

# **SUBMISSION:**

## **re Scientific, Ethical and Regulatory Considerations relevant to Cloning of Human Beings**

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Rapid increases in technology in the area of genetics has prompted organisations nationally and internationally to consider the impact of the use of this technology on the community. As a result AHEC have produced this paper concerning the Scientific, Ethical and Regulatory considerations relevant to Cloning of Human Beings; and it is as a concerned member of the community that I respond to the call for submissions to comment on this paper.

Firstly I would like to say that I thought the paper was well written and brought up many of the salient scientific and ethical issues, both intrinsic and consequential, arising from gene technology as it pertains to cloning of human beings. Secondly I welcome this opportunity to comment on the paper and voice my opinion and concern about the various issues.

The intrinsic and consequential issue that were dealt with in most detail, were those questioning the safety and feasibility of the technology itself. While these are important I believe that a fundamental consideration underpinning any ethical discussion is to acknowledge the social structures which permeate our views. Personally I feel that regardless of Australian and International regulation, it is only a matter of time before technical expertise progresses to a point where questions about safety and feasibility are moot. Then the consideration of the broader, deeper politico-environmental aspects will be vital. It would be prudent to acknowledge and consider the social underpinnings, such as the driving force behind biotechnology .

Many of the concerns I will raise in this submission, while in this context regard cloning specifically, have significant bearing on human gene technology and the whole of biotechnology in general. Where this is true I intend my arguments to be inclusive; nevertheless I acknowledge that this is beyond the scope of the Considerations presented in this paper.

### **1) Recommendations**

**1:** I am pleased the Commonwealth Government will reaffirm its support for the UNESCO *Declaration on the Human Genome and Human Rights*, in particular, in the context of this paper, Article 11 which pertains to cloning. I believe however that the standards reflected in this Declaration should lead to overarching, binding, enforceable Commonwealth Legislation.

**2 & 3:** I agree with the Commonwealth Government in their urging that all States and Territories should establish uniform legislation regulating embryo research, and prohibiting the cloning of human beings; and the formation of statutory authorities to enforce this regulation. The principles and guidelines outlined by the NHMRC's *Ethical Guidelines on Assisted reproductive Technology* and *Statement on Human Experimentation and Supplementary Notes* are voluntary and only enforceable against institutions receiving NHMRC funding. As the possibility exists that a private institution could decide to undertake such work, I believe it is imperative that legislation is formulated across Australia. Some believe that bodies such as NHMRC (and GMAC) operate too closely with industry, therefore I personally believe that we require independent overarching national legislation.

**4:** Community discussion regarding cloning and other gene technology should be mandatory if the Commonwealth Government is to be seen as following democratic

process. Regulation must be responsible, involving the principles of transparency, accountability, and informed public participation in the decision making process.

## **2) Regulation**

The following concepts and the values in them, should form the basis of principles for Responsible Regulation. Although the context here is Human Cloning, these principles are applicable to, and inclusive of gene-technology / biotechnology / technology in general.

The concepts are Interdependence, Wholeness and Emergence, forming the basis of ecological principles such as Ecologically Sustainable Development and the Precautionary Principle. The constituent parts of the inorganic, biological, social and intellectual systems are not fragmented or discrete. They interact dynamically to produce an ordered self-organising stable complex whole; it is not just the constituent parts but the interactions between them that are important to a more profound understanding of nature and the role of humans in it.

Understanding the interdependent nature of the world enables us to see the connections between the biological and cultural worlds. Issues of risk become relative and contextual and must therefore be determined by a process that involves all stakeholders. As mentioned above, an independent, national, open, visible, accountable, reflexive regulatory mechanism involving public participation is essential in the process of assessing the impact of cloning techniques and other biotechnology.

Although not directly applicable to cloning technology, the above are relevant when talking about nature and biotechnology in general, and hence are pertinent to discussions about responsible regulation. For gene technology to be regulated, ecological, social, religious, ethical and cultural impacts must be considered. That is, not regulating simply the process or the product.

Proponents of research projects must be accountable and able to prove that their projects work to responsible broader socio-environmental criteria. The legislative body must be committed to the principle of comprehensive evaluation, multidisciplinary and broadly representative of society.

Please see Appendix 1 for further details.

## **3) The Social underpinnings of Science Medicine and Health**

Modern Western thought invests much of what it believes to be true about the nature of the universe to the insights of science. The modern features of which still reflect the philosophical world view of Descartes and Bacon. This leads to the reduction of all things to the sum of their smallest measurable units, defining them mechanistically by these component parts, and determining future functions on the basis of a belief in linear cause and effect. These are fundamental constructs in the interpretation of life with regard to gene technology in general, and human genetics and cloning specifically; quite contrary to the principles listed above.

Genes function in a multi-dimensional manner beyond the molecular. While this is, quite rightly, acknowledged in this paper, this consideration does not appear to guide research regarding human health; rather, despite this contextual nature of genes, much research today is conducted on the basis of genetic determinism.

This scientific world view has permeated modern medicine. This framework leads to certain types of remedy that are highly specific to the symptoms, and predominantly involve repair, replacement or removal of a part, and are curative rather than preventative in their nature. These remedies now potentially include gene technology and cloning techniques.

It can be argued however that health has positive attributes that make it more than the lack of disease; that it is multifaceted and not merely a reflection of physical wellbeing. Human beings exist in, and respond to, not only internal changes, but to external physical and social environments. A new model for health and medicine is required. A more complete epistemology would be one that encourages contextual understanding and recognises the interconnectedness of factors. Public health policy should reflect this holistic view.

#### **4) The Politics of Disease, Disability and Infertility**

Many of the areas of interest in genetic studies of humans are those with stigma attached, and are very emotive. Examples include Alcoholism various disabilities and Infertility. Our society makes people disabled by not providing various types of aids. Poor access to buildings, little suitable transport or housing prevent people from being able and leading fully autonomous lives.

A crucial point with talking about disease is to ask, Is it bad? Who is it bad for? Whose burden is actually being lifted when relieving the suffering of the sick? it makes a difference whose evaluation it is and who's purpose it serves. I believe this is an important consideration with regard to regulation of human biotechnology and cloning.

An major area of concern raised several times in this paper's context of ethical considerations relevant to cloning is reproductive technology. Studies have shown that male infertility is a very significant cause of a couple's infertility. The suspected sources are predominantly environmental or lifestyle in nature; things that can and should be altered. Yet the focus is women, and part of this I believe is the social stigma that ensues from being childless, and partly due to the vested interests of the multinational pharmaceutical companies exploiting those stigmas by now investing in human gene technology including cloning.

I believe that this concern should be further investigated with regard to regulation of assisted reproductive technology and cloning.

For further discussion see below and Appendix 2.

#### **5) The Politics of Technology and Research**

I believe this discussion paper needs to show greater acknowledgment that our understanding of genes, medicine, science and technology have a cultural origin; and consider this for future assessment of research proposals.

I think it is appropriate to raise here that science, technology and research are not neutral. Science is not objective; it is value laden. The priorities of research and the goals and methods chosen dictate which information is used, and are influenced by the ethical and moral state of the society in which the research is being conducted. Justification for research methods generally come from the unquestioned, accepted anthropocentric, hierarchical and reductionist view of nature, with little regard for organisms other than humans.

A more holistic view of our health and our world will lead to the questions about the moral considerability of non-human animals. I am pleased that the issue of animal testing was raised in this paper on cloning. I think more consideration must be given to the efficacy of animal modelling, as well as their intrinsic value. I believe non-human animals have value above and beyond their instrumental value to humans. I would like to see serious consideration of this with the formulation of regulation of any research, including transgenics and cloning. This would lead to alternative research measures. A more holistic approach to human health, pursuing environmental causative agents for example, may obviate the need to test on non-humans.

I believe that the driving force of biotechnology in general is business. Even in presumably more neutral spheres such as universities, scientific foundations and state health and medical research agencies, research is often funded and directed by powerful multinational corporations. Their aims are ostensibly humanistic, but are fundamentally self serving and profit driven. This is another serious issue that must be considered by our regulatory bodies with regard to human cloning.

Stemming from this, is the issue of patenting DNA sequences. HUGO is worried that patenting would ultimately not be in the public's best interest, because it would impede the development of diagnostics and therapeutics. I believe our regulatory mechanisms should prevent this.

A further salient point to raise here is the disparity between the developed world and the undeveloped world with respect to health. Advances in molecular biology and the promises offered by genetic engineering to benefit human life do not carry across to those in our own society who due to socio-economic status have limited access to health care, let alone people like those in Africa. In stark contrast, in Africa there is intense poverty, widespread starvation and infectious diseases. Much of this misery could be relieved through basic health care measures, but this is undermined by the fact that the political and economic situations are in disarray and there is a lack of democratic process. With regard to health policy therefore, including biotechnology and cloning, must take into account the bigger picture.

## **Conclusion**

While much of what I have discussed may be deemed beyond the scope of this paper, I believe that the socio-political and environmental constructs of biotechnology ought to be key factors in future decision making by policy makers, reviewers and enforcers such as NHMRC, AHEC, GMAC, GTRAP and RTAC. I think the policies and recommendations for what they are good but our public health policies and allocation

of funds need to look beyond, and whether or not Institutions are complying, but whether their research has real efficacy, especially with regard to social justice.

Deeper, broader socio-environmental issues should outweigh commercial pressures and technical feasibility concerns when it comes to human health. Aims should be to promote democracy, community health, alternatives to gene technology, which promote holistic health; and to do this by decreasing the disparity between the rich and poor, the developed and undeveloped, treating environmental causes and promoting ESD and not the commodification of our resources, and balancing the rights of the individual with that of the community.

# Appendix 1:

## GENETHICS

### Regulating Unnatural Acts

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#### Principles for Responsible Regulation

Currently the values reflected in the regulation and application of GE are inappropriate. Science and technology are being explicitly driven by a flawed philosophy that privatises the wealth generated from natural resources yet socialises the costs.

The route to an alternative world view comes through the foundations of general systems theory, ecological principles, chaos and non-linear mathematics, the implications of quantum mechanics and a whole-range of spiritual beliefs. From these, several key concepts or themes can be distilled. Several of these themes offer insights as to how a new technology, such as GE, might be applied responsibly in the future in order to avoid ecological mistakes.

The following concepts or themes, and the values inherent in them, form the basis of a responsible alternative regulatory policy and framework for the release of genetically engineered organisms in Australia. These are:

Interdependence and wholeness- elements within and between systems are related to form an 'unbroken wholeness'. The understanding of relationships is vital to understanding the system as a whole.

Emergence- the interaction and interrelatedness of the elements of a system confers an emergent stability on a system. Complex systems such as nature are self-organising and inherently tend toward stability. Sufficient diversity amongst the elements within the system is necessary for the integrity and stability of that system.

Understanding the interdependent nature of the world enables one to see the connections between the local and the global, between the scientific and the social worlds or between the biological and the cultural. In the context of GE and the current political economy in Australia, scientific knowledge and the role of scientists or experts must be seen clearly in context. Issues of risk become relative and contextual and must therefore be determined by a process that involves as many people as possible who are to be affected by the particular release proposal; a visible, open regulatory mechanism involving public participation is therefore essential in the process of assessing the impact of genetically modified organisms (GMOs) into the environment.

Interdependence is a guiding principle, is fundamental to the proposed structures for a better model of regulation. The interdependence and complexity of natural systems implies that there can be no realistic 'experimental' field release of GMOs where the manipulated organism is absolutely isolated. So-called field releases and commercial releases should be regulated by the same mechanisms and policies. The issue of scale in relation to field releases is secondary to the issue of preserving environmental integrity. Traditional democratic ideals need reiterating in the context of our current political economy and GE regulatory policy. Economics should not override social policy.

**Principle 1:** The regulation of the release of GMOs should be done by an independent body operating at a national level.

**Principle 2:** Public participation in the decision making process including affected or interested parties is essential.

**Principle 3:** An education program that more equitably funds the full range of stakeholder's views and makes visible the underlying social structures that permeate it.

**Principle 4:** An open and accountable regulatory structure that is self-critical and able to react to changing social and environmental conditions.

**Principle 5:** GMOs should not be regulated as either a product or a process, but rather as a system. Ecological, social, religious, ethical and cultural impacts of GMO release must also be considered.

The second principle criterion for responsible regulation of GE concerns the concept of 'emergence' as recognised in Complexity Theory. Life, order and stability are emergent properties of natural systems. GE does not take this into account. The repercussions of developing and implementing new technologies that run counter to, or ignore emergence, evolution and the immanent creativity in dynamic systems will be devastating. Nature has an inherent tendency to self-organise; to stabilise. The current ecological crisis is a direct result of attempts to defy these principles through the domination and subjugation of nature. Ecological stability is a function not of simplicity and homogeneity but complexity and variety. The capacity of an ecosystem to retain its integrity depends not upon the uniformity of the environment but upon its diversity. This has serious implications for GE projects that reduce biodiversity.

Policy toward GE then must take into account the importance of emergence inherent in the ability of natural systems to self-organise towards stability. Such stability may only be achieved with sufficient diversity. Diversity is important in all systems: social, political, regulatory and cultural systems included.

**Principle 6:** GMO releases must not contribute directly or indirectly to a reduction in biodiversity.

**Principle 7:** GMO releases should work with nature, and be aware of the unpredictability of natural systems. Long term monitoring of all GMO releases must be mandatory.

**Principle 8:** Since natural systems self-organise towards stability, any manipulation of nature is likely to result in side effects. The onus of proof and accountability must rest therefore with the proponent.

## **Evaluation of the Existing Regulatory System for GE Proposals**



Current legislation is primarily reactive and it presupposes a world constructed from the foundations of a morally neutral science. Science is value laden. Science has become aligned with technology and economics. Science has become more accountable to industry and the growth economy, than to society as a whole or the environment. The unification of science and industry is very strong in the world of biotechnology and genetic engineering.

GE is currently regulated primarily through the Commonwealth government's Genetic Manipulation Advisory Committee (GMAC), currently the dominant Australian decision-making body responsible for development and release of GMOs. GMAC is flawed in that it does not embody the principles detailed above. Currently there is no legislation in Australia regulating the release of GMOs. GMAC is a non-statutory body established by the Commonwealth Government in 1987. The prime directive of GMAC shows that it is supposed to have a facilitative role rather than an evaluative one, in the development of GE.

Summary of recommendations to the current regulatory structure: GMAC:  
As per the principles outlined above, the role and structure of the regulatory agencies should examine the following criticism and incorporate the following recommendations:

- The referral of release proposals to GMAC and its decisions about release proposals have no legislative basis, and compliance therefore depends upon peer review mechanisms (IBCs) and the sanction of adverse publicity and jeopardy to future research funding. Instead:

**Recommendation 1:** The regulatory system for GE should have a legislative basis.

- In effect, the biotechnology industry is operating under a voluntary code of conduct administered by a non-statutory advisory committee which is appointed and reports to the Minister for Industry, Science and Technology. Instead:

**Recommendation 2:** The regulatory system for GE should be administered by the Department of Environment, Sport and Territories (DEST).

- It is apparent from GMAC's objectives that it is expected to have a facilitatory role in the development and use of GE. Instead:

**Recommendation 3:** The decision-making body should be committed to the principle of independent and comprehensive evaluation.

- At present, there are no substantive public interest criteria to govern the development, implementation and evaluation of GE proposals, and although GMAC's assessment can extend to broader environmental and social issues (eg. unsustainable practices, the political economy), in practice GMAC has focussed its assessment on bio-safety factors and is reluctant to consider broader environmental, ethical and social issues. Instead:

**Recommendation 4:** it is recommended that an ethics committee be devised to administer and implement a set of responsible socio-environmental criteria.

- GMAC's membership is dominated by representatives from a narrow range of scientific disciplines and commercial interests, with limited representation from ecology, ethics and other scientific and social disciplines, and no representatives of the general public. Thus the independence and comprehensiveness of GMAC's evaluation of release proposals is open to question. Instead:

**Recommendation 5:** The membership of the decision-making body needs to be interdisciplinary and broadly representative of society, including representatives of the general public and sectorial interests relevant to the specific GE proposal under consideration.

- IBCs are in effect generic proponents and thus the independence and comprehensiveness of the decisions of IBCs are also open to question. Instead:

**Recommendation 6:** The membership of IBCs needs to be interdisciplinary and more broadly representative of society, including representatives of the general public and sectorial interests relevant to the specific GE proposal under consideration.

- The evaluation process:

**Recommendation 7:** The comprehensive evaluation should take place of the bio-safety and broader environmental, ethical and social issues associated with a release proposal.

- The concept of Commercial-in-Confidence cannot reasonably be extend to information about the potential environmental and social impacts of a release proposal.

**Recommendation 8:** Subject to substantiated Commercial-in-Confidence, the public have a right to obtain all the documents comprising the proposal, the decision-making body's assessments and its decision about release, and the comments and submissions of other parties.

- The public's capacity to participate in the evaluation process depends upon being informed and educated about release proposals. Presently the public only has a very limited right to be notified and comment upon release proposals.

**Recommendation 9:** Release proposals and decisions should be extensively advertised and explained to the public. Members of the public should also have a right to participate in public hearings, which should be convened whenever objections are received.

- The public Information Sheet prepared by GMAC to explain its release decisions are an insufficient.

**Recommendation 10:** GMAC's evaluation of the aim of the release proposal, the intended eventual use of the GMO and the advantages of the chosen strategy

compared with other methods; and any comments or submissions received from members of the public, the local council and relevant State and Commonwealth agencies should be disclosed in the PISs.

- Presently there are no rights to appeal the release decisions of GMAC. Instead:

**Recommendation 11:** Persons aggrieved by a release decision of the decision-making body should have a right of appeal to an independent review body.

**Recommendation 12:** The evaluation of release proposals should satisfy the characteristics of environmental impact assessment (EIA) under the Environment Protection (Impact of Proposals) Act 1974.

- Presently the monitoring of released GMOs is limited to bio-safety effects and only over a relatively short time span. Instead:

**Recommendation 13:** Monitoring should be conducted over a significant time span and include the evaluation of broader environmental and social impacts. The monitoring function should be the responsibility of the decision-making body and the GEC rather than left to IBCs.

**Recommendation 14:** Each release proposal should be evaluated by reference to the eventual general release of that GMO. Given the significance of an approval for general release, an independent EIA should be conducted for each proposal for general release. In addition, the environmental and social impacts of general releases need to be comprehensively monitored and evaluated for future generations.

### **A New Model for the Regulation of GMOs in Australia**

The principles and recommendations outlined above could best be dealt with by disbanding GMAC and establishing a Gene Ethics Council (GEC) and Gene Technology Authority. Building on the above recommendations it is proposed that GMAC be disbanded and replaced with a regulatory system comprising two bodies: one to oversee the implementation of the guiding principles, and the GE policy (Gene Ethics Council); and one to assess proposals (Gene Technology Authority).

The proposed system is designed to fit into the current social, legislative and constitutional framework. It will provide safeguards, a monitoring regime, more democratic public representation, and liability for releases which are not approved or result in harm or damage.

The Gene Ethics Council (GEC) will be the primary body in the process, constructed to be self-critical and set up like a Ministerial Council, answerable to the Minister for the Environment and with input where necessary from the Minister for Health. These Ministers are directly responsible to the Federal Parliament for the actions of their Councils. Unhappy citizens can seek to have Ministers removed or even vote a government out of office.

Selection to council would reflect the diversity of interested parties by including professionals from a variety of disciplines: scientists, philosophers, sociologists, environmentalists, religious bodies, unionists, labourers, tradespeople etc.

The role of the GEC is to use the set of guiding principles outlined above, and from these principles develop a set of public interest criteria to guide the development, implementation and evaluation of GE proposals. These principles and selection criteria, as well as international conventions, will dictate the development of governmental GE policy for the Gene Technology Authority (GTA) as developed by the GEC.

Right of appeal to GTA decisions is given to both proponents and opponents via a GEC subcommittee which has the power to change the GTA's decision where appropriate. The GEC will have the power to impose sanctions on proponents whose releases have caused damage to the environment.

The GTA is subordinate to the GEC in that it implements the social criteria developed by the GEC. Its role is to accept or reject GMO development and release proposals. All proposals will need GTA approval.

The GTA would comprise public servants appointed by the Minister for the Environment, representing a variety of disciplines including law and science (but not just (Biological) sciences). Their role is to assess the proposals against the criteria developed by the GEC and administer the governmental genetic engineering policy, developed in conjunction with the GEC. The GTA would ensure that the proposals include a detailed analysis of any potential risks and that the proposals include contingent plans to deal with potential risks.

The IBCs in the proposed model will be made up of a much broader representation of professionals from a variety of disciplines, from both within and without the proponent organisation. Commercial-in-confidence issues are secondary to the provision of public information regarding potential risks. The details of the GMO to be developed, the reasons for developing it, and the risk mitigation proposed, along with the safety procedure and contingent emergency measures must be provided to the GTA.

All funding bodies of GE, including the government, must be provided with the GEC's principles and criteria. The GEC will also review the rebate given to funding of all GE activities.

Monitoring of GMO releases can be defined as an ongoing examination of the GMO and its effect on the environment, other organisms and society. The monitoring body in our model needs to be independent of both the GTA and the proponents to ensure objectivity. Monitoring must be an ongoing, long term process, for as long as the release is in the environment, as it may take decades for effects to be realised. The monitoring body needs the power to be able to shutdown any release it deems to be dangerous to the environment, subject to the appeal to the GTA, where the onus is on the proponent to show that the release is not the danger the monitoring body claims.

Education programs for the public; wider public debate and involvement in decision making.

# Appendix 2

## THE HUMAN GENE THERAPY DEBATE AND A NEW EPISTEMOLOGY FOR HEALTH

**Author: Maryke Vaartjes**

### **1. INTRODUCTION**

#### **1.1 The issue of human genetic engineering.**

The benefits, risks, and social consequences arising from human genetic engineering have received substantial discussion in medical, biological, ethical and legal literatures. A protracted debate continues, primarily between some scientists, believing that the potential consequences of this technology are good; and ethicists, believing that the consequences are potentially dangerous.

The issues are various, but one of the most important is the issue of where to draw the line in the application of the technology. This debate will remain irreconcilable while both advocates and critics of human genetic engineering focus on the too narrow view of genes and genetic engineering as the sole cause and treatment for disease. To achieve consensus and closure in the debate, this view must be transcended, gone beyond to a broader more encapsulating epistemology of health. With a more holistic approach to the healthcare of individuals and communities there will be no need to draw lines for the application of genetic engineering.

#### **1.2 Aim**

The purpose of this paper is to discuss why the debate over human engineering cannot be resolved, and why a broader epistemology of health is required. The sociocultural contexts from which our understanding and classification of the world emerge will be used to illustrate this argument. The contexts of scientific, and hence medical knowledge, and in turn notions of health and disease will be explored to show that the genetic focus is socially constructed and to some degree politically motivated. By demonstrating the influence of environmental factors (both physical and psycho-social) on disease cause and expression the case for a broader epistemology of health will be argued.

#### **1.3 What is Genetic Engineering (GE)?**

For millennia humans have intervened in natural hereditary processes to alter the genetic constitution of organisms. Until recently the interventions have been confined to artificial selection of animals and plants, breeding in order to select for a number of visible, important traits. This can be considered as genetic engineering in its broadest sense.

Now genetic engineering has a more scientifically precise definition as it involves recombinant DNA technology. DNA, or deoxyribonucleic acid, is the primary hereditary molecule in most species, the linked nucleotide subunits of which can be

divided into genes. Genes are the basic physical and functional unit of heredity that are transmitted from one generation to the next.

Recombinant DNA technology is used to alter "...the genetic makeup of cells or individual organisms by deliberately inserting, removing or altering individual genes...DNA molecules derived from different sources are artificially spliced together to form hybrid DNA molecules not normally encountered in nature" (Suzuki and Knudtson, 1989 p.115). Genetic engineering now is essentially a collection of techniques that allow the manipulation, recombination and exploitation of genes, or segments of DNA.

#### **1.4 The Human Genome Project and the emergence of Gene Therapy**

In organisms such as ourselves, it is difficult to isolate single genes for many heritable traits such as height or intelligence, or heritable diseases such as cancer or heart disease. In an endeavour to sequence human DNA the Human Genome Project (HGP) was launched in 1988 and is currently underway. The HGP is a coordinated worldwide research effort to map and sequence the estimated 3 billion bases and then determine the function of these sequences (Kirby, 1993). Basic sequencing has been completed, through which it has been found that there are many normal variants of genes. There is a long way to go therefore in achieving comprehensive knowledge of the entire complex genome.

This major biological research effort, will, and to a certain extent already does, have significant implications for public health. The hope is that research will reveal many genes involved in the development of genetic diseases. HGP research has already led to increased screening of prenatal and newborn genetic diseases such as Down's syndrome, trait carriers of diseases such as cystic fibrosis, as well as presymptomatic screening of late onset genetic diseases such as Huntington's, and screening for genetic based susceptibility for common diseases such as cancer and heart disease, mediated by either or both lifestyle and environmental factors. It is anticipated that this will only expand. Ultimately it is hoped that developments will result in better forms of diagnosis, treatment, cure and prevention (Sullivan, 1993 and Sorenson and Chevront, 1993).

Since the development of recombinant DNA technology, the promise of the technology for dramatically improving the practice of medicine has been vigorously championed. Most notably, by some members of the scientific community, institutions with vested interests in the application of recombinant DNA technology, as well as the media.

An article in *The Age* newspaper, 9 February 1996 described how some genetic research was aimed at "...fighting anaemia, combating ageing, ensuring freedom from disease and promoting longevity". Advertisements also appear in popular newspapers, magazines and even television. For instance, the Children's Medical Research Institute in NSW uses a photo of a baby with the caption "It's not a boy. It's not a girl. It's a miracle", to promote how GE can give life. The Garvan Institute has advertisements in magazines and on television promoting GE as "turning lifesaving into a science" as well as conducting the "jeans for genes day". These theme days are endorsed by staff of public institutions such as the Alfred Hospital in Melbourne

(*Group Express*, 1996), lending legitimacy and further momentum to this technology's applications in medicine.

Until 1990, while genetic diseases could be identified, treatment could only be directed at alleviating the symptoms rather than curing the cause. From then biotechnology has advanced such that scientists have realised their goal to treat genetic disease by replacing defective genes with normal ones (Blaese, 1991, Roemer and Freidmann, 1992). It must be pointed out that public health strategies aimed at managing diseases such as diabetes, heart disease, cancer and phenylketonuria, through environmental or lifestyle changes can be highly effective.

From years of scientific enquiry into the basis of heredity, gene therapy, as it is now known, can be seen as the inevitable outcome and ultimate application of this work. Gene therapy can be defined as the transfer of different or modified genetic material to the cells of an individual with resulting therapeutic benefits to that individual. There are two types of gene therapy used or potentially able to be used: somatic cell and germ-line cell gene therapy.

Somatic cell gene therapy involves the attempted correction of genetic defects in any of the cells in the body, with the exception of the reproductive cells, and conventionally involves the insertion of DNA into the cells of the organs affected by the disease, such as the lungs in the case of cystic fibrosis sufferers. Germ-line gene therapy on the other hand involves DNA transfer into the reproductive cells or very early embryos, and traits introduced to these cells would be passed on to future generations. (Suzuki and Knudtson, 1989, Anderson, 1992). The important distinction between the two from an ethical point of view is that somatic cell gene therapy effects only that individual being treated, while germ-line gene therapy will effect the whole population in future generations.

## **2. THE GENE THERAPY DEBATE**

### **2.1 The 'Slippery slope' argument.**

Concerns and arguments raised in the literature regarding human GE deal with issues ranging from technical feasibility to ethical acceptability of the technology. More specifically they include discussions on such things as technical safety standards, the financial cost and the allocation of finite resources, patency and ownership of information or DNA sequences, the efficacy of the regulatory mechanisms currently in place, the confidentiality of results obtained through genetic testing, and the potential for discrimination of people on the basis of genotype.

One of the more important issues raised, and influential argument against the use of gene therapy (in particular human germ-line gene therapy) is that it would lead us down a slippery slope toward genetic enhancement (Berger and Gert, 1991, Juengst, 1992, Hubbard and Wald, 1993a, and Macklin, 1995). The argument holds that once genetic manipulation has begun, there is a potential for it to be directed toward healthy people who have no evidence of genetic disease, with the aim of eradicating or enhancing particular physical and mental characteristics deemed to be favourable or not at the time, culminating in the eradication of certain people, as was the case in Nazi Germany.



The fear is that while human gene therapy might begin merely as an attempt to eradicate genetic diseases, it might eventually lead to the alteration of human beings for various other unjustified purposes, culminating in the potential for a modern eugenics movement, whereby human evolution is orchestrated through encouraging the transmission of 'desirable' traits and discouraging the transmission of 'undesirable' ones. The belief is that genetic enhancement will cause significant harm to future generations and violate important principles of social justice; equality, liberty, and opportunity. Many writers argue that on this basis of this potential consequence human germ-line gene therapy must never be attempted.

The slippery slope argument addresses the issue of where the line will be drawn in the application of recombinant DNA technology to humans, and is the fundamental issue at the centre of the human GE debate. Some writers (Berger and Gert, 1991; Zimmerman, 1991, Resnik, 1994) argue that the slippery slope argument is unsound because we can avoid sliding down the slope to social and ethical disaster with adequate regulations and safeguards. Other writers (Anderson, 1989, Lappe, 1991) argue that regulations and safeguards will not stop the slippery slope; once we begin gene therapy, in particular human germ-line gene therapy, there will be no turning back.

Nowhere in the world at this time is germ-line gene therapy allowed. In Australia all somatic cell gene therapy is to be considered experimental and subject to the National Health and Medical Research Council's (NHMRC) Statement on Human Experimentation and Supplementary Notes (1992). The NHMRC's position on germ-line gene therapy is that due to unknown potential hazards to future generations it will for the time being be considered unethical.

Many, including Tonti-filipini who spoke at the Round Table Conference on Human Gene Therapy (1988) and the Australian Genethics Network (1992) believe that the NHMRC's guidelines are inadequate for regulating genetic research, however it beyond the scope of this paper to discuss this issue further.

## **2.2 The arguments for gene therapy.**

The arguments in favour of germ-line gene therapy follow the line that only with the development of germ-line gene therapy can true cures be offered to many genetic diseases and that therapeutic interventions at any level other than at the causal gene can be palliative or symptomatic only. Preventing the transmission of disease genes, would obviate the need to perform other costly treatments, and would prevent suffering, especially in the case of highly prevalent disorders such as Cystic Fibrosis. These writers argue that to rule out this therapy in principle would mean breaking with a long standing tradition of medicine to either treat or prevent all types of disease (Zimmerman, 1991, Juengst, 1992, Wivel and Walters, 1993, and de Wachter, 1993). Other treatment measures such as lifestyle changes for sufferers of heart disease have proven to be very effective in the past however.

## **3 THE SOCIAL CONSTRUCTION OF SCIENCE, GENETICS, HEALTH AND DISEASE.**

### **3.1 Medicine and Cartesian Dualism.**

Defenders of human gene therapy and advocates of the slippery slope argument, in their irreconcilable attempt to draw the line between justifiable and non-justifiable application of GE technology, both take one fundamental premise for granted, the Cartesian principles inherent in inventing, defining, measuring and diagnosing the genetic basis of disease and health.

A major change in the history of Western medicine came with the Cartesian revolution in the seventeenth century. Before Descartes, most healers had addressed themselves to the interplay of body and soul, and had treated their patients within the context of their social and spiritual environment. As world views changed over the ages, so did views of illness and methods of treatment. Descartes' strict division between mind and body led physicians to concentrate on the body machine and to neglect psychological, social, and environmental aspects of illness (Epstein, 1995).

Epstein (1995) states that another major change in Western medicine also leading to a biological reductionist view of illness was the germ theory and the discovery of viruses. This change in knowledge led to the belief for a time that all diseases were the result of the body's invasion by germs. Increased information about physiology continually kindles renegotiation of the body in relation to culture.

Cartesian dualism now occupies much of western thought, epitomised by modern scientific principles, and has occasioned a sharp shift toward a mechanistic biology and medicine. A central theme of this epistemology is the search for a single rule capable of explaining everything. Embodied in this theme are a number of characteristics and assumptions that can be applied to most situations. Dualism is the belief that phenomena exist independently; while reductionism is the belief that phenomena are divisible into categories or units; and mechanism involves defining something by its component parts. Phenomena are assumed to be quantifiable or measurable, and to arise through a linear cause and effect relationship while also existing in a hierarchy, ranking phenomena in a 'natural' order. These assumptions lead to the belief in the ability to 'know' and predict the future (Shiva, 1995).

Modern western medicine, as a scientific discipline exemplifies the above characteristics. Medical science now conceives the individual, unique, whole person as split into parts which then become the material for scientific investigation and treatment. People are reduced to bodies, to organs, to cells, to genes and molecules such as DNA, while health is reduced to the presence or absence of biological disease. Microscopic and biochemical hierarchical levels are valued more highly than the macroscopic and psycho-social levels of existence (Hubbard and Wald, 1993).

This mode of thinking has been successful in understanding the physiological makeup of the body and finding cures for many biological diseases. However, this success is dependent on the reductionist Cartesian definitions and assumptions upon which that understanding is based. When this reductionist thinking is applied to diseases which encompass more than biological functioning, such as the already mentioned cancer and heart disease, it is totally inadequate.

### **3.2 Health and Disease in context: their social construction.**

Concepts of health and disease are essential to the form of medicine. Definitions of health and disease vary over time from culture to culture, and from social group to

social group. Not only do the epistemological conceptions vary from culture to culture, they are created by them and exist contextually within them. Historically and socially determined beliefs impinge upon them.

Preliterate cultures understood disease within a spiritual framework. In Aristotelian times a human being was viewed as greater than simply the sum of the body parts, possessing, interacting subsystems. From the fourth and fifth centuries BC diseases were individualised as an imbalance of the humours, an idea that persisted in one form or another across many centuries.

Not until the seventeenth century did a notion of physiological systems begin to replace this framework for explaining disease. Since then in the West the human body and its functions have been defined by a biomedical science that assumes the body obeys a reductionist, mechanistic and linearly causal logic. This model of disease complements the medical model of the human being. The primary referent of health and disease is the body; diseases being independent, discrete entities written on and in the body, while health is viewed as the absence of disease (Epstein, 1995).

Currently various pathological conditions are classified as diseases. These include for example, defects or disabilities such as blindness, behavioural problems such as attention deficit disorder, and lifestyle related illnesses such as alcoholism and other addictive behaviours. The biomedical model leads to types of remedy that are highly specific, and predominantly involve repair, replacement or removal of a part, and are curative rather than healing in their nature (Hubbard and Wald, 1993). It is from this epistemological framework that human genetic engineering has developed, culminating in the ultimate repair of humans, gene therapy.

Since WWII the discussions concerning definitions of disease mostly make some place for extra physiological circumstances and for the idea that disease is, in greater or lesser part, socially constructed. Disease should be defined as the aggregate of those conditions which, judged by the prevailing culture are deemed painful or disabling, and which at the same time, deviate from statistical norm or from some idealised status (Amick, Levine, Tarlov, and Walsh, 1995).

### **3.3 Examples of diseases which are socially constructed.**

Historically and socially constructed conditions that are currently, or have been, classified as diseases through the biomedical model include, alcoholism, homosexuality and some learning difficulties. Studies are currently underway to find the genetic basis for these, and many other conditions. Many of the traits of interest in genetic studies are very difficult to define, such as the amorphous trait of intelligence, and measure in an objective way. The validity of the measurement tools such as IQ tests must be called into question too. We need to unravel the cultural constructions of these diagnoses before we can move on to a more encapsulating view.

#### **3.3.1 Alcoholism**

The consumption of alcohol has occurred for centuries, however alcoholism as a disease historically has appeared only recently. Not until 1956 did the American Medical Association classify alcoholism as a disease. Definitions of alcoholism have changed over time, and there is great variation from place to place, era to era, in what is considered acceptable. Alcohol consumption varies between genders,

socioeconomic strata and occupations, making it is very difficult to determine what is 'normal' for alcohol consumption. Consequently there remains a lack of consensus about the actual definition of alcoholism (Steen, 1996).

Fishman (1992) argues that much of the categorising of alcoholism as a disease has to do with social mores, and political motivations rather than real pathology. For discussion of the environmental mediators in the aetiology of alcoholism see section 3.5 this paper.

### **3.3.2 Homosexuality**

The notion of homosexuality as an abnormality or as a disease exists also in a historical, cultural, political context. It relies for its independent existence on the social recognition and sanctions that surround it. From this perspective, homosexuality is neither functionally equivalent across cultures nor inherently meaningful beyond particular cultural abstractions. A wealth of evidence from the historical and cross-cultural records support the constructivist viewpoint. For more detailed discussion of this see Abramson and Pinkerton, 1995.

In the early nineteenth century, persons engaging in same-sex love were called invert. The terms in common use today, homosexual and lesbian, were not coined until after the 1850s. This act of naming implied that homosexuals were different from 'normal' people and thus constituted a medical abnormality in need of scientific study and cure. Over the years since this naming event, homosexuality has been extensively studied, and interventions have been carried out with the biomedical establishment's self proclaimed goal of helping the homosexual to readjust to the presumed normal state of heterosexuality (Abramson and Pinkerton, 1995).

A homosexual person may suffer social and or legal disabilities because of their orientation, and wants to avoid these disabilities. This is a political and moral question, not a medical one (Hare, 1993).

Homosexuality is inadequate as a construct as it ignores environmental factors (discussed in section 3.5 this paper). The cultural context of this construction needs to be addressed more fully by those positing strictly biological theories of sexual preference.

### **3.3.3 Learning disabilities.**

'Hyperactivity', was a word that had been used to describe a behaviour problem within the social context of the classroom, but in 1980 it was renamed 'attention deficit disorder'. In the case of Hyperactivity, a problem in classroom dynamics has been reframed as a problem located specifically within the brain of the individual student, independent of the social group. This refined classification implies that such a problem is pathological, and therefore a disease state. (Nelkin and Tancredi, 1994). An important point here is that a person's behaviour is not distinguished from their health.

The quantifiability and measurement of intelligence, and the preoccupation with tests employed to do this, play a large part in the emergence and defining of learning disabilities.

Intelligence tests and the intelligence quotient (IQ) score they provide are given meaning through their cultural context, depending on what intelligence is believed to be at the time. Precisely what intelligence is has been the subject of a great deal of uncertainty and debate. Hanson (1994) argues that 'intelligence' as it is represented in intelligence tests is not some independently existing natural phenomenon but a reality as construed by culture. Labelling, quantifying and measuring something does not make it real or independent. Intelligence can be, and is, conceptualised differently over time and in other cultural traditions. Intelligence is too complex to capture with a single number, it is not a linear single scalable thing. The IQ score should not be seen as an entity unto itself, or given meaning out of context (Gould, 1992).

If intelligence is undefinable and tests are culturally biased (in that they assume literacy, among other things), then it is difficult to believe that learning difficulties are not socially constructed too, and their medicalisation is a further expansion of the socially constructed biomedical model, while also serving the school's institutional requirements of greater accountability; they allow schools to explain educational failure, deflecting blame and responsibility from themselves and parents.

### **3.4 Genes in context: their social construction**

The concepts of genetics and the gene itself are socially constructed, just as the concepts of disease and health are. Genetics is the systematic description of hereditary mechanisms, but to a large extent it is also, as Hubbard (1995) states, a reading into nature of the dominant ideologies of science and biological reductionism.

For a long time genes were purely theoretical constructs. The materialist and reductionist impulse led biologists to assume quite early that inheritance is mediated by intracellular, hereditary particles, the posited invisible element called the gene. The hypothetical gene became concrete pieces of DNA in 1953. Nevertheless the concept of the gene means different things to different people depending on what scientists choose to focus on, molecules, chromosomes, populations or evolution for example. The gene is given meaning through its context (Hubbard and Wald, 1993).

### **3.5 Genes in context: their environmental interaction**

The gene also interacts with its context, unfolding within and interacting with the social and physical environment.

Genes do not exist in a vacuum, they are embedded in a network of biological and ecological relationships that interact in many different ways. Genes operate not just at a molecular level, but at a multidimensional level also, their action is not additive but synergistic and at times antagonistic. As a result of this multidimensional functioning, genetic disease should only be provisionally defined. (Nelkin and Tancredi, 1994).

Many scientists, such as Haseltine (1997) believe that malfunctioning genes are deeply involved in most diseases, not just clearly inherited ones. Involvement is not the same as causation. Genes as causative agents however are being sought for a vast array of conditions such as alcoholism, homosexuality and learning disorders as

mentioned above, as well as breast cancer, lung cancer, asthma, coronary heart disease, schizophrenia, drug abuse, and obesity.

The above conditions have no clear patterns of inheritance or genetic markers and are all influenced by social and physical environmental factors. It is more realistic to think of genes as participating in disease processes rather than controlling them. Even those diseases that do have clear genetic markers may have their expression or effects mediated by the environment. The presence of a genetic condition must not be confused with the actual disease. The detection of a genetic abnormality will not necessarily provide information about the timing or severity of a disease or how it might affect the normal functioning of the individual (Steen, 1996).

A gene that fails to perform to our satisfaction under one set of nutritional, climatic or other environmental conditions might possibly perform quite satisfactorily under another. An often cited example of this is Sickle-cell anaemia, a disease whereby a genetic mutation in a single base pair in the DNA which codes for haemoglobin, results in an altered haemoglobin molecule and can cause cellular perfusion problems. Individuals carrying only one copy of the altered gene may only have problems in conditions of extreme exertion or altitude, but lead normal lives under all other conditions. In malarial regions it is actually beneficial to have the 'defective' genotype as the sickle-cells hamper the malarial parasites to grow and reproduce (Suzuki and Levine, 1994).

Another often cited example is that of Phenylketonuria (PKU). Individuals with PKU have an inherited sensitivity to phenylalanine which manifests itself predominantly as mental retardation. This disease is easily controlled however through environmental changes, that is diet. One can in fact, have the gene, yet with proper dietary changes never manifest the disease (Nelkin and Tancredi, 1994)

It is clear that social and environmental factors interact with the biological expression of traits. In the above examples, the genes' 'defectiveness' have a transient quality, suggesting that identifying environmental conditions that inhibit expression of the disease, and manipulating them, may be a more appropriate treatment of disease compared to genetic intervention.

Tremendous advances have been made even in the treatment of Cystic Fibrosis, the most common genetic disease in countries such as the US where it affects 1 in 2000 births and 1 in every 20 Caucasians is a carrier. There are well over 150 known mutations in the gene for cystic fibrosis which makes prenatal diagnosis and gene therapy treatment that much more complex. Characterised by pulmonary and digestive problems, improvements have come about, and continue to be made, through aggressive antibiotic regimens and intensive physiotherapy (Reiss and Straughan, 1996). Recent research even suggests that correct versions of the faulty gene and protein are not required for adults to be healthy, as long as the protein is provided for the development of the correct cells in airway and gut linings during foetal growth (Coghlan, 1997). Even this disease can be managed through environmental means.

An issue arising here is that the majority of human traits and many genetic disorders are polygenic, arising from the interplay of more than one gene. It is also important to realise that any given gene may be responsible for several traits. To alter a

constellation of genes could disturb other seemingly unrelated cellular processes influenced by those genes (Nelkin and Tancredi, 1994).

Extensive research into the impact of sociocultural factors on health has been carried out by Amick et al. (1995). Their studies showed that socioeconomic factors contribute greatly to lifestyle and environment and hence the state of health and wellbeing (physical and psychological) and were correlated with gender, race and more polluted urban areas.

Despite the search for genes for heart disease and the evidence that suggests that there are genes that predispose people to heart disease, it remains that risk factors such as smoking, diet and obesity, exercise and alcohol intake contribute to heart disease and that heart disease can be prevented through their modification (Wise and Graham-Clarke, 1994 and Henderson, 1996).

Regarding the examples of socially constructed diseases discussed earlier there are environmental influences at work also. There appears to be some degree of inherited predispositions to alcoholism. Nevertheless there are also environmental influences which must be addressed in any public health policy regarding it. That is, there is an interaction of biological, psychological, and social factors contributing to a person's drinking. There is a higher incidence of alcoholism in certain population groups that face other problems. What these groups have in common are poverty, low socioeconomic status, isolation and limited access to treatment (Fishman, 1992).

Learning problems are correlated with many of the environmental factors that influence alcoholism. Also school curriculum and classroom structure have a large effect. Since virtually all of our behavioural development occurs in an environment full of stimuli, we must assume that these stimuli have an effect (Nelkin and Tancredi, 1994).

Decades of study by the medical community have not only consistently failed to demonstrate that homosexuality is a pathology, but also have found no single environmental explanation to account for its development. Human sexuality is complex and it is likely then that the answer lies in an interaction between biology and environment.

Even if there are genes found for conditions like homosexuality, alcoholism or attention deficit disorder, or diseases such as cancer or heart disease, is this information useful, given the social construction, and/or complex aetiologies of these conditions? It depends how this knowledge will be used. This is discussed further in section 5.

## **5. POTENTIAL CONSEQUENCES OF CURRENT REDUCTIONIST MEDICAL PARADIGM AND GE/GT.**

Through most of the history of biology as a science there has been a pervasive bias that nature, in the form of hereditary forces at work in the individual, is dominant in the origin of human traits.

Reducing all human conditions and behaviours of complex aetiology to genetic causes leads to the notion of genetic 'fate' or 'destiny'; implying that genes carry a programme that is immutable. The search for genes for conditions such as homosexuality implies that it is an aberration, and that somehow the genes can provide the solution to the condition. Ideas can have great power, and the consequences may be unforeseeable by scientists.

Biological determinism has a long (and disastrous) sociological history of which discrimination is a large part, and ought not to be ignored when discussing human GE. Grounding difference in biology perpetuates bigotry. In the case of homosexuality and alcoholism, questions about origin would be of little interest if they were not stigmatised behaviours (Hubbard and Wald, 1993).

Many writers (Suzuki and Levine, 1994, Hubbard and Wald, 1993, Nelkin and Tancredi, 1994, Hanson, 1993, and Gould, 1992) are concerned about the potential use to which genetic information will be put. The accumulation of diagnostic information about individuals can indicate preventative actions or therapeutic procedures, however, nonclinical institutions may use these tests in ways that the medical profession do not intend. The fear is that people will be discriminated against, excluded from employment or health insurance on the basis of genotype.

As the HGP moves onward, and the potential for predictive screening develops, there are powerful economic incentives to use them, especially for any organisation concerned with future costs, namely, insurance companies, employers, the health care system, schools and the courts. The need for cost containment and fear of litigation reinforce the search for 'objective' indicators of an individual's health and conduct. If diagnostic technologies identify and predict the future health problems of potential clients, those whose problems might tax the economics of an institution could be excluded.

The most important concern of the application of human GE regards the 'slippery-slope' argument as discussed earlier, and the potential for a modern eugenics movement. The area of greatest debate in the last decade has been the issue of where to set the boundary between therapy and enhancement. There already are existing precedents for treating conditions that are not diseases. For example, children of short stature were treated with recombinant human growth hormone (HGH) while having no evidence of HGH deficiency. The criticism of this treatment largely centred around the argument that short stature in itself is not a disease, therefore the intervention was an enhancement rather than a medically indicated treatment (Wivel and Walters, 1993).

## **6. AN INTERACTIONIST APPROACH TO HEALTH: GENES AND THE ENVIRONMENT. A MORE ENCAPSULATING VIEW.**

There is nothing wrong with recombinant DNA technology per se, it is its application that raise concerns. Any technology exists in a contextual framework and must be



reflected upon in that context; it isn't absolutely good or bad. Absolute lines of acceptability or nonacceptability regarding human GE cannot be drawn, because what is acceptable at one time is dependent on society's values at that time. Society must be reflexive regarding human GE technology and the uses to which it is put. A broader more encapsulating notion of health and hence health programmes should bring closure to the debate regarding the 'slippery slope'.

Human bodies and their genes exist in an environmental (social and physical) context. Rather than treating people as compilations of genes, we have to move toward a more unified understanding of health, taking that context into account. As shown throughout this paper, the environment, both social and physical, play a large role in the aetiology of many diseases. To concentrate on genes as their only cause, and hence the only treatment, is inadequate when dealing with public health issues such as cancer and heart disease. An interactionist approach should be embraced (Epstein, 1995).

It has been found (Murray and Lopez, 1997a and b), that alcohol, tobacco, physical inactivity, and air pollution are among the major risk factors contributing to mortality from diseases such as heart disease, cerebrovascular disease and cancer. These diseases are among the most frequent causes of mortality in the developed world. Public health policy should reflect this.

Ultimately most public health problems that confront medicine are multiply determined, therefore the complex interacting dynamics that constitute human health should be examined. Genes and the environment are indissoluble, interconnected codeterminants of health and disease. An interactionist, holistic, multidisciplinary approach, which considers both biological and cultural influences in concert is a more complete epistemology, the only viable means by which we can hope to comprehend the complexities of human health.

Reclassifying diseases from an interactionist position may suggest alternative therapeutic treatments to human gene therapy. These alternatives may be preferred and deemed to be more appropriate. It may be that for simple, single gene, single coded enzyme metabolic diseases such as Adenosine deaminase deficiency (ADA), with little or no recourse to environmental management strategies, that gene therapy is the appropriate form of treatment (Morgan and Anderson, 1993). Environmental management and lifestyle changes may be the most appropriate treatments for complex diseases such as heart disease. A case by case assessment, reflecting on physical and social environmental contexts must be made,

Amick et al. (1995) describe that an holistic approach would focus more on the promotion and conservation of health and the prevention of disease; the protection and care of people's environment, both social and physical. There would be an increasing emphasis on the care of the family and community as well as the individual, and the use of education as a means of both prevention and cure. It may be that the greatest use of the information obtained through the HGP is not the promotion of human gene therapy, but rather the ability to identify those with genetic predispositions for diseases of complex aetiology such as cancer, and at greatest risk from certain lifestyles and environments. The emphasis would then be to target those

at risk groups through education and encourage them to make appropriate lifestyle changes

Fishman (1992) provides an example of an holistic approach to treatment of a public health problem. This approach to alcoholism acknowledges that it is a way of life, in which it is not only the alcoholism which is the disease but also environmental, psychological and biological pressures that bear on the alcoholic. The holistic approach recognises the importance of treating the psychological, sociological, nutritional and physical consequences of excessive drinking. Therefore in addition to abstinence, treatment includes diet, exercise, the improvement of social skills, and the establishment of a total social support system.

As many of these people belong to groups that are apt to face other problems as well, it is important that these problems be dealt with during treatment. In many cases treatment must be adapted to special sociocultural circumstances. Each sub-group may view the world in a different way, and these differences may have serious implications for treatment.

The holistic movement is growing, largely due to the increasing awareness of the failure of the conventional healthcare system, but not yet enough developed to provide a solution to the reductionist, mechanistic model.

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