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## Defective Newborns and Government Intermeddling

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### ABSTRACT

Whenever a genetically defective infant is born, a triptych of interests is challenged directly. For such a case not only tests the extent of the natural rights of the parents in making decisions regarding the infant's capacity for qualitative life, but the personal needs or the welfare of the child itself and the nature of the responsibilities of the State in ensuring the welfare of its citizens regardless of age or infirmity. Aggressive posturing by the United States government, through a complex regulatory scheme designed to assure protection of handicapped newborns, has in fact wreaked havoc on the whole decision-making process and assaulted the integrity and privacy of the family decisional unit. While lacking a similar governmental regulatory process of protection in England, the judiciary, nevertheless, has given a strong indication that circumstances may merit respect of parental decisions which preclude aggressive efforts being undertaken to maintain life for such infants. What would be helpful to parents, doctors and judges alike in deciding the gravity of birth impairment and ultimately whether to maintain life or allow it to abate with dignity and mercy would be criteria which would attempt to structure pragmatic medical standards for decision-making.

### INTRODUCTION

*The Sunday Times* of 4 December 1983 carried an absorbing article concerning the current tragedy of the so-called 'Baby Jane Doe' in the United States and raised a vexatious question at the conclusion regarding the possibility of such a saga being written in Britain.<sup>1</sup> Only time, of course, can provide a definitive answer to this question. A comparative analysis of what has transpired in the United States may prove instructive in predicting whether in fact such an incident might occur in England; this together with a consideration of the leading English case precedent in the area.

### THE CASE HISTORY

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 20 years—but in a state of retardation, constant pain, epileptic, and paralyzed below the waist.<sup>2</sup>

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 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.<sup>3</sup>

Although refusing to deal directly with the need to establish criteria for validating decision-making in 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, parental inaction regarding needed surgical intervention will not be permitted.<sup>4</sup>

### Federal intervention

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,<sup>5</sup> as amended by the 1978 Rehabilitation, Comprehensive Service and Developmental Disabilities Act.<sup>6</sup> 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 employment<sup>7</sup> and who has a physical or a mental impairment which limits substantially one or more of the major life activities.<sup>8</sup> It specifically declares, as observed,<sup>9</sup> that no handicapped citizen of the United States, solely for reasons of a handicap, will 'be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . .'<sup>10</sup>

### Regulations

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, DC, if they knew of any such acts of discrimination.<sup>11</sup> 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.<sup>12</sup>

'New' regulations, redrafted in the light of this challenge, were submitted for public comment on 5 July 1983,<sup>13</sup> and promulgated in final form on 12 January 1984.<sup>14</sup> In essence these rules declare that where medical care is clearly beneficial it should always be provided to a handicapped newborn.<sup>15</sup> Although recognizing a presumption should always be 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.<sup>16</sup> Thus, decisions are not to commence futile treatment which would not be of medical benefit to the infant and would in fact present a risk of potential harm will be respected.<sup>17</sup>

Infant Care Review Committees are encour-

aged, although not mandated, to be structured in the 7000 health care providers receiving federal financial assistance.<sup>18</sup> These committees will not only be charged with developing and recommending institutional policies concerning the withholding or withdrawal of medical treatment for infants with life-threatening conditions, but with providing counsel in specific cases under present review.<sup>19</sup>

### Further litigation

In a suit in the United States District Court in Brooklyn, November, 1983, the Justice Department sought access to the medical records of Baby Jane Doe in order to determine whether a violation of her federal civil rights guaranteeing equal protection of the laws to disabled persons had been violated.<sup>20</sup> The hospital where she was born, and remained, refused to co-operate by providing the government investigators with the records. The court ruled that there was no discrimination and, furthermore, if the operation had been performed, 'the infant would live longer—as a vegetable, paralyzed, disabled'.<sup>21</sup> A further appeal by the federal government from this decision and yet a final one to the United States Supreme Court yielded no reversals.<sup>22</sup> The Supreme Court Justices let stand the decision of the New York Court of Appeals upholding the parents' determination to avoid surgery.<sup>23</sup>

### THE ENGLISH POSTURE

A case determined by the Court of Appeal on 7 August 1981 gives the closest indication of a judicial perspective in this area.<sup>24</sup> The facts showed that B, a female child, was born suffering not only from Down's syndrome but an intestinal blockage as well and would require a surgical intervention in order to relieve the obstruction if she were to have a life of more than a few days. Although the surgery provided no guarantee of long life—in fact, there was a possibility that B might die within a few months—the evidence pointed to the fact that she could have an expectancy of normal mongol life anywhere from 20 to 30 years if the operation were successful. Her parents decided that in 'the kindest . . . interests of the child'<sup>25</sup> no operation should be performed. Accordingly, they advised the doctors of this decision and it was respected. The local authority thereupon made the infant

a ward of the court and sought an order authorizing the operation to be performed by other surgeons. The lower court respected the parental decision and refused to order the surgery. On appeal by the local authority, the Court of Appeal reversed and held that parental wishes were secondary to what was in the best interests of the child. The parents made a strong argument that, owing to the fact that the child would be severely handicapped both mentally and physically, no measure of the qualitative life of a mongoloid could be evaluated properly during its predicted limited life span. The court determined that insofar as a 'happy life' could be provided for a mongoloid, baby B was entitled to that life.<sup>26</sup>

Noting that a judicial decision in a case of this nature requires the court to consider the evidentiary proofs as well as the views of the parents and their doctors, the court acknowledged that 'at the end of the day it devolves on this court in this particular instance to decide whether the life of this child is so awful that in effect the child must be condemned to die, or whether the life of this child is so imponderable that it would be wrong for her to be condemned to die'.<sup>27</sup> The court continued, stating: 'There may be cases, I know not, of severe proved damages where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion.'<sup>28</sup>

Mention must be made, of course of *R. v. Arthur*, an unreported case decided at the Leicester Crown Court on 5 November 1981—but three months after the *In re B* decision. Here, a mongoloid was born on 28 June 1980, and thereupon rejected by his parents. The consultant paediatrician, Dr Leonard Arthur, prescribed 'nursing care only' (i.e. a regime which included no food) for the child and prescribed regular doses of the drug DF118 for purposes of sedation.

Originally a charge of murder, during the course of the trial the charge was reduced to attempted murder and a subsequent degree of acquittal rendered by a jury. In his summation, the judge indicated—without apparent reference to the *In re B* decision—that it was lawful to treat a baby with a sedating drug and offer no further care by way of food or drugs or surgery provided two criteria are met:

1. the child is 'irreversibly disabled' and
2. rejected by its parents.

Thus, the Arthur case seems to suggest that the issue of treatment of a severely handicapped newborn child is a private matter between physician and parent and—in the light of *In re B*—makes the law an absolute 'mess' as stated by one writer.<sup>29</sup>

While it is clear that the Arthur verdict does not legitimize the use of drugs in order to accelerate death it is unclear whether it establishes a uniform policy of non-treatment as legal and whether 'holding procedures' are valid in all cases.<sup>30</sup>

### RECONCILING VIEWS—STRUCTURING A CONSTRUCT

While the leading reported English case speaks of a defective newborn being given every opportunity for a 'happy life', the court recognizes further that where pain and suffering together with 'severe proved damages' would so plague life, parental decisions of inaction might be respected. The leading case authority in the United States states that where no 'reasonable chance' exists for such an infant leading a fulfilling and useful life, parental decisions to forego extraordinary treatment to sustain its life will be respected.

Both the English Court of Appeal precedent and the United States cases draw persuasive if not conclusive authority for their decisions by utilization—understood as such, or not—directly or indirectly, of a principle of a 'substituted judgment'. Thus, the court will seek to place itself in the position of the infant *in extremis* and determine whether, given its medical condition, it would wish to live under present or altered conditions—whether a meaningful or qualitative life could be achieved.

Inherent in the effectiveness of application of such a principle is the employment of a cost-benefit analysis or balancing test. Or, stated simply, the costs (social, economic) of maintaining life are weighed against the benefits (religious, ethical, spiritual, etc.) of preserving it. Any balancing test is strengthened when a construct is developed which, in turn, allows the person or persons deciding the issue to employ objective standards, medical or otherwise, to reach a conclusion.

Some have postulated various qualities, attitudes or indicators of humanhood<sup>31</sup> which, if absent in a defective newborn, serve as a construct for decision-making; with neo-cortical functions or capacities a most crucial indicator. Others have stressed the essential for being recognized as a human as the possession of a 'potential for human activities' which comes from having a functioning brain.<sup>32</sup> Yet another leading authority has observed that decision makers should evaluate the 'potential' for the development of human relationships in deformed infants and whether this potential, even assuming it exists, will so sap or drain the time and attention as well as social and economic resources of not only the infant, but those associated with it that, in reality, the possibility for engendering human relationships will be lost.<sup>33</sup> Low birth weights (usually 1000 g) have also been suggested as an indicator of a potential for humanhood—with aggressive treatment being withheld justifiably in such cases.<sup>34</sup>

#### The Sheffield criteria

Even more specificity in designing a construct is to be found in the list of six defects which emerged from a study at the Children's Hospital in Sheffield, England, in the early 1970s, which may be taken as precluding the possibility of an independent, dignified life—for one where it might be said meaningful interpersonal relations can be enjoyed. They are:

1. Thoracolumbar or thoracolumbosacral lesion.
2. Gross paralysis with a neurologic segmental level at L3.
3. Kyphosis or scoliosis.
4. Gross hydrocephalus with a head circumference at least 2 cm above the 90th percentile related to birth weight.
5. Other gross congenital factors, such as cyanotic heart disease.
6. Intracranial birth injury.<sup>35</sup>

A pre-eminent paediatric surgeon, Professor Benjy F. Brooks, of the University of Texas Medical Center in Houston, and Visiting Fellow at Clare Hall, Cambridge University, suggested in a lecture at Cambridge, on 27 February 1984, that modern medicine and surgical technique have made significant advances since the Sheffield Study and that concern should now be

had for only three non-treatable categories among newborns: cyclops, encephaloceles and anencephalics.

#### CONCLUSIONS

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 to tread between familial privacy in decision-making matters and government intervention.<sup>36</sup> 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 the best interests of all others immediately concerned.<sup>37</sup> This is a proper judicial inquiry and a proper role for it to pursue. The construct for decision-making proposed herein is of value not only to the courts but also to the parents of a handicapped infant who, themselves, must confront the initial decision regarding sanctified or qualitative living.

Given the medically agreed upon components of this construct, and the laws already in place protecting children from abuse,<sup>38</sup> there is no need for direct government involvement or intrusion into the sensitive area of familial autonomy by way of federal regulatory schemes of the nature being structured in the United States. There is every reason to hope that this federal intrusion will, when once again tested in the courts, be recognized as unnecessary and invalid and as such not worthy of duplication in England or other parts of the international community.

#### Endnote

On 23 May 1984, a United States federal district court judge struck down the 'new' Baby Doe Regulations. American Hospital Association, *American Medical Association v. Heckler*, 585 Fed. Supp. (So. Dist. New York) 541 (1984). The United States Department of Justice is, at present, appealing this decision to the United States Second Circuit Court of Appeals in Manhattan.

At the legislative level, the United States Congress has sent to a Conference Committee proposed amendments to the Federal Child Abuse Prevention and Treatment Act (H.R. 1904, S. 1003) which, if enacted would mandate a standard of required treatment for handicapped at risk newborns from hospitals receiving federal funds for their operation. 98th Congress, 1st Sess., House of Representatives, Report No. 98-159. See generally *The Economist* 14 July 1984. p. 42.

## REFERENCES

1. Marton, K. (1983) Fight for Baby Jane. *The Sunday Times*, 4 December, col. 1, p. 45. See also Singer P., Kuhse H. (1984) The future of Baby Doe. *The New York Review*. 1 March, p. 17.
2. *Newsweek*, International ed., 12 December 1983, p. 27.
3. In the matter of *William E. Webster, Guardian Ad Litem for Baby Jane Doe v. Stony Brook Hospital, et al.* 28 October 1983. Slip Opinion, 676, pp. 4 and 5.
4. Application of Frank T. Curio, MD, 421 NYS 2d 965, 968 (1979).
5. Public Law 93-112. 87 Stat. 355, 361, 394 (1973). Barringer F. (1983) US seeks records of 'Baby Jane Doe'. *Wash. Post*, 3 November 1983, col. 6, p. 1.
6. 29 United States Code Sec. 794 (1983).
7. Id. at Sec. 706 (7) (A).
8. Id. at Sec. 706 (7) (B).
9. 29 United States Code Sec. 794 (1983).
10. Section 504 of The Rehabilitation Act has been codified as Sec. 794.
11. 48 Federal Register 9630 at 9631, 9632 (7 March 1983).
12. *Am. Academy of Pediatrics, et al. v. Margaret M. Heckler, Sec., Dept. of Health and Human Services* 14 April 1983, 51 United States Law Week 2628 (26 April 1983).
13. 48 Federal Register 304-52 (5 July 1983).
14. 49 Federal Register 1622.
15. Id. at 1652.
16. Id.
17. Id. at 1653-1654.
18. Id. at 1652.
19. Id.
20. Barringer F. (1983) US, seeks records of 'Baby Jane Doe'. *Wash Post*, 3 November 1983, col. 6, p. 1.
21. Barringer F. (1983) Judge rejects Federal role in Baby Doe case. *Wash. Post*, 18 November 1983, col. 3, p. 1.
22. *Newsweek*, International ed., 12 December 1983, p. 27.
23. *International Herald Tribune*, 13 December 1983, col. 3, p. 6.
24. *In re B (A minor)*, CA 1981, 1. WLR 1421.
25. Id. p. 1422.
26. Id. p. 1423.
27. Id. p. 1424.
28. Id.  
See Dickens B.M. (1981) The modern function and limits of parental rights. *The Law Quarterly Rev.* 97, 462.
29. Kennedy I. (1982) Reflections on the Arthur Trial. *New Society* 59, 13.
30. Glover J. (1982) Letting people die. *London Rev. of Books* 4, 3.
31. Fletcher J. (1972) Indicators of humanhood: a tentative profile of man. *Hastings Center Report*, p. 1.
32. Brody B. (1975) *Abortion and the Sanctity of Human Life: a Philosophical View*. Cambridge, Massachusetts, MIT Press. p. 114.
33. McCormick R. (1981) To save or let die: the dilemma of modern medicine. In: McCormick R. (ed.) *How Brave a New World?* New York, Doubleday, p. 339.
34. Strong C. (1983) The tiniest newborns. *Hastings Center Report*, pp. 14-16.
35. Lorber J. (1973) Early results of selective treatment of spina bifida cystica. *British Medical J.* 4, 201-204; *Pediatric News*, 8, 11.  
See also Soskin R.M., Vitello S.J. (1979) Defective newborns: a right to treatment or a right to die? (re factors for developing criteria). *Amicus*, pp. 120, 126; and Lorber J., Salfeld S. (1981). Results of selective treatment of spina bifida cystica. *Archives of Diseases in Childhood*. 56, 822.
36. Dickens, B.M. (1981) The modern functions and limits of parental rights. *The Law Quarterly Rev.* 97, 462.
37. Burger W. (1982) Reflections on law and experimental medicine. In: Smith G. (ed.) *Ethical, Legal and Social Challenges to a Brave New World*. Port Washington, New York, Associated Faculty Press. p. 211.
38. See e.g. in England, The Child Care Act, 1980; Children Act, 1975; Children and Young Persons Act, 1963; Children and Young Persons Act, 1933; and the Infant Life (Preservation) Act, 1929.