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HANDICAPPED BABIES AND THE LAW — UNITED STATES

PROFESSOR GEORGE P SMITH, II

A six pound baby boy, born with Down's syndrome in Bloomington, Indiana, in 1982, who lived but six days, caused a national re-thinking of issues of infanticide, parental decision-making and power under the Common

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Law to exercise jurisdiction over the care of children and perhaps the most central issue of whether quality of life standards are more significant and fundamental than principles of sanctity of life. In addition to being born a mongoloid, with consequent mental retardation, 'Baby Doe' (as he was dubbed by the popular press) had a malformed esophagus together with multiple physical problems. The esophageal condition prevented food from reaching the stomach. Rather than authorise corrective surgery, the parents chose to direct a withholding of food and medical treatment — save pain killers — from their son. Before an emergency appeal to the United States Supreme Court could be taken of an unwritten decision of the Indiana Supreme Court not to overturn two Monroe County Circuit Court orders preventing interference with the parental decision, Baby Doe died.¹

Baby Jane Doe was born on Long Island, New York, on 11 October, 1983, with spina bifida and an abnormally small head which was swelling with excess fluid. After consultation with physicians and members of the clergy, her parents refused to allow corrective surgery. If successful, the operation might have allowed the infant to live some twenty years — but in a state of retardation, constant pain, epileptic, and paralysed below the waist.²

The highest court in the State, the Court of Appeals, decided that the parents' decision must be respected. It refused to enumerate the circumstances which would trigger judicial protection of an infant of this type's interest — merely observing that there may be occasions where it would be appropriate to intervene. Rather, it noted that the Legislature had designed a statutory scheme designed specifically for protecting children from abuse — and, at the same time safeguarding familial privacy and relationships — and that this procedure would be adhered to unless the Legislature, again, decided to amend the process.³

Although refusing to deal directly with the need to establish criteria for validating decision making in

not be permitted.⁴

cases of this nature, a key lower court decision in New York has indicated that only if there is a 'reasonable chance' to lead a fulfilling and useful life, will parental inaction regarding needed surgical intervention

The Rights of the Child

On 2 November, 1983, the United States Department of Justice argued in federal court that the failure by a hospital receiving federal monies to order surgery for an infant with severe birth defects could well violate the civil rights accorded the child under the *Rehabilitation Act of 1973*,⁵ as amended by the *1978 Rehabilitation, Comprehensive Service and Developmental Disabilities Act*.⁶ As such, the Act defines a handicapped individual as one who has either a physical or mental disability which in turn constitutes or results in a substantial handicap to employment⁷ and who has a physical or a mental impairment which limits substantially one or more of the major life activities.⁸

On 22 March, 1983, in a subsequent federal regulatory scheme, specific steps were designed to assure that there be no discrimination of defective newborns: prominently displayed signs in maternity wards and in other parts of hospitals announcing a non-discriminatory policy for handicapped infants and a prohibition against the denial of good or customary medical care (which was not defined) were set in operation; anonymous tipsters were encouraged to call a 'Handicapped Infant Hotline' at the United States Department of Health and Human Services in Washington, D.C., if they knew of any such acts of discrimination.⁹ When challenged, these regulations — dubbed by the popular press as the 'Baby Doe' regulations — were voided by a federal court as being arbitrary and capricious.¹⁰

'New' regulations, redrafted in light of this challenge, were submitted for public comment on 5 July, 1983;¹¹ and, on 12 January, 1984, Final Rules were promulgated which attempt to balance the confidentiality of the doctor-patient relationship with the right of the government to protect the lives of all its

citizens — regardless of age.¹²

Although not required by the finalised rules, *Infant Care Review Committees* are encouraged in the seven thousand health care providers receiving federal financial assistance. Consisting of at least seven members, with one member designated to act as 'special advocate' for the infant, the mandate of these Committees will be to develop and recommend for adoption by participating hospitals institutional policies concerning the withholding or withdrawal of medical treatment for infants with life-threatening conditions. Additionally, the Committees will provide counsel in specific cases under review and review — retrospectively — on a regular basis the records of infants where either life sustaining medical or surgical treatment has been withheld or withdrawn.

Adhering to various principles approved by such groups as *The American Academy of Pediatrics* and *The National Association of Children's Hospitals*, the ICRC's will work under the premise that where medical care is clearly beneficial, it should be provided.¹³ Although recognising a presumption should always be made in favour of treatment, reasonable medical judgments will be respected regarding treatment and nourishment so long as such decisions to forego or withhold are not made on the basis of present or anticipated physical or mental impairments.¹⁴ Presumably, the validity of the test of reasonableness will depend upon the facts of each case that is considered and thus allow for a standard of flexibility to be utilised.

Informational notices, posted where nurses and other medical professionals may view them, are required to include a statement of non discrimination of health services on the basis of handicap, and be of a size no smaller than five by seven inches and list a twenty-four hour, toll free 'hot line' at the United States Department of Health and Human Services and/or state child protective services agency where violations may be reported.¹⁵

In the supporting documentation of these final rules is a revelation that of the forty-nine *Infant Doe* cases of alleged discrimination in maternity wards handled to date and current as of 1 December, 1983, no case was documented where a finding of a discriminatory withholding of medical care could be substantiated.¹⁶

Conclusion

Child protection laws are, of course, necessary. Their design and promulgation by the government are crucial if standards of equal protection for all its citizens — regardless of age or physical stature — are to be assured. It is a dangerously thin line however, to tread between familial privacy in decision making matters and government intervention.¹⁷ The judiciary, when called upon to evaluate cases of alleged abuse for handicapped newborns, can be aided by a close working partnership with the medical profession in seeking to determine those situations where the withholding of needed medical or surgical modalities of treatment would be in the infant's best interests — as well as all others immediately concerned.¹⁸ This is a proper judicial inquiry and a proper role for it to pursue and one which will have to be chartered on a case-by-case basis.

Footnotes

- 1 See Van der Dussen, High Court May be Asked to Save Baby, *Bloomington Herald-Telephone*, April 15, 1982, at 1, col. 1; Van der Dussen, *Infant's Death Ends Feverish Appeal for Life*, *Bloomington Herald-Telephone*, April 16, 1982, at 1, col. 1; Van der Dussen, *Givan: Court's 'Doe' Action Set No Legal Precedent*, *Bloomington Herald-Telephone*, April 23, 1982, at 1, col. 1.
- 2 NEWSWEEK, Int'l Ed., Dec. 12, 1983, p.27.
- 3 In the Matter of William E. Webster, *Guardian Ad Litem for Baby Jane Doe v. Stony Brook Hospital, et al*, Oct. 28, 1983. Slip Opinion No. 676 at ps. 4, 5.
- 4 Application of Frank T. Curio, M.D., 421 N.Y.S.2d 965, 968 (1979).
- 5 Public Law 93-112. 87 Stat. 355, 361, 394 (1973).
- 6 29 United States Code Sec. 794 (1983).
- 7 Id. at Sec. 706(7)(A).
- 8 Id. at Sec. 706(7)(B).
- 9 48 Federal Register 9630 at 9631, 9632 (Mar. 7, 1983).
- 10 Am. Academy of Pediatrics, et al v. Margaret M. Heckler, Sec., Dept. of Health & Human Services, April 14, 1983, 51 United States Law Week 2628 (April 26, 1983).
- 11 48 Federal Register 3046-52 (July 5, 1983).
- 12 49 Federal Register 1622 (1984).
- 13 Id. at 1652.
- 14 Id.
- 15 Id. at 1651.
- 16 Id. at 1646-1649.
- 17 Dickens, *The Modern Functions and Limits of Parental Rights*, 97 L.Q. Rev. 462 (1981).
- 18 Burger, *Reflections on Law and Experimental Medicine in 1 ethical, legal and social challenges to a brave new world at 211* (G. Smith, ed. 1982).