

THE POLITICS OF HANDICAP

Recently there have been two widely publicised cases in which it was necessary to make a decision to treat or not treat a very handicapped child who had another acute medical problem. The debate has been presented in terms of morality and ethics: but it is in fact deeply political. It has a bearing not only on the treatment of the handicapped, but on campaigns about maternity care and abortion. The most important issue is the provision of services to prevent handicap, and the current debate obscures this. It is also clear that anti-abortion organisations like 'Life' and the Society for the Protection of Unborn Children (SPUC) are extending their activities into this area to further their attack on the 1967 Abortion Act.

The most recent case involved a child with Down syndrome (a 'mongol') who also had a malformed heart and whose parents did not want him to live. He was heavily sedated, fed on demand, and eventually died. 'Life' reported the paediatrician concerned to the

Director of Public Prosecutions. The number of children born with Down syndrome and rejected by their parents at birth is pretty small. A few more are born with severe spina bifida, where the choice is whether to operate, which means that the child may survive into young adult life paralysed and incontinent, or not to operate, when she will almost certainly die. Again the numbers are fairly small. Down syndrome and spina bifida are two of the most common handicapping conditions. They are also the two main conditions that can be detected long enough before birth to offer the pregnant woman an abortion. In many parts of the country all pregnant women are checked for spina bifida, and those most at risk, usually older women, for Down syndrome. Many foetuses are aborted because spina bifida or Down's has been detected. 'Life's' attitude is easily understood. Their efforts on behalf of these newborn children are an extension of their anti-abortion activities, as their spokespeople have occasionally admitted. If it is seen to be murder to deprive a multiply handicapped child of life at birth, how can it be moral to kill such a child twelve weeks earlier? It is easy to condemn this as a restriction of a woman's right to choose but, as all of us who have fought them on abortion campaigns know, 'Life' play skilfully on people's genuine fears: for

there are real problems here.

About 0.3-0.4% of children are severely mentally handicapped. Most of them, especially when they are young, live at home. As they get older more move to institutions which are still often very large, old and remote. Few of us know a subnormal person well — we are isolated from them and often afraid of them. People with all sorts of disabilities, both physical and mental, have written eloquently about the prejudice they face daily. The resources for the care of the handicapped remain scandalously scarce, as we discover each time another 'shock-horror-inmates-mistreated' story breaks from an under-financed, understaffed institution. There is a lack of interest in working with the mentally handicapped. Doctors, nurses and teachers of the severely subnormal tend to be despised by others in their profession. Cuts make a bad situation worse, and there is increasing reliance on the unpaid labour of women at home to do what is often an exhausting and dirty job.

In the face of such poverty and prejudice, how can parents or doctors make sensible decisions? The family, not the paediatrician, will have to carry the main burden either way, so the decision should in most cases be taken by the parents with access to the best possible medical and social information and advice. A further difficulty is that there is often no moment when a child's life is *clearly* in the balance and she is *clearly* irreversibly handicapped. Nor is there always time to consult the parents and weigh up the ethical problems. As a result of intensive care for sick newborn babies, many children survive in perfect health who would otherwise have died or been severely handicapped. Unfortunately some who would have died now survive with terrible handicaps. Nor can medical science always predict accurately for an individual child.

I have several times saved a baby and afterwards regretted it. The story usually went something like this: I was called at midnight to the delivery of a very small baby, perhaps only weighing a pound or so. No one was sure how long the woman had been pregnant. There were problems in labour. The baby emerged and did not breathe. I put a tube into her lungs and started her breathing. She continued to be very ill, unable to breathe unaided, in an incubator for many weeks. On numerous occasions she would suddenly become much worse and swift action would be needed to save her life. Eventually she would be big enough and well enough to go home. At three years old she would still be unable to sit up, reach out for toys, or speak. At what stage could parents or doctors have decided to write that

story differently?

The obvious solution to the problem overall, though it is no use in individual cases, must be to look at *why* children are born with handicaps. Before it was possible to detect them antenatally, Down syndrome accounted for a 5 and spina bifida for 5% of severely mentally handicapped children (IQ under 50). 20% had other inherited disorders and the rest had other less clearly identifiable problems — some related to birth trauma and others dating back much earlier. Because physical handicap and mild mental handicap are harder to define, it is difficult to be as precise about these groups. A smaller proportion will have genetic disease, a larger proportion will have spina bifida or brain-damage that occurred around the time of birth, and many of them will have been born very small, very prematurely, or both.

Research has repeatedly shown that birth weight is related to social class. Put crudely, the better off your parents are, the bigger you will be at birth, the better your chances of survival and the slighter your chances of handicap. The difference is probably largely due to nutrition — not just during pregnancy, but throughout life. Smoking is also common among working class women and is known to slow the growth of unborn babies. The job a woman does and the housing she lives in affect her health and that of her

children even before they are born.

If high-risk pregnancies are picked up early there is a chance of preventing handicap by financial and dietary support, special delivery techniques, and sometimes selective abortion. But a woman must be very keen on antenatal care to travel a long way, wait a long time, and then be treated as part of a production line. Working class women, especially the unskilled and unsupported mothers, usually get less and worse antenatal care than their middle class sisters. So while attempts to restrict a woman's right to choose must be resisted, we should recognise that lack of resources and the attitude of society to the handicapped also restrict her choice. If more handicapped people are enabled to live alongside the rest of us, attitudes will begin to change, but a proper community care service will be at least as expensive as institutional care. Antenatal care must be made available, accessible and acceptable to all pregnant women. Intensive care should be available to all sick infants whose parents want it, but it is a last resort. There should also be more research into the causes and prevention of handicap: we must recognise that a lot of handicap can be prevented by political measures that improve the living standards of working class women.

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