Editorial

In search of justice

Over the first three years of publication of this Journal the issue of justice in the provision of health care has been discussed regularly, though perhaps with less frequency than it merits. In an early issue Ivan Illich claimed that there was an 'expropriation of health' by the medical profession – a theme now fully elaborated in his recent books Limit to Medicine and The Disabling Professions. In our second volume Elizabeth Telfer, of the Department of Moral Philosophy in Glasgow University, explored the moral implications of different systems of health care provision ranging from 'laissez-faire' to 'pure socialist'. Telfer's survey of possible systems was subsequently questioned by Hillel Steiner of Manchester University. In our last issue (December 1977) a former Conservative Minister of Health, Enoch Powell MP, declared that the UN Declaration of Human Rights makes statements about health care which are 'both nonsensical and pernicious' – an opinion subjected to critical scrutiny by Robin Downie, Professor of Moral Philosophy at Glasgow University. Finally in the present issue (and in the preceding one) Raymond Plant has provided an exhaustive analysis of the late Richard Titmuss's celebrated attack on the market approach to medicine in his essay on blood donation, The Gift Relationship.

These articles, although very different in many respects, have all been concerned with two major themes: the safe-guarding of individual freedom and the achievement of a fair distribution of health care resources. Within the tension between these two moral values there lies the problem of justice in health care policy. Too great a stress on individual liberty leads quickly to a philosophy of 'weakest to the wall': too heavy an enforcement of health care standards leads, at best, to paternalism and, at worst, to the horror of 'final solutions'. Individual responsibility and initiative must be protected and fostered, but never at the cost of disregarding the vulnerability created by illness and social disadvantage.

The achievement of the required balance in moral values is much more than merely a challenge to the ingenuity of moral philosophers. The issues to be faced demand political solutions of one kind or another. In the USA commentators have been describing for many years a 'crisis in health care delivery', yet the enactment of legislation which will make any real difference to the maldistribution of medical manpower and resources seems to be as far away as ever. In Britain the debate about the effectiveness of the National Health Service, provoked by the recent financial crisis, is beginning to die down as public confidence in some kind of economic kingdom of heaven on earth is restored. Yet the health care problems in Britain, and in other nations, will not be solved by increasing prosperity. Indeed on both a national and an international scale all the evidence points in the opposite direction: economic expansion brings with it the twin problems of an ever widening gap between the living conditions of the advantaged and the disadvantaged, and, for those who profit from the prosperity, the penalty of the 'diseases of affluence'.

Thus, in adversity or prosperity, the moral issue for health care legislators remains the same: how is a society to cope with the recurrent problem of ill health in a way that enhances equally the life prospects of all its members? We believe that no quick answers should be offered to that question. There is no short cut through the maze of arguments by economists, political theorists, sociologists and philosophers about the design of social institutions. We see our task to be one of keeping all the questions open by continuing to publish articles, from a range of disciplines and viewpoints, on the political reality of justice in health care.

References

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Screening for Spina Bifida

The Health Departments in the United Kingdom are now considering the wisdom of performing tests on all pregnant women in order to forestall the birth of infants with open spina bifida by selective abortion.

Alpha-feto-protein is normally present in the bloodstream of the human fetus. In cases of open neural tube defect (open spina bifida, anencephaly) this protein is found in a higher-than-normal concentration in the amniotic fluid, and also in the
maternal blood. If a sample of maternal blood is tested between the 16th and 20th weeks of pregnancy, those mothers with high values can be offered amniocentesis, so that a specimen of amniotic fluid can also be tested. High levels of alpha-fetoprotein in the amniotic fluid are evidence of a fetal open neural tube defect in almost all cases. The patient can then be offered termination of pregnancy usually between the 18th and 20th weeks.

There are several practical difficulties in a screening programme of this kind. It is essential to know the exact stage of pregnancy at which the tests are taken: this may necessitate prior accurate sonar scanning, a facility which is not yet available everywhere. If the first maternal blood test gives a borderline result, the test may need to be repeated a few days later. Amniocentesis can only be performed with minimal risk if sonar screening is available. Even so, the procedure may precipitate abortion; it may lead to rhesus antibody formation; and it may result in clubfoot (talipes) in a few instances. Moreover, it has been pointed out that cases of anencephaly detected in this way would not have survived delivery. Cases of closed neural tube defect are not identified, nor do the tests give any indication whether an open spina bifida would be amenable to correction by surgery, or not. It is obvious that a screening programme which would achieve adequate national coverage would entail major expenditure to provide laboratory facilities, sonar equipment and skilled personnel. The costs, however, are estimated to be less than those currently incurred in the care of infants and children born with spina bifida.

The tests themselves, if skilfully performed, have a very small margin of error, which is probably acceptable, but the amniocentesis test is not without danger to the expectant mother and would have to be performed on a large number of patients with normal pregnancies, a few of whom would be adversely affected by the procedure. The use of such tests is quite pointless unless each patient is willing to undergo termination of pregnancy in the event of positive tests. Is it then desirable to confront each woman in early pregnancy with this painful choice, in obtaining her prior consent to the tests? Alternatively, is it ethical to proceed with testing without her consent, in the hope that the issue will not arise?

Apart from these obvious difficulties, the introduction of this type of screening may raise other less tangible problems. A society which routinely ‘screened out’ children with spina bifida might undergo a marked change in attitude to those children who slipped through the mesh either because of a mother’s decision not to consent to abortion or because of testing errors. In addition, since the sample of amniotic fluid can also be used to examine the infant’s chromosomes, Down’s syndrome (mongolism) and other less serious chromosomal anomalies would be identified. Inevitably the question of selective abortion would be raised in those instances also. The outcome might be increasing social intolerance toward any children with congenital abnormalities, even when these are relatively minor ones. Even if such a gloomy prediction is ill-founded, the social implications of mass screening programmes deserve much closer examination than they have so far received, before policy decisions are taken.