Eugenics

Free speech, democracy, and eugenics
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Attempts to stifle debate in medical ethics must be strongly resisted

On 30 September and 1 October this year a conference on “Ethics, Science and Moral Philosophy of Assisted Human Reproduction” was held at the Royal Society in London. The conference was organised by the German philosopher Edgar Dahl and the eminent embryologist Robert Edwards, and the speakers included scientists, IVF practitioners, and philosophers from the UK, the USA, Europe, and Australia (you can see the programme at http://www.humanreproethics.org/welcome.htm).

Because the programme included discussion of preimplantation genetic diagnosis and reproductive choice the conference was targeted by an anonymous group calling itself “People Against Freedom and Reproductive Choice” the discussion of preimplantation genetic diagnosis and reproductive choice. The judge held that Charlotte Wyatt should not be subjected to any further invasive or aggressive treatment to prolong her life, despite her parents’ insistence that she be given every chance to survive a little longer. The judgment was limited in scope. The judge did no more than authorise Charlotte’s doctors “in the event of a disagreement between the parents and themselves, not to send the child for artificial ventilation or similar aggressive treatment”.

The fate of baby Charlotte attracted massive media coverage. Just a week later another dispute between a mother and her child’s doctors hit the headlines. A third dispute about the care of an older child also looks likely to end up in court. However, Charlotte’s case is unusual only in that the case was heard in open court and because it attracted such publicity. For at least 23 years, the Family Division of the High Court in England has heard a series of cases when parents and professionals have
profoundly disagreed about how best to treat, or not to treat, a very sick baby. As happened in Charlotte’s case, the courts have usually, in the end, endorsed the professionals’ judgment about the best interests of the infant. The coincidence of three such high profile cases has prompted speculation that parents will now become more ready to ‘challenge professional judgment. The assumption that any of these cases is simplistically about the enduring influence of medical paternalism is as wrong as the claim that judicial involvement in decisions about the care of severely ill infants is novel.

**CHARLOTTE’S CASE**

Charlotte Wyatt was born at 26 weeks’ gestation weighing about 458 g. She has multiple medical problems. All the professionals caring for her acknowledge that she is severely brain damaged and highly unlikely to live for more than a few more months whatever is done for her. She does not respond to stimulation but she does experience pain and distress. Her parents do not dissent from this gloomy prognosis. Her doctors do not seek to withdraw existing treatment from the baby. The dispute revolves around whether if Charlotte stops breathing again she should be ventilated. Ventilation would cause her further pain and distress. Charlotte’s parents, who are devout Christians, pray for a miracle and firmly believe that Charlotte can respond to their love and that their child is not ready to die. The judge concluded that, in the light of the evidence that ventilation would not produce significant benefits to Charlotte and would add to her suffering, it was not in her best interests to request that doctors accede to her parents’ wishes and ventilate her should she stop breathing. He reached his decision about Charlotte’s interests primarily by concluding that, making all allowances for both the doctrine of sanctity of life and the human instinct to survive, Charlotte’s life might well be “intolerable”. Mr Justice Hedley emphasised that intolerability per se was not the legal test. The test is the best interests of the child to which intolerability is no more than a valuable guide. The facts of this particular tragic case have attracted general support for its outcome. I understand that the parents accepted the decision and have chosen not to appeal. The crucial evidence that the process of attempting to resuscitate Charlotte again would cause her pain for no commensurate benefit to her made it inevitable that the judge would endorse the professional judgment. He could scarcely order doctors to inflict unjustifiable suffering on the child in their care.

Other cases are more difficult. What of the infant who survives for parentally with no prospect of more than a few further months of a life of which she senses little but experiences no pain? What of the child who, if ventilated, may live another 10 years but live a life afflicted by major disabilities—perhaps blind, deaf, and unlikely ever to leave hospital? These are the cases which touch more closely on the thorny issue of quality of life. The decision in Charlotte Wyatt’s case will be of little assistance. The sad truth in Charlotte’s case was not whether she should be allowed to die but how and when she would die. English law operates on a presumption that parents are the best judges of their children’s interests. Parental love and care offers the best prospect of maximising the quality of life of a disabled child. Supporters of Charlotte Wyatt’s parents might well argue that, except in the clearest of cases, the parents’ view must prevail. Based on the facts of Charlotte’s case pro life groups would agree with them, but what of the reverse situation where doctors want to operate to prolong life and loving parents disagree? The courts have in the past overruled such decisions—for example, requiring that a baby born with Down’s syndrome be operated on to remove a potentially fatal intestinal obstruction. Parental choice is not unfettered. Sanctity of life is accorded different weight by different judges. With respect to Mr Justice Hedley, the prevailing factor knitting together most of the diverse judicial reasoning in these tragic cases is intolerability: is the treatment proposed likely to render the continued life of the child demonstrably awful?

**Medical skill now enables babies born at ever earlier stages of gestation to be kept alive**

Every time a court becomes involved in the fate of a sick child, a private grief is exacerbated by the trauma of court proceedings—however kindly the judge seeks to conduct the proceedings. As Mr Justice Hedley says, there has to be a means by which intractable disputes are resolved. The European Court of Human Rights has ruled that when doctors judge that a child should not continue to be treated and parents disagree, the hospital authorities must seek the intervention of the courts, except in genuine emergencies. Are there better ways to resolve such disputes and could fewer family tragedies end in the courtroom? Months before Charlotte Wyatt’s case went to court, I was invited by the Nuffield Council on Bioethics to chair a Working Party examining the ethics of prolonging life in severely disabled fetuses and the newborn. Medical skill now enables babies born at ever earlier stages of gestation to be kept alive. Sadly many such babies die and a significant number of others survive with serious disabilities. Some children flourish and many parents whose children do survive rejoice in their child’s life, regardless of its limitations.

Over the next 18 months, the Working Party will attempt to explore whether constructive guidance can be formulated to assist all those involved in making decisions about whether to treat, how to treat, and when to stop treating babies who are profoundly sick both before and after birth. The members of the Working Party—doctors, nurses, social scientists, philosophers and lawyers—begin their task with a range of different personal values and expertise. Two important members of our group come from organisations who work on a daily basis with families of very premature and disabled children. We intend to consult widely in the spring of 2005. We shall not shy away from controversy. Other European jurisdictions are moving to set rules to restrict the resuscitation of babies born before 25 weeks.

The economic implications of neonatal care cannot be ignored. There is little that can be done by way of guidance in a society that has such radically different opinions on the nature of life and the moral status of the fetus and infant. Each case is in a sense unique, yet not to try is to accept that more grieving parents and concerned professionals will resort, perforce, to the law courts.

**REFERENCES**

1 Re Wyatt [a child] (medical treatment: parents’ consent) [2004] EWHC 2247.
2 The Times, 14 October 2004.
4 See Re B [A Minor] [1991] 2 WLR 1421 CA.
5 One notable exception to this trend is to be found in the case of Re T [A Minor] (wardship: medical treatment) [1997] All ER 956 CA.