Editorial

Section 504, Handicapped Newborns, and Ethics Committees: An Alternative to the Hotline

by A. Edward Doudera, J.D.

The issues surrounding the care of critically and terminally ill patients, including handicapped newborns, have been the subject of numerous articles in *Law, Medicine & Health Care*.[1] In this issue, two articles are offered that focus on the so-called Infant Doe or hotline regulations promulgated by the federal Department of Health and Human Services (the Department).

The proposed regulations are part of a section entitled *Nondiscrimination on the Basis of Handicap in Programs and Activities Receiving or Benefiting from Federal Financial Assistance*.[2] It consists of rules formulated by various federal agencies under authority of Section 504 of the Rehabilitation Act of 1973.[3] The section contains various Department regulations which protect from discrimination those affected with a variety of handicaps, including individuals with impaired hearing, drug and alcohol addicts, and institutionalized persons. The present proposed rule adds handicapped newborns to the list of protected persons, and provides a procedure by which individuals improperly discriminating on the basis of handicap can be identified to federal and state authorities.

Section 504 of the Rehabilitation Act of 1973 provides that "[n]o otherwise qualified handicapped individual... shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefit of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency...."[4] The statute directs the head of each federal agency to promulgate regulations to effectuate the policies of the Act. It is under the authority of this language that Secretary Heckler promulgated the Infant Doe regulations.

Whether this application of Section 504 accords with the congressional intent behind the Act will most likely be determined in future litigation.

In the Department's view, the proposed regulations do not "in any way change the substantive obligation of health care providers previously set forth in the statutory language of Section 504."[5] Rather, they provide "procedural specifications designed (1) to specify a notice and complaint procedure... and (2) to modify the existing regulations to recognize the exigent circumstances that may exist when a handicapped infant is denied food or other necessary medical care."[6]

The Department first took action in this area in June 1982, when it published a Notice in the Federal Register "to remind affected parties of the applicability of Section 504" in the context of health care.[7] The notice stated that hospitals receiving federal financial assistance were prohibited from withholding life-saving medical or surgical treatment from handicapped infants.[8] This "reminder" was followed by the first version of the Infant Doe regulations which imposed the requirement that hospitals post a specified notice, which allowed immediate access to records and facilities, and which established the hotline.[9]

Barely a month after this "interim final rule" was published in April 1983, it was invalidated by the United States District Court for the District of Columbia.[10] In response to a suit brought by the American Academy of Pediatrics, the National Association of Children's Hospitals and Related Institutions, and the Children's Hospital National Medical Center, Judge Gerhard Gesell held the rule invalid on several grounds.

First, Judge Gesell said that in promulgating the rule, the Department had failed to comply with the public notice and comment requirements of the federal Administrative Procedure Act, and that the rule was therefore "arbitrary and capricious."[11] The Secretary's failure to follow the public notice and 30-day delay-of-effective-date requirements necessitated invalidations of the rule. Judge Gesell also recognized that grounds "existed for undertaking a regulatory approach to the problem of how newborns should be treated in government-financed hospitals;" nonetheless, he held it improper that so "many highly relevant factors central to any application of Section 504 to medical care of newborn infants... [had] not [been] considered prior to promulgation of the challenged rule."[12]

In discussing the issue of whether Section 504 could be read to apply to the problem of handicapped newborns, Judge Gesell found no evidence of legislative intent of such application.[13] "As far as can be deter-

Mr. *Doudera, Executive Editor of* Law, Medicine & Health Care, *is Executive Director of the American Society of Law & Medicine, in Boston, Massachusetts.*

https://doi.org/10.1111/j.1748-720X.1983.tb00823.x Published online by Cambridge University Press

mined, no congressional committee or member of the House or Senate ever even suggested that section 504 would ever be used to monitor medical treatment of defective newborns. . . ."[14] However, this lack of evidence did not mean to the court that the statute was not open to a broader interpretation that would permit its application to the problem. The court concluded that whether or not the statute should be so applied, "section 504 was never intended by Congress to be applied blindly and without any consideration of the burdens and intrusions that might result."[15]

After the court invalidated the first set of regulations, the Department published revised regulations as "proposed rules" and invited public comment on the regulations and on a series of specific questions.[16] The period for public comment closed on September 6, 1983. It is these rules that the two articles in this issue of *Law, Medicine & Health Care* address.

An appendix to the proposed rules deals with the applicability of Section 504 to the provision of health care for handicapped infants. The Department maintains that "[t]he protections of Section 504 apply to all handicapped persons without regard to age"[17] and that the Section is therefore applicable to handicapped infants in health care institutions. According to the Department's position, the Act will not affect treatment decisions that are solely medical in nature, but will only prohibit non-treatment based exclusively on the presence of a handicap. Whether such an application of Section 504 accords with the congressional intent behind the Act will most likely be determined in future litigation challenging the Department's rule.

There is, of course, a more pressing question than the legal applicability of the Rehabilitation Act, and that is the effect on patient care. The proposed rules, which differ little from the interim final rules issued on March 7 and struck down by Judge Gesell, require hospitals receiving "federal financial assistance" to post notices stating that "discriminatory failure to feed and care for handicapped infants in this facility is prohibited by federal law."[18] Notices are required to be posted in each of the nursing stations responsible for the hospitals' delivery, maternity, pediatric and neonatal intensive care wards. The required notice urges persons having knowledge of discriminatory medical practices to call an anonymous, toll-free hotline.[19] The proposed rules waive otherwise applicable requirements—provisions limiting access to records to usual business hours and imposing a 10-day waiting period between notification of non-compliance and investigation by the Department.[20]

The comments of the American Hospital Association,[21] the American Medical Association,[22] and the American Academy of Pediatrics[23] all mentioned substantial problems with the approach advocated by the Department. Numerous news articles, opinion pieces, and editorials were written on the subject,[24] and television news items were significantly involved with spreading the popular discussion about Infant Doe.[25]

In the first of the accompanying articles, the American Society of Law & Medicine's Committee on the Legal and Ethical Aspects of Health Care for Children publishes its comments and recommendations. This multidisciplinary committee, chaired by Professor Alexander Morgan Capron of Georgetown University Law Center, rejects the hotline approach and urges that institutional ethics committees be utilized to protect handicapped newborns from inappropriate treatment decisions.

A more pressing question than the legal applicability of the Rehabilitation Act concerns the effect on patient care.

The Committee on the Legal and Ethical Aspects of Health Care for Children is charged with identifying issues and developing educational programs in the area of children's health. The difficult situations on which the Infant Doe hotline regulations focused were selected as the first target for the Committee's multidisciplinary review and analysis.

In the second article, Father John Paris and Dr. Anne Fletcher take issue with what they see to be a fundamental inconsistency in the proposed regulations on an issue that incites emotional responses. Noting that the Department claims that Section 504 "does not require the imposition of futile therapies which merely temporarily prolong the process of dying of an infant born terminally ill," Paris and Fletcher object to the position taken by the Department that "basic provision of nourishment [and] fluids . . . is a fundamental matter of human dignity, not an option for medical judgment."[26] They argue that, in some circumstances, "nourishment and fluids may be entirely futile treatment."

Regardless of the outcome of the proposed rule, we must continue to protect the interests of handicapped infants and to ensure good decisionmaking procedures.

A recent telephone inquiry to the Department's office that received the public comments on the proposed regulations revealed that over 16,000 individual responses had been received. In early October, Secretary Heckler, in response to a question by this writer, indicated that it would probably be months, rather than weeks, before the Department published further rules on this difficult subject. In the meantime, readers of *Law, Medicine & Health Care* can and must continue to protect the interests of handicapped infants and to do all in their power to ensure that good decisionmaking procedures are utilized in the institutions in which they practice or which they represent.

In this regard, institutional ethics committees can provide a useful vehicle for involving all the relevant participants—physicians, nurses, other members of the health care team, families, and advisors—in forging solutions for the tough legal, medical, and ethical dilemmas that confront

https://doi.org/10.1111/j.1748-720X.1983.tb00823.x Published online by Cambridge University Press

us. The functions of such committees are varied—from the role of confirming prognoses as advocated by the *Quinlan* court[27] and more recently in the State of Washington,[28] to an informal consultative, collegial group that discusses hypothetical cases, to a committee that actually reviews treatment decisions.[29] The true diversity of such committees was evidenced at the Society's April 1983 national conference, *The Role and Function of Institutional Ethics Committees.*

Ethics committees can provide a useful vehicle for involving all the relevant participants in forging solutions for the tough legal, medical, and ethical dilemmas that confront hospitals.

Representatives from almost 300 institutions and organizations gathered to talk about ethics committees and what they could and could not do. The proceedings of that conference will be published later this year by the Society in conjunction with Health Administration Press.

As part of its response to the proposed Infant Doe regulations, the American Academy of Pediatrics offered a "proposed condition of participation setting forth the functions and operations of an infant bioethical review committee" (IBRC).[30] In these guidelines, the Academy attempted to avoid the criticism that committees comprised only of physicians or hospital staff would be ineffective, a charge allegedly made in many of the 98 percent of the replies favoring the regulation, many of which were attributable to representatives or members of right-to-life groups.[31] Thus, the Academy proposed that "physicians and non-physicians, hospital and non-hospital staff" be involved. Its model IBRC consisted of:

- a practicing physician
- a hospital administrator
- an ethicist or member of the clergy
- a representative of the legal profession
- "a representative of a disability group, developmental disability expert, or parent of a disabled child"
- a lay community member
- a member of the facility's organized medical staff
- a practicing nurse.[32]

The functions of the IBRC were said to be threefold and involved

> providing advice when decisions are being considered to withhold or withdraw from infants life-sustaining medical or surgical treatment; recommending institutional policies concerning the withholding or withdrawal of medical or surgical treatments to infants, including guidelines for IBRC action for specific categories of life-threatening conditions affecting infants; and reviewing retrospectively infant medical records in situations in which life-sustaining medical or surgical treatment has been withheld or withdrawn.[33]

The Academy's statement concludes that "the creation of infant bioethical review committees constitutes a direct, effective, and appropriate means of addressing the existing education and information gaps"[34] among physicians and families.

Only time will tell whether the legacy of Infant Doe will be IBRCs or some other form of institutional ethics committee. In the meantime, the Academy's document will be commented on by many in various forums,[35] and the debate and discussion over the roles and functions of ethics committees will continue. Nonetheless, ethics committees are being formed and increasingly being viewed as a mechanism that will serve many institutional and practical purposes. Several conferences have been held, and more are planned, by the Society and by others. Creation of ethics committees has been endorsed by such groups as the American College of Hospital Administrators and the California Medical Association. The Society has created a special newsletter devoted to sharing and exchanging information among those who serve on such committees, and urges all readers to forward news or other information. We hope that, as institutions create and utilize ethics committees, their benefits and implications will be documented and their efficacy established.

References

1. Strong, C., *Defective Infants and Their Impact on Families: Ethical and Legal Considerations*, LAW, MEDICINE & HEALTH CARE 11(4): 168 (September 1983); Cohn, S.D., *The Living Will from the Nurse's Perspective*, LAW, MEDICINE & HEALTH CARE 11(3): 121 (June 1983); Dunn, L.J., *The* Eichner/Storar *Decision: A Year's Perspective*, LAW, MEDICINE & HEALTH CARE 10(3): 117 (June 1982); Paris, J.J., *Terminating Treatment for Newborns: A Theological Perspective*, LAW, MEDICINE & HEALTH CARE 10(3): 120 (June 1982); Rothenberg, L.S., *The Empty Search for an Imprimatur, or Delphic Oracles Are in Short Supply*, LAW, MEDICINE & HEALTH CARE 10(3): 115 (June 1982); Corless, I.B., *Physicians and Nurses: Roles and Responsibilities in Caring for the Critically Ill Patient*, LAW, MEDICINE & HEALTH CARE 10(2): 72 (April 1982); Taub, S., *Withholding Treatment from Defective Newborns*, LAW, MEDICINE & HEALTH CARE 10(1): 4 (February 1982).
2. 48 Fed. Reg. 30,846 (1983) (to be codified at 45 C.F.R. §84.61).
3. Rehabilitation Act of 1973, 29 U.S.C. §794 (Supp. V 1981).
4. *Id.*
5. 48 Fed. Reg. 30,850 (1983).
6. *Id.*
7. 47 Fed. Reg. 26,027 (1982).
8. *Id.*
9. 48 Fed. Reg. 9,630 (1983).
10. American Academy of Pediatrics v. Heckler, 561 F. Supp. 395 (D.D.C. 1983).
11. *Id.* at 399.
12. *Id.*
13. *Id.* at 401.
14. *Id.*
15. *Id.* at 402.
16. 48 Fed. Reg. 30,846 (1983).
17. 48 Fed. Reg. 30,851 (1983) (to be codified at 45 C.F.R. §84.61).
18. *Id.*
19. *Id.*
20. *Id.*
21. *See* Tomaselli, L.A., McCann, R.W., *AHA Files "Baby Doe" Comments; Criticizes Proposed Rule*, HEALTH LAW VIGIL 6(19): 1-3 (September 16, 1983).
22. *See* Statement of the American Medical Association to the Department of Health and Human Services Re Nondiscrimination on the Basis of Handicap Related to Health Care for Handicapped Infants (August 26, 1983).
23. *See* Comments of the American Academy of Pediatrics on: Proposed Rule Regarding Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants (1983) (submitted to the Department of Health and Human Services in response to proposed rule). *See also The American Academy of Pediatrics Comments on the "Baby Doe II" Regulations*, NEW ENGLAND

Continued on page 236

HANDBOOK OF HEALTH, HEALTH CARE, AND THE HEALTH PROFESSIONS. Edited by David Mechanic, Ph.D. (Free Press, New York, N.Y.) (1983) 806 pp., $49.95.

ORPHAN DRUGS AND ORPHAN DISEASES: CLINICAL REALITIES AND PUBLIC POLICY. Edited by George J. Brewer (Alan R. Liss, Inc., New York, N.Y.) (1983) 298 pp., $38.00.

VALUE CONFLICTS IN HEALTH CARE DELIVERY. By Bar Gruzalski and Carl Nelson (Ballinger Publishing Co., Cambridge Mass.) (1982) 230 pp., $24.50.

Editorial — references

Continued from page 202

JOURNAL OF MEDICINE 309(7): 443-44 (August 18, 1983).

24. *See, e.g.*, Knox, *Journal Urges Reagan to Drop "Baby Doe" Rules*, Boston Globe, September 15, 1983, at 8; *Bound by Reagan's Commitment to "Baby Doe" Rule, Task Force Debates Whether Rule Could Broaden Civil Rights Protections*, Washington Post, May 23, 1983, at All, col. a.

25. *See* 48 Fed. Reg. 30,847 (referring to Boston television series, "Death in the Nursery," aired February 1983).

26. *Id.* at 30,852.

27. *In re* Quinlan, 355 A.2d 647, 671 (N.J. 1976), *cert. den.*, 429 U.S. 1922 (1976) (court ruled that guardian, family and physician should consult hospital "ethics committee" which would agree whether there was a reasonable possibility of patient's recovery).

28. *In re* Colyer, 660 P.2d 738 (Wash. 1983) (court advocated reliance on a hospital "prognosis board" to determine a patient's reasonable medical probability of recovery; rejected use of ethics committees containing nonphysician personnel in decisions to discontinue life support).

29. *See* Youngner, S.J., *et al.*, *A National Survey of Hospital Ethics Committees*, in PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS (U.S. Government Printing Office, Washington, D.C.) (1983) at 443-49.

30. American Academy of Pediatrics, *supra* note 23, at 51 (Conditions of Participation set out in Appendix pp. 1-4).

31. *See Medical Groups Divided on "Baby Doe" Alternative*, American Medical News, September 16, 1983, at 1.

32. American Academy of Pediatrics, *supra* note 23, at 52-53.

33. *Id.* at 53.

34. Id. at 54.

35. *See* Americans United for Life Legal Defense Fund, *Letter*, Ethics Committee Newsletter, No. 2 (October 1983).

Health Care Financing

Blacker RA, Mickelson AA, *Negotiating Contracts with PPOs*, HEALTHCARE FINANCIAL MANAGEMENT 37(9): 48-51 (September 1983) [11-780].

Califano, Jr. JA, *The Chrysler Story: How an Ailing American Firm is Tackling Health Care Cost Problem*, FEDERATION OF AMERICAN HOSPITALS REVIEW 16(4): 12, 16-19 (July/August 1983) [11-1114].

Calligaris CF, *Who Pays for Hospital Care in the State-Supported Institution?* NEW YORK STATE JOURNAL OF MEDICINE 83(7): 963-4 (June 1983) [11-1183].

Hadley J, *Medicaid Reimbursement of Teaching Hospitals*, JOURNAL OF HEALTH POLITICS, POLICY AND LAW 7(4): 911-26 (Winter 1983) [11-915].

Hay JW, *The Impact of Public Health Care Financing Policies on Private-Sector Hospital Costs*, JOURNAL OF HEALTH POLITICS, POLICY AND LAW 7(4): 945-53 (Winter 1983) [11-917].

Iglehart JK, *Medicare Begins Prospective Payment of Hospitals*, NEW ENGLAND JOURNAL OF MEDICINE 308(23): 1428-38 (June 9, 1983) [11-748].

Loop FD, *et al.*, *A Strategy for Cost Containment in Coronary Surgery*, JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION 250(1): 63-66 (July 1, 1983) [11-739].

Pattison RV, Katz HM, *Investor-Owned and Not-for-Profit Hospitals: A Comparison Based on California Data*, NEW ENGLAND JOURNAL OF MEDICINE 309(6): 347-53 (August 11, 1983) [11-755].

Petersdorf RG, *Progress Report on Hospital Cost Control in California: More Regulation than Competition*, NEW ENGLAND JOURNAL OF MEDICINE 309(4): 254-56 (July 28, 1983) [11-754].

Relman AS, *Editorial: Investor-Owned Hospitals and Health-Care Costs*, NEW ENGLAND JOURNAL OF MEDICINE 309(6): 370-72 (August 11, 1983) [11-756].

Editorial: Cost Containment and Coronary Artery Surgery, JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION 250(1): 76-77 (July 1, 1983) [11-740].

FEDERAL GRANTS AND COOPERATIVE AGREEMENTS: LAW, POLICY, AND PRACTICE. By Richard B. Cappalli (Callaghan and Co., Willmette, Ill.) (1983) 221 pp., $202.50 (three volumes).

● HEALTH-CARE FINANCE. By Robert J. Buchanan (Lexington Books, Lexington, Mass.) (1981) 174 pp., $23.95.

THE SECOND SICKNESS: CONTRADICTIONS OF CAPITALIST HEALTH CARE. By Howard Waitzkin (Free Press, New York, N.Y.) (1983) 282 pp., $19.95.

Health Care Planning

Greenfield WM, *New Approaches to Using the Determination-of-Need Process to Contain Hospital Costs*, NEW ENGLAND JOURNAL OF MEDICINE 309(6): 372-74 (August 11, 1983) [11-757].

James, Jr. AE, *Certificate-of-Need in an Antitrust Context (Research Note)*, JOURNAL OF HEALTH POLITICS, POLICY AND LAW 8(2): 314-19 (Summer 1983) [11-767].

Health Facility Management

Horty JF, *Court Ruling on Tax-Free Status Casts Shadow on Common Financing Strategy*, MODERN HEALTHCARE 13(9): 215-18 (September 1983) [11-792].

Muder RR, *et al.*, *Nosocomial Legionnaires' Disease Uncovered in a Prospective Pneumonia Study*, JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION 249(23): 3184-88 (June 17, 1983) [11-735].

Wright RA, Allen BH, *Marketing and Medicine*, JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION 250(1): 47-48 (July 1, 1983) [11-738].