

allow them to be put to death rather than burden their parents.

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### References

1. 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. Gov't Printing Off., Washington, D.C.) (1983) at 223.
2. *Id.* at 229.

Dear Editors:

One need but glance through the Stinsons' graphic and tragic account of *The Long Dying of Baby Andrew*<sup>1</sup> to learn of the devastating effects — financial, emotional, psychological, and marital — of caring for a profoundly compromised newborn. In the face of the physicians' repeated failures but constant refrain that not to do everything possible to save the life of such infants is murder, one fairly wants to scream: "In the name of God, stop the torture. Let the child die."

The issue, though, is the torture to whom. Both Robert and Peggy Stinson vividly present their own pain and suffering, but it is not that, but the futile pain and suffering of baby Andrew, which moves them to tears and pleas for mercy.

Their plaintive story reflects a markedly different approach from the plea of Carson Strong in the September issue. Strong argues that unless the government provides financial and institutional assistance to families of physically and mentally impaired children, families ought to be permitted to reject life-saving treatment for the child.

There is no denying that our society has seriously defaulted on its obligation to provide adequate assistance to the retarded, to the handicapped, and to their families. As Glick's recent report on pediatric nursing homes illustrates, even the more progressive programs fail to meet the practical needs of such families.<sup>2</sup> Moreover, those programs that do exist are now

falling victim to the Reagan Administration's cutbacks in the area of children's services. But neither of these facts justifies Strong's thesis that the state pays or the child dies.

Strong claims that his recommendation differs from previous proposals and guidelines inasmuch as it gives explicit attention to the potential hardships to families. It is, unfortunately, no novel theory; it is simply Raymond Duff's views writ long. In his famous (and surprisingly uncited) article, *Moral and Ethical Dilemmas in the Special Care Nursery*, Duff specifically stated that since it is the parents who bear the burden of the defective newborn, it is they who should decide if the infant lives or dies.<sup>3</sup>

It is that essay, more than anything subsequently written, which sets the stage for the Infant Doe regulations, and it is that view — that the infant's right to life is predicated on parental acceptance — which threatens to force a fearful society into demanding that *all* life, no matter how disabled or compromised, must be sustained if physically and technically possible.<sup>4</sup>

As one who has testified against the Infant Doe regulations before Senator Denton's sub-committee in April, and as one who has been subjected to virulent attacks for my writings on withdrawal of treatment from profoundly defective newborns, I wish to join those who raise their voice against the theory that children are to be accepted or rejected — to live or be killed — because of their burden on others.

One might well ask what limit there is to Strong's principle: "When interference with parental liberty would cause a grave burden to a family, we should consider such interference [the survival of the child] to be unwarranted." He applies it to both physical and mental impairments, to spina bifida as well as to retardation. He then justifies his position on the grounds that there is no discrimination against the disabled because it is not the impairment, but the burden on the family that is "the morally relevant factor." With such logic, whose right to existence is protected?

Nor can we take much consolation from Strong's reading of the common law. While acknowledging that "[t]he court will interfere with parental authority only when outweighed by considerations of great magnitude, such as death or other serious harm to the child," he seems to forget that it is precisely the *death of the child* that he balances against the financial and emotional harm to the family.

The fundamental error and inexcusable failure of Strong's essay is the deviation from the first principle of medical ethics: *Primum Non Nocere*. It is the interest of the patient, the good of the patient, and the harm to the patient which have been and ought to be the primary focus of medical ethics.<sup>5</sup> To deviate from that norm is to distort if not destroy medicine's role in society.

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### References

1. R. STINSON, P. STINSON, *THE LONG DYING OF BABY ANDREW* (Little, Brown & Co., Boston) (1983).
2. Glick, P.S., et al., *Pediatric Nursing Homes — Implications of the Massachusetts Experience for Residential Care of Multiply Handicapped Children*, *NEW ENGLAND JOURNAL OF MEDICINE* 309(11): 640, 641, 643 (September 15, 1983).
3. Duff, R.S., et al., *Moral and Ethical Dilemmas in the Special-Care Nursery*, *NEW ENGLAND JOURNAL OF MEDICINE* 289(17): 890, 894 (October 25, 1973).
4. See Angell, M., *Editorial: Handicapped Children: Baby Doe and Uncle Sam*, *NEW ENGLAND JOURNAL OF MEDICINE* 309(11): 659-60 (September 15, 1983).
5. See Paris, J.J., *Terminating Treatment for Newborns: A Theological Perspective*, *LAW, MEDICINE & HEALTH CARE* 10(3): 120, 124 (June 1982).

### The author responds:

Dr. Lynn and Father Paris maintain that seriously impaired newborns should be treated aggressively, without consultation with parents, even when doing so is likely to result in great harm to — perhaps dissolution of — the family. However, none of the reasons they give in support of this opinion withstand critical scrutiny.

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