Introduction

The recent U.K. Government White Paper, *Our Inheritance, Our Future* (2003), is interestingly sub-titled ‘Realising the potential of genetics in the NHS’. The importance attributed to genetics and genetic services for the future of health and healthcare in the United Kingdom is restated by the Secretary of State for Health in his Foreword to the White Paper (2003, 5). Developing the potential of genetics and genetic services is the ‘vision’ (2003, 5) encapsulated in this document: ‘that the NHS should lead the world in taking maximum advantage of the application of the new genetic knowledge for the benefit of all patients’ (2003, 5). This commitment follows the Government’s allocation of £30 million in 2002, and is underlined by Dr Reid’s pledge in this document to invest a further £50 million in England ‘in developing genetics knowledge, skills and provision within the NHS.’ The air of enthusiasm that permeates the White Paper is, perhaps, unsurprising given both the assumption of benefit that genetics holds for healthcare, and the composition of the Advisory Panel, the majority of whom have a direct professional interest in genetics and genetic services.

Nevertheless, one cannot fail to recognise the excitement that has been generated by the so-called genetics revolution even amongst those with little experience in the field. Equally, of course, this revolution has generated considerable anxiety and concerns about its possible implications. While it may be the case that ‘[g]reater knowledge of genetics will have a major impact of our understanding of human illnesses and herald a step-change in disease prevention, diagnosis and treatment . . .’ (2003, 7), the White Paper also recognises that ‘there are difficult moral issues raised by genetics advances . . .’ (2003, 7). One of these issues revolves around the issue of screening of children, a matter raised in chapter 3 of the White Paper. Paragraphs 3.28–3.39 outline the
strategy for future screening programmes and propose specific antenatal and neonatal screening tests that are to be made available either immediately or in the near future.

**Screening programmes for genetic disorders**

At this point, the difference between screening and testing becomes important. The White Paper essentially covers both, without identifying or clarifying the issues which may arise from the distinctions between the two. The results of screening may be similar on occasion to those which flow from testing, but the intention behind each is different, as are some of the consequences. We feel that this situation should be clarified before we proceed to further analysis.

By and large, ante-natal genetic screening is population based, albeit carried out on a selected population – pregnant women. It is, in our view, designed to establish the occurrence of harmful genes within that population and has two main objectives. The first is purely demographic and this carries its own special socio-political problems with which we are not, here, concerned. The second is designed to control the ‘gene pool’ in the general population; as such, and despite the unfortunate connotations, it can be described as eugenic. Thus, the programme described in the White Paper, para. 3.31, bullet point 2, is undoubtedly a screening programme. By contrast, the post-natal programme described in para. 3.31, bullet point 1, is clearly designed to target individual neonates and is, accordingly, better considered as a testing programme. Similarly, say, the ‘screening’ programme for cystic fibrosis that is offered is actually an offer to ‘test’ all newborn babies for the relevant gene. This is more than a semantic quibble. It is apparent that screening programmes as defined here have negligible impact on those who are children at the time they are conducted. Genetic testing, however, as proposed in the White Paper, is aimed at children and strikes at the heart of children’s rights.

Additionally, the problems associated with the identification of disorders of any sort can be looked at in two ways. In the first, one can look at the practicalities and ethical principles that underlie screening programmes as a whole. Many of the arguments both for and against such measures as applied to genetic disease have already been well-rehearsed and we reconsider them below. Alternatively, one can isolate specific genetically controlled conditions and review the advantages and disadvantages of testing for them on an individual basis. This is the route we intend to travel initially, paying particular attention to the conditions selected for mention in the White Paper (2003, paras. 3.28–3.31); a consideration of these priorities may serve to disclose the Government’s general intentions.