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George Barbaresi

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Should the Baby Live? The Problem of Handicapped Infants

By Helga Kuhse and Peter Singer. Oxford: Oxford University Press. 1985. Pp. vii, 228.

There is a limit to the burden of dependence which any community can carry. If we attempt to keep all handicapped infants alive, irrespective of their future prospects, we will have to give up other things which we may well regard as at least equally important. . . . The amount needed to care for one patient . . . could be used to save the lives of a score of children suffering from malnutrition in less well-developed countries.¹

I. INTRODUCTION

Advances in medical technology can save the lives of severely handicapped infants, who, only several years ago, would have died within a few days of birth. But saving these lives is not without cost. In their book, *Should the Baby Live? The Problem of Handicapped Infants*, authors Helga Kuhse and Peter Singer examine the emotional strains put upon a family with a severely handicapped child as well as the financial burdens of expensive medical and institutional care, usually put upon society. The authors also expose the medical practice of sometimes just letting a severely handicapped infant die. The authors illustrate these problems with several studies and case histories which are discussed in Part II of this book note. In Part III, the solutions suggested by the authors are presented and analyzed.

II. THE BURDEN CAUSED BY THE SEVERELY HANDICAPPED

A. *Emotional Burdens*

The authors propose that "the survival of a handicapped child is also the creation of a handicapped family."² This is supported by several studies of families with a severely handicapped child. Raising a handicapped child puts a devastating strain on

1. H. KUHSE & P. SINGER, *SHOULD THE BABY LIVE? THE PROBLEM OF HANDICAPPED INFANTS* 170, 171 (1985) [hereinafter KUHSE].

2. *Id.* at 146.

the family, most of which falls on the mother. Babysitters are difficult or impossible to get. Even the simplest chores become so unpleasant as to be avoided as much as possible.³ Studies of families with handicapped children show a high rate of marital break-up. In one study, the divorce rate in families with a handicapped child was twice as high as that of a control group of families without a handicapped child.⁴

One study on families with a severely mentally handicapped or functionally disabled child found that sixty percent of the families had a "disturbed" sibling and between ten and fifteen percent had a "seriously disturbed" sibling.⁵ The study found that "[w]hen a child is retarded, older siblings tend to be held back in their development and younger siblings lack that spur to develop which a normal sibling would provide."⁶

The authors also present an argument that requiring a family to keep a handicapped child not only puts an oppressive burden on the family, but in most cases precludes the parents from having a normal child. This is based on a disturbing finding that parents with a handicapped child tend to have no more children. One study found that of 160 mothers with handicapped children, 101 decided not to have anymore children. The reason given by ninety of these mothers was directly related to the presence of a handicapped child.⁷ "Given an abnormal child, parents will very likely limit their further reproduction; if the child is lost, they will have another one, and this time (in all probability) the child will be normal. . . . Keeping a badly damaged child alive is likely to eliminate the potential existence of a normal one."⁸

3. See generally *id.* at 146-49; Simms, *Severely Handicapped Infants: A Discussion Document*, 98 *NEW HUMANIST*, no. 2 (Summer 1983); C. HANNAM, *PARENTS AND MENTALLY HANDICAPPED CHILDREN* (2d ed. 1980).

4. KUHSE, *supra* note 1 at 149 (citing Tew, Payne & Lawrence, *Must a Family with a Handicapped Child be a Handicapped Family?*, 16 *DEV. MED. CHILD NEUROL.*, 95-98 (1974)).

5. KUHSE, *supra* note 1 at 150 (citing S. KEW, *HANDICAP AND THE FAMILY CRISIS* (1975)) [hereinafter KEW]. See also A. GATH, *DOWN'S SYNDROME AND THE FAMILY: THE EARLY YEARS* 69 (1978).

6. KUHSE, *supra* note 1 at 151 (citing KEW, *supra* note 5 at 136-37).

7. *Id.* at 155 (citing KEW, *supra* note 5 at 52).

8. *Id.* at 65 (citing Slater, *Wanted—A New Basic Approach*, *BRIT. MED. J.*, May 5, 1973, at 285).

B. Financial Burdens

For the handicapped child, the alternative to life with the family is life in an institution. However, caring for the severely handicapped is labor intensive and therefore expensive. An adequately staffed institution requires almost one staff member per patient. The cost per patient is around \$40,000 per year.⁹ Nevertheless, a 1973 study showed that "[l]iving conditions in most public institutions are intolerable."¹⁰ The authors debate whether society can financially afford to adequately care for its handicapped.

The cost of the modern medical technology available to save infants can be prohibitive. In 1983, the cost of operating an artificial respirator and caring for a handicapped baby was \$1500 per day. In one case, the cost of keeping the baby alive for nineteen months was nearly \$1 million.¹¹ The average bill for a baby weighing under 1000 grams¹² at birth was \$40,000, which included the cost of caring for babies which did not survive.¹³ The cost of trying to keep these handicapped infants alive, and the fact that some will not survive and some of those that do survive will be severely handicapped, prompted one pediatrician to state, "[y]ou could philosophically ask, is it better to spend \$50,000 on the small premature infant or tell the parents to go away and have another baby?"¹⁴

C. One Present Reaction Within the Medical Profession

The medical profession recognizes the enormous burden created by the severely handicapped. The authors suggest that many handicapped infants, rejected by their parents, are routinely allowed to die. As an example, the authors present the cases of two babies born with Down's syndrome¹⁵ who were allowed to die. Down's syndrome involves permanent mental re-

9. *Id.* at 164 (citing THE ATLANTA JOURNAL, Dec. 11, 1983).

10. *Id.* at 163 (citing R. CONLEY, THE ECONOMICS OF MENTAL RETARDATION 370, 372 (1973)).

11. *Id.* at 168 (citing *Playing God in the Nursery*, Chicago Tribune, Feb. 6-10, 1983). The respirator scarred the baby's lungs so badly that it was unable to breathe without it.

12. One-thousand grams is approximately 2.2 pounds.

13. *Id.*

14. The Age (Melbourne), Dec. 30, 1983 (quoted in KUHSE, *supra* note 1 at 169).

15. A Down's syndrome child has slanting eyes, a broad, flattened nose, a large tongue, and a broad, short head. People with Down's syndrome are often called mongols.

tardation and is often accompanied with other complications such as heart problems or blockage in the stomach or intestines.

The first case presented involved a baby born in England in June 1980. The baby had no apparent abnormalities other than Down's syndrome, but his parents did not want him. He was given only water and a pain killer in his bottle and nothing else to eat. The baby was born on a Saturday and died the following Tuesday. An autopsy revealed that the baby had a lethal level of the pain killer in his blood and liver. The autopsy also revealed that the baby died of bronchial pneumonia, caused by lung inactivity due to the pain killer.

The doctor was tried for attempted murder.¹⁶ At trial, medical experts stated that "deliberately letting handicapped infants die is common medical practice, and is endorsed by some of the most respected members of the medical community."¹⁷ One expert witness stated that "in cases such as this, food would be withheld 'in the hope that complications would develop which would lead to death by natural causes.'"¹⁸ According to another expert "it would be ethical to put a rejected child upon a course of management that would end in its death . . . I say that it is ethical that a child suffering from Down's syndrome . . . should not survive."¹⁹ The jury found the doctor not guilty.

The second case involved a baby born in Indiana in April 1982. In addition to Down's syndrome, the baby had other problems, the most severe being incomplete formation of the passage from the mouth to the stomach. Although this condition is common in Down's syndrome babies, it also occurs in infants without Down's syndrome. Attempts to feed a baby with this condition result in the food getting into the child's lungs, suffocating it. If not directly suffocated, the baby does not get enough nourishment and dies of dehydration or pneumonia caused by stomach acid in the lungs. The usual procedure, an operation, is risky, "but in a majority of cases the child can subsequently eat normally."²⁰

In this case, the doctors felt it was better not to operate but

16. At trial, it was shown that the baby had some abnormalities of the lungs, heart, and brain and consequently might have developed pneumonia naturally and therefore might have died of natural causes.

17. KUHSE, *supra* note 1 at 8.

18. *Id.*

19. *Id.*

20. *Id.* at 11.

to simply keep the baby until it died. The parents decided to follow the advice of the doctors. However, the hospital contacted the county court for a hearing on the issue. The judge decided the parents had the right to choose "a medically recommended course of treatment" for their minor child²¹ and directed the hospital to allow the treatment prescribed by the doctors. The judge also appointed the county department of public welfare as guardian of the infant to determine if there should be an appeal to a higher court. The county welfare officials decided not to appeal, but the county prosecutor's office asked another judge to order intravenous feeding to keep the baby alive at least on a temporary basis. The judge refused. The prosecutor's office then went to the state supreme court, which in turn refused to overturn the lower court. The baby died before the prosecutor's office was able to get emergency intervention from the United States Supreme Court.

In addition to Down's syndrome, doctors routinely decide that some babies with spina bifida will be treated, while others will be allowed to die. Spina bifida is characterized by a split and exposed spinal cord. In its most severe form there is swelling in the middle of the back from which spinal fluid leaks, infection is likely, and because spinal nerves are damaged, partial or complete paralysis in the legs occurs and the child is unable to control its bowels or bladder. About sixty-five percent of spina bifida infants develop hydrocephalus (water on the brain) which causes the head to swell and leads to brain damage. Many victims, therefore, become mentally retarded, but others do have normal intelligence.

In the 1950s it became possible to keep children with spina bifida alive for an appreciable length of time. By the late 1960s, all children with spina bifida were being operated on. About eighty-five percent of those who survived were severely handicapped. By the early 1970s, the practice evolved to operate selectively, allowing some to die. The selection criteria are not standard among physicians.

The authors show that the medical profession is, to some extent, sympathetic to the problems of caring for handicapped children, and some doctors are willing to let the infants die. In addition, it is accepted medical practice to not care for all severely handicapped infants. The authors argue that family and

21. *Id.* at 13.

society are not able to cope with the increasing burden of caring for the increasing numbers of handicapped children being kept alive by improving medical technology. However, a large part of the book unsuccessfully attempts to morally justify allowing handicapped infants to die or even be killed.

III. JUSTIFICATION FOR ALLOWING THE BABY TO DIE

The authors explain that society's desire to save the life of a severely handicapped child is a result of Western culture's belief in the sanctity of human life. They suggest that this belief is founded on two principles.

The first is that all human life is of equal worth. "Life is not valuable because of the qualities it may possess; it is valuable in itself."²² Under this premise, the life of a severely handicapped baby is no less valuable than the life of a normal baby. The second principle is based on the concept of human rights. Our society believes that all humans have certain rights and that all should share in them equally. It is impermissible to deny rights to people based on some irrelevant classification, such as race or sex. In America, a handicap, like race or sex, is not a relevant factor in determining how a person is to be treated.²³ The right to live is the most basic of all human rights, so handicapped persons cannot rightfully be denied the right to live because of their handicap.

A. *The Quality of Life*

The authors point out that, despite a belief in the sanctity of human life, decisions on treating a severely handicapped infant are often based on the estimated quality of that life. One example is the Child Abuse Prevention and Treatment Act²⁴ which prohibits the withholding of "medically indicated treat-

22. *Id.* at 19.

23. Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1988), prohibits all recipients of federal funds from withholding treatment from handicapped citizens simply because they are handicapped.

The regulations on caring for children promulgated by the Department for Health and Human Resources under the authority of § 504 were struck down in *American Medical Association v. Heckler*, 585 F. Supp. 541 (S.D.N.Y.), *aff'd*, 794 F.2d 676 (2d Cir. 1984). See also *United States v. University Hosp.*, 729 F.2d 144, 161 (2d Cir. 1984) ("[C]ongress never contemplated that section 504 of the Rehabilitation Act would apply to treatment decisions involving defective newborn infants . . .").

24. 42 U.S.C. §§ 5101-16g (1988).

ment." Medically indicated treatment is defined as treatment likely to be effective in ameliorating or correcting life-threatening conditions.²⁵ There are three exceptions: (1) the infant is chronically and irreversibly comatose; (2) the treatment would merely prolong dying, would not be effective in correcting all of the infant's life-threatening conditions, or is otherwise futile in terms of the survival of the infant; or (3) the treatment would be futile in terms of the survival of the infant and the treatment itself under the circumstances would be inhumane.²⁶

The authors argue that the conclusion that life in an irreversible coma is not worth prolonging is based on quality of life, not medical, considerations. Also, the idea of inhumane treatment allows ethical judgments which weigh the suffering of the infant against the doubtful prospects of life-prolonging treatment. Therefore the authors conclude that although the regulations appear to be quality of life neutral, the guidelines require a quality of life determination.

The problem is defining what is medically beneficial to the patient. Medical techniques can indefinitely prolong the life of children with anencephaly (born without a brain), but there is no cure. The authors claim that the decision that this life should not be prolonged "is not a medical judgment but a judgment reflecting the desirability of prolonging this particular life."²⁷ Compare this to the treatment for the diabetic, also for whom there is no cure, and who must be treated for life. A diabetic can enjoy a near normal life with insulation injections. However, no matter how long you prolong the life of an anencephalic child, he would never have anything like a normal life.

Giving insulin to a diabetic keeps him alive and lets him enjoy his life. Prolonging the life of someone in a coma or with anencephaly is medically beneficial in that it prolongs the life, but the patient has no increase in his quality of life. Thus, the authors conclude, it is not really a medical judgment; it is a determination of whether the life is worth prolonging.

Although the authors contend that any judgment as to whether to keep the child alive must be based on whether the life is worth living, they fail to address the critical problem of what standards govern whether the life is worth living. In the

25. *Id.* § 5106g(10).

26. *Id.*

27. KUHSE, *supra* note 1 at 27.

authors' own judgment, "it is often possible for a Down's syndrome infant to live a reasonably happy, if simple, sort of life."²⁸ Perhaps any life, even a simple life, is a quality life for a Down's syndrome baby, and is worth more to the baby than no life. The authors have misstated the question—what they ask is not whether the life is worth living, but whether it is worth society's effort to preserve. Perhaps their answer would be that if the life is not worth society's time and money to preserve, it is not worth living.

B. *What is Human Life?*

Having determined that all human life is not of equal worth, that some lives have a higher quality than others, and therefore there is not an equal right to live, the authors try to determine what human life is. The authors accept Joseph Fletcher's list of "indicators of humanhood" as those characteristics which "have undeniable moral significance."²⁹ These indicators include "self-awareness, self-control, a sense of the future, a sense of the past, the capacity to relate to others, concern for others, communication, and curiosity."³⁰

The authors believe that simply being a member of the human species is not an indicator of humanhood and give the example of anencephalics. Although human in the sense that they are members of the species, they have none of the other indicators of humanhood.

However, the authors fail in their attempt to define human life. Even if Fletcher's list of indicators is assumed to be valid, the authors do not explain how it should be applied. They do not suggest how to determine whether indicators are lacking or which ones or how many must be lacking before the person is not human. Therefore, they fail to show whether a handicapped child is human or not. Failure to present a workable definition of human life is fatal to the authors' thesis because they go on to propose that if a person is not human, he has no right to live.

Having rejected the sanctity of human life, the authors propose that "the wrongness of an action is related to the extent to which the action prevents some interests, desires or preferences

28. *Id.* at 141.

29. *Id.* at 120 (citing Fletcher, *Indicators of Humanhood: A Tentative Profile of Man*, 2 THE HASTINGS CENTER REPORT, no. 5 (1972)) [hereinafter Fletcher].

30. *Id.* at 120 (citing Fletcher, *supra* note 29).

from being fulfilled."³¹ Therefore the indicators of humanhood are relevant because they determine whether the being has a desire to go on living. It is the desire to go on living which makes a person human, and, if the desire to live is present, then it is wrong to end the life.

The authors' inability to determine when a person possesses the indicators of humanhood, and therefore the right to live, creates an insurmountable obstacle to their proposals. They state,

No infant is born with self-awareness or a sense of the future. . . . [N]o new-born infant has a right to life. Just when normal human infants acquire some minimal degree of self-awareness is difficult to say Whichever way we decide this difficult factual question, infants will be deemed not to have a right to life at birth, nor for some time afterwards.³²

But the authors also write, "it is plausible to suppose that new-born infants can feel pain . . . can feel cold . . . can feel hungry."³³ This makes the authors' proposition self-contradicting since it is just as plausible to suppose that new-born infants have a self-awareness or a sense of the future, and therefore have a right to live.

It appears the authors have assumed, because they cannot communicate with the infant (which is only one of the indicators of humanhood), that the infant does not possess any of the other indicators. Until the authors can determine with certainty that the indicators are in fact lacking, their proposition is unworkable.

C. Killing the Severely Handicapped Infant

Although the authors claim that a person who is not human does not have a right to live, they never determine whether the right to live means the right to be kept alive or merely the right not to be killed. However, the authors attempt to show that there is really no difference between letting the infant die and actively ending its life.

Once it is decided that a baby will not be treated (but will be allowed to die), should the doctors do something to end the baby's suffering? It has taken as long as fifteen days for a

31. *Id.* at 131 (citing M. TOOLEY, *ABORTION AND INFANTICIDE*, 1983) [hereinafter TOOLEY].

32. *Id.* at 132 (emphasis in original) (citing TOOLEY, *supra* note 31).

33. *Id.* at 135.

Down's syndrome baby to starve to death.³⁴ Several surveys have shown that although a majority of doctors would allow an infant to die, they would also refuse to kill it. The authors suggest that one reason for the distinction is that "if we kill, we are responsible for the resulting death; if, however, a doctor allows a patient to die, it is nature that is responsible."³⁵ The authors then argue that the failure to treat the baby is an omission which is one cause of death and conclude that "[d]octors who deliberately leave a baby to die when they have the awareness, the ability, and the opportunity to save the baby's life, are just as morally responsible for the death as they would be if they had brought it about by a deliberate, positive action."³⁶

The authors continue by reasoning that since there is no moral difference between letting a baby die and killing it, active euthanasia, which brings a quick and painless death, is the preferable alternative. But the whole premise is flawed because killing a baby and letting it die are not the same. Letting a baby die may merely be a question of not being able to help; but the ability to help raises a professional obligation to do so. In other words, that it cannot be fixed does not mean it should be destroyed.

The authors also argue that there is no difference between aborting a deformed fetus and killing the handicapped infant after birth. Amniocentesis can determine if an infant will be born with spina bifida. In such a case, the woman could have an abortion. The death of the aborted fetus takes a matter of seconds. Spina bifida babies have a slow, lingering death. Most untreated spina bifida infants die within three months, but ten to twenty percent live for one to two years.

The authors suggest setting a time period after birth, for example, twenty-eight days, during which the baby could be legally terminated. This is long enough to allow "adequate time for any defects to be identified and properly confirmed."³⁷ They continue: "The change in the law would do no more than allow parents to make, shortly after birth, the decision they are now legally entitled to make before birth: to end a life which has started out with difficulties so great that it is best that it not be

34. *Id.* at 74 (referring to the Johns Hopkins Case).

35. *Id.* at 81.

36. *Id.* at 85.

37. *Id.* at 194.

prolonged."³⁸ In effect, the authors are proposing to extend the time when an abortion can legally be performed to twenty-eight days after birth. However, when the public sentiment and recent Supreme Court decisions appear to be heading toward stricter abortion laws, a recommendation to liberalize the law would have difficulties.

IV. CONCLUSION

The authors explore what they perceive to be a very serious problem, that severely handicapped children impose an unacceptable emotional burden on their families and an unaffordable financial burden on society. Unfortunately, the authors' proposals, although well presented and academically interesting, cannot be practically implemented. They fail in that their proposal is based on an assumption that a severely handicapped person is not human and therefore has no right to live. Until they can absolutely determine when a life is human, their proposal is without merit. In addition, it must be recognized that a human life, even a severely handicapped life, can provide benefits above those which are measured only by financial values.

Reviewed by George Barbaresi

38. *Id.* at 196.