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

Norman L. Cantor\*

\*Rutgers U. School of Law, Newark, [ncantor@andromeda.rutgers.edu](mailto:ncantor@andromeda.rutgers.edu)

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

Norman L. Cantor

## Abstract

“The Relation Between Autonomy-based Rights and Profoundly Mentally Disabled Persons” Competent persons have fundamental rights to decide about abortion, methods of contraception, and rejection of life-sustaining medical treatment. Profoundly disabled persons are so cognitively impaired that they cannot make their own serious medical decisions. Yet some courts suggest that the mentally impaired are entitled to “the same right” to choice regarding critical medical decisions as competent persons. This article discusses the puzzling question of how to relate autonomy-based rights to never-competent persons. It argues that while profoundly disabled persons cannot be entitled to make their own medical decisions, they have a 14th Amendment right to have a bonded surrogate make important medical decisions on their behalf. Such a right is necessary in order to protect the disabled patient’s constitutionally grounded interests in bodily integrity, well being, and dignity. This right invalidates the state cases (in California, New York, Wisconsin, and Michigan) that have sought to confine end-of-life decisions to situations where the dying patient has given clear and convincing instructions. Such preclusion of surrogate choice leaves every never-competent patient in a medical limbo that sometimes constitutes an undignified and inhumane status. The Supreme Court’s 1990 Cruzan decision is criticized and distinguished.

## CHAPTER II

### **The Profoundly Disabled as Rights Holders: No Rights, The Same Rights, or Some Rights?**

#### Attributing the “Same Rights” to the Profoundly Disabled

The notion of a constitutional right to make important medical decisions dates to the middle of the twentieth century. In 1965, the Supreme Court in Griswold v. Connecticut<sup>1</sup> indicated that certain unenumerated but fundamental elements of liberty, including a prerogative to make certain personal choices, are protected by the federal Constitution. (There, the Court struck down a Connecticut ban on the use of contraceptives by married couples, finding that access to contraception is part of a fundamental liberty interest within marital privacy). Cases and commentators promptly sought to apply that liberty rationale to a competent patient’s rejection of life-sustaining medical intervention.<sup>2</sup> They relied on the legal doctrine of informed consent as establishing traditional respect for personal medical choice in an effort to bolster the claim to fundamental liberty status for terminal medical choices. Roe v. Wade, in 1973, added impetus to the claim by reinforcing the constitutionally protected status of intimate personal choices, including a joint patient-physician decision to terminate a pregnancy.<sup>3</sup>

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<sup>1</sup> 381 U.S. 479 (1965).

<sup>2</sup> See, e.g., *In re Brook’s Estate*, 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 P. Cannon, *The Right to Die*, 7 Hous. L. Rev. 654 (1970); Dana J. Sharpe & Robert F. Hargest, *Lifesaving Treatment for Unwilling Patients*, 36 Ford. L. Rev. 695 (1968).

<sup>3</sup> *Roe v. Wade*, 410 U.S. 113 (1973); *Lawrence v. Texas*, 123 Sup. Ct. 2472 (2003) recently confirmed the principle that certain intimate personal choices are entitled to special constitutional protection.

In the landmark Quinlan<sup>4</sup> case in 1976, the New Jersey Supreme Court ruled that a competent patient does indeed have a constitutionally protected right to decline or accept life-sustaining medical intervention. Furthermore, the court found that this liberty right had application even in the context of a patient mired in a permanently unconscious state. According to Chief Justice Hughes' opinion, "the only practical way to prevent destruction of the right [meaning the now-incompetent patient's right to decline treatment]"<sup>5</sup> was to permit a conscientious guardian to determine how the patient would exercise the right in the circumstances at hand. Accordingly, a devoted father was deemed entitled to decide, on behalf of his permanently unconscious daughter, whether to withdraw respirator support.

A number of other courts followed suit and subscribed to the position that a surrogate should be able to exercise choice on behalf of the now-incompetent patient so that the constitutional right to decline treatment would not be lost.<sup>6</sup> The exercise of substituted judgment by a surrogate -- seeking to replicate what the now-incompetent person would decide, if miraculously competent -- was seen as a necessary means to preserve the patient's constitutional prerogative.<sup>7</sup> Some courts even declared that incompetent persons enjoy "the same right" to

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<sup>4</sup> In re Quinlan, 355 A.2d 647, 670 (N.J. 1976).

<sup>5</sup> Id. at 664. See Donald Beschle, Autonomous Decisionmaking and Social Choice: Examining the Right to Die, 77 Ky. L. Rev. 319, 327 (1988-89).

<sup>6</sup> See Rasmussen v. Fleming, 741 P.2d 674, 686 (Ariz. 1987); John F. Kennedy Hospital v. Bludworth, 452 So.2d 921, 924 (Fla. 1984); Foody, 482 A.2d 713, 718 (Conn. 1984); In re Colyer, 660 P.2d 738, 746 (Wash. 1983); Severns v. Wilmington Medical Center, 421 A.2d 1334, 1347 (Del. 1980); Matter of Ingram, 689 P.2d 1363, 1370-72 (Wash. 1984).

<sup>7</sup> "The right of incompetent individuals to refuse medical treatment is effectuated through the doctrine of substituted judgement." Matter of R.H., 622 N.E.2d 1071, 1075 (Mass. App. 1993). See also Rosebush v. Oakland City Prosecutor, 491 N.W.2d 633 (Mich. App. 1992);

make medical decisions as competent persons.<sup>8</sup> And a similar approach emerged in cases dealing with sterilization determinations on behalf of mentally incapacitated persons. Courts considering sterilization sought to preserve the disabled patient's right to choose contraceptive means.<sup>9</sup> They did so by authorizing sterilization at least when the court agreed with the patient's guardian that sterilization would serve the disabled patient's interests.

Numerous commentators questioned the extension of a right to reject medical treatment to a decisionally incapacitated person. For them, the patient's constitutional prerogative 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. A typical query: "Whatever 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?"<sup>10</sup> For these commentators,

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Brophy v. New England Sinai Hospital, 497 N.E.2d 626, 635 (Mass. 1986); In re Ingram, 689 P.2d at 1369; In re Moe, 432 N.E.2d 712, 719-20, 725-26 (Mass. 1982); Bludworth, 452 So. 2d at 923-24; Rosebush v. Oakland County Prosecutor, 491 N.W.2d 633 (Mich. App. 1992).

<sup>8</sup> Superintendent of Belchertown v. Saikewicz, 370 N.E.2d 417, 423 (Mass. 1977); Bludworth, 452 So.2d at 926; Colyer, 660 P.2d at 744. Another court has commented: "The constitutional right to choose or refuse treatment extends to incompetent as well as competent individuals. Guardianship of Ruth E.J., 514 N.W.2d 213, 217 (Wis. App. 1995).

<sup>9</sup> See Wentzel v. Montgomery General Hospital, 447 A.2d 1244, 1258 (Md. App. 1982), quoting from In re Grady; 426 A.2d 467, 482 (N.J. 1981); Matter of Hayes, 608 P.2d 635, 637 (Wash. 1980).

<sup>10</sup> Sanford 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; 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").

personal freedom to choose could not survive incompetency. For them, “proxy exercise of the right of self-determination is simply not possible.”<sup>11</sup>

This critique of applying notions of self-determination and substituted judgment to decisionally incapacitated persons is certainly unconvincing in the context of previously competent patients. If a person, while competent, either made a prospective choice, as in an advance medical directive, or articulated values and preferences sufficient to guide post-competency medical decisions, self-determination is indeed respected when a surrogate implements the now-incompetent patient’s wishes. Prospective choice may not be as robust as contemporaneous choice, as the advance decisionmaker may not have the detailed information and experience that would normally aid and instruct a medical decision. Yet a person anticipating future medical situations may have well-developed values about intolerable suffering or indignity that can be implemented even after the person has become incompetent. So a surrogate meaningfully promotes an incapacitated patient’s self-determination when an end-of-life medical decision is grounded on values -- e.g., religious principles or personal convictions about dignity -- previously embraced by the patient.

It is true that where a previously competent patient’s prior expressions and values are murky or opaque regarding end-of-life treatment preferences, autonomy in the sense of actual weighing of options is no longer possible. Even then, efforts can be made to reach decisions that would likely reflect the now-incompetent patient’s wishes as reasonably projected. I would argue that constructive preference -- imputing choices to a formerly competent patient based on what

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<sup>11</sup> Allan Buchanan, *The Limits of Proxy Decision Making*, 29 *UCLA L. Rev.* 386, 407 (1981); Martha Minow, *Making All the Difference* (1990), 325.

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.<sup>12</sup> I have little sympathy, then, with the commenators who have categorically condemned the application of notions of self-determination and substituted judgment to the context of formerly competent medical patients.<sup>13</sup>

But the subject of inquiry in this book is profoundly disabled persons. How can substituted judgment and surrogate effort to implement a patient's constitutional liberty interest be meaningfully applied to a person who has never been able to make considered choices about medical issues or to formulate important values relevant to such issues? Can such a person have "the same right" to refuse medical treatment as a capacitated person?

Several courts have suggested that even profoundly disabled persons enjoy "the same panoply of rights and choices" as fully capacitated persons. The first articulation of that sentiment came from the Massachusetts Supreme Judicial Court in the Saikewicz<sup>14</sup> case decided

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<sup>12</sup> For a detailed presentation of this argument, 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. See *Rasmussen v. Fleming*, 741 P.2d 674, 686 (Ariz. 1987). And we do know strong majority preferences as to certain end-of-life scenarios such as a revulsion toward being mired in a permanently unconscious state.

<sup>13</sup> Rebecca Dresser, Confronting the Near Irrelevancy of Advance Directives, 5 J. Clinical Ethics 55, 56 (1994); Rebecca Dresser & John A. Robertson, Quality of Life and Non-Treatment for Incompetent Patients, 17 J. Law, Med. & Ethics 234 (1989).

<sup>14</sup> *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1976). See also *John F. Kennedy Memorial Hospital v. Bludworth*, 452 So.2d 921 (Fla. 1984); *Foody*, 482 A.2d at 718.

scarcely six months after Quinlan. Joseph Saikewicz was a 67 year-old resident of an institution for the developmentally disabled. He was severely retarded, with a mental capacity to function at the level of a child two years and eight months old. Joseph was dying of leukemia and the question arose whether to administer chemotherapy in the hope of producing a remission that could last from 4 to 13 months. The Massachusetts court ruled that a court (as opposed to the head of the institution) should resolve Joseph's medical fate and that the applicable decision-making standard would be substituted judgment -- requiring a determination of what Joseph would want to do if miraculously competent and fully aware of all the circumstances. 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.<sup>15</sup> 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.<sup>16</sup> And a few courts have taken a similar approach with regard to sterilization decisions and abortion decisions on behalf of profoundly disabled persons.<sup>17</sup>

The notion that profoundly disabled persons have the same right to choose as the abled is inaccurate. The right to refuse medical intervention is, in part, grounded in self-determination --

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<sup>15</sup> Id. at 428, 434. The New Jersey Supreme Court has also suggested that incompetent patients have the "same right of self-determination" as competent patients. In re Jobes, 529 A.2d 434 (N.J. 1987). See also In re Peter, 529 A.2d 419, 423 (N.J. 1987).

<sup>16</sup> See In re Hamlin, 689 P.2d 1372, 1375 (Wash. 1984); In re 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).

<sup>17</sup> In re Jane Doe, 533 A.2d 523, 525-26 (R.I. 1987); In re Jane A., 629 N.E.2d 1337 (Mass. App. 1994); In re Moe, 579 N.E.2d 682, 685 (Mass. App. 1991).



a weighing and choosing among competing options. As mentioned, substituted judgment implements self-determination if the now-incompetent patient previously articulated actual choices about end-of-life care or expressed preferences or values sufficient to project what course of medical treatment that patient would likely choose for himself or herself. Yet a profoundly disabled person has never been able to make autonomous choices. A surrogate cannot be implementing a never-competent patient's right of self-determination.<sup>18</sup> (As will be explained in Chapter VI, there are good reasons for a surrogate decisionmaker to gather and consider evidence about a profoundly disabled patient's feelings and preferences regarding prospective medical treatment, but not because the surrogate is honoring the patient's own autonomous choice).

Many courts and commentators have recognized the problematic of applying notions of autonomy and substituted judgment to the profoundly disabled. Commentators commonly note that capacity for autonomous decisionmaking is a prerequisite to a right to self-determination<sup>19</sup> and they scorn application of a substituted judgment formula to infants or to profoundly disabled adults who lack mental function beyond that of an infant or young child.<sup>20</sup> Any notion of

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<sup>18</sup> Matter of Susan S., 1996 WL 75343 (Del. Ch. 1996)(recognizing that a surrogate's decision for a profoundly disabled woman is not a "personal choice" or "genuine choice" though the surrogate may still be entitled to choose on behalf of a ward.)

<sup>19</sup> See, e.g., Mark Strasser, *Incompetents and the Right to Die: In Search of Consistent Meaningful Standards*, 83 Ky. L.J. 733, 738-40 (1994-95); William L. Webster, 'Right to Die' Cases: A Model for Judicial Decision-Making? 7 N.Y. L. Sch. J. Human Rts. 140, 147 (1990); Buchanan, *supra* note 11 at 407.

<sup>20</sup> Peter G. Filene, *In the Arms of Others* (1999), 137; Bernadette Tobin, *Did You Think About Buying Her a Cat? Some Reflections on the Concept of Autonomy*, 11 J. Contemp. Health L. & Policy 417, 422-23 (1995); Susan R. Martyn, *Substituted Judgment, Best Interests, and the Need for Best Respect*, 3 Cambridge Q. Of H.C. Ethics 195, 198-99 (1994); Minow, *supra* note 11 at 325.

determining what a person with a mental age of two years and eight months (i.e., with the level of mental function of a Joseph Saikewicz) would decide on his or her own behalf is dismissed as a figment of the imagination.<sup>21</sup> Most courts, when asked to apply substituted judgment to an infant or to a profoundly disabled adult, have therefore rejected the idea as involving an “unrealistic” or “impossible” task. That judicial response has been forthcoming in a variety of medico-legal contexts -- provision of life-sustaining medical intervention,<sup>22</sup> petitions for sterilization,<sup>23</sup> and organ donation.<sup>24</sup> All these sources repudiate the logic of imputing self-determination to profoundly disabled beings and of claiming that a surrogate is exercising “the same right” to control medical intervention as a competent patient.

Other critics couple the apparent illogic of ascribing autonomy-based rights to never-competent persons with suspicion about abuses that supposedly ensue from surrogate decisionmaking on behalf of this vulnerable population. The perceived hazards are several. Roger Dworkin notes a risk that surrogate decisionmakers would act according to utilitarian concerns -- i.e., the interests of society or surrounding persons -- rather than the disabled patient’s interests.<sup>25</sup> Others, including advocates for the disabled, fear substituted judgment as a cover for

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<sup>21</sup> Tobin, *supra* note 20; Louise Harmon, *Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment*, 100 *Yale L.J.* 1, 64-65 (1990).

<sup>22</sup> See *In re L.W.*, 482 N.W.2d 60, 69-70 (Wis. 1992); *In re K.I.*, 735 A.2d 448, 460 (D.C. 1999); *In re Storar*, 438 N.Y.S.2d 266, 275, 420 N.E.2d 64, 72 (N.Y. 1981)

<sup>23</sup> *In re Eberhardy*, 307 N.W.2d 881, 893 (Wis. 1981); *In re Moe*, 432 N.E.2d 712, 724 (Mass. 1982)(Nolan, J. dissenting); *Matter of Susan S.*, 1996 WL 75343 (Del. Ch. 1996).

<sup>24</sup> *Curran v. Bosze*, 566 N.E.2d 1319, 1326 (Ill. 1990).

<sup>25</sup> Roger B. Dworkin, *Limits: The Role of the Law in Bioethical Decision Making* (1996), 117. See also Lynn E. Lebit, Note, *Compelled Medical Procedures Involving Minors and*

exploitation based upon prejudice and stereotyped views of the quality of life experienced by the profoundly disabled.<sup>26</sup> These critics commonly worry about the hazards of imputing indeterminate feelings or preferences to the profoundly disabled. They cite the Nazi justifications of euthanasia claiming to be in the interests of the euthanized and to be what the victims would want if they could only express their wishes. (More later about the hazards of abuse accompanying surrogate decisionmaking. I will shortly be discussing state efforts -- based on concern for vulnerable disabled persons -- to exclude entire areas of decisionmaking from the hands of surrogates acting for the profoundly disabled).

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 is now established as a fundamental aspect of liberty under the Fourteenth Amendment.<sup>27</sup>

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Incompetents and Misapplication of the Substituted Judgment Doctrine, 7 J. L. & Health 107, 124-27 (1992-93).

<sup>26</sup> See Robert Burt & Monroe Price, “Nonconsensual Medical Procedures and the Right to Privacy,” in *The Mentally Retarded Citizen and the Law* (Kindred, Cohen, Penrod, & Shaffer, eds. 1976), 95-96; Walter M. Weber, *Substituted Judgment Doctrine: A critical Analysis*, 1 *Issues in L. & Med.* 131, 152-53 (1985); Harmon, *supra* note 21.

<sup>27</sup> The status of a constitutional right to refuse treatment was assumed by the Supreme Court in 1990 and confirmed in 1997. See *Cruzan v. Missouri Dep’t Health*, 497 U.S. 261, 278 (1990) and *Washington v. Glucksberg*, 521 U.S. 702, 720 (1997). “[T]he right to self-determination in matters of personal health is deeply rooted in our constitutional tradition.” *In re Cincinnati Radiation*, 874 F.Supp. 796, 815 (D. Ohio 1995).

The right has at least three components: an interest in self-determination, i.e., in making a choice about treatment; an interest in well-being, i.e., in having net interests advanced by a decision about treatment; and an interest in maintenance of bodily integrity, i.e., freedom from unnecessary bodily invasion. (This interest in bodily integrity is really part of a broader interest in preserving personal dignity). While the 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 for the profoundly disabled patient. And while the disabled person's self-determination is not exercisable by a surrogate acting for a never-competent person, a surrogate can meaningfully implement the other two elements within the right to refuse treatment. A conscientious surrogate can seek to determine whether a medical intervention will promote the net interests (well being) 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 an impossibility. To quote one case: "The 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]."<sup>28</sup>

All this explains what prompted the Saikewicz court to talk about "the same panoply of

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<sup>28</sup> Conservatorship of Valerie N., 707 P.2d 760, 772 (1985); see also Wentzel, 447 A.2d at 1258.

rights and choices” for a 67 year-old adult who had always had the mentality of a three year-old. The court erred in talking about substituted judgment (when the patient had never been able to make a considered judgment) and about the “same” right to choose as a competent person (when the patient could never exercise self-determination). But the court was surely correct in its conclusion that 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.<sup>29</sup> Only in that way could Joseph’s well being and dignitary interests in bodily integrity and avoidance of suffering -- all of them integral parts of the constitutional right to reject treatment -- receive the consideration they deserve. Only in that way -- permitting surrogate choice regarding potentially beneficial medical options -- can a never-competent person have access to important benefits available to other persons.

In some instances, a person’s well being is promoted by being allowed to die, as when proffered treatment will only prolong a dying process dominated by suffering or by deterioration to an unconscious or barely conscious status. Categorical exclusion of surrogate choice to reject life-sustaining treatment on behalf of a profoundly disabled person then prejudices the well being interest of that patient. The same phenomenon occurs when a medically indicated abortion or sterilization is in 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.

A profoundly disabled person’s human dignity interests can be jeopardized by exclusion of surrogate choice. This can occur in at least two ways. First, the exclusion of surrogate choice

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<sup>29</sup> Saikewicz, 370 N.E.2d at 435. See also Brophy 497 N.E.2d at 634-35.

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. That spectre 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.”<sup>30</sup> 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, denial of access to the same range of potentially beneficial medical options as would be enjoyed by a decisionally capacitated patient denies the profoundly disabled patient’s equal status with other persons and thereby offends that patient’s dignitary interest in equal treatment -- unless there is a convincing reason for the differential handling. The Massachusetts Supreme Judicial Court commented in Saikewicz: “To 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 persons by placing a lesser value on his [or her] intrinsic human worth and vitality.”<sup>31</sup> Years later, that court made a similar observation about indignity in the context of sterilization: “To take away the right to obtain sterilization from persons who are incapable of exercising it personally is to degrade those whose disabilities make them wholly reliant on other, more fortunate, individuals.”<sup>32</sup>

The story of Sheila Pouliot illustrates how a state’s preclusion of surrogate choice can

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<sup>30</sup> Bludworth, 452 So.2d at 923. See also In re Schiavo, 851 So.2d 182 (Fla. App. (2003)).

<sup>31</sup> Saikewicz, 370 N.E.2d at 428.

<sup>32</sup> Matter of Moe, 432 N.E.2d at 720.

implicate human dignity.<sup>33</sup> Ms. Pouliot was a 43 year-old woman, chronically disabled by mental retardation and cerebral palsy. She had lived with her family for many years, but at the critical period in 1999 she was living in a New York State facility for the developmentally disabled. 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.

Sheila Pouliot's sister Alice served as representative of Sheila and her family. Alice determined, in conjunction with the hospital's medical staff, that Sheila was unavoidably dying, was permanently reduced to a semi-conscious state, was unable to digest artificial nutrition, and that further medical intervention, including artificial nutrition and hydration (ANH), would only prolong Sheila's dying process. The hospital ethics committee concurred. Comfort care, including morphine sulfate, was provided for Sheila's abdominal pain and for pain secondary to various muscle contractures and dislocated joints.

That medical course was followed for several days until the State Attorney General's office intervened. The Attorney General insisted that New York law would not permit removal of ANH from a person in the absence of clear prior instructions declining life support in the circumstances at hand. (Sheila Pouliot, as a never-competent person, could never meet that standard). In the wake of that legal intervention, the physicians renewed artificial hydration and

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<sup>33</sup> Blouin v. Spitzer, 213 F.Supp.2d 184 (N.D.N.Y. 2002), *aff'd* 356 F.3d 348 (2d Cir. 2004).

administration of a glucose solution via an I.V. For the next 7 weeks, Ms. Pouliot lingered, unable to relate to her environment and occasionally moaning, crying, and grimacing with pain (despite substantial pain relief medication). She swelled up with total body edema until her skin began to break down in several places. Finally, on March 3<sup>rd</sup>, 2000, the family and medical staff secured a court order permitting removal of all life support. Sheila Pouliot died with the attorney general's office still scrambling to pursue an appeal and to prevent removal of the artificial hydration that had swelled Ms. Pouliot to a caricature of her former self. Her course of dying was inconsistent with both medical standards of palliative care and with humane and compassionate care.<sup>34</sup> That course of dying, supposedly required by New York law preventing surrogate removal of ANH from a never-competent person, surely deprived Sheila Pouliot of intrinsic human dignity.

#### A Constitutional Claim to Appropriate Medical Options

A connection between access to surrogate choice (regarding important medical issues) and intrinsic human dignity is thus clear. Do the incapacitated person's dignity interests, coupled with an interest in well being tied to a medical option, rise to a constitutional plane? Could a profoundly disabled person be constitutionally entitled to a surrogate medical decision? The U.S. Supreme Court has acknowledged a connection between constitutional liberty and surrogate decisionmaking on behalf of a mentally disabled person. In 1988, the Supreme 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 [surrogates] acting with the best interests of their

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<sup>34</sup> This determination flows both from common sense and from the affidavit submitted by a palliative care expert, Dr. Kathleen McGrail, in litigation involving Ms. Pouliot's estate.



principals in mind.”<sup>35</sup> Implicit in that quote is recognition that a “best interests” of the incapacitated patient formula allows surrogates to consider the well being, bodily integrity, and dignity interests that partially underlie the profoundly disabled patient’s constitutional liberty interest in issue. Other sources have also recognized the important interests of incapacitated persons in securing needed medical options. Courts considering end-of-life treatment for the profoundly disabled have sometimes noted that while self-determination or free choice are 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.”<sup>36</sup> Surrogate decisionmaking employing a best interests standard at least assures to the profoundly disabled person the benefits of reasoned choice -- consideration of the possible gains or harms of a contemplated medical procedure -- thereby promoting that person’s constitutionally based interests in well being, bodily integrity, and dignity.

Most courts that have spoken to the issue therefore allow a surrogate to make end-of-life medical decisions on behalf of profoundly disabled persons and dictate application of a best interests standard for decisionmaking. Even courts that articulate a substituted judgment standard -- that is, a standard that purports to replicate what the incompetent patient would decide

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<sup>35</sup> Thompson v. Oklahoma, 108 S.Ct. 2687, 2693 n.23 (1988). See also *In re Hocker*, 2003 WL 21540381 (Mass. 2003) acknowledging that a mentally disabled person may have rights and interests vindicated by a surrogate.

<sup>36</sup> *In re 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*, 426 N.Y.S.2d 517, 542-43 (N.Y. App. Div. 1980); Larwrence J. Nelson et al., *Forgoing Medically Provided Nutrition and Hydration in Pediatrics Care*, 23 J. Law, Med. & Ethics 33, 38 (1995); William A. Krais, Note, *The Incompetent Developmentally Disabled Person’s Right of Self-Determination: Right to Die, Sterilization, and Institutionalization*, 15 Am. J. L. & Med. 333, 350 (1989).

-- tend to modify that approach in its application to profoundly disabled persons. In 1992, the Massachusetts Supreme Judicial Court (the court that had decided Saikewicz in 1976) admitted that substituted judgment is “a legal fiction” as applied to a never-competent person and is retained in an effort to vindicate the patient’s “liberty interests” including the rejection of treatment.<sup>37</sup> The court presumably meant liberty interests such as bodily integrity and dignity, rather than self-determination, because the very fiction acknowledged by the court was the attribution of autonomous judgment to Joseph Saikewicz.

In application to a profoundly disabled person, the substituted judgment standard inevitably gets transformed into a best interests approach. That transformation took place in Saikewicz itself when the court ended up deciding Joseph’s medical fate by emphasizing the prospective negative impact of pain and anxiety, as would be done under a best interests formula. And in deciding the medical fate of a small child stricken with leukemia, the Massachusetts court admitted that in such a context the substituted judgment and best interests standards are “essentially coextensive.”<sup>38</sup>

A similar melding or blending of the substituted judgment and best interests standards can also be noted as to other medical issues involving profoundly disabled persons. In a case considering sterilization of a profoundly disabled woman, the New Jersey Supreme Court talked about substituted judgment on behalf of the woman but ended up articulating a formula dictating

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<sup>37</sup> In re Jane Doe, 583 N.E.2d 1263, 1267-68 (Mass. 1992).

<sup>38</sup> Custody of a Minor, 393 N.E.2d 836, 844 (Mass. 1979). See also David S. Lockemeyer, Note, At What Cost Will the Court Impose a Duty to Preserve the Life of a Child? 39 Cleveland St. L. Rev. 577, 586 (1991)(noting the judicial melding of substituted judgment and best interests in the context of decisions affecting small children).

careful attention to the same criteria as in a best interests approach.<sup>39</sup> One Justice of the court called this a best interests analysis “cloaked in a substituted judgment formulation.”<sup>40</sup> The melding of substituted judgment with best interests has also occurred in at least one case involving the transplantation of a kidney from a profoundly disabled person to a desperately ill sibling.<sup>41</sup>

All this is not surprising in light of the illogic, previously noted, of using substituted judgment to try to replicate decisions of persons who have always lacked capacity to make autonomous decisions. As Joel Feinberg has noted,<sup>42</sup> 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. The best that can be done is to charge a conscientious surrogate with considering and balancing the incapacitated patient’s interests, including prospects for pleasure, pain, and satisfaction. While a profoundly disabled person, lacking autonomy, cannot have “the same rights” as a capacitated person, that person retains important interests (such as well being and dignity) that deserve respect even if the disabled person cannot decide when and how to advance those interests. Does the presence of those interests translate into a constitutional right to have a surrogate exercise

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<sup>39</sup> *In re Grady*, 426 A.2d 467, 482 (N.J. 1981). See *In re P.S.*, 452 N.E.2d 969, 974 (Ind. 1982); Harmon, *supra* note 21 at 48-49.

<sup>40</sup> 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 (1988).

<sup>41</sup> *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. 1969).

<sup>42</sup> Joel Feinberg, *Freedom and Fulfillment* (1992), 20-23.

choice on behalf of a profoundly disabled person? That issue is confronted in the following section.

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.<sup>43</sup> His argument was that the incapacitated have a cognizable liberty interest in beneficial treatment in various medical contexts and such an interest can only be implemented by allowing surrogate choice. According to Garvey, government should be foreclosed from interfering in decisions by surrogates who have caring ties to an incapacitated patient so long as the surrogate is acting consistently with the interests of the patient. Parents or other closely connected surrogates would be entitled to make judgments as to appropriate treatment choices and those judgments could be supplanted only if demonstrably contrary to the helpless patient's interests.

Some other commentators (and some courts) have a very different perspective on surrogate decisionmaking for the profoundly disabled. They view the profoundly disabled as vulnerable and subject to arbitrary and abusive manipulation in medical decisionmaking even by surrogates with close family ties to the patient.<sup>44</sup> They perceive even bonded surrogates as

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<sup>43</sup> John Garvey, Freedom and Choice in Constitutional Law, 94 Harv. L. Rev. 1756, 1777-78, 1782-83, 1791-94 (1981).

<sup>44</sup> See, e.g., Martha A. Field, Killing 'The Handicapped' -- Before and After Birth, 16 Harvard Women's L.J. 79, 95 (1993); Martha Minow, Interpreting Rights: An Essay for Robert Cover, 96 Yale L.J. 1860, 1888-90 (1987); Carl E. Schneider, Rights Discourse and Neonatal Euthanasia, 76 Calif. L. Rev. 151, 175 (1988); Lois Shepherd, Dignity and Autonomy after Washington v. Glucksberg: An Essay about Abortion, Death, and Crime, 7 Cornell J. L. & Pub. Policy 431, 455 (1998).

having significant conflicts of interest as to a variety of medical decisions critical to a disabled patient's life or well being. 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 family may be influenced by the spectre of monitoring the disabled person's behavior or even caring for what the family regards as deficient potential offspring. If the issue is organ donation, the family may be wracked by pressure to salvage a desperately ill relative of the incapacitated potential donor. According to some advocates of the disabled, family members may be subject to prejudice against the handicapped, with an accompanying tendency to undervalue the handicapped person's life and to project sentiments to the disabled person that match the family members' interests and preferences. In the context of life-sustaining medical intervention, these advocates fear quality of life determinations from the perspective of people oriented to independence and self-sufficiency as ideals. In the context of sterilization, they fear insensitivity toward the disabled person's interests in procreation or in remaining free from unwanted bodily invasions. Because of the perceived hazards of exploitation of vulnerable populations like the profoundly retarded, these sources would foreclose whole categories of decisions -- such as removal of life support or sterilization -- from the hands of surrogate decisionmakers responsible for profoundly disabled persons.<sup>45</sup>

Can Garvey's notion (of a constitutional right of an incapacitated person to have a surrogate decision) prevail in the face of these concerns by advocates of the disabled? Is a state

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<sup>45</sup> See *In re Jane Doe*, 432 N.E.2d, at 1272 (Nolan, J. dissenting); *Matter of Finn*, 625 N.Y.S. 2d 809-11 (Sup. Ct. 1995).

constitutionally compelled to allow a surrogate to assess and seek to effectuate a profoundly disabled person's interests in important medical issues, or may a state foreclose surrogate decisions in potentially hazardous subject areas such as withdrawal of end-of-life care, sterilization, and participation in experimental medical protocols?

In at least two subject areas -- sterilization and life-sustaining medical interventions -- a few states have sought to either exclude or radically constrain surrogate decisions for the decisionally handicapped.<sup>46</sup> The apprehension about sterilization is most understandable in light of its long and checkered history. In this book's Introduction, I noted the eugenics movement that peaked in the United States between 1900 and 1930. Part of the agenda of that movement was passage of involuntary sterilization laws affecting primarily the "feeble-minded" residents of state institutions. The first such statute was adopted in Indiana in 1907, but approximately 32 states followed suit in the period up to 1940.<sup>47</sup> The justifications for these laws were varied. The prime rationale was protection of society by avoiding the birth of assertedly inferior beings who would become burdens upon the state either because of their dependency or anti-social conduct and who would go on to produce similar offspring. Preventing misery and suffering to prospective offspring was another rationale for the legislation. (The assumption was that

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<sup>46</sup> Regarding sterilization, see Ohio Stat. §§5123.86(A) and 5123.86(B). For state cases radically restricting surrogate removal of life support, see note 56, *infra*. The federal government has also sought to limit end-of-life medical decisionmaking 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 Assoc.*, 106 S. Ct. 2101 (1986). The current regulations purport to limit the circumstances in which life support may be withheld from an infant, but the impact of those regulations is uncertain. See note , *infra*.

<sup>47</sup> Jonas Robitscher, *Eugenic Sterilization* (1973), 9-14.

feeble-minded parents would be utterly incapable of decent child rearing). The laws also supposedly promoted the well being of the feeble-minded potential parents who might thrive without the burdens of parenthood for which they were ill-suited to deal. While some state courts invalidated local involuntary sterilization statutes,<sup>48</sup> the U.S. Supreme Court upheld the Virginia statute in 1927<sup>49</sup> and a few courts upheld such statutes against constitutional attack as late as the 1970's.<sup>50</sup> During the first half of the 20th century, approximately 60,000 people were compulsorily sterilized.<sup>51</sup>

By the second half of the 20th century, the picture regarding compulsory sterilization had dramatically changed. The scientific underpinnings of the eugenics movement were in disrepute. 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.<sup>52</sup> Commentators cast doubt on the constitutional

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<sup>48</sup> Some state courts ruled that the statutes denied procedural due process in not providing sufficient notice or a sufficient opportunity to contest a petition for sterilization. A few state courts found that statutes denied equal protection by mandating sterilization only of institutionalized feeble-minded persons (in contrast to non-institutionalized feeble-minded persons). See generally Elizabeth S. Scott, *Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy*, 1986 Duke L.J. 806, 809-13 (1986).

<sup>49</sup> *Buck v. Bell*, 274 U.S. 200 (1927).

<sup>50</sup> *North Carolina Assoc. For Retarded Children v. State of North Carolina*, 420 F. Supp. 451, 457-58 (M.D.N.C. 1976); *Cook v. Oregon*, 495 P.2d 768, 771-72 (Or. Ct. App. 1972); Erika T. Blum, Note, *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 Prob. 1962).

<sup>51</sup> Burt & Price, *supra* note 26, at 97.

<sup>52</sup> *Ibid.*.

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.<sup>53</sup> Many of the statutes providing for compulsory sterilization had lapsed, been repealed, or fallen into disuse by the 1950's.

The central issue in the 1960's and 70's 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.<sup>54</sup> These courts had a lingering revulsion toward the 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.<sup>55</sup> Also, by the late 1960's and early 1970's, procreation was well established as a fundamental aspect of liberty under the Fourteenth Amendment. A number of courts therefore expressed special reluctance to authorize

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<sup>53</sup> Donald Giannella, *Eugenic Sterilization and the Law*, in *Eugenic Sterilization* (J. Robitscher, ed. 1973), 74-75.

<sup>54</sup> 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 (Tex. Civ. App. 1969); *Holmes v. Powers*, 439 S.W.2d 579 (Ky. 1968); *In re DD*, 408 N.Y.S.2d 104 (App. Div. 1978); *A.L. v. G.R.H.*, 325 N.E.2d 501 (Ind. App. 1975); Annot., *Jurisdiction of Court to Permit Sterilization of Mentally Defective Person in Absence of Specific Statutory Authority*, 74 ALR3d 1210, 1213 (1976). But see *In re Simpson*, 180 N.E.2d 206 (Ohio Prob. Ct. 1962); *Jessin v. County of Shasta*, 79 Cal Rptr 359 (Cal. App. 1969).

<sup>55</sup> 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*, 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. Policy 401, 419-21 (1998).



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.<sup>56</sup> Today, most of the states that had refused in the 1970's to find inherent jurisdiction to authorize sterilization of a mentally disabled person have changed their law; statutes or cases 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.<sup>57</sup>

The question under discussion is whether a state's exclusion of surrogate consent to important medical matters such as sterilization is constitutional. That constitutional issue can be raised regarding a number of states that have severely restricted surrogate decisions seeking to remove life-sustaining medical care from profoundly disabled persons. The judicial phenomenon started in New York in 1981.<sup>58</sup> The patient, John Storar, was a 52 year-old, profoundly retarded man dying of bladder cancer. His mother opposed continuation of blood transfusions because they caused extreme pain and discomfort to the uncomprehending patient. New York's highest court refused to uphold the mother's determination. Absent a prior declaration from the patient expressing a preference about life-sustaining care, the court refused to permit a surrogate

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<sup>56</sup> M.K.R., 515 S.W.2d 467 (Mo. 1974).

<sup>57</sup> Martha A. Field and Valerie A. Sanchez, *Equal Treatment for People with Mental Retardation* (1999), 87. See Ohio Stat. Section 5123.86(A).

<sup>58</sup> *In re Storar*, 438 N.Y.S.2d 266, 420 N.E.2d 64 (N.Y. 1981), cert. denied 454 U.S. 858 (1981).

decision to end life support. New York's restrictive approach continued in 1988.<sup>59</sup> This time the patient, Mary O'Connor, was a 77 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. 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; they cited statements that Mrs. O'Connor had made to that effect. Nonetheless, New York's highest court ruled against the daughters. According to Chief Judge Saul Wachtler (a jurist who later did jail time for threats and harassment), New York would not allow removal of life-support from an incapacitated patient without clear and convincing evidence that the patient, while previously competent, had chosen such a course with regard to the circumstances now present. Mrs. O'Connor's prior statements were not focused enough on her present circumstances to satisfy the clear and convincing evidence standard. A single concern moved the New York court -- apprehension of abuse or exploitation of helpless populations. Judge Wachtler asserted that "no person or court should substitute its judgment as to what would be an acceptable quality of life for another."<sup>60</sup>

Since 1988, several other state courts have joined New York in demanding clear and convincing evidence of the incapacitated patient's prior preferences before allowing withdrawal of life-sustaining medical intervention.<sup>61</sup> A couple of these courts apply their restrictive approach

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<sup>59</sup> Westchester Medical Center (O'Connor), 534 N.Y.S.2d 886, 521 N.E.2d 607 (N.Y. 1988).

<sup>60</sup> 534 N.Y.S.2d at 892.

<sup>61</sup> Matter of Wendland, 28 P.3d 152 (Calif. 2001); Cruzan v. Harmon, 760 S.W.2d 408 (Mo. 1989); DeGrella v. Elston, 858 S.W.2d 698 (Ky. 1993); Mack v. Mack, 618 A.2d 744 (Md.

only to incapacitated persons who are still conscious. That is, these courts would permit a surrogate to withdraw life support from a permanently unconscious patient, but not from a patient who retains any measure of consciousness, at least not without clearcut prior expressions. The whole approach demanding clearcut prior expressions has devastating impact on profoundly disabled persons. Never-competent persons, by definition, could never have supplied the requisite prior expressions.

The consequences of this restrictive approach to end-of-life care will be addressed shortly. Note first that this restrictive approach to terminal decisions raises a constitutional issue similar to that raised by the previously mentioned exclusion of sterilization from the realm of surrogate decisionmaking. Does wholesale exclusion of a subject matter from surrogate decisionmaking violate a profoundly disabled person's right to liberty where the disputed decision has the potential to benefit the disabled person?

Certain cases in the 1980's, in the contexts of both end-of-life and sterilization decisions, supported the notion that a decisionally incapacitated person might have a constitutional right to have a surrogate choose a medical course on the incapacitated person's behalf. Recall that Saikewicz in Massachusetts in 1977 had asserted that a dying, profoundly disabled cancer patient should have a right to the "same range of choices and options" as an autonomous patient would have. That idea flourished in the 1980's, first in cases involving severely disabled women whose parents or guardians sought judicial authorization of sterilization, later in the jurisprudence of death and dying.

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1993); *In re Martin*, 538 N.W.2d 399 (Mich. 1995); *Spahn v. Eisenberg*, 543 N.W.2d 485 (Wis. 1997)

In re Grady,<sup>62</sup> decided by the New Jersey Supreme Court in 1981, is illustrative.<sup>63</sup> Lee Ann Grady was a 19 year-old so severely mentally impaired by Down's Syndrome that she could not understand pregnancy and would never be able to care for a child. Her parents sought judicial endorsement of their determination as guardians that Ms. Grady's interests would be promoted by sterilization. The parents felt that such reliable contraception would facilitate Lee Ann's move to a desirable group home setting. Writing for the Court, Justice Morris Pashman saw 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."<sup>64</sup> Justice Pashman understood that the patient could never exercise autonomous choice, but that freedom to have a surrogate opt for a result beneficial to the patient's interests was critical both to the patient's well being and to her constitutional interests. He noted the coexistence of Ms. Grady's two liberty interests -- in procreating and in not procreating.<sup>65</sup> He observed that a competent person has a constitutional right to choose between the two courses and that such a critical choice would

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<sup>62</sup> 426 A.2d 467 (N.J. 1981).

<sup>63</sup> A few cases decided even before the 1980's upheld the jurisdiction of courts to authorize sterilizations sought by parents and guardians on behalf of their profoundly disabled charges. See *Ruby v. Massey*, 452 F. Supp. 361, 368 (D. Conn. 1978); *Sallmaier*, 378 N.Y.S.2d 989 (N.Y. Sup. Ct. 1976); *In re Simpson*, 180 N.E.2d 206 (Ohio Prob. Ct. 1962); *Jessin v. County of Shasta*, 79 Cal. Rptr 359 (1969). *Grady* in 1981 was a landmark case -- in part because of the carefully considered judicial analysis -- that influenced almost all succeeding courts.

<sup>64</sup> *Grady*, 426 A.2d at 469.

<sup>65</sup> Sterilization is just one instance where a medical choice impacts 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).

impact on the choosing person's well being. 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 in inadequate attention to her best interests.<sup>66</sup> The exercise of surrogate choice would then be the only way to preserve the benefits of a considered decision about Lee Ann's procreational future and about her well being with or without sterilization. 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."<sup>67</sup> (Best interests was adopted as the operative inquiry on the assumption that a never-competent person – if miraculously able to express a choice – would want to have her interests furthered when medical choices are made for her). The opinion added:

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 made in her behalf produces a more just and compassionate result than leaving Lee Ann with no way of exercising a constitutional right.<sup>68</sup>

(The Court also dictated safeguards aimed at preventing exploitation by the surrogate decisionmaker. The matter of protecting the profoundly disabled against abuse will be picked up later in this chapter).

Several courts adopted Grady's perspective that failure to permit surrogate choice

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<sup>66</sup> 426 A.2d at 474.

<sup>67</sup> 426 A.2d at 475.

<sup>68</sup> 426 A.2d at 481.

regarding sterilization would deny a patient's constitutional right to procreational choice and might seriously jeopardize a disabled patient's well being.<sup>69</sup> For example, the Massachusetts Supreme Judicial Court, in finding that equity courts have inherent authority to act in a mentally disabled person's best interests (including authorization of sterilization), reinforced its conclusion by noting that a contrary conclusion would impinge the disabled person's constitutional rights. The opinion explained: "government deprives a mentally retarded individual of his or her right to privacy [meaning liberty to avoid procreation] if it denies the person the opportunity to exercise that right [by means of a conscientious surrogate considering various means of contraception]."<sup>70</sup>

That was 1982, a year after Grady. Three years later the California Supreme Court used similar reasoning in invalidating a legislative framework that had purposefully excluded a sterilization option from the prerogatives of conservators (guardians) acting on behalf of mentally disabled people. In Valerie N.,<sup>71</sup> the court declared that the legislative denial of an opportunity to have a surrogate opt for sterilization had deprived developmentally disabled persons of procreative choice -- a fundamental liberty interest -- in violation of both the federal and state

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<sup>69</sup> For a list of the relevant cases, 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). See also John Hackett, Note, Procreative Choice for the Incompetent Developmentally Disabled, 36 DePaul L. Rev. 95, 102-03, 111 (1986). Not every judicial decision in the 1980's favored allowing surrogate consent to sterilization. See *Matter of Eberhardy*, 307 N.W.2d 881 (Wis. 1981) (finding no jurisdiction to authorize a guardian's choice of sterilization for a profoundly disabled ward).

<sup>70</sup> *Matter of Moe*, 432 N.E.2d 712, 719 (Mass. 1982). See also *Wentzel v. Montgomery General Hospital*, 447 A.2d 1244, 1258 (Md. App. 1982).

<sup>71</sup> *Conservatorship of Valerie N.*, 707 P.2d 760 (Calif. 1985).

constitutions. The court noted not just the disabled person's constitutional interests at stake, but the practical interests in having a procreative decision that would best promote personal growth and development. 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 than does her competent sister."<sup>72</sup> 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.

An intermediate appellate court in California in 1988 employed similar reasoning in the context of an end-of-life decision on behalf of a now-incompetent patient.<sup>73</sup> The patient, William Drabick, was a 44 year-old male mired in a permanently unconscious state as a result of severe brain damage incurred in an automobile accident several years earlier. His brother as conservator (guardian) sought judicial approval of removal of a life-sustaining feeding tube. The intermediate appellate court (the highest court to consider the matter, as the California Supreme Court declined review) ruled that the now-incompetent patient has a right to have a surrogate make a choice about continued life support according to a standard or guideline that reflects the patient's interests. The court acknowledged that William could not currently (and did not previously) make a conscious choice, and so invoking a right to choose in some sense involves a legal fiction. According to the court, though, absence of capacity to choose ought not entail

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<sup>72</sup> 707 P.2d at 773.

<sup>73</sup> *Matter of Drabick*, 200 Cal. App. 3d 185 (Cal. App. 1988). But see *Conservatorship of Wendland*, 28 P.3d 151 (Cal. 2001).

forfeiture of William's fundamental interest in sound medical treatment decisions.<sup>74</sup> 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."<sup>75</sup>

By embracing surrogate choice reflecting the patient's interests rather than a technological imperative to do everything possible to preserve life, the court saw itself as promoting "respect for persons."<sup>76</sup> For the Drabick court, incapacitated as well as capacitated persons ought to be entitled to the exercise of treatment options that would advance their personal interests.<sup>77</sup> The connection between respect for persons and access to beneficial surrogate choice thus echoed a theme first uttered in Saikewicz in 1977 and repeated in the Moe and Valerie N. cases previously described. The notion is that 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

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<sup>74</sup> 200 Cal. App. 3d at 208

<sup>75</sup> Id. at 205.

<sup>76</sup> Id. at 208.

<sup>77</sup> See also *Matter of L.W.*, 482 N.W.2d 60, 68-69 (Wis. 1992)(allowing a surrogate choice to end life support for a 79 year-old lifelong incompetent now deteriorated to a permanently vegetative state). Unfortunately, both California and Wisconsin have retreated from this favorable disposition toward surrogate end-of-life decisions. Both states confine a surrogate 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 *Wendland and Spahn*, *supra* note



suffering or indignity might be entailed.<sup>78</sup> The accompanying blow to personal well being and dignity warrants recognition of a constitutional right to a surrogate decision when a mentally disabled person's critical medical interests are at stake. The previously described saga of Sheila Pouliot illustrated the inhumane consequences of ignoring such a right.

In 1990, the United States Supreme Court put a significant crimp in 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. The relevant case is Cruzan v Missouri Department of Health<sup>79</sup> and it involved review of Missouri's policy on decisionmaking for incompetent medical patients as applied to a 29 year-old woman named Nancy Beth Cruzan. Ms. Cruzan's parents had sought judicial endorsement of their request to physicians to end the artificial nutrition and hydration (ANH) sustaining their daughter who was lying in a permanently unconscious state as a result of brain damage sustained in a tragic automobile accident years earlier. Missouri's highest court -- in contrast to cases like Quinlan and Drabick in other states -- refused to authorize removal of life support in the absence of "clear and convincing evidence" that the now-incompetent patient had previously dictated such a medical course.<sup>80</sup> The Missouri court upheld the state's "unqualified interest" in preserving life, fearing that without prior instructions from the patient surrogate decisionmakers would be making arbitrary quality of life determinations. The court perceived no impingement of the unconscious patient's

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<sup>78</sup> Mark Kuczewski, Narrative Views of Personal Identity and Substituted Judgment in Surrogate Decision Making, 27 J.Law, Med. & Ethics 32, 34 (Spring 1999).

<sup>79</sup> 110 S. Ct. 2841 (1990).

<sup>80</sup> Cruzan v. Harmon, 760 S.W.2d 408, 426 (Mo. 1989).

constitutionally protected liberty interest because, according to the court, exercise of that interest required an autonomous patient or some clearcut choice by a previously autonomous patient.

Nancy Beth Cruzan's parents sought redress in the United States Supreme Court. They argued that Missouri's restrictive policy for allowing removal of life support denied Nancy Beth liberty in violation of the Fourteenth Amendment. Her parents contended that part of Nancy Beth's liberty interest was to have choices about her medical treatment in a permanently unconscious state made for her in a way that best reflects her interests and values.<sup>81</sup> (One of the personal interests to be protected by a surrogate would be freedom from unwarranted bodily invasions). According to the parents and their supporting amici curiae, Nancy Beth should be constitutionally entitled to an individualized decision about her medical treatment by people who know her previously formed values and preferences and who love her and care about her best interests -- all without the restrictive requirement of clear and convincing evidence that this young woman had previously made an explicit determination about maintenance of life support in case of permanent unconsciousness.<sup>82</sup>

In an opinion for 5 members of the Court, Chief Justice Rehnquist upheld the constitutionality of Missouri's insistence on clear and convincing evidence of the now-

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<sup>81</sup> Petitioners' Brief in *Cruzan v. Director, Missouri Department of Health*, 110 S. Ct. 2841 (1990).

<sup>82</sup> See Brief of Society for the Right to Die, amicus curiae in *Cruzan*. Besides attacking Missouri's restrictive decisionmaking standard, the petitioners in *Cruzan* also argued 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 decisionmaker. Attention to that constitutional claim is deferred to Chapter III dealing with who decides for the profoundly disabled person.

incompetent patient's prior wishes as a prerequisite to removal of life support.<sup>83</sup> While assuming that a competent patient would have a constitutionally protected liberty interest in refusing unwanted medical treatment (in which case state interference with a patient's choice would be subjected to strict judicial scrutiny), Chief Justice Rehnquist showed no similar solicitude for end-of-life decisionmaking on behalf of a now-incompetent patient. While he did not specify the precise standard of judicial scrutiny applicable to Missouri's restriction on surrogate choice, in essence he applied a rational basis standard of review. (The rational basis standard dictates judicial deference to any plausible, legitimate governmental interest underlying a legislative policy -- even if the policy is ill considered and unsound). Using that undemanding approach, he had little trouble finding some legitimate and rational basis for Missouri's restriction on surrogate decisionmaking. Chief Justice Rehnquist viewed 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."<sup>84</sup> Missouri's insistence on personal choice also made some sense to Chief Justice Rehnquist as a prophylactic against potential abuse in surrogate decisionmaking or arbitrary quality of life determinations. Because of such legitimate concerns about abusive or arbitrary decisionmaking, Rehnquist did not think that the Constitution requires states to confer broad "substituted judgment" authority upon surrogates.<sup>85</sup>

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<sup>83</sup> Cruzan v. Director, Missouri Department of Health, 110 S.Ct. 2841, 2846 (1990).

<sup>84</sup> 110 S. Ct. at 2852.

<sup>85</sup> 110 S.Ct. at 2855-56. See 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).

For several reasons, the Supreme Court's 5 to 4 determination in Cruzan constitutes bad jurisprudence. For starters, the Missouri policy was arbitrary in that, at least as applied to permanently unconscious patients like Nancy Beth Cruzan, it accomplished the opposite of its intended result. The Missouri approach insisting on clearcut prior expressions was aimed at implementing the now-incompetent patient's wishes. Yet, by confining removal of life support to the relatively rare instance when a patient previously spelled out such a course, the state mandated life support for the permanently unconscious Ms. Cruzan even though the overwhelming likelihood is that the patient herself would have wanted life support discontinued.<sup>86</sup> (That conclusion flows from data showing that approximately 90% of people consistently prefer death to the insentient limbo of permanent unconsciousness).<sup>87</sup> In other words, by precluding removal of life support from Nancy Beth Cruzan, the chances were better than 9 to 1 that the state was contravening her wishes.<sup>88</sup> Chief Justice Rehnquist conceded that the Missouri approach may have frustrated Nancy Beth's actual wishes and lamely responded:

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<sup>86</sup> For a similar critique of the recent Wendland case from California, see Mary Ann Buckley, Note, In re Wendland: Contradiction, Confusion and Constitutionality, 11 J. of Law & Policy 255, 299 (2002); Howard Brody et al., N. Eng. J. Med.

<sup>87</sup> Citations to relevant surveys can be found in Norman L. Cantor, The Permanently Unconscious Patient, Nonfeeding, and Euthanasia, 15 Am. J. L. & Med. 381 (1989). Since 1989, many additional surveys have confirmed the original findings about people's strong aversion to permanent unconsciousness. Peter A. Singer et al., Quality End of Life Care: Patients' Perspectives, 281 JAMA 163 (1999); Robert A. Pearlman et al., Insights Pertaining to Patient Assessments of States Worse than Death, 4 J. Clinical Ethics 35 (1993).

<sup>88</sup> In her case, the chances were probably even more lopsided since she had uttered expressions that, while not definitive enough to satisfy the Missouri standard of clear and convincing evidence, still indicated a preference not to linger in a permanently unconscious status.

“the Constitution does not require general rules to work faultlessly.”<sup>89</sup>

It is true that the Constitution doesn't require that legally imposed presumptions or default rules be faultless. An age line (such as a minimum age requirement for voting) is constitutional even though the age line, in its pursuit of maturity in voting, excludes some young but mature persons and includes some old but immature persons. Most, or at least many, persons below the age line would indeed be immature. So the age line generally (albeit inexactly) promotes the object of enhancing voter maturity. Similarly, a mandatory retirement policy can have a perverse effect in ousting some still capable workers, but at least if fixed at a sufficiently advanced age, it also rids the employer of many workers whose capabilities have declined with age. By contrast, Missouri's policy as applied to permanent unconsciousness would have a perverse effect of contravening the desires of the patient (albeit desires not fully articulated) in approximately 90% of the cases.<sup>90</sup> Chief Justice Rehnquist argued that a life-affirming presumption is defensible because a mistaken judgment to withdraw life support is irremediable.<sup>91</sup> Yet a mistaken (in the sense of contrary to the patient's wishes) judgment maintaining life support accomplishes an irreparable injury in three respects -- contravening the patient's likely will, preserving an existence that the patient would deem intolerably undignified, and soiling the survivors' memories of the once vital patient. “[C]ontinuing treatment for a patient who would have wanted treatment stopped is as unfortunate as discontinuing treatment

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<sup>89</sup> 110 S.Ct. at 2854.

<sup>90</sup> On the irony of “protecting” vulnerable patients by mandating life support contrary to what they would likely prefer, see Steven Miles & Allison August, Courts, Gender, and the Right to Die, 18 Law, Med. & Health Care 85, 92 (1990).

<sup>91</sup> 110 S.Ct. at 2854.

for a patient who would have wanted treatment continued \* \* \*.”<sup>92</sup> If promoting the wishes of the now-incompetent patient is the ultimate goal, it makes much more sense -- in the absence of clearcut prior expressions from the patient -- to examine first the patient’s values and goals and then, if they are not definitive, to follow what a strong majority of people would want done in the circumstances at hand.<sup>93</sup>

Justice Brennan, dissenting in Cruzan, picked up on the perverse impact of a state’s insistence on clearcut prior expressions as a prerequisite to any removal of life support.<sup>94</sup> Brennan acknowledged a state interest in providing Ms. Cruzan with a treatment course that would mirror her personal wishes. But he castigated the state and the Supreme Court majority for using evidence of clearcut prior expressions as the sole determinant of her likely wishes. For Justice Brennan, Missouri’s framework discarded evidence of Ms. Cruzan’s values and ignored meaningful (even 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.”<sup>95</sup>

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<sup>92</sup> Laurence Tribe, *Constitutional Law* Section 15-11, p. 1369. For other views that mistakenly preserving a person’s life can have dire consequences, see Nancy Rhoden, *Litigating Life and Death*, 102 Harv. L. Rev. at 436; David J. Mays & Martin Gunderson, *Vitalism Revitalized*, 32:4 Hastings Center Report (July 2002) 14, 19.

<sup>93</sup> See *In re A.C.*, 573 A.2d 1235 (D.C. App. 1990); *In re Bryant*, 542 A.2d 1216, 1220 (D.C. App. 1988); *Wentzel v. Montgomery General Hospital*, 447 A.2d 1244, 1258 (Md. App. 1982). There would be various means of measuring majority sentiment toward medical handling in particular circumstances. See Cantor, *supra* note 12 at 1255-67. Of course, majority sentiment would be known only as to certain common situations (such as permanent unconsciousness or extreme mental deterioration). In other situations -- i.e., where no knowledge exists about strong majoritarian preferences -- a life-preserving presumption would prevail.

<sup>94</sup> *Cruzan*, 110 S.Ct. at 2868-69.

<sup>95</sup> 110 S.Ct. at 2878.

Cruzan's defects extend beyond this glaring discrepancy between the object of accomplishing the patient's wishes and the means chosen by Missouri to accomplish that object. Chief Justice Rehnquist's majority opinion pays scant attention to the forfeiture of critical interests that takes place when government precludes withdrawal of life support from an incapacitated patient absent clearcut prior expressions. (Missouri's policy forecloses surrogate resort to the unconscious patient's best interests, including interests of constitutional dimension such as bodily integrity, avoidance of suffering, and human dignity).

The majority's inadequate attention to Ms. Cruzan's constitutional interests did not escape Justice Stevens. Justice Stevens' Cruzan dissent highlighted the harm to constitutionally cognizable interests caused by Missouri's narrow decision-making scheme and condemned the majority for neglecting those interests.<sup>96</sup> Justice Stevens pointed to an incapacitated patient's interest in bodily integrity and a concomitant right to be free of unwarranted bodily invasions, matters sacrificed by Missouri except for the extraordinary patient with the foresight to issue unambiguous prior instructions. Justice Stevens also recognized the incapacitated patient's interests in avoiding suffering (though probably not applicable to the unconscious Ms. Cruzan), in being remembered as a vital individual (i.e., in preserving her lifelong image), and in obtaining a life closure consistent with her own values, beliefs, and preferences (even if those preferences are not spelled out in detail).

In the case of a permanently unconscious patient like Ms. Cruzan, the patient also has an important interest in having her intrinsic human dignity respected. Ms. Cruzan's counsel accurately portrayed the degrading limbo to which Missouri seemed to be condemning her:

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<sup>96</sup> 110 S.Ct. at 2890-92.

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 \* \* \*.<sup>97</sup>

Justice Stevens responded appropriately. He labeled Missouri's neglect of Ms. Cruzan's various interests -- other than biological existence -- as a denial of personhood,<sup>98</sup> thus recalling the admonition of state cases like 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 costs.<sup>99</sup> Justice Stevens clearly appreciated the important connection between human dignity and mentally incapacitated patients' access to surrogate medical decisions potentially benefitting the patients.

By contrast, the Cruzan majority, in upholding Missouri's approach demanding clear prior expressions, showed precious little appreciation for the consequences of that approach upon debilitated, dying patients. In Ms. Cruzan's instance, she was unconscious and therefore unsensory of the various affronts to her interests perpetrated by Missouri's rule. Other dying patients, even if mentally incapacitated, can acutely experience the affronts involved. Philip Peters has commented: "The irrebutable presumption [absent clearcut prior expressions] that all

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<sup>97</sup> Petitioner's Reply Brief in Cruzan. Ms. Cruzan's limbo did not endure 30 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 A. Leschensky, Note, Constitutional Protection of the Refusal of Treatment, 14 Harv. J. L. & Public Policy 248, 259 (1990).

<sup>98</sup> 110 S. Ct. at 2890.

<sup>99</sup> Justice Brennan also invoked Drabick and its notion that respect for persons demands allowing surrogates to take incapacitated persons' interests into account. 110 S.Ct. at 2888. See also Strasser, *supra* note 19, at 756.



lives are worth living will condemn many patients to unnecessary treatment, suffering, indignity, or pointless existence.”<sup>100</sup> The negative consequences are perhaps starkest with regard to the suffering experienced by some still conscious patients. American courts have generally recognized that for some dying patients the burdens of continued existence outweigh the benefits, and that conscientious surrogates may sometimes make such a judgment and order a cessation of life-sustaining medical intervention.<sup>101</sup> Recall the case of Sheila Pouliot, the profoundly disabled woman who lingered semi-conscious for 2 months, swelled up like the Michelin man and unable to interact with her environment except to moan in pain -- all because New York law would not allow removal of life support from a dying person in the absence of clearcut prior instructions. Consider also the case of infants born with certain grave deficits 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 some surrogate be able to put an end to medical intervention that is prolonging extreme and unremitting suffering.<sup>102</sup> Even the federal regulations aimed at narrowing medical decisions not

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<sup>100</sup> Philip 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: “[The *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.” Moreno, *Who's to Choose? Surrogate Decisionmaking in New York State*, 23:1 Hastings Cent. Rep. (1993), 5,6.

<sup>101</sup> See, e.g., *Matter of Conroy* 486 A.2d 1209, 1242 (N.J. 1985); *Rasmussen*, 741 P.2d at 689; *Grant*, 747 P.2d at 457.

<sup>102</sup> *In re K.I.*, 735 A.2d 448 (D.C. 1999); *Newmark v. Williams*, 588 A.2d 1108 (Del. 1991); *Matter of AMB*, 640 N.W.2d 262 (Mich. App. 2001); *In re Christopher I.*, 131 Cal. Rptr. 122, 136 (Cal. App. 2003); *In re C.A.*, 603 N.E.2d 1171 (Ill. App.1992). See Carol A. Heimer, *Competing Institutions: Law, Medicine, and Family in Neonatal Intensive Care*, 33 Law & Society Rev. 17, 42-43 (1999). But see *Montalvo v. Borgevec*, 647 N.W.2d 413 (Wis. 2002).

to treat afflicted newborns leave some leeway for non-treatment where intervention would be “virtually futile and inhumane.”<sup>103</sup>

To sum up Cruzan, the Supreme Court’s willingness to uphold Missouri’s approach to end-of-life decisionmaking for the mentally disabled imperiled both the constitutional interests of incapacitated patients like Nancy Beth Cruzan and the temporal welfare of other, conscious dying patients. While Chief Justice Rehnquist’s opinion accepted the premise that a competent Ms. Cruzan would be constitutionally entitled to reject life support,<sup>104</sup> the prerogative of ending medical intervention prolonging a dying process could be preserved in Missouri only by the extraordinary prescience of the young woman in anticipating and spelling out in advance her desires concerning medical intervention in a permanently unconscious state. Once Ms. Cruzan lost decision-making capacity without clearcut advance instructions, her incompetent status allowed the state to erect a “protective” bar to any terminal decision despite the contravention of her likely wishes and impingement of her bodily integrity and dignity interests. Missouri’s concern about exploitation of vulnerable patients provided -- according to Chief Justice Rehnquist -- a sufficient constitutional justification, i.e., a rational basis, for its policy.

What *should* the Supreme Court have done in Cruzan? What constitutional doctrine

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<sup>103</sup> Development in the Law, *supra* note 10, 103 Harv. L. Rev. at 1602-03, quoting from the Child Abuse Amendments of 1984. Those regulations in any event are not directly applicable to health care providers. Heimer, *supra* note 102, at 57-58; Tucker & Goldstein, *The Legal Rights of Persons with Disabilities* (1992), 19:26; *Miller v. HCA*, 2003 WL 22232090 (Tex. 2003).

<sup>104</sup> 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, 117 S.Ct. 2258, 2270 (1997).

should have been crafted to deal with medical decisionmaking for a now-incompetent patient?

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) control post-competence medical decisions and to recognize every incapacitated patient's constitutional right to have her contemporaneous well being considered by a surrogate decisionmaker operating on the patient's behalf.<sup>105</sup> Justice Stevens set a fitting course when he suggested that the Constitution (meaning 14<sup>th</sup> Amendment liberty "requires the State to care for Nancy Cruzan's life in a way that gives appropriate respect to her own best interests."<sup>106</sup>

Appropriate respect in this context means having a conscientious surrogate consider the patient's various interests (including prior values and preferences, as well as current well being).<sup>107</sup> For profoundly disabled, never-competent persons, prior values and preferences can never have an autonomous force,<sup>108</sup> so that a surrogate's focus must be on the patient's well being.

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<sup>105</sup> See *Guardianship of Ruth E.J.*, 540 N.W.2d 213, 217 (Wis. App. 1995)(invalidating state efforts to exclude electroconvulsive treatment); Rebecca M. Keown, A Case-Based Approach to Sterilization of Mentally Incompetent Women, 1 *Princeton J. Bioethics* 94, 106 (1998).

<sup>106</sup> 110 S.Ct. at 2879. See also Michael T. Morley, Note, Proxy Consent to Organ Donation by Incompetents, 111 *Yale L. J.* 1215, 1218 (2002) (favoring a constitutional right to a surrogate's determination); Deborah K. McKnight & Maureen Bellis, Foregoing Life-Sustaining Treatment for Adult, Developmentally Disabled, Public Wards, 18 *Am. J. L. & Med.* 203, 213 (1992) (urging incapacitated persons' "right to have appropriate medical decisions made on their behalf").

<sup>107</sup> See Strasser, *supra* note 19 at 739; John Robertson, *Cruzan* and the Constitutional Status of Nontreatment Decisions for Incompetent Patients, 25 *Ga. L. Rev.* 1139, 1187 (1991). *Contra*, *Matter of Wendland*, 28 P.3d 181 (Calif. 2001); *In re Martin*, 538 N.W.2d 399 (Mich. 1995).

<sup>108</sup> The fact that a profoundly disabled person cannot make autonomous choices does not mean that the person's preferences and expressions can be ignored. Chapter VI, *infra*, speaks to

Consideration of current well being, in turn, means surrogate weighing of the various benefits and burdens associated with the medical choice being contemplated, with the patient's net best interests serving as the surrogate's decisional guide. In end-of-life contexts, a surrogate ought to be able to sometimes conclude that the disabled patient would be better off dead than alive because of unremitting suffering or grievous debilitation (to the point of intrinsic indignity), so that life support should be withdrawn. 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. (More on the contents of the best interests formula, including human dignity, in Chapter IV, *infra*).

I am aware of 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 implement an incapacitated person's constitutional interests. Several cases dealing with abortion require that a regulating state -- in seeking to impose a parental notification requirement -- must provide a judicial bypass process enabling a judge to rule on the best interests of any minor seeking an abortion, including an immature minor who lacks capacity to make her own determination.<sup>109</sup> The judicial bypass process must be made available to any minor unwilling to involve her parents in the critical abortion decision. This mandatory access to a neutral decisionmaker who is

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the importance of a profoundly disabled person's voice to a surrogate's assessment of a ward's feelings and interests.

<sup>109</sup> Lambert v. Wicklund, 117 S.Ct. 1169 (1997); Ohio v. Akron, 110 S.Ct. 2972, 2979 (1990); Bellotti v. Beaird, 99 S.Ct. 3035, 3048-51 (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, 48 UCLA L. Rev. 1125, 1165-66 (2001).

required to follow the minor's best interests is aimed at safeguarding the minor's liberty interest in deciding 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 entailing careful consideration of the minor's various interests.<sup>110</sup>

These abortion cases involving minors provide an analogy to the broader issue of medical decisionmaking for the profoundly disabled. In both settings, a fundamental liberty interest is at stake -- in one a choice about continuing a pregnancy, in the other a choice about receiving life-sustaining medical intervention (or sterilization or any other serious medical intervention). In both settings, state failure to allow surrogate choice relegates the incapacitated patient to a status quo (without access to a possibly desirable medical option) in a way that offends human well being and, sometimes, human dignity by precluding consideration of that person's various interests. In both settings, I suggest, an incapacitated person's liberty interest triggers a requirement that a surrogate be allowed to choose among medical options according to the dependent person's interests. The abortion cases support the argument here that constitutional liberty ought ordinarily be deemed to include surrogate choice when the mentally incapacitated rights bearer cannot exercise the medical choice at stake.

The constitutional principle for which I am arguing would be limited in ways I will sketch here. First, the contemplated decision-making authority lodged in a surrogate must be constrained in a manner consistent with the helpless ward's interests. Unbridled authority in the

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<sup>110</sup> "[E]very minor must have the opportunity . . . to go directly to a court without first consulting or notifying her parents." Guggenheim, *supra* note 109 at 589.

hands of a surrogate would raise the spectre of arbitrary decisionmaking 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 helpless populations against abuse. This means that a surrogate's decision-making prerogative must be limited -- bound by standards such as substituted judgment (where the now-incompetent person was formerly competent) and best interests (where the person was never competent or, if formerly competent, never provided meaningful guidance about the decision at hand). This lesson about standards limiting surrogate discretion can be gleaned from older cases dealing with sterilization of profoundly disabled persons.<sup>111</sup> Those 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 grounded on the best interests of the ward. A similar message emanated from numerous decisions in the 1980's upholding a surrogate's authority to seek sterilization *in the best interests* of a child or ward.<sup>112</sup>

In the contemplated constitutional framework, 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 the fiduciary standards that bind a parent or guardian in charge of decisions on behalf of a

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<sup>111</sup> North Carolina Ass'n for Retarded Children, 420 F. Supp. 451, 455-56 (D. 1976); Wyatt v. Aderholt, 368 F. Supp. 1383, 1385 (M.D. Ala. 1974). See Kraus, *supra* note 36 at 342.

<sup>112</sup> See, e.g., In re A.W., 637 P.2d 366, 376 (Colo. 1981); In re P.S., 452 N.E.2d 969 (Ind. 1982); In re Debra B., 495 A.2d 781, 783 (Me. 1985).

mentally disabled individual.<sup>113</sup> The enforcement responsibility that would be incorporated into the constitutional framework would include criminal machinery to punish serious deviation from acceptable guardianship standards and civil machinery to actively intervene and supplant surrogate decisions inconsistent with the well being of the ward. I have in mind the kinds of child protection and adult guardianship agencies found in most states.<sup>114</sup>

What about state prophylactic rules -- efforts to bar entire subject areas from surrogate choice in order to preclude mistreatment of vulnerable disabled populations?<sup>115</sup> This was Missouri's rationale in Cruzan in barring surrogate end-of-life decisions in the absence of clear and convincing evidence of the patient's explicit wishes. While the state's protective concern is entirely legitimate, its sweeping means to accomplish its object are unacceptable. At least in the context of a fundamental liberty interest, such as choice about life-sustaining medical intervention, Missouri should be required to make a stronger showing than it did in two ways. A state ought to be able to exclude an entire area of potentially beneficial medical decisions from surrogate choice only upon a showing of substantial abuse -- or the threat of such abuse -- by surrogates. Missouri made no showing that helpless patients had been exploited in a manner

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<sup>113</sup> Grady, 426 A.2d at 479. See generally Douglas R. Rendleman, *Parens Patriae* from Chancery to the Juvenile Court, 23 So. Car. L. Rev. 204, 240 (1971).

<sup>114</sup> For description of the kinds of agencies that protect developmentally disabled persons against abuse, see McKnight & Bellis, *supra* note 106 at 217-19.

<sup>115</sup> Many states foreclose guardians' 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.

warranting a virtually wholesale exclusion of surrogate choice in the area of end-of-life decisionmaking. Moreover, even if there appeared to be a substantial threat of abuse of surrogate authority, a state should have to consider less drastic alternatives -- i.e., means of protecting helpless populations short of excluding all surrogate choice -- before excluding an entire subject matter from surrogate control.<sup>116</sup>

A variety of alternative safeguards are available to make sure that surrogate decisions affecting the disabled are not abusive. One technique is to refine the best interests standard by spelling out the factors that are supposed to govern a surrogate's decision. For example, in the context of sterilization, best interests could be broken down to include focus on the physical and mental needs of the disabled patient (as opposed to the convenience of surrounding family or caretakers), as well as on the availability of alternative contraceptive techniques.<sup>117</sup> An additional protective step is to explicitly warn surrogates and medical personnel against allowing common prejudices or stereotypical misconceptions to play a role in surrogate decisionmaking.<sup>118</sup> 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

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<sup>116</sup> See *Valerie N.*, 707 P.2d 760, 775 (Calif. 1985)(striking down a statute that excessively impeded surrogate decisionmaking regarding sterilization).

<sup>117</sup> See, e.g., *In re A.W.*, 637 P.2d 366, 375 (Colo. 1981); *Hayes*, 608 P.2d at 641. Cf. *In re Branning*, 1998 WL 21855, 1998 Ill. Lexis 6 (Ill. 1998)(invalidating a statutory scheme for authorization of electroconvulsive therapy because of inadequacies in spelling out the decisionmaking standards).

<sup>118</sup> 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. *In re Grady*, 426 A.2d 467, 472 (N.J. 1981).



standards of patient care.<sup>119</sup>

Beside carefully articulating a standard for surrogate decisionmaking, a state can build in procedural safeguards to ensure that the standards are adhered to. If a parent or guardian is accorded decisionmaking authority, that surrogate's decision can be subjected to mandatory independent review, such as by an institutional ethics committee. That review can scrutinize both the underlying facts and the surrogate's application of the relevant decision-making standard to those facts.<sup>120</sup> Or, as in the case of sterilization decisions, decision-making authority can be relegated exclusively to a judge charged with deciding after fair hearing processes. (Chapter III further considers both existing decision-making frameworks for critical medical decisions and desirable alterations. There, I express my opposition to systematic judicial involvement in medical decisions for profoundly disabled persons). Typical hearing requirements regarding a sterilization decision include appointment of a guardian ad litem to represent the incapacitated person's interests and appointment of medical experts.<sup>121</sup> Another possible safeguard is to adjust the standard of proof to be utilized by the surrogate decisionmaker. For example, many decisionmaking frameworks applicable either to end-of-life or sterilization determinations have

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<sup>119</sup> AMA Council on Ethical and Judicial Affairs, Policy E-2.20.

<sup>120</sup> For a model framework designed to provide non-judicial review of surrogate end-of-life decisions, see McKnight & Bellis, *supra* note 106 at 228-31. That model -- applicable to surrogate end-of life decisions regarding institutionalized patients -- includes independent medical review and scrutiny by an institutional ethics committee as well as an agency charged with protecting the developmentally disabled.

<sup>121</sup> 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.

insisted upon “clear and convincing” evidence that the incapacitated patient’s interests dictate a particular medical course.<sup>122</sup> These various safeguards provide alternative means to curb abusive treatment of disabled persons short of preventing all access to a possibly beneficial medical decision.

This sketch of the constitutional approach that should have been applied in Cruzan leaves unresolved issues. As to 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. Justice Stevens in his Cruzan dissent commented that it is “debatable” whether judicial process could be imposed as a prerequisite to a withdrawal of life support.<sup>123</sup> (Chapter III will further discuss the question of who should decide, i.e., who should be surrogates for profoundly disabled patients with regard to various types of medical decisions. As will be seen, while I argue here 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 decisionmaker must be. In other words, allocation of serious medical decisions to judges would be constitutional, even though it would not be sound public policy).

The applicable standard of proof binding the surrogate could also be controversial. Many

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<sup>122</sup> See, e.g., *Matter of Hayes*, 608 P.2d 635 (Wash. 1980); *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. App. 1985).

<sup>123</sup> 110 S.Ct. at 2884 n.13.

sources would argue that a conscientious surrogate ought to have discretion to make a judgment about a ward's best interests without a requirement that the judgment be grounded on clear and convincing evidence. However, as already noted, many states have imposed a requirement of clear and convincing evidence of best interests. That standard is probably constitutionally acceptable (even if 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.<sup>124</sup> While a clear and convincing evidence standard is constitutionally tolerable, any higher standard would probably be unconstitutional. For example, setting proof beyond a reasonable doubt as a prerequisite to surrogate action is probably an unconstitutional barrier to surrogate choice.<sup>125</sup>

A requirement that a surrogate medical decision be grounded on clear and convincing evidence of best interests may be constitutionally tolerable, but that doesn't mean that it is 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 for a fatally stricken cancer patient impacts the patient's rights to bodily integrity and to reject life-sustaining medical intervention, but a decision against chemotherapy preserves bodily integrity and fundamental interests in continued life. Given that

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<sup>124</sup> *Lambert v. Wicklund*, 117 S.Ct. 1169 (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*, 1998 WL 21885 (Ill. 1998); *Matter of Shirley Hilstrom*, 363 N.W.2d 871, 877 (Minn. App. 1985).

<sup>125</sup> *Angela D.*, 70 Cal. App.4th 1410, 1418 (Cal. App. 1999).

the surrogate medical choice affects important personal interests no matter what the option chosen, a case can be made for allowing the surrogate to act upon a preponderance of the evidence in either direction.<sup>126</sup> Medical uncertainty may too often inhibit a clear and convincing conclusion one way or the other, even though the surrogate determines that the incapacitated person's best interests probably lie in a particular direction. Some medical issues are so tied up with uncertain variables and professional judgment that they are not readily susceptible to a clear and convincing standard of proof.

On the other hand, even when important constitutional interests lie on either side 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 sterilization be based upon clear and convincing evidence. Nonetheless, if failure to perform a 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 (e.g., heart bypass) involves a serious bodily intrusion and some mortal risk, but failure to perform the surgery seriously endangers the patient's life. A preponderance of the evidence standard is therefore defensible<sup>127</sup> and perhaps even wise.

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<sup>126</sup> See Buckley, *supra* note 86 at 303-04 (criticizing a clear and convincing evidence standard in the context of refusal of medical intervention).

<sup>127</sup> Cf. *Addington v. Texas*, 441 U.S. 418, 430 (1979) (upholding a lesser standard of proof (than clear and convincing) for civil commitment) and *In re Wirsing*, 573 N.W.2d 51, 55 (Mich. 1998) (rejecting a clear and convincing proof standard for sterilization).

My suggested constitutional approach -- recognizing 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 withholding of treatment decisions (pursuant to previously issued instructions) to a point where the now-incompetent patient is “terminal,” variously defined. Sometimes, terminal is defined to mean that death is unavoidable within a short period. For example, terminal may be defined as an unavoidable death within six months (or some other period).<sup>128</sup> A terminal patient limitation excludes surrogate decisions (despite their 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 definition of terminal. 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. The same constitutional infirmity affects some state surrogacy laws designating next of kin (in descending order) as authorized decisionmakers for incapacitated patients.<sup>129</sup> Some of these statutes empowering next of kin to act as medical decisionmakers confine the decisionmakers’ authority regarding end-of-life decisions to circumstances where the ward is terminal. Similar constitutional doubt hangs over advance directive legislation purporting to exclude withdrawal of artificial nutrition and hydration (ANH) as a surrogate option. No persuasive government interest warrants treating ANH differently from other forms of medical intervention, the Pope’s opinion to the contrary notwithstanding.

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<sup>128</sup> E.g., Cal. Health & Safety Code, Section 1250(B);

<sup>129</sup> Ore. Rev. Stat. §97.083, 127.635; Va.Code §54.1-2986; No. Car. Gen.Stat. §90-322.

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 within a surrogate’s decision-making calculus, or must the disabled person’s interest be the 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? I suggest that the answer to these questions is yes, but those issues will not be resolved at this point. Chapter IV will continue discussion of the bounds of a best interests formula as a matter of public policy, though it will not pursue the constitutional aspects of that matter. Chapter V considers the tension between best interests of the incapacitated person and medical decisions, such as tissue donation and participation in non-therapeutic medical research, that primarily benefit others.

My basic point here is that Cruzan was wrongly decided, and that constitutional liberty dictates, in most contexts affecting an incapacitated person’s critical interests, that the incapacitated person is entitled to a surrogate determination grounded in that incapacitated person’s interests. (I say *most* contexts because, as noted in the Introduction, 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). The proposed constitutional right to a surrogate determination at least applies to the important, potentially beneficial medical decisions at the heart of this book.

To this point, the constitutional analysis has centered on the Cruzan case which involved

a previously competent person who had permanently lost cognitive capacity. The subject of this book is lifelong profoundly disabled persons. Does the constitutional analysis change when the medical fate of a never-competent person is in issue? There are some distinctions between the case of a previously competent person and that of a never-competent person, but they probably do not change the bottom line argument in favor of a liberty right to have critical medical determinations made by a surrogate bound to respect the incapacitated person's interests. In fact, some distinctions between the typical case of a never-competent person and that of a permanently unconscious being like Ms. Cruzan make the former's case even stronger than Ms. Cruzan's.

One distinction between the previously competent and never-competent patient relates to the personal interests affected if a state excludes surrogate decisions on behalf of a now-incompetent patient. A previously competent patient's self-determination interest may be at stake while that is not so for a never-competent person. The previously competent patient has had an opportunity to exercise personal choice, i.e., self-determination, via prior expressions, so that state constraints on surrogate choice may impede implementation of the dependent person's constitutional liberty in the sense of autonomous choice. For example, Ms. Cruzan by age 27 had had an opportunity to form personal values and preferences -- and even express specific choices - - that would inform how she would want to resolve the issue of life support in case of permanent unconsciousness. A profoundly disabled person never has the capacity for this level of self-determination, so that exclusion of surrogate choice on an issue like 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 are even more severe on a lifelong 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). A lifelong profoundly disabled person has no opportunity to meet the Missouri standard.

Another contrast between Ms. Cruzan and the typical 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 forgoing possibly life-sustaining medical intervention. Recall Sheila Pouliot who lay moaning for two months as edema swelled her body and broke down her skin. Avoidance of unnecessary suffering has even been recognized by a number of Supreme Court justices as an interest of constitutional dimension safeguarded by Fourteenth Amendment liberty.<sup>130</sup>

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<sup>130</sup> That recognition came in several concurring opinions issued in the 1997 decisions rejecting constitutional challenges to state laws punishing physician assistance to suicide. *Washington v. Glucksberg*, 117 S.Ct. 2258 (1997); *Vacco v. Quill*, 117 S.Ct. 2293 (1997).



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.<sup>131</sup> State exclusion of such an option would be cruel and inhumane.

Angela Holder explains:

The plight of a severely retarded woman who cannot understand that she is having a baby and why it hurts so much is a situation where any discussion of her right to procreate makes a mockery of her humanity and her dignity.<sup>132</sup>

The medical circumstances of a profoundly disabled person might also make sterilization a needed process in order 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.<sup>133</sup> (In that instance, the disabled woman had a seizure condition that would be

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Several justices indicated that they would perceive significant constitutional problems if a state banned 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 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 to Palliative Care*, 337 N. Eng. J. Med. 1234 (1997).

<sup>131</sup> See *In re Jane A.*, 629 N.E.2d 1337, 1340 (1994); *Jane Doe*, 533 A.2d 523, 526 (R.I. 1987); *D.W.*, 481 N.E.2d 355 (Ill. App. 1985)..

<sup>132</sup> Angela R. Holder, *Legal Issues in Pediatrics and Adolescent Medicine* (1985) 285.

<sup>133</sup> *Angela D.*, 70 Cal. App.4th at 1419. See also *Ruby v. Massey*, 452 F. Supp. 361, 363 (D. Conn. 1978); *Matter of Susan S.*, 1996 WL 75343 (Del. Ch. 1996); *Matter of E.J. Nilsson*, 122 Misc. 2d 458 (N.Y. Sup. Ct. 1983).

exacerbated by pregnancy. The California court ruled that she had a right to have a sterilization decision made on her behalf in order to enjoy the same benefits as a non-disabled person).<sup>134</sup>

Again, categorical exclusion of surrogate choice of 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 isolation in social relations or intrusive monitoring of behavior in order to avoid pregnancy. The New Jersey Supreme Court commented in the previously discussed Grady case:

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.<sup>135</sup>

When Justice Rose Bird dissented from the California Supreme Court's authorization of a 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?<sup>136</sup>

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.

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<sup>134</sup> Angela D., 70 Cal. App.4th at 420.

<sup>135</sup> In re Grady, 426 A.2d 467, 486 (N.J. 1981).

<sup>136</sup> . Dworkin, supra note 25, at 59-60.

I suggested in Chapter I that intrinsic human dignity has an important role in shaping the medical handling of profoundly disabled persons. This context is one example. 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 decisionmaking 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,<sup>137</sup> 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.<sup>138</sup> 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 Beth Cruzan a slave of medical technology. Alex Capron viewed Ms. Cruzan as “enslaved by the extraordinary and evergrowing ability of medicine to sustain vital functions.”<sup>139</sup> Giles Scofield called Cruzan the twentieth century’s equivalent of Dred Scott in its failure to “treat Nancy Cruzan as a person instead of a slave.”<sup>140</sup>

The dehumanizing effect of excluding surrogate choice also accounts for the previously

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<sup>137</sup> “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 , at 976.

<sup>138</sup> See Peters, *supra* note , 50 Ohio St. L.J. at 960-61.

<sup>139</sup> Capron, July 1990 presentation in Bellagio, Italy, at 23-24.

<sup>140</sup> Giles R. Scofield, 21:5 Hastings Center Rep. (Sept. 1991), 44.

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 saying that divorce is so personal a choice that a surrogate can never initiate a divorce on behalf of a now-incompetent spouse. The traditional 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 decisionmaker can effectively replicate what the now-incompetent spouse would want. Yet, as recognized in several recent decisions,<sup>141</sup> the categorical exclusion 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."<sup>142</sup> 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.

I have argued to this point that Cruzan was wrongly decided and that the Supreme Court should have ruled that states cannot, constitutionally, circumscribe surrogate choice on behalf of

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<sup>141</sup> Ruvalcalba v. Ruvalcalba, 850 P.2d 674, 681 (Ariz. App. 1993); Nelson v. Nelson, 878 P.2d 335 (N.M. App. 1994); Vaughan v. Vaughan, 648 So.2d 193, 195 (Fla. App. 1994); Kronberg v. Kronberg, 623 A.2d 806, 811-812 (N.J. Ch. Div. 1993). Cf. Newman v. Newman, 191 N.E. 2d 614, 619 (1963) (allowing a surrogate to elect between alimony and a property settlement).

<sup>142</sup> Ruvalcalba, 850 P.2d at 681; Nelson, 878 P.2d at 339-40.

incapacitated persons in the way that Missouri did. John Garvey was right and Chief Justice Rehnquist was wrong. At the same time, I concede that the result in Cruzan was not terribly surprising. The Court was being asked to constitutionalize the handling of incapacitated, dying patients less than 15 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 Chapter -- 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. I contend 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 an end-of-life decision absent clearcut prior expressions (an approach that entirely forecloses a terminal choice for a profoundly disabled person) as well as any state barring the possibility of a sterilization

procedure. My 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 unrelenting suffering.

Of course, my suggested constitutional analysis may not prevail.<sup>143</sup> 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 a disabled patient entails 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"<sup>144</sup> 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 I have urged.

Even if the issue of surrogate decisionmaking 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 interests of the disabled person. This approach ought to apply at least in the contexts of end-of-life decisions, abortion, and sterilization. (The appropriate approach to surrogate decisionmaking relating to organ or tissue donation and participation in medical research is discussed in Chapter V). I have tried to show how it is inhumane and a denial of respect for persons to exclude the

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<sup>143</sup> See *Blouin v. Spitzer*, 2004 WL 187146 (2d Cir. 2004)(refusing to distinguish between the case of a conscious, suffering patient and a permanently unconscious patient like Ms. Cruzan).

<sup>144</sup> 110 S.Ct. at 2859.

profoundly disabled from potentially beneficial surrogate decisions. A legal approach allowing conscientious surrogate decisionmaking yields “a more just and compassionate result,” to use the words of the New Jersey Supreme Court in Grady.<sup>145</sup> The objectives of justice and compassion surely underlie the elaborate guardianship structures that every jurisdiction now supplies on behalf of profoundly disabled persons.<sup>146</sup> Those structures 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.”<sup>147</sup> Even staunch advocates on behalf of disabled persons’ rights sometimes acknowledge that preclusion of surrogate choice can single out and disadvantage the disabled.<sup>148</sup>

The central message of this Chapter, then, is that the profoundly disabled have some rights, though not identical rights with competent persons. One of those rights -- to be established either by constitutional law or public policy -- should be a prerogative to have a conscientious surrogate make critical medical decisions according to the best interests of the disabled patient. The next two Chapters consider who those surrogates should be and what the “best interests” concept embodies.

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<sup>145</sup> Grady, 426 A.2d at 481.

<sup>146</sup> E.g., Conn. Gen. Stat. Annot. Section 45a-682; Mich. Laws Annot. Section 700.5215; Neb. Rev. Stat. Annot. Section 30-2627.

<sup>147</sup> Strasser, *supra* note 19, at 771.

<sup>148</sup> Burt & Price, *supra* note 26, at 102-03. Michael Kindred, Guardianship and Limitations Upon Capacity, in *The Mentally Retarded Citizen and the Law* (Kindred, ed. 1976), 79-80.