GE Free New Zealand

In Food And Environment Inc.
106A Grove Street, Nelson
Phone/Fax: (03) 546 7966
Email: susie@tasman.net
www.gefree.org.nz

GE FREE NZ INC. SUBMISSION ON THE SUPPLEMENTARY ORDER PAPER ON THE HUMAN ASSISTED REPRODUCTIVE TECHNOLOGY BILL.

GE Free NZ wants to speak about this submission to the Health Select Committee

The Beginning of the End of the Human Race and the Start of a Posthuman Future?

> "The lessons of history have shown us what happens when people are ordered as better and worse, superior and inferior, worthy of life and not so worthy of life….What can happen when the technology used in support of genetic thinking is not the crude technology of shackles and slave ships, of showers that pour lethal gas and of mass ovens, or even the technology of surgical sterilization, but the fabulous, fantastic, extraordinary technology of the new genetics itself?…My children will not be led to genetic technology in chains and shackles, or crowded into cattle cars.
> It will be offered to them."
> Barbara Katz Rothman, Professor of Sociology, City University of New York.[i]

Introduction

GE Free New Zealand Incorporated (GEFNZ) is a non-governmental organisation with over 3,000 members that is committed to the safe and ethical use of genetic engineering and genetically modified organisms in containment. In recent years our focus has been on trying to keep our food and our environment free from GMOs. However, the fear has always been there that someone would actually try to legitimise the genetic engineering of human beings. We did not expect that it could happen here in New Zealand and that those promoting it would come from the Labour party.

The Human Assisted Reproductive Technology bill (HART) put forward by Labour is the 21st century equivalent of 20th century Nazi Germany eugenics policies the only difference being as Professor Rothman points out above is the methods it would use to achieve the genetic purity of society and creation of a master race. In a world first that will legally allow for the first time ever the creation of genetically engineered designer babies the New Zealand (NZ) government intends to make this possible through allowing the germ-line genetic modification (GLGM) of human embryos. The other eugenic technology is called embryo selection (ES) and this would allow parents to choose the embryo with the desired genetic inheritance they want including its gender. The intention in HART to remove the prohibition against mandatory genetic screening is also a particularly disturbing move in relation to GLGM and ES as it augurs the age of mandatory state control of citizens genetic profile and inheritance. This combination of legalising mandatory genetic profiling, embryo selection and genetic engineering of designer babies will give the NZ government the power to eugenically change the future of human evolution in ways only dreamed about in Nazi Germany.

The first section is about our support for prohibiting those reproductive technologies already listed in Schedule 1. The second section outlines our reasons for opposing germ-line genetic modification (GLGM). The third section deals with embryo selection (ES), sex selection and mandatory genetic testing. The fourth section analyses why the current HART decision making framework with the ministerial and ethics committees is completely inadequate. The fifth section points out the main reasons why embryo cloning for non-reproductive purposes is unethical and unnecessary. The sixth section details the unethical nature of creating human-animal embryo hybrids for research purposes. The seventh section analyses the dangers from embryo splitting. Section eight puts forward the proposition that it should be illegal for New Zealanders to use prohibited technologies overseas and that any use of restricted reproductive technologies overseas should require regulatory approval. The ninth section discusses why a key principle of HART needs to be the protection of human rights and equality. The tenth section proposes that the penalties for breaching Schedule 1 need to be increased.

GE FREE NZ Issues For Change in HART

1. We support prohibiting those things already listed in Schedule 1 e.g. human cloning.
2. We want germ-line genetic modification prohibited by being added to Schedule 1.
3. We want embryo selection, sex selection and mandatory genetic testing prohibited by being added to Schedule 1.
4. We want the proposed HART decision making model dropped and instead have the creation of an independent assisted human reproduction regulatory authority modelled on the Human Fertilisation and Embryology Authority in the United Kingdom. We also want to see far reaching public consultation processes initiated to ensure the concerns of the New Zealand public and all ethnic and minority groups on all assisted human reproductive technologies can be acted on.
5. We want embryo cloning for non-reproductive purposes added to Schedule 1 so that it is prohibited.
6. We want the prohibition of creating human/animal hybrid embryos for research purposes.
7. We want embryo splitting to be prohibited from being used as a way of cloning humans.
8. We want genetic tourism where people could go overseas to access prohibited or restricted reproductive technologies to be made illegal.
9. We want a sub-section added to section 4 of the HART bill stating the need for the protection of human rights enshrined in the Universal Declaration of Human Rights as well as the equality of all people and the protection of present and future generations.
10. We want the penalties for breaching Schedule 1 to be increased to a maximum fine of $2 million and a maximum of 10 years imprisonment.

Key Issues of Most Importance

The HART bill as it stands is the most comprehensive and far reaching eugenics piece of legislation the like of which the world has not seen since Nazi Germany in the 1930’s and 1940’s. Why the NZ government believes it has the right to be the first government in the world to legalise GLGM when every other country who has created law on it so far has always prohibited it is beyond logical comprehension. However, even though GLGM is the most dangerous of all eugenic technologies because it potentially allows for the creation of new genetically enhanced species of humans the government haven’t stopped there as they are proposing to lift the prohibition on mandatory genetic testing and to legalise sex selection and ES which also present nightmare scenarios for the “genetic cleansing” of the NZ population. Whether this would happen by social norms, market forces or government persuasion or coercion is not the issue – the issue is why does this government think it can get away with leading not just NZ but the whole world down this slippery slope to the genetic genocide of whole sections of a society and the potential creation of a genetically engineered master race. The HART bill as it currently stands is in itself a potential crime against humanity waiting to happen and must be drastically changed to avoid the eugenic nightmares it contains. For the sake of humanity we ask the Select Committee not to aid and abet the government in bringing to life these potential crimes against humanity and to at least make the key changes we propose by prohibiting GLGM, ES and mandatory genetic testing. It is not too late to pull back from the brink……..

1. SECTION 7 PROHIBITED ACTIONS & SCHEDULE 1
- SUPPORT FOR THE GOOD THINGS IN HART

To start off with it is worth while to point out that there are some notable positives in HART, particularly the proposed bans in Schedule 1:

- cloning for reproductive purposes;
- the creation of human/non-human hybrid embryos for reproductive purposes;
- the implantation of human and hybrid embryos into animals;
- the implantation of animal and hybrid embryos into humans;
- commercial surrogacy (including advertising);
- commercial supply of embryos and gametes.

GEFNZ supports the banning of all of the above, however, there is a notable lack of consistency throughout the rest of HART looking at the first four technologies in the above list. All four of them would lead to unprecedented and dangerous changes in the ethical, psychological, social and physical meaning of what it would mean to be a human (Homo sapien). Cloning humans for reproductive purposes, for example, is a species changing technology that is clearly ethically, socially and medically dangerous for all concerned.

However, the same could be said of germ-line genetic modification (GLGM) and embryo selection (ES) and yet they are poised to be allowed under HART. The only possible explanation for banning cloning and legalising GLGM and ES is as a direct result of the fraudulent claims by the Raelian cult that they had cloned a child in December 2002, which led to such a public backlash that the politicians appear to have got the message that this is not an acceptable practice. And yet GLGM is just as much, if not more, likely to have negative consequences than cloning for changing the human species as some people would like to use it to create entirely new and superior species of humans.

In comparing cloning and GLGM some commentators have concluded that they, "can be seen as crimes against humanity of a unique sort: they are techniques that can alter the essence of humanity itself (and thereby threaten the foundation of human rights by taking evolution into our own hands and directing it towards the development of a new species, sometimes called the 'post human'."[ii] This argument could be extended to include ES as it would also lead to a profound change over time of the idea of what it means to be human by threatening the human rights of all those who do not fit some eugenic social ideal of genetic perfection. If it is good enough to ban cloning then it is equally valid to ban GLGM and ES for the same reasons.

2. SECTION 36 (c) - GERM LINE GENETIC MODIFICATION –
A CRIME AGAINST HUMANITY

"Using the new genetics to try to make a `better human' by genetic engineering goes beyond discrimination to elimination by raising the prospect of genetic genocide….Is this inflammatory language justified?…[G]iven the history of humankind, it is extremely unlikely that we will see the posthumans as equal in rights and dignity to us, or that they will see us as equals. Instead, it is most likely either that we will see them as a threat to us, and thus seek to imprison or simply kill them before they kill us. Alternatively, the posthuman will come to see us (the garden variety human) as an inferior subspecies without human rights to be enslaved or slaughtered pre-emptively….It is this potential for genocide based on genetic difference, that I have termed 'genetic genocide,'
that makes species-altering genetic engineering
a potential weapon of mass destruction, and makes the unaccountable
genetic engineer a potential bioterrorist."
Professor George J. Annas,
"Genism, Racism, and the Prospect of Genetic Genocide," presented at the *World Conference Against Racism, Racial Discrimination, Xenophobia and Related Intolerance* (Durban, South Africa,

September 3, 2001)[iii]

Under section 36 (c) of HART the government wants to fully legalise germ line genetic modification (GLGM) which would allow for the genetic engineering of designer human beings. GLGM is a eugenics technology that is medically dangerous, unethical, a threat to human rights, human equality and society as a whole. Indeed, as will be explored later on there are some who describe GLGM as a weapon of mass destruction and a crime against humanity in and of itself. Germ-line genetic engineering involves the genetic engineering of either the sperm, egg or embryo so that the modified genetic makeup is passed on to the baby and future generations. This could involve the insertion of new genes considered desirable or the deletion of genes considered undesirable. What is clear is that an evolutionary threshold will have been passed if this bill becomes law as scientists will be legally allowed for the first time anywhere in the world to genetically design babies.

Medical Risks

Professor Stuart A. Newman of the New York Medical College in his expert witness brief (see appendix 1) supports the ban on cloning and implantation of animal/human hybrid embryos, however, he views HART as being scientifically inconsistent when it does not have a ban on GLGM as well. In writing about the medical dangers of trying to carry out GLGM Professor Newman states, "Laboratory experience shows that insertion of foreign DNA into inopportune sites in an embryo's chromosomes can lead to extensive perturbation of development. For example, the disruption of a normal gene by insertion of foreign DNA in a mouse caused abnormal circling behaviour when present in one copy, lack of eye development, lack of development of the semi circular canals of the inner ear and anomalies of the olfactory epithelium (the tissue that mediates the sense of smell) when the mice were inbred so that the mutation appeared in the homozygous form (i.e. on both copies of the relevant chromosome). Another such 'insertional mutagenesis' event led to a strain of mice that exhibited limb, brain, and craniofacial malformations, as well as displacement of the heart to the right side of the chest, in the homozygous state. Each of these developmental anomaly syndromes were previously unknown. The prediction of complex phenotypes on the basis of knowledge of the gene sequence inserted or disrupted is elusive and likely to remain so."

Some of the other main points of medical danger Professor Newman Points out is that:

- somatic cell modification, a technique currently in use, is plagued with unexpected and even fatal outcomes.
- during development the situation is much more complicated. Tissues and organs taking form during this period, and the activity of genes is anything but modular.
- during development many if not most, gene products can have multiple effects on the architecture of the organs and the wiring of the nervous system, including the brain.
- there is no way to assess the safety of germline procedures in human beings, without exposing prospective children to unwarranted experimentation.
- the experimental alteration of prospective humans cannot be justified under any ethical standard of justifiable risk.

On the basis of this medical expertise Professor Newman concludes with the statement, "I therefore urge you to include germline and other developmental-genetic manipulations of human embryos intended to be brought to term under the same category of prohibited procedures in the proposed amendments to the HART Bill as reproductive cloning and animal - human hybridisation." (see appendix 1 for complete information).

Protecting the Endangered Humans Rights

In our first attempt at GEFNZ to come to grips with the issues surrounding human cloning and genetic engineering we based our initial thoughts and conclusions around an article entitled "Protecting the Endangered Human: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations."[iv] The basic thrust of "Protecting the Endangered Human" article is useful in understanding the lessons of World War II and human rights developments since then in trying to avoid crimes against humanity being committed through GLGM. It states that, “Cloning and inheritable genetic modification [GLGM] can be seen as crimes against humanity of a unique sort: they are techniques that can alter the essence of humanity itself (and thus threaten the foundation of human rights) by taking human evolution into our own hands and directing it toward the development of a new species, sometimes termed the ‘posthuman’” (Annas, et.al., page 4).

They make the points that with GLGM (and cloning) it would:

- require massive dangerous and unethical human experimentation;
- be bad for the resulting children produced by restricting their right to an open future;
- lead to a new eugenics movement for designing children; and
- create new species/subspecies of humans.

The end result of all of this could be that, “The new species or ‘posthuman’ will very likely view the old ‘normal’ humans as inferior, even savages, and fit for slavery or slaughter. The normals on the other hand, may see the posthumans as a threat and if they can may engage in a preemptive strike by killing the posthumans before they themselves are killed or enslaved by them.” (Annas, et.al, page 13). This is a frighteningly predictable given examples provided by the 20th century. As such, they state that technology that aims to change the human species is a weapon of mass destruction and human genetic engineers potential bioterrorists. They believe it would be appropriate for GLGM and cloning to officially be made a crime against humanity via an international treaty with any breaches of it punished by the recently established International Criminal Court.

The genetic engineering of designer babies has been pushed most prominently in public recently by James Watson (co-discoverer of the structure of DNA in 1953) as part of the celebrations surrounding the 50th anniversary of the determination of the double-helix structure of DNA. Watson has recently been quoted as saying, “"If you are really stupid, I would call that a disease.…The lower 10 per cent who really have difficulty, even in elementary school, what's the cause of it? A lot of people would like to say, 'Well, poverty, things like that.' It probably isn't. So I'd like to get rid of that, to help the lower 10 per cent.… People say it would be terrible if we made all girls pretty. I think it would be great." In Watsons recently published book “DNA: The Secret of Life” he wrote as part of this his thoughts on how designer babies would be a positive step forward for human evolution. Susan Lindee who reviewed his book questions, "how such a convoluted nexus of belief and prophecy [held by Watson] could gain cultural legitimacy, or even a sympathetic publisher. What forces made this incoherent tangle of mysticism, historical ignorance, religiosity, corporatism, exaggerated technocratic rationality, intemperance, and social naïveté plausible to so many people? Or even to James D. Watson?”

Unfortunately, the problem is not just confined to Watsons personal opinion. Dr Mae Wan Ho of the Institute in Society (UK) has pointed out that, “arch genetic determinists and other prominent scientists as well as ‘bioethicists’ are advocating human germline gene therapy and human cloning. They see the creation of a gene-rich class of human beings to be inevitable due to the free reign of the global marketplace. The rich will pay to genetically enhance their offspring, in the same way that they will pay for expensive private education. Consequently, there will be a genetic underclass - children of the poor - that will eventually become a separate, inferior species. Social inequity can thereby be translated into genetic inequity and *vice versa*.”[v] In her analysis Dr Ho has stated in an email to GEFNZ that, “The NZ Human Assisted Reproduction Technology Bill is state-sanctioned eugenics by another name, which, is rejected by most, if not all countries around the world. It is, furthermore, based on an utterly retrograde and discredited ideology of genetic determinism posing as science. Recent research has revealed the futility as well as the dangers of somatic gene therapy.” Dr Ho has offered to appear as an expert witness before the Health Select Committee via video link or telephone.

Jeremy Rifkin in his book “The Biotech Century” has written: "Genetic engineers believe that a future genetocracy is all but inevitable. Molecular biologist Lee Silver of Princeton University writes about a not too distant future made up of two distinct biological classes, which he refers to as the Gen Rich and Naturals. The Gen Rich, which account for 10% of the population, have been enhanced with synthetic genes and have become the rulers of society. They include Gen Rich businessmen, musicians, artists, intellectuals, and athletes, each enhanced with specific synthetic genes to allow them to succeed in their respective fields in ways not even conceivable among those born of natures lottery. At the centre of this new genetic aristocracy are the Gen Rich scientists, who are enhanced with special genetic traits that greatly increase their mental abilities, giving them the power to dictate the terms of future evolutionary advances on Earth. Silver says that:

> ....with the passage of time, the genetic distance between the Naturals and the Gen Rich has become greater and greater and now there is little movement up from the Natural to the Gen Rich class.......... All aspects of the economy, the media, the entertainment injury, and knowledge industry are controlled by members of the Gen Rich class.... In contrast, naturals work as low paid service providers or as labourers....Gen Rich and Natural children grow up and live in segregated social worlds where there is little chance for contact between them...[eventually] the Gen Rich class and the Natural class will become the Gen Rich humans and the natural humans-- entirely separate species with no ability to cross breed and with as much romantic interest in each other as a current human would have in a chimpanzee."[vi] (Rifkin, 1998, p. 168).

Silver himself is an advocate of this human genetically engineered future regarding it primarily as a natural offshoot of what occurs already between the rich and poor with the rich having all the advantages that money can buy anyway. Genetic engineering simply provides wealthy people the opportunities to further enhance themselves and their offspring to gain a competitive advantage in society.[vii]

Dr David King of Human Genetics Alert in the United Kingdom has provided us with a written expert witness brief (see appendix 2) where on the topic of GLGM, or human genetic engineering (HGE) as he refers to it, agrees with the proposition that GLGM will lead inescapably to a new eugenics with unacceptable ethical and social consequences. Furthermore, it would have devastating consequences for the children subject to being genetically engineered:

- ‘enhancement’ of human characteristics would turn children into designed objects and puts parents in a position of ‘playing ‘God’. This objectification of children undermines their basic ethical status as human subjects, and thereby ultimately, the basis of human rights
- Where normal parents hope their children will display particular characteristics and talents, those parents who have engineered their children will expect them to do so, and will surely have a greater tendency to put pressure on them to do so. As consumer goods, they will likely be viewed as defective if they fail to live up to their expensive genetic programming.
- children will likely end up feeling tyrannised by their parents, and as less than fully their own person, who can choose what to make of their lives; in short, they will feel like objects.
- early models [of children created by HGE] will be at an irreversible competitive disadvantage to children who are born five years later [or more] with more advanced genetic programming that will result from scientific advances.

On the governments claim that GLGM will be limited to dealing with genetic diseases Dr King states that, “Experience suggests that it will be impossible to limit HGE to therapeutic applications and that permitting any form of HGE opens the door to ‘enhancement’.” He provides two main reasons for this:

1. There is acknowledged to be no firm line between therapy and ‘enhancement’. There is a grey area, exemplified by contestable ‘diseases’ such as attention deficit and obesity, and an also

widely-acknowledged trend, driven partly by the pharmaceutical industry, to pathologise characteristics which have previously been thought to be part of normal variation.
2. Attempts to draw firm lines in the application of medical technologies will only work if there is a clear, firm (and therefore legally defensible) conceptual basis for the distinctions being drawn. This is clearly not the case between therapy and 'enhancement'.

Huntington's Disease Just an Excuse
As an example of the debate on how it is not possible to draw a line between genetic diseases Dr King states that, "Huntington's disease, the condition cited by the NZ government on its website is certainly not an example of a condition severe enough to warrant elimination: people with the HD gene live unaffected lives to the age of 40 or greater and are thereafter disabled. However, in these limited number of cases, there are many other possibilities, including non-parenthood, 'social parenting' (i.e. sharing parenting roles with other families), adoption, gamete donation". In light of this he concludes that the, "demand for HGE can be considered as a little more than parental desire for the 'cutting edge technology'."

Human Rights – Humanitys Greatest Achievement
There are those who claim that to ban cloning and GLGM is anti science, progress and individual human freedom, however, it can be more accurately described as a, "movement down a slippery slope to a neo-eugenics that will result in the creation of one or more subspecies of humans." The ant-science claim, "sees science as our guide and ultimate goal." while the GEFNZ perspective is based, "firmly on our human history as it has consistently emphasised differences to justify genocidal actions." (Annas, et.al., page 24). The most important point on the anti science argument is that, "science cannot tell us what we should do, or even what our goals are, therefore, humans must give direction to science." (Annas et.al., page, 24).

The lessons of World War II and the genocidal crimes against humanity perpetrated by Nazi Germany shows the dark side of human nature when minorities are classified as being of less worth than some perceived majority and is a real and dangerous part of the human psyche. The purpose in the development of human rights since then has been to make sure such crimes against humanity cannot happen again by developing a code of human rights that protects every human no matter what their ethnicity, genetics, religion, gender or nationality. The most important development of the 20th century is not that humans have been shown to have the potential to commit gruesome and degrading crimes against other humans, but that we can rise above this when we develop a human species consciousness based on equal rights and democracy for all. GEFNZ agree with the statement that :

> **"The greatest accomplishment of humans has not been our science but our development of human rights and democracy."** (Annas, et.al., page 24).

From this point of view we adopted the "Declaration for the Preservation of the Human Species" from this article and adapted it to fit NZ's conditions and included it in our submission on discussions for amendments to the HSNO Act in November 2002 and can be seen in full in appendix 3.

The Implications of not Banning HGE
Dr King is quite clear that the implications of the NZ government, "not banning HGE are profound. This is not just another decision about just another biomedical technology. Permitting HGE would represent a decision to cross a critical threshold for the whole of humanity. Humankind would begin to take charge of its own evolution, and so enter into a new era of human history. Even if the consequences of doing so were uniformly good, this would require deliberation and a high degree of consent from humanity as a whole; in fact, as we have argued, the consequences are almost uniformly bad. And for this reason, international opinion, so far as the topic has been discussed, is strongly against HGE. All countries which have legislated on the issue have banned HGE This includes the U.K. and all the countries party to the European Convention on Biomedicine and Human Rights, as well as proposed legislation in Canada. While for many countries HGE is still a non-issue, no country

has taken the position that New Zealand proposes to: to give HGE positive endorsement by designating it a normal, regulated technology. New Zealand does not have the right to unilaterally decide to take humankind over this threshold." (see appendix 2 for full information on the Human Genetic Alert witness brief).

Richard Hayes the Executive Director for the Center for Genetics and Society in their expert witness brief in appendix 4 reiterates the same point that, "All countries that have to date enacted comprehensive legislation addressing the new human genetic technologies have banned IGM [GLGM]. The landmark 1997 Council of Europe *Convention on Biomedicine and Human Rights* explicitly bans germline modification. Noted international health lawyers and bioethicists have called upon the United Nations to begin negotiations on an international convention that would ban germline modification. And just last week, Dr. James Peacock, President of the International Congress of Genetics, announced his opposition to IGM [GLGM]. It would be quite unfortunate, then, if New Zealand were to become the first country to officially allow that IGM [GLGM] might in fact be an acceptable application of human genetic science."

As a medically dangerous and unethical experiment with no distinction being possible between therapeutic and species changing enhancement uses of GLGM, and as a potential weapon of mass destruction and instrument of committing crimes against humanity that could lead to war between Natural humans and genetically engineered Gene Rich sub-species of humans there is no possible justification for NZ being the first country in the world to legalise GLGM. GLGM must be banned by being added to Schedule 1.

3. SECTION 36 (b) (iii) - EMBRYO SELECTION – THE NEW EUGENICS

"There is no them, there is only us!"
Bono of U2

"You inspire us to know that all obstacles to human achievement and progress are surmountable. Your achievements remind us of the potential to greatness that resides in every one of us.
May the world learn from your example."
Nelson Mandela

From the Opening Ceremony for the Special Olympics in Ireland

The opening ceremony of the Special Olympics in Ireland on June the 21st 2003 was a special occasion for both those present and those watching on television at home. A gala line up of entertainers welcomed the athletes who have learning difficulties and included Irish super group U2. U2 sung two of their hit songs the first being "One" where Bono ad-libbed saying "there is no them, there is only us" to rapturous applause followed by "Pride" their tribute song to Dr Martin Luther King which was also an introduction to Nelson Mandela who in his speech called the athletes, "ambassadors of the greatest of humankind".

The positive reception that the NZ athletes and other nations competitors with learning difficulties got at the Special Olympic is in complete contrast to the thrust behind the HART bill with its eugenic agenda. If taken to its logical conclusion it is unlikely that NZ will be able to send a team to the Special Olympics in the longer term if Labour gets their way to pass this bill as it will set up a scenario for the progressive elimination of all those deemed to have genetic diseases and defects through the legalisation of mandatory genetic screening and embryo selection (ES) under section 36 (b) (iii).

GEFNZ and disabled people take are opposed to both germ-line genetic modification and embryo selection. Dr Gregor Wolbring a founder and Executive director of the International Center for Bioethics, Culture and Disability has called the eugenic technology of embryo selection “geneism” and states that there is “no convincing arguments to point the way to an acceptable line regarding the use of predictive tests and eugenic solutions”. He points out that, “The only protection we have available at the moment, the only way to avoid tragedy, is to be a society which does not view any human characteristic as a disaster, whether it be not having legs or having some other disability or being gay or being female. We need to have a place for every one and to support each other. We need to terminate the Animal Farm philosophy ; it can only lead to a bloodbath within the equality/human rights movement. We cannot work with each other when some view themselves as superior to others. The society we create is our only protection against the "gene-ism" (as in racism, sexism and able-ism) that in the end, we are told, will make targets of 60% of us all.”

As an example, the Special Olympics is part of the process as a global society of ensuring we support and value equally every sector of society no matter how different they may be from the majority of the non-disabled population. Unfortunately, the Animal Farm philosophy of some people being more equal than others is the very essence of eugenic thinking and the rationale behind allowing ES (and GLGM) to supposedly avoid so called genetic “diseases”. These issues and others that are directly related to them are explored much further in the following sections with quotes from articles Dr Gregor Wolbring has put together for this GEFNZ submission and can be found in appendixes 5 through to 8. Dr Wolbring is a member of the Executive of the Canadian Commission for UNESCO, a biochemist at the Dept. of Biochemistry and Molecular Biology Faculty of Medicine, Adjunct Assistant Professor for bioethical issues at the Dept. of Community Rehabilitation and Disability Studies Faculty of Education and Adjunct Assistant Professor with the John Dossetor Health Ethic Center all at the University of Alberta, Edmonton, Alberta, Canada.

Free Choice is an Illusion

Dr Wolbring points out that science is a value laden process and the values one brings to defining if or what is a problem in regards to genetics and the disabled is dominated by two main models of thought:

“These may be expressed in a dialectic of ‘medical model”(mM) versus ‘social model’(sM). Within the medical individualistic model, disability is viewed as a defect, a problem inherent in the person, directly caused by disease, trauma, other health conditions, or a deviation from certain norms and leading to a low quality of life for the person and their relatives. Management of the disability of the disabled person or person-to-be is aimed at cure, prevention, or adaptation of the person (e.g. assistive devices) to ensure an as normative functioning or existence as possible. Medical care, preventive medicine, and rehabilitation are viewed as the primary issues, and at the political level, the principal response is that of modifying or reforming health care policy and making preventive medicine more efficient. At the emotional level, the principle response is one of pity and rejection. Disabled people are seen as a suffering entity and as having a low quality of life. However, the medical model is in contradiction to studies, which show that disabled people (sM) rate their own quality of life as equal to or higher than their non-disabled counterparts, do not see themselves as a medical condition and mostly feel that their quality of life is not worse than the one of non disabled people per se but that their life is made difficult by societies unwillingness to accept and to accommodate their needs.” (Appendix 5).

How these models are played out in relation to embryo selection (otherwise called pre-implantation genetic diagnosis) is that ES is:

> “mainly sold as a tool for fixing disabilities, impairments, diseases, and defects, (DIDD) and diminishing suffering. These promises raise quite a few questions. Which and whose values and perceptions are reflected in the definitions of DIDD and the attached ‘suffering’? Which and whose values and perceptions are reflected in the choice of solutions for the ‘problem’ of DIDD? How do the predominant societal values and perceptions that define DIDD, its

> attached suffering, and the proposed solutions affect the self-esteem and self-understanding of the people viewed as suffering from DIDD? Does the self-perception of people who are labelled as DIDD (the afflicted) match the perception that the non-afflicted have of the 'afflicted'? Do 'afflicted' people define their 'problems' and the solutions to them in the same way as the 'non-afflicted' do?" (Appendix 5).

In deciding what DIDD needs to be "fixed" or "cured" has more to do with social beliefs and norms than it has to do with deciding where the cut off line is on a medical basis. Indeed, this is not actually possible as UNESCO has found out:

> "In reality no distinction can be made between different 'medical' characteristics based on their severity because a) to distinguish between different 'medical' characteristics would stigmatise further the selected 'medical' characteristics and the carriers of these 'medical' characteristics; b) nearly every 'medical' characteristic still can exhibit itself phenotypical in variants of different severity and clinical course and c) the same 'characteristic which is seen by some as a 'disease' ('medical' characteristic) may be perceived differently by different people depending on their family history, religious and socio-economic background, life situation and future expectations. To quote paragraph 65 of the draft report on pre-implantation genetic diagnostic and germ-line intervention from the International Bioethics Committee of the UNESCO, which states:
> "An often-debated subject is line drawing in case of the indications both for PGD [preimplantation genetic diagnostic] and PD [prenatal diagnostic]. Thus far all professional organizations in clinical genetics and reproductive technology as well as advisory groups on bioethics have argued against lists of diseases which can be defined as severe enough to justify PGD or PD. The number of monogenic diseases alone exceeds 5000 and nearly each of these has variant of different severity and clinical course. In addition, the same disease may be perceived differently by different couples depending on their family history, religious and socio-economic background, life situation and future expectations." (Appendix4).

In conclusion Dr Wolbring finds that:

> "From a disability rights perspective the question arises, which models of disability will carry the day? Disability groups want the acceptance of the social, the universalist, and the human rights model, models that might allow the disability community to join the human rights movement. However, there are problems in achieving this goal.
>
> Society has a long history of seeing disabilities within a medical framework. Many legal instruments describe a disabled person as someone with subnormal, diminished functioning in need of special care not seeing disabled people as having a biological reality leading to different sets of abilities and different ways of functioning and different needs.
>
> The medical understanding of disabilities is essential for the acceptance of many disability discriminations as evident in the governance of predictive prebirth testing, wrongful life and wrongful birth suits, genetic and non genetic therapy, genetic and non genetic enhancement, anti genetic discrimination laws, access to health care insurance and life insurance. Furthermore the marketability of predictive pre-birth testing, wrongful life and wrongful birth suits, genetic and non genetic therapy, genetic and non genetic enhancement, compassionate homicide laws, for example depends on the availability of a devalued target characteristic which in this case are the characteristics labelled as 'disabilities (mM) defects and diseases.
>
> That's how the sales pitch with predictive pre-birth testing went. The sympathy of the public in western countries for the development of the technology was initially ensured by using Tay-Sachs and Downs Syndrome as an example of possible elimination through prenatal testing

and selective abortion. However, the same technology is now used for the elimination of different characteristics depending on the existing prejudice in any given society. Like sex selection is popular in India and China.

In order to keep the support of the general public an ethical trick had to be developed namely the ethical distinction between a medical and social reason. That of course means that disabilities (mM), diseases and defects have to be labeled as a medical problem and traits as social problems in order to assure that the average public the ‘non-disabled’ does not feel threatened by these technologies. This has a consequence that disabled people have a hard time in being accepted as part of the social justice movement as the remedy for them seems to be a medical one and not a social justice one. In the moment whenever disabled people demand equal treatment in the above areas they receive answers such as below.

In recent years the militant disability movement has developed a whole new confident and strident identity - no more pathetic cripples pleading in soppy charity ads, but a strong demand for equal rights in the tradition of the battles for black, women's and gay rights. After women's pride, black pride and gay pride, proud-to-be-disabled seems to make sense too. But each of these four campaigns is different. Each group's identity, cohesiveness and claim to victimhood is based on markedly different circumstance. Disability campaigners have over- identified with other civil rights issues, talking as if they were a race or a gender.

Sexual orientation, left handedness, blue eyes, recessive or X-linked carrier status in the absence of symptoms and ‘low normal IQ’ are all shared by a substantial portion of the population though none is a characteristic of the majority. All of them have social dimensions. Nevertheless, so many people have one or more of the characteristics that the characteristics must be considered part of normal human variation. Statistically these characteristics cannot be compared with the ‘population risk’ of about 3% for having a child with a genetic condition or ‘birth defect’. There are so many different genetic conditions that no one condition even comes close to affecting 1% of the population (Downs Syndrome is around 0.1%).

With no convincing arguments to point the way to an acceptable line regarding an equitable use of the above mentioned technologies, a much more thorough debate is needed, with all the parties involved. We need to terminate the Animal Farm philosophy where some people are seen as being more equal than others; it can only lead to a bloodbath among humans in general and within the equality/human rights movement in particular. We cannot work with each other when some view themselves as superior to others.

The society we create is our only protection against the "gene-ism" (as in racism, sexism and able-ism) that in the end, we are told, will make targets of 60% of us all. Germline gene therapy should stay prohibited as should sex selection. Furthermore taking into account the above the prohibition of mandatory genetic screening should also be prohibited. In light of prohibiting these technologies and applications then it is only logical and ethical and equitable to also prohibit embryo selection, prenatal deselection and somatic gene therapy.

Furthermore it has to be assured that non genetic enhancements and therapies will not be mandatory. Recent developments and facts quoted in this article [appendix 5] suggests that we will be moved away from a concept of choice. They suggest that women don’t actually have a free choice, but are to be led down the path of medical intervention. In the absence of a possible social cure for disability, the only option that may appear to be left is the medical *cure*, in whatever shape and form, and independent of its usefulness. Compounding this, in order for someone to have free choice, the

> person has to see the issue without prejudice in the first place (see appendix 8). For this to happen society would have to shed its prejudice against disabled people and their characteristics." (Appendix 5).

Legalisation of Sex Selection

It is stated that when HART becomes law it will allow parents the ability to choose the sex of their children. From a technological point of view sex selection is a spin off of ES, however, the issues it raises deserve a section addressing them on its own. In the Human Genetics Alert expert witness brief in appendix 2 there is an excellent section on why sex selection should not be allowed and parts of this are summarised and quoted in verbatim here as it also touches on issues to do with eugenics and ES. They key points it makes are:

Sexism:

Sex selection is the exercise of sexism at the most profound level, choosing who gets born, and which types of lives are preferred. Choices that are being made are still based on rigid, sexist, gender roles. In how many cases where parents are 'desperate for a girl' will they be hoping for a loud tomboy that grows up to be an engineer? Society must continue to fight sexist gender stereotypes, not allow them to dictate who is born.

'Family Balancing'

It is sometimes suggested that so-called 'family balancing', whereby families where there are two or more children of one sex, choose a child of the opposite sex is a less objectionable use of sex selection. The motivation for such choices is still likely to be sexist, and the process is still likely to turn the child into a commodity. Furthermore, any line to be drawn between family balancing from unacceptable consumerism will be arbitrary and unfair. For example, those with one child who want only one more child, would justifiably be able to claim that they were being discriminated against, if the line were drawn at two children of the same sex. Thus, if an exception is made for 'family balancing' we are inviting future slippage, and opening the door to the future unrestricted use of sex selection.

Consumerism and Objectification

As noted above with regard to HGE, [human genetic engineering] these techniques objectify human beings. In the case of sex selection. parents who have chosen a girl will tend to put greater pressure on her to conform to their hopes and expectations of her behaviour, rather than allowing her to become the person she is and wants to be. Such a child may feel that she is only wanted when she behaves the 'right' way.

Choice and 'reproductive rights'

The final defence of sex selection is the appeal to liberty. It is often suggested that there exists a right for individuals to reproduce in whatever way they wish. These consumerist arguments are increasingly assuming the character of an ideological doctrine, which is wielded as a blunt instrument, to effectively silence all other ethical concerns.

Strong claims for autonomy may seem plausible, but a closer inspection reveals that they cannot be sustained. For example, the Universal Declaration of Human Rights, includes 'the right to marry and found a family'. This article arose from the Nazi atrocities and from eugenics laws restricting disabled people's reproduction in many countries. It is negative right of non-interference by the state; this is very different to a right of access to any form of technological assistance needed to reproduce, when this is not possible in the normal way, whatever the consequences.

It is often thought that strong individual rights protect against eugenic interference by the state. However, at present, as many commentators have noted, in Western countries, the greater threat is of a free-market eugenics, driven by commerce and by consumerist desires for the perfect baby. Rather than non-interference, what is needed now is more state regulation to restrain the eugenic trend. (See Appendix 2 for more details from the Human Genetics Alert submission).

What's in it for the NZ Government?

According to a 1995 New Zealand report on "Priorities for Genetic Services in New Zealand: A report to the National Advisory Committee on core health and disability support services", it stated that, "New Zealand genetic disorders whilst individually rare constitute a significant contribution to morbidity and mortality when taken together as a group. Two to three percent of couples are at high and recurrent risk of having a child with an inheritable disorder. 5 percent of the overall population will develop a genetic disease by the age of 25. If conditions with a genetic predisposition like diabetes, coronary artery disease, cancer are included than it has been estimated that about 60 percent of the population will be affected doing their lifetime."[viii] Given that the health budget is already the biggest drain on government finances and likely to become worse with an ageing population the attraction of being able to eliminate up to 5% or more (up to 60%) of the population from ever being born with genes considered to lead to genetic diseases and thus being a financial burden on society it is not surprising that some in government would consider promoting this option. Add to this the possibility of genetically engineering potentially even healthier, more intelligent and more productive human beings then on the financial basis alone eugenically cleansing and enhancing the genetics of the NZ population would appear ideologically to be the most fiscally responsible path of action for the government to take.

The government in the United Kingdom is already taking steps to utilise new genetic screening technologies where they are, "convinced that better application of greater genetic information will help its citizens stay healthier longer, and save the National Health Service lots of money in the long run. It has, for example, asked the Human Genetics Commission, an independent advisory group, to look into the possibility of genetically screening all new-born babies to create comprehensive DNA profiles."[ix] They are also starting a Biobank project to find out the genetic profile of 500,000 people so that a genetic profile can be gained to develop tests that will detect diseases. Once they have this information it is only a small step to allowing parents acting under social norms to eliminate potential children who do not have the socially desired genetic profile through embryo selection. The most efficient way of achieving this would be by making genetic screening mandatory – but what government could contemplate mandatory genetic testing as being politically acceptable?

Legalising Mandatory Genetic Screening – A Genetic Witch Hunt?

Francis Crick the co-discoverer of the DNA double helix said at the Ciba Geigy Symposium in London in 1962, "We have to take away from humans in the long run their reproductive autonomy as the only way to guarantee the advancement of mankind." (see appendix 8). The NZ government appears to have taken this advice to heart and is proposing to lift the prohibition on mandatory genetic screening which is mentioned on page 36 of the HART supplementary order paper. This is a very disturbing development particularly as combined with embryo selection and GLGM it could bring about an era of state control of the genetic "health" of NZ's citizens.

The question remains why is this prohibition against mandatory genetic screening being lifted if the government never intends to use it? Or is it only going to make it compulsory for that 5% of the population it considers to carry genetic diseases and how does it intend to force these people into being genetically screened? And once screened what is the government going to do with this information and the people they deem to be carriers of "diseased" genes? What of the claim by a government minister earlier this year that 20% of the Maori population have learning difficulties and that this will negatively impact on NZ's economy, will this result in the mandatory genetic screening of Maori and the genetic engineering or embryo selection of future generations to increase their intelligence? And who will be the next group targeted after this and where will these genetic witch hunts go in the future? If ever there is a technology whose sole use can only be described as being for the purpose of committing crimes against humanity then mandatory genetic screening is it. It would appear that despite the military defeat of the Nazis around 60 years ago their political agenda of genetic purity and the creation of a master race is gaining increasing political legitimacy within the NZ government. Is mandatory genetic screening really an unthinkable prospect, some seem to think not:

> "Lori Andrews one of the 100 most influential lawyers in the USA writes, "There will be a time, said Andrews -- a professor at the Chicago-Kent College of Law and author of The Clone Age -- when governments will force prenatal genetic testing, hoping to encourage women to abort rather than cause taxpayers and insurers to foot the bill for a sick child." (Appendix 8).

The NZ government must step back from the brink and must reject the possibility of mandatory genetic screening of the NZ public.

GEFNZ Supports Disability Rights Movement

GEFNZ supports the arguments put forward by Dr Wolbring in appendixes 5 to 8 and specifically supports the 2002 bioethics resolutions by Disabled People International that states:

I. We demand the right to be different

II. We believe that no parent has the right to design and select their unborn child to be according to their own desires and no parent has the right to design their born child according to their own desires.

III. We defend and demand a concept of "person" that is not linked to a certain set of abilities.[x]

GEFNZ rejects eugenics as an ideology and a practice no matter what form it takes. The reality is that embryo selection will not provide choice as such it is simply a slippery path to increasing social intolerance of human beings who deviate from socially prescribed genetic norms. In the end there will be no choice as the government, health system, employers and insurance companies demand the right to save money through having greater "genetic efficiency" in the population at large. Particularly as it will require a period of experimentation that will result in many adverse health effects on the first generation. This attempt at starting a eugenic future through the HART bill must be stopped by adding embryo selection and gender selection to Schedule 1 and thus banning them.

4. SUBPARTS 2 & 3 – SECTIONS 14 TO 39 ETHICS AND ADVSIORY COMMITTEE DECISION MAKING PROCESS COMPLETELY INADEQUATE

A good example of the normative creep that Dr Wolbring talks of (appendixes 5-8) in the social classification of the genetically undesirable can be seen in the governments thinking in their proposed decision making process with HART's Assisted Human Reproductive (AHR) technologies where they are supposed to be dealt with by the putting in place of a Ministerial Advisory Committee (MAC) and ethics committee in sections 14 through to 39. The government claims that the purpose of putting in this decision making process is to, "establish a framework for ethical decision-making, rather than prescribing what may or may not be done in relation to procedures and technology that are known now." They have developed this framework so that as "societal values can change over time" increasing access to these techniques will be allowed for. Or as they put it "To future proof the legislation the Government has decided to establish a framework for ethical decision-making, rather than prescribing what may or may not be done in relation to procedures and technology that are known now."

At present the government are hiding behind the excuse of using medical reasons for allowing GLGM and ES, while deliberately putting in place a slippery slope that will lead to much more. To call this the start of a policy that can lead to the full scale social genetic engineering or embryo selection of designer babies on demand by parents in the future is not beyond the realm of possibilities. Indeed, we are left to speculate as to whether this is in fact the reason for proposing this model in the first place – a way of government bringing about eugenic solutions via the market demands of parents (as discussed in Dr Wolbrings article).

Richard Hayes states that, "It is true that the HART bill provides that proposals to initiate IGM research or trials be approved by advisory bodies. But that is the problem. As written, the provision regarding IGM [GLGM] would serve to encourage those who look forward to a world of "designer babies," in a way that no other legislation current in force does. The point is to make clear that proposals to begin work towards inheritable genetic modification are not to be assayed in the first place." (Appendix 4).

Human Assisted Reproductive Authority

The decision making process as outlined in HART is completely inadequate. What is needed is a strong regulatory authority to be put in place modelled on the Human Fertilisation and Embryology Authority in the United Kingdom. A potential name for it could be the Human Assisted Reproductive Authority (HARA). HARA must license and monitor the use of, and research into all, assisted human reproductive technologies, and to oversee a process ensuring wide-ranging public debate and input. At present this bill has less regulation and opportunity for public input on the genetic engineering and selection of babies than what is currently necessary to get approval by the Environmental Risk Management Authority (ERMA) to allow the release of genetically engineered plants or animals.

The new assisted reproduction regulatory authority must have an open process of decision making that allows the public to make submissions on both the development of an ethical framework for the potential use of assisted reproductive technologies as well as individual applications (not germ-line genetic modification or embryo selection which should just be banned). After developing the ethical framework within which specified assisted reproductive technologies may be used it must also hold public hearings where all sides can state their cases before a decision is made on any application to authorise the use of a new assisted reproduction technology just as ERMA does for genetically modified organisms. These decisions need to be able to be appealed to a Court of Law, not just on if the lawful process has been carried out correctly, but also on whether the substance of the decision is correct.

Health Ministers Right to Call in Sensitive Applications

The Minister of Health must have the right and the responsibility to call in assisted reproductive applications that raise serious issues for both the health of the unborn child concerned as well as any potential impacts on society and the human rights of present and future generations. When dealing with these technologies there cannot be enough public oversight and double check within the system when it comes to research using human reproductive material and changes in human reproductive possibilities. The Minister should be required to call for public submissions on any application that is called in before they make any decision.

5. SECTION 36 (b) (ii) - EMBRYO CLONING FOR NON-REPRODUCTIVE PURPOSES

Embryo cloning for non-reproductive purposes is to be allowed under Section 36 (b) (ii) of HART. GEFNZ believe that it is unethical and unnecessary to tamper with the fundamentals of human life using embryo cloning for non-reproductive purposes. What follows is en extended quote from an article entitled “The Unnecessary Evil of ‘Therapeutic’ Human Cloning” by Drs. Mae-Wan Ho and Joe Cummins, where they explain why ‘therapeutic’ human cloning is both morally unacceptable and scientifically unjustifiable.

“What are stem cells?

Stems cells are cells in mammals including human beings that have the ability to divide and give rise to specialized, differentiated cells. The fertilized egg cell possesses this ability to the highest degree, for it has the potential to divide and develop into the entire organism with the full complement of cell types. The fertilized egg cell is *totipotent*.

Totipotency is retained as the egg divides into two and even four cells, so that each cell, when separated, is capable of developing into a complete foetus. That is how twins, triplets and quadruplets come about; they are natural human clones with identical genetic *and* cytoplasmic makeup.

When the embryo is four days old, and after several rounds of cell division, a hollow sphere is formed, called a *blastocyst*, within which is a cluster of cells called the *inner cell mass*. The outer layer is destined to form the placenta and other supporting tissues needed for the development of the foetus in the womb. The inner cell mass will go on to become all the tissues of the foetus’ body. These cells are no longer totipotent, but *pluripotent*, i.e., they can give rise to many types of cells, but not all of the ones required for foetal development.

As development proceeds, the inner cell mass divides further and become more restricted in the range of cells they will become. For example, blood stem cells will eventually give rise to red blood cells, white blood cells and platelets, and skin stem cells will give rise to all the various types of skin cells. These more specialized stem cells are said to be *multipotent*.
Pluripotent and multipotent stem cells in the embryo came to be known as *embryonic stem cells* or ES cells.

Stem cells are also found in children and adults, these are known as *adult stem cells*. Blood stem cells, for example, are found in the bone marrow of every child and adult, and in very small numbers, also in the blood stream; they continually replace the supply of blood cells throughout life. Recently, adult stem cells have also been found in brain as well as muscle, liver, skin and other tissues.

One of the main arguments used in favour of ‘therapeutic’ human embryo cloning is that adult stem cells are much more restricted in their potential to become different cell types than ES cells. However, it is beginning to appear that adult stem cells have the potential to give rise to a far greater range of cell types than previously imagined, and stunning results have been obtained. Furthermore, there are ways to obtain ES cells other than human cloning.

Embryonic stem cells are not all equal

There are three kinds of ES cells. The first is derived from the inner cell mass, a procedure pioneered in Dr. James Thomson’s laboratory in the University of Wisconsin using ‘excess’ embryos from *in vitro* fertilization clinics. The second, embryonic germ cells, is isolated from the regions of the embryo destined to become ovaries or testes. This was first carried out by Dr. John Gearhart’s group in John Hopkins’ University, using foetuses from terminated pregnancies. The cells resulting from the two laboratories appear to be very similar.

The third kind of ES cells involves somatic cell nuclear transfer, the technique that created Dolly, the lamb cloned from a cell of an adult sheep. Researchers take a normal human (or animal) unfertilised egg and remove the nucleus, replacing it with the nucleus from a somatic cell of a human donor. The perceived advantage of this procedure is that the somatic cell donor could be the patient requiring tissue replacement, thus avoiding problems associated with immune rejection of transplanted cells or tissues that are foreign to the body.

As is clear from the description, the first two categories of ES cells do not involve the creation of human embryos, and research on those ES cells has already been going on for the past two years. Many people may find research on those stem cells morally acceptable, though it will be difficult to justify research on those cells in view of the latest discoveries on the enormous developmental potentials of adult cells (see below), which make ES cells completely redundant.

It is research on ES cells obtained by nuclear transfer that raises the most serious moral concerns, for it requires the creation of embryos specifically for providing ES cells, the embryos being destroyed in the process.

In December 1998, researchers in the Infertility Clinic at Kyeonghee University in Korea announced that they had successfully cloned a human embryo by transferring the nucleus from the somatic cell of a 30 year old woman into one of her unfertilized eggs. This embryo was reported to have developed to the fourth cell division stage, when it would have been implanted. But it was destroyed on ethical considerations. Meanwhile, researchers in the United States and Australia have created ‘human’ embryos by transferring the nucleus of human cells into the eggs of the cow and the pig. It is of course questionable whether the embryos created by such procedures are human, and whether they are justifiable on moral grounds. These were destroyed at day 14. It was not clear, however, whether ES cells have been extracted from the embryos before they were destroyed.

Proponents claim that one of the major advantage of ES cells is that established cell lines can be obtained only from ES cells and not adult stem cells; though this may no longer be true (see below).

ES cells carry health risks, and there are major technical difficulties in creating them with nuclear transplant cloning techniques.

- ES cells can give rise to teratomas – malignant tumours (cancers) consisting of a disorganized mass of differentiated cells – on being transplanted.
- Nuclear transplant cloning is a very inefficient process with massive failure rates, requiring a large number of donor eggs.
- Nuclear transplant clones created by transferring human nuclei into cow and pig egg carry even greater risks, as it is well-known that such interspecific nuclear-cytoplasmic hybrids fail to develop normally.

ES stem cell research serves commercial interests, not public good

There are powerful commercial interests in ES stem cells. Geron Corporation of Menlo Park California gained first rights to exploit cells commercially, and also funded the isolation of embryonic germ cells. A total of ten companies were involved in exploiting stem cell technology and stem cells in 2000. Geron already owns dozens of patents on ES cells.

Companies investing in adult stem cell technology include Nexell Therapeutics of Irvine California and Anastrom Biosciences of Ann Arbor. Osiris Therapeutics of Baltimore identified mesenchyme stem in the supportive tissue that surrounds the bone marrow, and has patented systems for isolating and producing those cells, and launched two clinical trials. Mesenchyme cells can differentiate into cartilage, muscle and even neurons. Neural stem cells came on the scene later, but already clinical trials have begun.

It is clear that the major impetus for both ES and adult stem cell research is coming from the biotech companies and scientists working with them. Therapy is likely to be very costly on account of the multiple license fees that have to be paid, not only on cells and cell lines but on isolation procedures.

Public opposition to ‘therapeutic’ human embryo cloning has been fierce. Apart from the moral objection to the creation of human embryos that are destined to be destroyed, many groups feel that ‘therapeutic’ human cloning is a slippery slope to reproductive cloning and the re-emergence of eugenics. The Clinton administration had forbidden such research in federally funded projects; and no European Government, with the exception of the United Kingdom, is in favour of such research.

The British government first announced plans to relax the law on human embryo cloning to allow the creation of human embryos up to 14 days to provide ES cells. Parliament voted in favour of the new law in December, against the advice of the European Group of Ethics in Science and New Technologies (EGE). The House of Lords endorsed Parliament’s decision with an overwhelming majority last night.

The EGE had warned that the creation of embryos by somatic cell nuclear transfer (‘therapeutic cloning’) for research on stem cell therapy would be premature", drawing attention to the rapidly developing research in adult stem cells. The EGE recommended that the EU should set up a budget to explore non-cloning sources of stem cells, especially adult tissue, and to enable the results of such research to be "widely disseminated."

Promises of adult stem cells

Mammals appear to contain some 20 major types of somatic stem cells. Stem cells have been described that can generate all the cells in the brain, the liver, pancreas, bone and cartilage. These adult stem cells are increasingly found to have the potential to become practically as many different cell types as ES cells. Furthermore, it appears that differentiated adult cells can be made to revert to cells remarkably similar to stem cells, and to have the ability to multiply for long periods in cell culture. Some of the findings are highlighted below.

- Mouse bone marrow stem cells can give rise to skeletal muscle and brain cells. Liver /pancreas stem cells can give rise to blood cells and brain cells. Brain cells can give rise to all previous cells types including the peripheral nervous system and smooth muscle. Brain cells have been found to differentiate to muscle, blood, instestine, liver and heart.
- Catherine Verfaillie of the University of Minnesota in Minneapolis is reported to have isolated bone marrow cells from children and adults that can become brain, liver, and muscle cells as well. These were found in adults between 45 and 50 years old. This research has not yet appeared in print.
- Scientists from the National Neurological Institute and Stem Cell Research Institute in Milan, Italy, succeeded in growing skeletal muscle from stem cells originating from an adult brain, both in culture and in animals receiving the transplanted stem cells (Galli, R. et al (2000) *Nature Neuroscience* 3, 986-991).
- A researcher in Britain, Dr. Ilham Abuljadaye, has just announced an efficient method for creating large quantities of adult stem cells from white blood cells, and her findings have been independently replicated, though not yet published. The method involves inducing the white blood cells to de-differentiate in the test-tube into stem cells ("Stem cell discovery reverses time" *The Times*, 15 Jan 2001, http://www.thetimes.co.uk/article). That means it will be feasible to prepare stem cells from the patient who is in need of cell or tissue transplant, greatly simplifying the procedure, avoiding immune reactions and reducing cost.
- Two research teams at University College London found that adult rat cells can be made to divide hundreds of times when provided with the right mixture of nutrients, and without taking on the undesirable characteristics of cancer cells, such as uncontrollable growth (Cohen, P. (2001). *New Scientist* 18 Jan. latestnews@newscientist.com). Adult human cells may have the same capacity.

- Another possibility is that the patient's own stem cells could be stimulated to multiply and replace cells and tissues within the body itself (McKay, R. (2000). *Nature* 406,361-364.)

Conclusion

We reject research on ES cells created by human 'therapeutic' cloning on the following grounds.

- It is totally unnecessary, given the promise of adult stem cells and adult cells from the patients themselves, which can be most effectively used for cell and tissue replacement.
- It is morally unacceptable to create human embryos for providing ES cells.
- It is a slippery slope to human reproductive cloning.
- Nuclear transplant cloning has very low success rates and generates many abnormalities.
- Cloning procedures involving transplanting human nuclei into animal eggs carry even greater risks.
- ES cells are already available using 'excess' embryos from *in vitro* fertilization clinics and aborted foetuses.
- ES cells carry cancer risks on being transplanted.
- ES cells are subject to multiple patents, on cloning and isolation procedures as well as on the cells themselves; this will make their use in cell or tissue replacement therapy very costly.
- Adult stem cells are already showing great promise in cell and tissue replacement; and are likely to be much less costly."[xi]

Drs Ho and Cummins conclude that "Therapeutic' human cloning is an unnecessary evil." GEFNZ support these scientists call for "research into non-cloning sources of stem cells, especially adult cells, with special emphasis on methods that do not involve patented procedures and cell lines."

United States to Prohibit all Human Cloning

United States of America Republican Senator Weldon has sponsored a new law called the "US Human Cloning Prohibition Act of 2003" which has been recently passed by Congress and is due for ratification by their Senate. This law will ban both reproductive and therapeutic cloning as well as the importation of medical products derived from therapeutic cloning into the USA. Weldon has personally made the point that if both types of cloning are not banned then "Research cloning will simply make it easier for those like the Raelians to create babies, since the procedure is the same."

United Nations in Process of Banning all Human Cloning

The United States of a America and its allies are also pursuing the development of a United Nations treaty that would ban all human reproductive and therapeutic embryo cloning. GEFNZ believe that the NZ government should support the United States of America and its allies in trying to ban all forms of human cloning through the development of this treaty. Eventually, GLGM and ES need to be banned via international law through a United Nations Treaty, such as the one being developed on cloning right now. **The NZ government needs to promote and support this development.**

7. SECTION 36 (1) (a) - HUMAN/NON-HUMAN HYBRID EMBRYOS

It is a positive move that the implantation of hybrid of genetically engineered human/non-human (HNH) embryos is to be banned, but allowing research into creating HNH will only increase the likelihood in the future that someone will want to bring one of their HNH creations to life. GEFNZ also does not believe that the medical ends would ever justify the means of creating HNH hybrid embryos. As such, GEFNZ believe the use HNH hybrid embryos for research purposes is unethical and immoral and should be banned by being added to Schedule 1.

8. SECTION 36 (b) (iv) - EMBRYO SPLITTING

The allowing of embryo splitting under section 36 (b) (iv) is potentially another form of cloning and raises all the risks mentioned previously on cloning and requires strict regulation to avoid abuses of this technology. Embryo splitting also presents the risk of copies of standard models of children being made available to parents through embryo selection and IVF. Strict regulations need to be put in place if this is to be used in AHR so that genetically original embryos, that is to say a new and unique combination of male sperm and female egg using IVF, should be strictly limited to use in one female patient only. In this way it will ensure that every child in a single pregnancy conceived using IVF is a genetic original that has never existed before, nor will ever again. This does not preclude the possibility of twins etc. occurring in a single pregnancy when a number of embryos are implanted at the same time in a woman's womb using IVF as occurs naturally now. However, it should exclude the possibility of a woman having two or more pregnancies over a number of years using the same cloned (split) embryo as this would just be cloning by stealth, for example, choosing to have three children at two or three years apart, but using the same original embryo to end up with three genetically identical children with the only difference being their date of birth.

9. GENETIC TOURISM NOT ADDRESSED

A major problem not addressed in the bill is the one of genetic tourism which is where New Zealanders could go overseas to access banned or regulated assisted reproductive technologies that they might be illegal (e.g. cloning) or have been declined use of in NZ. People must be actively prevented from utilising human assisted reproduction technologies overseas and should be made liable for prosecution under HART, even if they return to NZ some years later after having used the technology to conceive a child or children. Unless, of course they get prior permission from the New Zealand AHR regulatory authority (as proposed above) who makes its decisions based on its own rules and regulations and not on an overseas jurisdictions. This could occur because an overseas clinic may have a better record at achieving AHR than what is on offer from clinics in NZ.

10. SECTION 4 - PRINCIPLES OF HART

Section 4 as it presently exists is focussed solely on the needs of individuals who might be created using AHR technology as if these individuals would have no relationship or impact on wider society and the human rights of others. These threats that GLGM and ES, in particular, would pose have been discussed in other sections above, but it is interesting to note that this Section 4 takes an extreme individualistic perspective that seems to be based on the old Margaret Thatcher and ideologically extreme free market supporters belief that the only meaningful entity that exists is the individual and society as such does not exist. Considering that the biggest impact of AHR technologies will be on those who are not conceived using these technologies this is a major oversight by the government. As such, section 4 needs to be amended to have an extra subsection added to it stating that those administering HART should do so in a way that upholds the Universal Declaration of Human Rights so that it protects society, the equality of all individuals and present and future generations.

11. SECTION 7 (4) PROHIBITED ACTIONS - PENALTIES NEED TO BE INCREASED

Considering that AHR technologies such as reproductive cloning, GLGM and ES could change the evolution of the human species and have been rightly described as crimes against humanity and potential weapons of mass destruction the penalties proposed in the current bill are far too lenient. As such, the penalties for breaching section 7 of the HART Act should be increased from its current maximum of 5 years in prison to a maximum of 10 years imprisonment. The financial penalty is proposed to be at a maximum $200,000 and should be increased to a maximum fine of $2 million. These new penalties would make them in line with the United States of America Human Cloning Prohibition Act of 2003.

CONCLUSION: THE END OF HOMO SAPIENS?

The proponents of germ-line genetic engineering try to paint a rosy future where they want this technology to be used so that individuals can be allowed to enhance their bodies, for example, through increased intelligence, athletic ability, better immune system etc. Although the NZ government are not going to the exactly the same eugenic extremes of Nazi Germany in that they are not seeking to destroy a particular ethnic or religious group they do want to legalise eugenic AHR technologies that will allow for the genetic "purification" of the NZ population and genetic enhancement through GLGM.

There can be no doubt that the most serious threat of AHR technologies is GLGM as it could allow the creation of genetically "superior" and separate species of humans beings. There are those who would use this species changing technology of GLGM as a means to establish their economic, social and political superiority and dominance over naturally born humans. A war of the human species with the Gene Rich vs. the Naturals is all but inevitable in the very long term if GLGM is not prohibited both in NZ and internationally. The good news is that we have the lessons of history and the foresight of today that can help us avoid this ever having to happen. We repeat **this war does not ever have to happen**, but this depends on the choices we make today as a society and as a nation right here and right now on the HART bill. We call on the Select Committee to support:

- the prohibition of those things already listed in Schedule 1 e.g. human cloning;
- the prohibition of germ-line genetic modification, embryo selection, sex selection and mandatory genetic testing by adding them to Schedule 1;
- the creation of an independent assisted human reproduction regulatory authority modelled on the Human Fertilisation and Embryology Authority in the United Kingdom;
- Proper facilitation of consultation processes with the public and the entitlement of society and the community to input in a meaningful way into the processes and decisions that enable this technology to take place before any AHR technology is allowed to go ahead.
- the prohibition of embryo cloning for non-reproductive purposes and the creation of human/animal hybrid embryos for research purposes.
- the regulation of embryo splitting so that it cannot be used as a way of cloning humans;
- a prohibition on genetic tourism where people could go overseas to access prohibited or restricted reproductive technologies.
- a sub-section added to section 4 of the HART bill stating the need for the protection of human rights enshrined in the Universal Declaration of Human Rights as well as the equality of all people and the protection of present and future generations; and
- increased penalties for breaching Schedule 1 to a maximum fine of $2 million and a maximum of 10 years imprisonment.

APPENDIX 1
Witness Brief: Professor Stuart A. Newman
New York Medical College, Dept of Pathology

To whom it may concern
As a biologist working in the US on issues related to embryonic development and a founding member of the Council for Responsible Genetics, a public interest group guarding against inappropriate uses of new genetic technologies, I have followed the debate in New Zealand on proposed amendments to the HART Bill with interest. In my view the proposed policy has many positive aspects, but it is also inconsistent from a scientific standpoint. Unless this inconsistency is remedied, the laudable objectives of the new policy will be undermined.

The recommended prohibition of cloning for reproductive purposes is essential to prevent adverse consequence to individual children of an untested (and untestable in any ethical fashion) experimental technique. Moreover, the prohibition on creation of human/non human hybrid embryos for reproductive purposes, implantation of animal and hybrid embryos into humans are farsighted policies that will prevent adverse consequences to society of producing near humans for medical and research purposes. The blurring of the boundary between human and non-human can only be divisive. It would lead, in my opinion, to attempts to produce non-human organisms as close to human as possible, for various instrumental purposes, and over time more and more problematic lines will be crossed.

However, it is a matter of great concern that germline gene modification, and more broadly, the introduction of genes into early embryos that are intended to be brought to full term, is not similarly prohibited under the proposed amendments to the HART Bill. Whereas the hazards of genetic modifications to humans are usually discussed in terms of somatic(body cell) modification, in which changes to an individual's DNA can be passed down to future generations, genetic modification to early embryos, similarly to cloning is hazardous to developing individuals even when there is no germline transmission to future generations.

The hazards of germline transmission are clear. For example, germline introduction in mice of an improperly regulated normal gene resulted in progeny with unaffected development, but a high tumour incidence during adult life. Such effects may not be recognisable for a generation or more.

It is important to recognise however that the hazards to the embryo of such alterations are not eliminated even if there is no germline transmission. The biology of the developing individual will still be profoundly altered by the manipulation of his, or her, genes at an early stage, hence the term "developmental manipulation" appropriately pertains to both cloning and germline procedures.

Laboratory experience shows that insertion of foreign DNA into inopportune sites in an embryo's chromosomes can lead to extensive perturbation of development. For example, the disruption of a normal gene by insertion of foreign DNA in a mouse caused abnormal circling behaviour when present in one copy, lack of eye development, lack of development of the semi circular canals of the inner ear and anomalies of the olfactory epithelium(the tissue that mediates the sense of smell)when the mice were inbred so that the mutation appeared in the homozygous form (i.e. on both copies of the relevant chromosome). Another such 'insertional mutagenesis’ event led to a strain of mice that exhibited limb, brain, and craniofacial malformations, as well as displacement of the heart to the right side of the chest, in the homozygous state. Each of these developmental anomaly syndromes were previously unknown. The prediction of complex phenotypes on the basis of knowledge of the gene sequence inserted or disrupted is elusive and likely to remain so.

It is instructive to compare germline modification with somatic cell modification, an technique currently in use, but plagued with unexpected and even fatal outcomes. The tissues of a developed organism are in some sense modular- if blood, skin , a heart or a liver is diseased or damaged it can be replaced by a substitute without changing the "nature" of the individual. Similarly, with gene alteration in a developed individual, in reasonable candidate cases for somatic therapy, the gene is playing a defined role in a particular tissue or organ, and the goal of the modification is to replace, or correct, the poorly functioning gene in one or a very limited set of tissues.

During development the situation is much more complicated. Tissues and organs taking form during this period, and the activity of genes is anything but modular. During development many if not most, gene products can have multiple effects on the architecture of the organs and the wiring of the nervous system, including the brain. Thus, attempts at developmental modification would be susceptible to a distinct category of hazard not shared by the somatic procedures.

It is therefore clear that there would be no way to assess the safety of germline procedures in human beings, without exposing prospective children to unwarranted experimentation. Unlike other procedures intended to save lives of existing people, the experimental alteration of prospective humans cannot be justified under any ethical standard of justifiable risk.

I therefore urge you to include germline and other developmental-genetic manipulations of human embryos intended to be brought to term under the same category of prohibited procedures in the proposed amendments to the HART Bill as reproductive cloning and animal - human hybridisation.

Professor Stuart A. Newman - 25.6.03
Department of Cell Biology & Anatomy
Basic Science Building
New York Medical College
Valhalla, NY 10595

APPENDIX 2

Unit 112 Aberdeen House, 22-24 Highbury Grove, London N5 2EA
Phone 020 7704 6100 fax 020 7359 8423 info@hgalert.org
www.hgalert.org

Human Genetics Alert

Witness Brief to New Zealand Health Select Committee Consultation on the Human Assisted Reproduction Technologies Standing Order Paper

July 3rd 2003

1. Introduction

Human Genetics Alert is an Independent Non-Governmental Organisation funded by leading UK and US charities. It is not a religious or ‘pro-life’ organisation and supports women’s right to terminate pregnancy.

The author of this witness brief, HGA’s Director, Dr David King, is a geneticist who was previously editor of Gen Ethics News an independent newsletter on ethical issues in genetics. Dr King has published widely on ethical issues in genetics in both academic and popular publications. He is a member of the ethics committee of the North Cumbria Community Genetics Project.

We will confine our submission to two aspects of the HARTSOP which we feel most strongly: human genetic engineering and sex selection.

2. Why human germline engineering (HGE) should be prohibited

The fundamental reasons for banning HGE is that to permit it will lead inescapably to a new eugenics with unacceptable ethical and social consequences. Furthermore, HGE is not necessary in order to avoid the birth of children affected by serious genetic diseases.

We are sure that it is apparent to the committee that the use of HGE for ‘enhancement’ of human characteristics is ethically and socially unacceptable. To do so turns children into designed objects and puts parents in a position of ‘playing ‘God’. This objectification of children undermines their basic ethical status as human subjects, and thereby ultimately, the basis of human rights.

Objectification is a bad thing in itself, but is also likely to have immediate harmful consequences for the individuals and families involved. Once we start to pick and choose the characteristics of our children, we damage the unconditional love between parent and child, which depends upon accepting the child whatever their characteristics. Where normal parents hope their children will display particular characteristics and talents, those parents who have engineered their children will expect them to do so, and will surely have a greater tendency to put pressure on them to do so. As consumer goods, they will likely be viewed as defective if they fail to live up to their expensive genetic programming. This is ethically unacceptable. There is a fundamental difference between pushing children in a particular direction by, for example insisting they undergo piano lessons, and writing genetic instructions for musical talent into their genomes (These arguments assume such scenarios to be technically feasible, which we realise is still uncertain). Genetic design of children is radically more dictatorial, because a child can always resist doing piano practice, and can give up when they become adult. However, being designed with a particular set of genes gives a child no choice in the matter. Such children will likely end up feeling tyrannised by their parents, and as less than fully their own person, who can choose what to make of their lives; in short, they will feel like objects. What these points illustrate is a fundamental truth about the human condition: that being a human subject depends upon not being tampered with by designer parents.

There is a further problem with such ‘enhancements’, which will be driven by parents desires to give their children a competitive advantage: early models will be at an irreversible competitive disadvantage to children who are born five years later with more advanced genetic programming that will result from scientific advances.

Socially, the prospect of ‘enhancement’ is disastrous. We should learn from the results of earlier eugenic attempts at social engineering, which feed off and enhance existing social prejudices and reduce tolerance for diversity. If HGE is permitted, it is likely that those with greater financial resources will use it to increase the competitive advantages that their children already enjoy, thereby increasing social class polarisation, with all the undesirable consequences thereof.

Can ‘enhancement’ be prohibited if HGE is used to eliminate genetic disease?

Experience suggests that it will be impossible to limit HGE to therapeutic applications and that permitting any form of HGE opens the door to 'enhancement'.

Firstly, there is acknowledged to be no firm line between therapy and 'enhancement'. There is a grey area, exemplified by contestable 'diseases' such as attention deficit and obesity, and an also widely-acknowledged trend, driven partly by the pharmaceutical industry, to pathologise characteristics which have previously been thought to be part of normal variation. This grey area will be exploited by parents who wish to utilise the latest genetic advantages, who will, if necessary, use litigation to force regulators to accede to their demands for 'reproductive freedom' and 'privacy', and to stop 'discriminating' against them.

Attempts to draw firm lines in the application of medical technologies will only work if there is a clear, firm (and therefore legally defensible) conceptual basis for the distinctions being drawn. This is clearly not the case between therapy and 'enhancement'. Therefore, those who wish to permit HGE must take responsibility for the inevitable future use of this technology for 'enhancement'.

Is the HGE necessary for the avoidance of Genetic Disease?

HGE is clearly unnecessary for the avoidance of genetic disease.

Firstly, we wish to challenge the dominant perception of genetic disease as disaster. Many disabled people and their representative organisations, who we have discussed these issues with, are clear that this view is based on prejudice and misinformation. Such advocates of disability rights argue that disability is primary caused by prejudice and the lack of resources devoted to ensuring access of disabled people to society, rather than being primarily due to physical impairments. They view the pressure to eliminate disabled people from society by pre-natal screening and pre-conceptual counselling etc. as a continuation of eugenic trends in our society. There is not space here for an adequate explanation of these views - we refer the committee to the increasing number of statements by representative disabled people's organisations, such as Disabled People International.

HGA acknowledges that there are some genetic conditions which are severe enough to make prevention of the birth of the people with such conditions a reasonable and ethically acceptable choice. We wish to emphasise that, in our view the number of such conditions is considerably smaller than what is currently permitted. Huntington's disease, the condition cited by the NZ government on its website is certainly not an example of a condition severe enough to warrant elimination: people with the HD gene live unaffected lives to the age of 40 or greater and are thereafter disabled. However, in these limited number of cases, there are many other possibilities, including non-parenthood, 'social parenting' (i.e. sharing parenting roles with other families), adoption, gamete donation, pre-natal testing, as a last resort pre-implantation genetic diagnosis. Given this, the demand for HGE can be considered as a little more than parental desire for the 'cutting edge technology'. Since the ethical and social objectification's to HGE are so great, such parental desires, however deeply felt, must be resisted.

It should be noted that the only 'advantage' the HE has over the alternative practices and technologies mentioned above is in its use for 'enhancement'. It is here that the real market for HGE will lie.

The implications of not banning HGE

The implications of New Zealand not banning HGE are profound. This is not just another decision about just another biomedical technology. Permitting HGE would represent a decision to cross a critical threshold for the whole of humanity. Humankind would begin to take charge of its own evolution, and so enter into a new era of human history. Even if the consequences of doing so were uniformly good, this would require deliberation and a high degree of consent from humanity as a whole; in fact, as we have argued, the consequences are almost uniformly bad. And for this reason, international opinion, so far as the topic has been discussed, is strongly against HGE All countries which have legislated on the issue have banned HGE This includes the U.K. and all the countries party to the European Convention on Biomedicine and Human Rights, as well as proposed legislation in Canada. While for many countries HGE is still a non-issue, no country has taken the position that New Zealand proposes to: to give HGE positive endorsement by designating it a normal, regulated technology. New Zealand does not have the right to unilaterally decide to take humankind over this threshold.

3. The case against sex selection

Sexism:

Sex selection is the exercise of sexism at the most profound level, choosing who gets born, and which types of lives are preferred. In traditional-patriarchal societies, such as in India and China, the preference for boys has led to huge imbalances in the sex ratio in the population. Worldwide, there are estimated to be 100 million missing women as the result of sex selection[xii]. Indian communities in the US and UK are now being targeted by clinics who have no scruples about exploiting these traditional prejudices for profit[xiii]. Sex selection in India is widely condemned, yet the Indian preference for sons is clearly economically rational, and therefore unsurprising. In many parts of India, the traditional dowry system still exists, making women an economic burden on families. Conversely, in western countries it is probable that there is a link between the observed increasing preference for girls and the demands of the labour market for more feminine skills. However, the choices that are being made are still based on rigid, sexist, gender roles. In how many cases where parents are 'desperate for a girl' will they be hoping for a loud tomboy that grows up to be an engineer? Society must continue to fight sexist gender stereotypes, not allow them to dictate who is born.

'Family Balancing'

It is sometimes suggested that so-called 'family balancing', whereby families where there are two or more children of one sex, choose a child of the opposite sex is a less objectionable use of sex selection. However, it is not clear that there is any difference between this and other cases. The motivation for such choices is still likely to be sexist, and the process is still likely to turn the child into a commodity.

Furthermore, any line to be drawn between family balancing from unacceptable consumerism will be arbitrary and unfair. For example, those with one child who want only one more child, would justifiably be able to claim that they were being discriminated against, if the line were drawn at two children of the same sex. Since the average number of children per family is now less than two, those many couples who only intend to have one child could reasonably ask why they were being excluded from the 'benefits' afforded to larger families. Attempts to pass legislation based on arbitrary rules would be overturned by legal challenges. Thus, if an exception is made for 'family balancing' we are inviting future slippage, and opening the door to the future unrestricted use of sex selection.

Slippery Slopes

There is consensus that selection techniques of any kind should only be used for the purposes of preventing serious disease. However, sex is not a medical problem, and to permit sex selection essentially destroys any possibility of holding the distinction between pathological states and normal genetic variation. It will be impossible to argue that parents should not select for IQ, appearance etc., since it is permitted for sex. If we allow sex selection by any means, the door to designer babies will not have been opened a crack-it will have been thrown wide open.

Consumerism and Objectification

As noted above with regard to HGE, these techniques objectify human beings. In the case of sex selection. parents who have chosen a girl will tend to put greater pressure on her to conform to their hopes and expectations of her behaviour, rather than allowing her to become the person she is and wants to be. Such a child may feel that she is only wanted when she behaves the 'right' way.

Choice and 'reproductive rights'

The final defence of sex selection is the appeal to liberty. It is often suggested that there exists a right for individuals to reproduce in whatever way they wish. These consumerist arguments are increasingly assuming the character of an ideological doctrine, which is wielded as a blunt instrument, to effectively silence all other ethical concerns. Yet while autonomy is an important value, other values, such as beneficence/non-maleficence, justice and the interest of others have equal importance. These values must be negotiated on a case-by-case basis, rather than there being a general assumption in favour of liberty.

Strong claims for autonomy may seem plausible, but a closer inspection reveals that they cannot be sustained. For example, the Universal Declaration of Human Rights, includes ‘the right to marry and found a family’. This article arose from the Nazi atrocities and from eugenics laws restricting disabled people’s reproduction in many countries. It is negative right of non-interference by the state; this is very different to a right of access to any form of technological assistance needed to reproduce, when this is not possible in the normal way, whatever the consequences.

It is often thought that strong individual rights protect against eugenic interference by the state. However, at present, as many commentators have noted, in Western countries, the greater threat is of a free-market eugenics, driven by commerce and by consumerist desires for the perfect baby. Eugenic social attitudes, especially about the value of disabled people’s lives clearly still persist, as do a whole set of social and economic factors, which exert eugenic pressure on individual choices . Rather than non-interference, what is needed now is more state regulation to restrain the eugenic trend.

Conclusion: sexism and racism

In summary sex selection is unacceptable both in terms of its motivations, and its consequences, for individuals, society and for our basic concepts of human dignity. We have already seen the consequences for Asian societies, yet there is a lobby that insists, that, somehow, when practised by white people it is enlightened and harmless. I would argue that the social forces that drive sex selection, and the outcomes are simply different in Asian societies, not worse. It is not racist for white people to criticise sex selection in India and China: what is racist is to assume that when white, western people do it, it is somehow better.

APPENDIX 3

GE Free NZ Declaration for the Preservation of the Human Species

The individuals and organisations who are a party to this submission,

- Noting the charter of the United Nations affirms human rights, based on the dignity and worth of the human person and on equal rights of all persons;
- Noting that the Universal Declaration of Human Rights affirms the right of every person not to be discriminated against;
- Noting that Te Tiriti o Waitangi (The Treaty of Waitangi) guarantees the equality of Maori with that of all other citizens;
- Realizing that human dignity and human rights derive from our common humanity;
- Noting the increased power of genetic science, which opens up vast prospects for improving health, but also has the power to diminish humanity fundamentally by producing children through human cloning or by producing an inheritable genetic change;
- Concerned that human cloning, which for the first time would produce children with predetermined genotypes, rather than novel genotypes, might cause these children to be deprived of their human rights;
- Concerned that by altering fundamental human characteristics to the extent of possibly producing a new human species or sub-species, genetic science will cause the resulting persons to be treated unequally or deprived of their human rights;
- Recognizing the history of abuses of human rights in the name of genetic science;
- Believing that no individual, nation or corporation has the moral or legal warrant to engage in species altering procedures, including cloning and genetic alteration of reproductive cells or embryos for the creation of a child;
- Believing that the creation of a new species or sub-species of humans could easily lead to genocide or slavery; and
- Stressing the need for the New Zealand government to enact national law and promote global cooperation to prevent the misuse of genetic science in ways that undermine human dignity and human rights;

We therefore call on the government of New Zealand to:

Article 1

Prohibit anyone from initiating or attempting to initiate a human pregnancy or other form of gestation using embryos or reproductive cells which have undergone inheritable genetic modification.

Article 2
Prohibit anyone from utilizing somatic cell transfer or any other cloning technique for the purpose of initiating or attempting to initiate a human pregnancy or other form of gestation.
Article 3
Develop publicly accountable, effective, ethical, moral and spiritually appropriate law for the regulation of all other human genetic technologies.

APPENDIX 4

TO: Health Select Committee, New Zealand Parliament
FROM: Center for Genetics and Society (USA)

RE: Proposed Human Assisted Reproductive Technologies Bill

5 July 2003

The proposed Human Assisted Reproductive Technologies bill contains many commendable provisions, but there is at least one provision that we believe should be changed before the bill is considered further.

We refer to the provision that lists germline genetic modification (hereafter "inheritable genetic modification," or IGM) as a technique that might, after review by the proposed advisory bodies, be approved for use.

It is widely recognized that IGM would afford no therapeutic applications that are not available using other means, and that its use would establish a new regime of high-tech eugenics that would profoundly and adversely impact human rights, human dignity, social equity, and in fact the very foundations of democratic civil society.

All countries that have to date enacted comprehensive legislation addressing the new human genetic technologies have banned IGM. The landmark 1997 Council of Europe *Convention on Biomedicine and Human Rights* explicitly bans germline modification. Noted international health lawyers and bioethicists have called upon the United Nations to begin negotiations on an international convention that would ban germline modification. And just last week, Dr. James Peacock, President of the International Congress of Genetics, announced his opposition to IGM.

It would be quite unfortunate, then, if New Zealand were to become the first country to officially allow that IGM might in fact be an acceptable application of human genetic science.

It is true that the HART bill provides that proposals to initiate IGM research or trials be approved by advisory bodies. But that is the problem. As written, the provision regarding IGM would serve to encourage those who look forward to a world of "designer babies," in a way that no other legislation current in force does. The point is to make clear that proposals to begin work towards inheritable genetic modification are not to be assayed in the first place.

We urge that IGM be removed from the list of applications that the proposed review boards might accept for consideration, and rather be designated as an application that is unacceptable on fundamental grounds, as is, say, reproductive human cloning.

Please let us know if there is any additional information or comment we might supply. We would appreciate knowing of your actions in the matter at hand.

Sincerely,

Richard Hayes, Executive Director
Center for Genetics and Society
Oakland, California, USA
www.genetics-and-society.org
richard.hayes@genetics-and-society.org

APPENDIX 5

Disability Rights

This article provides some thoughts in regards to key issues mentioned in the HART law proposal namely the issues of embryo selection, sex selection, germline gene therapy and mandatory genetic screening with a particular emphasis on a disability rights view towards these issues.

Introduction:

Science and technology (S&T) have had throughout history, and will have in the future, both positive and negative consequences for humankind. As the result of human activity, S&T is imbued with intention and purpose. The goals for which S&T are advanced are value-laden, reflecting the cultural, economical, ethical, spiritual and moral framework of society. S&T embodies the perspectives, purposes, prejudices and objectives of society, and of powerful social groups within society.

Human Bio/gene technology through it uses of genetic selection/ deselection/ therapy/ enhancement has the potential to fundamentally alter society and to affect many, many people. It has the potential to divide society into two classes: the genetic positive-people who fit expectations- and the genetic negative -people who do not fit the expectations- (“defect” positive). It also has the potential to prod us to exchange a "right to be healthy" - the basis of universal public healthcare coverage - for "no right to be unhealthy".

Thanks to bio/gene technology, whenever it is detected that a human being is not measuring up to societal expectations, whether prior to birth or after, the "offending" human being will have his/her right to existence as they are put at risk. Our propensity to judge each other based on characteristics we attribute to each other, fuelled by the unravelling of the genetic code, will increase our potential for intolerance of human characteristics viewed as undesirable and preventable (especially if those characteristics require accommodation by the majority of society).

The potential for abuse is immense and can easily outweigh the positive points if we are not careful. To prevent the negative impacts, safeguards should be put in place. It is of paramount importance that scientists be vigilant in monitoring the use of their results in any given society and stand up against unethical use of their research results. The public must be enabled to monitor and control the use of research results; they also must be involved in the development of policies concerning which research should be publicly funded and what safeguards are appropriate to prevent the misuse of research results. In order to understand the impact of human bio/gene technology on disabled people we have first to look at the meaning of disability.

What is a disability?

There are two main interpretations of the term ‘disability’. These may be expressed in a dialectic of ‘medical model”(mM) versus ‘social model’(sM). Within the *medical individualistic model, disability* is viewed as a defect, a problem inherent in the person, directly caused by disease, trauma, other health conditions, or a deviation from certain norms and leading to a low quality of life for the person and their relatives. Management of the disability of the disabled person or person-to-be is aimed at cure, prevention, or adaptation of the person (e.g. assistive devices) to ensure an as normative functioning or existence as possible. Medical care, preventive medicine, and rehabilitation are viewed as the primary issues, and at the political level, the principal response is that of modifying or reforming health care policy and making preventive medicine more efficient. At the emotional level, the principle response is one of pity and rejection. Disabled people are seen as a suffering entity and as having a low quality of life[xiv] However, the medical model is in contradiction to studies, which show that disabled people (sM) rate their own quality of life as equal to or higher than their non-disabled counterparts,[xv]do not see themselves as a medical condition [xvi] and mostly feel that their quality of life is not worse than the one of non disabled people per se[xvii] but that their life is made difficult by societies unwillingness to accept and to accommodate their needs.

This view of many disabled people is reflected in the social model (sM) of disability, which sees disability mainly as a socially created problem and as a matter of the full integration of individuals with different biological realities and abilities into society. Disability is not seen as an attribute or defect of an individual, but as caused by the reaction of society towards the biological reality of the individual. Disability is a complex collection of disadvantages, many of which are created by the environment, particularly the social environment and socially mediated aspects of the physical environment. On this view, the management of the problem requires social action, and it is the collective responsibility of society at large to make the environmental and emotional modifications necessary for the full participation of people with different biological realities in all areas of social life. The issue is therefore an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights.

The social model allows able-ism[xviii] (discrimination based on the lack of expected abilities) to be seen in the same light as racism or sexism. The social model of disability does not negate that a disabled person has a certain biological reality (like having no legs), which makes her/him different in her/his abilities, which make her/him not fit the norm. However, it views the 'need to fit a norm' as the disability and questions whether many deviations from the norm need a [xix]medical solution (adherence to the norm) or a social solution (change/elimination of norm). The social model also does not negate that the disabled is in need of medical care. Every human needs medical care. However the social model questions whether many of the so called 'medical problems are really medical problems and whether a medical treatment is often the solution. Another model similar to the social model namely the universalist model of disability describes disability as follows[xx]:

> Disability is a *limitation on participation* resulting from an *interaction* between: (a) bio-physiological conditions including *differences* in psychological, physiological, and anatomical structure, range, and function; and (b) environmental and external conditions including historical, social, economic, political, and behavioural factors. It is important to clarify the meaning of "limitation on participation" in the new approach. Unlike "functional limitation", this new term represents limitations on an individual's full participation in a range of life activities as a result of his or her disabilities. Thus, any range of limitations on participation across a range of activities resulting from bio-physiological characteristics and environmental factors may constitute a disability.

The debate around pre-birth "characteristic selection"

Preimplantation genetic diagnosis (PGD) and prenatal diagnostic (PD) are mainly sold as a tool for fixing disabilities, impairments, diseases, and defects, (DIDD) and diminishing suffering. These promises raise quite a few questions. Which and whose values and perceptions are reflected in the definitions of DIDD and the attached 'suffering'? Which and whose values and perceptions are reflected in the choice of solutions for the 'problem' of DIDD? How do the predominant societal values and perceptions that define DIDD, its attached suffering, and the proposed solutions affect the self-esteem and self-understanding of the people viewed as suffering from DIDD? Does the self-perception of people who are labelled as DIDD (the afflicted) match the perception that the non-afflicted have of the 'afflicted'? Do 'afflicted' people define their 'problems' and the solutions to them in the same way as the 'non-afflicted' do?

There are many ways to achieve characteristic control of one's offspring or of living members of society. Characteristic control can happen on the level of a cell, a zygote, an embryo, a foetus and a human being. A two-step procedure is employed to achieve this characteristic control. First, the genotype of cells, zygotes and embryos and the geno/phenotype[xxi] of foetuses, newborns and older human beings is checked by employing prefertilization genetic diagnostics, preimplantation diagnostics, prenatal testing, postnatal testing. This is followed by e.g. selection of sperms and eggs from sperm and egg banks and embryo selection after preimplantation genetic diagnostic to just highlight two examples of selection procedures. Abortion of a foetus after prenatal testing and infanticide of newborns after postnatal testing are two examples of deselection procedures. Character control occurs around the world because we discriminate against and seek to eliminate unwanted characteristics from our midst. Today, the nature and extent of the characteristics we can control is increasing with advancements in genetic and non-genetic (nanotechnology, cognitive sciences, information technology) knowledge and procedures (see below).

The key question is how does a society or a person decide, which characteristics are permissible in offspring. Can a society influence or regulate the decisions at any level? Is there a rational way to draw a line between characteristics? Is there a rational way to draw a line between characteristics with such names as Tay-Sachs, Beta-Thalassemia, sickle cell anemia, thalidomide, Alzheimer's, PKU, female, male, gay, lesbian, bisexual, mental illness, cystic fibrosis, cerebral palsy, spina bifida, achondroplasia (dwarfism), hemophilia, Down Syndrome, coronary heart disease, osteoporosis, or obesity to just name a few?

Many different lines could be drawn at what is an acceptable and unacceptable use of embryo selection and deselection:[xxii]

1) We could limit the use of prebirth characteristic control to genotype/ phenotype which ensure a certain death shortly after birth such as Tay Sachs.

2) We could limit the use of prebirth characteristic control to genotype/ phenotype which ensure certain death later on in life such as Alzheimer or Huntington Chorea
3) We could limit the use of prebirth characteristic control to genotype/ phenotype where the availability of affordable treatment and support is seen as a problem e.g. cystic fibrosis, hemophilia, insulin-dependent diabetes and many others. Note that all of these conditions are deadly if treatment is not provided.
4) We could limit the use of prebirth characteristic control to genotype/ phenotype which are perceived as severe.
5) We could limit the use of prebirth characteristic control to genotype/ phenotype, which are perceived as to ensure a low quality of life for the individual and his/her family.

Option 1) is rarely used. Characteristics, which fall under option 1) are used as an example for option 4). Furthermore characteristics from option 2) are also often used to justify option 4).
Indeed the sales pitches for new emerging selection and deselection technologies often uses option 4) implying that there is a way to distinguish between different 'medical ' characteristics based on their severity and that indeed the use of these technologies for 'non-severe' 'medical' characteristics might be distinguishable from the use for 'severe' 'medical' characteristics. However as the acceptance and penetration level for these technologies increases the implied limited application for 'severe 'medical' characteristics' vanishes rightly so. In reality no distinction can be made between different 'medical' characteristics based on their severity because a) to distinguish between different 'medical' characteristics would stigmatize further the selected 'medical' characteristics and the carriers of these 'medical' characteristics;[xxiii] b) nearly every 'medical' characteristic still can exhibit itself phenotypical in variants of different severity and clinical course[xxiv] and c) the same 'characteristic which is seen by some as a 'disease' ('medical' characteristic) may be perceived differently by different people depending on their family history, religious and socio-economic background, life situation and future expectations.

> To quote paragraph 65 of the draft report on pre-implantation genetic diagnostic and germ-line intervention from the International Bioethics Committee of the UNESCO, which states:
>
> "An often-debated subject is line drawing in case of the indications both for PGD [preimplantation genetic diagnostic] and PD [prenatal diagnostic]. Thus far all professional organizations in clinical genetics and reproductive technology as well as advisory groups on bioethics have argued against lists of diseases which can be defined as severe enough to justify PGD or PD. The number of monogenic diseases alone exceeds 5000 and nearly each of these has variants of different severity and clinical course. In addition, the same disease may be perceived differently by different couples depending on their family history, religious and socio-economic background, life situation and future expectations.[xxv]

If the arguments against option 4) are valid they would make option 3) also useless as any characteristic could fall under option 3). Interestingly option 3) is often used by parents to sue in so called wrongful birth suits where they claim the cost to themselves is to great (see appendix 5 on Wrongful Birth, Wrongful Life Suits).

The same technology now used to deselect against 'medical' characteristics can of course also be used to control characteristics normally not labelled as disabilities ('medical' characteristics) but as traits such as sex[xxvi] ('non-medical' characteristics). And this is where the line drawing seems to be. If we look at what drawing of lines are proposed it seems that the deselection of disabilities is labelled as being performed for medical reasons and therefore judged acceptable whereas deselection of traits such as sex is labelled as being performed for social reasons and therefore judged unacceptable. [xxvii] So the line is drawn between the use of the technology for 'medical' versus 'social' reasons. Deselection of characteristics labelled as diseases, defects or as a disability –whereby disability in this context is another term for disease and defect something subnormal- are all seen within the framework of 'medical reasons' and therefore acceptable (medical characteristics). It is even seen as the right thing to do [xxviii] Deselection or selections based on characteristics labelled as 'traits' or 'normal variations of being' such as sex are unacceptable as they are all seen within the framework of 'social reasons (non 'medical' characteristics).
This type of line drawing works with the public because disabilities are seen by the public within a medical framework ('medical' characteristics) and seen as leading to a low quality of life.[xxix]

Deselection of them is seen as the right thing to do.[xxx] A mother could be considered to commit child abuse if she refuses to deselect after disabilities are detected in an embryo or foetus. This type of line drawing has a few consequences namely the appearance of an animal farm philosophy where the same ethical argument is accepted for one characteristic (sex, trait, 'non-medical characteristic') but not for another characteristics (disabilities, 'medical' characteristic').[xxxi] Furthermore in order to keep this artificial boundary between disabilities and traits alive studies, which show that disabled people rate their own quality of life as equal to or higher than their non-disabled counterparts and do not see themselves as medical conditions and mostly feel that their quality of life is threatened by societal attitudes[xxxii] have to be and are ignored or even denounce by non-disabled people as irrelevant.[xxxiii]

The views of the afflicted in regards to ability control

How do the disabled view these technologies used and developed for characteristic and ability control? Lets have a look for example at the Ascender Alliance the first disabled transhumanist group recently founded in the UK. [xxxiv] Their writings contain a few key demands in regards to the use and development of science and technologies namely:

The right for self-determination, which is interpreted in my view rightly to be extended to the pre birth stage and the future generation.

The prohibition of negative eugenics through e.g. prenatal deselection

The prohibition of germ line genetic intervention

The prohibition of somatic genetic intervention of children and foetuses

As it is may be impossible to ensure that somatic manipulations will be confined to somatic cells and won't effect germ line reproductive cells point a) and c) might also mean the prohibition of somatic genetic intervention of adults

The prohibition of non-genetic interventions of children and foetuses

The acceptance of the right of adults to modify themselves through somatic (may be) and non genetic interventions

The general message of the Ascender Alliance is twofold: a) No one has the right to judge people with disabilities (independent on whether they are born yet or not) and prevent or change them based on that judgement and b) everyone has the right to change themselves as long as these changed abilities are available for everyone and are not transmitted to the next generation.

Let's give you the views of some other disability groups. The resolutions of the bioethics workshops at the 6th World Assembly of Disabled People International[xxxv] 2002 say[xxxvi] e.g.

> Resolutions: Theme: Bioethics Topic: Genetics & Discrimination
>
> I We demand the right to be different
>
> II We believe that no parent has the right to design and select their unborn child to be according to their own desires and no parent has the right to design their born child according to their own desires.
>
> III We defend and demand a concept of "person" that is not linked to a certain set of abilities.

On 12/13 February 2000, 130 disabled people and parents, delegates from Disabled People International (DPI) organisations in twenty-seven countries in Europe, African, Australia and North America, met in Solihull, UK to discuss bioethics and human rights. The Solihull declaration says among other things:

> "We demand an end to the bio-medical elimination of diversity, to gene selection based on market forces and to the setting of norms and standards by non-disabled people."
>
> "Biotechnological change must not be an excuse for control or manipulation of the human condition or bio-diversity."
>
> "An absolute prohibition on compulsory genetic testing and the pressurising of women to eliminate - at any stage in the reproductive process - unborn children who, it is considered, may become disabled."
>
> "That European governments do not ratify the Convention on Human Rights and Biomedicine as some sections are in contravention of the two documents adopted at the 1999 UNESCO Conference on Sciences."
>
> "That disabled people have assistance to live - not assistance to die."
>
> "That having a disabled child is not a special legal consideration for abortion."

> ”That no demarcation lines are drawn regarding severity or types of impairment. This creates hierarchies and leads to increased discrimination of disabled people generally.”[xxxvii]

Many disabled people and disability organizations do not feel that there can be a difference in the usage of the selection/deselection technologies based on the characteristic. Indeed if the HART is any indication the demand to lift the prohibition of sex selection seems to indicate the correctness of the disability rights assessment. Appendix 7 outlines the ethical arguments used to justify the prohibition of sex selection and appendix 7 shows further that none of the arguments used are solely the domain of the characteristic sex but can be used by other characteristics as well. The only argument which would allow such a distinction is the one used to distinguish between ‘medical’ and ‘non-medical’ characteristics which of course is not an ethical argument but a power argument. Every characteristic can be seen as medical or non medical based on the societal setting. In some countries gay is seen as a medical characteristic in some as a non-medical characteristic. Not to long ago even being a women was seen as a medical problem. The term and definition of ‘medical characteristic’ is in essence by itself a social construct.[xxxviii]

The consequence of this is the ethical schism between medical reasons and social reasons. The applied ethics as evident in the debate around the justification of the different selection/deselection procedures has a few consequences in regards to other bio/genetic technologies.

Genetic and non-genetic ‘cures’ ‘therapies’

There are two types of gene therapies. Somatic gene therapy is supposed to fix a ‘defective’ gene in cells other than egg and sperm, by delivering a ‘non-defective’ gene to the target cell. Changes are not supposed to be passed on to children, allowing the option of birth and later treatment. Germ line gene therapy includes genetic changes in reproductive cells, the egg and sperm. This altered genetic make-up would be passed on to children and following generations.

The HART law asked for the lifting of the prohibition of germ line gene ‘therapy’. Nothing is said about the other form of ‘therapy the somatic gene ‘therapy’. I assume that somatic gene ‘therapy’ is allowed as only the lifting of the prohibition of germ line gene ‘therapy’ is demanded in the HART law.

Some people feel they can draw a line between somatic and germ line gene therapies, allowing the former and prohibiting the latter, because the consequences of somatic gene therapy are confined to the person whereas germ line gene therapy can affect future generations. However, there are problems with this distinction: a) it can’t be guaranteed that somatic gene therapy does not modify reproductive cells[xxxix]; b) germ line gene therapy might work in some cases where somatic gene therapy doesn’t; c) germ line gene therapy might seem more cost effective because it fixes the problem irrevocably, whereas with somatic gene therapy the same ‘defect’ might occur in offspring, necessitating somatic gene therapy again and d) justifications for somatic over germ line gene therapy are cynical, based on assumptions that it is acceptable for individuals to put themselves at risk, without affecting future generations or society.

If as a society we embrace biological eugenics, then it’s only fair that society bears the danger. Furthermore if somatic gene therapy does not work but germ line gene therapy does, can we oppose the latter? And if somatic gene therapy is safe, can we see germ line gene therapy as unsafe?

However independent of the shaky distinction between somatic and germline gene ‘therapy’ it seems that the lifting of the prohibition seems to be a logical consequence of the increased usage and legalistic acceptance of PGD and PD.
If it is socially irresponsible knowingly to bring an infant with a ‘serious’[xl] genetic disorder into the world in an era of prenatal diagnosis[xli] and if it is unfair to the child to be born with a disability[xlii] shouldn’t it also follow that it is irresponsible to not provide your child with a genetic cure (there are reported linkages of prelingual deafness to a variation in the gene for the protein connexin [xliii]) as bioethicist John Harris claims?[xliv] Furthermore, wouldn’t parents be obliged to give their child ‘non-genetic cures’ especially in the absence of ‘genetic cures’? Wouldn’t deaf parents be obliged to give their deaf child hearing ability by fixing the ‘assumed genetic defect’ through cochlear implants independent of whether they see ‘being deaf’ as a variation of being and believe in a ‘deaf culture’ or not?[xlv] Might parents have been considered to commit child abuse if they would have refused artificial limbs for their Thalidomide children in the 1950’s1960’s? Could a mother be considered to commit child abuse if she refuses to terminate her pregnancy after ultrasound showed phocomelia (i.e., hands and feet attached close to the body without arms or legs) in the foetus or other characteristics

labelled as diseases, defects and disabilities (mM)? In general, would the mother/parents abuse society and or the child by not fixing the “problem”? If the parents have an obligation to the child and society to fix their kid wouldn’t disabled adults themselves be obliged to accept and seek any cure genetic or otherwise?[xlvi] These are all open question, which seem to move towards the answer ‘Yes‘[xlvii] as long as the justification is based on medical reasons and the prevention of suffering caused by diseases defects and disabilities (mM).

Genetic and non-genetic enhancement

However what would the answer be if parents could add ‘advantageous’ genes to their children’s genetic make-up?[xlviii] Like if a gene could transmit immunity to AIDS, wouldn’t parents be obliged to add this ‘advantageous’ gene to their children’s genetic make-up? Although the feasibility of somatic and germline gene therapy is still far off and it has to be seen whether it will ever be feasible wouldn’t parents be obliged to give their children (who fit the norm) genetic enhancements (to better the norm) as long as it seen as advantageous to the child? Furthermore in the case of non-genetic enhancement it is more difficult to draw a line between cure and enhancement. Lets take the example of artificial legs. The bionic artificial legs on the horizon, which will take advantage of the advancements in the fields of nanotechnology, cognitive science, artificial intelligent and information technology will be more able than human legs. You could define these bionic legs as enhancements not just cures. Why should only parents with a ‘below the norm’ child be obliged to bring their child ‘up to’ the norm and if we look at non genetic cures could they actually avoid enhancements? The above dynamics will lead to a ‘normative creep’ where the bell curve is moved towards the right to higher abilities and ‘improvement of the norm’.

It is interesting that a draft report on preimplantation genetic diagnostic and germ line genetic intervention by the international bioethics committee of UNESCO seems to be in favour of enhancements as long as they are done for “medical reasons’ when it says:

> 96. Without further elaboration our Committee rejects the idea of testing and/or enhancing any human characteristic other than those of importance in alleviating suffering by disease.[xlix]

Their reasoning for rejecting enhancement for ‘social reasons’ is the following:

> 1) The most fundamental argument is that we do not have the right to predetermine characteristics of future generations. The notion of justice between generations, defended by philosophers from completely different backgrounds also demands respect for human conditions of life of future individuals who should be free to develop their potentialities without being biologically conditioned by the particular conceptions of “good” and “bad” human traits that were dominant at the time of those who preceded them. PGD nor genetics in general should become an instrument for “intergenerational tyranny”.[l]
>
> 2) Another argument against genetic enhancement of normal human characteristics is that it would profoundly affect our self-perception as “persons” - that is as autonomous beings. Instead we might consider ourselves to be mere “things” or biological artefacts designed by others.[1li]
>
> 3) even if social agreement on the “ideal” human being would be reached, it will inevitably reinforce stigmatization and discrimination of those who do not fall into the accepted standards of genetically desirable traits. And looking back, who is able to define now the ideal human characteristics for the future?lii

However, it is very doubtful that a distinction between ‘medical and social reasons’ is tenable using these arguments because defining something as ‘subnormal’ and then allow enhancement towards the norm “will inevitably reinforce stigmatization and discrimination of those who do not fall into the accepted standards of genetically desirable traits” and it will effect the self-perception of the “subnormal” as “persons”. Furthermore if,

> “the notion of justice between generations, demands respect for human conditions of life of future individuals who should be free to develop their potentialities without being biologically conditioned by the particular conceptions of “good” and “bad” human traits”[liii]

suggests, that “traits” are up to interpretation within cultural settings and that future generations have the right to develop without being burdened by these cultural societal prejudices of today’s societies. But isn’t the same true in regards to the determination of diseases, defects and disabilities? Aren't we subjectively based on societal prejudice deciding what we view as diseases, defects and disabilities? Aren't they the -above mentioned- "bad traits"? Being gay was seen not to long ago as a disease, a "bad trait" in North America and is still seen as a disease, a "bad trait" in some cultural settings in some societies.

Interestingly the above arguments reflect the arguments of disabled people namely that the elimination of their characteristic affects their own self-perception and that it increases the stigmatizations against disabled people. The arguments used above are true for all characteristics targeted. Again the only way to justify the use of these technologies for disease disabilities but not for 'traits' lays in the basic fact of labelling something as a disease or trait. But that is a political societal decision not an ethical one (see Appendix 8 on Free Choice and Autonomy). And that can change and will change due to the concept of normative creep.

Conclusion

The above has shown that the arguments used in regards to the usage of prenatal testing have an influence on the usage of other technologies such as embryo selection genetic/non-genetic cures and genetic/non-genetic enhancements. From a disability rights perspective the question arises, which models of disability will carry the day? Disability groups want the acceptance of the social, the universalist, and the human right model, models that might allow the disability community to join the human rights movement. However, there are problems in achieving this goal.

Society has a long history of seeing disabilities within a medical framework. Many legal instruments describe a disabled person as someone with subnormal, diminished functioning in need of special care not seeing disabled people as having a biological reality leading to different sets of abilities and different ways of functioning and different needs.

The medical understanding of disabilities is essential for the acceptance of many disability discriminations as evident in the governance of predictive prebirth testing, wrongful life and wrongful birth suits, genetic and non genetic therapy, genetic and non genetic enhancement, anti genetic discrimination laws, access to health care insurance and life insurance.
Furthermore the marketability of predictive pre-birth testing, wrongful life and wrongful birth suits, genetic and non genetic therapy, genetic and non genetic enhancement, compassionate homicide laws, for example depends on the availability of a devalued target characteristic which in this case are the characteristics labelled as 'disabilities' (mM) defects and diseases.

That's how the sales pitch with predictive pre-birth testing went. The sympathy of the public in western countries for the development of the technology was initially ensured by using Tay-Sachs and Down Syndrome as an example of possible elimination through prenatal testing and selective abortion. However, the same technology is now used for the elimination of different characteristics depending on the existing prejudice in any given society. Like sex selection is popular in India and China[liv].

In order to keep the support of the general public an ethical trick had to be developed namely the ethical distinction between a medical and social reason. That of course means that disabilities (mM), diseases and defects have to be labeled as a medical problem and traits as social problems in order to assure that the average public the 'non-disabled' does not feel threatened by these technologies. This has a consequence that disabled people have a hard time in being accepted as part of the social justice movement as the remedy for them seems to be a medical one and not a social justice one. In the moment whenever disabled people demand equal treatment in the above areas they receive answers such as below.

> In recent years the militant disability movement has developed a whole new confident and strident identity - no more pathetic cripples pleading in soppy charity ads, but a strong demand for equal rights in the tradition of the battles for black, women's and gay rights. After women's pride, black pride and gay pride, proud-to-be-disabled seems to make sense too. But each of these four campaigns is different. Each group's identity, cohesiveness and claim to victimhood is based on markedly different circumstance. Disability campaigners have over- identified with other civil rights issues, talking as if they were a race or a gender[lv].
>
> Sexual orientation left handedness blue eyes recessive or X-linked carrier status in the absence of symptoms and 'low normal IQ' are all shared by a substantial portion of the population though none is a characteristic of the majority. All of them have social dimensions.

> Nevertheless, so many people have one or more of the characteristics that the characteristics must be considered part of normal human variation. Statistically these characteristics cannot be compared with the 'population risk' of about 3% for having a child with a genetic condition or 'birth defect'. There are so many different genetic conditions that no one condition even comes close to affecting 1% of the population (Down Syndrome is around 0.1%)[lvi]

With no convincing arguments to point the way to an acceptable line regarding an equitable use of the above mentioned technologies, a much more thorough debate is needed, with all the parties involved. We need to terminate the Animal Farm philosophy where some people are seen as being more equal than others; it can only lead to a bloodbath among humans in general and within the equality/human rights movement in particular. We cannot work with each other when some view themselves as superior to others.

The society we create is our only protection against the "gene-ism" (as in racism, sexism and able-ism) that in the end, we are told, will make targets of 60% of us all. Germline gene therapy should be completely prohibited as should sex selection. Furthermore taking into account the above mandatory genetic screening should also be prohibited. In light of prohibiting these technologies and applications then it is only logical and ethical and equitable to also prohibit embryo selection, prenatal deselection and somatic gene therapy.

Furthermore it has to be assured that non genetic enhancements and therapies will not be mandatory. Recent developments and facts quoted in this article suggests that we will be moved away from a concept of choice.[lvii] They suggest that women don't actually have a free choice, but are to be led down the path of medical intervention. In the absence of a possible social cure for disability, the only option that may appear to be left is the medical *cure*, in whatever shape and form, and independent of its usefulness. Compounding this, in order for someone to have free choice, the person has to see the issue without prejudice in the first place (see appendix 8). For this to happen society would have to shed its prejudice against disabled people and their characteristics concludes Dr Wolbring.

APPENDIX 6

Wrongful life suits and Wrongful birth suits

The Situation:

In a wrongful life suit[lviii]the disabled child or someone on behalf of the child sues for compensation for general damages namely for the pain and suffering incurred as a result of the harm or injury of being born impaired rather than not being born and compensation for special damages namely for the extraordinary expenses medical, hospital, institutional, educational and otherwise which are necessary to properly manage and treat the congenital or genetic disorder till the child has reached the age of majority or even for his/her whole life. The essence of wrongful life lawsuits is that the disabled child's life is, in itself, wrongful because life with a disability (mM) is worse than non-existence[lix]. On the other hand, recognition of wrongful life would be consistent with interests to future children. It accepts that where medical knowledge and technology permits, a child should not be born to suffer extreme pain and suffering that could be avoided but for someone's negligence. Thus, some American judges have talked about a fundamental right of a child to be born as a whole functional human being. [lx]

In wrongful birth suits, the parents of a disabled child initiate a lawsuit, typically against a doctor who is accused of not performing proper genetic screening or not adequately counselling prospective parents. The essence of wrongful birth is that the defendant's negligence resulted in the birth of a disabled child whom the mother would have aborted had she received adequate medical information. In essence, wrongful birth suits are genetic or prenatal or preimplantation malpractice suits tort cases. And they seem reasonable if we take into account that mothers are told that the disabled child is a burden damage to them. As Botkin says:

> Parents of a child with unwanted disability have their interests impinged upon by the efforts, time, emotional burdens, and expenses added by the disability that they would not have otherwise experienced with the birth of a healthy child[lxi]

And as Wertz says

> Many who are willing to concede that people with disabilities could have lives they themselves would enjoy nonetheless argue that the cost to families of raising them justifies abortion. Women are seen to carry the greatest load for the least return in caring for such a child. Proponents of using the technology to avoid the births of children with disabilities insist that the disabled child epitomizes what women have fought to change about their lives as mothers:

> unending labor, the sacrifice of their work and other adult interests, loss of time and attention for the other children in the family as they juggle resources to give this disabled child the best available support, and uncertain recompense in terms of the mother's relationship with the child[lxii].

In wrongful pregnancy suits, the mother initiates a lawsuits stating that she is now burdened with an unwanted non-disabled child because the pregnancy wasn’t detected or a sterilization procedure failed.

Wrongful life suits and wrongful birth suits are a logical consequence of the fact that we tell parents that it is socially irresponsible knowingly to bring an infant with a serious[lxiii] genetic disorder into the world in an era of prenatal diagnosis” and that it is unfair to the child to be born with a disability.[lxiv] In this kind of climate we tell the parents and the child that there is the option of preventing the birth of a disabled child whether through the use of prenatal testing and selective abortion after the foetus was labelled as having a disability (mM) or through preimplantation diagnostics and the selection of an embryo deemed as being non defective/disabled for implantation into a womb using IVF. If they (the disabled and the non disabled) are conditioned to think that the occurance of the disabled child was preventable and that it is bad to live as a disabled it is clear that many parents would sue on their own behalf and on the behalf of the child.

Wrongful life suits are accepted or debated in many countries such as the USA[lxv] South Korea[lxvi] South Africa.[lxvii] The supreme court of Israel allows wrongful life suits since 1986[lxviii] and the courts made clear that these wrongful life suits would not be acceptable for ethnic differences or illegitimate birth.[lxix] In France, two wrongful life suits were recently accepted[lxx] and only through a political decision are wrongful life suits not acceptable anymore not by a legal decision. [lxxi].

In the UK the only wrongful life suit happened in 1982 and was rejected [lxxii] but the Congenital Disabilities Act 1976[lxxiii] was recently amended with section 44 of the Human Fertilization and Embryology Act (1990)[lxxiv] section1a) which would allow for the child born based on the selection of an embryo and IVF to sue for wrongful life. Although in the way the law is written it seems that the child can’t sue if the parents have known about the possible disability and decided to implant the embryo nevertheless, if the parents haven’t known they can themselves sue for wrongful birth and the child can sue for wrongful life
However there are countries, which do not accept wrongful life suits such as Germany and Canada. Wrongful birth suits are accepted in many countries such as USA[lxxv] Canada[lxxvi], Germany[lxxvii], South Africa[lxxviii], Austria[lxxix], and Spain[lxxx]

The Discrimination:

The disability discrimination of wrongful life suits is evident in the fact that although courts hear wrongful life suits if the child is disabled (and the future will tell whether they will become more popular and winnable) courts refuse to entertain a wrongful life case on other basis such as illegitimacy, poverty, or race as these are seen as wrongful unsatisfied life cases whereas wrongful life cases based on disability (mM) are entertained as they are seen as wrongful diminished life cases.
Wrongful birth suits discriminate in two ways. One is based on the fact that parents can receive compensation for the birth of a disabled child reflecting the estimated amount of money needed till the child has reached the age of majority or even longer [lxxxi] but if a mother sues in a wrongful pregnancy case to be compensated for the cost of upbringing an unwanted but non-disabled child she will in many countries such as the USA[lxxxii] only be compensated for the cost of e.g. the failed sterilization procedure but NOT for the cost this additional child will cost the mother till the child reaches majority. The rational for not giving costs compensation to the mother in case of an unwanted non-disabled child is that having a child is so great that you can't get reimbursed for it. But in case of the disabled child this argument is not used because having a disabled child is truly not a good thing and the mother was harmed[lxxxiii]. This type of discrimination does not exist e.g. in Germany.[lxxxiv] However, another way to discriminate exists. It is based on the fact that mothers are not to allowed to act on certain characteristics of their child namely many countries have laws or law proposals prohibiting sex selection[lxxxv]. That means the mother can’t sue if a predictive prenatal test misinterprets the sex of the foetus, as the mother wouldn’t be able to act on it anyway.

One of the consequences of wrongful birth and wrongful life suits might be that we see an increase in defensive medicine meaning that the physician or whoever counsels the mother might push her to terminate the pregnancy if a disabled foetus is detected. This was one of the arguments of the German Society for human genetics against the acceptance of wrongful birth suits[lxxxvi] Furthermore these suits will entrench further a negative view of disabled people[lxxxvii] As a South African judge said:

> Thus the legislature has recognized, (...) as do most reasonable people, that cases exist where it is in the interest of the parents, family and possible society that it is better not to allow a fetus to develop into a seriously defective person causing serious financial and emotional problems to those who are responsible for such person's maintenance and well being.[lxxxviii]

APPENDIX 7

Sex Selection Debate

The practice of sex selection is as old as humankind. For the greater part of the history of humankind this selection of one gender over another (mostly male over female) took place after birth and lead to infanticide or neglect of the newborn with the wrong sex (mostly female). Infanticide and neglect of the newborn is increasingly replaced by new technologies such as prenatal sex diagnostic (PD) and termination of pregnancies or preimplantation sex diagnostic (PGD) and the selection of the embryo with the right sex for the implantation into the womb of the mother or by the use of sperm sorting. The demand for these new technologies is not only generated in countries like China (79%) and India (70%) (Wertz & Fletcher, 1998, Table 3) where the preference for boys is still strong (ICBCDb, 2002) but also in countries such as the USA (62%), Australia (67%), and Germany (47%) (Wertz & Fletcher, 1998, Table 3) where the negative prejudice against women is somewhat diminished. The reasons might be different in the first two (prejudice against girls) and last three cases (sex balanced family) but the acceptance/demand for using prenatal diagnostic to have a child with a desired sex seems to be equally high (Wertz & Fletcher, 1998, Table 7).

Taking into account the high demand for sex selection worldwide how does the legal system deal with the demand for sex selection procedures? A variety of laws and law proposals exist which prohibit sex selection for 'non-medical reasons' (Pennsylvania USA, 1989; see also India 1994; China 1994; Germany 1990; Turkey 1995; Canada, 2002). Furthermore at least three international documents demand the prohibition of sex selection for 'non-medical reasons', namely:

a) The European Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine which states in Article 14 – Non-selection of sex: "The use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided"(European Convention, 1997).
b) The WHO draft guidelines for bioethics, which states in paragraph 21 "that sex is not a disease" (WHO, 1999).
c) The Draft Report on Pre-implantation Genetic Diagnosis and Germ-line Intervention by the Pre-implantation Genetic Diagnosis and Germ-line Intervention working group of the International Bioethics Committee of UNESCO (UNESCO, 2002) which states in paragraph 71: "Destruction of embryos for non medical reasons or termination of pregnancies because of a specific gender are not "counterbalanced" by avoiding later suffering by a severe disease. Sex selection by PGD or PD is therefore considered as unethical".

The debate around the prohibition of sex selection leads to a few questions for disabled people namely

a) Whether the arguments used to demand the prohibition of sex selection are not also valid to demand the prohibition of ability selection and disability deselection,
b) Whether the demand of sex selection prohibition also leads to the demand of ability selection/disability deselection prohibition and
c) Whether the line of arguments lead to another discriminatory approach towards the characteristic disability.

Are the arguments used to demand the prohibition of sex selection not also valid to demand the prohibition of ability selection and disability deselection?

1) One line of arguments says that sex selection poses significant threats to the well-being of children and siblings and the children's sense of self worth and the attitude of unconditional acceptance of a new child by parents, so psychologically crucial to parenting (Wertz & Fletcher, 1989, p. 484; see also President's Commission 1983, p.58; HFEA, 1993 p. 6 point 26 and p. 8, point 38).

However, is this a specific argument for the prohibition of sex selection?

Could the sentence not read as follows "One line of arguments says that ability selection/disability deselection poses significant threats to the well-being of children and siblings and the children's sense of self worth and the attitude of unconditional acceptance of a new child by parents, so psychologically crucial to parenting".
Would this argument not also justify the prohibition of ability selection/disability deselection? Is the unconditional acceptance not also endangered if parents choose their kid based on wanted abilities or unwanted disabilities?

People can debate whether the above argument is a valid one but if it is a valid one to use in demanding the prohibition of sex selection than it is a valid to use in demanding the prohibition of ability selection/disability deselection prohibition and in essence the prohibition of selecting for whatever reason. This is not a sex selection specific argument.

2) A second line of arguments justifies sex selection prohibition by pointing out the negative consequences for the unwanted sex. Sherwin, Wertz, and others explain that sex selection is leading to the oppression of the people with the unwanted sex leading to social injustice (Wertz & Fletcher, 1993; Sherwin, 1992, p.74). Others see sex selection as a form of sex discrimination (Grifo, 2001; see also Asch & Parens, 1999, p. S2; Mallik, 2002, Wertz & Fletcher, 1998 p. 265) and others again see sex selection leading to the enhancement of sex stereotypes which means that people will have certain expectations towards people with one sex or another (President's Commission, 1983, p.58-59; see also Wendling, 2001; Wertz & Fletcher, 1998 p. 255).

Would the following version of the above not also hold true?
"People explain that ability selection/disability deselection is leading to the oppression of the people with unwanted disabilities leading to social injustice. Others see ability selection/ disability deselection as a form of disability discrimination and others again see ability selection/disability deselection leading to the enhancement of ability/disability stereotypes which means that people will have certain expectations towards people with one ability/disability or another.

Indeed these arguments were and still are used by disabled people and others when they look at the consequences of gene technology for disabled people (Wolbring, 2000; see also Wolbring, 2001; Kirschner, 2000; Diederich & Maroger, 2001; Middelton, 2001; TAB, 2000, p. 81; Solihull Declaration, 2000; DPI, 2000; DOK, Zürich, 1998, p.29; Netzwerk gegen Selektion durch Pränataldiagnostik, 2001; LPA, 1997; Hubbard, 1990; Lippman, 1991; Asch & Parens, 1999; Kaplan, 1993; Down Syndrom Netwerk Deutschland, 1994; Alderson 2001a;Retsinas, 1991; Ärztezeitung, 22.03.2001).

Some connect the use or prenatal testing of Down Syndrome with the diminishing rights of people with Down Syndrome. Andrew Brown of Amnesty International says:

> If society regards the presence of such disease as an acceptable reason for aborting a foetus, this makes it harder to preserve equality of respect for those already born. One might argue that their human worth, if not their human rights, have been diminished (Brown, 1998, p.19).

3) A third line of arguments sees sex selection leading to 'designer babies and trivializes the selection procedure leading to the selection of children based on 'cosmetic reasons' (HFEA, 1993; see also Wertz & Fletcher, 1998, p. 265). However, what is cosmetic. Cosmetic is something based on established norms. Is it cosmetic to have no legs or being shorter or being obese or having black hair, being intelligent or having blue eyes? Is cosmetic another synonym for characteristics not affecting abilities? But that leads to the question like what abilities are needed which are still fitting within the acceptable variation from the norm and which don't. Who decides what are cosmetics? The same questions have to be raised for the usage of the term designer baby.

4) A fourth line of argument says that sex selection is wrong because it is not a disease (WHO, 1999; see also UNESCO, 2002, paragraph 100; Wertz & Fletcher, 1998 p. 265).

This argument is not really an ethical argument but a 'hierarchy argument. Someone decides based on his/her prejudice and power ability that testing for one characteristic is ok and for another characteristic isn't. Furthermore the term disease is rather undefined and by itself a social construct (Wolbring, 2000a)

What are the reactions if disabled people use the arguments used to demand the prohibition of sex selection to demand a prohibition of disability deselection?

The reaction is one of non-acceptance and some of the arguments used to justify the non-acceptance are:

1. The deselection of characteristics labelled a disability is already happening with other methods without the consequence of neglecting living disabled people (Knoopers, 1992 p.21-22; see also Skene, 1993 p. A12)
2. We prevent also the birth of non-disabled people without diminishing the worth of the ones who are living (Nelson, 1999 p. S3).
3. Disabled people are not necessarily stigmatizes as there are disabled people with high self-esteem who do not wish that there kid would have the same disability they have themselves (Torbjorn, 1998 p. 245).
4. Disabled people simply can't be seen as a variation of being but only as an aberration as there numbers are just not great enough A higher amount of disabled people within society leads to less support for them (Wertz, 2000 p 266).
5. Sex is not a disease (WHO, 1999; see also UNESCO, 2002, paragraph 100).

However, the question is whether these arguments are valid and if they are whether they are not also valid to denounce the arguments used to demand the prohibition of sex selection.

1) The first argument is obviously not true, as disabled people feel neglected within society. However it is hard to prove that the situation of a particular group worsened after tests to eliminate their characteristic, which defines their group was developed. Like did the situation of polio people worsened after the introduction of the polio vaccine? Some people actually say yes, however no statistics exist to prove or disprove the above statement. Furthermore, independent of the truth of the above statement it is obvious that the argument can be used just as well to negate the prohibition of sex selection because no studies exist which can prove that the introduction of sex selection diagnostics led to a decrease in quality of life for women. The link seems to be logical because if we feel so bad about a characteristic that we don't think our family or our kid should have the characteristic it can't improve the perception of the people with the non-wanted characteristic but it is hard to draw a direct link between availability of tests and quality of life decrease.

2) The second argument would also support the opposition to sex selection prohibition because obviously abortion of unwanted children takes place also in countries where sex selection takes place.

3) The third argument would also support the opposition to sex selection prohibition as there are obviously strong women who still support sex selection. However, the counterargument within the group supporting sex selection prohibition goes like that.

> Sherwin believes that it is possible to evaluate a community's moral system on the basis of how the system evolved (its history), whose interests it serves (its power structure), and whose interests are sacrificed. The fact that those whose interests are sacrificed - usually women - often concur in a community practice such as sex selection or genital mutilation does not establish ethical validity for that practice. In the history of oppression, including slavery, the oppressed often identified with the values of the oppressors.[234] Sherwin argues that, "Unless there is evidence that women would agree to this practice if they were free of patriarchal coercion, we cannot treat it as an acceptable local custom, even if the majority of citizens in areas where it is customarily practiced now approves of it."[183 (p. 74)]. According to Sherwin's criteria, sex selection in Asian cultures is wrong because it results from and contributes to the oppression of women. Sex selection is wrong even if the woman herself requests it without direct coercion from her husband or partner, because her request emanates from a coercive culture. (Wertz & Fletcher, 1993b)

Now disabled people can use this counter argument just as well because most countries adhere to a culture of able-ism and are oppressing disabled people.

4) The fourth argument begs the question whether the statement would be accepted if it would read "A higher amount of women within society leads to less support for them"
Furthermore Wertz justifies the distinctions purely based on the numbers:

> Sexual orientation left handedness blue eyes recessive or X-linked carrier status in the absence of symptoms and 'low normal IQ' are all shared by a substantial portion of the population though none is a characteristic of the majority. All of them have social dimensions. Nevertheless, so many people have one or more of the characteristics that the characteristics must be considered part of normal

> human variation. Statistically these characteristics cannot be compared with the 'population risk' of about 3% for having a child with a genetic condition or 'birth defect'. There are so many different genetic conditions that no one condition even comes close to affecting 1% of the population (Down Syndrome is around 0.1%) (Wertz, 2000, p. 266).

This is again not a moral argument but a power argument. We are more so we win. If this is the level of debate than we just have a new type of bioethics philosophy namely an animal farm bioethics (some are more equal than others).

5) The fifth argument is also not an ethical argument but an argument based on preference. Why should none of the ethical argument used to demand sex selection prohibition be applicable for the prohibition of disease deselection, which in essence often also means defect deselection and disability deselection be valid just because it is applied to characteristics labelled as diseases, defects, and disabilities? That does sound like an animal farm philosophy. However, this argument raises a few more questions. There is obviously a huge variety of characteristics, which are labelled as diseases, defects, and disabilities. Does the above include every disease, disability, and defect or just the 'severe' ones as often claimed? In the end there is no way to distinguish between different disabilities, diseases, and defects (Solihull, 2000; see also European commission, 1996; UNESCO, 2002, point 67; HFEA, 1993, p. 7 point 32). Now an expert commission of the European community used the following argument to denounce a distinction between different disabilities, diseases, and diseases by stating: "we can't make distinctions between disabilities in regards to the usage of predictive testing because to label some disabilities as severe enough for disability deselection would stigmatize these disabilities" (European commission, 1996). This argument raises one question. If this argument were true, wouldn't a distinction between sex and disability or the targeting of 'disabilities in general' not stigmatize the 'disabled' and their families? Indeed disabled people and their families are quoted as saying that they felt stigmatized by the use of prenatal diagnostic for disability deselection (TAB, 2000, S. 82).

The draft report on pre-implantation genetic diagnostic and germ-line intervention from the International Bioethics Committee of the UNESCO, uses the following argument:

> An often-debated subject is line drawing in case of the indications both for PGD [preimplantation genetic diagnostic] and PD [prenatal diagnostic]. Thus far all professional organizations in clinical genetics and reproductive technology as well as advisory groups on bioethics have argued against lists of diseases which can be defined as severe enough to justify PGD or PD. The number of monogenic diseases alone exceeds 5000 and nearly each of these has variant of different severity and clinical course. In addition, the same disease may be perceived differently by different couples depending on their family history, religious and socio-economic background, life situation, and future expectations (UNESCO, 2002, paragraph 67).

If we can't make a distinction between diseases because every single disease is perceived differently based on societal settings would the same not be true for any characteristic? Which characteristics parents can cope with in general depends on their cultural, societal, economical, and other settings. Indeed some bioethicists use this argument to demand that parents should have the right to select for whatever characteristic they wish (Savulescu, 1999; see also Birnbacher, 1999).

Furthermore, wouldn't that statement not also extent to the fact that people perceive different characteristics as diseases? Diseases are a societal construct. In different cultural, societal settings different characteristics will be seen as diseases. One prime example is that 'being gay' is seen in some cultural, societal settings as a disease and in others as a trait or lifestyle.

The consequence:

It seems that every argument used to justify sex selection prohibition could also be used to demand disability deselection prohibition and the arguments used to denounce the arguments used to demand the prohibition of disability deselection can be used just as well to denounce the arguments used to demand the prohibition of sex selection.

The only possible way to justify disability deselection but not sex selection is by arbitrarily defining disabilities, defects, and diseases as medical problems in need of medical solutions and seeing them in a different moral light based on the medical label leading to the development of a double morality/ethics an animal farm philosophy.

Just define something as a medical problem and the acceptable acting broadens. The argument ‘it’s a medical problem’ trumps all other arguments.

This animal farm philosophy is evident in the debate around many bioethics issues such as end of life issues, Anti-genetic discrimination laws, genetic enhancement, non-genetic cure and enhancement, wrongful life suits, wrongful birth suits, bionics, transhumanism, debate of personhood, mercy killing, infanticide, treatment of neonatals and it depends in every of these issues on the fact that disabilities, diseases, and defects are seen as a medial problem.

The animal farm philosophy is strengthened by the fact that a disability rights approach is mostly excluded from the discourse –academic or otherwise- of bioethics issues and the development of bioethics theories and that a disability rights approach towards bioethics issues and the development of bioethics theories can be ignore without much fear for repercussion because of the marginalization of disabled people.

The animal farm philosophy leads to a chasm between different groups as defined by their characteristics as it builds up a ‘hierarchy of applied ethics’ e.g. the one being more powerful than the other will draw a line in regards to the ethical usage of gene technology between them and others.

The animal farm philosophy, which makes a distinction between ‘medical reasons’ and ‘social reasons’, makes it impossible for disabled people to establish able-ism within the same human rights framework as racism, sexism, age-ism, homophobia and other isms.

As Polly Toynbee says:

> In recent years the militant disability movement has developed a whole new confident and strident identity - no more pathetic cripples pleading in soppy charity ads, but a strong demand for equal rights in the tradition of the battles for black, women's and gay rights. After women's pride, black pride and gay pride, proud-to-be-disabled seems to make sense too. But each of these four campaigns is different. Each group's identity, cohesiveness and claim to victimhood is based on markedly different circumstance. Disability campaigners have over- identified with other civil rights issues, talking as if they were a race or a gender (Polly Toynbee, 2001)

Furthermore, Anti Disability discriminations’ laws such as the ‘American with Disabilities Act’ might only cover disabled people, until a medical/technological cure is found for them. They might not be seen as disabled people anymore if medical/technological fixes are available which would rob them of any legal Anti Discrimination protection and might force them into using medical/technological fixes even if they don’t want. They might be forced into the medical understanding of their characteristics. At least this scenario is at the horizon after the USA Supreme Court ruled in Sutton v United States, in 1998 that “the Americans With Disabilities Act does not cover people whose disabilities can be sufficiently corrected with medicine, eyeglasses or other measures” (see also Murphy v. United Parcel Service, 1998).

In short, the whole atmosphere of the debate makes it very difficult to gain acceptance for a social justice view of disability something the disability movement itself identifies with.

APPENDIX 8

Free Choice and Autonomy

The autonomy and choice for women are terms, which are often used in the debate around the usage of prenatal diagnostic. Question is whether choice is simply the fact that I can or cannot choose now a technology or whether the process of choice is embedded into societal structures, which for the most part influence the choice. If there is in reality not much of a choice in how to use prenatal diagnostic technologies than this prenatal diagnostic becomes a tool to strengthen the status quo. Therefore it is reasonable to assume that the diagnostic is not utilized for the good of the women but for the good of societal structures. At the end of this chapter you will find a variety of quotes, which illustrates that real choice is very unlikely. The quotes are used because they come from highly influential and prominent people who have a certain influence on the policy making process and the policy makers including politicians. However, below I discuss data from certain studies in the context of freedom of choice in regards to genetic diagnostics

One study from the Canadian Royal Commissions on New Reproductive Technologies (1993) showed data indicating that 25% of women undergoing amniocentesis were doing so because they felt pressured by the hospital staff. 33% felt pressure to perform an abortion after the amniocentesis indicated that the foetus might have a non-normative condition/characteristic (disability) (Glover, N.M. and S. J. Glover. 1996).[lxxxix]

A study from 1995 investigated at the perception of pregnant and non-pregnant women men, and geneticists from the UK Portugal and Germany towards the birth of a child with Down syndrome. Two case studies were investigated. In the first one a prenatal diagnostic test was offered to a women who was 38 of age, which she refused to take. In the second case the women was 37 years old and was not offered the test as it was only routinely offered to women 38 years and older. (Marteau TM, Drake H. 1995).[xc]

If the women gave birth to a child with Downs syndrome the studies showed that acceptance of the right of the women to refuse the test was high but that the woman who was offered and refused the test was blamed 2-3 times more for the birth of the child with Down Syndrome than the woman who wasn't offered the test. (Marteau TM & Drake H. 1995). [xci]

A study from the 1994 in the UK asked gynecologists whether the following statement is right: "The government should not pay for costs associated with a disabled child if the condition could have been detected through prenatal diagnostic and the parents refused the test". (Green J., 1995).[xcii]

Table 1: "The government should not pay for costs associated with a disabled child if the condition could have been detected through prenatal diagnostic and the parents refused the test".[xciii]

Statement	%
Strongly agree	9
Agree	4
Don't agree	28
Strongly disagree	58

A study asked in 1998 physicians from hospitals and privat praxis in Ontario Canada whether they would agree with the following statement:

a) I would offer a genetic test even if the parents would not consider a 'therapeutic abortion'
b) I would only offer a genetic test if the parents would consider a 'therapeutic abortion'

Table 18 Offer of a genetic test for myopatic dystrophy [xciv]

Statement	Probably	Not sure	Unlikely
I would offer a genetic test even if the parents would not consider a 'therapeutic abortion'	55	10	36
I would only offer a genetic test if the parents would consider a 'therapeutic abortion'	30	12	*68*

A study from 1994-1996 asked human geneticists from the former East and West Germany whether they would agree with the following statements.[xcv]

a) I am unsatisfied when patients refuse a prenatal diagnostic where it is medical necessary
b) The decision of parents to have a child which carries a 25% chance of developing cystic fibrosis is unfair to the child
c) It is unfair to bring a child with a severe medical problem into the world
d) People who have a high risk of giving their child a severe problem should not have children if they don't use prenatal diagnostic and selective abortion

e) I am dissatisfied with the counseling if the patient decides to give birth to a foetus with a severe medical problem.
f) It is societal irresponsible to give birth to a child with a severe genetic defect in the age of prenatal diagnostic

Table 2

Statement	**Agree (East Germany)**	**Agree (West Germany)**	**Don't agree or disagree (East Germany)**	**Don't agree or disagree (West Germany)**	**Disagree (East Germany)**	**Disagree (West Germany)**
I am unsatisfied when patients refuse a prenatal diagnostic where it is medical necessary	51	17	24	37	25	46
The decision of parents to have a child which carries a 25% chance of developing cystic fibrosis is unfair to the child	37	11	26	39	37	50
It is unfair to bring a child with a severe medical problem into the world	31	15	38	35	31	50
People who have a high risk of giving their child a severe problem should not have children if they don't use prenatal diagnostic and selective abortion	25	11	25	15	50	74
I am dissatisfied with the counseling if the patient decides to give birth to a foetus with a severe medical problem.	16	5	43	27	41	68
It is societal irresponsible to give birth to a child with a severe genetic defect in the age of prenatal diagnostic	12	7	15	4	73	89

A study performed by Wertz and Fletcher in 19 countries from 1988-1989 questioning geneticists found that the majority of geneticists from Canada (68%), Great Britain (71%), the USA (78%), France (81%) und in 15 other countries (74%) believe that the eugenic goal of "improvement of the general health and vigor of the population" is still very important. Furthermore (51%) of geneticists from Canada, (48%) from the UK, (47%) from the USA, (50%) from France and (54%) in 15 other countries believed that the diminishing of carriers of genetic defects in society is an important goal of genetic counseling. (Wertz, D. C. and J. C. Fletcher, 1989).[xcvi]

When 2901 genetic professionals from 36 countries were asked in a survey performed between 1994-1996 whether they agreed with the statement that, "it is unfair to a child to be born with a disability," the majority in 24 countries agreed, along with 40% in USA, Canada and Chile; 36% in Finland and UK; 33% in Switzerland

and the Netherlands; 29% in Argentina, 27% in Australia 25% in Sweden 18% in Japan and 52% of US primary care physicians (Wertz, D.C. 1998).[xcvii]

There was also widespread agreement with the statement, "It is socially irresponsible knowingly to bring an infant with a serious genetic disorder into the world in an era of prenatal diagnosis." Although there is no legal definition of "serious," more than 50% agreed in South Africa, Belgium, Greece, Portugal, Czech Republic, Hungary, Poland, Russia, Israel, Turkey, China, India, Thailand, Brazil, Columbia, Cuba, Mexico, Peru, and Venezuela; as did 26% of US geneticists, and 55% of US primary care physicians (Wertz, D.C. 1998).[xcviii]

A study of the National Childbirth Trust (UK**)** from 1997 which looked at the stress of prenatal test during the pregnancy found that the right of parents to refuse prenatal testing was often undermined by the fact that the medical personal often assumes that testing and selective abortion would be the best option (Dodds, R., 1997).[xcix]

Clarke et al explains that non-directive counseling is not possible and also not desired by the people asking for advice and that is should be replaced with a 'shared decision making' (Elwyn G, Gray J, Clarke A. 2000).[c]

The insufficient economical and societal supports for parents with disabled children is a reality which has implication for the freedom of choice.[ci]

Discussion of the freedom of choice argument
The numerous above listed studies and the quotes at the end reflect the reality of an increase in the general, cultural, and sociopolitical support for the deselection of characteristics which are labelled as diseases defects impairments or disabilities. Furthermore the studies and the quotes indicate that the availability of prenatal diagnostic does not necessarily lead to an increase of choice for women but that it leads more to the situation where women are objectified and are used as the quality control gate keeper of the human gene pool to quote the English bioethicist Chadwick,

> "Whether or not genetic information promotes autonomous choice, however, is increasingly questioned, from at least three points of view. First, it is necessary to have regards to the context in which choices are made. A social environment hostile and indifferent to certain forms of disability does not facilitate genuine choice. Second, the amount of genetic information forthcoming (which may be poorly understood) may turn out to be a burden to parents rather than help. Third, there is more than one possible interpretation of autonomy. Autonomy may not simply be a matter of having a great deal of information on the basis of which a decision should be taken. On the contrary, it may mean the right not to know certain genetic information."[cii]

The concept of prognostic prenatal diagnostic contains the concept of personal eugenics. However because the freedom of choice of women does not take place in a societal vacuum it is clear that personal eugenics is at the same time a societal eugenics. It is telling that human geneticists believe that disabled people will never receive enough support from society which indicated the limit of freedom of choice for women. Furthermore the fact that many countries allow selective abortion for characteristics seen as defects diseases impairments and disabilities but NOT FOR SEX shows that the free choice for women is not a free choice for women but a 'society sanctioned' free choice for women.

1) Francis Crick, another Nobel laureate, said at the Ciba_Geigy Symposium in London in 1962, "We have to take away from humans in the long run their reproductive autonomy as the only way to guarantee the advancement of mankind."[ciii]

2) The U. S. Nobel laureate Joshua Lederberg, one time adviser to Cetus Corporation, said in 1970 in testimony before the U.S. House of Representatives that 25 percent of all hospital beds and institution places are filled with patients whose illness was more or less geneticin origin. He added that these numbers would increase the genetic burden over time, just as environmental pollution would increase over time. Therefore, he proposed as the most important ad hoc action the advancement of prenatal diagnosis combined with selective abortion.[civ]

3) In their book on Ethics and Human Genetics, Dorothy Wertz and Joseph Fletcher two important American bioethicist write, "The main arguments for selective abortion arises from: 1) the obligation to reduce suffering

for the affected family and the foetus when a serious and untreatable genetic disorder has been diagnosed, and 2) the obligation to prevent genetic disease and its impact on present society and future generations, in the absence of effective genetic therapies”.[cv]

4) The Institute for Medicine in Washington writes, "The potential for manipulation or control in the direction of human reproduction is also implicit in genetic testing. The public needs to understand that testing for genetic conditions raises value judgments about what is normal versus what is abnormal-- and that the social and illegal acceptance of such judgments can create the pressure for genetic conformity".[cvi]

5) Author Laura Hershey says: “although prenatal testing appears to empower women because it allows for reproductive choices, it is actually asking women to ratify social prejudices.”[cvii]

6) Dr.Margaret Thomson former president of the Genetics Society of Canada, said while a defense witness for the Alberta government in the Leilani Muir sterilization case, "some causes of mental defectiveness are hereditary and when the eugenics board was created there was a real danger of passing on those causes because contraceptive choices were limited. Today, people at risk of inheriting or passing on a defect to their children have the pill and other contraceptives available. They can seek genetic counseling before a child is born and can abort a child likely to be defective."[cviii]

9) Choice is heavily circumscribed by cultural, social and economic pressures and all these are powerfully against women choosing to continue with a pregnancy after "an abnormality" has been detected. The British Abortion law enshrines this prejudice by not allowing termination after 24 weeks unless a likely problem has been discovered. British Coalition of Disabled People (BCODP). The International Sub-Committee of 1999. The new genetics and disabled people: a discussion document. Available at http://www.bcodp.org.uk/general/genetics.html

10) At a 1999 conference on fertility, world-renowned embryologist Bob Edwards said that the increasing availability of prenatal screening for genetic disease makes parents morally responsible not to give birth to disabled children. He noted that, "Soon it will be a sin of parents to have a child that carries the heavy burden of genetic disease. We are entering a world where we have to consider the quality of our children."[cix]

11) The former bioethicist of the WHO said in The Age in Australian: “The state of a nation's gene pool should be subject to government policies rather than left to the whim of individuals, a World Health Organization ethicist told a symposium yesterday. Professor Dan Wikler said such intervention had proved disastrous in Nazi Germany, but governments could not avoid taking a role in tackling the ethical dimensions of modern genetics. Governments were widely accepted to have a legitimate role in health and would have to decide which genetic screening measures to fund _ an ethical decision in itself, he said.” [cx]

13) A societal decision in favor of PGD will diminish the freedom of the choice for women to decide in favor of a genetically unproven child.

14) "Although reasonable disagreement exists about whether some failures to prevent harmful genetically transmitted conditions would be morally wrong, in other cases, such failures would be as clearly and uncontroversially wrong as cases of child abuse and neglect whose wrongness is not seriously questioned. Just as nondirectiveness about those cases of child abuse and neglect would be indefensible, so too is nondirectiveness about genetic transmission of comparable harmful conditions. The norm of nondirectiveness in genetic counseling may function as a useful reminder of reasonable disagreement about whether prevention of a particular harmful condition is morally required, but it is indefensible as an inflexible and systematic norm to guide all genetic counseling."[cxi]

15) “Couldn’t they (the medical profession) warn or tell you about your second child?- that there was then no screening, that no one knew the cause, and they still don’t. But the implication was that if we had known and continued the pregnancy we would have been irresponsible. We had produced ‘drains’ on society. Who was to bear the cost of their care?”[cxii]

16) Kitcher writes in his book: “Only if prospective parents are assured that all people, however disabled, have a serious chance of receiving respect and support can they make a decision on the basis of their own.”[cxiii]

17) Chadwick a known bioethicist in the UK writes, “Whether or not genetic information promotes autonomous choice, however, is increasingly questioned, from at least three points of view. First, it is necessary to have regards to the context in which choices are made. A social enviroment hostile and indifferent to certain forms of disability does not facilitate genuine choice. Second , the amount of genetic information forthcoming (which may be poorly understood) may turn out to be a burden to parents rather than a help. Third, there is more than one possible interpretation of autonomy. Autonomy may not simply be a matter of having a great deal of information on the basis of which a decision should be taken. On the contrary, it may mean the right not to know certain genetic information.”[cxiv]

18) Lori Andrews one of the 100 most influential lawyers in the USA writes, “There will be a time, said Andrews -- a professor at the Chicago-Kent College of Law and author of The Clone Age -- when governments will force prenatal genetic testing, hoping to encourage women to abort rather than cause taxpayers and insurers to foot the bill for a sick child.”[cxv]

References

Alderson, P. (2001a). Prenatal Screening: Past, Present and Future, directed by Dr Ettorre, University of Helsinki, 1996-1999. funded by the European Commission Biomed II) For the EC Biomed Programme, no. BMH4-CT96-0704, Prenatal Screening in Europe 1996-1999 To be published in Before Birth ed E Ettorre Ashgate London autumn 2001 chapter 11

Ärzte Zeitung. (2001). 22.03.Absage an Gentests, PID und Pränataldiagnostik. Retrieved January 26, 2003, from: http://www.aerztezeitung.de/docs/2001/03/22/054a0602.asp.

Asch, A. (1989). Reproductive technology and disability. In Cohen S & Taub N, (Eds.), *Reproductive Laws for the 1990s (pp. 69-127).* Clifton, NJ: Humana Press.

Asch.A. & Parens E. (1999). The disability rights critique of prenatal genetic testing. *Hastings Center Sept/Oct Special Supplement* S1-S25

Bayerische Behindertenbeauftragte . (2000). *Presseerklärung der Behindertenbeauftragten der Bayerischen Staatsregierung, Frau Ina Stein, zum Welttag der Menschen mit Behinderungen am 03.12.00.* Retrieved January 26, 2003, from: http://www.behindertenbeauftragte.bayern.de/presse/pr0012.htm

Beauchamp & Childress. (1978). *Principles of Biomedical Ethics* p.20 New York, Oxford, Oxford University Press.

Birnbacher, D. (1999). Kongreß für Philosophie, Konstanz, 4.-8.10.99, Referat am 07.10.99 Dieter Birnbacher, Selektion am Lebensbeginn - ethische Aspekte. Retrieved January 26, 2003, from: http://www.selbsthilfe-online.de/p99/p9910/birnbacher.shtml and retrieved January 26, 2003, from: http://www.netlink.de/gen/Zeitung/1999/991007e.htm

Brown, A. (1998). Amnesty’s latest fear: how our genes may determine our fate *The Independent*, Feb. 18th, page 19

Buchanan, Brock, Daniels, & Wikler. (2000) -*Chance to Choice: Genetics and Justice*- Cambridge UP, p.255

Canada. (2002). an Act respecting assisted human reproduction Bill C-13 First reading, October 9, 2002 Retrieved January 26, 2003, from: http://www.parl.gc.ca/37/2/parlbus/chambus/house/bills/government/C-13/C-13_1/C-13_cover-E.html & Retrieved January 26, 2003, from: http://www.hc-sc.gc.ca/english/protection/reproduction/index.htm

Diederich, N. & Maroger D. (2001) Lespersonnes handicapées face au diagnostic prénatal : éliminer avant la naissance ou accompagner? Editions ERES near Toulouse (Ramonville Ste Anne)

DOK Zürich Schweiz. 1998. Diskriminierung behinderter Menschen in der Schweiz. Benachteiligungen und Maßnahmen zu deren Behebung. Hg.: Dachorganisationenkonferenz der privaten Behindertenhilfe, (p.29). Retrieved January 26, 2003, from: http://216.239.37.100/search?q=cache:vgGZEQAGfx8C:www.disability-research.ch/d/shared/dokumente/Diskb98d.pdf+Diskriminierung+behinderter+Menschen+in+der+Schweiz&hl=en&ie=UTF-8 p.29

Down Syndrom Netwerk Deutschland 1994 *Eltern fordern Lebensrecht und Unterstützung ohne Einschränkung*. Retrieved January 26, 2003, from: http://www.down-syndrom.org/ak204b.htm

European Commission (1996). *The Ethical Aspects of Prenatal Diagnosis*. Opinion of the Group of Advisers on the Ethical Implications of Biotechnology, Brussels, 1996) quoted in Pembrey, M. (1998). In the light of preimplantation genetic diagnosis: some ethical issues in medical genetics revisited, *European Journal of Human Genetics 6,4-11* page 9

European Convention. (1997). *European Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine Oviedo, 4.IV.1997Article 14* <http://conventions.coe.int/treaty/en/Treaties/Html/164.htm>,

Germany.(1990). *Gesetz zum Schutz von Embryonen* (Embryonenschutzgesetz - ESchG) Vom 13. December 1990 BGBl. I 1990 S. 2746-2748 (BGBl III 453-19) ' 3 Verbotene Geschlechtswahl. Retrieved January 26, 2003, from: http://www.bmgesundheit.de/rechts/genfpm/embryo/embryo.htm

Grifo, (2001) quoted by Gina Kolata in Fertility Ethics Authority Approves Sex Selection *The New York Times* September 28, 2001. Retrieved January 26, 2003, from: http://www.genetics-and-society.org/resources/items/20010928_nytimes_kolata.html

Harris, J. (2000). Is there a coherent social conception of disability? *Journal of Medical Ethics, Apr;26 (2)*, 95-100 page 96-97.Abstract retrieved January 26, 2003, from: http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10786318&dopt=Abstract

Hubbard R. (1990). *the Politics of Women's Biology.* New Brunswick, NJ and London: Rutgers University Press chapter 12-14

HFEA, 1993 Human Fertilization & Embryology Authority Sex selection public consultation document p. 8 paragraph 38

ICBCD, (2003)a. International Centre for Bioethics, Culture, and Disability; Retrieved January 26, 2003, from: http://www.bioethicsanddisability.org/Centerrational.htm

ICBCD,(2003)b. International Centre for Bioethics Culture and Disability; Retrieved January 26, 2003, from: http://www.bioethicsanddisability.org/sex.html

India. (1994). The Pre Natal Diagnostic Techniques (Regulation and Prevention of Misuse) Act 1994 India Article 12 point 277. Retrieved January 26, 2003, from: http://wcd.nic.in/CEDAW4.htm; Law on Maternal and Infant Health Care (Article 8, The Law on Maternal and Infant Health Care, Renmin Ribao (Peoples Daily), 28 October 1994);

Jones, O.D. (2001) Controlling Consequences of Preconception Sex Selection American Journal of Bioethics Volume 1, Number 1, 19

Kaplan D. (1993a) Prenatal screening and its impact on persons with disabilities. *Clin Obstet Gynecol* 36(3):605-12. Abstract retrieved January 26, 2003, from: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8403607&dopt=Abstract

Kirschner, K.L., Ormond, K.E., & Gill, C.J. (2000). The Impact of Genetic Technologies on Perception of Disability. *Quality Management in Health Care, 8(3),* 19-26. Abstract retrieved January 26, 2003, from: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10947381&dopt=Abstract

Knoopers BM. (1993). Picard Lecture in Health Law--1992. Human genetics: parental, professional and political responsibility. *Health Law Journal Vol. 1*,14-23.

Lippman A. (1991). Prenatal genetic testing and screening: constructing needs and reinforcing inequities. *American Journal of Law and Medicine. 17(1-2),* 15-50. Abstract retrieved January 26, 2003, from: http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=1877608&dopt=Abstract

LPA. (1997). under *What is LPA's position on the implications of these discoveries in genetics?* http://www.lpaonline.org/resources_faq.html

Mallik R. (2002). *A Less Valued Life: Population Policy and Sex Selection in India Center for health and gender equity.* Retrieved January 26, 2003, from: *http://www.genderhealth.org/pubs/MallikSexSelectionIndiaOct2002.pdf*

Middleton A, Hewison J, Mueller R. (2001). Prenatal diagnosis for inherited deafness--what is the potential demand? *J. Genet. Couns., 10(2),*121-31. Abstract retrieved January 26, 2003, from: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11767801&dopt=Abstract

Murphy v United Parcel Services. (1998) Retrieved January 28, 2003, from: http://www.washingtonpost.com/wp-srv/national/longterm/supcourt/1998-99/murphy.htm; see also MURPHY *v.* UNITED PARCEL SERVICE, INC. certiorari to the united states court of appeals for the tenth circuit No. 97-1992. Argued April 27, 1999--Decided June 22, 1999. Retrieved January 28, 2003, from http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&vol=000&invol=97-1992.

Nelson, J. (1999). "Meaning of the act" in The Disability Rights Critique of Prenatal Genetic Testing *The Hastings Center Report Sept-Oct, Special Supplement* p. S3

Netzwerk gegen Selektion durch Pränataldiagnostik 2003 Retrieved January 26, 2003, from: http://www.bvkm.de/netzwerk/

Norway. (1994). Act relating to the application of biotechnology in medicine (No. 56 August 5th. 1994) Chapter 4 Preimplantation diagnosis Section 4-3 (Sex selection) Chapter 5 Prenatal diagnosis Section 5-4 (Information about the gender of the foetus). Retrieved January 26, 2003, from: http://www.helsetilsynet.no/htil/avd2/bio_act.htm

Overall, C. (1987). *Ethics and Human Reproduction: A Feminist Analysis*. Boston: Allen & Unwin; 17-39.

Pennsylvania. (1989). Pennsylvania Consolidated Statutes Annotated, title 18, [189] 3204 (c), as amended November 17, 1989, P.L. 592, No. 68, [189] 2.o,

President's Commission. (1983). *President's Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Screening and Counseling for genetic conditions*. US Government Printing Office, Washington, (p. 58)

Roberto Rivera y Carlo. (2002). *Targeting the disabled.* Boundless Magazine. Retrieved January 26, 2003, from: http://www.boundless.org/2002_2003/features/a0000685.html

Retsinas J.(1991). *Impact of Prenatal technology on attitudes toward disabled infants*. In: Wertz D. Research in the Sociology of Healthcare Westport, Conn: JAI Press, (p. 89/90)

Savulescu, J. (1999). Sex selection: the case for. *Medical Journal of Australia, 171*, 373-375. Retrieved January 26, 2003, from: http://www.mja.com.au/public/issues/171_7_041099/savulescu/savulescu.html

Sherwin, S. (1992). *No Longer Patient: Feminist Ethics and Health Care*. Philadelphia: Temple University Press, (p. 74).

Singer, P. (2001). Response to Mark Kuczewski. *American Journal of Bioethics Volume 1 Number 3 Issue 1,* 55-57

Skene, L. (1993). "Why Prenatal screening is not eugenics" *The Age Thu. 28.10.* p. A12.

Solihull Deklaration. (2000). The Right to Live and be Different. Retrieved January 26, 2003, from: http://www.johnnypops.demon.co.uk/bioethicsdeclaration/index.htm

Sutton v United States. (1998). Retrieved January 28, 2003, from :http://www.washingtonpost.com/wp-srv/national/longterm/supcourt/1998- 99/sutton.htm; see also full text SUTTON *et al. v.* UNITED AIR LINES, INC. certiorari to the united states court of appeals for the tenth circuit No. 97-1943. Argued April 28, 1999--Decided June 22, 1999. Retrieved January 28, 2003, from: http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&vol=000&invol=97-1943

,
Stein, E. (1998). Choosing the sexual orientation of children. *Bioethics 12 (1),* p. 1,14,15.

TAB. (2000). Hennen, L., Petermann, T., Sauter, A., Bericht des TAB's „ Stand und Perspektiven der genetischen Diagnostik" April 2000 TAB *Arbeitsbericht Nr. 66* Büro für Technikfolgen-Abschätzung beim Deutschen Bundestag, Deutschland. Retrieved January 26, 2003, from: http://www.tab.fzk.de/de/projekt/zusammenfassung/Textab66.htm

Tannsjorn, T. (1998). Compulsory sterilisation in Sweden. *Bioethics Vol.12 No.3,* 236-249

Toynbee, P. (2001). Rights are for the living Friday August 24, The Guardian. Retrieved January 26, 2003, from: http://www.guardian.co.uk/comment/story/0,3604,541665,00.html

Turkey. (1995). Calaça, C. & Akin, A. The Issue of Sex Selection in Turkey. *Human Reproduction*, 10,1631-1632,

Tyson, J.E. & Broyles, R.S. (1996). Progress in assessing the long-term outcome of extremely low-birth-weight infants. *JAMA*; *276*, 492-493.

UNESCO. (2002). Draft Report on Pre-implantation Genetic Diagnosis and Germ-line Intervention WORKING GROUP OF THE IBC ON PRE-IMPLANTATION GENETIC DIAGNOSIS AND GERM-LINE INTERVENTION September 30th. 2002 paragraph 71 Retrieved January 26, 2003, from: http://www.unesco.org/ibc/en/actes/s9/ibc9draftreportPGD.pdf

Wendling, M.(2001). *UK Authorities Look To Tighten Sex Selection Laws* November 05, 2001 CNSNews.com. Retrieved January 26, 2003, from: http://www.cnsnews.com/ViewForeignBureaus.asp?Page=/ForeignBureaus/archive/200111/FOR20011105h.html

Wertz, D. C. & Fletcher, J.C. (1989). *Ethics and Human Genetics: A Cross-Cultural Perspective. In* Springer Verlag: New York. (p.484).

Wertz, D., C & Fletcher, J., C. (1993). A critique of some feminist challenges to prenatal diagnosis. Retrieved January 26, 2003, from: <http://www.shriver.org/Research/SocialScience/Staff/Wertz/critique.htm>

Wertz, D., C & Fletcher, J., C. (1998). Ethical and Social Issues in Prenatal Sex Selection: A Survey of Geneticists in 37 Nations. *Social Science and Medicine Vol 46 (2)* pp 255-273. Retrieved January 26, 2003, from: http://www.shriver.org/Research/SocialScience/Staff/Wertz/sexselect.htm

Wertz, D., C. (2000). "Drawing lines for Policymakers. *In* Erik Parens, Adrianne Asch (Eds), *Prenatal Testing and Disability Rights* Georgetown University Press Washington DC (p. 268)

Wolbring, G. (2000). Science and the disadvantaged an occasional paper of The Edmonds Institute I.S.B.N. 1-930169-12-4. Retrieved January 26, 2003, from: http://www.edmonds-institute.org/wolbring.html

Wolbring, (2001). Expert opinion for the Study Commission on the Law and Ethics of Modern Medicine of the German Bundestag with the title "Folgen der Anwendung genetischer Diagnostik fuer behinderte Menschen" (Consequences of the application of genetic diagnostics for disabled people). Retrieved January 26, 2003, from: http://www.bundestag.de/gremien/medi/medi_gut_wol.pdf

World Health Organization (WHO). (1999). *Draft guidelines on bioethics 1999 Paragraph 21* http://helix.nature.com/wcs/b23a.html>,

---

[i] "A Sociological Skeptic in the Brave New World," *Gender & Society*
(Vol. 12, No. 5, October 1998)

[ii] Annas et.al., American Journal of Law and Medicine, Volume 28, Numbers 2 & 3. "Protecting the Endangered Human: Toward an International Treaty Prohibiting Cloning and Inheritable Modifications". Page 4.

[iii] http://www.bumc.bu.edu/www/sph/lw/pvl/genism.pdf

[iv] Annas, G., Andrews, L., Isasi, R. "Protecting the Endangered Human: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations". American Journal of Law and Medicine, Volume 28, Numbers 2 & 3. A copy of this article can be found at the home page of www.gefree.org.nz

[v] http://www.i-sis.org/HumangenTWN-pr.shtml or http://cgi.isisnet.force9.co.uk/cgi-bin/index.php

[vi] Rifkin, J. (1998). *The Biotech Century – Harnessing the Gene and Remaking the world*. New York: Penguin Putnam Inc. Page 168.

[vii] Silver, L. (1997). *Remaking Eden: Cloning and Beyond in a Brave New World*. New York: Avon Books, p. 4-7.

[viii] Dixon, J.K.,W. I. Winship and D.R. Webster. 1995. Priorities for Genetic Services in New Zealand: A report to the National Advisory Committee on core health and disability support services. The Core Service Committee (P.O. Box 5013, Wellington, New Zealand).

[ix] http://www.economist.com/world/europe/displayStory.cfm?story_id=1877407

[x] http://www.bioethicsanddisability.org/DPI.html

[xi] http://www.i-sis.org.uk/stemcells-pr.php

[xii] British Medical Journal 1992 **304**, 587-8.

[xiii] See HGA press release http://www.hgalert.org/pReleases/pr12-12-02.htm

---

[xiv] Royal College of Physicians, 1989 *Prenatal diagnosis and genetic screening.* RCP, London; Caplan, Arthur L. 1992 If gene therapy is the cure, what is the disease? in Annas, George J.; Elias, Sherman, eds. Gene Mapping: Using Law and Ethics as Guides. New York: Oxford University Press; page 128-141; Diane Coleman TESTIMONY BEFORE THE CONSTITUTION SUBCOMMITTEE OF THE JUDICIARY COMMITTEE OF THE HOUSE OF REPRESENTATIVES April 29, 1996 <http://www.mcil.org/mcil/mcil/testimon.htm>

[xv] (Ray C West J 1984, Social, sexual and personal implications of paraplegia Paraplegia, 1984, vol. 22, 75-86 <http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=6483467&dopt=Abstract>, Eisenberg MG and Saltz, CC 1991 Quality of life among aging spinal cord injured persons: long term rehabilitation outcomes Paraplegia, Vol. 29, 514-520

[xvi] Adrianne Asch Prenatal diagnosis and selective abortion: A challenge to practice and policy American Journal of Public Health 1999 89 11 1649; Miringoff ML. The Social Costs of Genetic Welfare. New Brunswick, NJ: Rutgers University Press; 1991; Hubbard R. The Politics of Women in Biology. New Brunswick, NJ: Rutgers University Press; 1990:chap 12_14; Lippman A. Prenatal genetic testing and screening: constructing needs and reinforcing inequities. Am J Law Med. 1991; 17(1_2): 15_50; Field NIA. Killing "the handicapped"_before and after birth. Harvard Womens Law J 1993; 16:79_138; Fine M, Asch A. The question of disability: no easy answers for the women's movement. Reproductive Rights Newsletter. 1982; 4(3): 19_20; Minden S. Born and unborn: the implications of reproductive technologies for people with disabilities. In: Arditti R, Duelli_Klein R, Mindin S, eds. Test_Tube Women: What Future for Motherhood? Boston, Mass: Pandora Press; 1984:298_312; Finger, A. Past Due: Disability, Pregnancy and Birth. Seattle, Wash: Seal Press; 1987; Kaplan D. Prenatal screening and diagnosis: the impact on persons with disabilities. In: Rothenberg KH, Thompson EJ, eds. Women and Prenatal Testing: Facing the Challenges of Genetic Technology. Columbus: Ohio State University Press; 1994:49_61; Asch A. Reproductive technology and disability. In: Cohen S, Taub N.Reproductive Laws for the 1990s. Clifton, NJ: Humana Press; 1989: 69_124; Asch A, Geller G. Feminism, bioethics and genetics. In: Wolf S, ed. Feminism and Bioethics: Beyond Reproduction. New York, NY: Oxford University Press; 1996:318-350

[xvii] Wolbring, G., 2001 Expert opinion for the Study Commission on the Law and Ethics of Modern Medicine of the German Bundestag with the title "Folgen der Anwendung genetischer Diagnostik fuer behinderte Menschen" (Consequences of the application of genetic diagnostics for disabled people) page 10-17 <http://www.bundestag.de/gremien/medi/medi_gut_wol.pdf> (German); see also Gerhart KA, 1994 Quality of Life Following Spinal Cord Injury; Knowledge and Attitudes of Emergency Care providers, Annals of Emergency Medicine, Vol. 23, 807-812
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8161051&dopt=Abstract
Ray C West J 1984, Social, sexual and personal implications of paraplegia Paraplegia, 1984, vol. 22, 75-86 <http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=6483467&dopt=Abstract>, Eisenberg MG and Saltz, CC 1991 Quality of life among aging spinal cord injured persons: long term rehabilitation outcomes Paraplegia, Vol. 29, 514-520 <http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=1775357&dopt=Abstract>, Saigal S, Feeny D, Rosenbaum P, Furlong W, Burrows E, Stoskopf B1996. Self-perceived health status and health-related quality of life of extremely low-birth-weight infants at adolescence. Journal of the American Medical Association JAMA. 1996; 276:453-459. P453 <http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8691552&dopt=Abstract> Cushman, LA und Dijkers, MP, and 1990 depressed mood in spinal cord injured patients: staff perceptions and patient realities. Archives of Physical Medicine and Rehabilitation, vol. 71, Seiten 191-196. <http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=2317136&dopt=Abstract>, Whiteneck GC et al., Rocky Mountain Spinal Cord Injury System Report to the National Institute of Handicapped Research, 1985, 29-33; Cameron, 1973; Bach, 1994).

[xviii] Ableism: a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then, is a diminished state of being human
Fiona A.K. Campbell (2001) Inciting Legal Fictions: Disability Date with Ontology and the Ableist Body of the Law, Griffith Law Review, Vol 2., <http://www.gu.edu.au/centre/glr/content2r.html#four>

[xix]

[xx] Jonathan Penney 2002 v1n1 Journal of Law and Equality of A Constitution for the Disabled or a Disabled Constitution? Toward a New Approach to Disability for the Purposes of Section 15(1) p83-94 <http://www.jle.ca/files/JLEv1n1art3.htm>

[xxi] Ultrasound is routinely used during pregnancy, and can detect, for example, cleft palate. A study in Israel revealed an abortion rate, after detection for cleft palate, of 95.8%. Blumenfeld, Z., I. Blumenfeld and M. Bronshtein. 1996. 'The cleft palate'. *Craniofacial Journal* 36(2): 105-107. In the UK, the annual birthrate for babies with cleft lip decreased between 1982-1992 from 820 to 464 births, and the birth of babies with Talipes (not straight legs) decreased from 2041 to 747 births per year Dept. of Health (UK). 1994. 'Health and Personal social service statistics for England 1994'. London HMSO, Table 4.3: 24.. A study that investigated the use of prenatal ultrasound to detect heart defects in 12 European counties found that the termination rate for this 'defect' ranges from 3.1 to 70%, depending on country Stoll C. *et al.* 2001. 'Evaluation of prenatal diagnosis of associated congenital heart diseases by fetal ultrasonographic examination in Europe' *Prenat. Diagn*. 21: 243-252.

[xxii] For a variety of different possibilities to draw lines see Wolbring 2000 Science and the disadvantaged an occasional paper of The Edmonds Institute I.S.B.N. 1-930169-12-4 <http://www.edmonds-institute.org/wolbring.html>

[xxiii] European Commission: The Ethical Aspects of Prenatal Diagnosis. Opinion of the Group of Advisers on the Ethical Implications of Biotechnology, Brussels, 1996) quoted in Pembrey, M., (1998) In the light of preimplantation genetic diagnosis: some ethical issues in medical genetics revisited European Journal of Human Genetics (1998) 6,4-11 page 9

[xxiv] Draft Report on Pre-implantation Genetic Diagnosis and Germ-line Intervention presented at the Ninth Session of the International Bioethics Committee of UNESCO (IBC) in Montreal (Canada), 27th. November 2002. point 67; point 65 in second draft Report of the UNESCO IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention SHS-EST/02/CIB-9/2 (Rev. 3), Paris, 24 April 2003
Original: English

[xxv] Supra note 10

[xxvi] Sex selection section of the International Centre for Bioethics Culture and Disability <http://www.bioethicsanddisability.org/sex.html>

[xxvii] point 68 in second draft Report of the UNESCO IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention SHS-EST/02/CIB-9/2 (Rev. 3), Paris, 24 April 2003
Original: English; Pennsylvania Consolidated Statutes Annotated, title 18, [189] 3204 (c), as amended November 17, 1989, P.L. 592, No. 68, [189] 2.o; The Pre Natal Diagnostic Techniques (Regulation and Prevention of Misuse) Act 1994 India Article 12 <http://wcd.nic.in/CEDAW4.htm>, Law on Maternal and Infant Health Care (Article 8, The Law on Maternal and Infant Health Care, Renmin Ribao (Peoples Daily), 28 October 1994) see also Mao X and Wertz DC in Clin Genet 1997: 52: 100-109; Gesetz zum Schutz von Embryonen (Embryonenschutzgesetz - ESchG) Vom 13. December 1990 BGBl. I 1990 S. 2746-2748 (BGBl III 453-19) ' 3 Verbotene Geschlechtswahl <http://www.bmgesundheit.de/rechts/genfpm/embryo/embryo.htm>; Calaça, C. and A. Akin. 1995. The Issue of Sex Selection in Turkey. *Human Reproduction* 10: 1631-1632; Human Fertilisation and Embryology Authority, WEDNESDAY OCTOBER 18 2000 The Times London Parents lose fight to choose sex of new baby. <http://www.thetimes.co.uk/article/0,,2-21185,00.html> <http://www.hfea.gov.uk/pgd/index2.htm#section>
Norway Act relating to the application of biotechnology in medicine (No. 56 August 5th. 1994) Chapter 4 Preimplantation diagnosis Section 4-3 (Sex selection) Chapter 5 Prenatal diagnosis Section 5-4 (Information about the gender of the fetus) <http://www.helsetilsynet.no/htil/avd2/bio_act.htm>
Canada, an Act respecting assisted human reproduction Bill C-13 First reading, October 9, 2002 <http://www.parl.gc.ca/37/2/parlbus/chambus/house/bills/government/C-13/C-13_1/C-13_cover-E.html> <http://www.hc-sc.gc.ca/english/protection/reproduction/index.htm>, European Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine Oviedo, 4.IV.1997Article 14 <http://conventions.coe.int/treaty/en/Treaties/Html/164.htm>,
World Health Organization (WHO) 1999 Draft guidelines on bioethics 1999 Paragraph 21 <http://helix.nature.com/wcs/b23a.html>,
Draft Report on Pre-implantation Genetic Diagnosis and Germ-line Intervention WORKING GROUP OF THE IBC ON PRE-IMPLANTATION GENETIC DIAGNOSIS AND GERM-LINE INTERVENTION September 30th. 2002 paragraph 71

[xxviii] When 2901 genetic professionals from 36 countries were asked in a survey performed between 1994-1996 whether they agreed with the statement that, “it is unfair to a child to be born with a disability,” the majority in 24 countries agreed, along with 40% in USA, Canada and Chile; 36% in Finland and UK; 33% in Switzerland and the Netherlands; 29% in Argentina, 27% in Australia 25% in Sweden 18% in Japan and 52% of US primary care physicians Wertz, D.C. 1998. ‘Eugenics is Alive and Well’ *Science in Context* 11(3-4): page 501.
There was also widespread agreement with the statement, “It is socially irresponsible knowingly to bring an infant with a serious genetic disorder into the world in an era of prenatal diagnosis.” Although there is no legal definition of “serious,” more than 50% agreed in South Africa, Belgium, Greece, Portugal, Czech Republic, Hungary, Poland, Russia, Israel, Turkey, China, India, Thailand, Brazil, Columbia, Cuba, Mexico, Peru, and Venezuela; as did 26% of US geneticists, and 55% of US primary care physicians. Wertz, D.C. 1998. ‘Eugenics is Alive and Well’ *Science in Context* 11(3-4): page 501.

[xxix] See footnotes 2- 4

[xxx] see footnote 14

[xxxi] Wolbring, 2001, Bioethics and Disability: Making Assumptions Explicit in Health Ethics Today Vol.12, No1, Fall 2001 http://www.phen.ab.ca/materials/het/het12-01h.html Wolbring 2001, Disabled People's Approach to Bioethics: American Journal of Bioethics Volume: 1 Number: 3 Page: 1 -- 2

[xxxii] supra note 4

[xxxiii] At the 10th “Genetic Technology & Public Policy in the New Millennium” symposium, Daniel W. Brock, a bioethicist at the National Institutes of Health, gave a presentation entitled “Genetic Testing and Selection: A Response to the Disability Movement’s Critique.” In which he said: “Our notion of how good a person’s life is [isn’t] fully determined by their own subjective self-assessment,” Brock told his audience. Quoted in Targeting the disabled by Roberto Rivera y Carlo (20020 Boundless Magazine<http://www.boundless.org/2002_2003/features/a0000685.html>; Harris, J. 2000. Is there a coherent social conception of disability? *J. of Medical Ethics* 26: 95-100 <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10786318&dopt=Abstract> Reindal SM. Disability, gene therapy and eugenics--a challenge to John Harris. J Med Ethics 2000 Apr;26(2):89-94 http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10786317&dopt=Abstract

---

[xxxiv] <http://www.geocities.com/primeascender> <http://groups.yahoo.com/group/Ascender_Alliance/files/ASCALLI-14JAN02-DISABLED%20CYBORGS.doc> <http://groups.yahoo.com/group/Ascender_Alliance/files/ASCALLI-07JAN02-MANIFESTO-V2.doc><http://groups.yahoo.com/group/Ascender_Alliance/files/ASCALLI-06SEP02-ANTIEUGENICS-RACISM%20POLICY.doc>

[xxxv] http://www.dpi.org

[xxxvi] http://wwwbioethicsanddisability.org/DPI.html

[xxxvii] http://www.johnnypops.demon.co.uk/bioethicsdeclaration/index.htm

[xxxviii] Gregor Wolbring, Health Ethics Today Vol 13 Number 1 2003 page 5-6 The social construct of health and medicine

[xxxix] e.g. point 80 in second draft Report of the UNESCO IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention SHS-EST/02/CIB-9/2 (Rev. 3), Paris, 24 April 2003

[xl] Many statement from expert committees exist which claim that no distinction between disabilities based on severity can be made see point 68 in second draft Report of the UNESCO IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention SHS-EST/02/CIB-9/2 (Rev. 3), Paris, 24 April 2003

[xli] *Supra* note 14

[xlii] *Supra* note 14

[xliii] Antoniadi T, Rabionet R, Kroupis C, Aperis GA, Economides J, Petmezakis J, Economou-Petersen E, Estivill X, Petersen MB, 1999 High prevalence in the Greek population of the 35delG mutation in the connexin 26 gene causing prelingual deafness. Clinical Genetics 55: 381-382
Antoniadi,T.; Pampanos,A.; Petersen,M.B. 2001, Prenatal diagnosis of prelingual deafness: carrier testing and prenatal diagnosis of the common GJB2 35delG mutation Prenatal Diagnosis 21:10-13
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11180233&dopt=Abstract

[xliv] "I do not believe there is a difference between choosing a preimplantation deaf embryo and refusing a cure to a newborn. Nor… an important difference between refusing a cure and deliberately deafening a child." He asks, "But {assume} now a cure for congenital deafness is discovered, it is risk free and there are no side effects. Would the parents in this case be right to withhold this cure for deafness from their child?" John Harris in *J. of Medical Ethics 2000, 26,* pp. 95-100 page 97

[xlv] A first lawsuit in the USA just happened where child welfare took away the kids from their mother because she refused to give them cochlear implants. She won her case but she still has not received her kids back. Cal Montgomery Oct. 4, 2002 Mom can refuse sons' cochlear implants, says court < http://www.raggededgemagazine.com/drn/10_02.shtml#446>

[xlvi] Sutton v United States, 1998 At Issue: Whether nearsightedness that can be corrected with glasses or contact lenses is a "disability" under the Americans With Disabilities Act.Decision: The court ruled that the Americans With Disabilities Act does not cover people whose disabilities can be sufficiently corrected with medicine, eyeglasses or other measures. <http://www.washingtonpost.com/wp-srv/national/longterm/supcourt/1998- 99/sutton.htm> full text SUTTON *et al. v.* UNITED AIR LINES, INC. certiorari to the united states court of appeals for the tenth circuit No. 97-1943. Argued April 28, 1999--Decided June 22, 1999 <http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&vol=000&invol=97-1943>, Murphy v. United Parcel Service At Issue: Whether medication or other mitigating measures should be considered in assessing if an individual is "disabled" under the terms of the Americans With Disabilities Act. Decision: The justices ruled that the condition the petitioner suffers and controls with medication is not considered "disabling" under the Americans With Disabilities Act. The condition and medication preclude him from performing only a particular job and do not substantially limit him in employment.
<http://www.washingtonpost.com/wp-srv/national/longterm/supcourt/1998-99/murphy.htm> MURPHY *v.* UNITED PARCEL SERVICE, INC. certiorari to the united states court of appeals for the tenth circuit No. 97-1992. Argued April 27, 1999--Decided June 22, 1999 <http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&vol=000&invol=97-1992>, Albertson's v. Kirkingburg At Issue: Whether a truck driver blind in one eye who received a waiver from Department of Transportation vision standards is disabled for the purposes of the Americans With Disabilities Act. Decision: The justices voted unanimously that the plaintiff in this case was not protected by the Americans With Disabilities Act. They ruled that employers who set job qualifications based on federal safety standards do not have to overlook those standards when a worker obtains a waiver from the federal agency. <http://www.washingtonpost.com/wp-srv/national/longterm/supcourt/1998-99/albertsons.htm> ALBERTSONS, INC. *v.* KIRKINGBURG certiorari to the united states court of appeals for the ninth circuit No. 98-591. Argued April 28, 1999--Decided June 22, 1999 <http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&vol=000&invol=98-591>

[xlvii] Supra note 30,31

[xlviii] Embracing Change with All Four Arms: A Post-Humanist Defense of Genetic Engineering J. Hughes Ph.D. <http://www.changesurfer.com/Hlth/Genetech.html>, A Transhumanist Perspective on Human Genetic Enhancements Nick Bostrom
http://www.nickbostrom.com/ethics/enhancements.html, and Institute for Bioethics, Culture and Disability Human enhancement section <http://www.bioethicsanddisability.org/geneticnongeneticenhancement.htm>

[xlix] point 96 in second draft Report of the UNESCO IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention SHS-EST/02/CIB-9/2 (Rev. 3), Paris, 24 April 2003 Original: English

[l] point 97 in second draft Report of the UNESCO IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention SHS-EST/02/CIB-9/2 (Rev. 3), Paris, 24 April 2003 Original: English

---

[li] point 98 in second draft Report of the UNESCO IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention SHS-EST/02/CIB-9/2 (Rev. 3), Paris, 24 April 2003 Original: English

[lii] point 99 in second draft Report of the UNESCO IBC on Pre-implantation Genetic Diagnosis and Germ-line Intervention SHS-EST/02/CIB-9/2 (Rev. 3), Paris, 24 April 2003 Original: English

[liii] supra note 36

[liv] <http://www.bioethicsanddisability.org/sex.html>

[lv] Polly Toynbee Rights are for the living Friday August 24, 2001 The Guardian <http://www.guardian.co.uk/comment/story/0,3604,541665,00.html>

[lvi] p.266 Wertz D. Drawing lines: Notes for policy makers in Prenatal Testing and Disability rights Asch Parens (ed) Georgetown University Press Washington 2000

[lvii] supra note 14,30,31

[lviii] For a list of USA wrongful life suits see <http://userpage.fu-berlin.de/~stsurfer/ha/methosem-ho.doc>

[lix] For an academic paper with this conclusion, see Lockhart LK, Ditto PH, Danks JH, Coppola KM, Smucker WD. (2001) The stability of older adults' judgments of fates better and worse than death. *Death Stud* 2001 Jun; 25(4): 299-317and Macran S, Kind P.(2001) "Death" and the valuation of health-related quality of life. *Med Care* 2001 Mar; 39(3): 217-27;

[lx] Liu A.N.C. 1987 Wrongful life: some of the problems. *Journal of Medical Ethics*; 13, 69-73 see also Shapiro A. 1998 *J. of Medical Ethics* 24, 369-375

[lxi] Botkin J. 1995, (Pp36, 37) Fetal privacy and confidentiality. *Hastings Cent Rep.* 1995; 25(3): 32-39

[lxii] Wertz DC, Fletcher JC. 1993 A critique of some feminist challenges to prenatal diagnosis. *J Women's Health.* 1993; 2:173_188.

[lxiii] Many statement from expert committees exist which claim that no distinction between disabilities based on severity can be made see *supra* note 87 and 88

[lxiv] *Supra* note 86

[lxv] Gleitman v. Cosgrove, 227 A.2d 689 (N.J. 1967, Speck v. Finegold, 408 A.2d 496 (Pa. 1979) and *supra* note 90

[lxvi] Um, YR., (2000) A critique of a 'wrongful life' lawsuit in Korea *Nursing Ethics*, &(3): 250-261

[lxvii] Strauss SA. 1996 'Wrongful conception', 'wrongful birth' and 'wrongful life': the first South African cases. *Medical Law* 15: 161-173; <http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8691997&dopt=Abstract>, Strauss SA. 1998 An unusual case of wrongful pregnancy: liability of doctor resulting from misrepresentation, *Medical Law* 17: 7-11 <http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9646588&dopt=Abstract>

[lxviii] Supreme Court of Israel CA 518, 540,82 Zeitzoff versus Katz (1986) 40(2) PD 85 Seite 373; Shapiro A. 1998 *Journal of Medical Ethics* 24, 369-375.

[lxix] Levi J., I 1987 in the Supreme Court of Israel sitting as Court of Civil Appeals. Zeev Yarmulovitz and the State of Israel v. Moshe Hovav: *Medical .Law* 6: 373-374.

[lxx] Wednesday, 28 November, 2001, 15:30 GMT Down's child paid for being born http://news.bbc.co.uk/1/hi/world/europe/1681041.stm>,
WRONGFUL LIFE? The strange case of Nicholas Perruche <http://www.commonwealmagazine.org/12002/march%2022,%202002/32202st.htm>,
Friedrich Graf von Westphalen Ein behindertes Kind als Schadensquelle - Perversion des Denkens <http://www.wernerschell.de/Rechtsalmanach/Heilkunde/behindertes_kind.htm>,

[lxxi] Thursday, 10 January, 2002, 14:16 GMT France rejects 'right not to be born'<http://news.bbc.co.uk/1/hi/world/europe/1752556.stm> see also <http://www.pregnantpause.org/court/wronlife.htm>

[lxxii] Jackson A, 1996 Wrongful life and wrongful birth. The English conception. *J. of Legal Medicine* V.17, N.3,P.349-381

[lxxiii] Congenital Disabilities (Civil Liability) Act 1976 (C. A Sec. 1 (5) Congenital Disabilities (Civil Liability) Act 1976)

[lxxiv] Human Fertilization and Embryology Act (1990 HFE Act1A;
In any case where a child carried by a women as the result of the placing in her of an embryo or of sperm and eggs or her artificial insemination is born disabled, the disability results from an act or omission in the course of the selection, or the keeping or use outside the body, of the embryo carried by her or of the gametes used to bring into the creation of the embryo, and a person is under this section answerable to the child in respect of the act of omission, the child's disabilities are to be regarded as damage resulting from the wrongful act of that person and actionable accordingly at the suit of the child.
Subject to subsection (3) below and the applied provision of section 1 of this Act, a person (here referred to as "the defendant") is answerable to the child if he was liable in tort to one or both of the parents (her referred to a "the parent or parents concerned") or would, if sued in due time, have been so; and it is no answer that there could not have been such liability because the parent or parents concerned suffered no actionable injury, if there was a breach of legal duty which, accompanied by injury, would have given rise to the liability.
The defendant is not under this section answerable to the child if at the time the embryo, or the sperm and eggs, are placed in the woman or the time of her insemination (as the case may be) either or both of the parents knew the risk of their child being born disabled (that is to say, the particular risk created by the act or omission).

[lxxv] Rifkin J 1998 Genesis II Across the Board; New York; Jun 1998; Jeremy Rifkin; Volume: 35 Issue: 6 pp 29-35 ISSN: 01471554

[lxxvi] Krangle (Guardian *ad litem* of) *v.* Brisco Neutral citation: 2002 SCC 9. File No.: 27891.
2001: October 3; 2002: January 24.
<http://www.lexum.umontreal.ca/csc-scc/en/rec/html/morrill.en.html>

[lxxvii] BGH 1999 BGHZ 124, 128 BGH, Urteil vom 16.11.93 - VI ZR 105/92 abgedruckt in den Juristischen Blättern 1999, S. 593, mit Besprechungsaufsatz Rebhahn, Schadenersatz wegen der Geburt eines nicht gewünschten Kindes? JBl 2000, S. 265 <http://www.alpmann-schmidt.de/urteile/skript-srbt4/bghz124.128.htm>; Looschelders 2000 <http://www.jura.uni-duesseldorf.de/dozenten/loosch/IPR-Fallblatt10.htm>;

[lxxviii] *supra* note 99

[lxxix] It is interesting that Austria accepts wrongful life suits but it does not allow for the compensation to be paid to the child. http://www.sbg.ac.at/oep/mitarbeiter/professoren/graf/grafpub/body_grafpub.htm>

[lxxx] de Angel Yaguez R 1999, The second decision pronounced by the First Tribunal of the Supreme Court in a case of wrongful birth (February 4, 1999). Does it contradict the resolution of the decision pronounced on June 6, 1997 about the same problem]? Law Hum Genome Rev 1999 Jan-Jun;(10): 117-55
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10822644&dopt=Abstract

[lxxxi] Harrer H., 1994, *The Journal of Legal Medicine*, 15:89-127 15 literature in reference 74

[lxxxii] *Ibid*

[lxxxiii] *Ibid*

[lxxxiv] Hamburger Abendblatt, 04.04.2001 S.6; BGH, 1984

[lxxxv] see footnote 161

[lxxxvi] (Deutschen Gesellschaft für Humangenetik anlässlich des Urteils des VI. Zivilsenats des Bundesgerichtshofes vom 16.11. 1993 zu oben angeführtem „Tübinger Fall“: (Kommission für Öffentlichkeitsarbeit und ethische Fragen der Deutschen Gesellschaft für Humangenetik e.V, 1993) (Schaffhauser Zeitung, 21.11.2000) Degener, Th. (**1998**): Die Geburt eines behinderten Kindes als Schaden? In: Hauffe, U. und Brähler, E. (Hg.): Moderne Schwangerschaften zwischen Machbarkeit, Zwang und Auslese, psychosozial 71, Heft 1, Seite 37 – 48 2001).

[lxxxvii] (Schaffhauser Nachrichten 21.11. 2000)

[lxxxviii] *Supra* note 99

[lxxxix] Glover, N.M. and S. J. Glover. 1996. Ethical and legal issue regarding elective abortion of foetuses with Down Syndrome. Mental Retardation 34 (4): 207 - 214.
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8828339&dopt=Abstract

[xc] (Marteau TM, Drake H. 1995 Attributions for disability: the influence of genetic screening. in Social Science and Medicine .Vol. 40 No. 8 page 1129
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7597466&dopt=Abstract)

[xci] Marteau TM, Drake H. 1995 Attributions for disability: the influence of genetic screening. in Social Science and Medicine .Vol. 40 No. 8 page 1127-1132 p.1129,1130
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7597466&dopt=Abstract

[xcii] Green J 1995 in British Journal of Obstetrics and Gynaecology Obstetricians' views on prenatal diagnosis and termination of pregnancy: 1980 compared with 1993. March 1995, Vol. 102 page 228-232
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7794848&dopt=Abstract

[xciii] Green J 1995 in British Journal of Obstetrics and Gynaecology Obstetricians' views on prenatal diagnosis and termination of pregnancy: 1980 compared with 1993. March 1995, Vol. 102 page 228-232
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7794848&dopt=Abstract

[xciv] (Hunter A, Wright P, Cappelli M, Kasaboski A, Surh L. 1998 Physician knowledge and attitudes towards molecular genetic (DNA) testing of their patients. Clinical .Genetics: 53: 447-455 page 453
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9712533&dopt=Abstract)

[xcv] Cohen PE. Wertz, DC., Nippert, I., and Wolff G., 1997 Genetic Counseling Practices in Germany: A Comparison Between East German and West German Geneticists Journal of Genetic Counseling, Vol. 6, No. 1, page 65-99; page 70

[xcvi] Wertz, D. C. and J. C. Fletcher. 1989 . Ethics and Human Genetics: A Cross-Cultural Perspective.Springer Verlag: New York.

[xcvii] Wertz, D.C. 1998. ‘Eugenics is Alive and Well’ *Science in Context* 11(3-4): page 501.

[xcviii] (Wertz, D.C. 1998. ‘Eugenics is Alive and Well’ *Science in Context* 11(3-4): page 501.

[xcix] (Dodds, R., 1997. The stress of tests in pregnancy, Summary of a National Childbirth Trust antenatal screening survey, London National Childbirth Trust.

[c] Elwyn G, Gray J, Clarke A. 2000; Shared decision making and non-directiveness in genetic counseling Journal of Medical Genetics 37:135-138
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10662816&dopt=Abstract)

[ci] (Rowntree J Foundation (1999) Supporting disabled children and their families. Foundations N79. York: Joseph Rowntree Foundation; Fletcher A 2001 a in Considered Choice by Lisa Ward,British Institute of Learning Disabilities Publication Seite 76; Fletcher A 2001b   in Considered Choice by Lisa Ward,British Institute of Learning Disabilities Publication Seite 74; Beresford, B. (1995) Expert opinion: a national survey of parents caring for a severely disabled child. Bristol: Policy Press/Community Care; Dobson, B., and Middleton, S., (1998) Paying to care: the cost of childhood disability. York York Publishing Services; Dept. of Health (UK) Health and Personal social service statistics for England 1994 edition Table 4.3: 24. London HMSO.

[cii] (Chadwick RF 2001 in Considered Choice by Lisa Ward, British Institute of Learning Disabilities Publication p.87)

[ciii] Wolstenholme, G.E.W. 1963. Man and his future; A Ciba Foundation Volume. Little Brown: Boston.

[civ] Lederberg, J. 1970. Biological Goal: Human Welfare. The New York Times (December 1) Lederberg, J. 1970. Genetic engineering and the amelioration of genetic defect. Bio-Science (20): 1307-1310.

[cv] Wertz, D. C. and J. C. Fletcher. 1989 . Ethics and Human Genetics: A Cross-Cultural Perspective.Springer Verlag: New York. pp.484.

[cvicvi] Institute of Medicine. 1993 Committee on Assessing Genetic Risks, Division of Health Sciences Policy, and Assessing Genetic Risks: implications for health and social policy. National Academy Press: Washington D.C. 1-21. Page 8 http://www.iom.edu

[cvii] Hershey, L. 1995. Choosing disability. Ms. Magazine 5: 26-32

[cviii] Thomas, D. 1995. Geneticist defends sterilization in era before the pill. Calgary Herald (June 29): A14.

[cix] (Rogers, L. 1999. Having disabled babies will be 'sin', says scientist. Sunday Times (July 4). Available at: http://www.sunday-times.co.uk/news/pages/sti/99/07/04/stinwenws02034.html?999)

[cx] BUTTON V Friday 21 July 2000a VICTORIA BUTTON The Age Australia Genetic testing: call for reform http://www.theage.com.au/news/20000721/A19870-2000Jul20.html
Button V. Friday 13 October 2000b VICTORIA BUTTON The Age Australia Control gene pool, says ethicist http://www.theage.com.au/news/20001013/A47350-2000Oct12.html

[cxi] Buchanan, Brock, Daniels, and Wikler, 2000 -Chance to Choice: Genetics and Justice- Cambridge UP, Seite 255

[cxii] Picton sue in Considered Choice by Lisa Ward (2001)British Institute of Learning Disabilities Publication Seiten 36-45

[cxiii] Kitcher (1997) The lives to come: the genetic revolution and human possibilities, Harmondsworth Penguin books

[cxiv] Chadwick RF 2001 in Considered Choice by Lisa Ward, British Institute of Learning Disabilities Publication p.87.

[cxv] Andrews, L Saturday, April 7, 2001, in the Akron Beacon Journal von der Rede gehalten an der Konferenz 2001: The Human Genome Odyssey Conference: The Science, Business, Law & Ethics of Engineering Human Life" sponsored by the University of   Akron.