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THE POLITICAL ECONOMY OF GENES

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The relationship between technology and society is complex. This paper considers the social shaping of the biotechnologies arising out of the Human Genome Project (HGP). It examines the political economic context in which the project has developed, and the values and assumptions that underlie the it.

Begun in the USA and now happening in a number of other countries including Australia, the project involves identifying and mapping the fifty to hundred thousand genes on the twenty-three human chromosomes and sequencing the approximately three billion nucleotide bases from which these genes are composed. Funded through the US Department of Energy, some three billions dollars are involved. This makes it the largest scientific project since the Moonshot. Since it began in 1988, rapid progress has been made and it seems likely that the whole Human Genome will be mapped by early next century. However, the pace at which the project is proceeding and the resultant discoveries of the locations of supposed disease-producing genes, is far outstripping the development of an understanding of the full social, cultural, legal and ethical implications of the findings.

Two approaches have run in parallel as the huge project has evolved. One is the basic molecular biochemistry scientific mapping of each human chromosome and its genes. The other is more targeted searches for genes thought to be responsible for certain ill health conditions, with the intention of trying to develop lucrative biotechnologies to alleviate them. This latter aspect of the project has two aims. The first target is what might be called disease genetics. This is the search for specific genes thought to cause certain ill health conditions. A number have

already been identified; for example certain types of breast and ovarian cancer, Huntington's disease, Cystic Fibrosis and other heritable conditions. The second and much more controversial target has been in the area of behavioural genetics. This has involved a search for genes which are thought are likely to affect behaviours associated with such conditions as depression, alcoholism, homosexuality, and obesity. Indeed, there have been claims that this research is resolving the nature/nurture debate finally in favour of nature. However, only weak associations have been found so far, and some of the early findings have not been able to be replicated by other research groups (see Hubbard and Wald, 1993; Peale and DeGrandpre, 1995).

The Social Shaping of Technology

Analysing the social shaping of biotechnology involves considering the social, political and economic processes that shape the project. In what ways has the sort of society in which we live given rise to the HGP? Scientific activity does not occur in some sort of political and economic vacuum, as has been shown by LaTour and Woolgar (1979) and other writers within the Social Studies of Scientific Knowledge (SSK) approach to the analysis of science and technology. This approach argues that scientific research represents not the uncovering of new knowledge, but a fierce fight to construct reality. As Sylvia Tesh (1988) has argued, science is essentially a social process in which scientists turn to values to decide what are the pertinent issues to research, rather than being an independent or neutral process. Values associated with alleviating the often terrible suffering associated with genetically caused diseases are important, but by no means the whole story.

There are several issues to consider. The first is the equity of resource allocation. The project represents a huge allocation of resources to this one scientific project. Although much research points to the social and political influences on patterns of disease (see Macklin, 1992), the world view underpinning the HGP remains within an individualised and biologically determinist view of human health and illness. Certainly, those affected with conditions influenced by genes experience considerable suffering. However, the relationship between health and

social class is very well documented (see Broadhead, 1985). What this project is doing is focusing on ill health as an individual and biological phenomenon rather than one with considerable social and political dimensions. Three billion dollars would make some impact on alleviating the sources of ill health but it is not given for those purposes. As a result of the huge investment in this project, there may be less money available for public health measures. Why is such a huge amount of money allocated to this project when there are many other pressing needs in the US, the most basic of which of course is the 37 million Americans who have no health insurance coverage at all?

The political economic context is important in explaining why this occurs. It suits the ideological climate of the day. The project was conceived in Reaganite times when the causes of disease were attributed to an individual's genes, rather than their social and political context. According to this genetic reductionist view, the individual is the sum of their genes. This represents the latest version of the 'biology is destiny' idea; a sort of 'genes-R-us' approach. It is a new twist to Social Darwinism and sociobiology. In the past the search was for 'germs'. The Rockefeller Foundation funded research into germs for laziness in the 1930s in the American South (see Brown, 1979). Now the focus is on genes. The move from germs to genes focuses attention away from the social environment. As Hilary Rose (1994:173) argues "This new genetics, a product of an alliance between an aggressively entrepreneurial culture and life sciences, fused the conservatism of biology as destiny with the modernist philosophy of genetic manipulation". It is a modernist project because it is based on a belief that the problems faced by humanity can be solved by rational applications of science and technology

Furthermore, there is a clear political program attached to this research project. This helps explain its funding in circumstances where neo-conservative economics blanket the globe and in the context of the hegemony of post-cold war American values. This context is important in providing a rationale and a justification for inequality, if people are the way they are because of their genes rather than the sort of society they live in. Government programs are not likely to make any impact: social justice programs can be abolished and taxes cut. Arguments for

the genetic basis to intelligence reflect this agenda. Writers such as US education professor Seymour Itzchoff (1994), for instance, advocate an end to welfare programs, radical reform of the US academic and Employment Affirmative Action programs and a tightening of immigration standards on the basis of what is claimed to be the demonstrated genetic basis to intelligence.

The conservative individualist world view at the basis of the Human Genome Project is also revealed by a number of other issues. The first is part of the project which is called the Human Genome Diversity Project (Genewatch, 1994:4). The controversy surrounds the world's threatened native peoples. This project is collecting DNA samples from the hair and blood of 10 to 15,000 indigenous persons from more than 700 ethnic communities, especially those that are endangered, at a cost of \$US23m. dollars. The reason is that slight variation in the Human Genome between different ethnic communities could have medical and commercial significance. The controversy has been brought to a head in Guatemala, where an indigenous group, the Guaymi Indians, have demanded that genetic samples taken without permission be returned to them; labelling what has occurred as 'biopiracy'. The main concern with this part of the Human Genome Project is that resources are being expended to catalogue hair and blood samples rather than trying to work in some broader way, such as advocating land rights, to try and save the worlds endangered ethnic groups.

Another area of the application of the findings of the Human Genome Project is in the occupational health and safety field. Employers are moving to protect workers' compensation cost by screening for genetic susceptibility (see Draper, 1991; Suzuki, 1990). So before commencing work in the chemical industry for instance, workers are screened for susceptibility to certain sorts of chemically induced ill health conditions. It is a form of victim blaming - focussing on individuals who are risky rather than on risky work practices or substances. It is done ostensibly in the name of protecting the interests of workers but is actually used to prevent apparently susceptible workers from doing particular jobs. The effect is to reinforce the traditional managerialist response to occupational health and safety - 'fix the worker, not the workplace'.

Finally, the Human Genome Project provides for opportunities for capital accumulation, with the entry of venture capital and the establishment of companies to benefit from bio-technology. Indeed, it could be argued that the purpose of the Human Genome Project, and the reason why the American Government has funded it so heavily, is to give the American bio-technology industry a competitive edge in the lucrative world market. Many geneticists have formed their own private companies with venture capital backing. In 1993, for example, \$85m was spent on private genetic research ventures in the United States (Anderson, 1993:300). As Rose (1994:201) comments "For capital what was on offer was the potential profits to the pharmaceutical industry as gene sequencing identified the potential sites of what were portrayed as disease threatening genes. Diagnostic kits to detect the new genes in routine screening were to be followed by therapeutic genetic interventions".

This commercialisation of gene research has led to a debate over the appropriateness of patenting, which is the conventional means of protecting investments in new technology, in this new 'industry'. Can you own genes? The official American position is that all life forms should be patentable. Others have argued that commodifying nature in this way encourages a new closed research culture to replace the traditionally more open approach to publication in scientific journals (see Chalmers *et al.*, 1995:31). Patent laws are concerned with inventions; something human genes are not. As a result human material should be exempted from the patent claims. Furthermore the fragile international collaborative effort would be and has been threatened by widespread patenting: a controversy that eventually led to the departure of the first director of the Project in the US, James Watson. The American view seems to have prevailed. In other words, the scientific effect is being shaped by values. The race is to develop a marketable product from which profits can be made. This contradiction between international cooperation versus national competitiveness is relevant to debates about globalisation.

The Implications for 'Normality'

The fact that gene research is now an arena for capital accumulation has other problematic effects. Once a market has been created, expansion of that market to other areas is sought. One clear example from the history of genetics is Human Growth Hormone (HGH): a synthetic genetically engineered product given to very short people to increase their height. HGH is very expensive (about US\$20,000 per year) and gives most children about two extra inches of height. This treatment was first developed for people who were very short as a result of rare medical problems such as pituitary dwarfism. Because there are too few of such people to maximise the market potential of the product, new markets have been sought, especially people at the short end of the normal height distribution. The company producing HGH has argued that any child whose height falls within the lowest 3% of the population should be considered for treatment. Parents who have been able to afford to pay for this technology and who know of the well documented research about the advantage of height in social terms, especially for their sons, have been prepared to buy the treatment (See Hubbard and Wald, 1993:69-70). There is also an emerging 'black' market in the body building subculture, where HGH is the performance-enhancing substance now replacing anabolic steroids. Because it is naturally occurring, this latest form of cheating cannot be detected by any drug test and so is attractive to sports people. Looming also is the controversial suggestion that HGH might slow some of the ageing processes (Wilkie, 1994:62,136).

The story of HGH offers insights into what might happen with technological developments arising out of the HGP. The unintended or unforeseen consequences may be as important as the intended ones. Take the discovery of the so called 'Fat Gene,' thought to cause obesity. If an effective treatment based on this discovery can be developed, it should help morbidly obese people. But there is also a huge market for people within the normal range of the body mass index but who are keen on body shaping. What it might do for people who have eating disorders such as anorexia is disastrous. Furthermore, like HGH, the technology is likely to be expensive and available only to those who can pay.

So the standard question of the social relations of medical technology is relevant - whom will it benefit? Will all people benefit or some more than others? David Suzuki (1990) poses a question which needs to be taken seriously, 'will the world as a whole be a better place for the Human Genome Project?'. Or will only some people benefit: those that can afford the technology?

Also relevant in the debates about the uses to which the scientific knowledge arising out of the project might be put is the hegemony of the (American) discourse about Rights. This has a highly individualist focus and is now strongly represented in the bio-ethics field. The assertion is that if people can pay, they should have the right to have treatments available. Why should the availability of technology be restricted? People should have the choice. This view is opposed to more collectivist notions about effective use of resources being directed to more public health ends from which everyone benefits.

One of the effects of this discourse is to narrow the range of what we consider 'normal'. The examples of height and weight given above illustrate this. Health and illness are culturally constructed categories so that what is considered health or illness changes with cultural and historical context. But as more and more tests become available as part of routine medical examinations, the 'pathology' that we all carry with us is more able to be diagnosed. It is like an iceberg. Only the 'tip' of this pathology is available for surveillance by current medical testing. The impact of developing more and better diagnostic tests is that the iceberg will rise out of water. With the development of more and more sophisticated diagnostic tests, we will be able to plumb the depths of pathology and narrow the range of what is considered normal. The consequences can be enormous, from denial of insurance cover and being refused jobs through to the creation of a 'genetic underclass' of asymptomatic individuals. The eugenicist notion of 'genetic hygiene' seems likely to reappear, perhaps in a new guise.

To understand the implications, it is useful to pose the following question: under what circumstances is the sort of knowledge which the Human Genome Project is going to generate likely to be oppressive or liberating for individuals? It seems likely for instance that disability will

become increasingly class related if you are not able to pay to overcome quite large areas of disability that may be the result of genetic 'defects'.

Media Reporting

The 'technophilia' with which the findings of the HGP are reported also have the effect of narrowing the range of normality. An example is the discovery of the so-called breast cancer genes, BRCA1 and BRCA2, which account for between five and ten per cent of all breast cancers (*New Scientist* 24\9\94:2), affecting younger women in particular. For those people the presence of these genes is obviously a major problem. But in the euphoria surrounding the finding of these genes, there is rarely more than a passing mention of the fact that this finding does not actually yet have any practical purpose. Knowing that you have the gene doesn't mean that you can do anything about it, except prophylactic breast removal. The efficacy of even that drastic a response is also unknown. But talking up the findings is important to the share price under venture capitalism. There is a parallel with the mining industry in the share market where reports of a 'find' are crucial to improvements in the share price.

Another example of inadequate media reporting was the news that a research team had discovered a gene for predisposition to alcoholism. This, making front page headlines in the *New York Times* for instance, was a major news story. A few months later, a report that two other teams had failed to replicate the original findings got a very small mention at page nine or ten (see Kevles and Hood, 1992:327).

Conclusion

Kenen (1995) has argued that control over nature has been a dominant theme in American culture and is part of a modernist (over)confidence that technological solutions can be found for problems facing the society. Such control over nature as a result of science and technological innovation, can also be seen as growing control of some people over

other people with nature as their tool. The Human Genome Project represents the commodification of nature. The 'technological imperative' is in fact an economic imperative with technology as the tool. What technologies are implemented and how they are implemented relates to questions of capital accumulation as well as power and social control.

Genetic research and technology are shaped by the sort of society in which we live. The social aspects are not merely technical details of implementation. Technology is not like a great boulder rolling down the hill smashing everything in its path in the name of a 'technological imperative.' A full account of the political economy of genes is indispensable in understanding the clear political choices which have been and continue to be made about the Human Genome Project.

References

- Anderson, C (1993) "Genome Project goes Commercial", *Science*, 259:300
- Brown, E.Richard (1979) *Rockefeller Medicine Men*. Berkeley, University of California Press.
- Chalmers, Don, Margaret Otlowski, Dianne Nicol and Loanne Skene (1995) "Current Research: Project on the Legal, and Ethical Aspects of Genetic Research In Australia" *Journal of Law and Medicine*, vol 3, no 1; pp30-35
- Draper, Elaine. (1991) *Risky Business: Genetic Testing and Exclusionary Practice in Hazardous Workplaces*, Cambridge, Cambridge University Press.
- Duster, Troy (1990) *Backdoor to Eugenics*, New York, Routledge.
- Genewatch (1994) "An Interview with Devon Pena" (Council for Responsible Genetics), vol 9, no 5-6, nov.
- Hubbard, Ruth and Elijah Wald (1993) *Exploding the Gene Myth: How Genetic Information is Produced and Manipulated by Scientists, Physicians, Employers, Insurance Companies, Educators and Law Enforcers*, Boston, Beacon Press.
- Itzkoff, Seymour (1994) *The Decline of Education in America: a Strategy for National Renewal*, Westport, Conn, Praeger.
- Kenen, Regina. (1995) "The Human Genome Project: creator of the potentially sick, the potentially vulnerable and potentially stigmatised" in Ian Robinson (ed) *Life and Death under High Technology Medicine*, Manchester, University of Manchester Press.

Kevles, Daniel and Leroy Hood (1992) "Reflections" in Kevles and Hood (eds) *The Code of Codes: Scientific and Social Issues in the Human Genome Project*, Cambridge, Mass, Harvard University Press.

LaTour, Bruno and Steve Woolgar (1979) *Laboratory Life: the Social Construction of Scientific Facts*, Beverly Hills, Sage.

Macklin, J. (1992) *Enough to make you sick: How income and environment affect health*, National Health Strategy, Research Paper No 1, Canberra

Peale, Stanton and Richard DeGrandpre (1995) "My Genes made me do it", *Psychology Today*, July/August, pp 50-68

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

Suzuki, David and Peter Knudson (1990) *Genethics: the Ethics of Engineering Life*, Rev edn, Toronto, Stoddart.

Tesh, Sylvia (1988) *Hidden Arguments: Political Ideology and Disease Prevention*, New Brunswick, N.J., Rutgers University Press.

Wilkie, Tom (1994) *Perilous Knowledge: The Human Genome Project and Its Implications*, London, Faber and Faber.

