

**Text prepared for the German Bundestag  
Study Commission on the Law and Ethics of Modern Medicine  
Consequences of Modern Genetic Diagnostics**

---

**Building Genethics from below.**

Professor Hilary Rose, Visiting Research Professor in Sociology , City University and joint Professor of Physic Gresham College , London.

In this paper I am going to focus on genetic testing and its association with reproduction. In the past genetics – or what was then genetics – primarily focussed on what women are ‘fit’ to mother, today the focus is on what embryos are ‘fit’ to survive. In this paper this shift of focus is spoken of as the move from state to consumer eugenics. This means that I leave for others those important issues of genetic testing for both employment and insurance. None the less, given the increasing marketisation of welfare and the move to the flexible and less protected labour market currently taking place within Europe, I would want to add that it seems to me imperative that Europeans look at the best of the now 14 plus US state attempts to regulate testing so as to prevent the development of a “genetic underclass” in a hyper- marketised context. These state, but alas not federal, policy makers have been quick to move to anticipate the risk that genetic tests would add even more people to the current 42.5 million Americans without medical insurance. But it is as a feminist sociologist that I want to pull into visibility the historical changes and continuities between who gets to decide, using what kinds of discourse, who or what is ‘fit’. For those who want to reconcile the claims of women’s reproductive freedom with the promises and risks offered by the new genetics there are few simple solutions.

This new fusion between genetic testing and the new reproductive technologies forms one of the most powerful site of moral anxiety about the limits to

biomedical intervention, it deeply affects our cultural ideas about who we are. Thus the new DNA testing has radically changed the nature of risk assessment for severe inherited disease but has also opened up a Pandora's box in terms of fears and enthusiasms for "designer babies". With the advent, (birth is too simple a word to write) of Dolly the sheep, Brave New World threatens for humans; no longer a science fiction narrative so remote as to be only a matter for dinner table debate but as an actual possibility in the everyday world. This is not to say that the moral anxiety cannot be appropriated and turned into a profitable entertainment. The judicious mixture of pleasurable titillation and social reassurance at work in the science fiction film Gattaca is exemplary. Here the usual boy gets girl Hollywood narrative is set in a future world Gattaca (a name composed from the four letters of DNA sequences) in which all the elite have been genetically engineered; the normals, meanwhile, are cast in the position of an underclass. The plot provides social reassurance by the figure of the young hero as a mere normal and hence destined to be an intellectual and physical inferior (needless to say because of his mother's foolish naturalistic longings) who nonetheless sets himself to pass for a genetically engineered superior. Gattaca thus works on two levels – first to mobilise pleasurable anxiety about the unnaturalness of a genetically manipulated future and second the conservative reassurance that given sufficient and heroic determination the normal man will still triumph. Because Gattaca is a truly appallingly made film it has not had the influence of say Brave New World which put such speculations strongly onto the cultural map. Instead it has been the dystopic speculations by the leading US molecular biologist Lee Silver which have sustained these fears and enthusiasms. His book Remaking Eden has in many ways become today's cultural equivalent of Brave New World. Where Brave New World posited a powerful state as its taken for granted context, Silver assumes the context of an hyper- marketised society. Thus his argument is the epitome of consumer eugenicism, his thinking is located within a distinctively US context with its

current adverts seeking to purchase for \$40,000 the gametes of high IQ, 175 cms tall, Ivy League women. (What of these melange of characteristics are believed to be transmissible through genetics is intriguing). From this location Silver argues that it is inevitable that well off people, given the technical possibility of genetically engineering their offspring's appearance and behaviour, will do so.

This new possibility in which intending parents get to choose the eye colour, height, intelligence, looks etc. etc., is part of a new consumer culture without limits. If you want it, can pay for it, and someone can provide it, then, whatever that 'it' is, it is yours. In Silver's future scenario a revitalised economic liberalism enthrones the consumer as king - or even - queen. Of course there will be some moral discourse questioning the desirability of letting the market into parenthood, but the ethicists within such a context are themselves weakened by their subscription to the thesis of the importance of the market as the chief arbiter of our futures. Thus while tasteless, absurd, even impossible, the dream of the perfect baby takes its place alongside other consumer fantasies, of the perfect house, suit, job, garden, partner, drink etc. The epitome of this unrestrained consumerism is as usual the US, and it is important not to dismiss or undermine the institutional structures of social solidarity still evident in European countries which though weakened still serve as a constraint against the marketisation of everyday life.

### **The Nash family and consumer eugenics?**

In recent days the case of Lisa and Jack Nash and their now two children has served as a microcosm of current genetic testing/ eugenic anxieties. Have the well heeled Nashes opened the door to the commodification of children, the eugenicism of the consumer society, or are they more mundanely and humanly

an expression of parental love muddling its ethical way through bio-technologically advanced times? Here I want to extend this analysis of the Nashs by looking not only at the story as it is told to us by the media, but at the mixed and varying responses reported in the media.

On Oct 4<sup>th</sup> 2000 the headlines of the broadsheet newspaper the Guardian were:

*“ Test-tube child designed in US as cell transplant donor. ”*

While the story was in every newspaper I here use the Guardian as a left of centre paper which followed the debates closely. The account reported the case of Lisa and Jack Nash, parents of Molly, a six year old with the fatal inherited disorder Fanconi anaemia who had learnt that her best chance of therapy was a cell transplant from an unaffected sibling. The parents who wanted a second but unaffected child, had decided to seek pre-implantation genetic diagnosis to select an unaffected embryo - but also one well matched to Molly. Thus the second baby was both to be free from Molly’s life-threatening genetic condition and also provide a potential life saving cell transplant resource to its sibling. Lisa Nash had to undergo four IVF cycles to produce the twelve embryos to test and select one matching both criteria. The resulting baby, Adam, is free from the disorder and blood from the umbilical cord (thus a non invasive procedure) has been used to treat his sister. So far it is too soon to say whether the treatment has worked.

Few commentators have seen the actions of the Nash family and their clinicians as straightforwardly unethical unless the entire procedure is ruled out by religious conviction. Secular minded others have drawn on the Kantian imperative that people should be treated as ends not means to argue that the new baby Adam has been treated unethically, he has been treated as a means not as an end in himself (e.g letter (D.S King, Guardian Oct 5<sup>th</sup> 2000). But this abstract imperative remains rather a long way from most peoples’ decision to

parent. Scrupulously examining any longings to have a child that you or I may have experienced is a confusing task. What did it mean that I wanted to have a baby? Where did that longing come from? Alongside the distinctly remote evolutionary view that such longings are necessary for the continuity of the species, recent anthropological work studying the decisions to parent made by young couples whether married or living together, shows that it is the social expectation on the part of family and friends which chiefly and more immediately influences why they chose to have a baby. (Edwards 1999). Their social circle assumes that the reason the couple chose to live together is a statement of their wish to have a family. Thus the casual questioning about “when are you going to have a baby” is translated into a steady pressure to conform to expectation. For those of us who are parents it is a little uncomfortable to reflect that deciding against having children may reflect a more worked out position than mere social compliance. But for all too many bioethicists the tendency is to turn to abstract philosophy, not least to principlism rather either to the distal explanations of evolutionary theory or to the messiness of proximal explanation rooted in the everyday world.

However there is an uncomfortable awareness that the Nash case with all its genetic testing and embryo selection for what is widely seen as a benign outcome, simultaneously opens the door to “designer babies”. In Britain the press has actively acknowledged and fostered widespread sympathy for the Nashes as parents who carry severe genetic risk. What is spoken of as a ‘let the parents decide’ position is curiously seen by commentators such as science writer, James Meek (Guardian Oct. 5<sup>th</sup>) as supporting Lee Silver and his argument that all rich would be parents in a high tech market society would opt for genetically engineered infants. Both Silver and Meek following him thus ignore the invasive IVF procedures to be undergone by only one of the partners, instead they assume that women would freely chose to enter such an invasive

procedures simply to enhance their child. A recent article from a member of the Human Fertilisation and Embryology Authority pointed out just how invasive and uncertain IVF still was. With one move the male scientist and the male science writer had equated Lisa Nash's courage and physical endurance with Jack Nash's important but supporting role. In this language undifferentiated by gender, the Nashes become not two people but one homogenised entity – the parents. Silver and Meek fail to recognise that in a loving partnership, such an invasive procedure and risk to one may well be only tolerable to either or both, if there is deep moral agreement that this risk is necessary to avert a huge and evident danger.

In the everyday world, where parents cope with their own and their would be children's actual or potentially flawed bodies and the limits of reproductive and genetic medicine, not the world of the andro-centric science fantasists, positive enhancement through genetic engineering looks risky both ethically and practically. In the present state of know how enhancing a child's physical and mental endowment, comes more directly from its access to life chances in historical context. Thus beautiful teeth are today the birthright of any child from a well-off US family, but it has been wealth and dental technology which has brought about this enhancement not genetics. Meanwhile the fantasy of genetic enhancement threatens to weaken our cultural confidence that our societies can manage the new genetic technologies.

### **Building genethics from below .**

Thus I want to distinguish between the ideologically constructed and homogenised “parents” of the andro-centric fantasists and contrast these parents not only with the Nashes but with the social research studies of the social world of genetic testing. One recently reported ten year study carried out by the

anthropologist Rayna Rapp and her colleagues has been studying New York women in all their diversity, confronting genetic risk together in negotiation with their genetic clinicians, their counsellors, their partners and their families. Rapp argues that these women are moral innovators. They are successfully negotiating the complex and historically new moral problems thrown up by the new genetics. It is interesting to find the US geneticist and leading figure in the Council for Social Responsibility in Genetics, Paul Billings, who is an outspoken opponent of consumer eugenics, echoing the view that such painful ethical matters are best decided by the people confronting the difficulty. He says of the Nash case, “this could theoretically commodify children, but on the other hand there is no evidence that children who are conceived this way are loved any less”. He goes on “ There is a danger we are making a mountain out of a personal tragedy. I don’t think people are going to rush to IVF treatments which are an alienating and expensive procedure”.

This view of genetics as best ‘bricolaged from below’, by directly affected women, their partners and their families is in some tension with conventional approaches to new social, cultural and ethical problems generated by advances in genetics. First genetics from below questions the cultural hegemony of mainstream bioethics. The expert in this ethics from below perspective becomes not the moral philosopher, the religious leader or the leading biomedical researcher but women and their partners confronting entirely new moral and material risks produced genetics and reproduction in everyday life.

Such individual women, supported by their partners, families and friends have to make their decisions within a macro-context; and although so far, I have spoken negatively of the pressures stemming from a hyper-marketised society on the practices of prenatal genetic testing and selection, here I want to turn to the

macro changes that have taken place not least in the practice of eugenics over the course of the 20<sup>th</sup> century.

### **The recovery of the history of State Eugenics**

For the second half of the twentieth century the Nazi episode has stood as the historical embodiment of state eugenics in all its violent horror. Indeed for much of that time eugenics became synonymous with the Nazi practice of compulsory sterilisation and the seemingly inexorable path to the death camps with some modest acknowledgement given to US eugenic practices. Although many, even most, contemporary geneticists hate to be reminded of it, genetics was both the scientific and institutional child of eugenics. No where was this connection made more sharply than in the case of the Nazi race science. The critical histories of genetics and biomedicine, produced by a post 68 generation of scholars (Cf Muller Hill 1988: Weindling 1989), pointed to the distasteful evidence that the directors of leading laboratories in the immediate postwar period had also been directors during the Nazi period, and deeply implicated in Nazi eugenic practices. In Britain Darwin's cousin Galton founded the discipline of eugenics and occupied its first chair at University College London, subsequently this department was to become a leading department of genetics. Both J.B.S. Haldane a co -theorist of the Modern Synthesis in the thirties, and currently the hugely successful populariser of genetics, Steve Jones, have held chairs there. Similarly the famous US Cold Spring Harbor laboratory was the home of first eugenics then of Jim Watson of DNA fame. The story can be endlessly repeated.

For many years following WWII the eugenic practices of other countries were allowed to pass more or less unremarked. Even in the case of the US it was difficult to gather statistics on compulsory sterilisation for this was primarily a state activity, in consequence it has taken historians a tremendous effort to make

visible just how widespread the practice was. But historians of eugenics have always had to work knowing that few contemporary fellow citizens want them to find this particular aspect of our past. It has been much more politically comfortable to demonise the Nazi demons and ignore our own histories. Thus for today's intellectuals it is still uncomfortable to recall the huge enthusiasm for eugenics in most industrial countries - socialist well as capitalist - energetically supported by socially progressive scientists and social thinkers. In the early twentieth century it would be true to say that barring Catholic intellectuals, eugenics commanded the support of most EuroAmerican intellectuals including feminists, reformers and marxists as well as racist and reactionaries (Pickens: 1968; Weeks: 1981; Kevles: 1985).

The 19<sup>th</sup> century theory of evolution, with its central notions of fitness, natural and unnatural selection was crucial in this, it played into how nations particularly as 'race' conceived of themselves. Nations as race stood both in competition with one another and had to be managed internally so as to minimise the production of the unfit. Darwinism and even more potently Social Darwinism thus became a hugely influential cultural current and could be mobilised around a range of political projects and take a multiplicity of forms. The Nordic countries saw compulsory sterilisation as integral to the formation and management of the Social Democratic Welfare State, sterilising those who were 'unfit' to parent, thus reduced the potential burden on the state and enabled it to provide universal high quality welfare. That Britain got little farther than a policy of custodial care and sexual segregation for mentally impaired women and men was less personally violent but it amounted to the same denial of what we now see as a basic human right- the right to a family life. It was only the advent of the Nazi mass extermination of the mentally impaired and sick in the hospitals and the mass extermination of the death camps which silenced such dangerous enthusiasms for racial improvement. Such eugenicist histories and

enthusiasms have been, if not actually hidden, at least distinctly underplayed in national cultural self accounting, leaving the Nazi episode to stand out as a singular horror story rather than as the monstrous epitome of a widespread current. Consequently the critique of 'state eugenics' is almost always set against the Nazi horror rather than this much more pervasive state eugenicism which lies uneasily, only half silenced, within culture and history. As the repressed rather than the confronted, such histories have returned slowly and with shame.

Thus for many years the Nordic experience was rendered invisible even though it was practised up to 1976 . It was only during the very last years of the 20<sup>th</sup> century that the Swedish Government apologised to and compensated those women whose ability to bear children had been taken away from them, typically on the grounds that they were unfit to mother. One of the specific features of Nordic sterilisation programmes is that they were primarily directed against women, in some cases 90% of all cases. Whatever role 'unfit' men might have to play in reproducing the 'unfit' was set to one side by the biomedical professional discourse and practice. Other states, including the Nazi were sexually equal in the sterilisation practices. Nordic biomedical science in the service of the welfare state had special skills, it saw itself as entirely able to judge that these women should be sterilised because they were 'unfit in mother' two distinct senses, to breed and care. The centrality of children in the Nordic welfare state and culture (so unlike the British variant) meant that the deemed 'unfitness' to provide adequate maternal care sustained sterilisation long after human genetics supplied any legitimacy that feeble-mindedness (above all in the form of Downs) was inherited. (The key chromosome work concerning Downs syndrome was done in the fifties, sterilisation went on until the mid seventies.)

Eugenicist enthusiasms died hard. In Britain the distinguished biologist Peter Medawar in his 1958 Reith lectures, expressed his concern that the Welfare State was permitting too many unfit children to live whom nature would have selected out. The wellbeing of the national stock depended on an acceptable version of eugenics. Such thinking gave ideological support for birth control and pro-abortion policies and made an extraordinary alliance with feminist ideology. ( In the sixties these were distinctive strands, earlier in the century century numbers of feminists, pace Marie Stopes, feminist founder of the birth control clinics, was a passionate a eugenicist). The 1967 UK legislation on abortion which was greeted with joy by the embryonic women's movement, is written in eugenicist language quite shocking to the contemporary ear. It has taken thirty plus years to develop a more or less abortion on demand practice on the ground.

Even in 1968, that year of revolutionary hope, eugenic enthusiasm were still openly expressed:

*'There should be tattooed on the forehead of every young person a symbol showing possession of the sickle cell gene or whatever other similar gene....It is my opinion that legislation along this line, compulsory testing for defective gene before marriage, and some form of semi-public display of this possession, should be adopted.'* (Linus Pauling quoted Kay, 1993: 276)

What is painful is that the author of this appalling statement was not some bizarre figure from the racist right, but a hero of the anti war and alternative health movements, none other than Nobel prize winning biologist Linus Pauling.

### **The Janus face of clinical genetics**

It was against this history of eugenics genetics that the clinical speciality now called medical or clinical genetics had to reconstruct itself in the post war years. Partly it was about changing names, re-branding the profession in today's advertising language, but also hugely about developing - in the light of Nuremberg and subsequently Helsinki - ideas of patients' informed consent. Counselling, spending time with patients making sure that co-operation was freely given became the hall mark of the best clinical practice. The non directive nature of the genetic clinic stands in sharp contrast with other clinical specialties. In the antenatal clinic, women have long been expected to comply with medical guidance to follow life style regimes, give blood and urine samples to be tested all for the good of the baby. Indeed here and elsewhere in medicine "compliance" is a routinely discussed problem. Occasionally welfare benefits have been tied to participation to ensure compliance. But while this non directive approach to patients was developing, clinical geneticists had to make their case to the state for support. To this resource granting or denying the argument radically changes and the profession now speaks in distinctly eugenic language about the reduction in the births of impaired infants thence the savings to the public purse. This Janus like stance implicitly assumes that the informed decisions of individual patients and the needs of the state will conveniently coincide. More recently Philip Kitcher adopts the same Janus like position indeed describing it as utopian eugenics.

Remembering that the original utopia was 'nowhere', the more sceptically minded might well note that this double agenda simply produces invisible norms which set the 'acceptable number' of genetically impaired infants to be born. Indeed UK clinical geneticists aware of these pressures report the invisible norms which indicate the acceptable number of Down's Syndrome babies to be born in their patch. To meet the invisible norm satisfies the double demands of Janus - first that the pregnant woman is enabled to make an informed choice and

second that the state's burden of genetically impaired is minimised. Given the current cultural struggle being waged by people with Downs and their allies to insist that theirs is alive worth living, it is reasonable to anticipate that Kitcher's eugenic utopia is more accurately viewed as a Panglossian. (All is for the best in the best.....). Meanwhile how such invisible norms are negotiated, established then re-negotiated is a research task yet to be carried out. What can only be clear is as new responses whether social ( support for learning disabled people) or biomedical therapeutics as in say PKU) are available then the definition of an unliveable life is likely to change in both clinical and public perception.

Pointing to the statistic that genetic impairment constitutes only some 3% of all impairment may weaken the cost-benefit effectiveness of the claims of clinical genetics to save public resources, it still echoes the ideology of eugenicism in which some 'right hands' (Fox Keller: 1992) decide which of the 'impaired' foetuses need to have maternal decisions made about their survival ( Hubbard and Henifin: 1984). It might seem straightforward, at least for secular people outside the genetic or the prenatal clinic, to see the value of prenatal tests which permit the identification of genetically transmitted conditions associated with terrible pain and premature death, and thus offer the possibility of terminating the pregnancy. However valued and however secure women and their partners are in their choices, dealing with this knowledge is humanly costly. Over the past twenty years research has systematically indicated that decisions to have an abortion as the result of prenatal diagnostic testing are associated with high levels of personal distress even where these are supported with appropriate levels of counselling. This high level of distress stands in marked contrast with the much lower levels felt by women who find themselves pregnant and choose an abortion because they have decided they do not wish to mother a potential child. The point is not that women who want to mother necessarily want to reverse the informed choice which led them to elect an abortion after genetic

testing, simply that the personal costs associated with living with genetic testing are high.

Scarcely surprisingly the movement of disabled people is deeply suspicious about the proliferation of genetic testing and sees it as inherently eugenic (Shakespeare: 1994). Learning disabled people have been at the fore front of these confrontations. In a culture which has for so long taken for granted that a woman would not want to give birth to a child with Down's Syndrome and would see amniocentesis or chorionic villa screening as helpful, these challenges are both disturbing and long overdue. Defending women's reproductive freedom while refusing to subscribe to an automatic categorisation of the life of a person with Downs as not worth living is not easy. When this debate takes place with learning disabled people arguing their rights to life itself the old certainties begin to yeild.

Understanding the speed of technical change that this Janus-like profession must presently contend is key. As Dorothy Nelkin and Lawrence Tancredi document in Dangerous Diagnostics (1994) , the new genetics has proliferated tests but few therapies. Indeed diagnostic technology is integral to the development of the field, both in the sense of the technics of production of the knowledge and in a more directly commercial sense. While the Human Genome Project was launched to the sound of promises of gene therapy and thus secured substantial investment from both state and venture capital, the new diagnostics, even without therapies, offers to provide those promised profits. But as leading French molecular biologist Bertrand Jordan recognised, in so far that as tests are offered to pregnant women the only 'medical treatment' that can be proposed is abortion for those foetuses defined as not normal.

*The impact of the genome programme on society as a whole is far from insignificant. The new knowledge thus gained leads to the elimination of embryos through prenatal diagnosis and pregnancy termination . (Jordan 1993:168)*

### **Arguments within biology**

With proliferating genetic diagnostics the meaning and value of the predictive claim comes under sharp questioning from fellow biologists including leading geneticists and molecular biologist. Over the years particularly from within the US leading biologists, such as Jonathan Beckwith, Ruth Hubbard, Sheldon Krimsky and Richard Lewontin, have successfully punctuated the self reported success story of the new genetics. Among the more conspicuous recent examples of such interventions was Lewontin's challenge to the near absolutist truth claims being made for the DNA 'fingerprinting' (Lewontin 1991). In similar vein, Hubbard as a feminist biologist deeply involved with the women's health movement has set out to both demythologise the new genetics and to alert women to the imperialising and mythical claims of the new diagnostics (1985; 1991; 1995). The pressures for genetic testing bear particularly sharply on pregnant women, and despite their ideological claim to certainty and precision are often rather course indicators which offer little other than abortion as a therapeutic response. Within Europe similar wave of technical criticisms linked to a profound social distaste for the eugenic past led to the German Greens successfully launching a critique of the European genetic programme which was to be launched under the title Predictive Medicine. Such technical criticisms challenge the crudity of the 'Gene for' ideology constantly produced by press releases from the biology laboratories (cf Nelkin Selling Science) and amplified in the media. 'Genes' the critics endlessly argue 'do not determine' but their

message, even while unquestionably integral to the genetic discourse, is almost drowned out by the deluge of Gene-talk.

Critical arguments from within biology have been supported by those from within the social sciences. Economic studies of the costs and benefits of genetic screening programmes can strengthen the state's hand in resisting pressures to mis-allocate limited public health care resources to such projects. US sociologist Troy Duster contrasts the UK experience in successfully resisting such programmes on the basis of cost benefit economic analysis. As an African American, Duster is less confident that state eugenics entirely belongs to the past. His study (1990) documents the replacement of material support to poor African American families by genetic testing programmes and concludes that genetic testing in this context is best understood as back door eugenics. As Duster observes:

*Once again whether this new genetic knowledge is an advantage or a cross depends only partly on the how the genes are arranged. It depends as well where one is located in the social order. (1990:92)*

### **Risk management of the new risk assessment?**

From the inception of the Human Genome Project (HGP) in the eighties, leading geneticists and molecular biologists have long understood (however much they simultaneously distanced their discipline and themselves from any taint with the topic) that their particular cultural bogey is eugenics. They made sure that around 7% of the total genomic budget, substantial monies by humanities and social research standards, were put into research on the ethical legal and social 'implications' and/or 'aspects' of genetics. With the HGP came ELSI and ELSA. Optimists could read this as a move to confront serious social and cultural

anxieties, sceptics could read this as an attempt to use the social sciences and humanities as handmaidens, whose task was to manage the public perception of the new genetics as positive. The 7% was to be a means of managing risks to genetic as much as risk to the public. It would take much longer than I have space for here, but there is considerable evidence backing both optimists and sceptics

Today with a much greater awareness that science and technology generate entirely new and very large risks above all to nature, there is a much greater consciousness of the need to manage risk. The sociologist Ulrich Beck some while ago entitled the way we live now the Risk Society. The anxiety around genetic testing is central in this discussion of risk. For what genetic testing does is to change the nature of risk assessment to human beings. In the past the most powerful predictive discourse on morbidity and mortality was epidemiology, the statistical study of the patterns of health illness of human populations. With this evidence governments in the 19<sup>th</sup> century could be moved to provide sanitation, clean water and eventually in this century this century clean air. Its interventionist discourse was that of public health, its target the improvement of the health of entire populations. It needed a robustly interventive state insisting that people complied with its advice. (It is, to say the least, uncomfortable to find that nazi public health research pioneered work on the tobacco cancer link.)

However what genetic testing does is to change nature of risk assessment from the prediction of the health of populations, or even groups within populations, to individuals. It is thus supremely the biomedical discourse which fits the increasingly individualising discourse of a liberal political economy. Genetic testing thus directs risk primarily towards individuals. Take the second battle to establish the association between smoking and lung cancer. Yet this had its puzzles, for smoking while dangerous statistically, everyone, especially smokers

finding it hard to give up, knew others who had smoked heavily for years only to die of old age not cancer. Of course even then it was obvious that some had probably more constitutional resistance than others, but who was safe and how could they know? Today genetic testing offers to predict for individuals whether for them smoking is extremely dangerous or merely rather unhealthy. Thus the public health struggle against lung cancer is waged on a global level against the machinations of the tobacco industry (and perhaps the tax dependency of governments). At local level it could soon be waged on the predictive reliability of genetic tests for individual risk.

It is by no means clear to me that culturally we are able to deal very effectively with the refinement of risk assessment that genetic testing claims to offer. Numbers of studies of prenatal testing for serious genetic disorders, such as Familial Cholesterolaemia, which unless the child is homozygote, is relatively clinically manageable, give rise to concern about the psychological effects of genetic knowledge. The mothers of such babies report feeling saddened and fatalistic. Given that treatment for young children with this problem is typically only in terms of managing diet and encouraging exercise there are good arguments for not testing pre-natally, but delaying this until the child is old enough to make an informed choice. Obviously in the case of genetic disorders – the classic is PKU- where therapeutics need to be started immediately then the argument is different. But here I simply want to insist in the complexity of genetical thinking. Genetic knowledge has to be situated in intimate context.

It has been the issue of genetic testing for the cruel late onset disorders like Huntington's Chorea which have taught humility about the value of genetic knowledge. Initially it was thought that those from at risks families would seize on the certainty offered by genetic testing. Some do some don't, some prefer to live with the general risk others want to know the exact risk. Observant clinicians

working with such families suggest that those who decide not to take a test often have some subtle sense, that they are already exhibiting the hints of symptoms associated with the disease. The harsh ethical and practical dilemma for both patient and the clinician is that there is still no effective therapy. The price of certain knowledge in this situation is indeed high

### **Genetic testing in the context of a directive medical culture**

Despite my analysis of the Janus face of clinical genetics, I want to argue that its non directive culture by and large serves to protect patients from being prematurely pushed into learning their own genetic risk status. What there is good reason to be much more concerned about is the spread of genetic testing into the other directive specialties, above all into the antenatal clinics. It is difficult to see how to slow down this process as medicine is being geneticised in its explanation, as both research and any cursory inspection of medical journals reveals. An already identified problem with genetic testing in antenatal clinic, is that it claims to give reassurance, to inform women that their foetus is 'normal', yet the very act of testing throws into question the hitherto taken for granted 'normality' of the foetus. The test thus raises anxiety which was not there initially. Josephine Green's survey of the psychological literature on antenatal genetic testing is not by chance called Harming not Calming? (1990). But even within the context of general practice where the patient and the clinician often have a long standing relationship the increasingly directive culture of general practice is hostile to the non directive culture required for genetics. This directive culture is embedded increasingly in the statutory requirements for family doctors to try to achieve targets of various measures of biomedical surveillance. Nor, even if the culture can be modified, is it easy on present staffing levels to see where the time for such counselling is to come from.

Certainly the current seven minutes per patient within UK general practice do not look to be a psychologically safe starting point.

### **The societal management of genetic risk assessment.**

Inevitably the societal management of genetic risk assessment is undergoing rapid change. Here I want to explore the changing contribution of governmental institutions. I use, because I know it best, the UK experience

The British approach to finding solutions to problems for which the political parties have no pre-made answers is typically to assemble a committee or commission of what are called the “great and the good”. These committees of eminent people with relevant expertise are supposed to produce disinterested advice that will be acceptable to most acknowledged interests. It is important to note acknowledged interests as while those of science, the arts, the professions and the church have long been privileged, many interests not least those of women and other socially weak constituencies were silently erased. This process is currently undergoing a considerable change as the management of risk generated by biomedical advance becomes more difficult and requires that hitherto excluded groups are brought in.

The change began with the Warnock Committee in the mid eighties with its brief to advise on the ethical management of embryological research and in vitro fertilisation. It was set up in the wake of the moral anxieties set in train by the birth of the first IVF baby, Louise Brown, in 1978. That the key scientist Robert Edwards had spoken publicly in 1971 of his intention, following the success of

John Gurdon with frogs to produce a human in-vitro fertilisation and birth in was left out of the discussion. Thus there was advance warning from science but with few influential hearers. The ethical anxieties the British Society for Social Responsibility sought to raise by giving a platform to Edwards were only to be explored post hoc. However the story is a sharp reminder that paying attention to what is happening up stream is potentially much more powerful as a regulatory move than pursuing events always downstream.

The Warnock Committee itself was both a classic example of the old elite approach to the construction of consensus in the face of morally disturbing risk created by biomedical science and also opened the way to a new more inclusive approach. While the great and the good were in evidence this was also the first occasion in Britain that such an advisory Committee was 50% women. Even the Thatcher government, not noted for its sympathy to women, could see that on this issue of reproduction women and their interests could no longer be safely ignored. Most other European countries with the technical capacity to engage in IVF used not dissimilar committee like mechanisms again involving women( even feminist in some usually Nordic countries) to establish consensual regulatory mechanisms. This was no fast process between the inception of discussion and the passing of legislation typically took some three to four years. Broadly speaking European legislation followed substantially a common pattern: embryological research, IVF and other approaches to assisted conception were continued within a now regulated framework.

Not everyone shared this consensus. Much of the feminist movement saw in the birth of this first IVF child the danger that someone other than the woman herself, was going to be able to control her reproductive capabilities. Someone other than the woman herself was going to be able to say, first, whether the woman should mother, and second, which foetus should be permitted to come to

full term. Unquestionably all the assumptions underpinning Warnock privileged the heterosexual and stable if not actually married couple. Although IVF technology was quite limited in its application, the critique was often mounted as if it was not uncertain, invasive and expensive and that these material barriers in themselves set no limits. IVF and similar forms of assisted conception were powerfully contested by a movement fighting for women's reproductive freedom. Ideologically the movement was right, practically it was wrong. Even today when IVF and similar technologies are more effective they are still difficult, and only a minority of would be mothers entering these programmes take babies home. The uncertainty of the procedures and their invasive and distressing nature made sure that IVF was a measure of the last resort. It remains today too much of a craft based activity involving high levels of human resources to offer the possibility of vast markets and corresponding profits.

### **Genetic diagnostics - a radically different problem.**

The new human genetics are radically different. This is a highly automated capital intensive system of production, it mass produces genetic information and must constantly search for new markets new outlets. It has come into existence by initially huge pump priming by the state but which is now substantially driven by venture capital. There are as with agricultural applications of biotechnology millionaires to be made from what were formally public sector scientists. In the accumulation of capital speedy innovation is of the essence. Thus genetics in its present form contains a huge drive to innovate and presses its time scale on governments, clinicians and patients alike.

Today the very possibility of genetic profiles being developed linked to medical records for ultimately whole populations as in the case of Iceland, and canvassed for the UK, or in place for the entire US military and for all US

convicted serious criminals indicates that big money has entered the picture in a way quite outside relatively modestly capitalised IVF problematic. Because of this IVF had four years to establish an ethical consensus . When immense financial interests are at stake, as with biotechnology and genetically manipulated organisms, the management of risk and satisfying the ethical anxieties surrounding risk become that much more difficult. The political and cultural task as the recent WHO advice on legislation suggests is to go slowly at the speed of society not that of the biotechnology industry.

The UK's approach to the new genetics began by denying that human genetics produced special problems but was soon moved under the last government to adopt the suggestion made by the Parliamentary Committee on Science and Technology for a new Human Genetics Advisory Commission. Still a young body this is being required by the new government to deepen its agenda and widen the range of represented interests. For example the Commission currently includes a leading figure from the disability movement yet many of the strongest voices within this movement regard genetic testing as inherently eugenic. If genetic testing is to be used at all, it is only to be used when surrounded by robust regulation and by ethically aware professionals and patients. For that matter the desirable norms of disabled people can be radically different from those of abled bodied. Thus parents who are themselves genetically deaf and who know from experience that they can successfully bring up a child like themselves to be happy may well think of selecting against a foetus likely to be hearing. In consequence admitting such a voice is to include people with potentially very different normative values who have hitherto been deliberately excluded.

### **A Halfway House?**

However given that all the members of the Advisory Commission on Human Genetics are screened and selected it would be premature to conclude that because it is unquestionably more representative than it is the equivalent of a democratically elected body. Thus it would be hard to see the Commission as the practical implementation of Ulrich Beck's ideas concerning the need to develop new social institutions for the democratisation of risk management. The updating of the Commission's form is not unlike a public version of a carefully chosen focus group, a key social research tool in the present government's approach and one much criticised from within and without the social sciences. The question remains whether this halfway house is adequate, or whether the UK government needs to move to new social institutions which are both more transparently democratic with greater legitimacy and power. Has the halfway house form sufficient legitimacy to effectively advise how to regulate the immense industrial and financial forces behind the new genetics while paying attention to the messy complex world of the ethics of genetic testing in practice. And how do governments committed to wealth creation and therefore seeking to foster the biotechnology industry receive and act upon such advice. Such a question could be posed even more sharply to members of current international bio-ethics committees whose members are typically either drawn from the great and the good by governments or who are civil servants with a formal brief to cover bio-ethics. The challenge of genetics is immense do such committees have sufficient will and clout to match the situation or do they sometimes feel like a collectivity of mice left with the task of belling the biotechnological cat.

### **Beyond the half way house**

I am with those who argue that the half way house is inadequate. To move away from both state and consumer eugenicism, requires new social institutions. The task of such new institutions, of consensus fora, citizens' juries and the like, is the

socio-technological assessment of both genetic claims and products. Such assessment, might entail the rejection of specific technological possibilities and would unlikely to avoid fierce resistance from vested interests. But such new social institutions do offer the possibility of restoring social trust in the process of technological innovation which is integral to a highly scientific and technological culture. Such trust is massively under siege not least because of a string of environmental disasters and threats to the environment and to human beings produced by scientific and technological innovation.

Creating new institutions does not of itself offer any guarantees of easy consensus, what it does bring is the democratic possibility of conversations between many differently situated people and groups - not least between potential consumers and providers of new technologies. There is some modest evidence that the biotechnology industry is likely to be more open to this than the old secretive traditions of state paternalism. Industry and the Ministry of Food, Fisheries and Agriculture (MAFF) were the joint funders of Dolly, but where industry was willing to talk about the ethics of sheep cloning, MAFF was (as usual) silent. But consumer resistance is also forcing industry to recognise that it must listen. Both in the US and the UK consumer resistance to Cystic Fibrosis genetic tests is compelling industry to recognise that the market model of the 'consumer' does not fit this world of women and their partners thinking about having a baby<sup>i</sup>. Such modest auguries which serve to limit and modify the emergence of a consumer eugenics are important to both providers and potential users of genetic tests

**To sum up . To move on, both out of the old state eugenicism and beyond the emergent consumer eugenicism, requires not only courageous experiment with new social institutions but also the societal acknowledgement of the**

**centrality of women and their partners, who in the process of picking their way through their reproductive choices are building a genethics from below.**

## References

Paul Billings (1994) 'Contribution to an International Seminar on Technology Assessment of Neurogenetics, January, Hamburg University

Walter Bodmer and Robin McKie (1994) *The Book of Man*, New York: Little Brown & Co.

Michael Callon (1987) 'Society in the Making: The Study of Technology as a Tool for Sociological Analysis' in W.Bijker, T. Highes and T. Pinch (eds) *The Social Construction of Technological Systems*, Cambridge MA., MIT Press

Troy Duster (1990) *Back Door to Eugenics*, New York, Routledge

European Science Foundation (1991) *Report on Genome Research*, Strasbourg

Ruth Hubbard (1984) 'Prenatal Diagnosis and Eugenic Ideology', *Women's Studies International Forum*, 8, 6, 567-76

Ruth Hubbard and Elijah Wald (1993) *Exploding the Gene Myth*, Boston: Beacon

Ruth Hubbard (1995) *Profitable Promises: Essays on Women Science and Health*, Monroe ME.: Common Courage

Alan Irwin and Brian Wynne (1996) (eds) *Mis-understanding Science: Making Sense of Science and Technology in Everyday Life*, Cambridge, Cambridge University Press

Betrand Jordan (1993) *Travelling Around the Human Genome*, Paris:Inserm

Evelyn Fox Keller (1992) 'Nature, Nurture and the Human Genome Project,' in Kevles and Hood (eds)

Daniel Kevles (1985) *In the Name of Eugenics: Genetics and the Uses of Human Heredity*, New York: Knopf

Daniel Kevles and Leroy Hood (eds) *The Code of Codes: Scientific and Social Issues in the Human Genome Project*, Cambridge MA.,:Harvard

Kings Fund (1987) *Screening for Foetal and Genetic Abnormality, Concensus Statement*, London: Kings Fund Centre

R.C. Lewontin (1991) *Biology as Ideology: The Doctrine of DNA*, NewYork: Harper

Daniel Koshland, (1989) Editorial, *Science*, October 13:246:189

Salvador Luria, (1989) Letter, *Science*, November 17: 246:873

Benno Muller Hill ( 1988) *Murderous Science: Elimination by Scientific Selection Jews Gypsies and others. Germany 1933-45*, Oxford: Clarendon

Rosalind Petchesky (1985) *Abortion and Woman's Choice: the State, Sexuality and Reproductive Freedom*, Boston: Northeastern University Press

Donald K. Pickens (1968) *Eugenics and the Progressives*, Nashville Tennessee, Vanderbilt University Press

Hilary Rose and Jalna Hanmer (1976) 'Women's Liberation, Reproduction and the Technological Fix', in D. Leonard Barker and S. Allen (eds) *Sexual Divisions and Society*, London, Tavistock

Hilary Rose and Steven Rose (1976) (eds) *The Radicalisation of Science*, London: Macmillan

Hilary Rose (1994) *Love Power and Knowledge: Towards a feminist transformation of the sciences*, Cambridge, Polity

Steven Rose (1995) 'The rise of neurogenetic determinism,' *Nature* 353, 2 February, 280-1

Shakespeare Tom (1995) 'Eugenics by the backdoor? The disability movement's concerns with the new genetics.' Paper given at the Edinburgh Science Conference, April

Meg Stacey (1992) (ed) *Changing Human Reproduction: Social Science Perspectives*, London: Sage

Wolfgang van den Daele (1994) *Technology assessment as a Political Experiment* Berlin: Wissenschaftszentrum Berlin für Social Forschung (WZB)

Jeffrey Weeks (1981) *Sex, Politics and Society*, London, Tavistock, 1981

Paul Weindling (1989) *Health, Race and German Politics between National Unification and Nazism: 1870-1945*, Cambridge, Cambridge University Press

Gary Werskey (1971) *The Invisible College*, Harmondsworth: Penguin

Edward Yoxen (1983) *The Gene Business: Who Should Control Biotechnology?* London: Pam Books

Juliette Zipper and Selma Sevenhuijsen (1987) 'Surrogacy: Feminist Notions of Motherhood Reconsidered' in M. Stanworth (ed) *Reproductive Technologies: Gender, Motherhood, and Medicine*, Cambridge, Polity.

---

'Research suggests that social pressure from family and friends on the 'young couple' is much more influential than any version of rational choice theory.