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MEDICAL AUTHORITY AND INFANTICIDE

PATRICK A. MALONE*

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I. INTRODUCTION

Professional licensing is widely criticized for creating state-sponsored cartels that frustrate competition and drive up the cost of professional services.¹ Regulatory reform has been aimed at promoting competition while at the same time invigorating licensing's ostensible function: the effective self-regulation of competence by members of a profession.² Yet professional licensing creates other costs to society that are not widely appreciated. This Article seeks to demonstrate those costs in the context of one profession, medicine, and one well-publicized but poorly understood problem within that profession, the withholding of life-sustaining treatment from handicapped infants.

Licensing of physicians does more than create an economic monopoly over the provision of medical services. It presumes professional expertise and lay incompetence in making decisions about health. This legal presumption, found throughout the legal regulation of health care, in turn embodies the medical

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¹ For the classic argument, see M. FRIEDMAN, *CAPITALISM AND FREEDOM* 137-60 (1962).

² See generally *ISSUES IN HEALTH CARE REGULATION* (R. Gordon ed. 1980); *REGULATING THE PROFESSIONS, A PUBLIC POLICY SYMPOSIUM* (R. Blair & S. Rubin eds. 1980).

profession's own presumption that illness is mainly an organic, individual-centered phenomenon for which expert treatment is appropriate. The medical profession's notions of the nature of illness, or what could be called the medical model, thus pervade the legal structure of health care. The issue of medical infanticide³ illustrates the consequences of a system of laws that enshrines the medical profession's understanding of illness as society's official understanding.

Because the medical model of illness rests on an individualized concept of health divorced from the social roots of illness, the issue of handicapped infants has been largely perceived in similarly individualized terms. The focus of attention has been on what kind of medical treatment individual infants are to receive, and how society can assure ethical decisions by doctors and parents on behalf of those individual infants.⁴ This individualized focus ignores the issue of the extent to which society is obliged to *prevent* handicaps and ameliorate their consequences.

In making individual decisions, physicians have claimed an expertise that the laws have enforced. The theory of professional expertise underlying both the

³ The practice is also commonly, but imprecisely, referred to as pediatric euthanasia. Euthanasia means death that is beneficial, i.e., a "mercy killing." But the benefit must be to the person who dies, not someone else. Foot, *Euthanasia*, 6 PHIL. & PUB. AFF. 85, 86 (1977). Commentators often have failed to make this distinction and thus have used the term in a conclusory and confusing way that begs a central question in the debate about handicapped newborns. See *id.* at 108-10 (arguing that withholding treatment is often not euthanasia because it is intended to benefit not infant but family or society).

Infanticide is the deliberate killing of an infant, without regard to motive, see BLACK'S LAW DICTIONARY 699 (rev. 5th ed. 1979), and thus can refer generally to the withholding of treatment when the caregiver knows that treatment would keep the infant alive. This article will adopt the term infanticide.

⁴ This has been the focus of the Reagan administration's regulatory efforts aimed at the infanticide problem. The Article does not analyze those efforts. Instead, it seeks to place the infanticide issue into the broader context of the legal regulation of the medical profession.

Last term, Congress passed compromise legislation that, among other things, requires states receiving federal child abuse funds to establish procedures for responding to reports of the withholding of medically indicated treatment from disabled infants with life-threatening conditions. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (codified as amended at 42 U.S.C. § 5102-5104). The act also defines "medically indicated treatment" and directs the Secretary of Health and Human Services to publish model guidelines to encourage the establishment of committees within hospitals to offer counseling and review of cases involving handicapped infants. For legislative history, see S. Rep. No. 246, 98th Cong., 2d Sess. 5-11, 16-19, reprinted in 1984 U.S. Code Cong. & Ad. News 2918; H.R. Conf. Rep. No. 1038, 98th Cong., 2d Sess. reprinted in 1984 U.S. Code Cong. & Ad. News 2947.

For a summary of the regulatory efforts of the Reagan administration leading up to the legislation, see Pearl, *Baby Jane and Infant Doe: Treatment of Newborns with Birth Defects*, 16 URBAN LAWYER 701 (1984). See also *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984) (rejecting Reagan administration's use of §504 of the Rehabilitation Act to investigate hospital where treatment withheld from newborn with spina bifida); *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983) (striking down rules establishing hotline and requiring posters to be posted in hospital nurseries).

medical model and the legal regulation of health care declares the incompetence of non-physicians — whether patients, legal representatives of patients such as parents, or other health care workers such as nurses — to judge the work of physicians. Individual physicians have been ceded effective control of decisions made about ill infants by allowing doctors both to dominate parents and to remain largely independent from outside review.

This Article tries to explicate the way in which legal regulation interacts with the medical profession's theories of health and illness in order to construct the social reality of health care and of specific issues such as infanticide. Part II of the Article demonstrates how the professional autonomy granted to medicine by the legal system makes possible professional domination over individual decisions and reinforces a societal view of health issues compatible with continued medical dominance. Part III shows how this legal dominance expresses itself in the infanticide context. Part IV analyzes basic flaws in the presumptions underlying the legal system of autonomy, as illustrated again by the infanticide example. The Article concludes that professional authority over health matters has been vastly overextended but that reclaiming lay control will require a serious re-examination of the basic legal structure of health care.

II. THE ROLE OF PROFESSIONAL AUTONOMY

The legal regulation of health care has established physicians as autonomous, self-regulated professionals. But legal regulation has gone much further and has given the medical profession dominion not only over the work of other health care occupations, but also over the decisions made on behalf of patients, and even society's basic conceptions of health and illness.

A. *The Legal Presumption of Professional Autonomy and its Justification*

Football players, musicians, journalists and members of a variety of other occupations requiring unique skills developed by arduous training often call themselves "professionals." I use the term more narrowly to refer to that class of occupations whose members are granted exclusive licenses by the state to practice their craft and who decide as a group the qualifications an individual needs to become licensed.⁵ Law and medicine are the classic examples of professions in this sense of state-granted autonomy from lay control.

Licensing is the bedrock supporting a system of professional autonomy. American medicine won professional status in the late nineteenth century with the passage of state licensing laws. The licensing led to the closure of large

⁵ Research on the sociology of work usually has focused on the official grant of autonomy as separating professions from other occupations. See, e.g., E. FREIDSON, *PROFESSIONAL DOMINANCE* 83 (1970); W. MOORE, *THE PROFESSIONS: ROLES AND RULES* 15-16 (1970).

numbers of medical schools and the decline of various alternative forms of healing that had competed with medical physicians.⁶ Like other occupations,⁷ medicine actively sought licensure, though the ostensible reason for licensing was to protect the public health, not the profession itself.⁸

A Supreme Court hostile to legislative protection of labor unions⁹ and most other trade groups¹⁰ accepted the rationale for medical licensure. In the 1889 case of *Dent v. West Virginia*,¹¹ the Court said:

Every one may have occasion to consult him [the physician], but comparatively few can judge of the qualifications of learning and skill which he possesses. Reliance must be placed upon the assurance given by his license, issued by an authority competent to judge in that respect, that he possesses the requisite qualifications.¹²

This is the core premise underlying professional autonomy — that laymen are not equipped to judge what experts do in their behalf. The layman thus cannot tell a competent expert from a charlatan, and the expert cannot prove his or her expertise without educating the layman in the expert's craft. Licensing transfers the task of persuading the layman to submit to treatment from the individual level of professional/client to the institutional level of profession/legislature.¹³ Clients, who may be in great need but ignorant, are assured that they can trust licensed professionals, less by the persuasive power of the

⁶ For the history of the licensing movement, see J. BERLANT, *PROFESSION AND MONOPOLY* (1975); P. STARR, *THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE* 102-07 (1982).

⁷ See W. GELLHORN, *INDIVIDUAL FREEDOM AND GOVERNMENTAL RESTRAINTS* 109 (1956).

⁸ See R. STEVENS, *AMERICAN MEDICINE AND THE PUBLIC INTEREST* 43 (1971).

⁹ See *Adair v. United States*, 208 U.S. 161 (1908) (invalidating federal "yellow dog" contract restriction); *Coppage v. Kansas*, 236 U.S. 1 (1915) (invalidating state law barring "yellow dog" contracts); *Truax v. Corrigan*, 257 U.S. 312 (1921) (invalidating state law restricting use of injunctions in labor disputes).

¹⁰ The best known example is *Lochner v. New York*, 198 U.S. 45 (1905), invalidating a 60-hour limit on the work week of bakers. The majority opinion cited with approval three state court opinions invalidating statutes licensing horseshoers, *id.* at 63, without mentioning or distinguishing its own opinion 16 years earlier approving state licensure of physicians. See also *Adkins v. Children's Hosp.*, 261 U.S. 525 (1923) (striking down minimum wage law for women). But see *Muller v. Oregon*, 208 U.S. 412 (1908) (upholding maximum working hours provision for women); *Holden v. Hardy*, 169 U.S. 366 (1898) (upholding maximum hours for coal miners).

¹¹ 129 U.S. 114 (1889).

¹² *Id.* at 122-23.

¹³ See E. FREIDSON, *supra* note 5, at 108-10. This type of authority stands somewhere between the personal authority of the expert and the legal authority of an office-holder. A scientist obtains authority by virtue of his personal demonstration to his peers, e.g., through scholarly writing, that he is an expert. On the other hand, the legal authority of an office-holder, such as a judge, is based not on expertise but on the powers inherent in the office. The physician exercises expert authority, but at least in relations with his patients, it is won not by virtue of any personal demonstration but by the imputation from his credentials (in a sense, his office) that he is an expert. The distinctions are developed by Talcott Parsons and Eliot Freidson. See *id.* at 123-25.

individual practitioner than by the persuasive authority of the institution that gave the practitioner credentials.¹⁴

Licensing is not simply a certification by the state that the practitioner meets minimum standards of competence. The state could provide such certification and still leave patients free to choose non-certified practitioners. Instead, all the states have licensing systems that forbid medical treatment by anyone without a license. Licensing laws typically allow other health care professionals such as nurses, and physical therapists to treat patients only pursuant to physicians' orders and supervision.¹⁵ This state-enforced monopoly removes from patients the choice of whether to seek out someone other than a licensed practitioner for their health problems. Thus, not only does licensure presume lay incompetence at judging the qualifications of professionals, it also presumes that lay persons cannot judge whether their own health problems require the services of a licensed physician or someone with different training.

Even if one presumes such pervasive lay incompetence, licensing becomes the inevitable mechanism for assuring physician competence only if one also assumes that medical care should be provided to patients by individual contract between doctor and patient. This is not the only way to provide medical services. The state itself could hire doctors to work in state-owned hospitals and clinics, insuring competence through hiring and firing rather than through licensing. Even without state-provided medical care, entities such as private hospitals rather than individual physicians could become the locus of payment by patients and regulation by the state. The state could license such institutions, and each institution would bear the responsibility of assuring the quality of its employees.¹⁶ Licensing of individual physicians is necessary only when the physician answers to no employer other than himself or herself. Given alternatives such as state provision of care or institutional licensure, individual licensure maximizes the control by individual physicians over physician/patient relationships and minimizes control by outsiders.

The presumption of lay incompetence underlying licensing is not limited to patients. Licensing also presumes that the state itself is incompetent to regulate

¹⁴ *Dent v. West Virginia*, 129 U.S. 114, 128 (1889) (licensing laws intended to promote professional competence so that "the community might trust with confidence those receiving a license under the authority of the State.")

¹⁵ See Dolan, *Antitrust Law and Physician Dominance of Other Health Practitioners*, 4 J. HEALTH POL. POL'Y. & L., 675, 677 (1980). Increasingly, these other professions have challenged the dominance of physicians, but with limited success. Generally, licensing statutes allow nurse practitioners, physician's assistants and other "allied health professionals" to practice only under some kind of physician supervision. See Rayack, *Medical Licensure: Social Costs and Social Benefits*, 7 LAW & HUM. BEHAV. 147, 152-54 (1983); F. GRAD & N. MARTI, *PHYSICIANS' LICENSURE & DISCIPLINE* 131-33 (1979); Kucera & Manson, *Allied Health Professions: An Opportunity and a Challenge*, 16 FORUM 787, 789 (1981). See also *Bowland v. Municipal Court*, 18 Cal. 3d 479, 556 P.2d 1081, 134 Cal. Rptr. 630 (1976) (upholding constitutionality of CAL. BUS. & PROF. CODE § 2141 forbidding unlicensed practice of healing arts in criminal prosecution of midwife).

¹⁶ See V. FUCHS, *WHO SHALL LIVE? HEALTH, ECONOMICS, AND SOCIAL CHOICE* 76-78 (1974).

professional quality. A state that believes its non-physician state employees are incapable of making licensure decisions could hire physicians as state employees to do the job. Instead, the power to grant and revoke the right to practice medicine is delegated, in all states, to independent boards or licensing committees dominated by physicians.¹⁷ These boards are assisted by state agencies, but the ultimate power rests with board members who are not state employees and who typically make their living practicing the profession they regulate.¹⁸

The Supreme Court has found dominance by a profession of its own licensing board not suspect unless board members can be shown to have actual personal pecuniary interests in the outcome of a decision.¹⁹ The Court also has refused to re-examine critically the presumption of lay incompetence first expressed in *Dent*,²⁰ even though it has shown some concern for the right to practice one's chosen occupation,²¹ and for the anticompetitive impact of professional rules. The Court has refused to extend to the professions a blanket exemption from the antitrust laws,²² and in cases specifically involving the medical profession, the Court has struck down medical society restraints on prices and advertising.²³ Yet the Court has consistently said that medicine and other professions are different from ordinary occupations and thus are not to be necessarily treated the same under the antitrust laws.²⁴

¹⁷ See H. SHUCHMAN, *SELF-REGULATION IN THE PROFESSIONS* 231 (1981). In 23 states, board membership consists entirely of physicians. *Id.* at 229; Derbyshire, *How Effective Is Medical Self-Regulation?*, 7 *LAW & HUM. BEHAV.* 193 (1983).

¹⁸ A board cannot be forced to act against a physician. *Downing v. Fraggassi*, 26 Pa. Commw. 517, 364 A.2d 748 (1976) (board's refusal to press charges against licensee is "prosecutorial discretion" not reviewable by courts), *cert. denied*, 436 U.S. 910 (1978); *Berman v. Board of Registration*, 355 Mass. 358, 244 N.E.2d 553 (1969) (court has no power to direct licensing board to perform discretionary act).

¹⁹ Compare *Gibson v. Berryhill*, 411 U.S. 564 (1973) (board found biased due to actual financial conflict in pending disciplinary case) with *Friedman v. Rogers*, 440 U.S. 1 (1979) (dominance by one faction of optometrists on board not suspect since no case pending to show actual conflict).

²⁰ *Dent v. West Virginia*, 129 U.S. 114 (1889). See *Williamson v. Lee Optical Co.*, 348 U.S. 483 (1955) (upholding statute requiring prescription from optometrist or ophthalmologist before an optician can even fit old lenses into a new frame); *Ferguson v. Skrupa*, 372 U.S. 726 (1963) (refusing even to examine basis for state law limiting debt adjustment to licensed lawyers).

²¹ See *Hampton v. Mow Sun Wong*, 426 U.S. 88 (1976) (invalidating civil service rule barring noncitizens from employment in federal civil service). But see *Kotch v. Board of River Port Pilot Comm'rs*, 330 U.S. 552 (1947) (upholding harbor pilot licensing rule that allowed nepotism by incumbent pilots to control who obtained new licenses).

²² See *Goldfarb v. Virginia State Bar*, 421, U.S. 773 (1975); *National Soc'y. of Professional Eng'rs. v. United States*, 435 U.S. 679 (1978).

²³ See *Arizona v. Maricopa County Medical Soc'y*, 457 U.S. 332 (1982); *American Medical Ass'n v. F.T.C.*, 638 F.2d 443 (2d Cir. 1980), *aff'd by an equally divided court*, 455 U.S. 676 (1982).

²⁴ See *Maricopa County Medical Soc'y*, 457 U.S. at 348-49, *Goldfarb*, 421 U.S. at 788 n.17; *National Soc'y of Professional Eng'rs*, 435 U.S. at 696. Commentators have suggested that the economic arrangements of professional practice should be subject to

The distinction in antitrust cases, as well as the Court's narrowed focus on actual pecuniary conflict of interest in other professional regulation cases, stems directly from the second key premise behind the justification for broad professional autonomy. The first premise — of professional expertise and concomitant lay incompetence — is only half of the justification for the state's grant of self-regulation to the profession. The second premise is that professionals will not abuse their expertise by taking advantage of their clients. Expertise alone could not justify independence from lay control were physicians not also able to assert that the profession would police its members' behavior to assure that client interests always were put first.²⁵ Thus one finds an emphasis within the medical profession, as in other licensed professions such as law, on the creation and enforcement of professional ethics codes. These codes presuppose the possibility of ethical behavior, that is, that there is no inherent conflict of interest in a profession regulating its own members on behalf of the state. The Supreme Court has explicitly accepted that the medical profession's "public service or ethical norms" may entitle it to deferential treatment by the law.²⁶ Indeed, it would be difficult for the Court to look beyond clear instances of individual conflicts between professionals and their clients to professional/client conflicts inherent in the structure without challenging the entire concept of professional licensure.

rigorous antitrust analysis while the technical content of the work should remain largely in the hands of professional self-regulation. See Kissam, *Antitrust Law, the First Amendment, and Professional Self-Regulation of Technical Quality*, in REGULATING THE PROFESSIONS, A PUBLIC POLICY SYMPOSIUM 143, 155 (R. Blair & S. Rubin eds. 1980).

²⁵ These two claims, expertise and ethicality, are central to the justification for professional autonomy. See E. FREIDSON, *PROFESSION OF MEDICINE* 342, 366 (1970); Becker, *The Nature of a Profession*, in THE SIXTY-FIRST YEARBOOK OF THE NATIONAL SOCIETY FOR THE STUDY OF EDUCATION 27 (N.B. Henry ed. 1962).

²⁶ *Maricopa County Medical Soc'y*, 457 U.S. at 348-49. See also *United States v. Oregon State Medical Soc'y*, 343 U.S. 326 (1952).

[T]here are ethical considerations where the historic direct relationship between patient and physician is involved which are quite different than the usual considerations prevailing in ordinary commercial matters. This Court has recognized that forms of competition usual in the business world may be demoralizing to the ethical standards of a profession.

Id. at 336. See also *Semler v. Oregon State Bd. of Dental Examiners*, 294 U.S. 608 (1935).

The community is concerned with the maintenance of professional standards which will insure not only competency in individual practitioners, but protection against those who would prey upon a public peculiarly susceptible And the community is concerned in providing safeguards . . . against practices which would tend to demoralize the profession by forcing its members into an unseemly rivalry which would enlarge the opportunities of the least scrupulous.

Id. at 612.

B. *The Expansion of Professional Authority*

No clear bounds on professional authority can be found in these interwoven justifications for professional autonomy. When the licensing system presumes that patients are incapable of knowing their own best interests, and that physicians can expertly judge and serve those interests as long as they show ethical dedication, then decision-making is naturally ceded to the profession's paternalistic judgments. Similarly, when the state believes itself incompetent to regulate professional behavior, and so delegates the duty to the profession itself, it becomes easier for the profession to claim a broad expertise over health issues to which lay persons, as either parents, patients, or policy-makers, should defer. Even if a profession must be allowed to regulate its members' conduct relatively free from outside control, it does not necessarily follow that the profession must also guide a society's health policies. However, the legal grant of autonomy has allowed just such an expansion of professional authority to occur by setting no clear bounds on professional expertise.

1. Expanded Authority Over Patients

The force of the presumption of professional authority is perhaps best illustrated by the legal doctrine of informed consent, which ostensibly stands as a bulwark against physician dominance over patients. Commentators often speak of the general right of patient control of medical decision-making in ringing and unqualified terms.²⁷ Closer examination shows that the ideal of informed consent is regularly surrendered to the contradictory presumption of professional autonomy.

Surveys of physicians show an ambivalent acceptance of the need for disclosure of at least some information about proposed treatment,²⁸ along with

²⁷ The best known of these statements is Judge Cardozo's proclamation that "every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages." *Schloendorff v. Society of New York Hosp.*, 211 N.Y. 125, 129, 105 N.E. 92, 93 (1914) (but denying recovery of damages in case before court). See also *Natanson v. Kline*, 186 Kan. 393, 406, 350 P.2d 1093, 1104 (1960) ("Anglo-American law starts with the premise of thorough-going self determination.").

²⁸ A survey by Louis Harris and Associates for the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research found that the great majority of physicians asserted they initiate discussions about the pros and cons of treatment with patients and seldom withhold information. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE & BIOMEDICAL & BEHAVIORAL RESEARCH, 1 MAKING HEALTH CARE DECISIONS at 79, 97 (1982) [hereinafter cited as MAKING HEALTH CARE DECISIONS]. Yet, the survey found that a similarly large majority of physicians, 72%, consciously evaluated at least once a week how much to tell a patient. *Id.* at 73. See also *infra* note 29.

a marked hostility to the possibility that a patient's consent can be truly informed.²⁹ Empirical evidence suggests that the kind of full and frank discussion between doctor and patient envisioned by the informed consent doctrine seldom occurs.³⁰

Despite this evidence that patients' rights of self-determination are regularly violated, lack of informed consent is seldom claimed in malpractice suits,³¹ and there is no recorded case of a patient winning damages solely for the dignitary harm of not being informed about the course of treatment.³²

This discrepancy is due in large part to the vitiation of informed consent doctrine in the law itself. Perhaps the most significant compromise in the doctrine concerns who decides what risks of treatment, and alternatives to the treatment proposed, must be disclosed to the patient. While some early cases established a "reasonable patient" standard concerning what information a patient would find material,³³ the medical profession asserted that the standard of disclosure should be set by professional custom.³⁴ A majority of states, reversing court decisions by statute in some instances, now have established the professional standard,³⁵ which accords little respect to disclosure. Other doctrinal limits

²⁹ Physician writers have frequently described informed consent as a myth or fiction. See, e.g., Laforet, *The Fiction of Informed Consent*, 235 J. A.M.A. 1579 (1976); Ravitch, *The Myth of Informed Consent*, SURGICAL ROUNDS, Feb. 1978, at 7. Their writings typically emphasize the emotional harm to the patient from disclosure of risks and the inability of patients to understand complex medical information. See also Coleman, *Terrified Consent*, PHYSICIAN'S WORLD, May 1974, at 11; Kaplan, Greenwald & Rogers, *Neglected Aspects of Informed Consent*, 296 NEW ENG. J. MED. 1127 (1977); Silk, *A Physician's Plea: Recognize Limitations of Informed Consent*, Am. Med. News, April 12, 1976 at 19.

³⁰ See 1 MAKING HEALTH CARE DECISIONS, *supra* note 28, at 80, 84-85, 110 n.80, 111 n.81; Lidz & Meisel, *Informed Consent and the Structure of Medical Care*, in 2 MAKING HEALTH CARE DECISIONS 317, 390-406 (informed consent "largely absent from the clinic . . ." *Id.* at 320.).

³¹ Thirty-seven states have recognized a legal right of recovery for lack of informed consent, but in one claims study, informed consent was raised as an issue in only three percent of the cases. 1 MAKING HEALTH CARE DECISIONS, *supra* note 28, at 21 n.22.

³² *Id.* There have been some recoveries for the dignitary harm of treatment without any consent at all, but none for lack of informed consent. See *Id.* at 25 n.35.

³³ See *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir.), cert. denied, 409 U.S. 1064 (1972); *Cobbs v. Grant*, 8 Cal. 3d 229, 502 P.2d 1, 104 Cal. Rptr. 505 (1972); *Wilkinson v. Vesey*, 110 R.I. 606, 295 A.2d 676 (1972). The fact that these 1972 cases can fairly be described as appearing early in the development of informed consent law shows how distinctly modern informed consent is. See also Katz, *Informed Consent — A Fairy Tale? Law's Vision*, 39 U. PITT. L. REV. 137, 169 (1977) (even when courts purport to set a lay standard, they fail to distinguish between professional expertise needed to determine the risks of and alternatives to treatment, and a judgment by professionals that such information might harm patients if disclosed).

³⁴ See MODEL INFORMED CONSENT LAW § 2 American Medical Association (1976); A. HARVEY, R. JOHNS & R. ROSS, *THE PRINCIPLES AND PRACTICE OF MEDICINE* 61-62 (19th ed. 1976) [hereinafter A. HARVEY].

³⁵ 1 MAKING HEALTH CARE DECISIONS, *supra* note 28, at 23 n. 30 (of states that have provisions on the subject, 26 have a professional standard and nine have patient-oriented standard).

discourage recovery for violation of informed consent. Many jurisdictions, for instance, allow no recovery for the lack of informed consent itself. They require a patient to show that he suffered a specific bodily injury whose risk was not disclosed in advance, and that if the risk had been disclosed, he would not have undergone the treatment resulting in the injury.³⁶

The illusory protection the informed consent doctrine provides to patients shows how professional autonomy, established by the licensing system, overwhelms countervailing forces in the law. The lack of respect for patient autonomy and the deference to professional authority, found in the implementation of a professional standard of informed consent by courts and legislatures, are the same themes underlying the licensing system.

Compounding the dominance of physicians over patients is the hierarchical legal structure of health care. Both individually and as a profession, physicians control the work of other health care professionals such as nurses, physical therapists, and social workers. These other workers are forbidden by licensing laws and the regulations of physician-dominated medical licensing boards from treating patients independent of physician's orders.³⁷ Similarly, payment by insurers, such as Blue Shield, is often limited to services supervised by physicians.³⁸ In hospitals especially, other health care professionals typically are forbidden from providing any information to patients inconsistent with that of the patient's physician. If these workers had greater independence from physicians, they might be able to act as a buffer between patient and doctor and to help promote patient autonomy. As it is, they reinforce physician authority.

The connection between the legal system of professional autonomy and physician dominance over patients in decision-making is clear. The legal system empowers physicians and constrains patients in both direct and indirect ways. Licensing is itself a direct constraint on patient choice. It establishes a monopoly that shuts out potential competitors. Not only must the sick rely on physicians; in addition, when the illness is serious, a sick person must be immersed in the self-contained environment of a hospital, which reinforces physician control and patient passivity.³⁹ But just as important are the indirect constraints

³⁶ See, e.g., *Canterbury*, 464 F.2d at 790. Even when courts have applied a patient-oriented standard of disclosure, the requirement that juries decide what a reasonable patient would have wanted disclosed rather than the particular patient suing, denies respect for the individual patient's idiosyncracies. Compare *Canterbury*, 464 F.2d at 788 (adopting objective standard) with *McPherson v. Ellis*, 305 N.C. 266, 287 S.E.2d 892 (1982) (adopting subjective standard; but note that North Carolina's legislature adopted objective standard, N.C. GEN. STAT. § 90-21.13 (1981)).

³⁷ See *supra* note 15.

³⁸ Rayack, *Medical Licensure: Social Costs and Social Benefits*, 7 LAW & HUM. BEHAV. 147, 154 (1983).

³⁹ Formal physician control in hospitals can be found in bylaws and other rules providing for self-governing medical staffs to decide all medical issues. Some state statutes as well as accrediting standards of the Joint Commission on Accreditation of Hospitals require such delegation. See Clark, *Does the Nonprofit Form Fit the Hospital Industry?*, 93 HARV. L. REV. 1416, 1445 nn.78-80 (1980). Informal physician control in hospitals is found in tacit rules that forbid other health care workers from openly criticizing the

licensing places on patients. As long as licensing is in place, so are the powerful presumptions that legitimize it: professional competence, lay incompetence, and professional ethicality. These presumptions have spread throughout the legal regulation of physicians, and have assured that restraints on physicians such as informed consent are ineffective.

2. Expanded Authority Over Social Policy

The dominance of physicians over societal decisions about health begins with the idea of physicians regulating their own competence and spreads to the notion that the profession itself should decide who gets what treatment. Part of this dominance is perhaps no more than the reflexive habit of turning to the putative experts in areas of uncertainty. But there is also a legally enforced dominance that begins with dominance over individual decision-making and eventually encompasses societal decisions.

Licensing envisions the therapeutic relationship as a bilateral contract between physician and patient. Licensing regulates this bilateral contract not by equalizing bargaining power, but by transforming the arms-length relationship assumed in most contracts into a fiduciary relationship. While this has important ethical ramifications in making decisions for individual patients,⁴⁰ the fiduciary relationship also has an important impact on societal decisions about resource allocations. When individual physicians are the agents, purchasing medical care on behalf of their patients, the sum of their decisions equals societal expenditures on medical care. Medical economists recognize that physicians, as both the providers and consumers of medical care, are in a unique position to set the demand for their own services.⁴¹ Generally, reform proposals have not challenged the basic fiduciary concept of physicians making decisions on behalf of their patients. Instead they have focused on creating financial incentives, such as health maintenance organizations, to encourage physicians to order fewer services for their patients.⁴²

Under insurance reimbursement mechanisms, the main economic control on a physician's medical purchases on behalf of his or her patients, aside from the patient's pocketbook, is the set of statistical norms established by the pattern of practice by the physician's peers. Reimbursement is based on whether the physician's decisions fit within the range of services normally provided for similarly situated patients. The most notable use of such standards is in the

work of physicians and that promote patient dependence in other ways. *See, e.g.*, E. FREIDSON, *supra* note 25, at 312-15 (uniformity of bureaucratic rules and restrictions on information reduce patients' decisionmaking ability); L. LANDER, *DEFECTIVE MEDICINE* 20-33 (1978) (hospital environment creates dependence and passivity in patients).

⁴⁰ *See infra* text accompanying notes 122-128.

⁴¹ *See* V. FUCHS, *supra* note 16, at 96; Klarman, *The Financing of Health Care*, 106 *DEADALUS* 215, 229 (winter 1977).

⁴² *See* V. FUCHS, *supra* note 16, at 138-41.

Medicare program. Congress established a nationwide system of local monitoring agencies controlled by the community's physicians, called Professional Standard Review Organizations.⁴³

Not all medical expenses are covered by insurance, so patients' ability or willingness to pay still limits how much care is provided and ensures that the profession does not completely determine the demand for its services. But when government mandates complete insurance coverage of a disease through public funding, as with kidney disease,⁴⁴ or that private insurers cover the costs of newborn intensive care,⁴⁵ it allows the medical profession to determine comprehensively the amount of resources society will allocate to that care.

The contractual model underlying licensure also furthers the view that health is an individual, private problem, and that medicine can provide a complete service that does not need integration with other health services. State provision of medical services, or, to a lesser extent, institutional licensing, would bring physicians' work under the same administration as that of other health care providers. This would encourage integration of medicine with other types of care and rationalization of expenditures on physician services with other forms of health spending.⁴⁶ Instead, the current system provides for physician dominance over decisions about how to coordinate their services with other forms of health care.

For example, the medical profession dominates accrediting boards for hospitals⁴⁷ that set standards for the relationship between physician services and those of other hospital health care workers. The medical profession's dominance of the accrediting board for medical schools⁴⁸ in turn provides control over curricular issues, such as the amount of emphasis placed on illness prevention. The profession also sets the standards of care enforced by tort law,⁴⁹

⁴³ Professional Standard Review Organizations (PSROs) decide whether care provided to Medicare and Medicaid patients is necessary and therefore eligible for reimbursement. Each PSRO is run by physicians elected by their peers in each locality or region. 42 U.S.C. § 1320c-1(b)(1). See generally Public Citizen Health Research Group v. HEW, 449 F. Supp. 937 (D.D.C. 1978) (history of PSRO legislation and summary of provisions).

⁴⁴ Social Security Amendments of 1972, Pub. L. No. 92-603, 86 Stat. 1329.

⁴⁵ See PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 203 n.28 (1983) [hereinafter cited as FOREGOING TREATMENT].

⁴⁶ See Sedgwick, *Medical Individualism*, HASTINGS CENTER STUDIES, Sept. 1974, at 69, 76.

⁴⁷ See H. SHUCHMAN, *supra* note 17, at 180-81.

⁴⁸ See *id.*

⁴⁹ In malpractice suits, the standard of care is controlled by professional custom. See A. HOLDER, *MEDICAL MALPRACTICE LAW* 59 (2d ed. 1978). Courts usually treat the professional standard as conclusively establishing the standard of care, unlike the general rule in negligence cases where conformity to customary practice is evidence of due care but not conclusive. J. KING, *THE LAW OF MEDICAL MALPRACTICE IN A NUTSHELL* 49 (1977).

and by agencies overseeing federally financed routine patient care⁵⁰ as well as federally funded research.⁵¹ These standards, setting acceptable levels of medical investment in different kinds of illness, involve the balancing of patient needs against societal resources. In addition, physicians are exempted altogether from several significant health care regulatory programs not run by fellow physicians.⁵² Reinforcing and reflecting the pervasive professional dominance in the legal regulation of health care is the typical dominance of physicians on panels advising legislatures and executive branches on health issues.⁵³

The presumption behind all of these facets of the medical profession's dominance in health care is not just that physicians should collectively set the standards for judging their own work. Rather, the presumption is also that they are better judges than anyone else, whether nurse, patient, or policy-maker, of what kinds of services the sick should receive.

C. *Implications of Professional Dominance of Societal Decisions*

The consequence of placing the medical profession in charge of many of society's health decisions has been to institutionalize the medical model of health and illness as the societal view. Paradoxically, this medical model derives much

But see *Helling v. Carey*, 83 Wash. 2d 514, 519 P.2d 981 (1974) (liability imposed even though physician behavior conformed to professional practice). *Helling* has not been followed in other jurisdictions. A. HOLDER, *supra*, at 54.

⁵⁰ See *supra* note 43.

⁵¹ Regulations governing Institutional Review Boards, which approve federally funded research in hospitals, provide for diverse board membership but permit as much as a four-to-one majority of physicians on a hospital's board. 45 C.F.R. § 46.106 (1982).

⁵² The Food, Drug and Cosmetic Act requires manufacturers to prove a drug's safety and efficacy for any purpose for which the drug is advertised. P.L. 87-781, 76 STAT. 781, § 102(C) (*as amended by* 21 U.S.C. 355(d) (1962)). Physicians are not obligated to prescribe a drug solely for approved uses; rather they are limited only by professional custom. See J. GIBSON, *MEDICATION LAW AND BEHAVIOR* 319 (1976) (quoting testimony of FDA general counsel to Congressional committee).

The National Health Planning and Development Act, 42 U.S.C. § 300k (1976), established a national network of Health Systems Agencies (HSA) to plan development of medical resources with a goal of preventing unnecessary duplication. Hospitals must win approval from an HSA before making substantial capital outlays. 42 U.S.C. § 300m-6 (supp. IV 1980). But individual physicians are exempt from the act. 42 U.S.C. § 300m-6(e)(1)(A); 42 C.F.R. § 100.102 (1982). *But see* *Whalen v. Roe*, 429 U.S. 589 (1977) (holding state computer compilation of names of patients receiving prescriptions for frequently abused drugs does not invade protected doctor/patient privacy).

⁵³ The most recent example was the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 7 of whose 11 members at the time it disbanded in 1983 were physicians. See *FOREGOING TREATMENT*, *supra* note 45, at ii. One particularly influential body was the Harvard Medical School's committee that proposed statutory changes in the definition of death that have been adopted by a number of states. See Ad Hoc Committee of the Harvard Medical School to examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 J. A.M.A. 337 (1968); Buchanan, *The Limits of Proxy Decisionmaking for Incompetents*, 29 U.C.L.A. L.Rev. 386, 386 & n.2 (1981).

of its influence from its putative objectivity. Yet the medical profession is so thoroughly entrenched as the official view, that it can no longer remain objectively self-critical about its theories of disease and illness, but has become obligated to defend those theories or lose power. What began as science becomes ideology,⁵⁴ no longer simply a theoretical approach to understanding disease but a culturally dominant way of understanding the human experience of illness.⁵⁵

That medical view is rooted in a theory of disease and illness that powerfully affects the way that physicians perceive patients.⁵⁶ Not surprisingly, this theory focuses on biological abnormalities within individuals and relegates the complex societal aspects of illness to the periphery of its vision.⁵⁷ Treating ill persons becomes transformed into treating the diseases located in their bodies.⁵⁸ Scientific treatment is judged to be that which works without regard to the non-objective factors of illness such as a patient's societal and psychological situation. Under this medical model, it is no coincidence that patients become

⁵⁴ While a science is disinterested in the reality it describes, ideology is committed. See C. GEERTZ, *THE INTERPRETATION OF CULTURES* 231 (1973). Ideologies provide "maps of perceptible social reality and matrices for the creation of collective conscience." *Id.* at 220.

⁵⁵ See, e.g., E. FREIDSON, *supra* note 25, at 330-31 (autonomy gives profession power to define and organize need for its own services). For the significance of medicine as ideology, see the discussion of radical critics, *infra* note 125; E. HUGHES, *MEN AND THEIR WORK* 79 (1958) (medical profession "tries to define for all of us the very nature of health and disease"); Engel, *The Need for a New Medical Model: A Challenge for Biomedicine*, 196 *SCIENCE* 129, 130 (1977) (medical approach has expanded beyond research role into cultural role as "folk model" explaining illness).

⁵⁶ This influence on perception is profound. Perception simultaneously embraces visual sensation and knowledge. Two people with different theories who look upon the same object do not see the same thing. See C. GEERTZ, *supra* note 54, at 214-18 (all perception is theory-laden); N. HANSON, *PATTERNS OF DISCOVERY, AN INQUIRY INTO THE CONCEPTUAL FOUNDATIONS OF SCIENCE* 4-30 (1961).

⁵⁷ This theory arose in the early nineteenth century with the development of pathological anatomy. This development transformed the concept of illness into one measurable by anatomic or biochemical abnormalities, and not dependent on a patient's subjective symptoms. See M. FOUCAULT, *THE BIRTH OF THE CLINIC, AN ARCHAEOLOGY OF MEDICAL PERCEPTION* 3, 35, 97 & *passim* (1973). Today, physicians still have no systematic vocabulary for describing what for patients is the essence of illness — the interaction of a human being with a disease. Thus, it is not surprising that physicians, especially in hospitals, ignore patients and focus on disease. See A. FEINSTEIN, *CLINICAL JUDGMENT* 72-79, 84-88, 118, 126, 364 (1967).

See generally T. KUHN, *THE STRUCTURE OF SCIENTIFIC REVOLUTIONS* 37 (2d ed. 1970) (system of theory, or paradigm, which dominates a science at any point in history can insulate a scientific community from socially important problems for which paradigm has no tools).

⁵⁸ This has far-reaching consequences in infant care. For example, physicians support the regionalization of neonatal intensive care units because they reduce infant death and disease. Little attention is given to the difficulties such systems create for parents who live long distances from the hospitals where their infants are placed, and the subsequent child abandonment and other psychological attachment problems that develop.

depersonalized⁵⁹ or that patient autonomy is regularly violated, because personal characteristics and patient choice are not viewed as significant aspects of causing or curing illness. This medical theory of illness remains dominant despite the inability of its proponents to demonstrate its superiority in healing.⁶⁰

Yet the legal grant of autonomy to physicians — and the medical profession's subsequent dominance of the health care system — have discouraged the development of non-medical understandings of health and illness.⁶¹ These

Compare Swyer, The Organization of Perinatal Care with Particular Reference to the Newborn, in NEONATOLOGY, PATHOPHYSIOLOGY AND MANAGEMENT OF THE NEWBORN 17, 25-30 (G. Avery 2d ed. 1981) (measures "improved outcome" in newborn care through regional centers only in terms of effects on morbidity and mortality rates) with Jones, Environmental Analysis of Neonatal Intensive Care, 170 J. NERVOUS & MENTAL DISEASE 130 (1982) (amount of time parents spend with newborns in intensive care varies inversely with distance between home and hospital; at over 50 miles distance is associated with infants becoming wards of the state).

⁵⁹ See Frader, *Difficulties in Providing Intensive Care*, 64 PEDIATRICS 10, 14 (1979) (emphasis on technology and "physiological detail" in pediatric intensive care unit depersonalizes both patients and staff and contributes to haphazardness of discussion of moral issues); A. FEINSTEIN, *supra* note 55, at 364 (physicians refer to patients as either diseases or surgical procedures).

The depersonalizing aspects of hospitals are not simply a function of the hospital as a bureaucracy but of the medical profession's effort to isolate the biological causes of illness from the social and psychological factors and to limit treatment primarily to the biological. See *supra* note 57.

⁶⁰ See T. McKEOWN, *THE MODERN RISE OF POPULATION* 91-109, 152-63 (1976) (most improvement in life expectancy due to sanitation, nutrition, other non-medical social changes); R. DUBOS, *MIRAGE OF HEALTH* 163, 212-19 (1958) (similar); OFFICE OF TECHNOLOGY ASSESSMENT, *ASSESSING THE EFFICACY AND SAFETY OF MEDICAL TECHNOLOGIES* (1978) (ten of seventeen drug and surgical therapies and diagnostic procedures reviewed, including intensive care after heart attacks and fetal monitoring during childbirth, show no benefit in survival or improved health despite high costs); A. COCHRANE, *EFFICIENCY AND EFFECTIVENESS* (1972) (similar review of variety of medical procedures); A. FEINSTEIN, *supra* note 57, at 40-41, 53 (even studies purporting to show efficacy "usually are not scientifically reproducible" and thus are of little worth in determining merit of treatment).

Some commentators argue that the inefficacy of modern medicine is precisely due to this depersonalization. See *Id.* at 365 (inattention to patients as persons has led to failure to classify systematically manifestations of illness in patients so that results of therapy can be judged scientifically).

⁶¹ Within medicine, there has been some attempt to accommodate more "holistic" understandings of illness. Commentators argue that this represents not enlightenment but an attempt to extend medical dominance even further beyond the bounds of technical expertise into social and psychological areas for which physicians are little trained. See Veatch, *The Hippocratic Ethic: Consequentialism, Individualism, and Paternalism in No Rush To Judgment — ESSAYS ON MEDICAL ETHICS* 238, 250 (D. Smith & L. Bernstein eds. 1978). See also H. FABREGA, *DISEASE AND SOCIAL BEHAVIOR* 218-19 (1974) (a truly unified view of illness as a confluence of biological, social and emotional factors would require a virtual revolution in the training of physicians.); Zola, *Medicine as an Institution of Social Control*, in *THE CULTURAL CRISIS OF MODERN MEDICINE* 87-88 (J. Ehrenreich ed. 1978).

understandings could contain the over-extension of medical authority by offering alternatives to the hegemony of the medical care system.⁶²

Examples of such competing alternatives that currently are subsumed to physician authority, and consequently are ill-funded and of low prestige, include public health, social work and nursing. Each of these fields has perspectives on illness and expertise different from physicians: public health in its focus on resource allocation and environmental interventions,⁶³ nursing in its whole-person focus on patients,⁶⁴ and social work in its attention to family and community support in mitigating the consequences of illness.⁶⁵

III. DECISION-MAKING FOR HANDICAPPED INFANTS

The issue of withholding treatment from handicapped infants provides a striking illustration of the consequences of the dominance of the medical profession over health care. Many of those troubled by the current way in which great discretion is vested in doctors and parents share an intuitive belief that this is an area where physicians lack exclusive expertise in making decisions. Yet surprisingly little attention has been given to what actually goes on in the decisions reached between doctors and parents, or to the relationship between those decisions and societal decisions. It is useful to explore these neglected areas of the issue to try to better understand both the phenomenon of handicapped infants and the effects of the legal structure of health care in a specific case.

A. *The Focus of the Controversy*

Nearly all of the controversy about care for infants with birth defects has centered on what happens in individual cases in the hours and days following birth.⁶⁶ Societal consensus exists only at the extremes: life-sustaining care should

⁶² See E. FREIDSON, *supra* note 25, at 369-70 (professional autonomy creates a "splendid isolation" in which very fact of autonomy encourages physicians to inflate the objectivity and importance of their work and to become unwilling to listen to outsiders).

⁶³ For example, public health long has emphasized non-medical interventions to prevent illness in pregnant women and infants. See M. GRANT, *HANDBOOK OF COMMUNITY HEALTH* 137-60, 165-66 (3d ed. 1981); J. HANLON, *PUBLIC HEALTH ADMINISTRATION AND PRACTICE* 320-34 (6th ed. 1974).

⁶⁴ See *infra* note 83.

⁶⁵ Social work, historically influenced by the individual-oriented medical model, has suffered from a similar narrow focus on treating individuals at the expense of attacking the social causes of clients' problems. See M. ADAMS, *MENTAL RETARDATION AND ITS SOCIAL DIMENSIONS* 59 (1971). However, the profession's focus has begun to shift to a more balanced approach between individual casework and activities such as community organization of parents' groups and lobbying legislatures for public funding of services. See *id.* at 248-85.

⁶⁶ The incidence of cases requiring such decisions is common. See *FOREGOING TREATMENT*, *supra* note 45, at 207 (such decisions "are part of everyday life" in newborn intensive care units); Campbell, *Which Infants Should Not Receive Intensive Care?*, 57 *ARCH. DISEASE CHILDHOOD* 569 (1982) (based on one intensive care nursery, estimates 20.5% of newborn deaths are from withholding treatment); Duff & Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 *NEW ENG. J. MED.* 890 (1973) (43 of 299 deaths in special care nursery followed decisions not to treat).

be given to infants with minor defects such as cleft palate; care may be withheld from infants whose defects are so severe that care would only prolong dying.⁶⁷ Controversy centers mainly on a broad middle category of infants with severe mental and physical handicaps, such as Down's syndrome and spina bifida.⁶⁸

⁶⁷ See, e.g., J. GOLDSTEIN, A. FREUD & A. SOLNIT, BEFORE THE BEST INTERESTS OF THE CHILD 91-96 (1979) (advocates of broad parental autonomy would intervene when non-treatment would deny child "relatively normal healthy growth," as when blood transfusion refused for otherwise normal child); P. RAMSEY, ETHICS AT THE EDGES OF LIFE 214 (1978) (critic of present physician/parent autonomy would make exception to duty to treat when infant "born dying" or otherwise beyond medical help).

⁶⁸ See Shaw, Randolph & Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588, 590 (1977) (pediatricians nearly unanimous in favoring non-treatment for anencephaly and for Trisomy 13-15 but split almost evenly on spina bifida and Down's syndrome).

While there are a variety of birth anomalies for which treatment has been withheld, most attention centers on the following conditions:

(1) Down's Syndrome. Down's is a chromosomal abnormality that occurs about once in every 600 births. H. JOLLY, DISEASES OF CHILDREN 195 (4th ed. 1981). It is associated with varying degrees of mental retardation and often is accompanied by heart defects and blockages in the intestine or esophagus. These blockages prevent normal digestion of food but are correctable by simple surgery. FOREGOING TREATMENT, *supra* note 45, at 202-03 & n.26.

(2) Spina bifida, or meningocele. This occurs about once in every 500 births when the fetus's developing spine fails to seal properly and the infant is born with part of the spinal cord protruding from its back. This causes nerve damage, including total or partial paralysis of the legs and loss of bowel and bladder control. *Id.* at 202. Surgery is required to close the spinal opening to prevent fatal infection and, in some cases, to shunt excess spinal fluid from the brain. H. JOLLY, *supra*, at 191-93.

(3) Low birth weight infants. These infants usually are given maximal treatment. See Strong, *The Tiniest Newborns*, HASTINGS CENTER REP., Feb. 1983, at 14. Some prominent physicians have argued for withholding treatment in selected cases. See Kirkley, *Fetal Survival — What Price*, 137 AM. J. OBSTETRICS & GYNECOLOGY 873 (1980) (as prematurity is leading cause of mental retardation, aggressive treatment of low birth weight babies without selection must be reassessed with view towards fact that much suffering has resulted in spite of massive effort of dedicated support teams; fact of survival not so much a tribute to medical achievement as misuse of medical power). Low-weight infants often become normal but occasionally suffer permanent brain damage that cannot be predicted at birth. See Strong, *supra*, at 16.

(4) Infants born with little or no brain, or anencephaly. These infants usually die within a few hours or days of birth no matter what care is given. FOREGOING TREATMENT, *supra* note 45, at 202.

(5) Infants who suffer brain damage at birth due to lack of oxygen. These infants usually are treated aggressively at first, but decisions sometimes are made later not to resuscitate infants who stop breathing or to withhold other care. See D. CRANE, THE SANCTITY OF SOCIAL LIFE: PHYSICIANS' TREATMENT OF CRITICALLY ILL PATIENTS 74-83 (1975). Predicting the extent of handicaps is often impossible in the early period after birth. H. JOLLY, *supra*, at 92.

(6) Infants with other anomalies. Less common birth defects include Trisomy 13 and Trisomy 18, most of whose victims die in a few weeks. *Id.* at 198.

This list can be divided into three categories: (1) infants who can receive no benefit from medical treatment because the severity of their condition dooms them to an early death, e.g., anencephaly, Trisomy 13 and Trisomy 18; (2) infants who clearly can benefit

Some commentators and parents maintain that such children are capable of happy, meaningful lives,⁶⁹ and so should be given comprehensive treatment. Others argue that in the absence of societal consensus about whether such lives are worth living, parents and physicians should decide on a case-by-case basis whether such infants live.⁷⁰

Parents and physicians have this broad discretion to decide whether and how vigorously infants with severe handicaps are to be treated. Occasionally, hospitals ask courts to authorize treatment when parents oppose it,⁷¹ but this is unusual because the prospect of litigation is enough to persuade most parents

from medical treatment because it will extend their lives and allow them to experience an arguably "meaningful" life despite the certainty of handicaps, e.g., Down's syndrome and spina bifida; (3) infants for whom the benefits of medical treatment are uncertain because of the impossibility of predicting at the time of treatment decisions whether they will survive and with what handicaps, e.g., low birth weight and birth trauma.

⁶⁹ See, e.g., Dorner, *Adolescents with Spina Bifida: How They See Their Situation*, 51 ARCHIVES DISEASE CHILDHOOD 439 (1976) (emotional adjustment not greatly different from normal adolescents); Brown & McLone, *Treatment Choices for the Infant with Meningomyelocele*, in INFANTICIDE AND THE HANDICAPPED NEWBORN 69 (D. Horan & M. Delahoyde eds. 1982) (motor function improves following early surgical treatment of spina bifida; nearly impossible to predict at birth future intellectual ability); Foot, *supra* note 3, at 109 (Down's children "are able to live on for quite a time in a reasonably contented way, remaining like children all their lives but capable of affectionate relationships and able to play games and perform simple tasks."). For comments by parents describing the benefits of raising a handicapped child, see, e.g., R. DARLING, *FAMILIES AGAINST SOCIETY, A STUDY OF REACTIONS TO CHILDREN WITH BIRTH DEFECTS* 185-87 (1979) (parents interviewed in study would not deliberately choose to have handicapped child but feel experience valuable to them); Fein, *We Couldn't Give Up on Jason*, FAMILY CIRCLE Oct. 26, 1982, at 40 (parents of Down's child); Schalck, *A Parent's Experience with a Child with Spina Bifida*, in DECISION MAKING AND THE DEFECTIVE NEWBORN 158 (C. Swinyard ed. 1978) [hereinafter cited as Swinyard].

⁷⁰ See, e.g., J. GOLDSTEIN, A. FREUD & A. SOLNIT, *supra* note 67, at 91-98 (parental autonomy should govern when no societal consensus that child's life is "worth living"); Duff & Campbell, *supra* note 66, (parents and physicians should decide because most familiar with circumstances of each case); Relman, *The Saikewicz Decision: A Medical Viewpoint*, 4 AM. J. LAW & MED. 233 (1978) (only check needed is on accuracy of medical diagnosis by a physician's peers).

This is the official position of the American Medical Association. See OPINIONS OF THE JUDICIAL COUNCIL OF THE AMERICAN MEDICAL ASSOCIATION, § 2.10 (1982) ("[i]n desperate situations involving newborns, the advice and judgment of the physician should be readily available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents.").

⁷¹ See, e.g., *In re Infant Doe*, No. GU8204-004A (Ind. Cir. Ct. App. 12, 1982) ("Infant Doe" case that prompted Reagan regulations; hospital sought court decision after doctors disagreed on whether to treat Down's infant); Application of Cicero, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (Sup. Ct. 1979) (court appoints guardian to consent to surgery for spina bifida infant); *Maine Medical Center v. Houle*, No. 74-145 (Me. Super. Ct. 1974) reprinted in R. WEIR, *ETHICAL ISSUES IN DEATH & DYING* (1977) (court orders treatment for infant with multiple defects); N.Y. Times, June 24, 1981, at A14, col. 6 (Miami judge orders treatment for infant with spinal defect).

to give in.⁷² When doctors and parents agree on nontreatment, the state rarely intervenes, either to impose treatment or to prosecute criminally.⁷³

Opponents of current practice maintain that physicians and parents have too much discretion. They argue that decisions can violate the best interests of helpless infants.⁷⁴ At one extreme, parents, encouraged by physicians, may focus on their own interests in avoiding the burdens of life with a handicapped child.⁷⁵

⁷² See Duff, *Counseling Families and Deciding Care of Severely Defective Children: A Way of Coping with 'Medical Vietnam'*, 67 PEDIATRICS 315-16 (1981) (The threat of internal guilt and of public notoriety resulting from court action brings most parents into line).

⁷³ The Reagan administration's attempt to intervene in the case of Baby Jane Doe in New York is a notable exception to the usual hands-off approach of government officials to treatment decisions. See *United States v. University Hosp.*, 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd* 729 F.2d 144 (2d Cir. 1984) (denying federal right to intervene where parents have made reasonable decision against surgery for handicapped child).

Only one criminal prosecution has been reported in this country. See Robertson, *Dilemma in Danville*, HASTINGS CENTER REP., Oct. 1981 at 5 (judge dismisses charges against couple for lack of evidence that non-treatment of Siamese twins was at parents' request). A British physician was acquitted of a charge of attempted murder involving the death of a Down's infant. See THE LANCET, Nov. 14, 1981 at 1101. See also Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 243 (1975) (describing a number of theories under which criminal prosecution could be brought but noting that rarity of prosecutions amounts to delegation of prosecutorial authority to physician/parent decision-making).

⁷⁴ A child has an interest in any treatment that will extend its life unless for the infant's own sake it is better to be dead than alive. This must be determined from the vantage point of the handicapped individual. To a person of normal intelligence, life with an IQ of 50 might not be worth living, but to a person who has never experienced normal intelligence, such a life might be preferable to death. See Foot, *supra* note 3, at 94 ("[o]n any view of the goods and evils that life can contain, it seems that a life with more evil than good could still itself be a good.")

Courts almost unanimously have sustained the view that life with even severe handicaps is better than no life at all, refusing to recognize a "wrongful life" cause of action for such children. See, e.g., *Phillips v. United States*, 508 F. Supp. 537 (D.S.C. 1980) (A child with Down's Syndrome has no cause of action against doctor for failing to advise a genetic test that could have led to abortion); *Berman v. Allan & Attardi*, 80 N.J. 421, 430, 404 A.2d 8, 13 (1979) (Pashman, J.) (for the court to say that a child with Down's Syndrome would be better off never existing ". . . would require us to disavow the basic assumption upon which our society is based . . ." namely, sanctity of life. *But see Curlender v. Bio-Science Laboratories*, 106 Cal. App. 3d 811, 165 Cal. Rptr. 477 (Cal. Ct. App. 1980) (Tay-Sachs victim given right to recover against genetic testing laboratory). The California Supreme Court overruled *Curlender* in *Turpin v. Sortini*, 31 Cal. 3d 220, 643 P.2d 954, 182 Cal. Rptr. 337 (1982), holding that while it could not agree with other courts that as a matter of law the value of impaired life always exceeded the value of nonlife, it was impossible to determine in any given case ". . . whether the plaintiff has in fact suffered an injury by being born with an ailment as opposed to not being born at all . . ." 643 P.2d at 963.

⁷⁵ See, e.g., Fost, *Counseling Families Who Have a Child with a Severe Congenital Anomaly*, 67 PEDIATRICS 321, 323 (1981); Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213, 255-59 (1975).

At the other extreme, parents or physicians may insist on all-out treatment that provides no benefit for the infant. Defenders of the present system respond that physicians can make sure that parents' choices are based on accurate facts and are ethically reasonable.⁷⁶

Both sides in this debate have cast the issue largely in terms of whether physicians and parents acting together have too much discretion. Neither has adequately focused on what happens between physicians and parents,⁷⁷ or the societal resource allocation problems that create the framework for the decisions in individual cases.⁷⁸ Physicians actually are much more dominant in making decisions about infants than either defenders or critics of the current system acknowledge, and the medical model of illness exerts a profound if subtle effect on the very shaping of the terms of debate.

B. Physician Dominance of Parents

The control of information is the key means by which physicians dominate parents in decision-making. As a rule, the physician in charge of an infant's care decides who talks to the parents — the doctor himself, or more often, nurses and social workers — and what is said.⁷⁹ The emphasis is on presenting to parents a "united front" of medical advice. Nurses, social workers, and other

⁷⁶ See, e.g., Campbell, *supra* note 66, at 571 ("[a]s pediatricians we have a major responsibility to ensure that the process of decision-making will stand up to the most rigorous scrutiny"); Duff & Campbell, *On Deciding the Care of Severely Handicapped or Dying Persons: With Particular Reference to Infants*, 57 PEDIATRICS 487, 491 (1976) (physicians "set limits").

⁷⁷ Thus, commentators frequently assume without evidence that parents are the primary decision-makers. See, e.g., Note, *Birth-Defective Infants: A Standard for Non-treatment Decisions*, 30 STAN. L. REV. 599, 602 n.15 (1978) (explicitly states parents make decisions); J. GOLDSTEIN, A. FREUD & A. SOLNIT, *supra* note 67, at 91-98 (implicitly assumes parents are main decision-makers since authors see threat to parental autonomy coming not from physicians but from courts). See also OPINIONS OF THE JUDICIAL COUNCIL OF THE AMERICAN MEDICAL ASSOCIATION, § 2.10 (1982) (relying on assertion that parents should be primary decision-makers to support view that current practice should not be interfered with).

⁷⁸ Discussions that try to put these individual decisions into the broader context of societal decisions are rare. See, e.g., E. KEYSERLINGK, *SANCTITY OF LIFE OR QUALITY OF LIFE IN THE CONTEXT OF ETHICS, MEDICINE AND LAW* 173-77 (1979); Smith, *On Letting Some Babies Die*, in *KILLING AND LETTING DIE* 95 (B. Steinbock ed. 1980).

⁷⁹ See Duff, *Guidelines for Deciding Care of Critically Ill or Dying Patients*, 64 PEDIATRICS 17, 21-22 (1979) (hospital policy provides that physician in charge of child's care decides whether staff disagreements about treatment are communicated to family); Bogdan, Brown & Foster, *Be Honest but Not Cruel: Staff/Parent Communication On A Neonatal Unit*, 41 HUMAN ORG. 6, 11 (1982) (study of neonatal unit finds doctors are in charge of communication with parents, and "[n]urses and social workers may discuss the child's larger diagnostic and prognostic picture but only in an attempt to clarify what physicians have already told the parents.")

non-physicians who disagree with the decision of the primary physician are expected to keep their disagreements to themselves, and those who speak out risk disciplinary action.⁸⁰

These other professionals have their own distinctive professional expertise and points of view toward handicapped infants. For example, nurses are the primary care-givers in intensive care nurseries, both in technical procedures⁸¹ and in non-medical nurturing care.⁸² Their professional ethic stresses recognizing the human qualities in handicapped infants and maintaining the dignity of patients as persons.⁸³ Social workers have two main roles in intensive care nurseries: as intermediaries in reducing physician/nurse conflicts⁸⁴ and as family

⁸⁰ See Statement of C. Everett Koop before the *Senate Subcomm. on Family and Human Services*, April 6, 1983 at 8 (surgeon general reports receiving more than 20 contacts from nurses threatened with discipline for objecting to orders from doctors to deny food to handicapped newborns). See generally J. MUYSKENS, *MORAL PROBLEMS IN NURSING* 48-49 (1982) (most nurses risk challenging physician orders only in extreme cases).

⁸¹ See Harper, Little & Sia, *The Scope of Nursing Practice in Level III Neonatal Intensive Care Units*, 70 *PEDIATRICS* 875, 877 (1982) (nurses, especially those with advanced training, perform duties identical to junior physicians and even train physicians in procedures historically in physicians' province).

⁸² See Jones, *supra* note 58, at 137 (79.1% of all adult contact with infants in intensive care nursery provided by nurses, most consisting of soothing, rocking, etc.).

⁸³ See American Nurses' Association Code for Nurses, *reprinted in* J. MUYSKENS, *supra* note 80, at 7 (ethical code emphasizes nurses' respect for "human dignity and the uniqueness of the client"); *Id.* at 36-40 (nurse "caring" functions aim at maintaining autonomy of patient). The "care" orientation of nurses distinguishes their work as being more than mere technical assistance to physicians. Beyond their work with the newborns themselves, nurses are heavily involved, with social workers, in helping the family adjust to their sick newborn. This includes both teaching practical home care when the infant is discharged, and showing the family the infant's worth as a person. See Brown & Bernstein, *Family-Centered Nursing Care*, in *NEONATOLOGY*, *supra* note 58, at 78, 82-84. See also Allen, *Normalization and the Child with Developmental Delays*, in Swinyard, *supra* note 69, at 333 (example of nurses establishing regional treatment program for handicapped children combining vocational, educational, family, and other non-medical services aimed at allowing handicapped to live in community rather than in institutions).

See generally M. MUNDINGER, *AUTONOMY IN NURSING* 63-105 & *passim*. (1980) summarizes nurses' efforts to maintain autonomy in variety of settings including independent nurse practitioner offices, public health nurses and hospitals, describes a "primary nursing" model of hospital care in which single nurse responsible for patient's nursing care parallels responsibility of primary physician for medical care).

⁸⁴ See Kornblum & Marshall, *A Clinical Social Worker's Function as Consultant in the Neonatal Intensive Care Unit*, 7 *SOCIAL WORK HEALTH CARE* 57 (1981) (liaison function mitigates physician dominance by sensitizing physicians concerned with nurse "burnout" to stresses experienced by nurses' lack of decisional authority). *But see* Thomstadt, *A Nurse Comments*, 7 *SOCIAL WORK HEALTH CARE* 64 (1981) (structural change of health care system better approach to nurse job stress than individual counseling).

therapists helping in the adjustment to a handicapped newborn.⁸⁵

Physicians not only control the information presented to parents but control aspects of the work of other health care workers. This reinforces physician dominance over parents, by reminding them who is in charge in the hospital authority structure. In addition, physician dominance means that other health care professionals have less of an opportunity to influence decisions.⁸⁶

Moreover, the physician in charge of a case enjoys great independence even from his peers,⁸⁷ due in large part to a professional notion of disease that stresses the superiority of bedside observation over textbook knowledge. The technological sophistication and emotional stress in an intensive care nursery, and the need for close teamwork in such an environment, encourage physicians and other health care workers to ignore moral disputes and focus instead on physiological detail.⁸⁸

In this setting, parents play a largely passive role, receiving the information which supports the physicians' recommendations, and then giving their consent.⁸⁹ While parents can influence what a doctor recommends depending on

Nurses generally identify conflicts with physicians — especially young physicians with similar skills as nurses but more authority — as a main source of stress in working in newborn intensive care. In contrast, physicians are not generally stressed by conflicts with nurses. See Astbury & Yu, *Determinants of Stress for Staff in a Neonatal Intensive Care Unit*, 57 ARCHIVES DISEASE CHILDHOOD 108, 109 (1982). This stress in decisional authority helps explain why nurses have a much higher "burnout" rate in intensive care nurseries than physicians. See *id.* at 111.

⁸⁵ See Siegel, *A Family-Centered Program of Neonatal Intensive Care*, 7 HEALTH & SOC. WORK 50, 53-54 (1982) (duties include assessing family's social and psychological adjustment to newborn, counseling family members, providing referrals to community agencies for follow-up care, financial assistance, etc.).

⁸⁶ Physicians sometimes emphasize that other professionals, particularly nurses, should be consulted; the motivation, however, is usually more to appease other health care workers than because their point of view is genuinely valued. See, e.g., Avery, *The Morality of Drastic Intervention*, in NEONATOLOGY, *supra* note 58, at 15 (physicians "must be careful to share the reasons for their decisions" with nurses); Duff, *supra* note 79, at 22 (nurses are better able to carry out duties if they understand reasons for treatment decisions).

⁸⁷ Fewer than one percent of hospitals have established ethics committees for such cases, and many of those provide only general guidelines, not review of specific decisions by physicians and parents. FOREGOING TREATMENT, *supra* note 45, at 161-64. See generally M. MILLMAN, *THE UNKINDEST CUT* 136 (1976) (physicians disagreeing with decision of primary doctor usually are "expressly forbidden" to tell family); J. BERLANT, *PROFESSION AND MONOPOLY* 71-73 (1975) (long tradition in medical ethics of not telling patients about conflicting medical opinions).

⁸⁸ See Frader, *supra* note 59, at 14 (dominance of technology and efforts to control emotions by burying feelings lead to depersonalization of both infant patients and staff).

⁸⁹ See Bogdan, Brown & Foster, *supra* note 79, at 10, 12-13 (parents' role is to receive information that is usually colored optimistically so parents are seldom aware of infant's true condition); Avery, *supra* note 86, at 13, 15 ("ultimately, the family has the

whether physicians perceive the parents as positive or negative toward the infant,⁹⁰ they are seldom active decision-makers in a meaningful way.⁹¹

Indeed, consistent with the medical profession's long-standing paternalism toward its clientele,⁹² many physicians regard parents, because of emotional shock and technical ignorance, as incompetent to make decisions.⁹³ It is unquestionable that parents suffer an initial period of emotional trauma, with varying amounts of denial, anger, rejection of the ill baby, grief and numbness, all mixed together in complex stages. But empirical evidence does not support the view that parents' emotional or intellectual handicaps prevent them from participating in decisions.⁹⁴ In fact, studies show that medical personnel frequently misjudge parental reactions to the infant as well as parental understanding of the medical issues. This is mainly due to the little time or attention given

authority to accept or reject the recommendation of the physician, but it is unfair to place the whole burden of decision on them.")

⁹⁰ See, e.g., Shaw, Randolph & Manard, *supra* note 68, at 591-92 (minority of physicians would leave entirely to parents decision of whether to repair surgically intestinal obstruction in Down's infant); D. CRANE, *supra* note 68, at 50-51, 83 (survey of pediatricians, pediatric heart surgeons and neurosurgeons found parental desires had only marginal influence on physician treatment decisions); Todres, Krane, Howell & Shannon, *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 PEDIATRICS 197, 198 (1977) (parental desire to withhold spina bifida surgery would be honored by 60% of pediatricians).

⁹¹ This conclusion is supported by surveys of physicians, *see supra* note 90, as well as by studies of neonatal units, physician comments, and articles by parents who have been through the experience. For studies, *see, e.g.*, D. CRANE, *supra* note 66, at 98-99 (hospital records review study showing heart surgeons unlikely to operate on Down's infants even if parents favor surgery and despite hospital policy favoring equal treatment for Down's and non-Down's infant heart patients); Bodgan, Brown, & Foster, *supra* note 79. For physicians' comments, *see, e.g.*, Campbell, *supra* note 66, at 570 (decisions should be made by doctor); Fost, *How Decisions Are Made: A Physician's View*, in Swinyard, *supra* note 67, at 228 ("the parents I see are at the mercy of the physician's presentation, and their 'consent' is rarely informed or uncoerced in any meaningful sense.") For articles by parents, *see infra* note 96.

⁹² See Szasz & Hollender, *The Basic Models of the Doctor-Patient Relationship*, 97 ARCHIVES INTERNAL MED. 585, 586-87 (1956) (doctor guides and patient is expected to cooperate); Relman, *supra* note 70, at 237 (according to prominent physician essence of doctor-patient relationship is patient trusting in physician's decisions).

⁹³ See, e.g., Fost, *supra* note 73, at 322 (parents unable to assimilate facts during initial shock after birth); Relman, *A Response to Allen Buchanan's Views on Decision Making for Terminally Ill Incompetents*, 5 AM. J. LAW & MED. 119, 120 (1979) (families often too grief-stricken or too ambivalent to decide).

⁹⁴ See Benfield, Leib & Vollman, *Grief Responses of Parents to Neonatal Death and Parent Participation in Deciding Care*, 62 PEDIATRICS 171 (1978); 1 MAKING HEALTH CARE DECISIONS, *supra* note 28, at 55-111 (1982) (discussing capacity of patients to participate in decisions).

in intensive care nurseries to dealing with parents.⁹⁵ Furthermore, parents of handicapped infants, interviewed about their hospital experiences, frequently stress their anger and frustration at their inability to get information and the attempts made to manipulate their decisions.⁹⁶

Medical decision-making thus can be characterized not as a painful but collegial process of shared decisions among equals but as an authoritarian, paternalistic process. This increases the risk of decisions that are arbitrary and inconsistent simply through the lack of a thorough airing of factual and moral issues.⁹⁷

These flaws in medical decision-making can be traced to the complex interplay between the medical model of illness and the legal structure of medical practice reinforcing that model. While the medical model acknowledges that factors such as lifestyle and environment can play a role in illness, it insists that the true causes and cures of illness lie in physiological factors within medicine's exclusive expertise. Under this model, there is little practical need for communication with parents; consent is regarded as a legalistic encumbrance of no benefit to the therapeutic process. The legal structure of medical practice establishes the medical model as the correct and normal way of viewing health and illness, and it establishes deference to professional judgment as the social norm. But it does more than create norms that emasculate protest. The legal monopoly granted to the medical profession directly constrains parents from obtaining expert help that is not controlled by physicians. The licensing system forces parents into an intimate yet subservient relationship with a physician. It enshrines this relationship as presumptively private and not to be invaded by outsiders. Even those with special expertise about handicapped infants are excluded except at the direction of the physician. Parents have little choice but to bend to the will of professional judgment.

C. *The Medical Model and Resource Allocations*

Despite the fact that the literature on handicapped newborns is overwhelmingly concerned with the individual decisions analyzed above, it should be clear that the issue is much broader. A series of societal decisions creates the matrix within which individual physicians and parents struggle with their consciences.

⁹⁵ See Bogdan, Brown & Foster, *supra* note 79, at 11 (staff tried to adjust information to parents' intelligence and attitude but often misjudged due to spending so little time with parents); Jones, *supra* note 58, at 136 (staff consistently misjudged degree of parental attachment to infants).

⁹⁶ See R. DARLING, *supra* note 69, at 128-44, 151-54; Bridge & Bridge, *The Brief Life and Death of Christopher Bridge*, HASTINGS CENTER REP. Dec. 1981, at 17; Stinson & Stinson, *On the Death of a Baby*, ATLANTIC MONTHLY, July 1979, at 64 (parents unable to stop doctors from treating terminally ill newborn son).

⁹⁷ One physician prominent in the treatment of spina bifida, Dr. David McLone, testified at a Congressional hearing that the single most common reason for denial of care was ignorance about modern improvements in treatment outcomes for such infants. See S. Rep. No. 246, 98th Cong., 2d Sess. 10, reprinted in 1984 U.S. Code Cong. & Ad. News 2927.

Perhaps most obviously connected are the societal decisions about the quality of educational and rehabilitative resources that will be made available to handicapped children. The decision-makers' perception of the quality of these resources will directly affect whether they choose to try to save the child's life.⁹⁸

But resource allocations do not merely affect decisions to treat or not to treat. To a large extent, resource allocations determine the existence and severity of the problem of handicapped infants. The number of handicapped children born is not a natural constant, but depends on broad social choices of how wealth is distributed and how services like pre-natal medical care are provided.⁹⁹ The mothers of low birth-weight infants are likely to be poor, nonwhite, single, poorly educated and lacking adequate health care during pregnancy.¹⁰⁰ Moreover, the very possibility of treatment choices for such children was created by decisions to invest in high-technology intensive care for newborns.¹⁰¹

These resource allocation decisions show a marked skewing toward investment in medical technology. Less attention is given to non-medical means of ameliorating handicaps. Hospital care for newborn handicapped infants is widely

⁹⁸ When discussed explicitly, post-hospital care available for handicapped children is often referred to by commentators in sweepingly bleak terms. See, e.g., Duff, *Counseling Families and Deciding Care of Severely Defective Children: A Way of Coping with 'Medical Vietnam'*, 67 *PEDIATRICS* 315, 316 (1981) ("even in better institutions where severely defective human beings are 'warehoused,' conditions are . . . unavoidably detrimental to any child's interests . . .") Cf. D. MACMILLAN, *MENTAL RETARDATION IN SCHOOL AND SOCIETY* 542 (2d ed. 1982) (only about 10% of the retarded live in institutions of any kind).

⁹⁹ Great discrepancies exist between the health of people in different social classes, particularly infants. Poor children are 13 times more likely to be mentally retarded than children from middle- and upper-class families. R. CONLEY, *THE ECONOMICS OF MENTAL RETARDATION* 21-22, 39 (1973). Infant death is 50% higher among black Americans than whites, and prematurity and congenital malformations — the focus of most nontreatment decisions in intensive care nurseries — are the two leading causes of infant death. M. GRANT, *HANDBOOK OF COMMUNITY HEALTH* 147 (3d ed. 1981). Studies have found that these class differences are not the result of unavoidable natural genetic variations but stem from inadequacies in pre-natal medical care, nutrition and the like. See, e.g., Naeye, *Causes of Fetal and Neonatal Mortality by Race in a Selected U.S. Population*, 69 *AM. J. PUB. HEALTH* 857, 860 (1979) (initial data showed black perinatal mortality rate to be 50.5 per 1,000 versus 34.4 per 1,000 for whites; the difference disappeared when only patients who began prenatal care during the first trimester of pregnancy were included in the statistical analysis). See also R. CONLEY, *supra*, at 323 (prevalence of moderate and severe retardation would drop by almost 80% if all classes had same incidence of retardation as upper- and middle-class whites).

¹⁰⁰ See Eisner, Brazie, Pratt & Hexter, *The Risk of Low Birthweight*, 69 *AM. J. PUB. HEALTH* 887 (1979).

¹⁰¹ Newborn intensive care units were first established in the 1960's and now can be found in more than 600 U.S. hospitals. About 6% of all live-born infants are treated in such units, at an annual cost most recently estimated (for 1978) at \$1.5 billion. See *FOREGOING TREATMENT*, *supra* note 45, at 203-04.

available and covered by health insurance¹⁰² despite costs that in a few days can exceed the annual income of many Americans.¹⁰³ Once parents take an infant home, they have found that in many cases services are nonexistent or difficult to obtain.¹⁰⁴

Compared to spending on medical care, funding for the prevention of handicaps has been similarly scanty.¹⁰⁵ Strikingly, the Reagan administration's strategy on the issue has focused on forcing hospitals to treat handicapped newborns at the same time that the administration has cut funding for programs with proven records of preventing birth defects¹⁰⁶ and programs providing non-medical services for the handicapped.¹⁰⁷ In the few instances when these factors are even mentioned in the literature of handicapped newborns, they are

¹⁰² During the 1970's nearly every state passed laws requiring private insurers to cover newborn intensive care, thus assuring the spread of such facilities. *See id.* at 203 n.28.

¹⁰³ The cost can amount to \$40,000. *See Cheating Children*, N.Y. Times, Feb. 20, 1983, at 16E, col. 1. The average cost of a stay in a newborn unit in 1978 was \$8,000. FOREGOING TREATMENT, *supra* note 45, at 204.

¹⁰⁴ Families "must often travel a financially and emotionally perilous path" to obtain services for their infants rescued by newborn intensive care. FOREGOING TREATMENT, *supra* note 45, at 205. One example is in obtaining intensive educational intervention in infants with Down's syndrome and other handicapping conditions. This early education has been proven so effective that in some cases such children have been able to enroll in regular school rather than special education programs. But such intervention is offered only on a pilot basis. *See Examination of the Implementation of the Developmental Disabilities Bill of Rights Act: Hearing before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Human Resources, 97th Cong., 1st Sess. 119-20 (1981) (statement of Dr. Norris G. Haring) [hereinafter cited as Haring].* The Education of the Handicapped Act, 20 U.S.C. §§ 1401-1461 (1976 & Supp. IV), does not pay for services until age three and even then many eligible children do not receive services for which they qualify. *See Haring, supra*, at 114, 119. The Supreme Court has interpreted the Act to require only that the state provide services sufficient to enable a child to benefit educationally, not that a state try to equalize educational opportunities for handicapped and non-handicapped children. *Board of Educ. v. Rowley*, 458 U.S. 176 (1982) (school need not provide interpreter for deaf student).

¹⁰⁵ *See G. BREWER & J. KAKALIK, HANDICAPPED CHILDREN — STRATEGIES FOR IMPROVING SERVICES (1979)* (only 1% of government spending on handicapped in mid-1970 went to prevention).

¹⁰⁶ The Reagan administration has cut nutritional programs for poor pregnant and nursing mothers that were shown to reduce infant deaths. Even before the budget cuts the programs did not reach a majority of those eligible. *See Robin, A Right to the Tree of Life*, *The Nation*, June 9, 1984 at 698-99; *Are Program Cuts Linked to Increased Infant Deaths?*, N.Y. Times, Feb. 13, 1983, at 6E, col. 1; Some of the budget cuts in maternal and child health grants to the states were restored in 1984, and Congress also mandated Medicaid coverage for many indigent children and pregnant women previously left to state option. Deficite Reduction Act of 1984, Pub. L. No. 98-369, U.S. CODE CONG. & NEWS (98 Stat.) § 2361(a) (to be codified at 42 U.S.C. § 1396a(a)(10)(A)(i)(III)). *See Health Care for the Poor in 1984*, Clearinghouse Rev., Jan. 1985 at 986.

¹⁰⁷ *See Examination of the Implementation of the Developmental Disabilities Bill of Rights Act: Hearing before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Human Resources, 97th Cong., 1st Sess. 6-28 (1981)* in which the director of the program coordinating office of the Office of Human Development Services, testified

treated as less urgent than the question of individual decisions and thus able to be put off to another day,¹⁰⁸ or simply dismissed as interesting but inconsequential background material.¹⁰⁹

The relationship between this neglect of resource allocation issues and the legal structure of health care is less direct than in the case of physician dominance over parents.¹¹⁰ The medical profession determines the amount society spends on newborn intensive care through the establishment of professional standards

concerning the administration's proposal to consolidate handicapped programs into block grants to the states accompanied by a 25% overall funding cut. Since only a few states mandate comprehensive services for the handicapped, the block grant system forces the handicapped to compete with other recipients of social services for scarce discretionary funds. See FOREGOING TREATMENT, *supra* note 45, at 206 n.40.

The Child Abuse Amendments of 1984 acknowledge this issue by providing for grants to the states to coordinate social and health services for families with handicapped infants and by requiring the Secretary of HHS to make recommendations to Congress on the use of federal funds for social services for such families and infants. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 1984 U.S. CODE CONG. & NEWS (98 Stat.) §§ 123, 125 (to be codified at 42 U.S.C. 1305, 5103).

¹⁰⁸ See, e.g., Jonsen, Phibbs, Tooley & Garland, *Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal*, 55 PEDIATRICS 756, 757 (1975) (issues of clinical decision-making must be considered before social issues of resource allocations).

¹⁰⁹ Perhaps the most prominent example is the recent presidential commission report, FOREGOING TREATMENT, *supra* note 45. After describing the role of resource allocations in determining how many seriously ill infants are born and how many can benefit from medical and other treatment, *id.* at 201-07, the commission devoted nearly all of its discussion and recommendations to improving decision-making by doctors and parents. *Id.* at 207-28. It devoted three paragraphs to suggesting increased public funding for post-hospital care for rescued children. *Id.* at 228-29. There is a striking contrast between this fleeting mention and the careful specificity and detail of the commission's recommendations on individual decision-making. See also Kelsey, *Which Infants Should Live? Who Should Decide? An Interview with Dr. Raymond S. Duff*, HASTINGS CENTER REP. Apr. 1975 at 5, 6 (funding for institutions for handicapped is irrelevant to hospital treatment decisions).

¹¹⁰ There is another link between the resource allocation issue and physician dominance over parents which can be seen by contrasting two approaches to the tragic dilemma faced by parents in any individual case. The common approach, fostered by the medical model and ignoring the resource allocation issue, regards this tragedy as entirely private: by an act of pure fate, parents are faced with a choice between deliberately letting their child die when the capability is at hand to save its life, or rescuing the child only to consign the child (and possibly themselves) to an uncertain future of suffering. Under an alternative approach stressing the role of resource allocation decisions, fate is still present, in assigning the tragedy to this set of parents rather than some other; however because social choices affected the creation of the tragedy, the tragedy becomes more public than private. The tragic choice is thus between making a heroic medical rescue of an infant whom society will later judge not worth saving, or, on the other hand, choosing not to rescue and thus affirming the child's lack of value to society.

For parents, each of these approaches carries its own appropriate response. The common approach, by isolating and privatizing the tragedy of individual cases, encourages parents to retreat into their own sorrow. The alternative approach links individual cases together and urges parents to lobby for community resources to ease their dilemma. The common approach is clearly far more amenable to physician control than the alternative.

determining which infants should receive such care. But the profession does not, of course, directly set spending priorities for birth defects prevention or handicapped rehabilitation programs. Yet the legal regulation of health care ensures that even when physicians are not directly in charge of a decision, theirs is the profession with the greatest expertise concerning society's health needs. Their professional view of health and illness, what I have called the medical model, has been institutionalized through a variety of legal regulations as superior to other theories of health and illness. Thus it should not be surprising that even when decisions are made by non-physicians, they follow the medical model by placing primary importance on curing illness in individuals by biological means, rather than by preventing and ameliorating illness through social interventions such as dietary program for pregnant mothers and improved educational programs for handicapped children.

There is a paradox here: physicians have been firmly established as society's official health experts, yet the medical model on which their expert authority is based contains an exceedingly narrow view of illness. This paradox helps explain the lack of attention given to rationalizing the medical and non-medical aspects of caring for handicapped infants. The profession's putative expertise maintains its preeminent role in health policy, yet because that expertise exists only over a narrow range of the issue, it is necessary for the profession to assert that the aspect of health over which it is expert is the centrally important aspect of health. Thus there is a need to minimize non-medical aspects of illness if the profession is to maintain its dominance.

The medical model, then, fosters an approach to the problem of handicapped infants that obscures the fact that the current system of spending exacerbates the tragic element in the birth of a handicapped infant. A different focus, on the social roots of birth defects, would threaten the prominence that medical care spending now enjoys in our social priorities.

IV. THE FLAWS IN THE PRESUMPTIONS OF PROFESSIONAL AUTHORITY

The paradox between narrow expertise and broad authority helps explain why the focus of discussion about handicapped newborns tends to be directed away from resource allocation issues. It also explains why the legal system maintaining the medical profession's dominance is based on a fundamentally flawed premise. Professional expertise, properly understood, cannot justify the kind of autonomy granted to the medical profession. The problem of handicapped infants again helps illustrate why this is so.

Aside from a few of the most severe birth defects, for which virtually any known medical treatment would be futile, physicians disagree about which defects warrant decisions to withhold lifesaving treatment.¹¹¹ This disagreement

¹¹¹ See *supra* note 67. Anencephaly is the only condition for which physicians almost unanimously agree that treatment is inappropriate. Shaw, Randolph & Manard, *supra* note 68, at 590; D. CRANE, *supra* note 68, at 44. This agreement is not based solely on the fact that the infant will die in a few days. Crane found that physicians were six times more likely (25% vs. 4%) to treat an infant with an inoperable heart defect (hypoplastic

involves elements of both expert and non-expert knowledge. It takes expert knowledge to determine whether a given infant has a certain handicap, and expert knowledge to weigh the probable outcomes of the medical treatments available.¹¹² But this factual knowledge can never form the sole basis for a decision not to treat an infant. That decision rests on normative judgments and assessments of non-medical factors that lie beyond medical expertise.

The normative assessments are made in regard to, first, what kind of life is worth living,¹¹³ and second, from whose perspective that first question should be considered: the infant's, his caretakers', or someone else's.¹¹⁴ These assessments involve personal and philosophical considerations that cannot be said to be within the technical expertise of professionals trained in biological science.¹¹⁵

left ventricle) even though an early death was as certain as for the anencephalic infant. *Id.* at 44.

Surveys have consistently shown an almost even split among physicians on whether they would treat a Down's infant. *Id.* at 44-45; Shaw, Randolph & Manard, *supra* note 68, at 590 (49.5% of pediatric specialists in sample would acquiesce in parents' decision to refuse consent for surgery on newborn with Down's syndrome and intestinal obstruction); Todres, Krane, Howell & Shannon, *supra* note 90, at 198 (51% of pediatricians would recommend surgery for child with Down's syndrome and duodenal obstruction). There is also significant disagreement for spina bifida and other handicaps. *Id.*

¹¹² However, even in this area of presumptive expert authority, there is pervasive uncertainty about the outcomes of treatment which erodes the degree of deference that is appropriate for such expert judgments. See Jonsen & Lister, *Newborn Intensive Care: The Ethical Problems*, HASTINGS CENTER REP., Feb. 1978 at 15. Physicians who deliver infants are often not aware of advances in newborn care, and thus underestimate an infant's chances. See Goldenberg, Nelson, Dyer & Wayne, *The Variability of Viability: The Effect of Physicians' Perceptions of Viability on the Survival of Very Low-Birth Weight Infants*, 143 AM. J. OBSTET. & GYNECOL. 678, 683 (1982).

¹¹³ Even if physicians could predict the outcomes of treatment with complete certainty, see *supra* note 112, deciding whether to treat is impossible without at least implicitly answering this question. See Jonsen & Lister, *supra* note 112, at 17-18.

The sharp division among similarly trained physicians about which birth defects are appropriate for non-treatment is itself evidence that the dispute lies beyond the realm of technical expertise. It is thus not surprising that one of the strongest factors associated with a physician's attitude toward treatment is his or her religious affiliation and degree of religious activity. See *D. Crane, supra* note 68, at 203. Cf. Shaw, Randolph & Manard, *supra* note 68, at 591 (willingness to obtain court order to overcome parental resistance to surgery for defective newborn associated with physician's religious affiliation).

¹¹⁴ This is often obfuscated by being treated as a broad "quality of life" question, without considering quality to whom. See Shaw, Randolph & Manard, *supra* note 68, at 596 (division among physicians about whether Down's infants should be treated for intestinal blockage had little to do with physicians' factual assessment of prognosis but rather was "strongly associated" with physicians' belief as to whether infant or family should take first priority in deciding treatment).

¹¹⁵ See H. FABREGA, *DISEASE AND SOCIAL BEHAVIOR* 218-19 (1974) (narrow biological definition of disease held by physicians commits them to a role as biological engineers and technicians; a more holistic definition would require systematic re-education of physicians).

The factual assessments are made in regard to the social dimension of illness. When complete cure cannot be offered for an illness, such as when a newborn has permanent physical or mental handicaps, then the consequences of the illness depend on the patient's adaptability to his social environment.¹¹⁶ That adaptability depends not only on what the child can do but on what others are willing to do to adapt the environment to the child. This in turn depends on intangibles such as the acceptance of a child in his home as well as on the quality of community resources such as schools, physical therapy, and live-in institutions.¹¹⁷ Physicians make decisions about newborns based on their own assessment of these social conditions even though they have no particular expertise and may be relying on outdated stereotypes, such as the belief that most handicapped persons must be institutionalized and that such institutions are invariably substandard.¹¹⁸

The handicapped-infant issue is only one example of the mixture of expert and non-expert knowledge required to make health decisions. Every health decision involves a judgment of what is best for the individual being treated. That judgment cannot be made without a normative assessment of what is valuable for that individual. Health itself is a normative concept measured by social standards, not exclusively by scientifically objective criteria.¹¹⁹ In cancer therapy, for example, a physician may set five-year survival as the health goal where the patient might choose instead to have a better quality life, even if a shorter one, by avoiding disfiguring surgery or debilitating chemotherapy.¹²⁰ No objective standard exists for saying the physician's choice is superior to the patient's. Indeed, any decision about health involves value judgments over which no one can claim objective expertise.¹²¹ Even a decision as fundamental to professional autonomy as setting standards for professional competence requires value judgments not amenable to professional expertise. For example, too high a standard of competence can conflict with the value of accessibility to health

¹¹⁶ Any judgment of abnormality makes reference to what is normatively desirable for a given social context. See G. CANGUILHEM, *ON THE NORMAL AND THE PATHOLOGICAL* 118 (C. Fawcett trans. 1978); Dubos, *Health as Ability to Function*, in *CONTEMPORARY ISSUES IN BIOETHICS* 96, 98-99 (T. Beauchamp & L. Walters eds. 1978).

¹¹⁷ See, e.g., Rynders, Spiker & Horrobin, *Underestimating the Educability of Down's Syndrome Children: Examination of Methodological Problems in Recent Literature*, 82 *AM. J. MENTAL DEFICIENCY* 440, 445-46 (1978) ("early intervention" programs have had marked success in improving IQ and other performance standards in Down's children.). There are now more than 4,000 community residential facilities for retarded persons operating as an alternative to large institutions. D. MACMILLAN, *supra* note 98, at 582-83.

¹¹⁸ See Duff, *supra* note 98, at 316; D. MACMILLAN, *supra* note 98, at 542.

¹¹⁹ A number of philosophers have made this point. See, e.g., Boorse, *On the Distinction between Disease and Illness*, in *CONTEMPORARY ISSUES IN BIOETHICS* 114 (T. Beauchamp & L. Walters eds. 1978); Sedgwick, *What is "Illness"?*, in *id.* at 120.

¹²⁰ See, e.g., Fisher, *Surgery of Primary Breast Cancer* in *BREAST CANCER* 35-36 (W. McGuire ed. 1977) (prominent cancer specialist maintaining that primary aim of treatment is disease-free life; attainment of best cosmesis and quality of life are secondary aims).

¹²¹ See Pellegrino, *The Anatomy of Clinical Judgments*, in *CLINICAL JUDGMENT: A CRITICAL APPRAISAL* 178-79 (T. Engelhardt ed. 1979).

care at a reasonable price. Too great a stress in medical school curricula on training physicians for expensive, sophisticated treatment of present patients can interfere with society's desire to allocate medical resources toward preventive treatment of future patients.

When physicians dominate decision-making about whether to treat handicapped newborns, they are inevitably in a position to impose their values on the parents. If this clash of values were starkly apparent to parents, or to outside regulators, it would be much easier to resist the dominance of physicians. But the grant of legal autonomy to the medical profession blurs the boundaries of professional expertise. It grants physicians broad authority to make choices on behalf of patients; yet those choices involve factors beyond the expertise of physicians. To maintain their right to professional autonomy, physicians must characterize the decisions they make as technical and esoteric beyond lay understanding, and they must ignore or conceal the non-expert elements of their decisions. To acknowledge the pervasive value judgments present in their decisions would require physicians to share their decision-making power with patients and with lay policy-makers. With such shared authority the justification for the present policy of deference to professional judgments over a broad range of health issues would collapse.

This fundamental flaw in the presumption of expertise underlying the grant of professional autonomy creates additional problems for the medical profession. That is because the validity of the second main presumption underlying autonomy, professional ethicality, depends on the validity of the first presumption of expertise. Ethicality requires physicians to do what is in their patients' best interests, but first they must know what in fact is in their patients' interest. Professional autonomy presumes physicians should have decision-making authority over patients because physicians know patients' interests better than patients do.¹²² But we have seen that this is simply false. It is of course possible that in any individual case, a physician can make a decision that is fortuitously in his or her patient's best interest. But this cannot justify special decision-making authority for the physician, because the physician's choice can just as easily conflict with the patient's interest.

Moreover, the broad grant of professional autonomy is itself in fundamental conflict with the notion of ethical decision-making for patients. In order for society to grant self-regulation to the medical profession, that self-regulation must serve the interest of both society and patients. Patients are interested in maximizing their individual health consistent with their other goals. If this is society's only interest as well, then an adequate societal check on the authority of physicians would be to enforce the ethical mandate that the patient's interests should take precedence over the physician's personal interests.¹²³ But there are

¹²² See R. VEATCH, *A THEORY OF MEDICAL ETHICS* 149 (1981) ("the Hippocratic ethic gives remarkable authority to the physician to use his judgment to decide what will be beneficial. The oath says, 'I will follow that system . . . which, according to my ability and judgment, I consider for the benefit of the sick.'").

¹²³ See J. BERLANT, *supra* note 6, at 29-31.

many occasions when social utility and individual utility are at odds, such as when society seeks medical cost containment and patients seek more care,¹²⁴ or when society maintains income differences among social classes that contribute to mental retardation and other birth problems.¹²⁵ Medicine is usually oriented to serving the individual. But it relies on the state for its grant of autonomy. Thus, a too-avid pursuit of the needs or rights of individual patients can risk autonomy when those clash with societal interests.¹²⁶ At the least, individual physicians are tempted to temper their patient advocacy when they perceive such a clash.¹²⁷ Beyond the level of the individual practitioner, the profession as an institution is tempted to ignore the societal causes of illness — such as the roots of some birth defects in poverty — that if attacked would upset the existing order.¹²⁸

¹²⁴ Significantly, physician autonomy has been most restricted in this area of the most obvious clashes between the interests of society and of patients. The share of the gross national product devoted to medical care doubled from 1940 to 1975 and is still rising. Klarman, *The Financing of Health Care*, 106 DAEDALUS 215 (1977). Federal regulation has been aimed both at increasing competition among physicians, see COMPETITION IN THE HEALTH CARE SECTOR: PAST, PRESENT AND FUTURE (W. Greenberg ed. 1978), and at restraining physicians' expenditures on behalf of patients through the PSRO and HSA programs. See generally Gordon, Howell & Alexander, *Is Government Regulation Helpful?* in ISSUES IN HEALTH CARE REGULATION (R. Gordon ed. 1980) (describing variety of government regulatory efforts all aimed at containing costs).

¹²⁵ See *supra* note 99. See generally G. CALABRESI & P. BOBBITT, TRAGIC CHOICES (1978) (society makes choices for death and illness by resource allocation decisions).

¹²⁶ See J. BERLANT, *supra* note 6, at 250-52, 305-06 (status of profession attained by "constellation of compatible interests" between profession and powerful elite); E. FREIDSON, *supra* note 25, at 72-73 (society's "dominant elite" must remain persuaded of harmlessness of the profession if it is to retain privileged status).

Compare *Dent v. West Virginia*, 129 U.S. 114 (1889) (upholding state licensure of physicians as legitimate health-related restriction) with *Lochner v. New York*, 198 U.S. 45, 63 (1905) (striking down health-related restriction on bakers, and citing with approval invalidation by state courts of licensing of other occupations such as horseshoeing, but failing to distinguish medical licensure or to mention *Dent*). This dichotomy is explainable not simply by the fact that lawyer-judges felt a professional kinship with physicians, but by the fact that medicine served the kinds of capitalist class interests that the Supreme Court in that era openly promoted.

¹²⁷ See, e.g., Shaw, Randolph & Manard, *supra* note 68, at 596 (56% of surgeons and 41% of pediatricians place family's interests ahead of infant's, and this significantly affected outcome of decisions); Matson, *Surgical Treatment of Myelomeningocele*, 42 PEDIATRICS 225, 226 (1968) (physician states doctors have responsibility to society not to prolong expensive care for severely handicapped newborns).

But while society has an interest in limiting its expenditures on behalf of the handicapped, see Lee, Jonsen & Dooley, *Social and Economic Factors Affecting Public Policy and Decision Making in the Care of the Defective Newborn*, in Swinyard, *supra* note 69, at 315, such cost-benefit calculations are almost never made explicitly when deciding individual cases. See G. CALABRESI & P. BOBBITT, *supra* note 125, at 21 (1978).

¹²⁸ Radical critics maintain that medicine's focus on individual-centered, biological causes and cures for illness serves to depoliticize social causes of illness and thus decrease pressure for income redistribution, workplace reforms and other measures threatening the status quo. See, e.g., Figlio, *Chlorosis and Chronic Disease in 19th-Century Britain: The Social Constitution of Somatic Illness in a Capitalist Society*, 8 INT'L. J. HEALTH

The issue of handicapped newborns thus manifests a number of the inherent problems in professional autonomy. It shows how physicians dominate patients (or in this case patient representatives) in one area of health care where such dominance seems clearly inappropriate. It also shows how professional autonomy exacerbates the problem of handicapped newborns through the lack of attention to rationalizing resource allocations. Yet what is even more significant is that it is not just the mere fact of physician dominance that causes such problems, but the flawed presumptions underlying the legal grant of autonomy to the medical profession. Those presumptions of professional expertise and ethicality are necessary to the grant of autonomy, yet are demonstrably false. But legal autonomy establishes the concept of professional expertise as an objective fact rather than an ideological assertion. Yet its success at so characterizing professional expertise bears a heavy price: it confuses for all of us the limits of professional expertise and the proper role of doctors, patients, and the public in making decisions about health.

V. CONCLUSION: REDEFINING MEDICAL AUTHORITY

In our society, dominance by one group over another can arise only from a claim of legal right or, more effectively, from the consent of those dominated. Medicine achieves its dominance over patients and over social debate about health by teaching us to think about health and illness in its terms. Once we accept the notion of illness as an objective, scientific phenomenon rather than a value-laden social construct, we are prepared to surrender authority over this realm of life to a group of experts. Once authority has been surrendered, a powerful symbiosis takes place between the system of legal rules and the system of professional thought to hold that professional authority in place. The legal rules assume and reinforce the correctness of the system of professional thought, and thereby legal right and consent become fused as one unified justification for professional dominance. Professional authority attains all the more power because by virtue of its authority the professional group gains an elite status that it has a strong self-interest in maintaining. This self-interest provides the motive for the profession to paper over the problems in its model of illness and the related flaws in the concept of professional expertise. The irony is that the grant of autonomy to the profession *itself* discourages a clear recognition of the flaws in professional autonomy.

Up to now, the medical profession has been strikingly successful at hiding the vulnerability of its claim to legal autonomy. Evidence of this can be found,

SERVICES 589, 605-12 (1978) (power of medicine lies in its putative objectivity when asserting illness is primarily a problem of and in individuals rather than one of social processes); Renaud, *Structural Constraints to State Intervention*, in *THE CULTURAL CRISIS OF MODERN MEDICINE* 109 (J. Ehrenreich ed. 1978) (through medical paradigm, society is "epistemologically eliminated as an important element in the etiology of disease"); Waitzkin, *A Marxist View of Medical Care*, 89 *ANNALS INTERNAL MED.* 264, 270 (1978) (medical ideology focuses on preventing illness through "victim-blaming" lifestyle change and reinforces domination of social life by elite experts rather than democratic choice).

for example, in its so-far-successful effort to avoid new regulation in the infanticide controversy,¹²⁹ its undermining of informed consent law with the cooperation of the courts and legislatures,¹³⁰ and its retention of control over state licensing boards¹³¹ in the face of controversy about anemic professional self-discipline. The push to make the profession more competitive through the antitrust laws and other regulatory efforts, far from providing contrary evidence, further demonstrates the power of the concept of legal autonomy. Such efforts have tried to distinguish between the economic context of medical practice, regarded as a legitimate target of reform, and the clinical content of medical practice, regarded as still within the exclusive sphere of professional self-regulation.¹³² These efforts have thus tried to purify professional self-regulation by eliminating the more egregious forms of self-interest from professional practice. These efforts thereby continue to hold out the possibility of self-regulation based on professional expertise, so long as the profession is disciplined into living up to its ethical ideal of placing patients' interests above those of professionals.

Yet while the ideology of professional authority is tenacious, it is not invincible. There are ways to begin reform that would not amount to an overnight revolution in health care regulation but that would set out on the path of ending control over decisions by a professional elite. One straightforward possibility would be to replace the system of medical licensure with a system of certification. This would limit the right of a person to call himself or herself a doctor but would not, in contrast to the current system of legal restrictions on the practice of medicine, prevent health care workers with non-medical healing philosophies from treating patients independently from physicians. The main difference between licensure and certification, then, is that certification allows greater patient choice.

Certification has been proposed as a way of increasing economic competition in health care,¹³³ but its possible effects on increasing ideological competition have not been appreciated. This can be seen in the case of withholding

¹²⁹ See, e.g., *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984); *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983). The new legislation passed by Congress, see *supra* note 4, which obtained the acquiescence of all relevant medical groups except for the American Medical Association, represents only a modest inroad on this autonomy.

¹³⁰ See *supra* text accompanying notes 34-36.

¹³¹ Several commentators have proposed that licensing boards should be comprised only of persons from outside the licensed profession. See, e.g., Rayack, *Medical Licensure, Social Costs and Social Benefits*, 7 *LAW & HUMAN BEHAV.* 147, 155 (1983); Cohen, *On Professional Power and Conflict of Interest: State Licensing Boards on Trial*, 5 *J. HEALTH POL. POL'Y. & LAW* 291, 304 (1980). No state as of 1980 had even a majority of non-physicians on medical licensing boards. See H. SHUCHMAN, *supra* note 17, at 197.

¹³² See, e.g., Kissam, Webber, Bigus & Holzgraefe, *Antitrust and Hospital Privileges*, 70 *CALIF. L. REV.* 595, 607-08 (1982); *American Medical Ass'n. v. FTC*, 638 F.2d 443, 452 (2d Cir. 1980), *aff'd by an equally divided court*, 455 U.S. 676 (1982).

¹³³ See, e.g., V. FUCHS, *supra* note 16, at 61; M. FRIEDMAN, *supra* note 1, at 137-60.

Such a proposal also was made recently in California. See Public Affairs Research Group, *Public Regulation of Health-Care Occupations in California*, (final report, undated) (recommendation to state Board of Medical Quality Assurance to end statutory

treatment from ill infants. If physicians' legal authority over other health care workers was loosened, many more health-care workers would be able to take a greater role in the decision-making dialogue.¹³⁴ Nurses and social workers, in particular, would no longer have to limit their communication with parents to make sure parents were faced with a "united front." Parents who have been told by a physician all that is physiologically wrong with their infant can receive a sharply different perspective from the nurse who provides the nurturing care for the infant and thus is more acquainted with the infant as a whole person. Social workers can present their own independent expertise about the integration of the infant into family and community. At the least, then, the substitution of collegial relationships for hierarchical ones on the hospital staff would help assure that more facts could be brought to bear on decisions.

Perhaps more important than the facts they could offer is the independent moral perspective these non-physician professionals could bring to making decisions. Nurses, especially, have a professional ethic of respect for the individual as a person that is at odds with the physician's utilitarian, paternalistic ethic. This ethic, if effectively voiced, could have a significant impact on decision-making.¹³⁵

In addition, if parents were given greater freedom to seek advice from non-physician health care workers, physicians would have less ability to coerce them. With collegial persuasion thus a more effective tool than paternalistic manipulation of information to obtain "consent," physicians would be encouraged to abandon their paternalism in favor of an ethic giving greater respect to patient autonomy.¹³⁶

Of course, certification alone would not end physician dominance over parents, nor unseat the dominance of the medical model in social debate about health. It would, however, establish a new legal presumption that final decisions in health matters should be left to the public and should not be vested in any one profession. With this in place, we could begin to see the value-laden nature of all health care decisions, both in social policy and at the level of individual decisions. Then we could begin to set policy not by delegation to a professional elite but by democratic debate.

restrictions on the right to practice medicine and instead determine through licensing those able to use the titles of physician, nurse, etc.).

¹³⁴ A hospital itself could impose physician control on other professionals such as nurses, but under a certification system, it would no longer have a legal imperative to do so. With nursing and social work personnel increasingly scarce, hospitals would have an incentive to attract such personnel by maximizing their independent status. A certification system thus offers no final answers to who would have ultimate control in an intensive care nursery, but envisions that in the absence of legal hierarchy, such questions would be worked out dynamically in each hospital.

¹³⁵ See *supra* note 83.

¹³⁶ See generally P. RAMSEY, *THE PATIENT AS PERSON* 5-7 & n.5 (1970) (Kantian ethic should control doctor/patient relations); Veatch, *The Hippocratic Ethic: Consequentialism, Individualism, and Paternalism*, in *NO RUSH TO JUDGMENT* 238, 250 (D. Smith & L. Bernstein eds. 1978) (ethic of "doing right by the patient" is superior to one of doing what will "benefit" the patient).

