Determinations for Children and Incompetent Patients*, 7 ISSUES L. & MED. 283, 320 (1991).

15. Sanford H. Kadish, *Letting Patients Die: Legal and Moral Reflections*, 80 CALIF. L. REV. 857, 870 (1992). See also *Developments in the Law—Medical Technology and the Law*, 103 HARV. L. REV. 1519, 1664-65 (1990); Thomas Mayo, *Constitutionalizing the Right to Die*, 49 MD. L. REV. 103, 146 (1990) (arguing that irreversible incompetency is “incompatible with notions of autonomy and personal decision-making”).

16. Allen E. Buchanan, *The Limits of Proxy Decisionmaking for Incompetents*, 29 UCLA L. REV. 386, 407 (1981). See also MARTHA MINOW, *MAKING ALL THE DIFFERENCE* 325 (1990).

17. See NORMAN L. CANTOR, *ADVANCE DIRECTIVES AND THE PURSUIT OF DEATH WITH DIGNITY* 29-32 (1993); ROBERT OLICK, *TAKING ADVANCE DIRECTIVES SERIOUSLY* 56 (2001).

may still have well-developed values about intolerable suffering or indignity that can be implemented after the person has become incompetent. A surrogate decision-maker meaningfully preserves the incapacitated patient's right of self-determination when an end-of-life medical decision is grounded on values, such as religious principles or personal convictions about indignity, previously embraced by the patient.

Self-determination, in the sense of weighing of values, is not feasible where a patient's prior expressions and values regarding end-of-life treatment are murky or unintelligible. Even where the patient's desires are unclear, efforts can be made to reach decisions that would likely reflect the incompetent patient's wishes. Arguably, constructive preference—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—is a meaningful way of promoting the patient's likely preferences in end-of-life care.¹⁸ The concept of constructive preference thus undermines any categorical condemnation of substituted judgment in the context of formerly competent medical patients.¹⁹

The subject of inquiry in this article is decision-making affecting profoundly disabled persons. How can substituted judgment and surrogate implementation of a constitutional liberty interest be meaningfully applied to a person who has never been capable of making considered choices or formulating values related to end-of-life medical treatment? Does such a person have the same right to refuse medical treatment as a competent person?

Several courts have suggested that even profoundly disabled persons enjoy “the same panoply of rights and choices” as fully capacitated persons.²⁰ The first articulation of that sentiment came from the Massachusetts Supreme Judicial Court in *Superintendent of Belchertown*

18. See Norman L. Cantor, *Discarding Substituted Judgment and Best Interests: Toward a Constructive Preference Standard for Dying, Previously Competent Patients Without Advance Instructions*, 48 RUTGERS L. REV. 1193, 1241-67 (1996). If a patient's condition fits a scenario as to which we know people's overwhelming preference, following group preference makes sense, at least where the individual's actual personal preference is unknown. *Id.* at 1241. And we do know majority preferences as to certain end-of-life scenarios, such as opposition to being mired in a permanently unconscious state.

19. Rebecca S. Dresser, *Confronting the Near Irrelevance of Advance Directives*, 5 J. CLINICAL ETHICS 55, 56 (1994); Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment for Incompetent Patients: A Critique of the Orthodox Approach*, 17 J.L. MED. & ETHICS 234 (1989).

20. *Foody v. Manchester Mem. Hosp.*, 482 A.2d 713, 718 (Conn. Super. Ct. 1984). See also *Professional Guardianships, Inc. v. Ruth E.J. (In re Guardianship of Ruth E.J.)*, 540 N.W.2d 213, 217 (Wis. Ct. App. 1995) (stating that denying lifesaving medical treatment to a person who is in a class of citizens unable to express consent violates that person's right to equal protection of the laws).

State School v. Saikewicz,²¹ which was decided six months after *Quinlan*. Joseph Saikewicz was a sixty-seven year-old resident of an institution for the developmentally disabled.²² Mr. Saikewicz was severely retarded, had the mental capacity of a child two years and eight months old, and was dying of leukemia.²³ The question became whether chemotherapy should be administered to prolong Mr. Saikewicz's life.²⁴ The Massachusetts court ruled that a court of law and not the director of a state institution was best equipped to resolve Mr. Saikewicz's medical fate and that the applicable decision-making standard would be substituted judgment. That standard required a determination of what Mr. Saikewicz would have wanted to do if he were somehow competent and fully aware of all the circumstances.²⁵ The court declared that incompetent persons must be accorded "the same panoply of rights and choices" as competent persons because the mentally incapacitated share the same "dignity and worth" as the capacitated.²⁶ Only by surrogate decision using substituted judgment could a range of choices be extended to Mr. Saikewicz. A few courts have followed the course set by *Saikewicz* and have applied a substituted judgment standard to end-of-life decisions on behalf of patients who have always been profoundly disabled.²⁷ A few courts have taken a similar approach with regard to sterilization decisions and abortion decisions on behalf of profoundly disabled persons.²⁸

The notion, however, that a profoundly disabled person has the *same* right to choose end-of-life treatment as a competent person is inaccurate. A person's right to refuse medical treatment is partly grounded in self-determination—a weighing and choosing among competing options. The traditional substituted judgment concept allows a surrogate or a court to implement an incompetent patient's self-determination where the patient

21. 370 N.E.2d 417 (Mass. 1976).

22. *Saikewicz*, 370 N.E.2d at 420.

23. *Id.*

24. *Id.*

25. *Id.* at 433-34.

26. *Id.* at 428. See also *In re Jobes*, 529 A.2d 434, 436 (N.J. 1987) (suggesting that incompetent patients have the same right of self-determination as competent patients); *In re Peter*, 529 A.2d 419, 423 (N.J. 1987) (stating that all patients, whether competent or incompetent, of limited cognitive ability or of a vegetative state, are entitled to choose whether or not they want medical treatment).

27. See *In re Guardianship of Hamlin*, 689 P.2d 1372, 1375 (Wash. 1984); *In re Conservatorship of Torres*, 357 N.W.2d 332, 341 (Minn. 1984); *In re L.H.R.*, 321 S.E.2d 716, 722 (Ga. 1984) (declaring that infants have a right to refuse treatment which can be exercised by their parents).

28. See *In re Jane Doe*, 533 A.2d 523, 526 (R.I. 1987); *In re Jane A.*, 629 N.E.2d 1337, 1340 (Mass. App. Ct. 1994); *In re Moe*, 579 N.E.2d 682, 685 (Mass. App. Ct. 1991).

previously articulated choices about end-of-life care or expressed preferences or values sufficient to project the course of medical treatment that patient would have chosen for himself or herself. A profoundly disabled person has never been able to make autonomous choices. A surrogate, therefore, cannot protect a never-competent patient's right of self-determination.

Many courts and commentators²⁹ have recognized the problems of applying notions of autonomy and substituted judgment to the profoundly disabled. Commentators commonly note that mental capacity for autonomous decision-making is a prerequisite to a right to self-determination. These commentators scorn the application of substituted judgment to profoundly disabled persons who lack mental function beyond that of an infant or young child.³⁰ Conjuring the end-of-life decisions of a person with a mental capacity of a child two years and eight months old (i.e., the mental capacity of Joseph Saikewicz) would be a "figment of the imagination."³¹ Most courts, when asked to apply substituted judgment to an infant or to a profoundly disabled adult, have rejected the idea as involving an unrealistic or "impossible" task.³² That judicial response has been forthcoming in a variety of medico-legal contexts, including life-sustaining medical intervention,³³ petitions for sterilization,³⁴ and organ donations.³⁵ These courts repudiate the logic of imputing self-determination to profoundly disabled persons and reject claims that a surrogate is exercising the "same right" to control medical intervention as a competent patient.

29. See, e.g., Mark Strasser, *Incompetents and the Right to Die: In Search of Consistent Meaningful Standards*, 83 KY. L.J. 733, 738-40 (1995); William L. Webster, "Right to Die" Cases: A Model for Judicial Decision-Making?, 7 N.Y. L. SCH. J. HUM. RTS. 140, 147 (1990); Buchanan, *supra* note 16, at 407.

30. PETER G. FILENE, *IN THE ARMS OF OTHERS: A CULTURAL HISTORY OF THE RIGHT TO DIE IN AMERICA* 137 (1998); Bernadette Tobin, *Did You Think About Buying Her a Cat? Some Reflections on the Concept of Autonomy*, 11 J. CONTEMP. HEALTH L. & POL'Y 417, 422-23 (1995); Susan R. Martyn, *Substituted Judgment, Best Interests, and the Need for Best Respect*, 3 CAMBRIDGE Q. OF HEALTH CARE ETHICS 195, 198-99 (1994); Minow, *supra* note 16, at 325.

31. Tobin, *supra* note 30, at 423; Louise Harmon, *Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment*, 100 YALE L.J. 1, 65 (1990).

32. *Lenz v. L.E. Phillips Career Dev. Ctr. (In re Guardianship of L.W.)*, 482 N.W.2d 60, 78 (Wis. 1992).

33. See *Id.* at 69-73; *In re K.I.*, 735 A.2d 448, 460 (D.C. 1999); *Dir. of Newark Developmental Ctr. v. Dillion (In re Storar)*, 420 N.E.2d 64, 72 (N.Y. 1981)

34. *In re Guardianship of Eberhardy*, 307 N.W.2d 881, 893 (Wis. 1981); *In re Moe*, 432 N.E.2d 712, 724 (Mass. 1982) (Nolan, J., dissenting); *In re Susan S.*, No. 7764, 1996 WL 75343, at *1 (Del. Ch. Feb. 8, 1996).

35. *Curran v. Bosze*, 566 N.E.2d 1319, 1326 (Ill. 1990).

Others go beyond the apparent illogic of ascribing autonomy-based rights to never competent persons and criticize surrogate decision-making on behalf of profoundly disabled persons because of the potential for abuse.³⁶ The perceived hazards are several. Roger Dworkin noted that surrogate decision-makers might act according to utilitarian concerns (i.e., the interests of society or surrounding persons) rather than the disabled patient's interests.³⁷ Others, including advocates for the disabled, fear that surrogates base their substituted judgment on prejudice and stereotypical views of the quality of a disabled person's life.³⁸ These critics express concerns with imputing indeterminate feelings or preferences to the profoundly disabled.³⁹ The Nazis, for example, justified euthanasia by claiming it to be in the interests of the euthanized and to be what the victims would have wanted if they could have expressed their wishes.⁴⁰

Saying that the profoundly disabled cannot enjoy the "same right" as the decisionally-capacitated does not mean that they have no constitutional rights or even no liberty-based constitutional rights. Liberty in the sense of autonomous choice is not the only aspect of liberty important to profoundly disabled persons. Even a constitutional prerogative that normally involves autonomous choice has constitutionally cognizable elements highly relevant to a profoundly disabled person. Take the right to refuse medical intervention as an illustration. That right, a protected liberty under the Fourteenth Amendment,⁴¹ has at least three components: (1) an interest in self-determination (i.e., in making a choice about treatment); (2) an interest

36. See Aaron N. Krupp, *Health Care Surrogate Statutes: Ethics Pitfalls Threaten the Interests of Incompetent Patients*, 101 W. VA. L. REV. 99, 100 (1998); Carl E. Schneider, *Rights Discourse and Neonatal Euthanasia*, 76 CALIF. L. REV. 151, 175 (1988); Lois L. Shepard, *Dignity and Autonomy after Washington v. Glucksberg: An Essay about Abortion, Death, and Crime*, 7 CORNELL J.L. & PUB. POL'Y 431, 448 (1998).

37. ROGER B. DWORIN, *LIMITS: THE ROLE OF THE LAW IN BIOETHICAL DECISION MAKING* 117 (1996). See also Lynn E. Lebit, *Compelled Medical Procedures Involving Minors and Incompetents and Misapplication of the Substituted Judgment Doctrine*, 7 J.L. & HEALTH 107, 124-27 (1993).

38. See Monroe E. Price & Robert A. Burt, *Nonconsensual Medical Procedures and the Right to Privacy*, in *THE MENTALLY RETARDED CITIZEN AND THE LAW 95-96* (Michael Kindred et al. eds., 1976) [hereinafter Price & Burt, *Nonconsensual Medical Procedures*]; Walter M. Weber, *Substituted Judgment Doctrine: A Critical Analysis*, 1 ISSUES IN L. & MED. 131, 152-53 (1985).

39. Schneider, *supra* note 36, at 159; Shepard, *supra* note 36, at 440; Lois L. Shepard, *Face to Face: A Call for Radical Responsibility in Place of Compassion*, 77 ST. JOHN'S L. REV. 445, 454 (2003).

40. Shepard, *supra* note 39, at 450.

41. See *Cruzan v. Dir., Missouri Dep't of Health*, 497 U.S. 261, 278 (1990); *Washington v. Glucksberg*, 521 U.S. 702, 720 (1997); *In re Cincinnati Radiation Litigation*, 874 F. Supp. 796, 816 (S.D. Ohio 1995) ("[T]he right to self-determination in matters of personal health is deeply rooted in our constitutional tradition.").

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). While a profoundly disabled person cannot exercise the self-determination component, the other two personal interests underlying a right to reject treatment—well-being and bodily integrity—are still present. And while a surrogate cannot exercise a profoundly disabled person's self-determination, a surrogate can meaningfully implement the other two elements within the right to refuse treatment. 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.

The same analysis applies to abortion and sterilization decisions. That is, never-competent persons have important potential interests (bodily integrity, physical well-being, and procreative capacity) in these medical options even if self-determination is impossible. To quote one case: "[t]he interests of the incompetent which mandate recognition of procreative choice as an aspect of the fundamental right to . . . liberty do not differ from the interests of women able to give voluntary consent to [sterilization]."⁴²

This reasoning helps explain the Massachusetts Supreme Judicial Court's opinion in *Saikewicz* according "the same panoply of rights and choices" to a sixty-seven year-old adult who had the mentality of a three year-old as to a competent person.⁴³ The court erred in its invocation of substituted judgment, since Mr. Saikewicz had never been able to make a considered judgment, and it erred in according Mr. Saikewicz the "same" right to choose as a competent person, since Mr. Saikewicz was never able to exercise self-determination.⁴⁴ Nevertheless, the court was correct in its holding. Permitting a surrogate to choose whether to initiate life-sustaining treatment was integral to respecting the "dignity and worth" of the profoundly disabled Joseph Saikewicz.⁴⁵ Mr. Saikewicz's constitutional interests in bodily integrity, avoidance of suffering, and well-being could only receive due consideration through his surrogate. By permitting

42. *Conservatorship of Valerie N.*, 707 P.2d 760, 772 (Cal. 1985). See also *Wentzel v. Montgomery Gen. Hosp.*, 447 A.2d 1244, 1258 (Md. App. 1981) (stating that a person's inability to make a meaningful choice between sterilization, contraception or procreation because of a mental impairment does not forfeit that person's constitutional right to make a choice).

43. *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 428 (Mass. 1977).

44. *Id.*

45. *Id.* at 435. See also *Brophy v. New Eng. Sinai Hosp.*, 497 N.E.2d 626, 634-35 (Mass. 1986).

surrogate choice regarding potentially beneficial medical options, a never-competent person has access to important constitutional benefits available to other persons.

In some instances, a person's well-being is promoted by being allowed to die. For instance, when proffered treatment will only prolong a dying process dominated by suffering or by extreme deterioration, a person's well-being may be best served by no treatment at all.⁴⁶ Under these scenarios, the categorical exclusion of surrogate choice prejudices the well-being interest of the patient.⁴⁷ The same phenomenon occurs when a medically indicated abortion or sterilization is at issue. That is, a state prohibition on surrogate consent to sterilization can seriously prejudice the well-being of a mentally disabled person whose physical condition would be jeopardized by pregnancy and/or childbirth.

The categorical exclusion of surrogate choice jeopardizes a profoundly disabled person's human dignity interests. This can occur in at least two ways. First, the exclusion of surrogate choice may leave the patient to linger in an intrinsically undignified state, the passive object of bodily invasions and manipulations, as in the case of permanent unconsciousness.⁴⁸ That specter of a demeaning limbo prompted a Florida court to declare that "terminally ill incompetent persons . . . have the same right to refuse to be held on the threshold of death as terminally ill competent persons."⁴⁹ A profoundly disabled, dying person may not have the capacity to personally refuse further life support, but that person surely has an interest in avoiding an undignified death. Second, denying a profoundly disabled patient access to the same range of potentially beneficial medical options as would be enjoyed by a competent patient denies the disabled patient's equal status with other persons and thereby offends that patient's dignitary interest in equal treatment.⁵⁰ In *Saikewicz*, the Massachusetts Supreme Judicial Court observed that: "[t]o presume that the incompetent person must always be subjected to what many rational and intelligent persons may decline is to downgrade the status of incompetent

46. See, e.g., *Lenz v. L.E. Phillips Career Dev. Ctr. (In re Guardianship of L.W.)*, 482 N.W.2d 60, 74 (Wis. 1992); *In re Moorhouse*, 593 A.2d 1256, 1259 (N.J. Super. Ct. App. Div. 1991); *Orange County Soc. Servs. Agency v. Moises I. (In re Christopher I.)*, 131 Cal. Rptr. 2d 122, 134 (Cal. Ct. App. 2003) (citing CAL. PROB. CODE § 4650, subd. (b)); *Truselo v. Truselo*, 2000 WL 33324536, at *16 (Del. Fam. Ct. 2000).

47. *L.W.*, 482 N.W.2d at 67-68.

48. See e.g., *L.W.*, 482 N.W.2d at 68; *Moorhouse*, 593 A.2d at 1259; *Christopher I.*, 131 Cal. Rptr. 2d at 134; *Truselo*, 2000 WL 33324536 at 14.

49. *John F. Kennedy Mem'l Hosp. v. Bludworth*, 452 So.2d 921, 923 (Fla. 1984). See also *In re Schiavo*, 851 So. 2d 182 (Fla. App. 2003).

50. *Saikewicz*, 370 N.E.2d at 428.

persons by placing a lesser value on his [or her] intrinsic human worth and vitality.”⁵¹ Years later, that court made a similar observation about indignity in the context of sterilization and stated “[t]o deny this right [of sterilization] to persons who are incapable of exercising it personally is to degrade those whose disabilities make them wholly reliant on other, more fortunate, individuals.”⁵²

The story of Sheila Pouliot illustrates how a state’s preclusion of surrogate choice can implicate human dignity.⁵³ Ms. Pouliot was a forty-two year-old woman who was severely disabled after childhood mumps, which resulted in mental retardation and cerebral palsy.⁵⁴ Ms. Pouliot was partially blind, bed bound and had lived with her family for many years, but at the age of twenty she moved into a New York State facility for the developmentally disabled.⁵⁵ In the months preceding her last hospitalization, she had suffered recurrent episodes of gastroesophageal reflux disease, aspiration pneumonia, and gastrointestinal bleeding. On December 21, 1999, Ms. Pouliot was admitted to University Hospital in Syracuse, New York, suffering from aspiration pneumonia, gastrointestinal bleeding, and an acute abdomen manifested by severe abdominal pain and a non-functioning intestine.⁵⁶

Alice Pouliot Blouin, Sheila Pouliot’s sister, served as the representative of Ms. Pouliot and her family. In conjunction with the hospital’s medical staff, Ms. Blouin determined that Ms. Pouliot was unavoidably dying, and that further medical intervention, including artificial nutrition and hydration (ANH), would only prolong Ms. Pouliot’s dying process.⁵⁷ The hospital ethics committee concurred. Fentanyl and morphine were prescribed for Ms. Pouliot’s abdominal pain and for secondary pain resulting from various muscle contractures and dislocated joints.⁵⁸

That medical course was followed for several days until the state’s Attorney General’s Office intervened. The Attorney General insisted that New York law would not permit removal of ANH from a patient in the

51. *Id.*

52. *In re Moe*, 432 N.E.2d 712, 720 (Mass. 1982) (quoting *In re Guardianship of Roe*, 421 N.E.2d 40, 51 (Mass. 1981)).

53. *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 194 (N.D.N.Y. 2002).

54. *Id.* at 186. See also “Sheila Pouliot’s Story,” a summary prepared by her physician, Kathy Faber-Langendoen, M.D., available at <http://www.familydecisions.org/pouliot.html> (last visited Nov. 25, 2003) [hereinafter Faber-Langendoen, *Sheila’s Story*].

55. *Blouin*, 213 F. Supp. 2d at 186.

56. *Id.* See also Faber-Langendoen, *Sheila’s Story*, *supra* note 54 and affidavit of Dr. Kathleen McGrail, part of the record in *Blouin*.

57. *Blouin*, 213 F. Supp. 2d at 186.

58. See *id.* Faber-Langendoen, *Sheila’s Story*, *supra* note 54.

absence of prior instructions that clearly expressed the patient's desire to forgo life-extending treatment.⁵⁹ Ms. Pouliot, never mentally capable of making such instructions could never meet New York's standard. In the wake of the Attorney General's intervention, the physicians renewed artificial nutrition and hydration.⁶⁰ For the next seven weeks, Ms. Pouliot lingered, unable to relate to her environment and occasionally moaning, crying, and grimacing from pain. She developed massive edema and her skin began to break down in areas surrounding the intravenous hydration support.⁶¹ Finally, on March 3rd the family and medical staff secured a court order permitting removal of all life support; intravenous hydration was removed and Ms. Pouliot died shortly thereafter.⁶² Her course of dying was inconsistent with both medical standards of palliative care and with humane and compassionate care.⁶³ That course of dying, supposedly required by New York law precluding surrogate removal of ANH from a never-competent person, deprived Sheila Pouliot of intrinsic human dignity.

II. A CONSTITUTIONAL CLAIM TO APPROPRIATE MEDICAL OPTIONS

The connection between surrogate choice (regarding important medical issues) and intrinsic human dignity is clear. Do an incapacitated person's well-being and dignity interests tied to medical options rise to a constitutional plane? Could a profoundly disabled person be constitutionally entitled to a surrogate medical decision? The United States Supreme Court has acknowledged a connection between constitutional liberty and surrogate decision-making on behalf of mentally disabled persons. In 1988, the Court noted, in a case unrelated to medical treatment, that the rights of incapacitated persons sometimes are "only meaningful as they are exercised by agents acting with the best interests of their principals in mind."⁶⁴ This quotation implies that a surrogate, acting in the best interests of the patient, should be able to consider the patient's well being, bodily integrity, and dignity interests which partially underlie the patient's constitutional liberty right.

Other sources have recognized the important interests of incapacitated persons in securing needed medical options.⁶⁵ Courts considering end-of-

59. *Blouin*, 213 F. Supp. 2d at 186.

60. *Id.*

61. Faber-Langendoen, *Sheila's Story*, *supra* note 54.

62. *Blouin*, 213 F. Supp. 2d at 187.

63. Affidavit of Dr. Kathleen McGrail, a palliative care expert, in litigation of Ms. Pouliot's estate.

64. *Thompson v. Oklahoma*, 487 U.S. 815, 825 n.23 (1988).

65. *E.g.*, Mary Ann Buckley, Note, *In re Wendland: Contradiction, Confusion, and*

life treatment for the profoundly disabled have sometimes noted that while self-determination or free choice is not relevant to lifelong disabled persons, surrogate choice can prevent such persons from being “stripped of basic rights” or from being rendered “passive subjects of medical technology.”⁶⁶ Surrogate decision-making that employs a “best interests” standard would ensure that a profoundly disabled person would receive the benefit of a reasoned choice. By weighing potential benefits and pitfalls of medical treatment and procedures, a surrogate would preserve and protect the profoundly disabled person’s constitutionally based interests, in well-being, bodily integrity and dignity.

Most courts that have addressed surrogate decision-making allow a surrogate to make end-of-life medical decisions on behalf of a profoundly disabled person in the disabled person’s “best interests.”⁶⁷ Even courts that articulate a substituted judgment standard—a standard that purports to replicate what the incompetent patient would decide—tend to modify that approach in its application to profoundly disabled persons.⁶⁸ In 1992, the Massachusetts Supreme Judicial Court (the court that had decided *Saikewicz* in 1976) recognized that substituted judgment is “a legal fiction” as applied to a never-competent person. The court, however, retained substituted judgment in an effort to vindicate the patient’s “liberty interests,” which included the rejection of treatment.⁶⁹

As applied to a profoundly disabled person, the substituted judgment standard is inevitably transformed into a best interests approach.⁷⁰ That transformation, for instance, occurred in *Saikewicz*. The Massachusetts Supreme Judicial Court ended up deciding Mr. Saikewicz’s medical fate essentially under a best interests analysis by emphasizing factors such as the

Constitutionality, 11 J.L. & POL’Y 255, 311 (2002); Marybeth Herald, *Until Life Support Do Us Part: A Spouse’s Limited Ability to Terminate Life Support for an Incompetent Spouse with No Hope of Recovery*, 24 T. JEFFERSON L. REV. 207, 213-14 (2002).

66. *Lenz v. L.E. Phillips Career Dev. Ctr. (In re Guardianship of L.W.)*, 482 N.W.2d 60, 68-69, 76 (Wis. 1992). See also *Gray v. Romeo*, 697 F. Supp. 580, 587 (D. R.I. 1988); *Eichner v. Dillon (In re Joseph Charles Fox)*, 426 N.Y.S.2d 517, 542-43 (N.Y. App. Div. 1980); William A. Kraus, *The Incompetent Developmentally Disabled Person’s Right of Self-Determination: Right-to-Die, Sterilization, and Institutionalization*, 15 AM. J.L. & MED. 333, 350 (1989).

67. See *In re Guardianship of Grant*, 747 P.2d 445, 457 (Wash. 1987); *In re L.H.R.*, 321 S.E.2d 716, 723 (Ga. 1984); *In re Conservatorship of Torres*, 357 N.W.2d 332, 337 (Minn. 1984); *In re AB*, 2003 N.Y. slip op. 23664, 2003 WL 21649677, at *4-5 (N.Y. Sup. Ct. May 16, 2003).

68. See *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 430-32 (Mass. 1977); *Strunk v. Strunk*, 445 S.W.2d 145, 149 (Ky. 1969).

69. *Guardianship of Jane Doe*, 583 N.E.2d 1263, 1267-68 (Mass. 1992).

70. See *In re Grady*, 426 A.2d 467, 482 (N.J. 1981); *Strunk*, 445 S.W.2d at 149; *Saikewicz*, 370 N.E.2d at 430.

prospective impact of pain and anxiety and the severe side effects of drugs on Mr. Saikewicz.⁷¹ In a similar context, dealing with the medical fate of a small child stricken with leukemia, the Massachusetts court recognized that substituted judgment and best interests standards are “essentially coextensive.”⁷²

A similar melding or blending of the substituted judgment and best interests standards is evident in other cases involving profoundly disabled persons. In a case considering sterilization of a profoundly disabled woman, the New Jersey Supreme Court first considered the substituted judgment approach, as adopted by the trial court.⁷³ Alternatively, the court articulated and applied a formula dedicating careful attention to the elements comprising the best interests of the patient.⁷⁴ One Justice of the court called this a best interests analysis “cloaked in a substituted-judgment formulation.”⁷⁵ A similar melding of substituted judgment with best interests occurred in at least one case involving a kidney transplant from a profoundly disabled person to a desperately ill sibling.⁷⁶

This melding of substituted judgment into best interests is natural in light of the previously mentioned illogic of using substituted judgment to replicate the decisions of persons who have always lacked capacity to make autonomous decisions. As Joel Feinberg has noted, a profoundly disabled person with the mental function of a small child cannot grasp the concepts of continued existence and death necessary to form a judgment or preference regarding life-sustaining medical intervention.⁷⁷ The best that can be done for the patient is to allow a conscientious surrogate to consider and weigh the incapacitated patient’s interests such as pleasure, satisfaction, and pain. While a profoundly disabled person, lacking autonomy, cannot have the same “rights” as a capacitated person, that person retains important constitutionally grounded interests (such as well-being and dignity) that deserve respect even if the disabled person cannot decide when and how to advance those interests. This raises the issue of whether a profoundly

71. *Saikewicz*, 370 N.E.2d at 430-33.

72. *Custody of A Minor*, 393 N.E.2d 836, 844 (Mass. 1979).

73. *Grady*, 426 A.2d at 480.

74. *Id.* at 481-84. See also *Harbin v. W.S. & P.S. (In re P.S.)*, 452 N.E.2d 969, 974-76 (Ind. 1983); *Harmon*, *supra* note 31, at 48-49.

75. Alan B. Handler, *Individual Worth*, 17 HOFSTRA L. REV. 493, 513-14 (1989). See also Stuart Pollock, *Life and Death Decisions: Who Makes Them and by What Standard?*, 41 RUTGERS L. REV. 505, 525-30 (1989).

76. *Strunk*, 445 S.W.2d 148-49. See also David S. Lockemeyer, *At What Cost Will the Court Impose a Duty to Preserve the Life of a Child?*, 39 CLEV. ST. L. REV. 577, 586 (1991) (noting the judicial melding of substituted judgment and best interests in the context of decisions affecting small children).

77. JOEL FEINBERG, *FREEDOM AND FULFILLMENT* 20-23 (1992).

disabled person has a constitutional right to have a surrogate exercise the disabled person's liberty interests.

III. A CONSTITUTIONAL RIGHT TO SOME SURROGATE DECISION ON BEHALF OF THE DISABLED PERSON?

In 1981, John Garvey argued in the *Harvard Law Review* that decisionally-incapacitated persons should be accorded a constitutional right to have important medical decisions made on their behalf by bonded surrogates.⁷⁸ Mr. Garvey contended that the incapacitated have a cognizable liberty interest in beneficial treatment in various medical contexts and that such an interest can only be implemented by allowing surrogate choice.⁷⁹ According to Mr. Garvey, states should be foreclosed from interfering with decisions by surrogates who have caring ties to the incapacitated patient so long as the surrogate is acting consistently with the interests of the patient.⁸⁰ Parents or other closely connected surrogates would be entitled to make decisions as to appropriate treatment and those decisions could not be displaced unless demonstrably contrary to the patient's interests.⁸¹

Other commentators⁸² and courts,⁸³ however, have a different perspective on surrogate decision-making for the profoundly disabled. They view the profoundly disabled as vulnerable and subject to arbitrary and abusive manipulation in medical decision-making even by surrogates with close family ties to the patient. Even bonded surrogates, according to these critics, have significant conflicts of interest when it comes to critical, end-of-life medical decisions. For example, if the issue is life-sustaining medical intervention, a family may be under considerable stress from the actual or prospective burden of caring for a severely handicapped person. If the issue is sterilization, the potential burden of caring for potentially handicapped offspring may influence the family.

Advocates for disabled persons also fear that surrogate decision-making may be based on prejudices against the disabled. According to that view,

78. John H. Garvey, *Freedom and Choice in Constitutional Law*, 94 HARV. L. REV. 1756, 1777-78, 1782-83, 1791-94 (1981).

79. *Id.* at 1778.

80. *Id.* at 1784.

81. *Id.*

82. See, e.g., Martha A. Field, *Killing "The Handicapped"—Before and After Birth*, 16 HARV. WOMEN'S L.J. 79, 95 (1993); Martha Minow, *Interpreting Rights: An Essay for Robert Cover*, 96 YALE L.J. 1860, 1888-90 (1987); Schneider, *supra* note 36, at 175; Shepherd, *supra* note 36, at 455.

83. See, e.g., Keiner v. Cmty. Convalescent Ctr. (*In re Estate of Longeway*), 549 N.E.2d 292, 306 (Ill. 1989) (Ward, J., dissenting); *In re Brophy*, 497 N.E. 2d 626, 645-46 (Mass. 1986) (Nolan, J., dissenting).

the surrogate may underestimate the disabled person's quality of life and make end-of-life decisions based on social and personal stereotypes.⁸⁴ Because of the perceived hazards of exploitation of vulnerable populations like the profoundly disabled, certain advocates would foreclose whole categories of decisions—such as removal of life support or sterilization—from the hands of surrogate decision-makers.⁸⁵

Can Mr. Garvey's argument that an incapacitated person has a constitutional right to a surrogate decision prevail in the face of these concerns by advocates for the disabled? Is a state constitutionally compelled to allow a surrogate to assess and exercise a profoundly disabled person's interests in important medical issues? May a state foreclose surrogate decision-making in potentially hazardous subject areas such as end-of-life care and sterilization?

Apprehensions about sterilization are most understandable in light of its long and checkered history. Between 1900 and 1930, the eugenics movement peaked in the United States. Concerned with improving the hereditary quality of future generations, eugenics advocates influenced state legislatures to pass involuntary sterilization laws that primarily targeted the "feebleminded" residents of state institutions.⁸⁶ In 1907, Indiana was the first state to adopt such laws. By 1940, approximately thirty-two states followed suit.⁸⁷ By preventing "feebleminded" persons from procreating, the states supposedly protected society from supporting potentially handicapped offspring whose dependency and antisocial behaviors would burden the state.⁸⁸ Preventing misery and suffering to prospective offspring

84. Field, *supra* note 82, at 89; Price & Burt, *Nonconsensual Medical Procedures*, *supra* note 38, at 93.

85. See *Guardianship of Jane Doe*, 583 N.E.2d 1263, 1272 (Mass. 1992) (Nolan, J., dissenting):

The possibilities that [the patient] wishes to terminate the provision of food and water is no more likely than the possibility that she fears this action and hopes, in her helpless state, that society will continue to meet her basic needs. Given this reality, where lies the logic, moral and ethical justification for depriving her of food and water?

See also *In re Finn*, 625 N.Y.S.2d 809, 811 (N.Y. Sup. Ct. 1995). The federal government has sought to limit medical decision-making for handicapped newborns. In 1984, HHS adopted the famous "Baby Doe" regulations seeking to limit circumstances in which life support is withheld from severely stricken infants. The regulations required states to institute systems to respond to any reports of newborns being denied medical treatment. Those regulations were invalidated in *Bowen v. American Hospital Ass'n.*, 476 U.S. 610 (1986), but newer regulations exist.

86. Elizabeth S. Scott, *Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy*, 1986 DUKE L. J. 806, 809-813 (1986).

87. JONAS B. ROBITSCHER, EUGENIC STERILIZATION 9-14 (Jonas Robitscher & Charles C. Thomas eds., 1973).

88. *Id.* at 4.

was another rationale for the legislation, under the assumption that feeble-minded parents could not adequately rear children.⁸⁹ By imposing sterilization, the laws also supposedly promoted the well-being of the “feeble-minded” who might have thrived without the burdens of parenthood.

While some state courts invalidated local involuntary sterilization statutes, the U.S. Supreme Court upheld a Virginia sterilization statute in 1927.⁹⁰ Thereafter, sterilization statutes survived constitutional attack in many states, a few as late as the 1970s.⁹¹ As many as 60,000 people were involuntarily sterilized during the first half of the twentieth century.⁹²

By the second half of the twentieth century, the attitude toward compulsory sterilization had dramatically changed. The scientific underpinnings of the eugenics movement were in disrepute.⁹³ The perception had grown that any effort to sterilize in wholesale fashion the institutionalized mentally retarded was grounded in prejudice and stereotyped images of sexual predators or creatures with uncontrolled sexual appetites.⁹⁴ Commentators cast doubt on the constitutional viability of non-voluntary sterilization laws both because of evolving Supreme Court jurisprudence protecting procreational choice and because of the “potential for social oppression and invidious discrimination” embodied in such laws.⁹⁵ Many of the statutes providing for compulsory sterilization had lapsed, been repealed, or fallen into disuse by the 1950s.

The central issue in the 1960s and 1970s became whether courts had inherent jurisdiction to authorize parents or other guardians to consent to sterilization on behalf of profoundly disabled persons. During that period, the predominant judicial response was negative—a series of rulings that the courts lacked authority to authorize such operations, at least in the absence of enabling legislation.⁹⁶ These courts had a lingering revulsion toward the

89. *Id.* at 10-12.

90. *Buck v. Bell*, 274 U.S. 200 (1927).

91. *See* N. C. Ass'n For Retarded Children v. North Carolina, 420 F. Supp. 451, 457-58 (M.D. N.C. 1976); *Cook v. Or.*, 495 P.2d 768, 771-72 (Or. Ct. App. 1972); Erika T. Blum, *When Terminating Parental Rights is Not Enough: A New Look at Compulsory Sterilization*, 28 GA. L. REV. 977, 989, 1000-05 (1994). *See also In re Simpson*, 180 N.E.2d 206, 208 (Ohio Law Abs. 1962).

92. Price & Burt, *Nonconsensual Medical Procedures*, *supra* note 38, at 97.

93. Donald Giannella, *Eugenic Sterilization and the Law*, in *EUGENIC STERILIZATION* 74-75 (Jonas Robitscher & Charles C. Thomas eds., 1973).

94. Price & Burt, *Nonconsensual Medical Procedures*, *supra* note 38, at 97-98.

95. Giannella, *supra* note 93, at 73, 75.

96. *See Hudson v. Hudson*, 373 So.2d 310, 312 (Ala. 1979); *In re M.K.R.*, 515 S.W.2d 467, 471 (Mo. 1974); *Frazier v. Levi*, 440 S.W.2d 393, 395 (Tex. Ct. App. 1969); *Holmes v. Powers*, 439 S.W.2d 579, 580 (Ky. 1968); *In re D.D.*, 408 N.Y.S.2d 104, 105 (N.Y. App. Div. 1978); *A.L. v. G.R.H.*, 325 N.E.2d 501, 502 (Ind. App. 1975); Thomas R. Trenkner, Annotation, *Jurisdiction of Court to Permit Sterilization of Mentally Defective Person in*

period when large numbers of mentally retarded people had been involuntarily sterilized despite the shaky basis of the underlying eugenic theory and its shoddy application in practice.⁹⁷ By the late 1960s and early 1970s, procreation was well established as a fundamental aspect of liberty under the Fourteenth Amendment.⁹⁸ A number of courts therefore expressed special reluctance to authorize sterilization of a disabled person—a possible deprivation of a constitutional prerogative—even when the parents or guardian argued that sterilization would be in the patient's best interest.⁹⁹ Today, most of the states that had refused in the 1970s to find inherent jurisdiction to authorize sterilization of a mentally disabled person have changed their law; statutes now permit sterilization where a court finds that the surgery will serve the incapacitated person's best interests. Only one state appears to continue to exclude all surrogate authorization of sterilization.¹⁰⁰ This evolution in the jurisprudence of surrogate decision-making regarding sterilization leaves unresolved the question of the constitutionality of state prohibitions of surrogate consent to important medical matters such as sterilization.

A similar constitutional question can be raised about the severe restrictions that several states have imposed on surrogate decisions to withhold life-sustaining medical care from profoundly disabled persons.¹⁰¹ The first of several important court decisions restricting such surrogate decision-making was issued in a 1981 case before the New York Court of Appeals, *Soper v. Storar (In re Storar)*.¹⁰² The patient, John Storar, was a fifty-two year-old profoundly retarded man dying of bladder cancer.¹⁰³ His

Absence of Specific Statutory Authority, 74 A.L.R. 3d 1210, 1213 (1999). *But see In re Simpson*, 180 N.E.2d 206 (Ohio Law Abs. 1962); *Jessin v. Shasta*, 79 Cal. Rptr. 359 (Cal. Ct. App. 1969).

97. Questions existed not only about the heritability of conditions, but whether the patients actually had the suspect conditions. For example, research indicates that Carrie Buck, the focus of *Buck v. Bell*, 274 U.S. 200 (1927), was not in fact mentally handicapped. See Roberta M. Berry, *From Involuntary Sterilization to Genetic Enhancement: The Unsettled Legacy of Buck v. Bell*, 12 NOTRE DAME J.L. ETHICS & PUB. POL'Y 401, 420-21 (1998).

98. *Eisenstadt v. Baird*, 405 U.S. 438, 453 (1972).

99. *In re M.K.R.*, 515 S.W.2d 467 (Mo. 1974).

100. MARTHA A. FIELD & VALERIE A. SANCHEZ, EQUAL TREATMENT FOR PEOPLE WITH MENTAL RETARDATION: HAVING AND RAISING CHILDREN 87 (1999).

101. See *Wendland v. Wendland (Conservatorship of Wendland)*, 28 P.3d 152, 175 (Cal. 2001); *DeGrella v. Elston*, 858 S.W.2d 698, 706 (Ky. 1993); *Martin v. Martin (In re Martin)*, 538 N.W.2d 399, 410 (Mich. 1999); *Cruzan v. Harmon*, 760 S.W.2d 408, 427 (Mo. 1988); *In re Westchester County Medical Center*, 531 N.E.2d 607, 615 (N.Y. 1988); *Spahn v. Eisenberg (Guardianship of Edna M.F.)*, 543 N.W.2d 485, 491-92 (Wis. 1997).

102. *Soper v. Storar (In re Storar)*, 420 N.E.2d 64, 72-73 (N.Y. 1981).

103. *Id.* at 66.

mother, who had been appointed his legal guardian, opposed continuation of blood transfusions because they caused Storar extreme pain and discomfort.¹⁰⁴ The court refused to defer to the mother's decision to cease treatment. The court was reluctant to endorse an end to life-sustaining care absent the patient's choice, and thus ordered treatment to continue contrary to the determination of Storar's mother.¹⁰⁵

The New York courts again applied a restrictive approach in 1988.¹⁰⁶ The patient, Mary O'Connor, was a seventy-seven year-old woman who had suffered a series of devastating strokes leaving her totally helpless and barely conscious, unable to recognize and relate to her surrounding loved ones or caretakers.¹⁰⁷ Her daughters opposed installation of tubes providing artificial nutrition and hydration, arguing that this formerly vital woman would never have wanted to be maintained in this totally debilitated status.¹⁰⁸ In support of their opposition, O'Connor's daughters testified to statements that O'Connor had made indicating her desire not to be "sustained artificially . . . if she could not take care of herself and make her own decisions."¹⁰⁹ Nonetheless the court ruled against the daughters.¹¹⁰ According to Chief Judge Saul Wachtler, writing for the court, it would be "unacceptable" to remove an incapacitated patient from life support without clear and convincing evidence that the patient had chosen such a course while still competent.¹¹¹ The court held that Mrs. O'Connor's statements had been too casually made to constitute clear and convincing evidence that she truly would have wanted life support removed under the circumstances.¹¹² As a matter of policy, the court seemed motivated by one primary concern: the potential that unfettered surrogate discretion would result in the abuse or exploitation of incapacitated patients unable to articulate their needs or desires.¹¹³ Judge Wachtler asserted that "no person or court should substitute its judgment as to what would be an acceptable quality of life for another."¹¹⁴

Since 1988, several other state courts have joined New York in demanding clear and convincing evidence of the incapacitated patient's

104. *Id.*

105. *Id.* at 72-73.

106. *In re Westchester Medical Center*, 531 N.E.2d 607, 615 (N.Y. 1988).

107. *Id.* at 608-09.

108. *Id.* at 611.

109. *Id.*

110. *Id.* at 613.

111. *Id.*

112. *In re Westchester Med. Ctr.*, 531 N.E.2d at 614.

113. *Id.*

114. *Id.* at 613.

prior preferences before allowing withdrawal of life-sustaining medical intervention.¹¹⁵ While a few of these courts have attenuated the impact of this more restrictive approach by limiting its application only to conscious patients,¹¹⁶ the impact is nevertheless devastating, particularly to conscious patients who have always been profoundly disabled and have thus never been capable of expressing a preference as to medical treatment. These patients risk having their interests ignored under a standard predicated entirely on the existence or non-existence of prior expressions.

The consequences of this restrictive approach to end-of-life care will be addressed *infra*. Note, however, that a restrictive approach to terminal decisions raises a constitutional issue similar to that raised by the exclusion of sterilization from surrogate decision-making. Does wholesale exclusion of a subject matter from surrogate decision-making violate a profoundly disabled person's liberty interest when the person stands to benefit from the surrogate's decision?

A series of cases decided through the 1980s, in the contexts of both end-of-life and sterilization decisions, support the notion that a decisionally-incapacitated person has a constitutional right to have a surrogate choose medical treatment. Recall that in 1977 the *Saikewicz* court held that a dying, profoundly disabled cancer patient should have the "same panoply of rights and choices" as an autonomous patient.¹¹⁷ That idea flourished in the 1980s, signaling a possible evolution in patient-choice jurisprudence. One of the first steps in this evolution was *In re Grady*, a sterilization case decided by the New Jersey Supreme Court in 1981.¹¹⁸ Lee Ann Grady was a nineteen-year-old who was so severely mentally impaired by Down's syndrome that she could not understand pregnancy and would never be able to care for a child.¹¹⁹ Ms. Grady's parents sought judicial approval of sterilization, arguing that her best interests would be served by affording her permanent

115. See *Wendland v. Wendland* (Conservatorship of Wendland), 28 P.3d 152, 175 (Cal. 2001); *DeGrella v. Elston*, 858 S.W.2d 698, 706 (Ky. 1993); *Mack v. Mack*, 618 A.2d 744, 753 (Md. 1993); *Martin v. Martin* (*In re Martin*), 538 N.W.2d 399, 410 (Mich. 1999); *Cruzan v. Harmon*, 760 S.W.2d 408, 427 (Mo. 1988); *Spahn v. Eisenberg* (Guardianship of Edna M.F.), 543 N.W.2d 485, 491-92 (Wis. 1997).

116. *Spahn v. Eisenberg* (Guardianship of Edna M.F.), 543 N.W.2d 485, 491-92 (Wis. 1997); *Martin v. Martin* (*In re Martin*), 538 N.W.2d 399, 410 (Mich. 1999).

117. *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 428 (Mass. 1976).

118. *In re Grady*, 426 A.2d 467, 475 (N.J. 1981). Earlier cases had upheld the jurisdiction of courts to authorize sterilizations sought by parents and guardians on behalf of profoundly disabled charges. *Ruby v. Massey*, 452 F. Supp. 361, 368 (D. Conn. 1978); *In re Sallmaier*, 378 N.Y.S.2d 989, 991 (N.Y. Sup. Ct. 1976); *In re Simpson*, 180 N.E.2d 206, 208 (Ohio Prob. Ct. 1962). However, *Grady* became particularly influential, in part because of the court's carefully considered analysis.

119. *Grady*, 426 A.2d at 469-70.

and reliable birth control allowing her to move from her family home into an adult group home without any concerns about inadvertent pregnancy.¹²⁰ Writing for the Court, Justice Morris Pashman presented the issue as how to “preserve the personal freedom of one incapable of exercising it by allowing others to make a profoundly personal decision on her behalf.”¹²¹ Justice Pashman understood that Ms. Grady could never exercise autonomous choice, but that her freedom to have a surrogate make a beneficial choice on her behalf was critical both to Ms. Grady’s well-being and her constitutional interests.¹²² He recognized that Ms. Grady had two interconnected liberty interests, a right to procreate and a right not to procreate,¹²³ and observed that a competent person has a constitutional right to choose between the two options in pursuit of her well-being.¹²⁴ To Justice Pashman, a disabled person’s inability to choose for herself “should not result in the forfeit of this constitutional interest [procreating or not procreating] or of the effective protection of her ‘best interests’.”¹²⁵ Thus, the court recognized surrogate choice as the only way to assure Ms. Grady of the benefits of a considered decision about her reproductive future and her well-being.¹²⁶ The court ruled: “When an incompetent person lacks the mental capacity to make that choice [regarding sterilization] a court should ensure the exercise of that right [liberty to procreate or not to procreate] on behalf of the incompetent in a manner that reflects his or her best interests.”¹²⁷ Thus, the court adopted the best interests standard on the assumption that a never-competent person would want to have her interests protected by a surrogate making appropriate medical decisions on her behalf:

We do not pretend that the choice of [Lee Ann’s] parents, her guardian ad litem or a court is her own choice. But it is a genuine choice nonetheless—one designed to further the same interests she might pursue had she the ability to decide herself. We believe that having the choice

120. *Id.* at 470.

121. *Id.* at 469.

122. *Id.* at 481.

123. *Id.* at 475. Sterilization is just one instance in which a medical choice implicates fundamental constitutional interests, however the choice is exercised. Just as a decision to submit to sterilization promotes one constitutional interest (non-procreation) while sacrificing another (procreation), a decision to choose heart surgery promotes one interest (life) while sacrificing another (the right to reject life-sustaining treatment and thus to preserve bodily integrity).

124. *Id.* at 474.

125. *Grady*, 426 A.2d at 474.

126. *Id.* at 480-81.

127. *Id.* at 475.

made on her behalf produces a more just and compassionate result than leaving Lee Ann with no way of exercising a constitutional right.¹²⁸

The Court also dictated safeguards aimed at preventing exploitation by the surrogate decision-maker.¹²⁹

Several courts adopted the view articulated in *Grady* that failure to permit surrogate choice regarding sterilization would deny a patient's constitutional right to reproductive choice and might seriously jeopardize a disabled patient's well being.¹³⁰ For example, just one year after *Grady* the Massachusetts Supreme Judicial Court held that equity courts have inherent authority to act in a mentally disabled person's best interests, including by authorizing sterilization.¹³¹ The opinion explained: "government deprives a mentally retarded individual of his or her [constitutional] right to privacy if it denies the person the opportunity to exercise that right [by means of a conscientious surrogate considering various means of contraception]."¹³²

Three years later the California Supreme Court used similar reasoning to strike down a statute that had prohibited conservators (guardians) from making sterilization decisions for mentally disabled people.¹³³ In *Mildred G. v. Valerie N. (Conservatorship of Valerie N.)*, the court held that the legislature's prohibition had deprived developmentally disabled persons of their fundamental liberty interest in procreative choice in violation of both the federal and state constitutions.¹³⁴ The court noted that what was at stake was not only the disabled person's constitutional interests, but also her practical interests in a procreative decision that would best promote her personal growth and development.¹³⁵ According to the majority opinion: "An incompetent developmentally disabled woman has no less interest in a satisfying or fulfilling life free from the burdens of an unwanted pregnancy

128. *Id.* at 481.

129. *Id.* at 482-83. These safeguards will be detailed and discussed *infra*.

130. See Edward J. Larson & Leonard J. Nelson, *Involuntary Sexual Sterilization of Incompetents in Alabama: Past, Present, & Future*, 43 ALA. L. REV. 399, 431 n.188 (1992) (listing cases). See also John Hackett, Note, *Procreative Choice for the Incompetent Developmentally Disabled: Conservatorship of Valerie N.*, 36 DEPAUL L. REV. 95, 102-03, 111 (1986). But see *Eberhardy v. Circuit Court for Wood County (In re Eberhardy)*, 307 N.W.2d 881, 899 (Wis. 1981) (finding no jurisdiction to authorize a guardian's choice of sterilization for a profoundly disabled ward).

131. *In re Moe*, 432 N.E.2d 712, 719 (Mass. 1982). See also *Wentzel v. Montgomery General Hospital*, 447 A.2d 1244, 1253 (Md. 1982).

132. *In re Moe*, 432 N.E.2d 712, 719 (Mass. 1982).

133. *Mildred G. v. Valerie N. (Conservatorship of Valerie N.)*, 707 P.2d 760, 777 (Cal. 1985).

134. *Id.* at 777.

135. *Id.* at 773.

than does her competent sister.”¹³⁶ In effect, the California Supreme Court found that a profoundly disabled person has a constitutional right to have a critically important medical decision made on her behalf.

A California appellate court employed similar reasoning in 1988 in the context of an end-of-life decision on behalf of an incompetent patient.¹³⁷ The patient, William Drabick, was, at the age of forty-four, mired in permanent unconsciousness as a result of severe brain damage suffered in an automobile accident several years earlier.¹³⁸ His brother as conservator (guardian) sought judicial approval to remove a life-sustaining feeding tube.¹³⁹ The appellate court ruled that Mr. Drabick had a right to have a surrogate decide whether to continue life support according to a standard that reflected Mr. Drabick’s interests.¹⁴⁰ The court acknowledged that Mr. Drabick had not made a conscious choice, and was incapable of doing so, therefore the invocation of a “right to choose” was a legal fiction.¹⁴¹ The court nevertheless held that Mr. Drabick’s interest in sound medical treatment decisions was so critical that it should not be vitiated by his incapacity to choose.¹⁴² The court explained: “It would be more accurate to say that incompetent patients retain the right to have appropriate medical decisions made on their behalf. An appropriate medical decision is one that is made in the patient’s best interests, as opposed to the interests of the hospital, the physician, the legal system, or someone else.”¹⁴³

Drabick was important because it furthered the propositions that surrogate choice reflecting the patient’s interests should prevail over the technological imperative to preserve life at all costs, and that upholding surrogate choice was a necessary extension of respect for persons.¹⁴⁴ The court sought to assure that all patients, both competent and incompetent,

136. *Id.*

137. *Drabick v. Drabick* (Conservatorship of Drabick), 245 Cal. Rptr. 840, 860-61 (Cal. Ct. App. 1988), *review denied*, July 28, 1988.

138. *Id.* at 842.

139. *Id.* at 842-43.

140. *Id.* at 855. *But see* *Wendland v. Wendland* (Conservatorship of Wendland), 28 P.3d 151, 162-63 (Cal. 2001) (approving the *Drabick* court’s holding that incompetent persons have a right to “medical decisions that reflect their own interests and values,” but noting that the right does not “equate with the conservatee’s right to refuse treatment”). The court interpreted a revised version of the statute under which *Drabick* had been decided, holding that a court was correct in refusing permission to withdraw life-sustaining nutrition where a conservator has not proven by clear and convincing evidence either that the conservatee wished to refuse nutrition or that withholding such nutrition was in the conservatee’s best interest.

141. *Drabick*, 245 Cal. Rptr. at 854.

142. *Id.* at 855.

143. *Id.* at 852.

144. *Id.* at 854-55.

would be allowed the exercise of treatment options that would advance their personal interests.¹⁴⁵ The court's equation of surrogate choice with respect for the individual drew on an important theme first articulated in *Saikewicz* in 1977 and reiterated in *Moe* and *Valerie N.*: governmental exclusion of a potentially beneficial medical option treats the incapacitated patient like an object whose feelings and emotions don't matter—a living organism that must be preserved no matter how much suffering and indignity might be entailed.¹⁴⁶ Protection of these critical interests—patient dignity and well-being—warrants recognition of a constitutional right to a surrogate decision when a mentally disabled person's critical medical interests are at stake. The saga of Sheila Pouliot illustrated the deplorable consequences of ignoring such a right.¹⁴⁷

In 1990, however, the Supreme Court effectively rejected the argument that a profoundly disabled person has a federal constitutional right to have critical medical decisions made by a surrogate acting according to the patient's interests.¹⁴⁸ In *Cruzan v. Missouri Department of Health*, the Court considered a challenge to Missouri's restrictive policy regarding end-of-life decision-making on behalf of incompetent patients. Twenty-nine year-old Nancy Cruzan had been involved in a catastrophic car accident that caused her severe brain damage and rendered her permanently unconscious.¹⁴⁹ Ms. Cruzan's parents sought a court order to end the artificial nutrition and hydration (ANH) sustaining their daughter.¹⁵⁰ The Supreme Court of Missouri—in contrast to cases like *Quinlan* and *Drabick* in other states—refused to authorize cessation of ANH in the absence of clear and convincing evidence that Ms. Cruzan had previously expressed opposition to life support in such a medical circumstance.¹⁵¹ In announcing

145. *Id.* See also *Lenz v. L.E. Phillips Career Dev. Ctr. (In re Guardianship of L.W.)*, 482 N.W.2d 60, 68-69 (Wis. 1992) (affirming guardian's right to end life support for a seventy-nine year-old incompetent in a permanent vegetative state). Unfortunately, courts in both California and Wisconsin have since adopted more restrictive guidelines for surrogate end-of-life decisions. Both states confine a surrogate's prerogative to end life support to instances where the patient is permanently unconscious or where the still-conscious patient previously gave clear and convincing instructions declining treatment or previously appointed a health care agent. See *Spahn v. Eisenberg (Guardianship of Edna M.F.)*, 543 N.W.2d 485, 490 (Wis. 1997); *Wendland v. Wendland (Conservatorship of Wendland)*, 28 P.3d 151, 162-63 (Cal. 2001).

146. See *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 424 (Mass. 1977); *In re Moe*, 432 N.E.2d 712, 719 (Mass. 1982); *Conservatorship of Valerie N.*, 707 P.2d 760, 773 (Cal. 1985).

147. See *supra* text accompanying notes 53-63.

148. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 286-87 (1990).

149. *Id.* at 266.

150. *Id.* at 265.

151. *Cruzan v. Harmon*, 760 S.W.2d 408, 426 (Mo. 1989).

a stringent standard for removing life support,¹⁵² the Missouri court upheld the state's "unqualified interest" in preserving life in light of fears that surrogates would make arbitrary quality-of-life decisions in the absence of a clear expression of a patient's wishes.¹⁵³ The court found no violation of Ms. Cruzan's constitutionally protected liberty interest, reasoning that the exercise of that interest required either an autonomous patient or clear cut choice when the patient was previously autonomous.¹⁵⁴

The Supreme Court of the United States granted certiorari. Ms. Cruzan's parents argued that Missouri's restrictive policy for allowing removal of life support violated Ms. Cruzan's Fourteenth Amendment liberty interest in having medical choices made for her in a way that best reflected her interests and values.¹⁵⁵ Their premise was that the Constitution guarantees freedom from unwarranted bodily invasions, and that a surrogate would protect this interest by rejecting inappropriate medical treatment. According to Ms. Cruzan's parents and their supporting amici curiae, Ms. Cruzan was constitutionally entitled to an individualized decision about her medical treatment by people who loved her, who had her best interests at heart, and who were familiar with what she would have wanted, all without the onerous requirement of clear and convincing evidence that Ms. Cruzan had explicitly articulated a desire to reject treatment in case of permanent unconsciousness.¹⁵⁶

The Court, by a five-to-four margin, upheld Missouri's clear and convincing evidence standard.¹⁵⁷ While the Court assumed that a *competent* patient would have a constitutionally protected liberty interest in refusing unwanted medical treatment,¹⁵⁸ it did not extend the protection to end-of-life decision-making on behalf of an incompetent patient.¹⁵⁹ The Court deferred to Missouri's restriction on surrogate choice as a rational and

152. Compare *Cruzan*, 760 S.W.2d at 426 with *Drabick*, 245 Cal. Rptr. at 854 and *In re Quinlan*, 355 A.2d 647, 670 (N.J. 1976) (recognizing patient autonomy exercised through surrogates).

153. *Cruzan*, 497 U.S. at 281.

154. *Cruzan*, 760 S.W.2d at 425.

155. Brief for Petitioners at 33, *Cruzan v. Dir., Mo. Dep't of Health* 497 U.S. 261 (1990).

156. See Brief for Petitioners at 33, Brief Amicus Curiae of the Society for the Right to Die at 7, *Cruzan v. Dir., Mo. Dep't of Health* 497 U.S. 261 (1990) (not only attacking Missouri's restrictive decision-making standard but also arguing for recognition of the patient's constitutional interest in having medical decisions on her behalf made by her loving and devoted family). In effect, petitioners were asserting a constitutional claim on the part of a bonded surrogate decision-maker. *Id.*

157. *Cruzan*, 497 U.S. at 282-83.

158. *Id.* at 279.

159. *Id.* at 280.

legitimate exercise of state regulation.¹⁶⁰ Chief Justice Rehnquist, writing for the Court, endorsed the state's insistence on clear and convincing evidence as "a procedural safeguard to assure that the action of the surrogate conforms as best it may to the wishes expressed by the patient while competent."¹⁶¹ Missouri's standard would, according to Rehnquist's opinion, effectively prevent abuse and arbitrariness in making critical medical decisions for incompetent patients.¹⁶² According to the Court, the dangers of such abuse and error in end-of-life decisions militated against requiring states to confer broad "substituted judgment" authority upon surrogates.¹⁶³

The Court's narrow view of surrogate-facilitated patient autonomy became the law of the land in *Cruzan*; however, it was unwise jurisprudence when it was decided, and remains unwise jurisprudence today. First, the Court failed to recognize that Missouri's overly-restrictive policy was arbitrary to the extent it was bound to produce results that would defeat the principles it was intended to further. Missouri's insistence on a living will or another clear expression of a patient's wishes was aimed at assuring compliance with those wishes. Yet by forbidding removal of life support except in the relatively rare instance when a patient has left explicit instructions for the contingency of incompetency (as with a detailed living will),¹⁶⁴ the state imposed treatment on Ms. Cruzan that she almost certainly would have refused.¹⁶⁵ Ms. Cruzan never indicated that she would differ from the vast majority of American adults who do not want life-extending medical treatment forced upon them if "treatment" means being maintained in permanent unconsciousness or other state of total physical dependency.¹⁶⁶ Indeed, in one recent survey of more than 1500 American adults, eighty-seven percent of respondents agreed that "total physical

160. *Id.* at 281.

161. *Id.* at 280.

162. *Id.* at 281.

163. *Cruzan*, 497 U.S. at 286-87. See also Cathleen A. Roach, *Paradox and Pandora's Box: The Tragedy of Current Right-to-Die Jurisprudence*, 25 U. MICH. J.L. REFORM 133, 144-45 (1991).

164. See Gerri Wills, *Creating a Living Will*, available at http://money.cnn.com/2003/10/24/pf/living_will (estimating that as few as 30% of baby boomers have living wills) (last visited Nov. 26, 2003).

165. See Buckley, *supra* note 65, at 299 (criticizing the *Wendland* case for similar reasons).

166. See GRETCHEN STRAW & RACHELLE CUMMINS, AARP KNOWLEDGE MANAGEMENT, AARP NORTH CAROLINA END OF LIFE SURVEY 8 (2003), available at <http://research.aarp.org>. [hereinafter AARP SURVEY]; R.A. Pearlman et al., *Insights Pertaining to Patient Assessment of States Worse than Death*, 4 J. CLINICAL ETHICS 35 (1993).

dependency would be worse than death.”¹⁶⁷ Thus, when Missouri forced life-extending treatment on the permanently unconscious Ms. Cruzan, it imposed on her a fate that she would in all likelihood not have accepted had she been conscious. Chief Justice Rehnquist conceded that Missouri’s catch-all approach may have frustrated Nancy Cruzan’s actual individual wishes, but responded that “the Constitution does not require general rules to work faultlessly.”¹⁶⁸

Of course, the Chief Justice was correct—the Constitution does not require that legal classifications and default rules perfectly match the problems they are intended to address. However, they must at least substantially fulfill the goals that motivated their enactment.¹⁶⁹ For example, age lines (laws establishing a minimum age for certain activities) are generally constitutional.¹⁷⁰ They are intended to assure a threshold level of maturity before persons are allowed, for example, to vote, drink, or drive. Such laws are permissible because they substantially achieve the intended goal of keeping immature persons off the roads and out of voting booths, even if they are somewhat over inclusive (barring some mature persons because they happen to be underage), or somewhat under inclusive (granting privileges to some immature persons who are “of age”). Likewise, while a mandatory retirement age may have the undesirable effect of prematurely forcing some still-capable workers from their jobs, it is permissible because it also serves to cycle out of the workforce many workers whose capabilities have declined with age. The age line thus substantially achieves the goal motivating the policy.¹⁷¹ By contrast, Missouri’s policy, as applied to permanently unconscious patients, would not substantially fulfill the critical goal of furthering personal choice, since it would contravene the real but unarticulated wishes of the vast majority of patients who do not want life-sustaining measures when mired in a permanently unconscious state.¹⁷²

Chief Justice Rehnquist upheld Missouri’s presumption in favor of preserving life, reasoning that a mistaken judgment to withdraw life support is both irreversible and irremediable.¹⁷³ Yet a mistaken decision to impose life support contrary to a patient’s wishes inflicts irreparable injury in at least three respects: 1) it almost certainly disregards the patient’s will; 2) it

167. AARP SURVEY, *supra* at note 166.

168. *Cruzan*, 497 U.S. at 284.

169. *See, e.g.,* Mass. Bd. of Retirement v. Murgia 427 U.S. 307, 314 (1976); *Manuel v. State*, 692 So. 2d 320, 341 (La. 1996).

170. *Manuel*, 692 So. 2d at 341.

171. *Murgia*, 427 U.S. at 314.

172. *See* AARP SURVEY, *supra* at note 166.

173. *Cruzan*, 497 U.S. at 283.

preserves an existence that the patient would deem intolerably undignified; and 3) it sullies the survivors' memories of a once-vital person now permanently reduced to an insentient helplessness. "[C]ontinuing treatment for a patient who would have wanted treatment stopped is as unfortunate as discontinuing treatment for a patient who would have wanted treatment continued."¹⁷⁴ If respecting the wishes of an incompetent patient is the ultimate goal, the more logical and principled approach, in the absence of explicit expressions of the patient's wishes, is to be guided first by the patient's known values and goals and then (if those values are not definitive) by following what a strong majority of persons would want done in the circumstances at hand.¹⁷⁵ That approach uses the normative force of a cultural preference for humane and dignified treatment.

Justice Brennan, dissenting in *Cruzan*, correctly perceived the paradoxical and undesirable consequences of a state requiring explicit prior expressions as a condition of removing life support.¹⁷⁶ While Brennan acknowledged a state interest in providing Ms. Cruzan with a course of treatment that reflected her personal wishes,¹⁷⁷ he strongly criticized the majority for sanctioning Missouri's insistence on clear cut prior expressions as the sole determinant of Ms. Cruzan's wishes.¹⁷⁸ According to Brennan, Missouri's framework discarded evidence of Ms. Cruzan's values and ignored meaningful, if less than carefully articulated, prior expressions and thereby deprived her of a "right to a decision as closely approximating her own choice as humanly possible."¹⁷⁹

Cruzan's defects extend beyond the glaring discrepancy between the accepted goal of respecting the patient's wishes and the means chosen by Missouri to accomplish that objective. Chief Justice Rehnquist's opinion also failed to adequately consider the critical interests threatened by the

174. LAURENCE H. TRIBE, CONSTITUTIONAL LAW § 15-11 (2d ed. 1988). See also David J. Mays & Martin Gunderson, *Vitalism Revitalized*, HASTINGS CENTER REP., July 2002, at 14, 19; Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 436 (1988).

175. See *In re A.C.*, 573 A.2d 1235, 1250 (D.C. 1990) ("Courts in substituted judgment cases have also acknowledged the importance of probing the patient's value system as an aid in discerning what the patient would choose."); *In re Bryant* 542 A.2d 1216, 1220 (D.C. 1988) ("It was not error for the trial court to consider whether a reasonable person in appellant's position would have chosen freedom over hospitalization."); *Wentzel v. Montgomery Gen. Hosp.*, 447 A.2d 1244, 1258 (Md. App. 1982). This approach would obviously require courts to make determinations about cultural norms. As explicated above, the cultural norms concerning vegetative-state life support are persuasively clear. In medical care situations for which norms are not as clearly established, however, a court would be correct in applying a general presumption in favor of preserving life.

176. *Cruzan*, 497 U.S. at 312-14.

177. *Id.* at 315-16.

178. *Id.* at 323-24.

179. *Id.* at 330.

inflexible prerequisite of explicit prior expressions for withdrawal of life support. Missouri's policy strongly impeded surrogates in protecting patients' essential and constitutionally-assured interests of bodily integrity, avoidance of suffering, and human dignity.

Justice Stevens, in dissent, called attention to the threat that Missouri's narrow decision-making scheme posed to patients' constitutional interests and condemned the majority for neglecting those interests.¹⁸⁰ Justice Stevens aptly noted that, under Missouri law, the only incapacitated patients who were assured of protection of their bodily integrity and concomitant freedom from unwarranted bodily invasions were those few who had the foresight to articulate unambiguous prior instructions.¹⁸¹ Justice Stevens also recognized an incapacitated patient's interests in avoiding suffering (though suffering was not applicable to the unconscious Ms. Cruzan), in being remembered as a vital individual (i.e., in preserving a lifelong image), and in obtaining a life closure consistent with her values, beliefs, and preferences, even if those preferences are not spelled out in detail.¹⁸²

A permanently unconscious patient like Ms. Cruzan also has an important interest in having her intrinsic human dignity respected. Ms. Cruzan's counsel vividly portrayed the degrading limbo to which Missouri was condemning her:

Her unconscious biological shell will be maintained by strangers in a sterile hospital room for 30 years, devoid of thought or perception and without hope of recovery. Such a choice will severely compromise her dignity for the rest of her days and will have devastating life-long effects for her family.¹⁸³

Justice Stevens assailed as a denial of personhood Missouri's disregard for Ms. Cruzan's interests beyond mere biological existence,¹⁸⁴ recalling the admonition in *Saikewicz* and *Drabick* that respect for persons demands allowing surrogates to consider the incapacitated patient's interests rather than imposing a technological imperative to keep the patient alive at all

180. *Id.* at 352-55.

181. *Id.* at 335-36.

182. *Cruzan*, 497 U.S. at 342-44.

183. Petitioner's Reply Brief at 9, *Cruzan v. Dir., Mo Dep't of Health*, 497 U.S. 261 (1990). Ms. Cruzan's limbo did not endure thirty years. After the Supreme Court's decision, her parents presented "new" evidence about Nancy Beth's prior expressions. That evidence was enough to prompt a trial court to find "clear and convincing" proof of her wishes to have ANH removed. The gastrostomy tube was then removed and Nancy Beth Cruzan was allowed to die. William L. Leschensky, Note, *Constitutional Protection of the "Refusal-of-Treatment": Cruzan v. Director, Missouri Department of Health*, 14 HARV. J.L. & PUB. POL'Y 248, 259 (1990).

184. *Cruzan*, 497 U.S. at 352-53.

costs.¹⁸⁵ Justice Stevens thus clearly understood the connection between preserving the human dignity of a mentally incapacitated patient and allowing her the benefit of surrogate decision-making.

The *Cruzan* majority, by contrast, demonstrated little concern for the potentially dire consequences of Missouri's restrictions on debilitated, dying patients. Ms. Cruzan's sad condition had perhaps one advantage: because she was unconscious, she was unable to perceive the affronts to her interests inflicted by Missouri's rule. But not every dying patient who has not given prior instructions is so unaware. Philip Peters has commented: "The irrefutable presumption that all lives are worth living will condemn many patients to unnecessary treatment, suffering, indignity, or pointless existence."¹⁸⁶ Often the most acute suffering and indignity is visited upon those dying patients who are still conscious. Courts have long recognized that, for some dying patients, the burdens of continued existence outweigh the benefits, and that conscientious surrogates should be able to make such a judgment and order a cessation of life-sustaining medical intervention.¹⁸⁷ Recall the case of Sheila Pouliot, the profoundly disabled woman who lingered in semi-consciousness for two months, swollen with edema and unable to interact with her environment except to moan in pain. That was her fate because New York law would not allow removal of life support from a dying person in the absence of clear cut prior instructions.¹⁸⁸ Consider also the case of infants born with certain grave defects that will inexorably cause their deaths in infancy or early childhood. In some such instances, continued existence entails almost constant medical intervention and unremitting suffering. Solicitude for the infant demands that a surrogate be able to put an end to medical intervention that is prolonging extreme and unremitting suffering.¹⁸⁹ Even the restrictive federal regulations aimed at

185. *Id.* at 349 n.21. Justice Brennan also invoked *Drabick* and its notion that respect for persons demands allowing surrogates to take incapacitated persons' interests into account. *Id.* See also Strasser, *supra* note 29, at 756.

186. Philip G. Peters, *The State's Interest in the Preservation of Life: From Quinlan to Cruzan*, 50 OHIO ST. L.J. 891, 943 (1989). Jonathan Moreno comments in a similar vein: "[T]he *Cruzan* approach] prevents families from making humane, common sense decisions for their loved ones, prolongs pain, suffering, and frustration for all concerned, and exacerbates the fiscal realities that lurk in the background." Jonathan Moreno, *Who's to Choose? Surrogate Decision-making in New York State*, HASTINGS CENTER REP., Jan.-Feb. 1993, at 6.

187. See, e.g., *In re Conroy*, 486 A.2d 1209, 1242 (N.J. 1985); *Rasmussen v. Fleming*, 741 P.2d 674, 689 (Ariz. 1987); *In re Grant*, 747 P.2d 445, 457 (Wash. 1987).

188. See *supra* text accompanying note 54.

189. See *Orange County Soc. Serv. Agency v. Moises I.* (*In re Christopher I.*), 131 Cal. Rptr. 2d 122, 136 (Cal. Ct. App. 2003); *Newmark v. Williams*, 588 A.2d 1108, 1120 (Del. 1991); *Truselo v. Carroll*, CN00-09299, 2000 WL 333242536, at *15 (Del. Fam. Ct. Sept. 19, 2000); *In re K.I.*, 735 A.2d 448, 466 (D.C. 1999); *Holum v. Morgan* (*In re C.A.*), 603

regulating decisions to withhold medical treatment from afflicted newborns leave some leeway for withholding treatment where medical intervention would be “virtually futile and inhumane.”¹⁹⁰

Thus, in *Cruzan*, the Supreme Court’s willingness to uphold Missouri’s approach to end-of-life decision-making for the mentally disabled imperiled both the constitutional interests of incapacitated patients like Nancy Cruzan and the temporal welfare of other, conscious dying patients. While the Court accepted the premise that Ms. Cruzan, if competent, would be constitutionally entitled to reject life support,¹⁹¹ the prerogative of a conscientious surrogate to end unwanted medical intervention in Missouri existed only if Ms. Cruzan had been so prescient as to anticipate and articulate her desires concerning medical intervention in a permanently unconscious state. Once Ms. Cruzan lost competence without leaving explicit instructions, the state could erect a “protective” bar to any terminal decision even if the bar contradicted her likely wishes or resulted in an impingement on her bodily integrity and dignity interests. The Court found Missouri’s concern about exploitation of vulnerable patients to be a sufficient constitutional justification, a rational basis, for the state policy.

What should the Supreme Court have done in *Cruzan*? What constitutional doctrine should have been crafted to deal with medical decision-making for an incompetent patient like Nancy Cruzan? The better jurisprudential course would have been to acknowledge a formerly competent person’s strong liberty interest in having her preexisting values and preferences (not just explicit end-of-life expressions) govern medical decisions and to recognize every incapacitated patient’s constitutional right to have her contemporaneous well-being considered by a surrogate decision-maker acting on the patient’s behalf. Justice Stevens was correct when he suggested that the Constitution “requires the State to care for Nancy Cruzan’s life in a way that gives appropriate respect to her own best interests.”¹⁹² Appropriate respect in this context means having a

N.E.2d 1171, 1182-83 (Ill. App. Ct. 1992). *But see* Miller v. HCA, No. 01-0079, 2003 WL 22232090 at *11 (Tex. Sept. 30, 2003) (permitting a physician to give life-sustaining treatment to a newborn in spite of parents’ refusal to consent); Montalvo v. Borkevec, 647 N.W.2d 413, 421 (Wis. 2002) (“[T]here is a presumption that continued life is in the best interests of the patient.”).

190. *See Developments in the Law - Medical Technology and the Law*, *supra* note 15, at 1602-03 (discussing the Child Abuse Amendments of 1984).

191. The Rehnquist opinion assumed *arguendo* that a competent patient would have such a right. Seven years later Chief Rehnquist acknowledged what had been implied in *Cruzan*—that a competent person has a constitutional right to reject life-sustaining medical intervention. *Washington v. Glucksberg*, 521 U.S. 702, 725 (1997).

192. *Cruzan*, 497 U.S. at 331. *See also* Michael T. Morley, Note, *Proxy Consent to Organ Donation by Incompetents*, 111 YALE L.J. 1215, 1218 (2002) (favoring a

conscientious surrogate consider the patient's interests (including prior values and preferences, as well as current well being).¹⁹³ For profoundly disabled persons who were never competent, prior values and preferences were not autonomously formed,¹⁹⁴ so a surrogate's focus must be on the patient's well-being. Consideration of current well-being, in turn, means that a surrogate must weigh the benefits and burdens of the contemplated medical choice while using the patient's overall best interests as a guide. In end-of-life contexts, a surrogate ought to be able to conclude, where appropriate, that a disabled patient would be better off dead than alive because of unremitting suffering or grievous debilitation (to the point of intrinsic indignity), and to order the removal of life support. A "best interests" formula respects the incapacitated patient's interests by permitting a range of beneficial options similar to those available to competent patients and by making room for both the patient's well-being and intrinsic dignity to be considered as integral factors.

There is only one context in which the Supreme Court has required, under the rubric of liberty and substantive due process, that a state permit a surrogate to protect an incapacitated person's constitutional interests. The Court has required states that impose a parental notification requirement on minors seeking abortions to also provide a process by which a minor can avoid parental notification/consent by seeking judicial approval of the abortion. The Court has held that a judge involved in such a proceeding must consider the best interests of the minor as determinative.¹⁹⁵ The judicial bypass process must be made available to any minor unwilling to involve her parents in the abortion decision. This mandatory access to a neutral decision-maker who is required to consider the minor's best interests is aimed at safeguarding the minor's liberty interest in deciding

constitutional right to a surrogate's determination); Deborah K. McKnight & Maureen Bellis, *Foregoing Life-Sustaining Treatment for Adult, Developmentally Disabled, Public Wards: A Proposed Statute*, 18 AM. J.L. & MED. 203, 213 (1992) (urging incapacitated persons' "right to have appropriate medical decisions made on their behalf").

193. See Strasser, *supra* note 29, at 739; John Robertson, *Cruzan and the Constitutional Status of Nontreatment Decisions for Incompetent Patients*, 25 GA. L. REV. 1139, 1187 (1991). *Contra* *Wendland v. Wendland* (Conservatorship of Wendland), 28 P.3d 151, 162-63 (Cal. 2001); *In re Martin*, 538 N.W.2d 399, 407-08 (Mich. 1995).

194. The fact that a profoundly disabled person cannot make autonomous choices does not mean that the person's preferences and expressions can be ignored. These expressions are integral to a surrogate's assessment of a ward's feelings and interests as part of a best interests calculus.

195. *Lambert v. Wicklund*, 520 U.S. 292, 297 (1997); *Ohio v. Akron Center for Reproductive Health*, 497 U.S. 502, 510-11 (1990); *Bellotti v. Baird*, 443 U.S. 622, 643 (1979). See generally Martin Guggenheim, *Minor Rights: The Adolescent Abortion Cases*, 30 HOFSTRA L. REV. 589 (2002); David D. Meyer, *Lochner Redeemed: Family Privacy After Troxel and Carhart*, 48 UCLA L. REV. 1125, 1165-66 (2001).

whether to terminate a pregnancy. But the mandatory access is not confined to mature minors capable of some measure of self-determination as to an abortion decision; immature minors are also entitled to pursue a judicial bypass in which the minor's interests are carefully considered.¹⁹⁶

The Court's jurisprudence on minors' abortions is instructive as an analogy to the broader issue of medical decision-making for the profoundly disabled. In both settings, a fundamental liberty interest is at stake; in one, the liberty interest is in continuing or terminating a pregnancy, and in the other, the liberty interest is in receiving or refusing critical medical treatment. In both settings, a state's failure to allow surrogate choice relegates the legally/medically incapacitated patient to the medical status quo, thus offending the patient's human dignity by preventing anyone from making a decision accounting for *her* interests. In both settings, an incapacitated person's liberty interest should trigger a requirement that a surrogate be allowed to choose among medical options in accordance with the dependent person's interests. The Court's jurisprudence as to minor abortions supports the proposition that constitutional liberty should include surrogate choice when a mentally incapacitated person is incapable of choosing for herself.

This suggested constitutional regimen furthering surrogate medical choice would necessarily include several protections. First, the surrogate's decision-making authority would have to be constrained in a manner consistent with the patient's interests. Unbridled authority in the hands of a surrogate would raise the specter of arbitrary decision-making and unconscionable exploitation of the vulnerable person. An integral part of the traditional relationship between government and citizens is the state's *parens patriae* obligation to protect vulnerable persons from abuse.¹⁹⁷ Thus, a surrogate's decision-making prerogative must be bound by standards such as substituted judgment, if a previously-competent patient has left meaningful guidance about the decision, or best interests, where the previously-competent patient left no meaningful guidance or if the patient is never-competent.

The importance of limitations on surrogate discretion is illustrated by several cases in which limitations were impliedly or explicitly imposed on decision-making about the sterilization of profoundly disabled persons.¹⁹⁸

196. *Bellotti*, 443 U.S. at 647 (“[E]very minor must have the opportunity . . . to go directly to a court without first consulting or notifying her parents.”).

197. *In re Grady*, 426 A.2d 467, 479 (N.J. 1981). See generally Douglas R. Rendleman, *Parens Patriae from Chancery to the Juvenile Court*, 23 S.C. L. REV. 204, 240 (1971).

198. N.C. Ass'n for Retarded Children v. N.C., 420 F. Supp. 451, 455-56 (M.D. N.C. 1976); Wyatt v. Aderholt, 368 F. Supp. 1383, 1385 (M.D. Ala. 1974). See William A. Kraiss, Note, *The Incompetent Developmentally Disabled Person's Right of Self-Determination*:

Courts in older cases struck down statutory schemes giving parents or guardians unlimited discretion to secure sterilization for profoundly disabled wards. The judicial message was that any decisions about sterilization must be made in the best interests of the ward. Courts delivered a similar message in several cases in the 1980s that affirmed a surrogate's authority to seek sterilization *in the best interests* of a child or ward.¹⁹⁹

In a constitutional framework assuring beneficial surrogate choice, the state would have to do more than simply articulate a limiting standard, such as best interests, to protect the disabled person from abuse by surrogates. A state would be required to allow surrogate choice on behalf of a profoundly disabled person, but would have a concomitant obligation to protect the dependent person against surrogate abuse. Pursuant to *parens patriae* authority, a state customarily enforces fiduciary standards that apply to a parent or guardian who makes decisions on behalf of a mentally disabled individual.²⁰⁰ Similar fiduciary standards would apply to surrogates making decisions for medically-disabled persons, and states would likewise be expected to enforce those standards. States would use criminal law to punish serious deviations from acceptable guardianship standards, and civil machinery to actively intervene and supplant surrogate decisions inconsistent with the well-being of the ward. Many states already have agencies that oversee child protection and adult guardianship that could readily assume oversight of medical surrogate decision-making.²⁰¹

What about state prophylactic rules that bar entire subject areas from surrogate choice in order to prevent mistreatment of vulnerable disabled populations?²⁰² This was Missouri's rationale in *Cruzan* for barring surrogate end-of-life decisions in the absence of clear and convincing evidence of the patient's explicit wishes. While a state *does* have a

Right-to-Die, Sterilization, and Institutionalization, 15 AM. J.L. & MED. 333, 342 (1989).

199. See, e.g., *In re A.W.*, 637 P.2d 366, 376 (Colo. 1981); *Harbin v. W.S.* (*In re P.S.*), 452 N.E.2d 969, 974 (Ind. 1982); *In re Debra B.*, 495 A.2d 781, 783 (Me. 1985).

200. *Grady*, 426 A.2d at 479. See generally Michael Kindred, *Guardianships and Limitations on Capacity*, in *MENTALLY RETARDED CITIZENS AND THE LAW* 85 (Michael Kindred et al. eds., 1976).

201. For description of the kinds of agencies that protect developmentally disabled persons against abuse, see McKnight & Bellis, *supra* note 192, at 217-19.

202. Many states foreclose guardians from making determinations on troublesome issues such as psychosurgery, electroconvulsive treatment, sterilization, or civil commitment. See Bruce Winick, *Advance Directive Instruments for Those with Mental Illness*, 51 U. MIAMI L. REV. 57, 79 (1996). These state provisions do not, however, exclude all access by disabled persons to such controversial services. Judges can ordinarily authorize resort to the services in issue as part of equity courts' *parens patriae* authority to act in the best interests of helpless populations.

legitimate interest in protecting vulnerable populations, it oversteps its constitutional bounds when it uses sweeping means to further that interest absent compelling justification. When those means encroach on a fundamental liberty interest, as Missouri's restrictions on decisions about life-sustaining medical intervention did, a state must provide more justification than did Missouri. A state ought to be able to exclude an entire category of potentially beneficial medical decisions from surrogate choice only upon a showing of significant abuse, or the threat of such abuse, by surrogates. Missouri made no showing that patients had been exploited so as to justify its virtually wholesale exclusion of surrogate choice from end-of-life decision-making. Moreover, even if there appeared to be a substantial threat of abuse of surrogate authority, a state should have to consider less drastic protective measures before excluding an entire subject matter from surrogate control.²⁰³

A variety of alternative safeguards is available to ensure that surrogate decisions affecting the disabled are not abusive. For example, the best interests standard can be refined to more thoroughly explicate the factors that govern a surrogate's decision. In the context of sterilization, best interests should focus on the physical and mental needs of the disabled patient and on the availability of alternative contraceptive techniques.²⁰⁴ Further, surrogates and medical personnel should be admonished not to allow common prejudices and stereotypes about disabled persons to play a role in surrogate decision-making.²⁰⁵ Medical personnel should also be reminded of their duty to seek review from an ethics committee or a court when a surrogate medical decision seems inconsistent with acceptable standards of patient care.²⁰⁶

In addition to carefully articulating a standard for surrogate decision-making, a state can develop procedural safeguards to ensure that the standards are enforced. A surrogate decision made by a parent or guardian can be subjected to mandatory independent review, such as by an institutional ethics committee. That mechanism can scrutinize both the underlying facts and the surrogate's application of the relevant decision-

203. See *Conservatorship of Valerie N.*, 707 P.2d 760, 772 (Cal. 1985) (striking down a statute that excessively restricted surrogate decision-making regarding sterilization).

204. See, e.g., *In re A.W.*, 637 P.2d 366, 375 (Colo. 1981); *In re Hayes*, 608 P.2d 635, 641 (Wash. 1980). Cf. *In re Branning*, No. 82662, 1998 Ill. Lexis 6, 19 (Ill. 1998) (invalidating a statutory scheme for authorization of electroconvulsive therapy because of inadequately detailed decision-making standards).

205. The New Jersey Supreme Court was careful to issue such a warning when it articulated standards for judicial approval of sterilization applications affecting profoundly disabled persons. *Grady*, 426 A.2d at 472.

206. AMA, COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, POLICY E-2.20, available at <http://www.ama-assn.org/ama/pub/category/2498.html>.

making criteria to those facts.²⁰⁷ In the case of sterilization decisions, decision-making authority can be vested in a judge charged with deciding after fair hearing processes. Typical hearing requirements for a sterilization decision include appointment of a guardian ad litem to represent the incapacitated person's interests and appointment of independent medical experts.²⁰⁸ Another possible safeguard is to adjust the standard of proof utilized by the surrogate decision-maker. For example, end-of-life and sterilization determinations have often been subject to a standard of clear and convincing evidence that the incapacitated patient's interests dictate a particular medical course.²⁰⁹ These kinds of safeguards provide alternative means to curb abusive treatment of disabled persons short of preventing all access to a possibly beneficial surrogate medical decision.

This approach to the issues considered in *Cruzan* still leaves issues unresolved. For example, as to the question of who decides on behalf of a disabled person, could a state require *judicial* determination of all critical medical issues affecting a profoundly disabled person, including end-of-life determinations? Parents and guardians seeking to act as surrogates would certainly argue that a requirement of judicial authorization is unduly burdensome, entailing too much expense and delay.²¹⁰ In *Cruzan*, Justice Stevens characterized as an open question whether the judicial process could be imposed as a prerequisite to a withdrawal of life support.²¹¹

Also controversial would be the standard of proof that surrogates would apply in making decisions. Some would argue that a conscientious surrogate ought to have discretion to make a judgment about a ward's best interests without being bound to a standard of clear and convincing evidence. However, as already noted, many states have imposed a

207. For a model framework designed to provide non-judicial review of surrogate end-of-life decisions, see McKnight & Bellis, *supra* note 192, at 228-31. That model—applicable to surrogate end-of life decisions for institutionalized patients—includes independent medical review and scrutiny by an institutional ethics committee as well as an agency charged with protecting the developmentally disabled.

208. See Eric M. Jaegers, Note, *Modern Judicial Treatment of Procreative Rights of Developmentally Disabled Persons: Equal Rights to Procreation and Sterilization*, 31 U. LOUISVILLE J. FAM. L. 947, 962-63 (1992) (describing the procedural safeguards typically mandated for sterilization hearings).

209. See, e.g., *K.C.M. v. Alaska (In re C.D.M.)*, 627 P.2d 607, 612 (Alaska 1981); *In re Debra B.*, 495 A.2d 781, 783 (Me. 1985); *In re Hilstrom*, 363 N.W.2d 871, 877 (Minn. Ct. App. 1985); *In re Hayes*, 608 P.2d 635, 640-41 (Wash. 1980).

210. While I argue that Fourteenth Amendment liberty should be deemed to require giving a mentally disabled person access to a surrogate's decision regarding potentially beneficial medical issues, I do not contend that the Constitution dictates who that surrogate decision-maker must be. In other words, allocation of serious medical decisions to judges would be constitutional, even though it would not be sound public policy.

211. *Cruzan*, 497 U.S. at 342 n.13.

requirement of clear and convincing evidence of best interests, a standard that is likely constitutional, though imprudent. The Supreme Court upheld a state provision that required a pregnant minor seeking a judicial bypass of a parental notification requirement to show by clear and convincing evidence that notification would not be in her best interests.²¹² While a clear and convincing evidence standard is constitutionally tolerable, any higher standard would probably be unconstitutional. For example, requiring proof beyond a reasonable doubt as a prerequisite to surrogate action would probably be an unconstitutional barrier to surrogate choice.²¹³

A requirement that a surrogate medical decision be grounded on clear and convincing evidence of best interests may be constitutionally tolerable, but it would not be wise policy. Recall that most medical decisions involve fundamental liberty interests on both sides of the choice. A decision in favor of sterilization impacts a disabled person's right to procreate and right to bodily integrity, but a decision against sterilization can impact a right not to procreate. A decision to institute chemotherapy on a terminal cancer patient implicates the patient's interests in bodily integrity and in continued life, but a decision against chemotherapy preserves bodily integrity and exercises a right to reject life-sustaining medical intervention. Given that the surrogate medical choice inevitably implicates a range of important personal interests, a case can be made for allowing the surrogate to act on a preponderance of the evidence.²¹⁴ Medical uncertainty may often preclude any sort of clear and convincing conclusion, as medical determinations are frequently muddled by conflicting variables and the vagaries of professional judgment. On the other hand, a surrogate will almost always be able to determine after careful consideration of the patient's circumstances and values that her best interests *probably* lie in a particular direction.

Even when important constitutional interests lie on both sides of a decision, the potential harm may appear greater on one side than the other. A decision in favor of sterilization entails a significant bodily invasion and severe impact on procreation prospects, while a decision against sterilization leaves the disabled person alone. This fact, coupled with a history of mistreatment of profoundly disabled persons, accounts for the common legal requirement that a surrogate's consent to a ward's

212. *Lambert v. Wicklund*, 520 U.S. 292, 295-96 (1997). For cases suggesting that clear and convincing evidence of the incapacitated patient's best interests is a constitutional prerequisite to invasion of bodily integrity, see *In re Branning*, No. 82662, 1998 Ill. Lexis 6, 19 (Ill. 1998); *In re Hilstrom*, 363 N.W.2d 871, 877 (Minn. Ct. App. 1985).

213. *Robert v. Angela D.* (Conservatorship of Angela D.), 70 Cal. App. 4th 1410, 1418-21 (1999).

214. See Buckley, *supra* note 65, at 303-04 (criticizing a clear and convincing evidence standard in the context of refusal of medical intervention).

sterilization be based upon clear and convincing evidence.²¹⁵ Nonetheless, if failure to perform sterilization would pose a serious risk of medical trauma for the patient, the balance of harms is not so clear. The same is true where a contemplated surgery involves a serious bodily intrusion yet failure to perform the surgery seriously endangers the patient's life. A preponderance of the evidence standard is therefore defensible²¹⁶ and perhaps even wise.

The constitutional approach proposed here, which recognizes a right to have a surrogate weigh important medical options, would also cast doubt upon some limitations on surrogate choice found in some state advance directive legislation. One common statutory limitation confines decisions to withhold treatment pursuant to previously issued instructions to a point at which an incompetent patient is "terminal." Sometimes, terminal is defined to mean that the patient's death will unavoidably occur within a particular time span (like six months).²¹⁷ Such a terminal patient limitation excludes surrogate decisions (despite conformity to patient wishes or well-being) to end dialysis or other interventions capable of sustaining the life of a dying patient for a period longer than the statutory period. Yet a competent patient's right to decline treatment is not confined to the terminal stages of an illness, and it is doubtful whether there is a constitutionally sustainable justification for so confining a surrogate. A patient suffering from a degenerative disease may reach an intolerable level of decline long before the ultimate statutory period. The same constitutional infirmity affects some state surrogacy laws designating the next of kin as authorized decision-makers for incapacitated patients.²¹⁸ Some of these statutes empowering next of kin to act as medical decision-makers confine the decision-makers' authority regarding end-of-life decisions to circumstances in which the ward is terminal. Similar constitutional doubt hangs over advance directive legislation purporting to forbid withdrawal of ANH as a surrogate option. No persuasive government interest warrants treating ANH differently from other forms of medical intervention.

There will also be dispute about the elements that can constitutionally be considered as part of a "best interests of the patient" decision-making standard. Can the interests of others, such as caretakers, be included in a surrogate's decision-making, or must the disabled person's interests be the

215. See *supra* notes 86-95 and accompanying text.

216. Cf. *Wirsing v. Michigan Protection & Advocacy Serv.* (*In re Wirsing*), 573 N.W.2d 51, 55 (Mich. 1998) (rejecting a clear and convincing proof standard for sterilization).

217. E.g., CAL. HEALTH & SAFETY CODE § 1250(B).

218. N.C. GEN. STAT. § 90-322 (2001); OR. REV. STAT. § 127.635 (1999); VA. CODE ANN. § 54.1-2986 (Michie 2002).

exclusive focus? Can a surrogate decision to authorize an “altruistic” course, such as tissue donation or participation in non-therapeutic medical research, be reconciled with the best interests limitation? Can the patient’s dignity be a legitimate consideration, or must the surrogate focus on the physical and mental well being of the now-incompetent patient? The resolution of these issues is beyond the scope of this article.²¹⁹

The basic point is that *Cruzan* was wrongly decided, and that constitutional liberty demands that, in most contexts affecting an incapacitated person’s critical interests, the person is entitled to a surrogate determination predicated on the interests of the incapacitated person.²²⁰ The proposed constitutional right to a surrogate determination at least applies to the important, potentially beneficial medical decisions at the heart of this article.

To this point, the constitutional analysis has centered on the *Cruzan* case, which involved a previously competent person who had permanently lost cognitive capacity. However, the subject of this article is persons who are profoundly disabled from birth. Does the constitutional analysis change when the medical fate of a never-competent person is at issue? There are some distinctions between previously competent persons and never-competent persons, but they probably do not change the essential argument in favor of a constitutional right to have critical medical determinations made by a surrogate bound to respect the incapacitated person’s interests. In fact, there is arguably a stronger case to be made on behalf of a never-competent person than for a previously competent person like Ms. *Cruzan*.

One distinction between the previously competent and never-competent patient relates to the personal interests affected if a state prohibits surrogate decisions on behalf of a now-incompetent patient. Unlike a never-competent person, a previously competent patient’s self-determination interest may be at stake. The previously competent patient had, until her incapacitation, an opportunity to exercise personal choice and to express preferences and values, so that state constraints on surrogate choice may impede implementation of that dependent person’s constitutional liberty in the sense of autonomous choice. For example, Ms. *Cruzan* by age twenty-seven had had an opportunity to form personal values and preferences and to express specific choices that would inform others of how she would want to resolve the issue of life support in case of permanent unconsciousness. A

219. For further discussion of these issues see Norman L. Cantor, “Deciding for the Profoundly Mentally Disabled” (forthcoming 2004).

220. This is so only as to *most* contexts because a few exclusions of surrogate choice for profoundly disabled persons such as those regarding marriage and voting can be sustained as necessary to the integrity of the institution involved.

profoundly disabled person never has the capacity for this level of self-determination, so the prohibition on surrogate choice as to end-of-life care does not violate that disabled person's liberty in the sense of personal choice. To that extent, the constitutional claim of a profoundly disabled person is weaker than that of a previously competent person.

On the other hand, the negative consequences of an approach like Missouri's would be even more severe on a life-long profoundly disabled person than they were on Ms. Cruzan. As a formerly competent person, Nancy Beth Cruzan had some opportunity to speak to the matter of end-of-life medical treatment in a fashion that would meet Missouri's clear and convincing evidence standard. Indeed, her representatives eventually satisfied a Missouri court that Ms. Cruzan had previously expressed enough about her preferences to show clearly that she would prefer death to permanent unconsciousness.²²¹ A lifelong profoundly disabled person has no opportunity to meet the Missouri standard.

Another contrast between Ms. Cruzan and the life-long profoundly disabled patient is that Ms. Cruzan, as a permanently insensate person, could not consciously experience the consequences of Missouri's insistence that she be kept alive in her gravely debilitated status. Most profoundly disabled persons are well aware of their surroundings and quite capable of experiencing acute suffering or affronts to dignity from intrusive medical technology. Recall the Massachusetts court's determination that Joseph Saikewicz would suffer so much in terms of pain, anxiety, and frustration from the uncomprehending receipt of intrusive chemotherapy that he would be better off foregoing possibly life-sustaining medical intervention.²²² Recall Sheila Pouliot who lay moaning for two months as edema swelled her body and broke down her skin.²²³ Avoidance of unnecessary suffering has even been recognized by a number of Supreme Court justices as an interest of constitutional dimension safeguarded by the Fourteenth Amendment.²²⁴

221. See Leschensky, *supra* note 183, at 259.

222. See *supra* note 21 and accompanying text.

223. See *supra* notes 53-63 and accompanying text.

224. In 1997, the Court decided two cases in which it upheld laws prohibiting physician-assisted suicide. *Washington v. Glucksberg*, 117 U.S. 702 (1997); *Vacco v. Quill*, 521 U.S. 793 (1997). However, in concurring opinions, several justices suggested that they would likely find unconstitutional a state ban on effective pain relief to dying patients, even if the pain relief would hasten the patient's demise. Commentators have suggested that these judicial expressions reflect an emerging constitutional "right to be free of unnecessary pain and suffering at the end-of-life." David A. Pratt, *Too Many Physicians: Physician-Assisted Suicide After Glucksberg/Quill*, 9 ALB. L.J. SCI. & TECH. 161, 223 (1999). See also David J. Garrow, *The Right to Die: Death with Dignity in America*, 68 MISS. L.J. 407, 417-19 (1998); Robert A. Burt, *The Supreme Court Speaks - Not Assisted Suicide But a Constitutional Right*

A state's policy of excluding surrogate choice could have severe negative consequences for profoundly disabled persons in contexts beyond end-of-life treatment decisions. Once a profoundly disabled woman becomes pregnant, her medical circumstances and her incomprehension of the events taking place may make an abortion the only way to avoid torturous consequences.²²⁵ State exclusion of such an option would be cruel and inhumane. The medical circumstances of a profoundly disabled person might also make sterilization necessary to avoid severe physical or mental harm. Severe mental distress from menstruation or severe hazards from pregnancy can even prompt a conclusion that, absent sterilization, a profoundly disabled person will undergo "devastating and perhaps fatal" consequences.²²⁶ Again, categorical prohibition of surrogate choice as to sterilization might be cruel and inhumane.

Even in the absence of medical necessity, sterilization can be in the best interests of a profoundly disabled person, at least if the alternative is social isolation or intrusive monitoring to avoid pregnancy. The New Jersey Supreme Court commented in *Grady*:

Lee Ann should have the opportunity to lead a life as rewarding as her condition will permit. Courts should cautiously but resolutely help her achieve the fullness of that opportunity. If she can have a richer and more active life only if the risk of pregnancy is permanently eliminated, then sterilization may be in her best interests.²²⁷

When Justice Rose Bird dissented from the California Supreme Court's authorization of sterilization for Valerie N., lamenting the prospective deprivation of Valerie's right to procreate, Roger Dworkin responded:

What are we doing for Valerie by respecting her primal right to procreate if we then lock her away to be sure she does not procreate, or if the procreation experience is a frightening and awful one for her? How can we justify making Valerie suffer for Justice Bird's ideals?²²⁸

to Palliative Care, 337 N. ENG. J. MED. 1234 (1997).

225. See *Jolivet v. Chuhak (In re D.W.)*, 481 N.E.2d 355, 356 (Ill. App. Ct. 1985); *In re Jane A.*, 629 N.E.2d 1337, 1340 (Mass. App. Ct. 1994); *In re Jane Doe*, 533 A.2d 523, 526 (R.I. 1987).

226. *Robert v. Angela D. (Conservatorship of Angela D.)*, 70 Cal. App. 4th 1410, 1417 (1999) (holding that, where a disabled woman had a seizure condition that would be exacerbated by pregnancy, the woman had a right to have a sterilization decision made on her behalf in order to enjoy the same benefits as a non-disabled person). See also *Ruby v. Massey*, 452 F. Supp. 361, 363 (D. Conn. 1978); *In re Susan S.*, No. 7764, 1996 WL75343 at *12 (Del. Ch. 1996); *In re E.J. Nilsson*, 122 Misc. 2d 458, 461 (N.Y. Sup. Ct. 1983).

227. *In re Grady*, 426 A.2d 467, 486 (N.J. 1981).

228. DWORKIN, *supra* note 37, at 59-60.

Professor Dworkin's point is well taken, even if couched in hyperbole. Access to sterilization can, at least in some instances, promote a disabled person's long-range happiness, dignity, and a fuller life.

Intrinsic human dignity has an important role in shaping the medical handling of profoundly disabled persons. A dignitary harm occurs to profoundly disabled persons when a state categorically excludes a potentially beneficial class of medical decisions from the range of surrogate decision-making authority. It is dehumanizing to the affected disabled person when surrogates are required to preserve the medical status quo rather than weigh the potential benefits and detriments associated with possible medical responses. This is so whether the medical option in question relates to abortion, sterilization,²²⁹ or life support. The disabled individual is treated like an inanimate object in contrast to the competent patient who would be entitled, in comparable medical circumstances, to exercise the potentially beneficial option.²³⁰ The inhumane impact of excluding potentially beneficial options from profoundly disabled persons helps account for the slavery imagery that some commentators evoked in the wake of *Cruzan*. According to that commentary, Missouri made Nancy Cruzan a slave of medical technology. Alex Capron described Ms. Cruzan as "enslaved by the extraordinary and ever-growing ability of medicine to sustain vital functions."²³¹ Giles Scofield called *Cruzan* the 20th century's equivalent of *Dred Scott* in its failure to "treat Nancy Cruzan as a person instead of a slave."²³²

The dehumanizing effect of prohibiting effective surrogate choice also accounts for the previously mentioned state cases like *Saikewicz*, *Drabick*, *Grady*, and *Valerie N.*, all of which cited the dignity of the profoundly disabled person as a basis for according surrogates a prerogative to exercise choice regarding either end-of-life treatment or sterilization. Courts have also begun to recognize the indignity of excluding surrogate choice in another, unusual context, that of the customary rule that divorce is so personal a choice that a surrogate can never initiate a divorce on behalf of a now incompetent spouse. The venerable rule barring a surrogate petition for divorce is grounded on the principle that a person's degree of tolerance of spousal mistreatment is so subjective that no surrogate decision-maker can effectively replicate what the now incompetent spouse would want.

229. "To take away the right to obtain sterilization for persons who are incapable of exercising it personally is to degrade those whose disabilities make them wholly reliant on other, more fortunate, individuals." Jaegers, *supra* note 208, at 976.

230. See Peters, *supra* note 186, at 960-61.

231. Capron, July 1990 talk, at 23-24.

232. Giles R. Scofield, 21 HASTINGS CENTER REP. 5, 44 (Sept. 1991).

Yet, as recognized in several recent decisions,²³³ the categorical prohibition of a surrogate petition for divorce tends to treat the now-incompetent spouse as an object locked into the status quo no matter how abusive or degrading the other spouse has been. These decisions see the incapacitated spouse as a “prisoner” who can be “captive to the whims of the competent spouse.”²³⁴ They therefore deviate from the traditional approach and allow surrogates to initiate divorce proceedings in order to allow full consideration of the incapacitated spouse’s interests and to assure dignified treatment for the incapacitated spouse.

The argument to this point has been that *Cruzan* was wrongly decided and that the Supreme Court should have ruled that states cannot, constitutionally, circumscribe surrogate choice on behalf of incapacitated persons as Missouri did. John Garvey was right and Chief Justice Rehnquist was wrong. At the same time, the result in *Cruzan* was not terribly surprising. The Court was asked to constitutionalize the handling of incapacitated, dying patients less than fifteen years after *Quinlan* ruled for the first time that a surrogate might legally be permitted to decline further life support for a helpless patient. The Court was faced with a state restriction on surrogate choice purportedly aimed at protecting vulnerable persons against exploitation. Protecting vulnerable populations against exploitation is a hallmark of the Supreme Court, a fact demonstrated not only in *Cruzan* in 1990 but in the physician-assisted suicide cases seven years later where the Court cited apprehension about undue pressure upon dying persons as one basis for upholding state bans on assistance to suicide. Moreover, the Court in *Cruzan* was not confronting a suffering disabled person, but rather the permanently insensate Ms. Cruzan. All this helps explain the reticence behind the five-to-four vote to uphold Missouri’s law.

In any event, *Cruzan* is not necessarily dispositive of the focal point of this article—the rights of profoundly disabled persons. At least those instances where exclusion of surrogate choice forces a profoundly disabled person to experience suffering or degradation are conceivably distinguishable from *Cruzan*. The contention is that it is an impermissible infringement of constitutional liberty (though not liberty in the sense of autonomy) when states categorically exclude surrogates from making potentially beneficial choices consistent with the best interests of the profoundly disabled person. This analysis applies to any state precluding

233. *Ruvalcalba v. Ruvalcalba*, 850 P.2d 674, 681 (Ariz. Ct. App. 1993); *Vaughan v. Vaughan* (Guardianship of Vaughan), 648 So. 2d 193, 195-96 (Fla. Dist. Ct. App. 1994); *Kronberg v. Kronberg*, 623 A.2d 806, 811-12 (N.J. Ch. 1993); *Nelson v. Nelson*, 878 P.2d 335, 339 (N.M. Ct. App. 1994). *Cf.* *Newman v. Newman*, 191 N.E. 2d 614, 618-619 (1963) (allowing a surrogate to elect between alimony and a property settlement).

234. *Ruvalcalba*, 850 P.2d at 681; *Nelson*, 878 P.2d at 339-40.

an end-of-life decision absent explicit prior expressions (an approach that entirely forecloses a choice for a profoundly disabled person) as well as any state barring the possibility of a sterilization procedure. This analysis would also invalidate the federal regulations seeking to prevent parental choice of non-treatment for infants born with multiple deficits likely to make their lives ones of unremitting suffering.

Of course, the above constitutional analysis may not prevail. The Court is naturally hesitant to constitutionalize legal doctrine about surrogate choice in the face of continuing concern about surrogate exploitation of vulnerable populations. As noted, acknowledgement of a liberty interest in having a surrogate decide on behalf of the disabled patient implicates subsidiary constitutional questions about who can serve as surrogate, the procedures to be followed by the surrogate, and the permissible scope of surrogate discretion. The Supreme Court may prefer to leave these matters to what Justice O'Connor dubbed "the laboratory of the states"²³⁵ without federal judicial intrusion. On the constitutional plane, that would still leave state courts free to apply state constitutional provisions protecting liberty along the lines urged.

Even if the issue of surrogate decision-making is left to public policy in the states, *i.e.*, to the state legislative laboratories, profoundly disabled persons should be given a right to have critical medical decisions made by conscientious surrogates acting according to the best interests of the disabled person. This approach ought to apply at least in the contexts of end-of-life decisions, abortion, and sterilization. The above analysis shows how it is inhumane and a denial of respect for persons to exclude the profoundly disabled from potentially beneficial surrogate decisions. A legal approach allowing conscientious surrogate decision-making seems to yield "a more just and compassionate result," to use the words of the New Jersey Supreme Court in *Grady*.²³⁶ The objectives of justice and compassion surely underlie the elaborate guardianship process that every jurisdiction now supplies on behalf of profoundly disabled persons.²³⁷ Those processes are consistent with the ancient *parens patriae* principle seeking to protect the interests of profoundly disabled persons. Legislatures should, therefore, "promote the human dignity of never-competent patients by affording access to beneficial results which competent patients could, and likely would, choose under similar circumstances."²³⁸ Even staunch

235. *Cruzan*, 497 U.S. at 292.

236. *Grady*, 426 A.2d at 481.

237. *E.g.*, CONN. GEN. STAT. ANN. § 45a-682 (West 1993); MICH. COMP. LAWS ANN. § 700.5215 (West 2002); NEB. REV. STAT. ANN. § 30-2627 (Michie 2003).

238. Strasser, *supra* note 29, at 771.

advocates on behalf of disabled persons' rights can recognize that preclusion of surrogate choice can single out and disadvantage the disabled.²³⁹ As protecting against abusive surrogate behavior is always a legitimate and important concern, surrogate decision-making machinery must include the kinds of procedural protections discussed above.

The central message of this article, then, is that the profoundly disabled have rights similar but not identical to those of competent persons. One of those rights—to be established either by constitutional law or legislative policy—should be a prerogative to have a conscientious surrogate make critical medical decisions according to the best interests of the disabled patient.

239. Price & Burt, *Nonconsensual Medical Procedures*, *supra* note 38, at 102-03; Michael Kindred, *Guardianship and Limitations Upon Capacity*, in *THE MENTALLY RETARDED CITIZEN AND THE LAW* 79-80 (Kindred et al. eds, 1976).