

of altered metabolism, for example, decreased excretion of 6-keto-PGF<sub>1α</sub>.

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## Ethical problems

1980 was designated the 'International year of the child' and 1981 the 'International year of disabled people'. Disabled children have therefore been the focus of much thought and constructive effort which, if the purpose of the international years has been properly comprehended, will continue. Yet an awkward ambivalence of attitude towards handicapped children persists, possibly more so within the medical profession than elsewhere. On the one hand we strive to provide better services for them and better support for their families; we set up handicap teams, day centres, fostering schemes and support groups, the net effect of which may be smaller than we care to admit.<sup>1</sup> On the other hand we pursue policies aimed at the elimination of handicapped children, overtly by programmes of prenatal diagnosis and abortion, covertly (still?) by accelerating inevitable deaths. The two philosophies are not necessarily in diametric opposition but they undoubtedly present a challenge to clear thinking.

A recent review<sup>2</sup> of the indications for, and consequences of, amniocentesis in south-east Scotland, and the impact of maternal serum alpha-fetoprotein (AFP) screening upon it, gives us useful data. About 5% of all mothers underwent this procedure, 37% because of maternal age (35 or older), 30% because of raised serum AFP, 10% because of previous neural tube defect (NTD), the rest for a variety of reasons. Altogether 2137 amniocenteses led to 104 terminations of pregnancy of which 75 were for NTD, 17

for chromosome abnormalities (including 11 with trisomy 21), and 5 for exomphalos. Of the 75 NTD cases, 29 had spina bifida, 42 anencephaly, 2 encephalocele, and 2 Meckel's syndrome. This report gives no information about the complications of the amniocenteses, and makes no reference to the anxiety generated by whatever number of blood tests gave rise to 637 abnormal results.<sup>3</sup> To these hidden costs must be added some of the 5 babies with exomphalos (all diagnosed because of raised serum AFP) who would have survived without disability. On the 'benefit' side we must calculate how many of the 29 with spina bifida would have been disabled long-term survivors, and we must consider for whose benefit those with abnormal karyotypes were aborted.

Facing the other way, the first hospice for terminally ill (not necessarily malformed) children is approaching completion in Oxford,<sup>4</sup> and a thoughtful pamphlet has recently been published by the Christian Medical Fellowship.<sup>5</sup> This includes articles by Richard Cook, a paediatric surgeon in Liverpool, and Jürgen Trogisch, a paediatrician working at a rehabilitation centre for severely mentally handicapped children in East Germany. Both have clearly given deep thought to the nature of the work they do and to the difficult decisions in which it involves them. Neither takes an extremist view of the problems he faces, which tends to confirm the instinctive feeling that those who see these matters in terms of absolute right and wrong need to do a lot more thinking.

Cook and Trogisch approach their subjects from the basis of their Christian

faith. Both emphasise the *caring* function of the doctor rather than the curing; neither sees death as something to be positively sought or negatively feared. They are concerned with the quality of the lives of their patients, and of their patients' families, but concentrate on their abilities rather than their disabilities.

It is fortuitous that the papers by Brock<sup>2</sup> and Bellman<sup>1</sup> and the Christian Medical Fellowship pamphlet<sup>5</sup> have appeared almost simultaneously. They all deserve reading, but will not resolve the dilemmas; when we are on the horns perhaps the operative word should be compassion.

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#### Additional reading

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