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ARE THERE CHECKS AND BALANCES ON TERMINATING THE LIVES OF CHILDREN WITH DISABILITIES? SHOULD THERE BE?

Thomas J. Balch^{*}

A person's right to reasonable notice of a charge against him, and an opportunity to be heard in his defense—a right to his day in court—are basic in our system of jurisprudence; and these rights include, as a minimum, a right to examine the witnesses against him, to offer testimony, and to be represented by counsel.¹

INTRODUCTION

Although the Child Abuse Amendments of 1984² set an objective standard of treatment for disabled infants with life-threatening conditions, by September 1989 a report of the U.S. Commission on Civil Rights concluded the following:

Surveys of health care personnel, the results of investigative reporting, the testimony of people with disabilities and their relatives, and the repeatedly declared views of physicians set forth in their professional journals all combine to persuade the Commission of the likelihood of widespread and continuing denials of lifesaving treatment to children with disabilities. . . . [E]vidence strongly suggests that the situation has not dramatically changed since the implementation of the Child Abuse Amendments of 1984 on October 1, 1985. . . . [C]lose working relationships among State child protective services agencies and members of the medical profession have resulted in

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1. *In re Oliver*, 333 U.S. 257, 273 (1948).

2. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (codified as amended at 42 U.S.C. §§ 5101–5106i (2006) and implemented in relevant part by 45 C.F.R. § 1340.15 (2008)).

the substantial failure of many such agencies to enforce effectively the Child Abuse Amendments of 1984.³

There is little basis to believe that the last two decades have seen more, rather than less, widespread implementation of the standards in the 1984 law. In a 2005 article, physician and attorney Sadath Sayeed bluntly asserted “the striking incongruity between federally derived legal doctrine and normative medical practice” and concluded that “it should come as no surprise that professional adherence to federal policy remains a fiction in the United States”⁴ On the contrary, it is apparent that instead resort has generally been had to the approach advocated by many ethicists and physicians: the use of ethics committees to consider initially controversial or questionable cases in which withholding or withdrawal of life-preserving medical treatment, food, or fluids from children with disabilities is contemplated.

While other articles in this symposium debate the standards incorporated in the Child Abuse Amendments of 1984, this article challenges this widely-promoted—and practiced—alternative. It raises the question whether the use of the ethics committee procedure, in theory and in practice, comports with fundamental norms of due process as they have been recognized in American jurisprudence.

I. THE PREVALENCE OF ETHICS COMMITTEES

Hospital ethics committees have emerged as a common forum for resolving ethical disputes associated with life and death health care decisions.⁵ The rise of the ethics committee to serve in this powerful

3. U.S. COMMISSION ON CIVIL RIGHTS, MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES 148–49 (1989). As a matter of full disclosure, the author served as an attorney-adviser for the commission, participating in the drafting of the report.

4. Sadath A. Sayeed, *Baby Doe Redux? The Department of Health and Human Services and the Born-Alive Infants Protection Act of 2002: A Cautionary Note on Normative Neonatal Practice*, 116 PEDIATRICS e576, e584 (2005).

5. “Although less than one percent of hospitals in the United States had an ethics committee in 1983, today eighty-four percent of large American hospitals have established such committees.” Robin

capacity may be traced to an initial endorsement by the New Jersey Supreme Court in the highly popularized Karen Ann Quinlan case⁶ more than three decades ago.⁷ Since then, the use of hospital ethics committees has been bolstered by the support of a host of influential medical associations⁸ and regulatory entities.⁹ A federal regulatory scheme endorses them in cases involving health care decisions for infants.¹⁰ Two states have mandated the use of ethics committees within hospitals,¹¹ numerous other states have implicitly endorsed the practice of ethics committees by statutorily authorizing their involvement in particular health care decisions,¹² and others have

Fretwell Wilson, *Hospital Ethics Committees As the Forum of Last Resort: An Idea Whose Time Has Not Come*, 76 N.C. L. REV. 353, 356–57 (1997–1998).

6. *In re Quinlan*, 355 A.2d 647, 668–69 (N.J. 1976).

7. See Randall B. Bateman, *Attorneys on Bioethics Committees: Unwelcome Menace or Valuable Asset?*, 9 J.L. & HEALTH 247, 249–250 (1995); Diane E. Hoffman, *Regulating Ethics Committees in Health Care Institutions—Is It Time?*, 50 MD. L. REV. 746, 754 (1991); Bethany Spielman, *Has Faith in Health Care Ethics Consultants Gone Too Far? Risks of an Unregulated Practice and a Model Act to Contain Them*, 85 MARQ. L. REV. 161, 161 (2001) (all commenting that the emergence of hospital ethics committees was spurred initially by *Quinlan*).

8. See Susan M. Wolf, *Ethics Committees and Due Process: Nesting Rights in a Community of Caring*, 50 MD. L. REV. 798, 799 n.10 (1991) (citing Judicial Council, American Medical Association, *Guidelines for Ethics Committees in Health Care Institutions*, 253 J. AM. MED. ASS'N 2698 (1985), AMERICAN NURSES' ASSOCIATION COMMITTEE ON ETHICS, *GUIDELINES FOR NURSES' PARTICIPATION AND LEADERSHIP IN INSTITUTIONAL ETHICAL REVIEW PROCESSES* (American Nurses Association 1985), AMERICAN HOSPITAL ASSOCIATION, *GUIDELINES: HOSPITAL COMMITTEES ON BIOMEDICAL ETHICS* (1984)).

9. See Gail J. Povar, *Evaluating Ethics Committees: What do we Mean by Success?*, 50 MD. L. REV. 904, 905–05 (1991) (citing THE PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT* (1983); THE PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *MAKING HEALTH CARE DECISIONS* (1982); *GUIDELINES RELATING TO HEALTH CARE FOR HANDICAPPED INFANTS*, 45 C.F.R. § 84 APP. C (2005) [Povar cites 1984 edition of *GUIDELINES*]). See also JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS, *COMPREHENSIVE ACCREDITATION MANUAL FOR HOSPITALS* 66 (1995).

10. See HHS MODEL GUIDELINES FOR HEALTH CARE PROVIDERS TO ESTABLISH INFANT CARE REVIEW COMMITTEES, originally published at 50 Fed. Reg. 14,893 (Apr. 15, 1985), as authorized by amendments to the federal CHILD ABUSE PREVENTION AND TREATMENT ACT, 42 U.S.C. §§ 5101–5117 (1988).

11. MD. CODE ANN., HEALTH-GEN. §§ 19-370 to 71 (LexisNexis 2008) (uses term “patient care advisory committee”); N.J. ADMIN. CODE § 8:43G-5.1(h) (2009) (“multidisciplinary bioethics committee, and/or prognosis committee(s), or equivalent(s)”).

12. ARIZ. REV. STAT. § 36-3231B (LexisNexis 2008); COLO. REV. STAT. § 15-18.5-103(6.5) (2008); DEL. CODE ANN. tit. 16, § 2507(8) (2008); FLA. STAT. ANN. § 765.401 (1)(h) (LexisNexis 2008); O.C.G.A. § 31-39-4(e)(2) (2008); MASS. ANN. LAWS ch. 119, § 38A (LexisNexis 2008); MISS. CODE ANN. § 41-63-3 (2008); N.Y. SURR. CT. PROC. ACT. § 1750-b(5)(d) (Consol. 2009); TEX. HEALTH & SAFETY CODE ANN. § 166.046 (Vernon 2007); W. VA. CODE ANN. § 16-30-5(d) (2008).

accorded immunity from liability to members of ethics committees.¹³

No longer serving in merely an advisory capacity, the hospital ethics committee has increasingly become the final decision maker for families in crisis about life or death decisions.¹⁴ With little or no judicial oversight, the hospital ethics committee has evolved into a quasi-legal entity, wielding enormous power. States have begun to immunize ethics committees and their members from liability through privilege and immunity statutes.¹⁵ At least one scholar has concluded that these statutes “maximize the authority of ethics committees while minimizing their accountability.”¹⁶

Though it has been argued that the ethics committee’s primary focus should be to “serve and protect the patient,”¹⁷ concerns have been expressed that they are more likely to serve as a “shield” for health care providers, reducing the risk of liability for actions that have been approved by them.¹⁸ while leaving the patient vulnerable. Susan Wolf argues:

Ethics committees are a due process wasteland. There is no indication that committees regularly offer patients any of the basic procedural protections such as notice, an opportunity to be heard, a chance to confront those in opposition, receipt of a written determination and a statement of reasons, and an opportunity to challenge that determination. . . . [T]he committee wields great influence over the treatment decision but accords no protections for the patient’s rights.¹⁹

13. HAW. REV. STAT. ANN. § 663-1.7 (LexisNexis 2008); KAN. STAT. ANN. § 65-4909(a) (2007); MD. CODE ANN., HEALTH-GEN. § 19-374(c) (LexisNexis 2008); MONT. CODE ANN. § 37-2-201 (2007); V.I. CODE ANN. tit. 19, § 248(h) (2008).

14. Wolf, *supra* note 8, at 808–09.

15. See MD. CODE ANN., HEALTH-GEN. § 19-374(c) (LexisNexis 2008); MONT. CODE ANN. § 37-2-201(1) (2007).

16. Wilson, *supra* note 5, at 405.

17. Wolf, *supra* note 8, at 805.

18. “[S]uch an entity could lend itself well to an assumption of a legal status which would allow courses of action not now undertaken because of the concern for liability.” Karen Teel, *The Physician’s Dilemma: A Doctor’s View: What the Law Should Be*, 27 BAYLOR L. REV. 6, 9 (1975).

19. Wolf, *supra* note 8, at 831.

The pervasive support for and widespread implementation of the hospital ethics committee, combined with the fact that such committees are empowered to resolve cases involving constitutionally protected rights,²⁰ warrants more careful scrutiny as well as due process protections. As Spielman aptly stated, “[t]he only limits on ethics consultants’ behavior are their own consciences and, to a limited extent, the law.”²¹

II. THE STANDARD FOR DUE PROCESS AND THE COMPETING INTERESTS

When decisions regarding the withholding or withdrawal of life-saving medical treatment from children with disabilities are made through an ethics committee process at a private—rather than a government—health care facility, the state action that is required to make the constitutional due process requirements of the Fourteenth Amendment applicable is not present. Nevertheless, because those requirements embody tenets of fundamental fairness central to the American legal heritage, they can provide a template to help measure, as a matter of public policy, the propriety and fairness of ethics committee procedures in private institutions.

The Fourteenth Amendment states, “nor shall any State deprive any person of life, liberty, or property, without due process of law”²² In *Cruzan v. Director, Missouri Dep’t of Health*, the Supreme Court noted that “[i]t cannot be disputed that the Due Process Clause protects an interest in life as well as an interest in refusing life-sustaining medical treatment.”²³

20. *Id.* at 802.

21. Spielman, *supra* note 7, at 182.

22. U.S. CONST. amend. XIV, § 1.

23. *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 281 (1990). *See also id.* at 283 n.10. Any putative “substantive due process” interest in life-saving medical treatment, food, or fluids is beyond the scope of this article; the claim here is simply that the interest in not being deprived of these is sufficient to trigger procedural due process requirements. *Hamdi v. Rumsfeld*, 542 U.S. 507, 530 (2004) (quoting *Carey v. Piphus*, 435 U.S. 247, 259 (1978)) (“Procedural due process rules are meant to protect persons not from the deprivation, but from the mistaken or unjustified deprivation of life, liberty, or property.”).

“To determine what process is constitutionally due,” the Supreme Court has “generally balanced three distinct factors”²⁴ identified in the seminal case of *Mathews v. Eldridge*: “First, the private interest that will be affected by the official action; second, the risk of an erroneous deprivation of such interest through the procedures used, and the probable value, if any, of additional or substitute procedural safeguards; and finally, the Government’s interest.”²⁵

It will be most useful to begin by assessing the competing interests before balancing them in application to the particular procedures used and in comparison to specific procedural safeguards that might be used but are lacking in the typical ethics committee process.

A. The Interest of the Child with a Disability in Life

Here, the first *Eldridge* factor, the “private interest that will be affected,” is the child with a disability’s interest in his or her life—and therefore against involuntary termination of the food, fluids, or treatment necessary to preserve it.

This is a weighty interest. It has been most specifically considered by the Court in *Cruzan*. That decision upheld Missouri’s decision to require, before an incompetent patient could be deprived of nutrition and hydration, clear and convincing evidence that this was her choice. The *Cruzan* Court concluded that “[w]e think it self-evident that the interests at stake [including the ‘interest in life’] are more substantial, both on an *individual* and societal level, than those involved in a run-of-the-mill civil dispute.”²⁶

It is true that *Cruzan* involved a reverse of the situation treated in this article, since in that case the government asserted an interest in protecting life while the private party, as surrogate for Nancy Cruzan, asserted an interest in rejecting food and fluids. The *Cruzan* opinion is nevertheless relevant here, since the Court, in assessing the weight

24. *Gilbert v. Homar*, 520 U.S. 924, 931 (1997). *See also* *Wilkinson v. Austin*, 545 U.S. 209, 224–25 (2005).

25. *Mathews v. Eldridge*, 424 U.S. 319, 335 (1976).

26. *Cruzan*, 497 U.S. at 283 (emphasis added).

of the government's interest in imposing the clear and convincing evidence standard, relied heavily on cases in which that standard has been deemed constitutionally required to protect individuals against the government.²⁷ The Court observed:

We recognize that these cases involved instances where the government sought to take action against an individual. Here, by contrast, the government seeks to protect the interests of an individual, as well as its own institutional interests, in life. We do not see any reason why important individual interests should be afforded less protection simply because the government finds itself in the position of defending them. . . . That it is the government that has picked up the shield should be of no moment.²⁸

Capital punishment cases have emphasized the importance of particularly careful due process when a human life is at stake. In *Ford v. Wainwright*, the Court held that when execution is contingent upon the establishment of a fact, "that fact must be determined with the high regard for truth that befits a decision affecting the life or death of a human being."²⁹ In *Woodson v. North Carolina*, the Court wrote:

27. *Cruzan*, 497 U.S. at 282–83. The Court wrote:

This Court has mandated an intermediate standard of proof—'clear and convincing evidence'—when the individual interests at stake in a state proceeding are both 'particularly important' and 'more substantial than mere loss of money.' *Santosky v. Kramer*, 455 U.S. 745, 756 (1982) (quoting *Addington v. Texas*, 441 U.S. 418, 424 (1979)). Thus, such a standard has been required in deportation proceedings (*Woodby v. INS*, 385 U.S. 276, 286 (1966)); in denaturalization proceedings (*Schneiderman v. United States*, 320 U.S. 118, 122–23 (1943)); in civil commitment proceedings (*Addington*, 441 U.S. at 424); and in proceedings for the termination of parental rights (*Santosky*, 455 U.S. at 756). Further, this level of proof, 'or an even higher one, has traditionally been imposed in cases involving allegations of civil fraud, and in a variety of other kinds of civil cases involving such issues as . . . lost wills, oral contracts to make bequests, and the like.' *Woodby*, 385 U.S. at 285, n.18.

28. *Id.* at 282 n.10 (citation omitted).

29. *Ford v. Wainwright*, 477 U.S. 399, 411 (1986).

[T]he penalty of death is qualitatively different from a sentence of imprisonment, however long. Death, in its finality, differs more from life imprisonment than a 100-year prison term differs from one of only a year or two. Because of that qualitative difference, there is a corresponding difference in the need for reliability in the determination that death is the appropriate punishment in a specific case.³⁰

Similarly, in *Zant v. Stephens*, the Court said that “although not every imperfection in the deliberative process is sufficient, even in a capital case, to set aside a state-court judgment, the severity of the sentence mandates careful scrutiny in the review of any colorable claim of error.”³¹

B. Interests to Be Balanced Against the Interest in Life of the Child with a Disability

On the other side are the interests that may be asserted against requiring a more rigorous due process procedure. These include protecting the “genuine” welfare of the child with a disability who, it may be contended, would be better off dead; promoting the “quality of life”; protecting the conscience rights of health care providers who consider it ethically wrong to participate in preserving the lives of those they consider to have a poor quality of life; and controlling costs, both those directly associated with any due process proceedings and any cost of providing treatment while those proceedings are prolonged. The government might also assert an interest in rationing health care; to the extent that the child with a disability uses health care resources while the due process review is continuing, those resources may not be available for other patients whose lives the government may feel should have higher priority

30. *Woodson v. North Carolina*, 428 U.S. 280, 305 (1976).

31. *Zant v. Stephens*, 462 U.S. 862, 885 (1983). *See also* *Callins v. Collins*, 510 U.S. 1141, 1149 (1994) (“There is a heightened need for fairness in the administration of death.”).

because of an assumed higher quality of life, better chances for recovery, or other factors. Let us consider each in turn.

1. The State Interest in Protecting the “Genuine” Interests of the Child with a Disability in Dying

Some argue that in some cases of disability it is in the child’s best interests to die.³² While this interest may perhaps be put forward as a justification for ultimately deciding to withhold or withdraw lifesaving medical treatment, food, or fluids, its use as a basis for less rather than more procedural protections seems dubious. The *Cruzan* Court noted:

An erroneous decision not to terminate [life-preserving measures] results in a maintenance of the status quo; the possibility of subsequent developments such as advancements in

32. Conflicts over treatment that may be provided or denied to a child with a disability obviously involve patients who are not currently competent to make health care decisions for themselves. Most states authorize surrogate decision-making by relatives or others on behalf of an incompetent patient who has not appointed a health care agent. ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* (3d ed. 2009) 8-24 to 8-25 (Table 8-1). These state statutes are collected in MICHAEL JORDAN, *DURABLE POWERS OF ATTORNEY AND HEALTH CARE DIRECTIVES* (4th ed. 2007). In the case of a minor, normally the surrogate decision makers will be the child’s parents.

It can of course be contended in individual cases that the decisions of a surrogate do not accurately reflect the best interests of the patient. The widely publicized and hotly contested Schiavo case involved such a dispute (different family members took opposing positions about Terri Schindler Schiavo’s wishes concerning the provision of nutrition and hydration and about whether the surrogate’s decisions about the level of rehabilitative treatment to be provided her were appropriate). See generally Schiavo *ex rel. Schindler v. Schiavo*, 357 F. Supp. 2d 1378 (M.D. Fla. 2005) (includes discussion of prior state court action in the matter), *aff’d*, 403 F. 3d 1223 (11th Cir. 2005).

Judicial proceedings in which the health care decision of a surrogate can be challenged as not properly representing an incompetent patient are widely authorized by state law and are an obvious forum in which to raise and resolve such issues. See ALASKA STAT. § 13.52.140 (2008); ARIZ. REV. STAT. ANN. § 36-3206 (LexisNexis 2008); CAL. PROB. CODE §§ 4765–4771 (Deering 2008); DEL. CODE ANN. tit. 16 § 2511 (2008); FLA. STAT. ANN. § 765.105 (LexisNexis 2008); HAW. REV. STAT. ANN. § 327E-14 (LexisNexis 2008); IND. CODE ANN. § 16-36-1-8 (LexisNexis 2008); ME. REV. STAT. ANN. tit. 18-A § 5-814 (2008); MASS. GEN. LAWS ch. 201D, § 17 (LexisNexis 2008); MICH. COMP. LAWS § 333.1059 (2008); MISS. CODE ANN. § 41-41-229 (2008); NEB. REV. STAT. ANN. § 30-3421 (LexisNexis 2008); N.H. REV. STAT. ANN. § 506:7 (2008); N.M. STAT. ANN. § 24-7A-14 (LexisNexis 2008); N.Y. PUB. HEALTH. LAW § 2992 (Consol. 2008); OHIO REV. CODE ANN. § 2133.08(E)(1) (LEXISNEXIS 2008); OR. REV. STAT. § 127.550 (2007); S.C. CODE ANN. § 62-5-503, 504 (2007); TENN. CODE ANN. § 68-11-1815 (2008); TEX. HEALTH & SAFETY CODE ANN. § 166.165 (VERNON 2007); WIS. STAT. § 155.60 (4)(a) (2008); WYO. STAT. ANN. § 35-22-415 (2008).

medical science, the discovery of new evidence regarding the patient's intent, changes in the law, or simply the unexpected death of the patient despite the administration of life-sustaining treatment at least create[s] the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction.³³

2. *The State's Interest in Promoting "Quality of Life"*

In *Cruzan*, the Court said that "a State may properly decline to make judgments about the 'quality' of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual."³⁴ Obviously, however, a state can also make the opposite choice: to promote the preservation only of lives judged to have adequate quality, as the courts of some states have done. Washington's Supreme Court, for example, maintains that "[t]he most significant state interest, the preservation of life, . . . weakens . . . in situations where continued treatment serves only to prolong a life inflicted with an incurable condition."³⁵

The distinction between a putative state interest in advancing the quality of life (by eliminating those whose lives are deemed to lack adequate quality) and that in promoting the "genuine" interests of the child with a disability in dying is that the government might claim that even if it is conceded to be in the patient's genuine interest to live, from a societal standpoint that outcome is undesirable. However, as with a state interest in promoting the "genuine" interests of the child with a disability, the potential governmental interest in promoting quality of life is more relevant to the substantive issue of whether patients *can* be denied life-preserving care against their will

33. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 283 (1990).

34. *Id.* at 282.

35. *In re Colyer*, 660 P.2d 738, 743 (Wash. 1983). *Accord* *Rasmussen v. Fleming*, 741 P.2d 674, 683 (Ariz. 1987); *McKay v. Bergstedt*, 801 P.2d 617, 626 (Nev. 1990) ("The State's interest in the preservation of life relates to meaningful life.").

than to limits on the *procedure* that may be necessary reliably to determine what their actual quality of life may be. No matter how weighty this governmental interest may be said to be, it does not weigh in the balance against whatever genuine individual interest there may be in more effective procedural due process.

3. *The State Interest in Promoting Freedom of Conscience*

Physicians, health care institutions, and other health care providers may maintain that it violates their conscience to require them to provide treatment that maintains the lives of children with disabilities in cases in which they believe the burdens of such a life outweigh its benefits. The Supreme Court has recognized a governmental interest in promoting freedom of conscience, albeit in a different context. *Locke v. Davey* upheld a state program generally providing scholarship funds but excluding those attending programs in devotional theology in significant part based on the state's interest in protecting the freedom of conscience of its citizens from being forced through taxes to support religions with which they might disagree.³⁶ It might similarly be argued that "health care professionals ought not and, in fact, cannot be coerced to treat when such treatment affronts their sense of ethics,"³⁷ and that the state has an interest in protecting them from being so compelled.

It may be questioned, however, whether deference to a governmental interest in protecting conscience rights can be absolute. In a different context, R. Alta Charo argues:

[L]icensing systems complicate the equation: such a claim [in defense of non-treatment on the basis of freedom of conscience] would be easier to make if the states did not give these

36. 540 U.S. 712, 722 (2004). *But see id.* at n.5 ("Justice Scalia notes that the State's 'philosophical preference' to protect individual conscience is potentially without limit . . . [H]owever, the only interest at issue here is the State's interest in not funding the religious training of clergy. Nothing in our opinion suggests that the State may justify any interest that its 'philosophical preference' commands.").

37. Erich Loewy & Richard Carlson, *Futility and Its Wider Implications*, 153 ARCHIVES OF INTERNAL MED. 429, 429 (1993).

professionals the exclusive right to offer such services. By granting a monopoly, they turn the profession into a kind of public utility, obligated to provide service to all who seek it. Claiming an unfettered right to personal autonomy while holding monopolistic control over a public good constitutes an abuse of the public trust³⁸

Were certain licensed health care providers to assert that their conscience precludes them from providing health care to members of a particular race, it seems doubtful that otherwise unconstitutional state action facilitating such treatment denials would be saved by an assertion of the governmental interest in protecting the consciences of health care providers.

Here, the issue may be a limited one—not necessarily one of a permanent infringement on the conscience of unwilling health care providers, but one of *for how long* it is temporarily infringed. The issue is whether the addition of due process safeguards would delay the ultimate determination. More extensive procedures may, by taking a longer time, increase the period during which health care providers must unwillingly provide treatment to which they object. The question is what weight to give any interest the state may assert in protecting those consciences, to the extent that it may further be infringed through additional delay that may be required by more rigorous due process.

4. *The State Interest in Reducing Costs*

It has been argued that “[t]he prolongation of human life, that is devoid of quality, creates significant financial . . . burdens for patients, families, medical care providers, and society.”³⁹ Providing more stringent due process can increase costs in two ways. First, the

38. R. Alta Charo, *The Celestial Fire of Conscience—Refusing to Deliver Medical Care*, 352 NEW ENG. J. MED. 2471, 2473 (2005).

39. Constance M. Holden, *Easing the Burden of Decisionmaking in Futile Situations*, 7 HEC FORUM 322, 322 (1995).

procedures themselves can be costly. To the extent there are more extensive hearings and the opportunity is given for discovery, additional medical examinations and opinions, or the involvement of counsel, there are obviously increased costs.⁴⁰ Second, to the extent that more rigorous due process delays denial of treatment, the costs of that treatment, and all the associated costs of maintaining the life of the patient, will continue to mount. There can be no question, therefore, that the government has a legitimate interest in limiting costs to be taken into account in the balancing process envisioned by *Mathews v. Eldridge*.

It is significant, however, that in another context in which a life is at stake, the imposition of capital punishment, quite substantial costs are tolerated in the effort to ensure that an innocent individual is not executed. The cost of ensuring procedural due process in a capital punishment case has been calculated at more than two million dollars.⁴¹

Examination of four potential governmental interests, therefore, leads to the conclusion that two of them—those in protecting the consciences of health care providers and in reducing costs—are relevant in the balance against the individual interest in preserving one's life under the *Mathews v. Eldridge* test to determine what procedural due process would be constitutionally required (were state action present) when health care facility ethics committees deny life-preserving medical treatment, food, or fluids to children with disabilities.

40. Cf. *Wilkinson v. Austin*, 545 U.S. 209, 228 (2005) (in balancing interests in order to evaluate what process is due a prisoner before being sent to a "Supermax" facility, "[t]he problem of scarce resources is [a] component of the State's interest").

41. Information Plus, *A General History of Capital Punishment in America*, in PUNISHMENT AND THE DEATH PENALTY 109 (Robert Baird & Stuart Rosenbaum eds., 1995) (cost of appealing capital murder conviction in Texas estimated at \$2,316,655); PHILIP COOK ET AL., DUKE UNIVERSITY TERRY SANFORD INSTITUTE OF PUBLIC POLICY, THE COSTS OF PROCESSING MURDER CASES IN NORTH CAROLINA 78 (1993) (estimating \$2.16 million per execution over the costs of a non-death penalty murder case with a sentence of imprisonment for life.).

III. THE FUNDAMENTALS OF DUE PROCESS

In the context of the detention of American citizens held as enemy combatants, the Supreme Court has reiterated the fundamentals of procedural due process:

We therefore hold that a citizen-detainee seeking to challenge his classification as an enemy combatant must receive notice of the factual basis for his classification, and a fair opportunity to rebut the Government's factual assertions before a neutral decisionmaker. *See Cleveland Bd. of Educ. v. Loudermill*, 470 U.S. 532, 542 (1985) ("An essential principle of due process is that a deprivation of life, liberty, or property 'be preceded by notice and opportunity for hearing appropriate to the nature of the case'" (quoting *Mullane v. Cent. Hanover Bank & Trust Co.*, 339 U.S. 306, 313 (1950))); *Concrete Pipe & Prods. of Cal., Inc. v. Constr. Laborers Pension Trust for S. Cal.*, 508 U.S. 602, 617 (1993) ("[D]ue process requires a 'neutral and detached judge in the first instance.'" (quoting *Ward v. Monroeville*, 409 U.S. 57, 61–62 (1972))). "For more than a century the central meaning of procedural due process has been clear: 'Parties whose rights are to be affected are entitled to be heard; and in order that they may enjoy that right they must first be notified. It is equally fundamental that the right to notice and an opportunity to be heard 'must be granted at a meaningful time and in a meaningful manner.'" *Fuentes v. Shevin*, 407 U.S. 67, 80 (1972) (quoting *Baldwin v. Hale*, 68 U.S. 223, 1 Wall. 223, 233 (1864); *Armstrong v. Manzo*, 380 U.S. 545, 552 (1965) (citations omitted)). These essential constitutional promises may not be eroded.⁴²

42. *Hamdi v. Rumsfeld*, 542 U.S. 507, 533 (2004) (plurality opinion). Although the quotation is from a plurality of four Justices, the basic assertions contained in it commanded a majority of the Court. *See id.* at 553 (Souter, J., joined by Stevens, J., concurring in part, dissenting in part, and concurring in the judgment) ("It is not that I could disagree with the plurality's determinations . . . that someone in

When children with disabilities are at risk of denial of treatment necessary to sustain their lives, does the procedure through which the determination is made meet these requirements?

A. Is an Unspecific "Best Interests" Standard Unconstitutionally Vague?

In order to "receive notice of the factual basis for [one's] classification, and a fair opportunity to rebut the . . . factual assertions," it is necessary for there to be an articulated standard for what facts are relevant and dispositive.

When specific standards such as those in the Child Abuse Amendments of 1984⁴³ are rejected, in its place the ethics committee is said to be guided by something like the "best interests" of the child with a disability, which has been described as incorporating "what a reasonable person would want or how a reasonable person would balance burdens and benefits"⁴⁴ A striking difference is the

Hamdi's position is entitled at a minimum to notice of the Government's claimed factual basis for holding him, and to a fair chance to rebut it before a neutral decision maker; nor, of course, could I disagree with the plurality's affirmation of Hamdi's right to counsel." (citations omitted)).

43. The statute seeks to prevent "withholding of medically indicated treatment from disabled infants with life-threatening conditions." 42 U.S.C. § 5106a(b)(2)(B) (2006). It offers the following definition of "withholding of medically indicated treatment":

'Withholding of medically indicated treatment' is defined as the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment—(A) the infant is chronically and irreversibly comatose; (B) the provision of such treatment would—(i) merely prolong dying; (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions; or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

Id. § 5106g(6). Detailed explication of the standard is provided in federal regulations and appended guidelines. See 45 C.F.R. § 1340.15 (2008).

44. Loretta M. Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J.L. MED. & ETHICS 187, 189 (2007); see also Loretta M. Kopelman, *Rejecting the Baby Doe Regulations and Defending a "Negative" Analysis of the Best Interests Standard*, 30 J. MED. & PHIL. 331 (2005); Loretta M. Kopelman, *Are the 21-Year-Old Baby Doe Rules Misunderstood or Mistaken?*, 115 PEDIATRICS 797 (2004).

comparative vagueness⁴⁵ of the basis under which treatment may be denied. How does this affect children with disabilities and their representatives?

One of the principal constitutional objections to vague standards is inapplicable in this context—that of the need to “give the person of ordinary intelligence a reasonable opportunity to know what is prohibited, so that he may act accordingly.”⁴⁶ It is not to be expected that children have control over their disabilities so as to be able to avoid them if they are on notice that they must do so in order to forestall their being denied life-saving health care. However, two other important problems with vague standards are directly relevant in judging whether a “best interests” standard would comport with constitutionally-mandated due process.

Vague statutes fail to “provide explicit standards for those who apply them.”⁴⁷ This is a serious flaw, because “[a] vague law impermissibly delegates basic policy matters to policemen, judges, and juries for resolution on an ad hoc and subjective basis, with the attendant dangers of arbitrary and discriminatory application.”⁴⁸ Under the “best interests” standard, whether a patient will be denied life-saving treatment in a particular hospital depends on whatever the consensus or majority on that hospital’s ethics committee considers “inappropriate.”

One ethics committee might deem it inappropriate to provide life-saving treatment to a child whose disability is expected to mean permanent incontinence, mental retardation, and the need to use a wheelchair. Across town, a different hospital’s ethics committee

45. Although vagueness doctrine is most commonly used to assess criminal laws, it has also been applied to statutes that are not enforced by a criminal penalty. *E.g.*, *Baggett v. Bullitt*, 377 U.S. 360, 374 (1964) (holding unconstitutionally vague loyalty oath required as a condition of state government employment); *Minnesota ex rel. Pearson v. Probate Court*, 309 U.S. 270, 274 (1940) (concluding that a civil commitment statute is not “too vague and indefinite to constitute valid legislation”).

46. *Grayned v. City of Rockford*, 408 U.S. 104, 108 (1972). If health care providers indeed faced any significant adverse consequences if they failed to abide by the standard of care—if, for example, denial of treatment that was held to violate the standard could lead in practice to disciplinary procedures or civil or criminal liability—then the vagueness of the Best Interests Standard could be a barrier to its constitutional enforcement and this objection could become relevant.

47. *Id.*, quoted in *McConnell v. FEC*, 540 U.S. 93, 170 n.64 (2003).

48. *Grayned*, 408 U.S. at 108–09.

might authorize treatment for such a child, but deny it to a “minimally conscious” child who could live indefinitely but whose mental condition is not expected to improve. Still a third ethics committee might be less concerned with the patient’s mental status than with whether she or he has a terminal condition. The inherent subjectivity of “quality of life” assessments and the wide variety of possible lines that could be drawn⁴⁹ suggest that, in the absence of more specific standards, the differences in how similarly-situated people might be treated, not only from facility to facility, but even within the same facility depending on the shifting composition of the facility’s ethics committee from year to year, could be wide indeed.

As with an unconstitutionally vague Cincinnati ordinance that prohibited gatherings of three or more persons conducted in a manner that “annoys” a police officer or other passerby, the “best interests” treatment standard is vague because it does not offer “an imprecise but comprehensible normative standard, but rather . . . no standard of conduct is specified at all.”⁵⁰ As the Court said in striking down as vague a Massachusetts law against “contemptuously” treating the U.S. flag:

Such a provision simply has *no* core. This absence of any ascertainable standard for inclusion and exclusion is precisely what offends the Due Process Clause. The deficiency is particularly objectionable in view of the unfettered latitude thereby accorded law enforcement officials and triers of fact . . . under a standard so indefinite that police, court, and jury were free to react to nothing more than their own preferences for treatment of the flag.⁵¹

49. Mary A. Crossley, *Selective Nontreatment of Handicapped Newborns: An Analysis*, 6 MED. & L. 499, 509–10 (1987) (identifying four distinct levels or varieties of quality of life standard that have been advocated in the professional literature).

50. *Coates v. Cincinnati*, 402 U.S. 611, 614 (1971).

51. *Smith v. Goguen*, 415 U.S. 566, 578 (1974) (emphasis added).

The second problem with a standard as vague as that of “best interests” is that it makes the giving of adequate notice of the subject matter of the hearing essentially impossible. A vague criminal statute “fails . . . to advise defendants of the nature of the offense with which they are charged,”⁵² and “real notice of the true nature of the charge . . . [is] the first and most universally recognized requirement of due process.”⁵³ As the Court held in a non-criminal case involving an engineer’s denial of a security clearance, “where governmental action seriously injures an individual, and the reasonableness of the action depends on fact findings, the evidence used to prove the Government’s case must be disclosed to the individual so that he has an opportunity to show that it is untrue.”⁵⁴ The “best interests” standard fails to advise the representatives of children with disabilities of the nature of what they must rebut in order to prevent the denial of treatment necessary to sustain the children’s lives. Notice in advance of a hearing is meaningful only to the extent that it allows the person notified an opportunity to prepare for the rebuttal or other presentation at the hearing. A standard so lacking in content as whether treatment is in the child’s “best interests” leaves the child’s representative at a loss in formulating a convincing presentation, effectively denying “a fair opportunity to rebut.”⁵⁵

How should the vagueness of the “best interests” standard be evaluated under the *Mathews v. Eldridge* factors?⁵⁶ The “risk of an erroneous deprivation . . . through the procedures used” when the child’s representatives have no advance notice of the specific standard to be applied is surely high, while “the probable value, if any, of additional or substitute procedural safeguards”⁵⁷ in the form of a clearly-spelled-out standard is also high, because it would then be more likely that the child’s representatives could effectively prepare for the hearing before the ethics committee. The child’s

52. *Musser v. Utah*, 333 U.S. 95, 97 (1948).

53. *Smith v. O’Grady*, 312 U.S. 329, 334 (1941).

54. *Greene v. McElroy*, 360 U.S. 474, 496 (1959).

55. *Hamdi v. Rumsfeld*, 542 U.S. 507, 533 (2004) (plurality opinion).

56. See *supra* text accompanying note 25.

57. *Mathews v. Eldridge*, 424 U.S. 319, 335 (1976).

interest in life, as we have already seen, is weighty. Of the government's interests, it is hard to see how either an interest in promoting the quality of life or in protecting the "genuine" interests of the child in death would be compromised by clearly setting out a specific standard intended to elaborate and define those interests. Nor would the existence of a more specific standard, in and of itself, increase the costs the government may wish to limit.

That leaves the governmental interest in promoting freedom of conscience for health care providers. This interest could indeed be affected by adoption of a specific standard. An indefinite standard that refers only to "best interests" affords the greatest conceivable range to the individual or collective conscience of health care providers. Anything that the ethics committee in any case finds to be inappropriate need not be provided beyond, presumably, the date of the ethics committee meeting. On the other hand, the articulation of a standard precise enough to give adequate notice would appear to protect only the consciences of those health care providers who agree with whatever the particular standard may be.

Upon further analysis, however, the impact of requiring a standard sufficiently precise to give adequate notice may be seen to have not so detrimental an impact on this governmental interest. There are two levels at which conscience is sought to be protected—that of the physician or other individual health care provider and that of the institution. An individual physician or other health care provider who objects could transfer responsibility to another within the same institution.⁵⁸ Thus, even if a specific standard defined in the statute would require treatment for some children with disabilities with a quality of life that is lower than the minimum an individual physician believes necessary to qualify them ethically for treatment, that individual's conscience would remain as well protected as before

58. See, e.g., TEX. HEALTH & SAFETY CODE ANN. § 166.046(d) (Vernon 2007) (an attending physician who continues to object to providing treatment even after the ethics committee has concluded that it is appropriate may have the patient transferred to the care of another physician within the institution or elsewhere).

enactment of the specific standard. The impact of a specific standard would be at the institutional level.

To the extent that the state action element of the Fourteenth Amendment means the hospitals *actually* affected by the constitutional requirements of due process are state and other public hospitals, it is counterintuitive to suggest that governmental hospitals have a conscience distinct from that of the government itself; consequently, whatever specific standard might be enacted by the legislature would itself constitute the ethical standard of those hospitals. Therefore, requiring a standard specific enough to give adequate notice would not impinge on the government's interest in promoting freedom of conscience.

In short, after examining the competing interests, a strong case can be made that the a standard no more specific than whether treatment is "inappropriate" is unconstitutionally vague and would violate the constitutional requirements of procedural due process.

B. Is the Ethics Committee a Neutral Decision Maker?

"[D]ue process requires a 'neutral and detached judge in the first instance,' and the command is no different when a legislature delegates adjudicative functions to a private party."⁵⁹ "Before one may be deprived of a protected interest, whether in a criminal or civil setting, one is entitled as a matter of due process of law to an adjudicator who is not in a situation 'which would offer a possible temptation to the average man as a judge . . . which might lead him not to hold the balance nice, clear and true'"⁶⁰ "That even purportedly fair adjudicators 'are disqualified by their interest in the controversy to be decided is, of course, the general rule.'"⁶¹ Is a hearing by a hospital ethics committee "a constitutionally adequate

59. *Concrete Pipe & Prods. v. Constr. Laborers Pension Trust*, 508 U.S. 602, 617 (1993) (citing *Ward v. Village of Monroeville*, 409 U.S. 57, 61-62 (1972) (citations omitted)).

60. *Id.* at 617-18 (citing *Ward*, 409 U.S. at 60).

61. *Hamdi v. Rumsfeld*, 542 U.S. 507, 538 (2004) (plurality opinion) (quoting *Tumey v. Ohio*, 273 U.S. 510, 522).

factfinding before a neutral decisionmaker”?⁶² Of course, ethics committees are constituted and appointed by the hospitals they serve. There is no provision to assure neutrality or independence. Many if not all the members of an ethics committee will generally be members of the hospital staff.

In *Schweiker v. McLure*, the Court held that there was no basis to question the impartiality of hearing officers selected by private insurance companies to adjudicate Medicare claims because their salaries and any payments they directed would come from the federal government, so neither the insurance companies nor the hearing officers selected by them had any inherent conflict of interest.⁶³ By contrast, the hospital staff members who typically serve on ethics committees are part of the institution and themselves intimately involved in the provision and withholding of treatment on a daily basis.

A closer parallel is found in *Ward v. Monroeville*, where the Court declared unconstitutional a statute allowing village mayors to serve as judges when violations of village ordinances were alleged, because any fines levied would go to the village treasury and “the mayor’s executive responsibilities for village finances may make him partisan to maintain the high level of contribution from the mayor’s court.”⁶⁴ Similarly, the hospital staff members who serve on ethics committees are well aware of the cost of treatment and of its impact on the resources of their institution.

62. *Id.* at 537.

63. *Schweiker v. McLure*, 456 U.S. 188, 196–97 (1982).

64. 409 U.S. 57, 60 (1972). *Marshall v. Jerrico, Inc.*, 446 U.S. 238, 247 (1980), rejected a claim that an administrator who assessed fines for violation of labor laws was not an impartial decision maker because the Court held the administrator’s role was not that of a judge or adjudicator, but rather “akin to that of a prosecutor or civil plaintiff.” Any person against whom the administrator assessed a fine could challenge it before an administrative law judge, whom the Court held to be an appropriately impartial adjudicator. However, it is not contemplated that an ethics committee decision to deny life-sustaining treatment to a child with a disability will be subject to any form of administrative—let alone judicial—review.

C. Does Due Process Demand a Right to Counsel Before the Ethics Committee?

Whether due process mandates a right to counsel can be divided into two questions: whether due process demands that counsel secured by the patient or patient's representative be permitted to provide representation at the hearing, and whether an indigent patient has the right to appointed counsel for this purpose.

Concerning the first question, "[o]riginally, in England . . . parties in civil cases . . . were entitled to the full assistance of counsel."⁶⁵ However, this statement in a 1932 case that a party in a civil case has a due process right to counsel the party obtains and pays for was discounted as dicta in 1975,⁶⁶ and the Court has since held that due process does not prohibit the exclusion of counsel from an administrative investigative proceeding.⁶⁷ Oddly, perhaps, there is less guidance from the existing precedents on a party's right in a noncriminal proceeding to have the assistance of counsel whom the party compensates than there is on the right to have appointed counsel if one is indigent. Of course, if in a given type of case due process requires that appointed counsel be provided for the indigent, *a fortiori* those parties who can afford to secure counsel for themselves must be permitted their assistance.

In *Lassiter v. Dep't of Social Services of Durham County, North Carolina*, the Court held that whether appointed counsel is required by due process in a termination of parental rights proceeding must be resolved on a case-by-case basis.⁶⁸ In doing so, the Court began by

65. *Argersinger v. Hamlin*, 407 U.S. 25, 30 (1972) (quoting *Powell v. Alabama*, 287 U.S. 45, 60 (1932)).

66. *Maness v. Meyers*, 419 U.S. 449, 466 n.15 (1975) ("Reliance seems to us misplaced on the statement in *Powell v. Alabama*, 287 U.S. 45, 69 (1932), that '[i]f in any case, civil or criminal, a state or federal court were arbitrarily to refuse to hear a party by counsel, employed by and appearing for him . . . such a refusal would be a denial of a hearing, and, therefore, of due process' Comments in a criminal case as to the law in a civil case hardly reach the level of constitutional doctrine, if indeed they are any more than dicta."). The *Powell* statement was, however, quoted with strong approval nine years later in *United States v. Cronin*, 466 U.S. 648, 654 n.8 (1984) ("Time has not eroded the force of Justice Sutherland's opinion for the Court . . .").

67. *In re Groban*, 352 U.S. 330, 335 (1957).

68. 452 U.S. 18, 31-32 (1981).

stating that “[t]he pre-eminent generalization that emerges from this Court’s precedents on an indigent’s right to appointed counsel is that such a right has been recognized to exist only where the litigant may lose his physical liberty if he loses the litigation.”⁶⁹ It seems evident that when loss of his or her life is at stake, a party ought to have at least the same right to counsel as when the issue is loss of physical liberty.⁷⁰

A strong case may therefore be made on procedural due process grounds that a child with a disability should be entitled to counsel to argue the case before the ethics committee that he or she should be permitted the life-sustaining medical treatment, food, or fluids necessary to prevent the child’s death.

D. Is the Procedure at the Ethics Committee Hearing Adequate?

What procedural safeguards exist for the child with a disability in the actual conduct of the ethics committee hearing? What ability does an advocate for the life of the child with a disability have to present witnesses or evidence, such as contrary evidence concerning the patient’s prospects for recovery or the exact nature of his or her quality of life?

The ability to challenge adverse evidence has been regarded as central to due process. There “are few subjects, perhaps, upon which this Court and other courts have been more nearly unanimous than in the expressions of belief that the right of confrontation and cross-examination is an essential and fundamental requirement for the kind of fair trial which is this country’s constitutional goal.”⁷¹

There are precedents for alternative procedures that do not follow the format for full criminal or civil trials. Some states provide for “contested cases” hearing procedures before administrative law judges. Under the Texas administrative hearing procedure, for example, the strict rules of evidence are not followed if “necessary to

69. *Id.* at 25.

70. See *supra* note 32 and accompanying text.

71. *Lee v. Illinois*, 476 U.S. 530, 540 (1986) (quoting *Pointer v. Texas*, 380 U.S. 400, 405 (1965)).

ascertain facts not reasonably susceptible of proof under those rules” and if the evidence is “of a type on which a reasonably prudent person commonly relies in the conduct of the person’s affairs.”⁷² Yet discovery and depositions are allowed.⁷³ A party may subpoena witnesses if good cause is shown.⁷⁴ Cross-examination “required for a full and true disclosure of the facts” is permitted.⁷⁵ A party may require the hearing to be transcribed.⁷⁶

The availability of this sort of administrative procedure is relevant in evaluating the nature and weight of two of the *Eldridge* criteria: “the probable value, if any, of additional or substitute procedural safeguards,” and the governmental interests at stake.⁷⁷ The state’s administrative procedure illustrates the feasibility and availability of substitute procedural safeguards and may undercut concern that the government’s interests, especially in cost control, would be unduly undermined by requiring procedures similar to those states routinely afford in other sorts of contested cases.

Without a defined procedure affording a clear ability to respond to and challenge adverse evidence and witnesses, including the opportunity to cross-examine, and affording the ability to present evidence and argument on each issue involved in the case, ethics committees deny essential elements of due process to children with disabilities whose lives are at stake.

IV. CONCLUSION

The Child Abuse Amendments of 1984, while they remain on the statute books, have been largely unenforced and have encountered consistent resistance and opposition from within the medical community, which has generally advocated and employed in their

72. TEX. GOV’T CODE ANN. § 2001.081 (Vernon 2007). The evidence must also not be precluded by statute. *Id.*

73. *Id.* §§ 2001.091, 2001.102.

74. *Id.* § 2001.089.

75. *Id.* § 2001.087.

76. *Id.* § 2001.059.

77. *Mathews v. Eldridge*, 424 U.S. 319, 335 (1976).

stead ethics committees operating under a “best interests” standard. This alternative, however, raises substantial procedural due process concerns that would likely render the approach unconstitutional as it is typically practiced if state action were present. Even when the death of a child with a disability is attributable to denial of treatment at a private, rather than a governmental facility, the absence of basic due process protections in the ethics committee process offends tenets of fundamental fairness essential to societal norms of justice.

