

# EUGENICS AND GENETICS: THE CONJOINT TWINS?

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Thinking about human genetics, not least the vaunted possibility of the 'perfect baby', seems, in the post millennium world, to be both near and light years away from the spectre of eugenics which haunted the twentieth century, above all in the hideous episode of Nazism. This new science fiction in which intending parents get to choose the eye colour, height, intelligence and looks of their prospective child is part of a new consumer culture without limits. If you want it, can pay for it, and someone can provide it, then it, whatever that 'it' is, is yours. A revitalised economic liberalism enthrones the consumer as king - or even queen. Of course we all know that accompanying this claimed new technological possibility there will be some moral questioning around the desirability of letting the market into parenthood, but with so many of the bio-ethicists weakened by their subscription to the thesis of the importance of the market as the chief arbiter of our futures and by their own positioning within biotechnology as consultants and advisers, they are unlikely to cut much ice. None the less, 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 or partner. Perhaps such unrealisable fantasies cast light on the current pandemic levels of depression in western societies.

Ten years ago the ideological and technological epicentre of this unrestrained consumerism was the US, and even writing from within the fifty-first state, it is important neither to dismiss or undermine the institutional structures of social solidarity still evident in most Western European countries. Though weakened these still serve as a constraint both against the marketisation of every day life and also the human body itself. Europe has yet to see, not least because most countries have regulated against the possibility, the kind of advertisement seen on the elite US campuses which invited 175cm tall women Ivy League graduates with high SAT scores to sell their gametes for \$50,000. (The implication that attendance at an Ivy League university comes in with the gametes owes rather little to any part of twentieth-century genetics). However, in the Blair-Brownite deregulated and privatised economy with science as the economic driver, the move towards consumer choice seems practically irresistible. Moral line after line in the sand, over 'saviour siblings' and 'cloning', are steadily crossed, with the blessing of the Human Embryology and Fertilisation Authority (HEFA) and endorsed by many of the country's scientific cheerleaders. In embryo stem cell research Britain has assumed ideological if not technical leadership, in part because Bush's religiously-driven attack on all human reproduction science and technology, and commercially driven attack on environmental science has set the US effort back. New Labour has assumed the ideological mantra of the atomic

bomb physicist Robert Oppenheimer that 'science is progress and cannot and must not be stopped'. Where most of Europe is morally opposed to creating embryos solely for 'therapeutic' cloning, Britain's political and scientific elite is committed to sweeping aside such moral caveats as inhibiting the forward march of a science-led global capitalism.<sup>1</sup>

1. Such is the UK political pressure for this research programme that even the Foreign Office has been recruited to its advocacy.

It is not just moral difficulties that are swept aside in this forward march: so are technical ones. For example, embryonic stem cell research using both human and other animal gametes seems to be showing something of the same problems that afflicted Dolly the sheep but this seems ignorable by the new capitalist progressivism. Embryonic stem cell research (cloning by another name) is to become the future and the therapeutic cornucopia a near certainty. Meanwhile those sceptical voices which point to the gap between biotechnological promise and actual delivery - such as the failure of the Human Genome Project (HGP) to deliver on its inflated claims of gene therapy - are dismissed as mere nay-sayers. Instead Britain's increasingly consumerist ideology - one shared by both dominant political parties - with its central emphasis on choice, works to facilitate the advance of technologies claiming to offer human perfection. In this context the ease with which the risk of a new kind of eugenicism has been variously dismissed, under-rated or even re-branded as a utopian project is disturbing.

## THE CENTURY OF EUGENICS

While Evelyn Fox Keller entitles her rich account of the role of genetics in building the organism, *The Century of the Gene*,<sup>2</sup> equally that self-same twentieth century could well be named *the century of eugenics*, for genetics and eugenics, have, like conjoint twins, both individual and linked histories over the course of that one hundred years. Genetics as the science of biological difference at last creates the possibility of realising Francis Galton's nineteenth-century bio-political project of eugenics - namely distinguishing the innately wellborn from the innately unfit. For the sake of the nation the birth of the former were to be encouraged and the latter discouraged. Eugenics, like genetics itself, has undergone huge transformations. Where genetics has become subsumed within the vast project of genomics, ranging from the completion of the Human Genome Project to what is often spoken of as the proliferation of the 'omics' (from proteomics to transcriptomics), eugenics first came into practical existence in the mid twentieth century as state eugenics, then was radically transformed to become the consumer eugenics of the twenty-first century.

2. Evelyn Fox Keller, *The Century of the Gene*, Cambridge MA, Harvard University Press, 2000.

Despite the wishful claims of a regrettable number of distinguished historians, geneticists and bio-ethicists from Daniel Kevles to Steve Jones and Onora O'Neill who insist that eugenics is nothing to do with the contemporary science of genetics and is no longer relevant to today's debates over genethics, in the twenty-first century the conjoint twins of genomics/genetics steadily raise the stakes with the ever-enhanced possibilities of biotechnologically-

aided unnatural selection.<sup>3</sup> Although the term ‘eugenics’ unquestionably became unusable after the Nazi death camps, it is important to slay an often-perpetuated soothing fiction. Eugenics as a policy and practice neither originated nor died with the Nazis.<sup>4</sup> Given the weight of historical scholarship mapping the eugenic programmes particularly of the welfare states for some thirty years after the defeat of the Nazis it should be unnecessary to speak of slaying this particular fiction, but the whole power of soothing fictions lies in their hydra-like reproductive capacities. Cut their heads off and they simply proliferate. In addition, emphasising the widespread forms of state eugenics from the thirties to the mid seventies - with Slovakia still compulsorily sterilising Roma women today - is not to de-demonise the Nazis, but rather to position this particular and terrible episode in the historical context of mid twentieth-century collectivism where the well being of the collective stood socially higher than that of the individual. There were both gains and losses in that stance.

What remains unique to the Nazi episode is that it was the biomedical discourse of Germany’s scientific elite which informed and sustained a genocidal project which systematically killed millions of Jews, Gypsies and homosexuals. While it is unlikely that a biological construction of race could play the same role as in the Nazi episode, biology seems to find it hard to relinquish that activity. This year in *Nature Genetics* biologists drawing on the powers of a molecularised biology were once again claiming that only they had the capacity really to distinguish one race from another. Most articles rejected this position, on the grounds that race was still not a biologically usable concept. But there can be no question but that the mainstream (not the racist fringe which has clung to biological racism throughout) biological discourse is once more claiming that DNA analysis gives it the power to construct race as a category of the life sciences. Those with any memory of the twentieth century are like to view this reclaiming with profound unease.

#### THE UNACCEPTABLE FACE OF THE WELFARE STATE?

An uncomfortable but fruitful way of thinking about National Socialism is as the unacceptable face of that great achievement of the twentieth century - the welfare state. Within the welfare states eugenic policies informed by theories of innate difference provided by the discourse of biomedicine sought to regulate the reproduction of the unfit and to encourage the reproduction of the fit. Positive eugenic policies were like the £50 per year added to my salary for each of my children when I was a lecturer at the London School of Economics in the 1960s. The explanation for this largesse was that William Beveridge, theorist of the British welfare state and an earlier director of the School, was also a keen eugenicist and took the view that university teachers were self evidently ‘fit’ and were to be encouraged to breed. Negative policies ranged from compulsory sterilisation to institutional incarceration aimed at preventing sexual contact and reproduction by the unfit - the so called

3. Daniel Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity*, New York, Knopf, 1985; Steve Jones *The Language of the Genes*, London, Harper Collins, 1994; Onora O’Neill *A Question of Trust: The Reith Lectures 2002*, Cambridge, Cambridge, 2002.

4. Gunnar Broberg and Nils Rolls Hansen (eds), *Eugenics and the Welfare State: Sterilisation Policy in Denmark, Sweden, Norway and Finland*, East Lansing, Michigan University Press, 1996.

5. Segregated incarceration as a gentler but equally effective eugenic practice was strongly supported by the Eugenic Society under the leadership of Leonard Darwin, Charles Darwin's son.

'feeble minded'. These were standard welfare state practices: the Nordic countries tended to use compulsory sterilisation while the Netherlands and Britain preferred what was for them the more socially acceptable policy of incarceration.<sup>5</sup> This would prevent sexual activity and thus prevent breeding and the reproduction of the unfit. Tacit within both mechanisms of the control of reproduction in these welfare state countries was the belief that unfitnes was transmitted (both biologically and socially) through the female: women not men mostly bore the costs of eugenic practices. The Nazis, by contrast, showed less gender bias: at first they sterilised, and later exterminated, the biomedically-defined unfit of both sexes.

At the core of the welfare state project, and indeed National Socialism itself, was a deeply-embedded idea of nation and the well being of the national collectivity. The British welfare state developed in a less than coherent way, initially placing the male employed citizen at its heart with all benefits to women and children derived from their relation to him. By contrast, the welfare state of the Nordic countries developed from a coherent theoretical attempt to find what they spoke of as a third way between communism and capitalism, in which women and men were theorised as equal citizens, and with children as the shared responsibility of parents and the state. But whatever the origins of the various welfare state forms it was the breakdown of these varied national collectivities, and the developing individuation over the third quarter of the twentieth century, which presided over the erosion of the welfare state. Globalisation sought to remove the very grounds on which the social contract between organised labour and national capital could take hold.

Nonetheless at the height of the national collectivism of the mid-twentieth century, state eugenics privileged the efficiency and the well being of the whole nation above that of the individual. Eugenics was integral to Protestant (but not Catholic) social democratic versions of national collectivity. But if this was the similarity between National Socialism and the Protestant welfare states, the difference lay in the totalising raw hatred of Nazi anti Semitism, anti gypsy and homophobia. These were, as race theory remorselessly spelt out, the ultimate Other - the '*untermenschen*': compulsory sterilisation began the eugenic process and the death camps provided the final solution.

Populist history thus promotes two unexamined assumptions: first that 1945 - above all Nuremberg - was a moral watershed, and second that eugenics had only this one horrific and genocidic form. As the high court judge, Stephen Sedley, recently noted, Roosevelt and Churchill were in favour of shooting the leading Nazis out of hand; it was Stalin who, knowing well the value of show trials, persuaded them of the benefits of the Nuremberg Trials. His reminder also makes Nuremberg as the favoured source for the origins stories of bioethics distinctly problematic. The watershed thesis also serves to erase the work of historians such as Paul Weindling and Benno Muller Hill who have documented how erstwhile Nazi race theorists, once Germany was

defeated, were swiftly restored by the Western allies to running leading genetic laboratories.<sup>6</sup> There they reassumed their place within a scientific community imbued with the ideology of ethical neutrality: thus science was privileged above human rights. Arguably it was not until the German student movement of the sixties that this history began to be confronted by a generation free from complicity in the past, and, armed with Adorno, no longer automatically deferential.<sup>7</sup> More damaging still, the idea of the moral watershed served also to erase from view the diverse eugenic policies practiced both in liberal and in social democratic countries.

Even while state eugenic policies were in place, eugenic enthusiasms were not restricted to the National Socialists: barring Catholics, most secular and Protestant intellectuals and professionals were deeply implicated. Many biologists, including geneticists, were supportive of eugenics: some, including the distinguished Marxist geneticist J.B.S. Haldane, were active research collaborators with those leading German geneticists who were also the theorists of Nazi eugenics. Feminists such as the birth control pioneers, the American Margaret Sanger and Britain's Marie Stopes, were passionate eugenicists, a stance shared by the Danish feminist novelist and literary Nobel laureate Ellen Keys.<sup>8</sup> The writer and Fabian George Bernard Shaw was a convinced eugenicist, and so were Alva and Gunnar Myrdal, the theorists of the Swedish welfare state. The Myrdals saw eugenics as integral to the national project of the welfare state, as without state intervention the new social services would be overwhelmed by the increase of the 'feeble-minded'. As a liberal democratic state, the US sterilised some 20 thousand 'feeble minded' women, mainly of African descent; Canada was equally energetic, while many of the Nordic countries had eugenic laws all too close to those of Nazi Germany.

It was only the advent of the Nazi extermination of the mentally impaired and sick in the hospitals, followed by the mass extermination of the death camps, which silenced intellectuals' overt enthusiasm for racial improvement through state-managed unnatural selection. But the intellectuals' concern about the national stock refused to disappear. The distinguished immunologist and director of the Medical Research Council Mill Hill Laboratories, Sir Peter Medawar, was still fretting away, in his 1958 Reith Lectures for the BBC, at the old eugenic question of whether the welfare state had interfered with natural selection, causing the quality of the UK national stock to deteriorate. Medawar entirely failed to see the incarceration of mentally disabled women as integral to an unspoken eugenic policy. Richard Titmuss, as a pioneering social policy analyst, was closely associated with the Eugenic Society and as late as the seventies, together with his economist colleague Brian Abel Smith, proposed an unequivocally eugenicist child allowance policy to the government of Mauritius. To deal with problems of both child poverty and what were seen as unacceptably large families, allowances were to be given only to those families who achieved the target size. Even the British Abortion Act of 1965 was conceived of as an unequivocally eugenicist project. It

6. Paul Weindling *Health, Race and German Politics between National Unification and Nazism: 1870-1945*, Cambridge, Cambridge University Press; Benno Muller Hill *Murderous Science: The Scientific Elimination of Jews, Gypsies and Others, Germany 1933-1945*, Oxford, Oxford University Press, 1998.

7. Theodor Adorno et al, *The Authoritarian Personality*, New York, W.W. Norton, 1983.

8. And indeed British 'New Women' novelists such as Sarah Grand – as discussed in Angelique Richardson, *Love and Eugenics in the Late Nineteenth Century: Rational Reproduction and the New Woman*, Oxford, Oxford University Press, 2003.

took the women's liberation movement and its impact on the medical and nursing professions for this to be transmuted into a service, which for early pregnancies, is de facto abortion on demand.

Within this consensus the voice of the Other who was to be on the receiving end of negative eugenics was excluded. It was not until the eighties that Swedish women who had been sterilised against their will, began to speak out against the abuse they had suffered. It is the unequivocal evidence of this widespread professional middle-class enthusiasm for eugenics in the past, from exactly the same social strata that today tend to downplay its risks, that should alert us to disingenuous claims masking the new forms of eugenics and the silences about the old.

## THE FIRST ETHICAL SPECIALITY

But the steady demythologising by historians of the vision of 1945 and the Nuremberg trials as a moral watershed is not simply a debunking of naïve hope. For one medical speciality, that renamed itself 'clinical' or 'medical' genetics, 1945 was indeed an ethical watershed. For this speciality had to confront, more than any other, the appalling revelations made public by Nuremberg of what their professional colleagues had been proudly engaged in, namely the selecting of the 'unfit' in order that they could be killed. Purging genetics from the moral contamination of the Nazis' monstrous eugenic project was crucial. The pioneering centres of eugenics, above all Cold Spring Harbor in the US, later under the directorship of Jim Watson to become the focus of the Human Genome Project, and also its British counterpart University College London (Galton's erstwhile academic address), were both reclaimed and renamed to become major centres of genetics.

Meanwhile clinical genetics radically transformed its values. Crucially it no longer saw itself as leading the eugenic programme on behalf of the state. Instead it began to develop new professional ethics that worked to put the patient at the centre of decision-making, with the clinician giving information about risk, but the patient being ultimately the one who took decisions. Giving information about genetic risk neutrally through non-directive counselling became the hallmark of the transformed speciality. Today much more of medicine shares this non-directive stance. Biomedical ethics - now integral to medical education - takes as central both the autonomy of the patient and also her right to give, or withhold, her informed consent.

Despite this transformation clinical genetics was and is caught in a major contradiction, most acutely seen in the old welfare state countries of Europe where medicine receives its resources from the state, and where a speciality such as clinical genetics has to make a political and economic argument that demonstrates its socio-economic value. This takes the form of cost benefit calculations made by the profession for policy consideration that turn on the collective eugenic advantages to be gained through providing clinical genetic services particularly in the antenatal clinic. It was argued by the profession

that the provision of diagnostic tests for, amongst others, Down's Syndrome, Cystic Fibrosis (CF) and Neural Tube Defect, to name three common problems, would lead to the reduction of children being born with these disabilities, and thus to considerable savings in public expenditure. However, increased DNA diagnostic capacity appears in a changing biomedical context, nowhere clearer than in the case of CF. In the 1950s many children born with CF were dead before the end of their first year of life, and typically that short life involved considerable respiratory distress for the infant. Finding a diagnostic tool which gave pregnant women the possibility of thinking about whether they wished to keep that pregnancy or to have an abortion seemed like a way of averting suffering. But both therapeutic and diagnostic capacity has radically changed over the years and today enhanced therapeutic skills give the majority of children born with CF a life expectancy of fifty.

Janus-like, clinical genetics shows one face to the patient and another to the state. It solves the contradiction in its position by making the assumption that the understanding of what constitutes a worthwhile life will be shared by service provider and service user alike. Further by making allowance for the personal, usually religious reservations of a statistical handful who will refuse abortion, clinical genetics argues that individual autonomy, informed choice and the state's wish to keep the numbers of children born with severe disabilities to the minimum will come together in a social and cultural consensus. Thus antenatal testing is based on an assumption of shared values of the worthwhile life, together with a built-in toleration for exceptions. Philosopher Phillip Kitcher goes so far as to advocate this situation as constituting utopian eugenics.<sup>9</sup> But however attractive this appeal to an invisible hand may sound, the claim requires empirical exploration. Does such a consensus of values exist, or do pregnant women often feel that the values of powerful others have been subtly, or not so subtly, imposed on them. Here the evidence is shakier as women in antenatal clinics often report feeling that they are on a conveyor belt and that it is not they who really get to make the decisions.

9. Phillip Kitcher, *Their Lives to Come: The Genetic Revolution and Human Possibilities*, London, Penguin, 1996.

In addition the tectonic plates of the belief that all women want a healthy normal baby - as defined by medical doctors - are beginning to crack. The voices of the disability movement begin to make themselves heard; hearing people uncomfortably learn to listen to the claims of deaf parents that they would much prefer a deaf child. A young man with Down's Syndrome intervenes effectively in a public debate about genetics testing and eugenics. Instead of the medical norm simply reigning unchallenged, ethical arguments increasingly have to be developed and argued for democratically. This is new moral territory.

The post-1945 muting of the potential and actual closeness of genetics and eugenics is in difficulties; many are aware of not just the difficulty but perhaps even the desirability of the stance of neutrality. Informed consent as material practice is being examined by ethnographers, and while few are ready to throw the idea away before we have some alternative, the reality of informed consent is, as a good deal of ethnographic research points out, a

good deal muddier than the bio-ethicist's armchair speculation would suggest. Above all, DNA information is understood by those working most closely with families with a history of risk of severe genetic disease as deeply embedded in context. Thence Italian jurist and EU bioethics committee member Stefano Rodota quotes evidence showing that, on being advised that their foetus shows problems, most pregnant women elect abortions where the regional authority provisions for disabled children and adults are poor, and least where provisions are good. What we get are the pregnant women's realistic appraisal of the life chances for themselves and their potential children. Such accounts suggest that Kitcher's belief in utopian eugenics can only be ethically sustained where women and their potential children are well supported.

## CHOICE AND THE NEW CONSUMER EUGENICS

With the state and biomedicine as the definer and enforcer of eugenic norms weakened as part of a general move towards greater individuality, the market, aided by biotechnological innovation, claims that this new alliance supports choice. But while compulsory state eugenicism is mostly a past matter, there is still plenty of eugenic pressure within a neo-liberal culture, economy and society.<sup>10</sup> Pointing to the statistic that genetic impairment only constitutes 3 per cent of all impairment may weaken the cost-benefit effectiveness of eugenicist claims that what is needed is a search and destroy operation, but what it does not do is to tackle the taken for granted eugenicism in which some 'right hands' decide which of the 'impaired' foetuses need to have maternal decisions made about their survival. Nor does antenatal testing which claims to give reassurance to the woman unambiguously provide it, for with it, as Josephine Green notes, comes a new anxiety as to whether the foetus is good enough to continue the pregnancy.<sup>11</sup>

When Jim Watson was once asked what he thought about the eugenic implications of the Human Genome Project and he replied 'well it's no fun being around dumb people', his remark was widely seen as offensive. But what is so very different, certainly so far as political activists with learning disabilities are concerned, between Watson's characteristic bluntness, and the routine offering of amniocentesis and chorionic villae tests to all women over thirty-five attending the antenatal clinic? Both are expressions of the dominant cultural assumption that the presence of learning-disabled people within the family and within society at large is problematic. It is this unresolved (and maybe irresolvable) debate which is now being articulated more clearly - and, for perhaps the first time, with the voices of the eugenicised 'unfit' as part of the conversation.

## THE LIMITS OF THE BIOETHICAL ENTERPRISE?

Of course, it is not only the cultural climate that has changed in the sixty years since 1945. Genetics as both a science and as a technology (more precisely

10. Troy Duster, *Back Door to Eugenics*, New York, Routledge, 1990.

11. Josephine Green, *Calming or Harming? A Critical Overview of Psychological Effects of Foetal Diagnosis on Pregnant Women*, Galton Institute Occasional Papers, 2 (1990).

a technoscience) has itself been transformed beyond recognition. From Crick and Watson's 1953 discovery of the structure of DNA as the genetic material, through the mapping of the human genome, to the widening practice of genetic diagnosis, population-wide genetic databanks and genetic manipulation of the embryo has moved steadily from the realms of science fiction into everyday experience in the laboratory and the clinic, throwing up ever-deeper challenges to ethical and social mores.

It was the recognition of these ethical and social challenges that led Watson, as the first director of the Human Genome Project, to allocate some 3 per cent of its budget to research on its ethical, legal and social implications to assuage public concerns. Today, as we confront the economic and technical power of biotechnology of the twenty first-century, eugenics/genetics again pose ethical problems of existential significance. Just what kind of human being is that bio-technologically constructed baby - the cloned child. As Jurgen Habermas asks: what do we do about a human nature that is no longer grown but made?<sup>12</sup>

Habermas' question poses a fundamental ethical and political challenge. As we are learning, genetics and eugenics already enter into personal life in intimately disturbing ways, as indeed my own distress in learning to live with the relatively minor problem of finding that I have an inherited predisposition to heart disease with the risk of early death. Genetics and eugenics are not just out there to be studied and thought about as two separate (or connected) cultural or social histories, nor is it just that they touch us deeply in our personal lives, but that they now raise the possibility of a different collective future, of genetically manipulated human beings. The extraordinary powers of biotechnology are disturbing at many levels simultaneously: our sense of origins, our identity and our future as human beings have to be confronted. Neither a playful postmodernist enthusiasm for cyborgs, nor a pragmatic modernism tacitly accepting biotechnological inevitability, can meet such an existential challenge.

Nor is it clear that bioethics, this spin-off from philosophy directed towards thinking about the ethical appropriateness of biotechnological advances, is capable of this confrontation. As US historian Charles Rosenberg observed, much of what goes under the name of bioethics is more an enterprise than a discipline.<sup>13</sup> At worst it serves as a handmaiden to smooth the way, making only small adjustments, for the acceptance of biotechnology. Indeed bioethics has become an institutionalised aspect of any significant biotechnological project, so that hiring a bioethicist is an essential on-cost to be built into the business plan of any project. The weakness of most bioethics rests in its location within, and thence uncritical acceptance of, modernism as it is presently understood with science and its construction of rationality at the core. Thus bioethics as secular criticism of biotechnology has no place to stand except more or less shoulder to shoulder with biotechnology itself.

Habermas's call for a post-secular ethical thoughtfulness represents an attempt to jump over this elision of secular ethics and the acceptance

12. Jurgen Habermas, *The Future of Human Nature*, Cambridge, Polity 2003.

13. Charles E. Rosenberg, 'Meanings, policies, and medicine: On the bioethical enterprise and history,' *Daedalus*, Fall 1999.

of biotechnological innovation. Without this move it is all too easy for the religious to be the only audible critics of biotechnology, and secular criticism become marginalised. Habermas' insight would explain why, in Britain, despite this being one of the most secular countries in the world, it is extremely difficult for non-religious opposition - apart from the disability movement - to make itself heard. The media, the government and the scientific elite play into the old dichotomy between traditionalism and modernism. Thus any public committee appointed to consider ethical aspects of genetics will be sure to include religious leaders even though they may have few followers. A post secular ethics which recognises the deep religious underpinnings to our concept of secularity, might help reconstruct the exhausted concept of modernity itself.

A modernist ethical evaluation of scientific and technological innovation rarely goes beyond 'how?' questions, and seems almost incapable of addressing 'whether?' questions. Faced with technological possibilities which are profoundly morally disturbing, the tendency - shown for example in the Warnock Committee's treatment of the possibility of human cloning - is to kick the problem into the long grass by declaring the possibility as technically remote. When the issue inescapably returns, as in the post-Dolly scenario, the research community and the bioethical enterprise together tend to offer reassurance along the lines that such a development is ethically unthinkable and therefore will not happen. The British government colluded with the belief that such linguistic strategies were adequate and it was only the successful legal challenge brought by Catholic Pro-Life interests which revealed its inadequacy and compelled legislation outlawing human reproductive cloning.

Gene therapy offers an illuminating case study both of the limits of bioethics as well as of the limits of the promises of biotechnology. Initially gene therapy was seen as 'the' solution for managing, not just known genetic disease, but every major killer from cancer to heart disease. The claims of gene therapy knew no bounds: the much quoted 1989 editorial of *Science* (the most influential US natural science journal) insisted that gene therapy would also cure nothing less than homelessness.<sup>14</sup> Alongside such Promethean claims was the recognition that gene therapy was ethically sensitive. With biology opening new possibilities with unknowable social implications, the molecular biology community, echoed by the ethicists, proposed a sharp ethical divide between somatic genetic therapy and germ-line therapy. The former, being limited to the body of the patient receiving the treatment, was seen as ethically acceptable because not fundamentally different from other therapies. The latter, germ therapy, as potentially affecting the population gene pool, was ruled out on bioethical grounds. Unfortunately somatic therapy proved to be technically much tougher to realise than initially envisaged, with rather few, if any, clear-cut successes. That some children with a severe genetic disease improved is a success; that a sub section of them developed cancer led to the work being terminated. The death of the eighteen-year-old American Jesse Gelsinger, recruited inappropriately into a risky genetic therapy trial,

14. Editorial, *Science*, October 13 1989, 246, 189.

led to gene therapy losing most of its support. Further, given that expert bio-ethicists were an integral component of such trials, their own role in the innovation process began to be questioned. Were bio-ethicists hired to protect the researchers and their commercial backers or were they there to protect patients?

As somatic therapy increasingly came to be seen as failing to deliver the promised biomedical results, the hitherto robust opposition to germ-line therapy began to falter. The technical possibilities of potentially realisable germ-line approaches, with concomitant benefits to the individual patient, were increasingly emphasised and the dangers to the gene pool de-emphasised. The hitherto unbridgeable ethical divide was beginning to be linguistically bridged.

A similar ethical and linguistic slippage has been taking place in the recent debates around therapeutic human cloning. The interpolation of the term 'therapeutic' was to indicate that although the technique of cloning directed towards reproducing a human being was identical to that of therapeutic cloning, the different intention (semantically marked and regulated by legislation) constructed an adequate line of defence between the two. British opponents of embryonic stem cell research, whether religious or secular, though comforted by the eventual legislation outlawing human reproductive cloning, remain unconvinced by this semantic and regulatory difference. Once the technique was developed the chances of limiting its use to therapeutic ends seemed over hopeful. However, the British Government determined to secure a biotechnological lead, accepted the therapeutic promise as real and eased the innovatory path in a way deplored by many of their fellow European member states. While it is not difficult to understand how those, like the actor Christopher Reeve confronting paraplegia after a riding accident, become enthusiastic supporters of embryonic stem cell research with its power charged language of toti-potent cells able to generate any kind of needed replacement tissue, it would surely be welcome if the political classes retained more scepticism. The very modest gains from the inflated claims of gene therapy should have warned them at least to be cautious about the molecular biologists again claiming to bear gifts.

Now UK resources have been committed to embryo stem cell research, over recent months another new shift in language is detectable. Increasingly those near the frontiers of therapeutic cloning are de-emphasising that once vaunted word 'therapeutic'. In nuanced tones they speak of the therapeutic word not being really 'useful', not really 'quite accurate', and speak instead of the length of time needed before such work produces therapeutic deliverables. Correspondingly, the promises to society are modified and, rather than therapeutic gains, we learn that the really important gain is for knowledge itself, namely that embryonic stem cell research will produce fundamental advances in biology. Thus the term currently favoured by the International Society for Stem Cell Research is 'nuclear transfer': a term both devoid of therapeutic promise and also avoiding the ethically provocative concept of

'cloning'. If this compressed reading of the way in which the therapeutic promises of stem cell research have first been flaunted by the research community, then modified and almost withdrawn once the material resources are secured, is accurate, then the hopes of Christopher Reeve lie as dead as his body. And, as in the gene therapy trials, bioethicists have been integral to the entire development.

The recognition of the importance of bioethics in contemporary debates about biotechnology led to the moral philosopher and influential bio-ethicist Onora O'Neill being invited to give the BBC Reith lectures in 2001-2. She took as her topic the currently much debated loss of trust, yet her treatment is emblematic of my concerns about the thin gruel of much of Anglo-American bioethics. O'Neil explores what she calls a culture of suspicion fostered by the media, modern managerial enthusiasms for targets and excessive transparency - processes she sees as damaging professionalism and thence trust. Nowhere does she address head on, as Habermas does, the possibility that the suspicions might be well founded, that science and technology are generating historically new risks to the humanness of our human nature. But it seems that our cultural ability to think about risks to our humanness is weaker than our ability to theorise the risks generated by science and technology for the environment. The risk to green nature is much better politically and culturally articulated than is the risk to the red nature of our own bodies. Thus environmental questions of 'whether' are clearly on the agenda, as in the current debate about nuclear power, while the debates about the implications of biomedical innovation about our humanness are less well articulated and the ethical questions in consequence are restricted to questions of 'how'.

## REMAKING HUMAN BEINGS

What human beings might become with these new biotechnological capacities is outlined by US molecular biologist Lee Silver, in *Remaking Eden: Cloning and Beyond in the Brave New World*.<sup>15</sup> His unequivocal view is that as biotechnology develops the capacity genetically to engineer foetuses, those who can afford to specify the physical and mental features of their future children will do so. For Silver, Aldous Huxley's dystopia has come into practical reach, not to be imposed by any state, but freely chosen by all those who can afford to do so. The prime technical means of this transformation would be through an expansion of pre-implantation genetic diagnosis (PGD), in which the embryo is tested in vitro and only implanted if its DNA profile meets the required specification. Such pre-implantation diagnoses are regarded with unease in Europe, and above all by Germany with its hard-earned understanding of eugenics. In Britain PGD is supposed to be strictly regulated, and be available only where would-be parents are at risk of having a profoundly disabled child. But as being profoundly disabled has been agreed by both clinicians and the court as including a foetus with merely a hare lip, British institutions appear to offer thin protection against a creeping consumer eugenics.

15. Lee Silver, *Remaking Eden: Cloning and Beyond in the Brave World*, London Phoenix 1999.

From PGD being used only in circumstances where it allows the selection of an embryo without some devastating disease, it has increasingly come into public visibility in selecting an embryo - the future saviour sibling - with a predefined DNA profile to provide healthy tissue for an already existing sick child. In the bioethical debates which took place within UNESCO and similar elevated settings, and which anticipated such possible technical developments, the idea of selecting a saviour sibling was rejected as ethically abhorrent, as turning a child into a mere instrument. It also abuses her right to bodily integrity, for there is no possibility of informed consent for that genetically selected child to give or withhold her tissue.

The first of these stories to hit the headlines was of the US Nash family. The Nash family, young and comfortably off, had a small daughter, Mandy, with a potentially fatal genetic disease. The only hope was a cell transfer from an appropriately DNA-matched donor. To achieve this matched donor, in vitro-developed embryos were subjected to pre-implantation DNA scrutiny to select an embryo whose DNA profile would have the healthy replacement cells. The sense of horror that a child could be brought into the world as a compulsory donor to save the life of an already existing child competed with the claim that this was the only way that the existing child could be saved, that human beings had children for a number of complicated reasons, and that as the Nashes wanted more than one child, the boy born as the result of these procedures would be loved anyway. The couple and their children were extensively interviewed and photographed. A potentially morally controversial innovation was personalised, the Nashes appeared to be ordinary loving parents, just in a tough place trying to do the best given the available technical and material resources. The personalisation alchemy worked, consumerist eugenicism disappears off the public agenda transmuted into an ideology of trust in parental love (and trust in biomedicine).

The reciprocal and complex relations between the Nashes, their biomedical advisors and the media create a template as a suffering but courageous family for other families and their biomedical advisers to copy. The story must begin with the imminent death of an already existing child and the biomedical claim that only the cell tissues from a DNA-selected sibling can save them. It helps if the parents are both photogenic and willing to appear posed with their existing affected child. Even in a recent British case where there were serious doubts by specialists in the management of Thalassaemia about the legitimacy of the claim of inexorable death, such a technical challenge so far has not been able to break surface. No one, it seems, is willing to take on the manifestly suffering parents and their sick child, and as emblems of suffering parental love they become the Trojan horse of a consumer eugenics through which a child is more made than grown.

What we see in the Nash case is the development of a consensus that these particular parents are so exceptional that they will love both the grown and the made children equally, the unborn child will be pleased with their unnatural selection and indeed that this is a happy ethical story for all the actors. Those

not quite able to sign up to this heart-warming tale, who worry about what propels parents to advertise their most intimate distress in the media and who have a sense of the contingency of family relationships, are left with the dour adage that bad law tends to be made from hard cases. The construction of such children from such babies demands deep moral collective reflection on the part of civil society, not just mediatic churning

## THE OTHER SPEAKS

The crisis of trust in science, which surfaced publicly in the mid eighties in Britain with the report of the Royal Society on *The Public Understanding of Science*, has seen a huge flurry of innovation in the European countries trying to close the trust gap between 'science' and 'society'. The extraordinary European-wide consumer rejection of genetically modified food - a rejection which did not significantly affect the United States - compelled European governments, who had historically depended on expert advice to frame their research policy, realise that they had to re-think the systems of governance in science. While other countries experimented with citizens' juries, social technology assessment, science shops and the like, the British initially followed the public understanding path to closing the trust gap. Predictably the monologic model was less than successful, and was soon replaced by the rather more dialogic model provided by the 'public engagement' with science. But the government also introduced new research policy advisory bodies such as the Human Genetics Commission, which brought in hitherto excluded voices, not least activists from the disability movement. While new lay experts in human genetics (in addition to the usual scientific experts) entered the advisory process, nonetheless there was, not least by comparison with the depth and range of the environmental debate, a much weaker debate about the larger bio-societal implications of human genetics. But these innovative, more socially inclusive institutions of science governance are far from secure. The liveliest has already been terminated by the government as being 'too green', but so far as human genetics is concerned there are still grounds for cautious optimism, simply because the genie of citizen involvement is out of the bottle. Most precious of all, in the plethora of expert voices, the hitherto silenced eugenicised Other speaks.