

## Other people's babies

### The ethics of life and death decisions concerning handicapped infants

ANN SHEARER — July 18<sup>th</sup>, 1984

Three years ago this month, a baby called Alexandra created legal history and gave our ethics a small collective nudge. But who thinks of her now and what difference did her case really make to the way we treat children born with severe disabilities?

Alexandra was born, you remember, with not just Down Syndrome but an intestinal block which would have killed her within a week if not operated on. Her parents refused permission; the local council had her made a ward of court; the surgeon nevertheless declined to operate when he heard the parents' views; the judge now refused consent in his turn; the appeal court decided that the operation should be done. So it was, and Alexandra was subsequently fostered.

The case was thought to be the first of its kind and the huge public comment about who should decide on the life or death of handicapped infants, and on what criteria, showed just how muddled we are. And when Dr Leonard Arthur was acquitted three months later of the attempted murder of an infant with Down's Syndrome, confusion seemed complete.

Both children were rejected by their parents: yet in the first case the parents' wishes were overruled in the best interest of the child, while in the second those wishes seemed to become a criterion by which it was lawful to offer a baby no further care than a sedating drug. Both children had Down's Syndrome: yet when the decision on their lives was made, it seemed that Alexandra, who lived, was more disabled than John Pearson, who died. Where do we go from here?

We've hardly been inundated with answers. Yet it's been estimated that one or two in every thousand live-born infants are 'allowed to die' every year in Britain each of them bringing individual anguishes perhaps the greater for society's apparent lack of concern. Who decided these deaths, and on what grounds? In a society grown used to seriousness measured by statistical significance would the matter more if there were more of them?

Doctors alone can hardly offer us the answers - and there are signs that they are no longer as willing as once they were to take the ethical burden from our collective shoulders by quietly deciding individual cases with individual parents. And what should we expect of them? Medical prognosis is neither individually sure nor static over time; American medical thinking is now, for instance, swinging away from the strict criteria of selection of infants born with spina bifida for surgery as improved medical technology offers a less handicapped future. And even paediatricians - as the English Court committee on child health underlined and the American Academy of Paediatrics has confirmed - can be terrifyingly ignorant and pessimistic about the social prospects for children born handicapped.

In the United States debate has at least joined on the issues. The effects have sometimes been ham-fisted and the results are far from settled; decent woolly liberals might wrinkle their noses at some of the hardline rightist moralists who have been prominent in promoting the debate. Yet in the search for ways not just to express but to enforce a collective view on the lives and deaths of handicapped infants, we are way behind them.

They have tried, for a start, to sort out the role of Government in this. The 'Baby Doe' regulations, first introduced by the Department of Health and Human Services in March 1983 to express President Reagan's personal concern that the civil rights of handicapped infants should be protected, were hardly the most subtle of instruments. In their original form, these laid down that any hospital receiving federal funds should post 'conspicuous notices' reminding that it is unlawful under the 1973 Rehabilitation Act to discriminate against people with disabilities and that this includes withholding sustenance or life-saving medical or surgical treatment; the notice included a 'hot line' to Washington that anyone who suspected a violation could phone for free.

The medical establishment was, of course, outraged at the thought of federal investigators barging in and harassing doctors and parents at a time of great grief. The judge who had the regulations withdrawn on a procedural technicality found them 'arbitrary and capricious' and unworkable as well.

But in the year that the regulations were debated, The United States seems to have found a way in which Government can share responsibility for what seems generally accepted to be 'society's decision'. The regulations are seen now as a procedure of last resort: State child protection agencies have been drawn in to create their own protective procedures and individual hospitals have set up their own clearly-defined ways of dealing with these appallingly difficult situations as well, through ethical review committees who share the decision,

If the United States seems a good deal further towards an answer to the question of who decides, the we are, it seems nearer, too, to defining the criteria for decision. Those hospital committees were recommended by the President's Commission for the Study of Ethical Problems in Medicine after two years of study of the principles that should govern decisions on foregoing life-sustaining treatment for anyone who is seen as at the margins of life. In a country where the Royal College seems to have no inclination at all to speak to the Law Commission and where neither nods to moral philosophy, the President's commission simply underlines our lack.

The Commission was clear that permanent handicaps justify a decision not to provide life-sustaining treatment except where they are so severe that continued existence would not be a net benefit to the infant. It doesn't pretend that 'net benefit' will always be easy to determine - though it does try to define those cases, as where a child would in any event die within days or weeks, where non-intervention is ethically justifiable. But what the Commission has done is to offer a clear view that a handicap like Down's Syndrome is no justification for failing to provide medically-proven treatment, and that no consideration of the possible effect of the child's living on other people should be allowed to influence whether it should.

The Commission was not alone in its view. At the end of last year, a Statement of Principles of Treatment of Disabled Infants took much the same line, It says a lot, perhaps, for the work that's been done in the United States in the past years that that statement was made jointly by not just major disability concerned organisations and pressure groups, but major medical ones as well. How long would it take our own to be so sure or so united?