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Our Inheritance, Our Future: Their Rights?

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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.¹ 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.

It is, however, to be noted that the proposals are not uniform, in that they involve both antenatal and neonatal testing – and, in some instances, for the same condition. This is of major practical and ethical importance.

Antenatal screening has, amongst others, the specific objective of ‘enabling more informed reproductive choice’ for women themselves (2003, para. 3.33) but, as the BMA notes:

Prenatal diagnosis and screening, whilst often seen as an unquestionable good, present parents with dilemmas which, with hindsight, they might prefer to have avoided. The availability of information requires decisions to be made. Once an unfavourable result to prenatal genetic testing has been provided, the woman must make a positive decision whether to act on the results; ‘leaving it to fate’ is no longer a neutral act. (BMA, 1998, 50).

Once having accepted screening, the choice is stark and, in many cases, lies between continuing and terminating the pregnancy – and the latter is undeniably performed on the basis of disability in the foetus.² An antenatal genetic screening programme can, thus, be seen as coming dangerously close to a eugenic programme – one in which the political parcel is passed to the patient, and one which, once again, moves the intervention closer to a testing rather than a screening exercise, the anticipated outcome of which is also likely to be the termination of an affected pregnancy. Indeed, as Whittaker has said (1992, 296):

[w]ith the availability of genetic tests, bringing an affected child into the world could be construed by some as reproductive irresponsibility.

Neonatal testing, by contrast, is directed to the detection of established genetic abnormality and, hence, to forewarning of possible clinically evident genetic disease. As such, it is a process that is imposed on a non-consenting subject and, given the current emphasis on personal autonomy as the mainstay of ethical medical practice, this can be done only if it is in the subject’s best interests. These interests will, of course, vary according to the individual under consideration. It follows that any specific test used as a screening procedure must conform to analysis based on this principle.³ As we will consider later, it is by no means certain that all genetic testing of the newborn will be to the advantage of the developing child or of the adolescent or adult that he or she may become⁴ – and this caveat is not confined to the identification of potential late-onset disease.⁵

Looking further forward, however, we find that the Government’s intentions are rather more ambitious in that, in addition to spelling out its immediate policy, it floats the ‘long term’ possibility that genetic profiling at birth may be used to create ‘a comprehensive map of children’s ‘key genetic markers or, even, their entire genome’ (2003, para. 3.36, pp. 44–45). This, it is postulated,

could 'be used throughout their lifetime to tailor prevention and treatment regimes to their needs as further knowledge becomes available about how our genes affect our risk of disease and our response to medicines' (2003, para. 3.36).

Certainly, the authors of the White Paper appreciate the concerns likely to be raised by such a programme and the text specifically states that it would be subject to 'voluntary participation' (2003, para. 3.37) – but this is impossible from the point of view of the child who is being profiled. We address this problem in detail in the next section. For the present, we do no more than re-emphasise that a profile is but the sum of its parts and, like it or not, the information obtained from the individual tests is there for the rest of the child's life, yet s/he has had no voice in how, why, whether or when it is obtained.

In summary, the ethical repercussions of genetic screening and testing are such that generalisations are seldom helpful and it becomes essential to consider individually the influence that each inquiry that is recommended within the Government's programme exerts on children's rights. We will do this initially with specific reference to those enumerated in the White Paper.

The tests proposed

Down's Syndrome

The Paper commits the Government to ensuring that all women are offered ante-natal screening for Down's Syndrome. Given that a high proportion of pregnancies in the UK are already screened for this condition, it is unlikely that this recommendation (or the counselling to be associated with it) will generate much controversy. It must, however, be borne in mind that there are some for whom such screening is objectionable in so far as it offers termination of an affected pregnancy as a main option.

Looked at from a rather different aspect, the inclusion of universal screening for foetal Down's Syndrome for all pregnant women as a flagship intention demonstrates what is, to us, a general element of inconsistency in this sector of the White Paper's proposals. It falls outside the general tenor of the debate in that, save in the rare event of it being due to a translocation trisomy, the recurrence risk is related almost entirely to maternal age. For practical purposes, the community 'gene pool' is unaffected by the birth of a Down's baby and no treatment is available for the child itself.

The proposal is suspect on many other grounds⁶ but perhaps the most important parameter lies in the 'best interests' of the foetus. Using current testing methods, there is no way in which one can assess the *extent* of foetal disability and a Down's child who has no physical defects is probably perfectly happy.

No matter how skilful is the counselling offered, the pregnant woman is, perforce, making a blinkered decision. The choice is, however, of the all-or-nothing variety; a positive test can be ignored or it can be regarded as an invitation to prevent the emergence of a disabled child. Down's syndrome raises, with particular clarity, the persistent dilemma – is a termination of pregnancy morally right because it is legally permitted?

Congenital deafness

It is expected that all babies born after 2005 will be tested for hearing defects (2003, para. 3.29). The incidence of childhood hearing defect is about 1:10,000 live births (or 900 cases in the United Kingdom each year) of which some 50% are genetic in origin; testing for the gene mainly responsible is said to be economically feasible despite the small numbers affected.⁷ It is difficult to imagine that any parent would object to screening for a condition in which early recognition is of major importance to the child. It is, however, to be noted that the test offered is purely physical and is not specifically directed to genetic disease. It is not easy to see why this, otherwise admirable, project should form so prominent a part in a 'genetic revolution'.

Cystic fibrosis

Cystic fibrosis is the commonest autosomal recessive disorder in Caucasian Europeans amongst whom the established disease occurs in about 1:2000 live births. The White Paper states that work is in hand to offer cystic fibrosis screening to all newborn babies but, again, we have to question the purpose behind this proposal. The ethical difficulties are two-fold. First, the gene can express itself as anything from a mild condition to one that is rapidly fatal and, second, the treatment is symptomatic and is largely confined to antibiotic therapy as and when infection arises. This is a condition where it seems that the *only* result of a positive neonatal test in the absence of an indication for testing is that the parents can be told that their child is likely to be unwell. It, then, illustrates *par excellence* the dilemma that is inherent in post-natal screening – if feticide was a legal option were the test available in utero, why is neonaticide not available when a post-natal test leaves us in the same position? One wonders what is the purpose of the test since that option is intolerable? Indeed, in 1997, a workshop held in the US concluded that '... before recommending universal CF screening for newborns as a routine public health intervention, policymakers will need more compelling data about its effectiveness' (1997, 16).

The thalassaemias and sickle cell disease

Screening programmes for sickle cell disease and thalassaemia are being developed (2003, para. 3.31). The recommendations are that, by the end of 2004:

- A newborn screening programme will be in place offering screening for sickle cell disease. This will cover around 320,000 births per year and pick up around 90% of affected infants
- An antenatal screening programme for sickle cell and thalassaemia will be in place aiming to offer screening to around 200,000 pregnant women a year, initially targeting areas of high prevalence for these diseases (2003, para. 3.31).

To speak of ‘a’ test for either thalassaemia or sickle cell disease is, of course, to over-simplify the problem – there are variations on each condition, they can be mixed and, to an extent, the severity of the disease is also variable. Again, treatment is not of the disease but, rather, of the resulting anaemia – i.e. by way of blood transfusion and management of any consequent iron overload. As a consequence, the haemoglobinopathies particularly demonstrate the economic paradox – the better the socio-economic conditions, the greater the economic strain imposed on society by long-term incurable disease. The natural distribution of the responsible mutant genes corresponds to a great extent with areas of economic hardship; as a consequence, something of an ecological balance has evolved. Improving the health care of the affected population – and, particularly of the infant population – disturbs this balance and can significantly increase the resource related problems of the responsible health service. As a consequence, some countries have introduced essentially eugenic policies such as pre-marital testing – and the effect, which rests on acceptance, seems to depend, in turn, very much on how the programme is presented (Mueller and Young, 1995, ch. 22). As a consequence, this aspect of the Government’s proposals, which are essentially demographic and directed to health care planning, merit particular consideration.

The ethnic distribution of the haemoglobinopathies is complex, but the base-line fact is that they are very uncommon in northern Europeans. Both α - and β -thalassaemias are most common in Asian communities though the latter, in particular, are very prevalent in the Mediterranean.⁸ Sickle cell disease is very largely associated with Africa and, consequently, the Caribbean, but it also occurs endemically in Arabic countries and in India and Pakistan. It follows that, before any screening for these conditions is acceptable, it must be shown to be non-discriminatory in its effect.

It must, also, be economically justified. The overall figures for occurrence

in England have been stated to be 28–60 conceptions and 17 births of thalassaemics each year and 133–238 conceptions and 160 births with sickle cell disease but, clearly, these will not be distributed uniformly (Streetley, 2000.) The White Paper expresses an initial intention to target areas of high prevalence for these diseases but the mode of selection is not made clear. In a way, selectivity of this type raises its own problem – what is the purpose of testing for the incidence of a condition if the areas of high prevalence are already known? It has been suggested that universal testing of neonates will be more cost-effective than selective screening if there are more than 5 cases of sickle cell disease or 15 sickle cell traits per 10,000 births, (Streetley, 2000) but this begs the question both as to the meaning of cost – is it the cost of testing or the cost of treating? – and of effective – what effect is sought? Is it the provision of better treatment facilities or is it the limitation of cases to treat?

In this respect, it is to be noted that the Government's proposals are in two parts – there is to be a neonatal screening, or testing, programme running in parallel with an antenatal programme involving pregnant women, primarily, as has been noted, in areas of 'high prevalence'. Clearly, these have different objectives. The latter can be described as a form of societal genetic engineering based on elective termination of pregnancy. The purpose behind the former is more difficult to identify. In common with many genetically controlled diseases, treatment of the haemoglobinopathies is symptomatic and does not have to be introduced early unless there is an already clear clinical indication; and, again, the genetic karyotype does not necessarily predict the severity of the disease. Many would question the value of 'picking up' 90% of affected infants – there is no certainty that improved medical surveillance will not have to be balanced against later, subtle forms of discrimination.⁹ And the shadow of racial discrimination, whether actual or perceived, overlies every aspect of this particular aspect of public health (Anionwu and Atkin, 2001).

It is, thus, apparent, first, that few of the individual proposals satisfy our criteria for acceptable genetic screening or testing and, second, that we find it difficult to discern a coherent policy behind them. We address this latter problem in the next section.

Genetic Screening – The General Part

The controversy that surrounds both genetic screening and genetic testing of neonates and children is only part of the wider debate that is concerned with issues around discrimination, privacy and consent. As we have already intimated above, many concerns relate to the possibility of discrimination which might follow from knowledge of a person's genetic status. The possible effects

of this are vast and include not only adverse reaction in the public domain, such as employment and insurance, but also wide-ranging *personal* impacts on those found to have specific genetic conditions. As Robinson put it (1994, 726):

Although knowledge about genes offers benefits, these must be balanced against possible harms, like stigmatization, anxiety due to ignorance or knowledge of genetic status, and discrimination.

Considerable attention has been paid to discrimination in the academic and other literature. Wolf has suggested, however, that much of this debate is conducted in terms that are too narrow to be useful. The rubric of 'genetic discrimination', she says:

. . . ignores years of commentary on race and gender demonstrating the limits of antidiscrimination analysis as an analytical framework and corrective tool. Too much discussion of genetic disadvantage proceeds as if scholars of race and gender had not spent decades critiquing and developing antidiscrimination theory. (Wolf, 1995, 345)

She concludes that the real concern in this area lies in an ' . . . eagerness to draw genetic conclusions, the search for supposedly deviant genes, and the conviction that such genes actually deserve disadvantage . . .' (1995, 347). She believes that we would better understand what is actually happening when genetic knowledge is wielded against individuals or groups if we were to acknowledge the concept of 'geneticism', which connotes 'an offensive and harmful practice, which remains harmful even when based on accurate rather than exaggerated understanding of the role of genes.' (1995, 350)

Wolf's critique has been considered by Hellman, (2003, 77) who proposed that:

Whether genetic discrimination wrongfully discriminates depends on whether such discrimination expresses that people with serious genetic conditions are less worthy of concern or respect. (2003, 113)

Whatever their disagreements as to terminology and effect, Wolf and Hellman, along with the majority of commentators in this area, do not dispute the very real possibility that discrimination, however conceptualised, will flow from the availability of genetic information.¹⁰ The Government's proposals to expand the screening/testing agenda must take serious account of the non-scientific, non-medical implications of so doing. Additionally, as has already been mentioned, the personal impact of discovering and/or holding genetic information on a particular individual or group of individuals should be taken into account. The Danish Council of Ethics, for example, pointed out that:

Just as persons found through screening to have a particular gene or chromosome composition may happen to feel abnormal or outright ill. . . so may others react to the persons involved by giving them a wide berth. The detection of certain

genetic traits can thus form the basis for branding certain persons and groups among the population with the possibility of discrimination proper as a result. (1993, 60).

Several authoritative organisations have commented on the problems associated with enthusiasm for the search for genetic information which underpins the White Paper's proposals, and have stressed the need for a careful approach. Thus, we have the Royal College of Physicians saying:

The problems of gathering genetic information seem to fall into two main areas. The first of these concerns the problem of whether a particular investigation should be undertaken at all. The second concerns the obstacles that may be encountered once a decision to investigate has been made. (1991, para. 3.1)

The Declaration of Inuyama cautions that:

The central objective of genetic screening and diagnosis should always be to safeguard the welfare of the person tested: test results must always be protected against uncontested disclosure, confidentiality must be ensured at all costs, and adequate counselling must be provided.¹¹

and the European Convention on Human Rights and Biomedicine states that genetic tests which identify a genetic predisposition or carrier status may only be performed for the purposes of health or scientific research and require appropriate counselling.¹²

It is clear, therefore, that safeguards – such as the need for counselling and potential restrictions on the kinds of testing which are appropriate – are essential even when testing is proposed for those who are adult and, therefore, able to consent; this being in recognition of the fact that taking a genetic test is different from other medical interventions, not least in terms of its non-clinical consequences. Young children, however, and especially neonates, will be unable both to participate in counselling and, as has already been emphasised, to agree to or refuse screening or testing. Given that the welfare of the child is generally the paramount principle when decisions are made on their behalf, and given that there are *prima facie* reasons for believing that there are potentially negative consequences from obtaining genetic knowledge of them, it is no wonder that there is an even more profound debate in this particular area.

Genetic Testing of Children

We have observed already that there is generally a distinction to be drawn between screening and testing, the former being population-based and the latter being directed towards the individual. At this stage, we turn our attention to genetic testing of children with particular reference to its relationship with children's rights.

In 1994, the Clinical Genetics Society issued a report entitled *The Genetic Testing of Children*.¹³ This divided testing into three main categories – genetic testing for childhood onset conditions, testing for adult onset conditions and testing for carrier status. Their conclusions on each differ, as might be expected given the kind of information being sought and its implications. In respect of testing for childhood onset conditions, the report recommended (as Recommendation 1):

The predictive genetic testing of children is clearly appropriate where the onset of the conditions regularly occurs in childhood or there are useful medical interventions that can be offered (e.g. diet, medication, surveillance for complications).

However, the Society believed that there were sound reasons for not performing such tests in relation to adult- or late-onset conditions. The report said, in recommendation 2:

. . . the working party believes that predictive testing for adult-onset disorder should generally not be undertaken if the child is healthy and there are no medical interventions established as useful that can be offered in the event of a positive test result. . . formal genetic testing should generally wait until the “children” request such tests for themselves, as autonomous adults. This respect for autonomy and confidentiality would entail the deferral of testing until the individual is either adult, or is able to appreciate not only the genetic facts of the matter but also the emotional and social consequences of the various possible test results.

As to carrier status, the Society recommended (see Recommendation 4):

The situation with regard to testing children for their carrier status for recessive disorders and balanced, familial chromosomal rearrangements is more complex. In general, the working party would make a presumption against testing children to determine their carrier status, where this would be of purely reproductive significance to the child in the future.

In response, the Genetics Interest Group argues that:

The report is overly preoccupied with psychological considerations, and the harm that knowledge of genetic disorders can cause within families. With little evidence, this seems to reflect more the fears of doctors that they will be held responsible for negative reactions, rather than the needs of families . . . Whilst we totally uphold the principle that families need counselling and support, we also believe that they should be given credit for being responsible and having coping capacities.¹⁴

These two reports highlight the tensions in this debate admirably. On the one hand, there are those who fear the detrimental potential of genetic information, particularly its emotional impact and most particularly where the knowledge is therapeutically valueless.¹⁵ Similar objections arise when obtaining information can justifiably be delayed until the individual concerned can consent or refuse testing on his or her own behalf. On the other hand, there are those who

urge the possible benefit of genetic knowledge to the family – and, arguably, through them, to the child. Indeed, the Genetics Interest Group claimed that:

. . . parents are responsible for the welfare of their children and at the end of the day most of them are better equipped to decide what is in the best interests of a particular child, and the family as a whole, than are outsiders.¹⁶

This may be so, and it is certainly a tenable proposition, but it could also be seen to miss the fundamental point. Most specifically, it seems to place the interests of the family above those of the individual child. It may well be true that families can both absorb and sensibly use information about the genetic status of a particular child. But it is also true that children have rights, the exercise of which should not be pre-empted precipitately. Certainly, the Genetics Interest Group appears to concede this in respect of testing for adult onset conditions (see para. 2.3):

The argument that testing of the child takes away their right to make an informed decision as an adult overrides all other considerations. The low uptake in testing for Huntington's disease shows that many people would prefer not to know that they will be affected at some time in the future.

Like many commentators, Ross (2002) agrees that a distinction must be drawn between testing for childhood and adult onset conditions, even while conceding that *any* testing may raise 'concerns regarding the psychosocial implication of being an individual "at risk"' (2002, 226).

It might, therefore, be anticipated that genetic tests could be neatly divided into two groups from the perspective of children's rights. Those which provide information which is therapeutically valid, and the discovery of which at an early stage is, therefore, beneficial, can be seen as being no different from other clinical diagnostic procedures. By contrast, those which threaten the child's well-being – whether hypothetically or in reality – seem clearly to be disadvantageous, potentially rights-reducing and, correspondingly, impermissible.

But even such an apparently simple assertion of the shape of children's rights is not universally approved. Robertson and Savulescu (2001), for example, debate the issue in different terms. First, in respect of predictive testing, they identify three arguments which might be used against such testing. Broadly, these involve:

- Failure to respect future autonomy
- Breach of confidentiality
- Harm to the child

In respect of the first, they suggest that it is incorrect to assume that childhood testing necessarily reduces future choice. Rather, they argue (2001, 39):

The child who is not tested is denied an option of growing up and adapting to the knowledge of their genetic status during their formative years. Thus the choice is not between two courses of action, one of which simply has more choice for the later adult, but between two mutually exclusive futures . . .

It is unclear why a future that includes knowledge of information which may have been rejected had the choice been available is the preferable option. They also maintain that the confidentiality issue is relatively insignificant, since families are already routinely in possession of sensitive information about other family members.

Finally, on the question of harm, the authors conclude that there is a paucity of evidence suggesting that children are indeed harmed by predictive testing. Evidence on the point is, however, as yet equivocal, and merely to state that harm might not accrue is insufficient justification for running the risk that it *may*. Certainly, there is some evidence (albeit anecdotal) that people fear the collection of genetic information and the uses to which it may be put. For example, in a poll conducted for *Time* magazine in 1994, those interviewed were equally divided on whether or not they would want to be tested to discover what conditions they may suffer from in the future. The British Medical Association also notes (at 103) that:

Raised levels of anxiety, usually transient, have been reported in all forms of screening programmes including cervical, breast, cancer, and general health screening as well as genetic screening. For some people, simply receiving an invitation to participate in screening causes anxiety and some people have been found to be more anxious after screening than before regardless of the result.

Given such ambivalence, we wonder if what evidence there is of perceived harm to adults should be extrapolated to children. Moreover, it must be asked whether the risk of harm should be discounted when any alleged benefits for children are suspect, even if some benefits may accrue to the rest of the family. Moreover, the child's situation is complicated by the additional dilemmas surrounding secondary disclosure. The subject's parents will have agonised over the decision to allow their child to be tested. In time, however, they will have to decide whether to pass on the information they have to their adolescent or adult offspring and, in the nature of things, this decision must be taken irrespective of the wishes of the person most concerned. Thus, not only is the pseudo-autonomy of the neonate invaded but so also is the actual autonomy of the mature minor; at the same time, the chance of harm arises twice following neonatal testing but only once in the case of an adult.

This takes on added significance when one raises the further issue of privacy. Although in the United Kingdom this concept has generally been subsumed by the notion of confidentiality, the Human Rights Act 1998 firmly introduces the concept of private family life into the UK's domestic arena.¹⁷ Although this

right could be interpreted as providing support for the concept of family rather than individual autonomy or privacy interests, the only evidence to support such an interpretation stems, indirectly, from a case in the Republic of Ireland¹⁸ where the family is protected by the Irish Constitution as the ‘natural, primary and fundamental unit group in society’.¹⁹ Here, the Supreme Court of Ireland upheld the rights of the parents to refuse, for no obvious reason, a heel-prick test on a child for the PKU gene. The decision was, however, based on Irish constitutional law and the European Convention was not considered.²⁰

Gostin, writing from the US – a country in which privacy rights are much better developed – has noted the capacity of modern technology to establish a ‘comprehensive genetic information system’.²¹ Indeed, this is precisely what is apparently envisaged by the UK Government in mooted the possibility of genetic profiling. Para 3.36 of the White Paper refers, with little or no reservation, to the possibility of producing a comprehensive map of children’s key genetic markers ‘or even their entire genome’. While no-one could doubt the entirely admirable intention to apply this to ‘lifetime prevention and treatment regimes’, one is, at the same time, reminded of the furore that surrounded the suggestion that identity cards should be introduced. As Gostin somewhat forbiddingly expressed it:

While this technology can markedly facilitate research, screening, and treatment of genetic conditions, it may also permit a significant reduction in privacy through its capacity to store and decipher unimaginable quantities of highly sensitive data. (Gostin, 1995)

Yet such sophisticated systems would need to be at the heart of genetic profiling – otherwise, the expressed aims of the project could not be met. Threats to privacy may outweigh the potential benefits of genetic profiling or testing, particularly in the very young, because no system of storage or manipulation of electronic or other data is failsafe.

Moreover, due to its indiscriminate nature, not everything that appears on a profile may be there for the subject’s benefit. It is easy, indeed ‘trendy’, to decry the slippery slope and its warning notices. The fact remains, however, that, if a test can be done, it will be done and there is no certainty that the risk/benefit analysis of each new advance will be the same simply because each is classified under the hallowed rubric of a ‘genetic test’.²²

Finally, we must revert to the question of consent. It is axiomatic that neonates cannot offer a decision on whether or not to accept genetic testing. This, as we have suggested, is less of a problem when the test has a predictable and effective therapy. Parents (or other legal guardians) are permitted by law to make decisions regarding the medical care of their children, both at common law and under statute. However, the right to provide a consent in these circumstances is bounded by the need for the decision to be in the child’s best

interests. This is a notoriously slippery test, and in the case of neonates has been used in ways which on occasion seem to be mutually contradictory – one is, for example, particularly reminded in the present context of the notorious case of *R v. Arthur*,²³ in which the parents of an apparently otherwise healthy Down's syndrome child simply did not wish him to survive and also of the numerous Jehovah's Witness cases where parents have imposed their religious views on sick children for what they believed to be their own good.

It is, in fact, clear that some parental decisions may – as in the Irish case referred to above – be less than self-evidently in the best interests of the child, unless these interests are seen as being served by reference to the interests of the parents and/or other family members. The arguments of the Genetics Interest Group imply that the interests of the family are intimately linked with those of the child, and this may well be so in some cases. However, given the nature of genetic information and the uses to which it may be put, it is not obvious that the discovery of information about one child can be justified on the basis of its benefits to other family members. This problem might be resolved were genetic information to become value-neutral, but there are few – if any – who would realistically envisage this scenario actually occurring. Health information as a whole is seldom value-free; it is even less likely to be so regarded within the complex and predictive field of genetic testing.

Conclusion

As we have suggested, the proposals in the White Paper can be subjected to critique from three distinct perspectives. The first challenges the basis on which the specific additional testing can be justified. The second demands a more in depth consideration of the merits of testing as a whole. The third relates to the implications of screening for genetic disease, perhaps particularly at the pre-natal stage. Moreover, the importance of the protection of the human rights of the young and vulnerable must not be underestimated. Many genetic predictions are suspect even from the scientific viewpoint. Hubbard and Wald, for example, have cautioned that:

Genetic predictions, whether they involve testing or screening, are based on the assumption that there is a relatively straightforward relationship between genes and traits. However, genetic conditions involve a largely unpredictable interplay of many factors and processes.²⁴

If so, then there are additional reasons why we should question the foundations on which the presumption of benefit to be derived from some kinds of post-natal genetic testing – and, perhaps, specifically genetic profiling – are based. Early detection of disease is generally regarded as a 'good thing', but this is

usually only so when successful therapy or the alleviation of symptoms is real possibility. We have already suggested that – even in the cases specifically proposed in the White Paper – this is by no means certain. The negative consequences of obtaining the information may far outweigh any benefits achieved.

Secondly, we have expressed concern as to the link between neonatal and ante-natal screening and testing. While the former may have at its root the treatment of predicted conditions, the latter seems more likely to have – at least in the current clinical climate – the aim of terminating affected pregnancies. This may or may not be objectionable; there is no intention to debate this in this paper, but it must be transparently and openly addressed in the public domain. Simply presenting genetic inquiries as just another part of medicine's capacities is insufficient in these circumstances, and women (and their partners) must be adequately informed of the possible outcomes of routine pregnancy screening in a way that, to date, we argue, they have not been.²⁵

We believe also that the proposals in the White Paper should be scrutinised carefully from the point of view of the general impression they give. It is imperative that they should not be interpreted as an encouragement to selective elimination of the disabled; but this remains a real possibility in the absence of explanation and debate.

Nor is neonatal testing for the specified conditions an unequivocally 'good' process. Not only does there appear to be some confusion surrounding the rationale for selection of these conditions, there are also some reasons to believe that subtle discriminatory consequences may follow.

It must, therefore, be conceded that neither screening nor testing are 'simply a neutral technique and a private issue; [they have] significant social consequences.'²⁶ Moreover, as the British Medical Association (1998, 101) has pointed out, the technical ability to screen is not sufficient justification for doing so.

Thirdly, although screening of pregnancies is widely accepted in the United Kingdom and elsewhere, the White Paper's endorsement of it – with no apparent justification – arguably side-steps an important opportunity to re-evaluate its underpinning rationale and bring it firmly into the public arena. Although the subjects of such testing (the embryo or foetus) do not hold legal rights, it is generally conceded that they are worthy of respect. The question must be asked, and answered, as to whether or not this respect is adequately satisfied by a steady growth of screening designed in large part, we would argue, to prevent live birth.

Our main concern, however, focuses on the rights of children – rights to which the mere fact of birth entitles them. These rights are not confined to the right to therapy; they also relate to the child's role in his/her family and community. Despite Robertson and Savulescu's conclusions, there is reason for

concern about the possible effects on children's rights of intrusive, non-therapeutic interventions, which, for example, would become reality were genetic profiling at birth to become routine. Whatever else it may be, it cannot be voluntary, and this – coupled with the legitimate and plausible fears of discrimination – is a significant reason for caution.

Our inheritance and *our* future may well be intimately and irrevocably linked to the so-called genetics revolution, but for future generations, *their* rights should not be compromised by our technological capacities or our interests in scientific inquiry. Commitment to intergenerational justice²⁷ requires that we do not compromise the rights of future children, and – as we have argued – these rights are wider than the purely medical. Sadly, the assumptions behind the White Paper's recommendations seem to be deeply in the thrall of scientific 'progress', and are less than adequately concerned with the consequential issue of children's rights.

Notes

¹ That is, of course, provided foetuses are not included among children.

² Abortion Act 1967, s.1(1)(d).

³ It is significant that the two tests which are *currently* offered to a neonate – for PKU and hypothyroidism (which is only rarely a genetically controlled disease) – are for conditions that can be *treated* (using the word in a broad sense) and which, moreover, must be treated early. Thus, there can be no question as to the best interests of the child and the tests have been accepted without demur.

⁴ (2003) Para. 3.35 raises this problem in particular relation to multifactorial genetic disease.

⁵ For a good analysis of the already extensive American experience, see D.E. Hoffmann and E.A. Wulfsberg (1995).

⁶ The overall incidence of Down's syndrome at birth is of the order 1/650 to 1/700 with a well-known association with maternal age – the incidence is some 1/30 by the age of 45. We are not here concerned with the economics of universal testing.

⁷ Deafness and Genetics Forum UK, <<http://www.deafgene.info/testing.htm>> (accessed on 30/06/04). It is to be noted that ante-natal testing for genetic deafness is not currently undertaken.

⁸ In practice, α -thalassaemia is a relatively uncommon problem in the population as a whole because it causes death in utero or in early infancy in the homozygous state and is surprisingly asymptomatic in the heterozygote.

⁹ For a useful overview, see G.T. Laurie (1999(a)).

¹⁰ Although not everyone would agree; Maddox, for example, says 'The reality of the use of a detailed knowledge of the human genome in discrimination between people is . . . almost certainly more distant than the fear.'

¹¹ Declaration of Inuyama (Council for International Organizations of Medical Sciences, 17–22 July 1990) *Human Genome Mapping, Genetic Screening and Gene Therapy*, Article IV.

¹² European Convention on Human Rights and Biomedicine (Council of Europe Convention for the Protection of Human Rights and Dignity of the Human being with

regard to the Application of Biology and Medicine) 164, European Treaty Series, Oviedo, 1997, Article 12.

¹³ A summary of its recommendations can be obtained at <<http://www.bshg.org.uk>> (accessed on 27/06/04).

¹⁴ Response to the Clinical Genetics Society Report "The Genetic Testing of Children" (1995), available at <http://www.gig.org.uk/docs/gig_testingchildren.pdf> (accessed 27/06/04).

¹⁵ This aspect of the debate is well argued by G.T. Laurie (1999)(6).

¹⁶ N. 14 above, para. 2.1, p. 4.

¹⁷ See European Convention on Human Rights Article 8.

¹⁸ *North Western Health Board v W(H)* [2001] IESC 70.

¹⁹ Constitution of the Republic of Ireland, Articles 41 and 42. This case is analysed in depth by G. Laurie (2002).

²⁰ Laurie suggests that Article 8 would not be applied in such a case due to the derogation permitted under Article 8(2) 'for the protection of the rights and freedoms of others' (2002, 138).

²¹ L.O. Gostin (1995, 324).

²² For the importance of a selective approach, see A. Barnicoat (1997).

²³ (1981) 12 BMLR 1.

²⁴ R. Hubbard and E. Wald (1993, 36).

²⁵ P. J. Edwards and D.M.B. Hall (1992).

²⁶ J. Black (1998, 45).

²⁷ Declaration on the Responsibilities of the Present Generation Toward Future Generations, UNESCO, Paris 1997. Article 1 of this Declaration reads as follows: 'The present generations have the responsibility of ensuring that the needs and interests of future generations are fully safeguarded'.

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