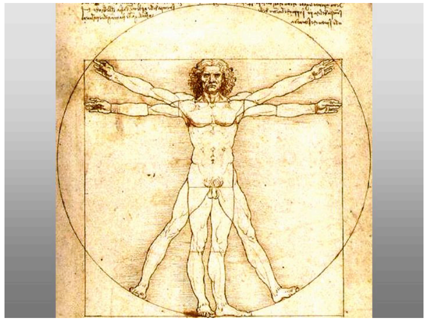


Disability and bioethics

by Bill Albert
for

UKDPC
United Kingdom
Disabled People's Council

Edited from : **Disability and bioethics. Life and death questions. A resource pack for trainers** by Helen Caplan and Bill Albert, British Council of Disabled People, 2004. Produced with the support of the Wellcome Trust under a grant from the Engaging Science Programme

2010

Helen Caplan

December 11, 1955 – December 7, 2008

This booklet is dedicated to the memory of my dear friend and colleague Helen Caplan, a passionate disability rights activist and gifted bioethicist. Without her skills, knowledge and dedication, the original project upon which this booklet is based could literally never have been completed.

As I edited our initial celebrative effort, I missed having her endlessly-patient guidance. Nonetheless, sometimes I could almost hear her talking me through some particularly difficult issue. Thanks for that, Helen.

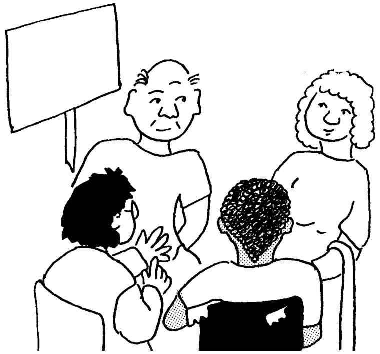
Table of contents

Introduction

This booklet discusses things that are important for disabled people – who gets health care, what babies are born, abortion and so on.

Why the booklet?

So disabled people can take part as equals in debates about questions that are about us and that effect our lives.

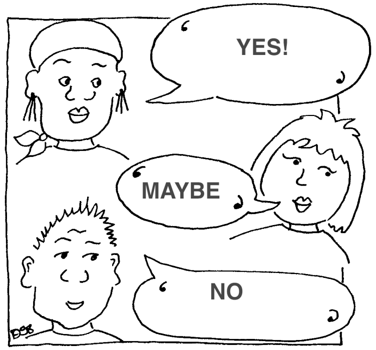


Introduction

Although not labeled as such, almost every day bioethics is in the news, and many of the stories are about or touch the lives of disabled people. It is all too clear that disabled people and our impairments are two of the principal objects of concern in bioethical debates about such things as rationing health care, judgments about people's quality of life, genetic testing and screening, abortion, euthanasia, gene therapy, stem-cell research and similar topics. However, because of a general lack of knowledge about and confidence with the issues, most disabled people have been disempowered and marginalised as active participants in these debates.

The main objective of this booklet is to begin to address this exclusion by offering disabled people accessible and balanced material about bioethical issues. This will not only help us to empower ourselves, but also serves a wider social purpose. As disabled people we have unique insights about the potential of our lives, crucial to developing a wiser and more informed social understanding of bioethics generally.

We have tried too give both sides of the arguments.



We are the real experts on disability!

As can be seen from statements at the end of the pack, the UKDPC (formerly the BCODP) and our European colleagues have debated and agreed positions on many bioethical questions. Nonetheless, we have tried throughout this review to offer a balanced presentation of the issues. Our intention is to stimulate thinking about these difficult and contentious questions, not provide pat answers.

Above all, we want disabled people to realise that in questions about living with an impairment, we are the real experts.

Background

This document is an edited update of a disability and bioethics resource pack for trainers produced in 2004 with a grant from Wellcome Trust's Engaging Science Programme. That marked the end of a series of initiatives undertaken by the British Council of Disabled People and Disabled Peoples' International Europe from 1997 to make disabled people more aware of the bioethical questions which effect their lives.

The original resource pack came out of a series of workshops on bioethics, disability and human rights with a group of experienced trainers who were members of organisations of disabled people. The workshops were funded by the Wellcome Trust and facilitated by Helen Caplan and Bill Albert.

This booklet is the result of many events and meetings run by disabled people from 1997 to 2004.

DPI-Europe/ BCODP Initiatives on Disability and Bioethics

1997 - Expert seminar in London on bioethics and disability, sponsored by the Wellcome Trust and the Joseph Rowntree Foundation.
1998 - BCODP begins a two-year process of developing and consulting on a position statement on genetics and disability.
1999 - DPI-Europe Action Plan 1999 – 2002, adopted in Syracuse, Italy. "… to educate disabled people within Europe and the rest of the world on .. bioethics".
2000 – BCODP position statement approved by the National Council
2000 - DPI-Europe/BCODP International Conference on Disability, Bioethics and Human Rights, Solihull, UK
2000 - DPI-Europe position statement**, Disabled People Speak on the New Genetics**
2002 - DPI-Europe training the trainers pack, **Bioethics, Human Rights and Discrimination Against Disabled People The Challenge for Disabled People in the New Millennium**
2004 – Disability and bioethics. Life and death questions. A resource pack for trainers by Bill Albert and Helen Caplan for the BCODP

Subjects covered here include general ones such as genetics and disability, our human rights, etc.

We also look at things such as abortion testing of unborn babies, etc.

Each section has

- **Brief definition of subject**
- **Different arguments about the subject**
- **Quotations and points for discussion**
- **Some case studies on end-of-life issues**

This document offers brief summary accounts at two levels. The first is concerned with overarching issues such as eugenics, genetics, bioethics, the social model of disability and human rights. The second focuses on specific technique-based topics spanning the arc from pre-conception to death. This includes screening and testing, abortion, euthanasia and so on.

Each section contains a concise factual definition of the particular subject followed, where appropriate, by a brief summary of the main debates, a number of quotations to illustrate different arguments, some suggestions for group discussion and a selected list of web-based references. In certain sections case studies are given to illustrate the issues.

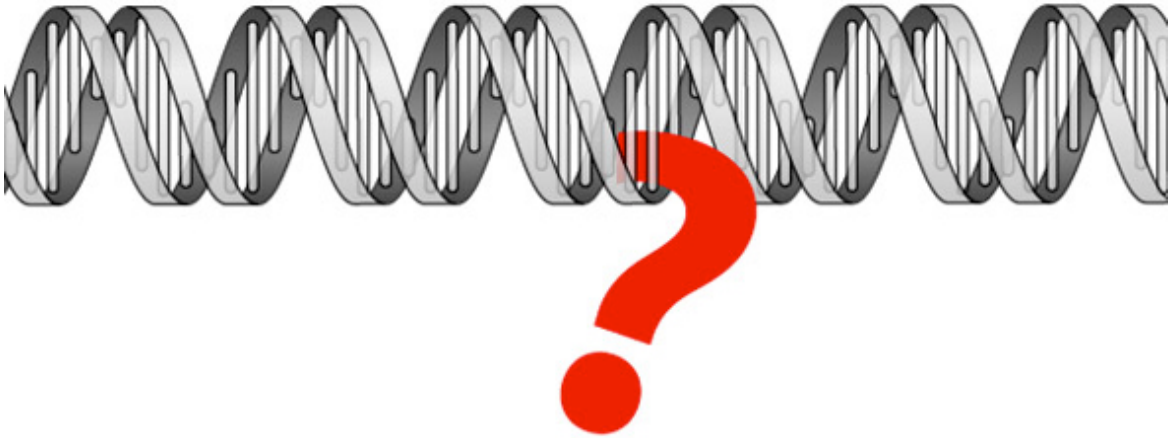
Don't I need to know about science?

You don't have to understand all the details of the science to have useful things to say about how it affects you.

The big questions don't just belong to scientists. They belong to all of us.

But, what about all the complicated science?

You don't need to understand the technical aspects of science to make a judgement on its use. How the science is used poses ethical, social and political questions. These questions touch everyone's ethical and moral sensibilities and are not the preserve of experts. They are owned by everyone.



Bioethics

Ethics = what is right/what is wrong

Bioethics = what is right/what is wrong about health care and the science related to health care

For example:

Who should get medical treatment?

How should organ donation being managed?

Bioethics

What is it?

- **Ethics** is about how we live our lives.
- **Ethics** is about deciding what is right and what is wrong.
- **Bioethics** is a branch of ethics dealing with issues surrounding health care and the biological sciences.
- **Bioethics** is ultimately concerned with the value we place on life, in particular human life.

[For a more detailed discussion on bioethics see Appendix 1]

Issues of concern in bioethics include:

1. Who should benefit from scarce medical resources? On what grounds should these decisions be made?
2. Should we have an opt-in or opt-out system for organ donation? Should payment be made to donors?

More examples of bioethical questions

Who should decide about a person's quality of life?

Should women have tests to see if their unborn baby might be disabled?

Who should know about your medical history?

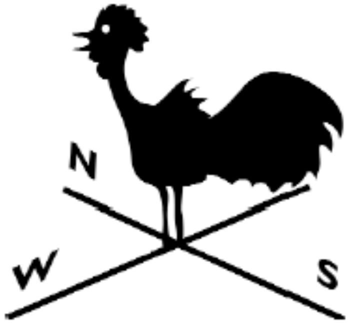
3. How should quality of life decisions be made and by whom?

4. What is the ethical way to proceed with population screening for disease?

5. Should health professionals keep your medical confidence even if this may harm someone else?

Discussion of bioethics may seem difficult, but because so much of it is about our lives, disabled people have a key role to play.

You should not be afraid of having opinions about bioethics, as you have the life experiences to have your voice heard and respected



"You don't need a weatherman to know which way the wind blows"

or

Why disabled people shouldn't be afraid of bioethics.

- Bioethics may seem a complex and difficult subject, but…
- It is not owned by scientists and philosophers
- It is everyone's concern how science is used
- **B**ecause disability is such a central aspect of bioethics, disabled people have a key role to play in bioethical debates

We should be afraid of having opinions about bioethical issues. We must have our experience heard, valued and respected.

I don't know how nuclear weapons are made but…

I can still have an opinion about how they might be used.

I am not sure how they make TV programmes but…

I can still decide what I want to watch.

Bioethics: Science and Society

<u>How many people understand the science of nuclear fission?</u>
Does this lack of understanding mean you can't have a valid opinion on the use or misuse of nuclear power or nuclear weapons?

<u>How many people understand the technical aspects of how television programmes are made?</u>
Does your lack of understanding mean you can't judge what is best for you to watch on TV?

It is the same with human genetics and ethical questions about medical practice. The way in which science is used is essentially a social and political question. As citizens we have a right, some would say an obligation, to ensure that science is used in a socially responsible way.

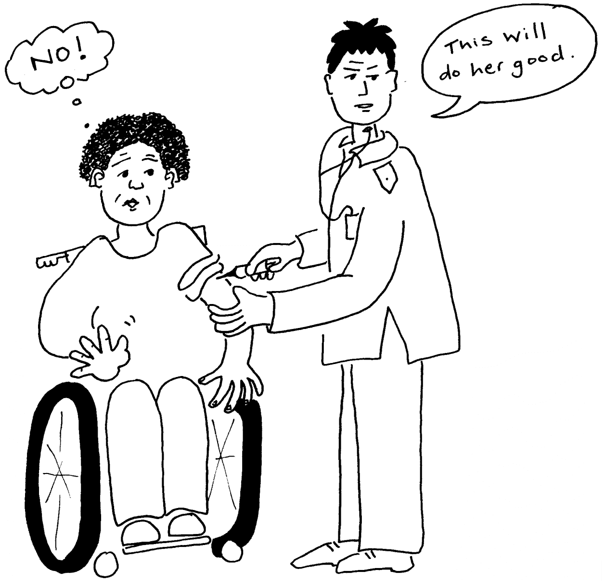
As disabled people we have an important contribution to make to the debate on the use of genetic technologies, because potential children with our conditions are the targets for testing and screening and elimination. Also medical decisions about what lives are worth living will have a major impact on the perceived social value of disabled people and the way we are treated.

Most importantly, on the experience of living with impairments … disabled people are the experts.

Disability and Bioethics

Bioethical questions – health care, decisions about life and death, etc. have an important impact on our human rights.

Many bioethical questions, ranging from pre-birth to death, as well as the intermediate stops in between, raise profound questions for disabled people's human rights. In this section we consider very briefly bioethics in relation to different ways of understanding disability.



Medical Model

Medical model of disability

People disabled by their impairments

Solution?

↓

Cure or prevention

Social Model

Social model of disability

People disabled by negative attitudes, social and environmental barriers

Solution?

⇩

Respect disabled peoples' human rights by changing attitudes and removing barriers to inclusion

Models of disability aren't perfect

It is necessary to stress that <u>models are not definitions</u> but rather simplified constructs devised to help understand the identification of and relationship between key variables.

To this extent no model can capture the complex totality of any issue, including disability.

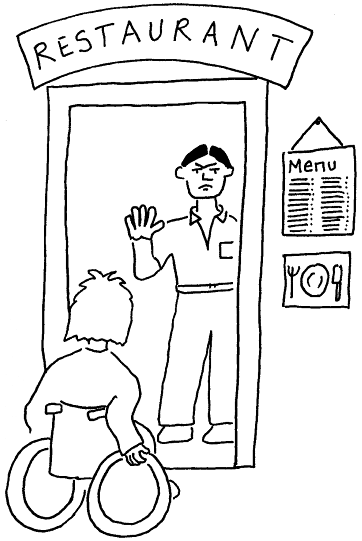
For example:

Those who embrace the medical model do not rule out the need for social justice, non-discrimination and inclusion.

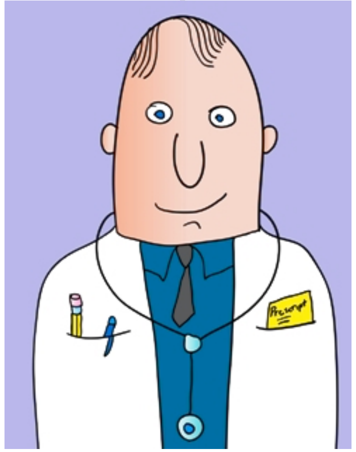
Those who embrace the social model do not rule out the need for impairment prevention and improved medical provision.

Nonetheless, the basic difference in understanding the key factors that disable people [impairment vs. social exclusion] remains and have a major influence on policy and practice over a wide range of bioethical issues.

Models can tell us what the most important factors are that make people disabled – their condition or being excluded from society because of their condition



Autism – Medical Model = Cure and prevention



For example:

A medical-model understanding of autism informs the work of Autism Speaks, that claims to represent people with autism in the USA (without those people being directly involved). Because it sees the condition primarily as a medical one, its response is to spend all but 4% of its considerable funds on looking for cures or ways to prevent autism. This is common for most big disability charities that tend to stress that disabled people's lives are defined and essentially broken and diminished by their impairments.

Autism – Social Model = Right to be treated as equal

A social model understanding of autism informs the work of the user-controlled Autism Network International, whose leader, Ari Ne'eman, says, "We need to stop making autism advocacy about trying to create a world where there aren't any autistic people, and start building one in which autistic people have the rights and support they deserve."

Quotes:

Why should doctors judge our quality of life?

Quotes

"I go to a doctor for health care. Who goes to be judged? Who goes for "justice?"
What has happened to the doctor's duty to patients?
Bioethics happened."

"Bioethics: introduction to theories from hell" Alice Mailhot, **Mouth**, 1994

"I have … ambivalence about the demand that if anyone is going to talk about the ethics of something related to the care of persons with disabilities, then someone with a disability should be on the panel to speak, or else the educational process is corrupt and should be shut down. I don't think that is a valid educational strategy; taken to its logical extreme, we would never finish any educational program because an indefinite number of people would have to be invited as panelists. … the demand is a way of getting attention to make a political statement."
Howard Brody, "Ethics, Education and Politics", **Medical Humanities Report**, Vol.18, No. 1, Fall 1996

Quotes:

"Disabled people must be included in discussions on bioethics."

"(In bioethics)… a failure to give a prominent place to the consideration of disability issues does not only mean that important areas of healthcare go unconsidered; it also means that many issues bioethicists consider will be distorted. Since many of the fundamental concerns of persons with disabilities are not about medicine at all but about the living of life, they point the way to transcend medical ethics and restore the original meaning to bioethics."
Mark G. Kuczewski ,"Disability: An Agenda for Bioethics", **American Journal of Bioethics**, Vol. 1, no.3 , Summer 2001, pp. 36-44.

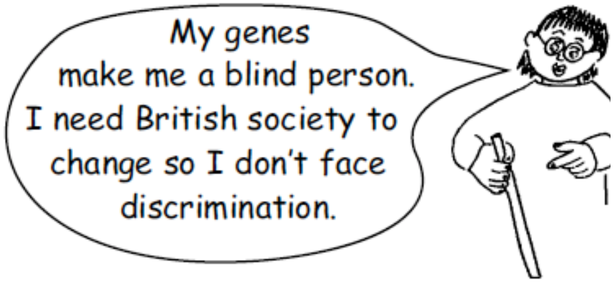
"Good health care is not so good because it means more old and disabled people to look after."

"Preventive medicine drives up the ultimate cost of health care to society by enlarging the population of the elderly and infirm. The child who would have died from polio will grow up to be a very expensive old man or woman.... Good medicine keeps sick people alive, thereby increasing the number of sick people in the population." - Willard Gaylin, M.D. and renowned bioethicist, ***Harpers Magazine***, October 1993.

Quotes:

"Disabled people cost to much to take care of."

"The social model of disability must be used in debates about bioethics."

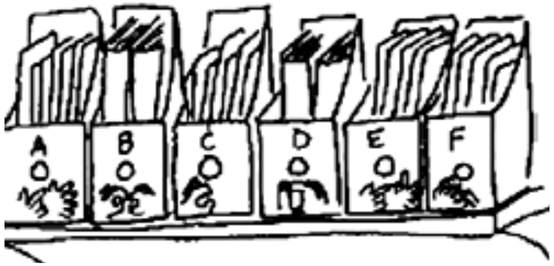


"Bioethicists teach medical professionals to put community health (and wealth) first, to count the cost of taking care of us against our apparent value to society." - Alice Mailhot, "Bioethics: introduction to theories from hell", Mouth, 1994

"If a social model of disability would be used within the debate of bioethics issues which would see able-ism on a par with racism and sexism, the debate around many bioethics issues might be different. I suggest, therefore, that this "disability perspective" deserves the attention of the bioethics community."
Gregor Wolbring, "Bioethics and Disability: Making Assumptions, Explicit", **Health Ethics Today,** Vol. 12, No. 1, Fall/November 2001.

Discussion	Points you may want to discuss
Do unborn babies have human rights?	○ How can you speak of the human rights of disabled people being threatened by such things as screening or testing when the object is a foetus, which is not afforded human rights in any international human rights document or convention?
Isn't it a human right to have a cure for an impairment?	○ If disabled people oppose a concentration on cure on the grounds that disability is a social rather than a medical issue where does this leave disabled people who are in chronic pain or dying of incurable diseases? What about their human rights to seek treatment or cure or assisted suicide?
Why can't you have both cures and social inclusion?	○ Understanding bioethical issues by focusing on different models of disability is too simplistic and creates an artificial division between the demand for social inclusion and the demand for cure and the prevention of impairment. Both are human rights concerns.
Why shouldn't people be given assistance to kill themselves?	○ If, as some disabled people have argued, legalised euthanasia threatens their human rights, what does this say about the rights of people who want to take their own lives?

Stuff to read



Bioethics Web. A gateway to evaluated, high quality Internet resources relating to biomedical ethics. http://www.intute.ac.uk/bioethicsweb/

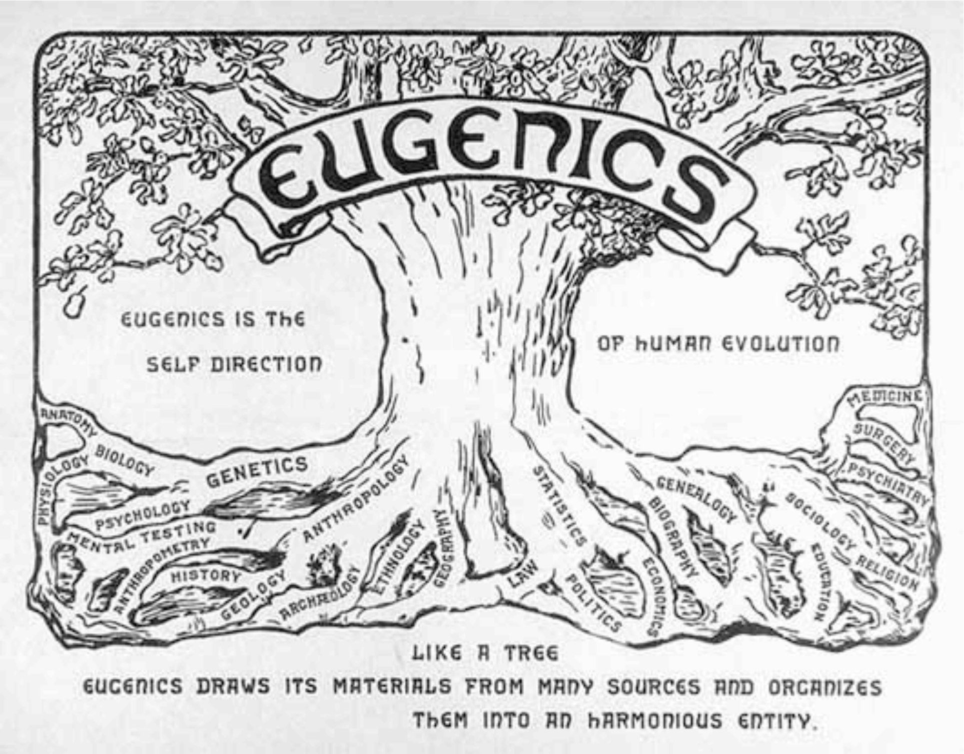
Disability Awareness in Action, Bioethics
A number of critical articles on disability and bioethics
http://www.daa.org.uk/index.php?page=left-bioethics

Fitzgerald, Jennifer, "Bioethics, Disability and Death: Uncovering Cultural Bias in the Euthanasia Debate", http://www.metafuture.org/articlesbycolleagues/JenniferFitzgerald/Bioethics,%20Disability%20and%20Death.htm

McGee, Glen, "The Perfect Baby: Eugenics, Race, and Bioethics", (May 26, 2010)
A fascinating talk that brings together bioethics, the history of eugenics together with current issues around testing and market-driven eugenics.
http://www.archive.org/details/ThePerfectBabyEugenicsRaceAndBioethics

National Institutes of Health, Bioethics Resources on the Web, http://bioethics.od.nih.gov/

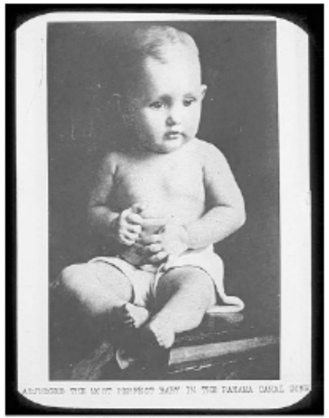
Wolbring, Gregor **Disability Rights Approach toward Bioethics?**
http://www.questia.com/googleScholar.qst;jsessionid=MrMbLGgwg6qfsTJQ6Cpjhv2XnghB5GDk2Kq75SGDQ123Pv4TBDRf!696839513!1358914628?docId=5002072788


EUGENICS
EUGENICS IS THE
SELF DIRECTION
OF HUMAN EVOLUTION
ANATOMY
PHYSIOLOGY
BIOLOGY
GENETICS
PSYCHOLOGY
MENTAL TESTING
ANTHROPOMETRY
HISTORY
GEOLOGY
ARCHAEOLOGY
ANTHROPOLOGY
ETHNOLOGY
GEOGRAPHY
LAW
STATISTICS
POLITICS
GENEALOGY
BIOGRAPHY
ECONOMICS
MEDICINE
SURGERY
PSYCHIATRY
SOCIOLOGY
EDUCATION
RELIGION
LIKE A TREE
EUGENICS DRAWS ITS MATERIALS FROM MANY SOURCES AND ORGANIZES
THEM INTO AN HARMONIOUS ENTITY.

Eugenics

Eugenics

Eugenics = good in birth



Eugenics = able people to have more children & less able people to have fewer children or none at all

> "Those who cannot remember the past
> are condemned to repeat it."
> George Santayana

What is it?

Eugenics is derived from the Greek meaning "good in birth" and is concerned with promoting the biological improvement of humanity.

The 'science' of eugenics was first proposed in 1883 by Francis Galton, who was concerned to improve the human stock of the nation. This was to be done in a positive manner by encouraging the most able and healthy to produce more children, thereby passing down good 'genes' to future generations.

To get the least able to produce fewer children, or preferably none at all, 'negative eugenics' was developed later, primarily in the

From late 1930s, eugenics led to Nazi murder ('mercy killing') of disabled children and adults

United States and Scandinavia, where, among other measures, laws were enacted to permit the compulsory sterilisation of 'degenerates', mainly disabled people. This strand of eugenics was taken up in Germany immediately after Adolf Hitler came to power in 1933. In the late 1930s they began the systematic "mercy killing" of disabled children (Aktion T 4) and later, with the first introduction of gas chambers, the wholesale murder of disabled adults.

Up until the 1930s eugenic ideas were championed across the political spectrum. It was only from about this time that its popularity began to wane and it was finally discredited by its direct association with the Nazi Final Solution.

In the years after 1945 geneticists, many of whom had been active in the eugenics movement, began to distance themselves from it. Various eugenics societies changed their names and explicit promotion of eugenic policies ceased. Nonetheless, as outlined below, many claim that the eugenic assumptions and the ideal of improving the gene pool, continue to underpin current clinical practice in genetics.

Arguments

Eugenics no longer exists

People are free to make their own choices about both birth and death

What are the arguments?

The definition of eugenics, its history and current relevance are all areas of intense debate.

The link between eugenics and genetics has been broken.

Many proponents of new genetics contend that eugenics was a pre-1945 phenomenon based on a pseudo scientific understanding of genetics and was associated with coercive state policies.

With the greater understanding offered by molecular genetics we have entered a new era where it is possible to harness these discoveries to help prevent or ameliorate the effects of illness and disability. This offers positive benefits for individuals and society.

Furthermore, modern genetic procedures are carried out in a non-coercive environment, one that actively promotes autonomy and fully informed choice. This is facilitated by the provision of non-directive genetic counselling. Reproductive decisions made under these circumstances could hardly be labelled as eugenic. Finally, seeing euthanasia as eugenic is equally mistaken, as those who promote its legalisation are concerned with easing pain and suffering and giving people the freedom to decide how and when to die.

Arguments

Some eugenics is good

For example, having fewer disabled children would be better for everyone

Eugenics still exists and it is bad

For example, testing babies before they are born creates the idea that disabled people are not wanted in our society

Eugenics is progressive

Some bioethicists have gone further and argue that as long as there is no coercion, eugenics, in the sense of either eliminating disabling conditions or enhancing children's genetic endowments, is not only unproblematic, but should be welcomed as socially progressive. After all, they ask, isn't this what medical science strives to achieve?

Eugenics is still with us and is still socially corrosive

Those opposing the above views argue eugenics in all its forms is biologically determinist (you are your genes) and socially divisive. In other words, there is no such thing as 'progressive eugenics'. They also point out that pre-war eugenics cannot be characterised by its most extreme manifestations (Nazi policies). This means that coercion is not necessary for there to be a continuation of eugenic ideas about promoting the biological improvement of humanity. These eugenic ideas continue to be found, although not acknowledged as such, in the new genetics and the structures, both medical and cultural, in which it has been developed.

Modern clinical genetics appear to promote autonomous decisions about reproduction. However, by the routine provision of tests to screen out children who have certain characteristics such as Down's

Syndrome, a clear message is given about the social desirability of making the 'right' decision, as well as what kind of people should inhabit the world.

This is reinforced by the popular cultural understanding of the Human Genome Project, which is that, in James Watson's phrase, 'our future is in our genes'. This has created a climate of genetic determinism which, hidden behind the liberal mask of improved public health, in effect stigmatizes disabled children as well as their parents, and thereby promotes eugenic outcomes.

Quotes:

"It is wrong to knowingly to give birth to a disabled child."

Quotes

"Why should society canonise a woman who refuses to abort a fetus with a genetic abnormality? There seems to be a better case for criticising them, for knowingly bringing someone into the world with a disability. Society has no hesitation in condemning a person who disables somebody while drunk behind the wheel of a car; so why praise a woman who knowingly gives birth to a disabled child? … from the point of view of improving the health of the population, it is entirely in line with the longstanding goals of medical science." John Gilliot, "The spectre of eugenics", **Living Marxism**, January 1996

Quotes:

"In Nazi Germany eugenics was behind the programmes to get rid of people who were seen as different and of less value."

"In Nazi Germany, harshly prejudicial ideas toward people with disabilities replaced other, less extreme ideas. Eugenics, for example, did not appear in and of itself sinister, but it was quickly co-opted for nefarious ends. The idea of eugenics was dangerous to people with disabilities because it propelled action with scant regard for decency and compassion. In the marketplace of ideas, eugenics was embraced largely because it served a wider prejudicial purpose, namely, to control and then rid Germany of people deemed different, inferior, and asocial. The minority who resisted were soon silenced in the tidal wave of a demand for conformity to a master race superior to all others. Other, less lethal ideas could have been adopted. For example, energy could have been directed to renewed efforts at understanding deviant behavior, especially behavior resulting from and characteristic of physical, emotional, and intellectual disabilities."

Mark P. Mostert, "Useless eaters: disability as genocidal marker in Nazi Germany", **Journal of Special Education**, Fall 2002.

Quotes:

"Eugenics is still around."

"It is only more hidden now than before the 1940s."

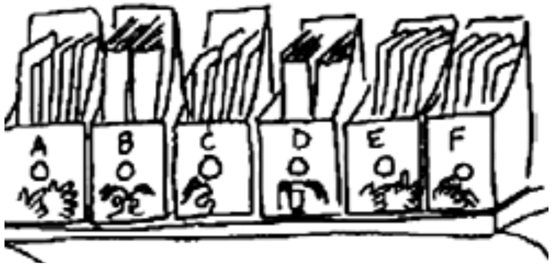
At least initially, a new eugenics will most likely be a laissez-faire eugenics. The dominant concept now is consumer choice in reproduction, an idea unheard of in the 1930s. Although we are unlikely to see a new generation of eugenic activists publicly arguing for such policies, the outcome will tend to be the same. It is rather pointless to debate definitions and whether or not we call this eugenics. The point is that the underlying drive towards control of reproductive mess is still very much alive, and scientific and social conditions are right for this drive to be expressed.

David King, "The Persistence of Eugenics", **Human Genetics Alert,** (http://www.hgalert.org/topics/geneticDiscrimination/eugenics.htm)

Discussion

	Points you may want to discuss
Why is improving people wrong?	• If eugenics only means improving the human race and there is no coercion involved, who could argue with that? • Eugenic is a mindless word of abuse used about people we disagree with.
Is it wrong to test babies before they are born?	• Can pre-natal diagnosis be characterised as eugenic in the case where carrier testing is offered as a standard of care, and where the couple receives and understands full and fair information and the possibility of economic and social support for whatever decision they make?
Are disabled people's human rights risk because of eugenic ideas?	• We want to live as active, equal and productive members of society but our perceived value and role, as well as our human rights, are continually diminished by the questionable medical ideas and discriminatory attitudes spawned by the new genetics.
Would the world be a better place without disabled people?	• A utilitarian ideology informs much of the new human genetics, particularly the assumption that society would be better off without the inconvenience and expense of disabled people.

Stuff to read



Gross, N. "The Persecution of Disabled People in Nazi Germany", 2008, http://www.slideshare.net/ZoeG/persecution-of-disabled-people-in-nazi-germany

King, D., "The Persistence of Eugenics", Human Genetics Alert, (http://www.hgalert.org/topics/geneticDiscrimination/eugenics.htm)

McGee, Glen, "The Perfect Baby: Eugenics, Race and Bioethics" (May 26, 2010) http://www.archive.org/details/ThePerfectBabyEugenicsRaceAndBioethics
A fascinating talk that brings together the history of eugenics with current issues around testing and market-driven eugenics.

Mendelshon, E, "The Eugenic Temptation: When Ethics lags behind Technology", **Harvard Magazine**, March-April 2000.
http://www.harvardmagazine.com/on-line/0300126.html

Not Dead Yet, website http://www.notdeadyet.org/

Not Dead Yet UK, website http://www.notdeadyetuk.org/

A history of eugenics in California. Radio discussion of a 2005 exhibition on eugenics. Highly recommended.
http://www.archive.org/details/Insight_051004

Image Archive of the American Eugenics Movement
http://www.eugenicsarchive.orgn/eugenics/

Nazi Persecution Of The Disabled : Murder Of "The Unfit", US Holocaust Memorial Museum.
http://www.ushmm.org/museum/exhibit/focus/disabilities/

Williams, Z., 'Abortion and euthanasia: was Virginia Ironside right?', The Guardian, Oct. 5, 2010.
http://www.guardian.co.uk/world/2010/oct/04/virginia-ironside-tv-euthanasia-abortion

Illness

What does it mean to be ill?

Some doctors think they can fix us like we are broken down cars.

Illness

What is disease? What is illness?

Illness and disease are concepts that have to be defined. So, how do we know what constitutes an illness or a disease? This seemingly straightforward question is the subject of long-standing academic debates, far too complex to unravel here.

For our purposes it is necessary, however, to indicate some of the key issues which arise, particularly as they relate to the rapid advances in genetic science. These issues have extremely important implications for many of the debates over testing, screening as well as clinical interventions.

What are the arguments?

Sociological concerns

Over the last couple of centuries, a medical understanding of illness and disease has seen the body as a kind of machine which, when appearing to function abnormally, needed to be investigated and, if possible, fixed. This is known as biological reductionism.

What is normal?

"Do I have an illness or am I just different?"

Dr. Tom Shakespeare

Biological reductionism was challenged by various sociological theories such as functionalism and Marxism. They did not question the biological 'reality' of the impaired body, but located the 'problem' of illness in the social sphere rather than the physical body.

Both approaches have in turn been criticised by social constructionism, which essentially holds that truth is a relative concept and the product of power relationships. In this schema, medical knowledge is not incremental but it is being continually socially renegotiated and redefined.

Bioethical concerns

Bioethicists have taken a somewhat different tack from social theorists. Most accept that disease is a harmed physical state but the two main questions are concerned with

- what is normal, and
- the role played by subjective values in defining disease.

The first point is important because abnormality is frequently equated with illness, whereas in fact variety and difference are in themselves normal. Diversity is an inherent part of nature.

The values ascribed to difference can also be critical because of a perceived negative social value. For example, it wasn't all that long ago that homosexuality was viewed by some people as an illness that called for psychiatric treatment.

Is not being the same as most people a bad thing?

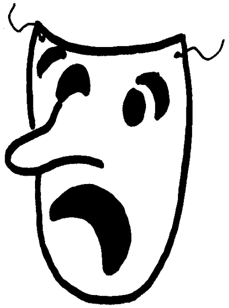
How impairments are defined

Body/Mind function that is perceived to be negatively different from some kind of preconceived sensory, physical, intellectual, psychological or genetic norm, is usually derived from standardised physical, intellectual or emotional tests.

Reproduced with thanks to Simone Aspis, Changing Perspectives.

Questions raised about normality and subjective value become particularly important when dealing with new genetics because everyone is known to carry many gene mutations, most of which will have little functional impact. Even when there is such an impact, as in the case of Down's Syndrome or achondroplasia, are we looking at disease or simply difference?

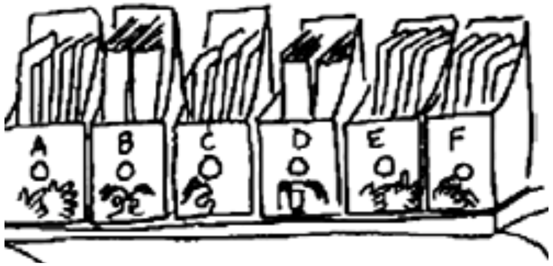
Does it mean you are a lesser person?



"If disease refers to abnormal states, either mental or physical, that are disvalued then the appearance of values seems to some to make the prospects grim for objectivity or consensus about what states are or are not healthy or diseased. Subjectivity and a lack of consensus could bode especially ill for the uses to which new knowledge of human heredity might be put since applications might be controlled by the powerful or the economically privileged to advance their own values."

Arthur L. Caplan, "If Gene Therapy Is the Cure, What Is the Disease?"

Stuff to read



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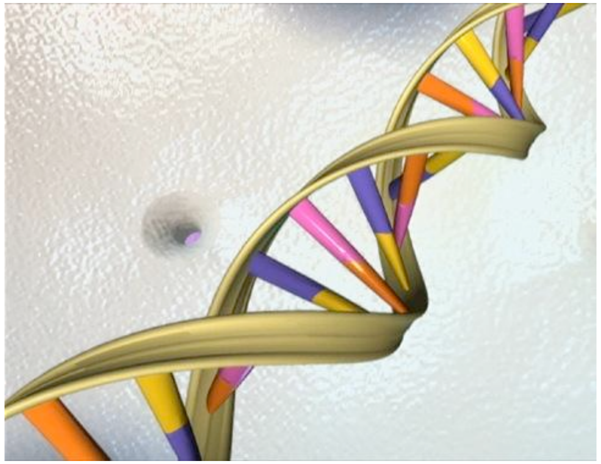


Human Genetics

Genes are the set of instructions for making all plants and animals

Human genetics is the study of those instructions for human beings

Each person has their own set of genes, which is one reason we are all different

Our genes affect all sorts of things, including the colour of our skin, our eyes and our hair

Human genetics

What is it?

Human genetics deals with genes, the basic units of inheritance

Every living system is made up of a constellation of cells. The way they work is determined by instructions within the DNA (deoxyribonucleic acid), found in every cell.

DNA is made up of a twisted ladder (double helix). The rungs of the ladder consist of pairs of chemicals (base pairs) (adenine (A), thymine (T), guanine (G), and cytosine (C)). These four chemicals are arranged in varying sequences and provide the instructions for creation of the organism.

The genome is the total genetic material of an organism. The human genome contains about 3 billion rungs of the ladder (base pairs) divided into genes made up of variable numbers of adjoining rungs and groups of rungs which have no apparent purpose (junk DNA). There are about 30,000 genes in the human genome that are distributed among 23 pairs of chromosomes of differing lengths. Each cell in the body, except mature red blood cells, has a complete copy of the genome.

If a gene is damaged this can lead to a substantial or minor physical difference

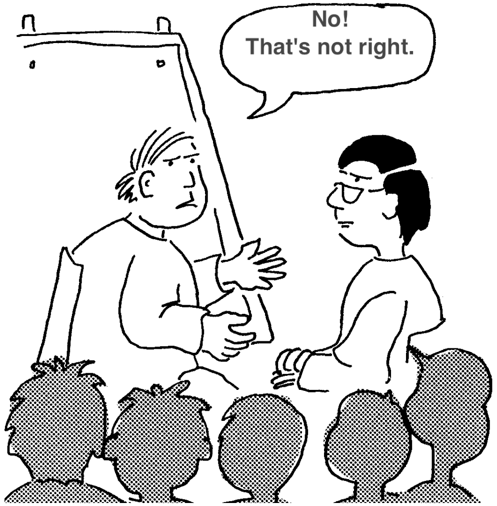
Newspapers tell us too simple a story about genes

Genes are not directly involved in the day to day functioning of the body. They do however provide the recipe for the creation of proteins which control the body's function as well as making up most of the body's structure. The recipe will be faulty if some instructions are missing, are in the wrong place or if an extra chromosome exists. This in turn may result in a functional or structural divergence from what is considered 'normal'. This may be immediately apparent, as in the case of Down's Syndrome (an extra chromosome 21) or delayed, as in a person being more likely to contract an illness at some time in their life.

Although the popular press writes about genes for intelligence or genes for musical ability, in fact we still know very little about the role genes play in these or similar characteristics. What we do know is that environmental factors are usually as, if not more, important. The same is true for most common medical conditions such as cancer or heart disease. Despite the fact that so much has been made of the health implications of the new genetics, we still don't know much about genes, how they interact and how they produce health and disease. While there may be a genetic predisposition of greater or lesser significance for any illness, it is environmental factors such as diet, life style, working conditions and so on, which in all but a small number of cases play the most crucial role.

Arguments about genetics are not about science versus religion

There are many people who are critical about the possible misuse of genetic information



There are 5,000 conditions that are caused by a single damaged gene

Science v Religion?

The ethical debates about the application of human genetics are not about science versus religion, because…

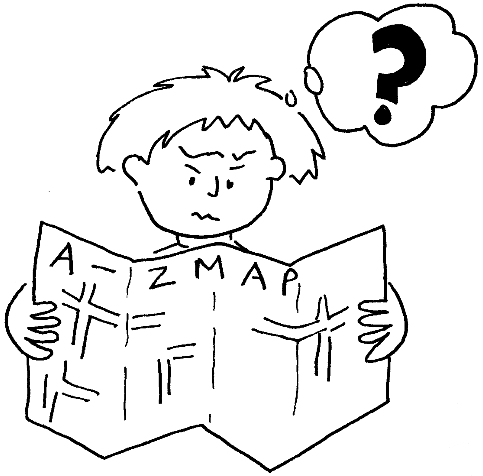
- There are many secular critics of the use/misuse of genetic science and…
- There are many scientific critics of the use/misuse of genetic science and…
- There are many medical critics of the use/misuse of genetic science

There are over 5,000 types of single-gene conditions, such as cystic fibrosis or sickle cell disease, where faulty copies of the gene are inherited. But even within these, there is great variation both in the particular gene mutation implicated and in how people experience these conditions. This points once again to the role of non-genetic factors as well as the complexity of apparently straightforward genetic conditions.

While the sequencing (discovering how all the rungs or base pairs are arranged along the ladder) of the human genome has been

We still have a long way to go before we understand how genes work together

So, genes don't give us 'the map of life'!



completed there is still a very long way to go before we understand how genes function, are turned on and off and interact with each other and the environment.

It is often said that the human genome is a map or the book of life. It isn't. However, if it was, so far we have discovered an alphabet without yet knowing the words, the syntax, the meaning of the words or the grammar, let alone the sentences.

Limits to the Clinical Application of Genetic Knowledge

- Genetic diagnosis is clumsy and slow in many cases. Where the specific mutation is not known, then it is very hard to discover whether a person (or a pregnancy) is at risk of the disease.

- The outcome of genetic diagnosis is often more uncertainty: a risk factor, rather than a definite prognosis.

- Genetic diagnosis will never be able to eliminate impairments, even if everyone accepted antenatal screening and opted for selective termination.

Finally, understanding the impact of genetic endowment on biological function or malfunction depends on a detailed knowledge of what is happening in the cells and tissues. In other words, we need to know about the action and interaction of proteins rather than simply the genes that produce them. This extremely complex process takes place at a level above the genes.

The equivalent of the genome within all the proteins in a cell is the proteome. Unlike the genome, which changes little throughout life, the proteome is fluid, changing by the second as it responds to signals from protein interaction and the environment. It will take many decades before scientists are able to unravel how the proteome works.

Arguments

Do genes make us who we are?

What are the arguments?

There are many debates about issues around human genetics. For example, the holding of individuals' DNA on health or police databases, the use of DNA by insurance companies or employers, the sale of DNA tests directly to the public, genetic-based paternity tests and so on. Here we concentrate on only one issue, genetic determinism.

'R Genes Us?

Quotes

"Our future is in our genes."

James Watson

Genetic determinism is the idea that our genes determine who we are at every level of being. Whilst of obvious significance in this age of revolutionary genetic discovery, in almost all respects it is a reprise of a long-running debate about the relative importance of nature (our biology) or nurture (the environment) in making us who we are.

With respect to models of disability, genetic determinism fits very clearly within a medical model understanding. The idea also powerfully informs much embryo and prenatal testing and, as with chromosomal tests such as amniocentesis, tends to reduce the prospective child to a single aspect of its genetic inheritance.

Quotes

"We used to think our future was in the stars. Now we know it is in our genes." James Watson

Quotes

"We are much more than our genes."

Francis Collins

"As genetic predispositions to everything from cancer or diabetes to novelty-seeking behavior or homosexuality are being reported almost daily in the scientific literature … a new and dangerous brand of genetic determinism is subtly invading our culture. Carried to its extreme, this 'Genes R Us' mentality would deny the value of social interventions to maximize individual potential, destabilize many of our institutions … and even deny the existence of free will. Surely a world in which every aspect of human behavior is hard-wired into our genes cannot comfortably exist with the concept of personal responsibility and free will to try …to follow the moral law of right and wrong which people of faith believe has been written into our hearts by a loving and holy God."

Frances S. Collins, Director, National Center for Human Genome Research 1997.

"Genetics is a way of thinking."

Barbara Katz Rothman

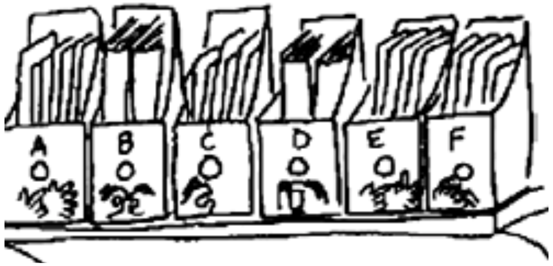
"Genetics isn't just science. It's a way of thinking, an ideology. … Whatever the question is, genetics is the answer."

Barbara Katz Rothman, Genetic Maps and Human Imaginations: The Limits of Science in Understanding Who We Are**, 1997.**

Discussion

	Points you may want to discuss
Do advances in genetics hold out hope to cure disabled people?	Advances in the understanding of human genetics offers hope for disabled people and their families
Do advances in genetics threaten the human rights of disabled people?	Advances in the understanding of human genetics contributes to undermining the human rights of disabled people
Being against genetics is silly !	Being against genetics is like being opposed to the tides.
Is anyone safe from genetic discrimination?	If the value of life is reduced to a matter of genetic inheritance, will anyone be safe from genetic discrimination?
Do our lives celebrate diversity?	Maintaining diversity is as essential for humanity as it is for life as a whole. Our lives as disabled people celebrate the positive power of diversity.
Why should anyone object to a genetic-based cure?	If disability is about having a functional limitation, and this can be solved by genetic intervention, why should anyone object, least of all disabled people?
Should genetic research be stopped?	Should research be stopped when, in the long term, it could lead to benefits for everyone?

Stuff to read



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Website has recent articles on all aspects of genetics

Council for Responsible Genetics
http://www.councilforresponsiblegenetics.org/
Website has many interesting articles on genetics

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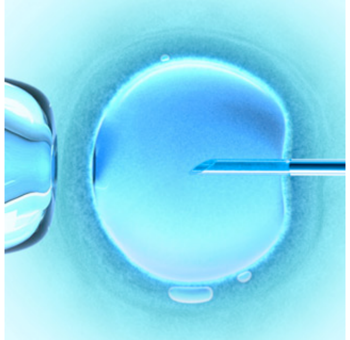
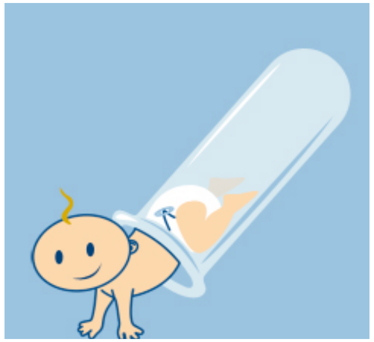
Pre-implantation Genetic Diagnosis/ Screening

Pre-implantation Genetic Diagnosis/ Screening (PGD/PGS)

PGD is a way to test embryos to see if they have a genetic problem before they are put in a woman's womb.



The process can only take place if the couple have a 'test-tube baby' – that is a child created by mixing a sperm and egg outside the mother's womb



What is it?

PGD is a technique that allows embryos to be tested for possible abnormalities at a very early (eight cell) stage before being implanted in the womb. It is done in association with *in vitro* fertilization (IVF). PGS refers to the process of using PGD for screening embryos to ensure they contain the correct number of chromosomes.

The object of PGD is to allow women or couples who know they are at risk of having a child with a serious impairment, to have a child that does not carry that genetic or chromosomal trait. Although frequently cited as a method of producing 'designer' babies, it is in fact not about genetic manipulation but about selecting specific embryos.

PGD can be used, and is used in some countries, for sex selection. This is not permitted in the UK, except in the case of serious sex-linked disorders. In the United States it has been used to identify and deselect embryos with a predisposition of developing a late-onset condition such as breast cancer. The first such case in the UK was reported in early 2009. PGD is also used where parents want to choose an embryo (so-called savior sibling) to provide a tissue match for a previous child with a life-threatening condition. In the UK, this latter procedure is licensed on a case-by-case basis by the Human Fertilisation and Embryology Authority (HFEA).

PGD has been used to identify many conditions such as muscular dystrophy and cystic fibrosis

PGD has been selected for use with a wide range of conditions (84 in the June 2009 HFEA list) including cystic fibrosis, Duchenne Muscular Dystrophy, Beckers Muscular Dystrophy, Fragile X, and others. Although the HFEA says each clinic needs to be licensed, once they have been they do not have to reapply for subsequent tests. There have also (2010) been discussions about whether all clinics should be able to test for a condition once it has been licensed by a single clinic.

A new test, Universal Genetic Test, can test for 100 different conditions

A new test (Universal Genetic Test from the company Counsyl) has been developed in the USA which gives prospective parents the chance to have a non-invasive DNA test that will tell them if their child may have one of about 100 genetic conditions. If one is found then PGD can be used to chose a non-effected embryo.

Pre-implantation genetic diagnosis and the new Universal Genetic Test touches on many wider issues, among which are:

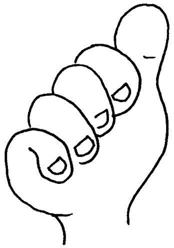
- Eugenics

PGD and other such tests raise many issues –

- **The value of disabled people**
- **How we think of babies before they're born and so on**

Arguments

Using PGD is good because:



- **Couple can have a healthy baby**
- **They don't need to have an abortion if something is not right**
- **They can have a baby that can help a sick brother or sister**

- How disabled people's lives are valued
- The use/misuse of genetic technology
- Quality of life issues
- The moral status of embryos
- Reproductive choice
- How disability is defined
- Human rights of prospective parents

What are the arguments?

PGD increases choice and avoids termination

The practical argument in favour of this procedure is that it gives couples at risk of having a child with a serious condition the possibility of giving birth to a healthy child, while avoiding the trauma of abortion. At the same time PGD holds out the possibility of effecting life-saving cures for existing children through the birth of tissue-compatible siblings.

Arguments

Using PGD to stop the birth of a disabled child is better for society

As with the case made for promoting screening and testing, the ethical case is that PGD extends the range of reproductive choice for prospective parents. Since this is done without doing direct harm to any third party there should be no reason, except on clinical grounds, to restrict its use.

NB: Embryos and foetuses have no legal rights, and some argue they have no moral rights. See section on late abortion

Furthermore, if you can prevent a disabled child being born, especially at this early stage and have another child who is not disabled, then it represents a positive social good, not only in terms of the welfare of the child and its family, but in terms of the costs to society as a whole.

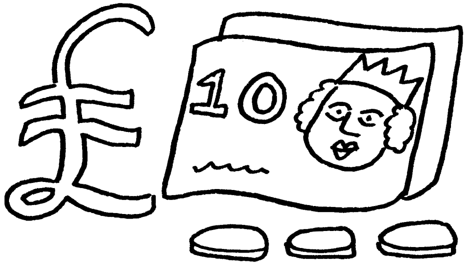
PGD in the Public Arena

Public debate on PGD focuses mainly on 'designer babies'

For most people selecting against impairment is not problematic

For most people selecting for impairment is problematic

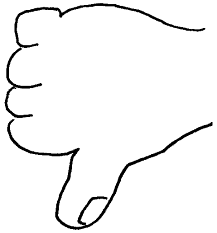
PGD is expensive and not widely used



Finally, this is a difficult (for the prospective mother) and relatively expensive procedure which is used so far in few cases. For example, in 2007, 42 babies were born in the UK after PGD selection, about the same

Arguments

Using PGD is not good because:



- **Disabled people are seen as only their impairments**
- **Its use gives the message that we're not wanted in society**
- **It could be the beginning of more widespread genetic elimination of potential disabled people**

number as three years earlier. This represents 0.31% of all IVF babies – around one in 270.

PGD is the ultimate eugenic tool

For many critics, both religious and secular, PGD simply moves the problem of discriminatory selection back one stage. The technique is informed by the same assumptions that underpin screening and testing, that disabled people are seen essentially as their impairments with all their potential attributes and social roles ignored. In this negative and socially truncated identity they are viewed as of less value. As PGD and the new Universal Genetic Test are used to screen out certain kinds of people they are eugenic techniques. That they are used in only a few cases doesn't alter the principled objection nor does it mean that new developments won't lead to more widespread use.

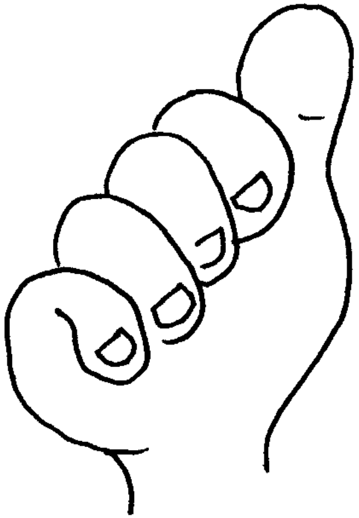
As with the debate about screening and testing, an important line is drawn here, not only between the way in which the social and medical models understand disability, but also between the outlook of potential parents and disabled people.

A broader criticism of PGD, particularly when the aim is to produce a saviour sibling, is that it is being used to create children not for their own sake but in pursuance of instrumental objectives, thereby compromising the child's identity and humanity.

Quotes

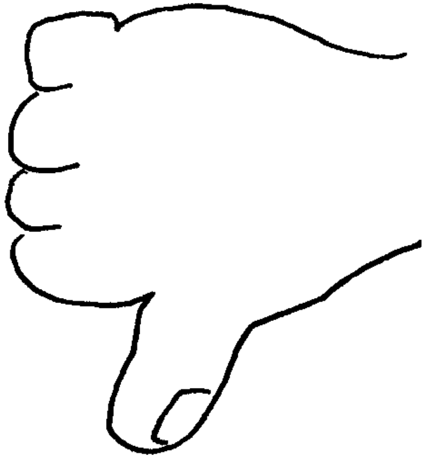
Quotes

"No one is harmed by PDG. Everyone is helped and it should be allowed. We shouldn't interfering with individual's liberty ."



"Who is harmed by allowing PGD to be performed solely for the benefit of a relative? Not the couple who wish to produce an embryo. Nor the child who would not otherwise have existed. Nor the person who receives the stem cell transplant that might save his or her life. We must avoid the trap of interfering with individual liberty by preventing such procedures for no good reason, simply out of the "genophobia" that grips much of society today. Some people object to using PGD along with in vitro fertilisation for any indication. But if these procedures are acceptable, as they are in many countries, it is reasonable to use them to both bring a new person into the world and to help save an existing life."

Robert J Boyle and Julian Savulescu, "Ethics of using pre-implantation genetic diagnosis to select a stem cell donor for an existing person", ***BMJ*,** 2001;323:1240-1243, “PGD is radically more effective as a eugenic tool of genetic selection and must be strictly regulated.”

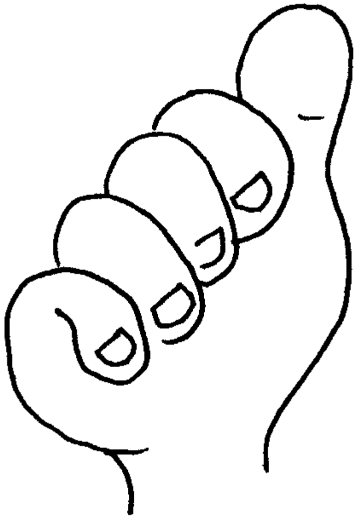


Pre-implantation genetic diagnosis (PGD) is often seen as an improvement upon pre-natal testing. I argue that PGD may exacerbate the eugenic features of prenatal testing and make possible an expanded form of free-market eugenics. The current practice of prenatal testing is eugenic in that its aim is to reduce the numbers of people with genetic disorders. Due to social pressures and eugenic attitudes held by clinical geneticists in most countries, it results in eugenic outcomes even though no state coercion is involved. I argue that technological advances may soon make PGD widely accessible. Because abortion is not involved, and multiple embryos are available, PGD is radically more effective as a tool of genetic selection. It will also make possible selection on the basis of non-pathological characteristics, leading, potentially, to a full-blown free-market eugenics. For these reasons, I argue that PGD should be strictly regulated.

David King, “Preimplantation genetic diagnosis and the 'new' eugenics”, **Human Genetics Alert,**)

Quotes

"We should not restrict the use of PGD … solely on the basis of disability rights."



"[Some disabled people argue] that prenatal or pre-implantation screening for disabilities results in discrimination against those with the disability by reducing the numbers of people affected. Moreover, they believe that by terminating the fetus or embryo we are sending a message that a life with the disability is not worth living at all. It is also argued that developing remedies is hindered by the ability to select against diseases either by PGD or abortion. Millions of people who are currently affected with these disorders are living happy and productive lives. These individuals argue that identifying people based on their circumstances has the tendency of perceiving abnormalities as inconveniences. In addition, they believe that "PGD and embryo selection against these traits will reinforce beliefs that they are inferior." However, one commentator cautions, "it would be a drastic step in favor of equality to inflict a higher risk of having a child with a disability on a couple …to promote social equality.... To attempt to prevent accidents which cause paraplegia is not to say that paraplegics are less deserving of respect." It is important to distinguish between disability and persons with disabilities. Selection reduces the prevalence of the former, but is silent with respect to the value of the latter. Consequently, we must evaluate our social institutions and beliefs regarding the disabled, but we should not restrict the use of PGD to screen for severe genetic disorders solely on the basis of disability rights."
Jason Christopher Roberts, "Customizing Conception: A Survey Of Pre-implantation Genetic Diagnosis And The Resulting Social, Ethical, And Legal Dilemmas", **Duke L. & Tech. Rev.** 0012, 7/23/ 2002 (http://www.law.duke.edu/journals/dltr/articles/2002dltr0012.html)

Discussion

Is PGD good because it reduces abortions?

Does PGD help eliminate genetic diseases?

Why should other people care if I don't want a disabled child?

Are there real dangers from using PGD to have a child with genes that can help cure a brother or sister?

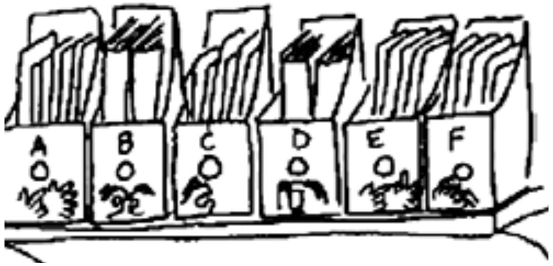
Won't PGD start a process of getting rid of disabled people?

Shouldn't people be free to make their own choice about their pregnancy?

Points you may want to discuss

- PGD is good because it lowers the incidence of abortion on the grounds of impairment.
- PGD gives you the best chance of having a healthy child if there is genetic disease in the family.
- Why should it be anyone else's concern if I have PGD to avoid having a disabled child?
- Are there any real social dangers in allowing PGD to be used to create saviour siblings?
- The development of PGD is the beginning of a process which will lead to the elimination of an increasing number of disabled people
- Everyone should be free to make their own reproductive choices

Stuff to read



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Universal Genetic Test, for more information on this see: https://www.counsyl.com/learn/universal-genetic-test/
Also see: http://www.nytimes.com/2010/01/29/business/29gene.html

Prenatal Screening and Testing

Prenatal Screening and Testing

What are prenatal screening and testing?

- **Screening = testing all pregnant women to see if the foetus may have Down's Syndrome or other conditions.**

- **Testing = testing a particular pregnant woman when screening has shown the foetus may have a specific condition or because of a family history of an illness.**

"It is an act of true moral cowardice to allow children to be born with known genetic defects." James Watson

What are they?

Prenatal screening is carried out on large numbers of pregnant women to check for so-called abnormalities in the foetus.

Screening is done by routine procedures such as ultrasound scanning and a blood test. The latter, called a triple test, measures levels of specific proteins in the blood, raised levels of which indicate an increased chance of Down's Syndrome or neural tube defects such as spina bifida or anencephaly. Screening for other conditions, for example, inherited blood disorders, such as sickle cell diseases and thalassaemia, are also offered to specific populations with a high probability of having these conditions.

Prenatal diagnostic testing, DNA or chromosomal tests, is done when screening has identified a potential problem. Testing can also be undertaken when the family is known to have a genetic marker or predisposition for a certain condition.

Once a couple has the test results they can decide whether or not to have an abortion.

Arguments

Screening and testing are good because they increase choice

The most common diagnostic tests are amniocentesis and chorionic villus sampling (CVS), done to identify Down's Syndrome and neural tube defects. If the test is positive, indicating that the foetus may have an impairment, then women and their partners can decide, after having counselling and the necessary information, whether to continue with the pregnancy. New tests are being introduced which will give earlier diagnoses.

It should be noted that diagnostic tests are not always accurate in predicting the degree of severity of a condition.

What are the arguments?

Screening and testing facilitate reproductive choice

The principal argument in favour of pre-natal screening for various conditions or foetal abnormalities is that it is the first stage of a process for facilitating reproductive choice. Screening provides vital health information so giving prospective parents the option of a diagnostic test and then, depending on the outcome of the test, the choice of whether to continue with the pregnancy.

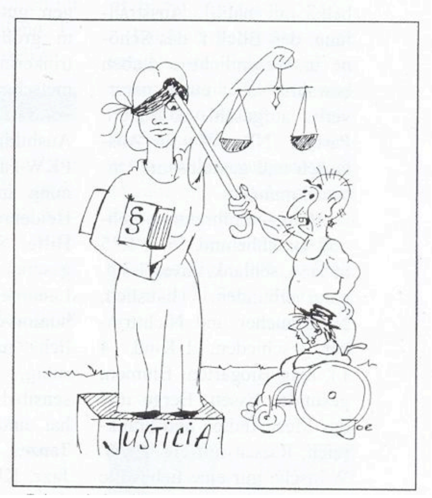
The case for pre-natal diagnostic testing being offered outside screening programmes by families with a known risk of having a child with a

Arguments

Screening and testing are not all that good because they tell us what kind of people are not acceptable in the world.

REJECTED

It is hard to have real free choice about having a baby who might be disabled in a world that discriminates against disabled people.



particular condition, is also one of offering reproductive choice. If it can be determined, families should not be denied vital medical information on which to base their decisions, as being without this information would seriously limit their autonomy. Being free to make informed choices, especially on such personal family issues, is a question of social justice and human rights.

Who should inhabit the world?

The disability right's critique of ante-natal screening and testing starts from a different set of assumptions. For example, rather than focusing on individual reproductive choice, which many support in any case, it sees the official promotion of screening and testing as framing a social understanding of what kind of people should inhabit the world. In other words, hidden in the popular rhetoric of choice a broader eugenic intention is perceived.

"The NDCS does not support the genetic screening of whole populations for genetic conditions, with the consequent risk of moving towards a society in which difference is no longer accepted or tolerated." National Deaf Children's Society (UK) NDCS Policy Statement on Genetics and Deafness, 1999.

Arguments

What does rejecting potential babies because they may have a certain condition tell us about the value of people living with that condition?

A disabled child is born

With thanks to Micheline Mason.

Why do all the people look so sad?
Why is the baby smiling?

Reproductive choices are made in a world in which disabled people are discriminated against in almost every aspect of life. It is a world in which parents of disabled children face continual battles to get the basic needs of their children met. It is a world in which disabled people are seen as little more than their conditions and where the rich complexity of their humanity often goes unrecognised. It is a world in which the medical establishment develops and promotes policies and procedures to screen out embryos and foetuses with certain impairments, thereby offering powerful social confirmation that this is not only acceptable but a desirable thing to do. It is a world that does all this in the name of promoting choice while ignoring the nature of the social space created in which that choice takes place. Given this background, it is not obvious how much real choice is actually taking place, irrespective of the information provided.

Finally, indicating that the lives of some embryos or foetuses will not be worth living suggests that individuals who are already living with similar conditions are of lesser worth, so implicitly stigmatising them and their families.

Quotes

"…prenatal testing and 'therapeutic abortion are based on prejudice against disabled people… the availability of such procedures does not increase reproductive choice. It limits that choice."

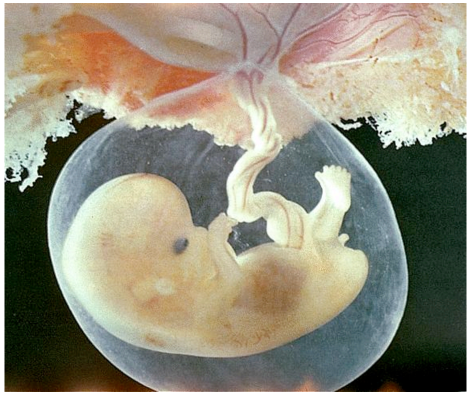
"We unequivocally support women's right to choose with respect to their pregnancies, for such decisions are made in circumstances unique to each person. However, women must also feel able to continue with a pregnancy, secure in the knowledge that they will be bringing a child into a society which does not discriminate against disabled people. This is because we reject the current framework of prejudice against and fear of disabled people, which the new genetics has considerably exacerbated, and which at the moment works such a powerfully negative influence on women's choice.

We assert that to the extent that prenatal testing and "therapeutic abortion" are informed by prejudice against disabled people, the availability of such procedures does not increase reproductive choice. It limits that choice."

BCODP Official Position on New Genetics 2000
(See Appendix 2)

Quotes

"New test will soon be offered. This will allow people to make better decisions about their pregnancy."



"Tests help families not to have a disabled child and save money for society."

"With better knowledge of the genetics of various diseases and a larger capacity of genetic technology, genetic screening at an early stage for an increasing number of medical disorders is possible. Justifications offered in support of genetic screening include early diagnosis and treatment and reproductive decisions." European Society of Human Genetics Public and Professional Policy Committee, **Population Genetic Screening Programmes: Principles, Techniques, Practices, and Policies** http://www.eshg.org/PPPC.htm

"Genetic testing can enable the avoidance of damaging psychological effects to the parents of having a seriously disabled child, which can be manifested as feelings of guilt and misplaced responsibility, as well as the considerable burdens associated with caring for such a child, especially when life expectancy is very limited and of negligible quality. The savings to society can be immense in terms of financial costs and depletion of scare resources related to the education, health care and community support of the disabled."

Janice Wood-Harper and John Harris, "Ethics of human genome analysis: some virtues and vices", in Theresa Marteau and Martin Richards, (eds.), **The trouble helix. Social and psychological implications of the new human genetics**, 1996, p.281.

Quotes

“Without suggesting there should be restrictions on abortion, it is legitimate for disability activists to question the general public consensus that fetal disability is one of the "best" reasons for abortion - right up there with rape or incest and what right-to lifers call "hard cases." It is not inevitable that prenatal diagnosis must change a wanted future baby into a "defective" fetus about which a decision must be made. As Adrienne Asch, a professor at Wellesley College has written, "..suppose down’s syndrome, cystic fibrosis or spina bifida were depicted not as an incalculable, irreparable tragedy but as a fact of being human? Would we abort because of those conditions or seek to limit their adverse impact on life?"

Lisa Blumberg, “The Bad Baby Blues. Reproductive Technology & the Threat to Diversity,” **Ragged Edge**, July/August, 1998 (http://www.raggededgemagazine.com/0798/a798ft1.htm)

“…It is legitimate for disability activists to question the idea that fetal disability is one of the ‘best’ reasons for abortion…”

Quotes

"It was not her handicaps which created the Hell in my life. All she created was love and joy. It was the society we lived in which handicapped us."

For the four-and-a-half years of her brief life I was proud to be the father of a beautiful but massively handicapped little girl. She was blind, incontinent, incapable of speech or verbal comprehension, and totally dependent upon others. She never knew my name, but she came to know my grip, my touch and my voice and loved me as she never loved another.

The hardships devolving from her care cannot adequately be described but are perhaps best summed up in that one long, terrible night when I started, semi-conscious, from my bed convinced that I was dead — that I had been for years, and that I was in Hell. Could screening have prevented her birth I would have been spared a great deal. But I would have missed and lost far more. I wish she was with me still, and were I presented with the prospect of another identical child I would not hesitate to fight again for the preservation of its precious life. It was not her handicaps which created the Hell in my life. All she created was love and joy. It was the society we lived in which handicapped us. It was a parsimonious State and the prejudices of the short-sighted. It was the meagreness of benefits, the inefficiencies of over-stretched hospitals and the lack of adequate respite care. It was people who prayed from help on their knees but delivered none on their feet. It was the sanctimonious mewling of middle-class advocates of abortion for handicapped foetuses and all those other inadequates who saw handicap solely as a problem to be solved rather than a challenge to be met. Letter in **The Guardian**, September 1999

Quotes

"I regret situations where pregnancies are terminated because of inaccurate or prejudiced information about what it is like to be disabled."

"What worries me most, however, are not the views of doctors, researchers or philosophers, or even policy-makers, but the views of ordinary men and women making reproductive decisions. While I support a woman's right to choose, I regret situations where pregnancies are terminated because of inaccurate or prejudiced information about what it is like to be disabled. If 'experts' cannot be relied upon to understand disability, then it could be hypothesised that the 'public' may be equally ignorant or prejudiced. Moreover, if the public read or hear the pronouncements of 'experts' in the media, or if they encounter 'experts' in the consulting room, then they may be influenced to end pregnancy because of these ideologies about the quality of life of disabled people. There is of course heartening evidence that many of the 'general public' are rather more accepting of impairment, and resistant of screening ideologies, than their professional advisors, perhaps because in the real world there is more familiarity with and acceptance of disability, or more important things to worry about. We hear a lot about public understanding of science. An equally urgent task is to improve scientists' understanding of the public."

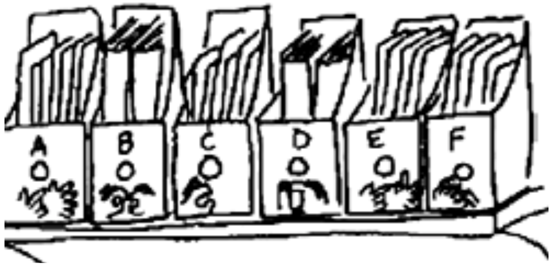
Tom Shakespeare, "The danger of disability prejudice", **The Gene CRC website**. http://www.genecrc.org/site/hi/hi3.htm

Discussion

Points you may want to discuss

- Is prenatal screening about a woman's right to choose?
- Should women be obliged to give birth to a disabled child?
- Families need to make reproductive decisions on the basis of their own needs and preferences not because it might upset disabled people.
- Down's screening is a eugenic policy clothed in the language of choice.
- It is not ethical to give birth to a disabled child, especially one who will have a brief and painful life.
- Screening is reassuring – you can find out that all is normal
- Pre-natal screening discriminates against and devalues the lives of disabled people?
- Should right to life decisions be based on a single characteristic such as impairment? Disabled people are people first.

Stuff to read



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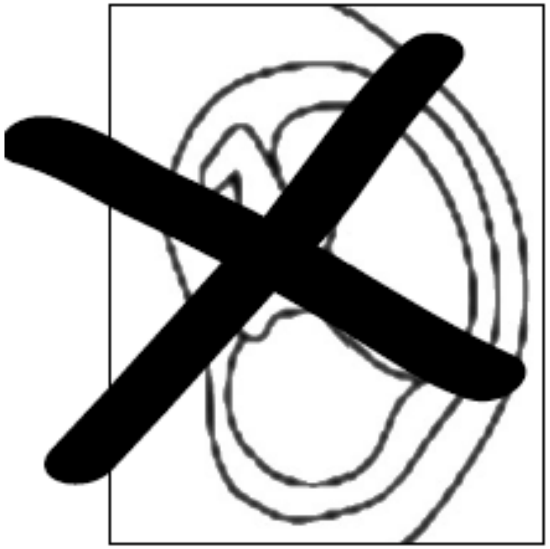
Late Abortion

In the UK you can only have an abortion after 24 weeks if:

1. **The baby may be ‘severely handicapped’**

Or

2. **The mother’s life is in danger**



Late Abortion

What is it?

Late abortion in the UK is defined in law as that which takes place after 24 weeks.

Abortion was legalised in 1967. The law was amended in 1990. In most cases, and with the agreement of two doctors, a foetus can be aborted up to 24 weeks. After this abortion is allowed only where the mother’s life is in danger or her health could suffer “grave permanent injury” or where the foetus is thought to be “severely handicapped”.

The Royal College of Obstetricians and Gynaecologists say (1996) that while it is not possible to offer a clear view on what ‘severe handicap’ is, they refer clinicians to section 3 (Assisted performance) and section 4 (Dependent performance) of the 1980 World Health Organisation classification.

“**Assisted performance**. …the individual can perform the activity or sustain the behaviour, whether augmented by aids or not, only with some assistance from another person.”

“**Dependent performance**. …the individual can perform the activity or sustain the behaviour, but only when some one is with him most of the time.”

WHO, International Classification of Impairments, Disabilities and Handicaps 1980.

Arguments

What are the arguments?

Women should not have to give birth to a disabled child

- **Women should have control over their pregnancy**
- **Women should not be forced to have a disabled child.**
- **Unborn children have no human rights.**
- **There are very few late abortions.**

There are a wide range of arguments in favour of abortion and late abortion. The primary one is that women should have an absolute right to control their reproductive life. For a number of psychological, social and economic reasons, women should not be compelled to have a child that is severely disabled. Underpinning both arguments is the contention that foetuses have no moral status because while human, they are not persons. Only persons are entitled to human rights. This approach, favoured particularly by Utilitarians, defines a person as a being with self- awareness (see below Moral Status of Foetus).

Sometimes after 24 weeks a condition is discovered which will cause the baby to die before term or very soon after birth. If the baby is non viable, it seems cruel to insist on the mother continuing to term and giving birth to a dying child, or continue until the baby dies, and then be delivered of a dead child. Some parents might prefer this 'natural' way, but others wish to avoid it, hence some late abortions.

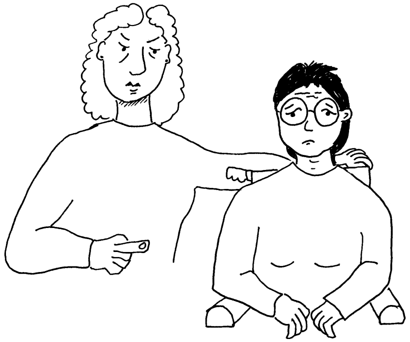
In any case, between 1998 and 2008, the number of abortions after 20 weeks has remained between only 1%-2% of all abortions.

Arguments

The current law and the guidelines on what is a 'severe handicap' discriminates against disabled people

UK abortion law is discriminatory

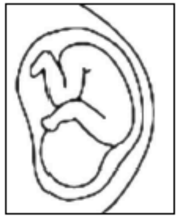
Some within the disability movement share the view that all abortion is unacceptable. However, the movement's agreed position, in line with the idea that the foetus has moral worth because of its potential, is that the current abortion law is discriminatory. Being devalued in a legal setting reflects how people judge moral worth and so it seems that disabled foetuses are worth less than non-disabled foetuses. A clear message is being sent out that it would be better if the birth of disabled people could be avoided. This is made worse by clinical guidelines (given above) on what is "severe handicap", which serve to undermine the dignity and social worth of disabled people.



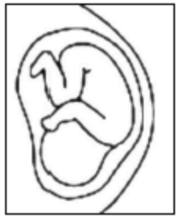
The debate on late abortion raises the vexed question of where one draws the line, and more significantly, if it is right to draw a line between what are acceptable and unacceptable impairments. Some have argued that certain conditions, such as Tay-Sachs disease or anencephaly, which result in a child's early and painful death, should be avoided at all costs. Others contend that once you draw a line that line moves.

Is it right to say what conditions are and are not acceptable?

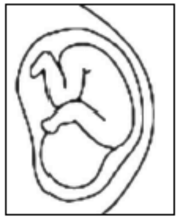
How do we value a baby before it is born?



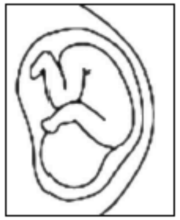
Seen to be as important as an adult or a child



Seen to be important because it will grow into an adult or a child



Seen to be more important the more it grows



Not important as it is not aware of itself

Moral Status of the foetus

The major positions are:*

1. The foetus has the same moral status as a child or adult.
2. The foetus has status because of its potential.
3. The foetus has increasing moral status during pregnancy.
4. The foetus has no moral status because it is not a person. Person being defined as a being with awareness of itself as an entity with a past, present and future, who is able to value his own life.

In position 1 abortion is unacceptable.
In position 2 abortion is acceptable for serious reasons.
In position 3 abortion is acceptable for any reason in the first trimester, for serious reasons during the second trimester and in extreme cases during the third trimester.
In position 4 abortion is always acceptable.

Position three is very similar to the abortion law, apart from two important differences. In theory there is no abortion on demand, while in practice there is in the early stages. Abortion post 24 weeks for foetal abnormality is not acceptable in what is called the “mixed strategy approach.”

Quotes

"Not all human beings are persons, for example, newborn infants and some intellectually disabled humans."

"We need to resist the belief that the value of human life lies in physical perfection."

Quotes:

"There are many beings who are sentient and capable of experiencing pleasure and pain, but are not rational and self-conscious and so not persons. I shall refer to these beings as conscious beings. Many non-human animals almost certainly fall into this category; so must newborn infants and some intellectually disabled humans." Peter Singer, **Practical Ethics**, 2nd ed. 1993, p. 395.

"We need to resist the belief that the value of human life lies in physical perfection." Joanna Jepson

In 2003, Joanna Jepson, an Anglican curate, took the West Mercia chief constable to court, because she said he should have prosecuted the doctor who performed a late abortion on a foetus with a cleft lip in 2001. This was not, she argued "a serious abnormality' under the law.

Quotes

"It is a good thing that the law recognises there is a difference between having a disabled or a non-disabled child."

"These are its positive aspects (of the abortion laws): first, it rests on the idea that fetal abnormality is a legitimate reason for ending a pregnancy. The law recognises that there is a difference between becoming a parent to a child with a disability and becoming a parent to a child without a disability. And a good thing this is, too."
Ellie Lee, "Abortion, Whose Right?", **Spiked**, 9 December 2003.

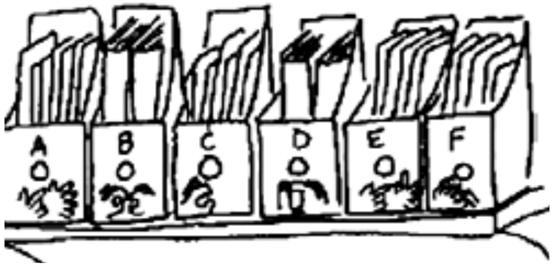
"It is flying in the face of reality to say that lives of disabled people are as worth living as lives of non-disabled people."

"It may still be objected that to replace either a fetus or a newborn infant is wrong because it suggests to disabled people living today that their lives are less worth living than the lives of people who are not disabled. Yet, it is surely flying in the face of reality to deny that, on average, this is so." Peter Singer, **Practical Ethics,** 2nd ed., 1993, p.188

Discussion

	Points you may want to discuss
Why not abort a disabled foetus?	• Why shouldn't you abort a foetus that will be disabled?
Is it responsible to have a disabled child?	• Surely it is not socially responsible to bring a disabled child into the world?
Doctors are the best people to decide on the life chances of a disabled child.	• Doctors who specialize in fetal abnormality are best placed to make judgments on what the condition will mean to the prospective child.
Is there a difference between killing a newborn baby and late abortion?	• Is there a real difference between aborting a foetus at thirty weeks and infanticide?
Everyone should be free to make their own choices about kids.	• Everyone should be free to make their own reproductive choices.
Do women have real choice in a world the discriminates against disabled people?	• Do women really have the freedom to make ante-natal decisions when their choice is limited because of the discriminatory social and economic context in which decisions have to be made?

Stuff to read



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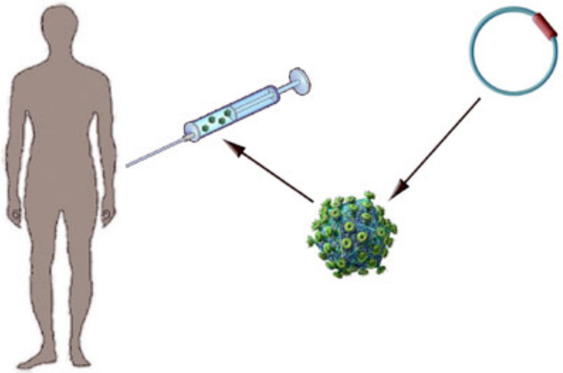


Genetic-based cures: gene therapy & stem cell research

Doctors have used gene therapy to try to repair genes that don't work correctly in order to cure various medical conditions.

So far there has been very little success.

Genetic-based cures: gene therapy & stem cell research

What are they?

Gene therapy

Gene therapy involves making changes to the gene in order to treat a condition. It comprises various techniques for repairing or replacing defective genes implicated in genetic disorders such as muscular dystrophy or cystic fibrosis, or non-hereditary illness such as cancer.

In most cases a working copy of the gene is inserted to replace the abnormal gene. A carrier, known as a vector, is used to take the new gene to the targeted cells, either in the form of genetic-based drug therapy or by using a virus. Once this happens the theory is that the new gene will restore normal functioning. The first gene therapy trials, using viruses to impart the working copy of the gene, were started in the early 1990s and to date (2010), there have been some potentially hopeful experimental results. However, with a couple of minor exceptions, none have led to establishing successful treatments. At the same time there has been one or two known deaths and many serious adverse reactions reported.

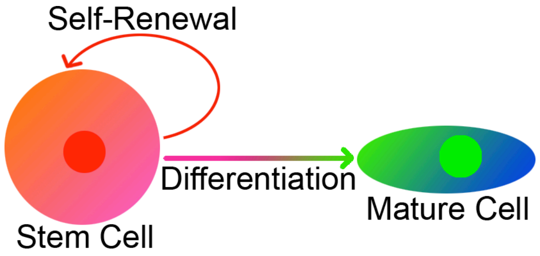
Gene therapy has so far failed for the most part because:

- **Body fights off new genes**
- **Genes don't survive long enough**
- **Most medical conditions involve a combination of genes**

There are two kinds of gene therapy:

- Somatic – alters the individual gene level
- Germ line (or human genetic engineering) – alters all the cells in the body, including the reproductive cells and therefore the effects can be passed on through reproduction.

There are many reasons for the failure of what at first seemed a promising line of research into somatic gene therapy. The body's immune system has put up a formidable barrier, new DNA has tended to be short-lived, there have been difficulties with the vector delivery systems and even single-gene disorders seem to involve more complex gene interaction than first supposed. This has prompted some working in the field to call for a form of gene therapy (germ line as opposed to somatic), which will alter defective genes at the pre-embryo stage and, therefore, pass the new genes on to any children. For ethical and safety reasons such procedures, which would amount to human genetic engineering, have been prohibited.



Stem cells can be changed into any kind of cell

Scientists hope by using stem cells they will be able to cure many medical conditions

Stem-cell research

Stem cells are unspecialised cells that reproduce indefinitely and, using certain techniques, have the capacity to develop into any cell in the body, i.e. new liver cells or lung tissue cells. Work has been done with both human stem cells from early embryos and adult stem cells. These cells not only have different characteristics, but also raise distinct ethical issues. The cloning of embryos to extract stem cells has presented particularly difficult questions about the creation of life for experimental purposes. By using stem cells it is claimed that it will be possible to treat a wide variety of degenerative and chronic diseases, as well as traumatic injuries. Although there has been millions of dollars spent and some promising results, so far (2010) no successful ongoing treatments have been developed.

Arguments

Gene and stem cell therapies will eventually cure all kinds of medical problems from cancer to muscular dystrophy to spinal cord injury

Most illness and injury is caused by the environment, not your genes

What are the arguments?

Genetic based medicine will relieve suffering

The case for both gene therapy and stem cell research are fairly straightforward. Both offer the possibility of much needed cures for those with diseases and illnesses such as stroke, Parkinson's, Alzheimer's disease, multiple sclerosis, spinal cord injury, heart attack, diabetes, osteoporosis, cancers, leukaemia and muscular dystrophy.

If genetic-based cures are the answer, what is the question?

There would seem to be little to argue against. However, there have been objections both from religious and secular groups about the creation of embryos for stem cell research, as this transforms the reproduction of life, with all its social and human significance, into just another production process. There is also the popular determinist message conveyed, that we are our genes. This ignores the fact that the vast majority of illnesses and impairments are created by environmental factors, such as accidents, with genetic endowment playing a minor part or no part at all.

Arguments

Putting money into gene research means less for the immediate support needs of disabled people

Gene therapy has raised hopes for many people but has not delivered cures

Promoting gene therapy has meant presenting disabled people as pitiful charity cases

Genetic-based medicine ignores real needs of disabled people

A disability rights argument rests more on how the 'suffering' of disabled people has been used, much as it has by charities, to take forward a commercial and scientific agenda. To raise funds for the research and get the necessary regulation to carry it out, disabled people have been presented as objects of pity in desperate need of being cured. This in turn reinforces the medical model which views disabled people as little more than their impairments. In doing this it also locates the 'solution' for disability in some distant future while ignoring the more immediate social and economic inequalities which transform impairments into disability.

> "This emphasis on the medical model of disability is further weakening the arguments for funding proper social support for disabled people to live fully and equally in their communities."
> **Disabled People Speak on the New Genetics – DPI Europe, 2000**

Hope? False Promises? Selling Pity?

A good example of this, which might be used by both sides of the debate, was the speech in December 2000, in the House of Commons by Yvette Cooper, Minister of State at the Department of Health. In putting the case for allowing the cloning of embryos for research she said that it was about; " … helping the young father confined by multiple sclerosis to a wheelchair who cannot play football with his son. It is about helping the schoolboy with a broken neck following a rugby injury who will never walk again. It is about helping the 1,500 children and adults with Friedrich's ataxia who cannot speak properly or co-ordinate their arms and legs. It is about helping the thousands of people paralysed by stroke each year, or the patients who die waiting for liver or heart transplants that never materialise."

Quotes

"There is no 'bright side to being disabled"

Quotes

"…seeing the bright side of being handicapped is like praising the virtues of extreme poverty"
James Watson

"It is wrong to say that you can cure disability. Society needs to change so that it accepts disabled people."

"The main discrimination that results from the creation and construction of disability is that various institutions refuse to give up individual models of disability. The very idea of "curing" disability is the core element in the discrimination of disabled people because the "curing ideal" resides in conformity and normalcy. The presupposition of the "curing" ideal makes the removal of disadvantage contingent upon the removal or "overcoming" of impairment: in other words, full participation in society is found through cure or fortitude."
Solveig Magnus Reindal, 'Disability, gene therapy and eugenics - a challenge to John Harris', *Journal of Medical Ethics* 2000; *26*:89-94

"If there were a new pill that would cure them, would wheelchair users refuse it?"

"If disabled people who must use wheelchairs to get around were suddenly offered a miracle drug that would, with no side effects, give them full use of their legs, how many of them would refuse to take it on the grounds that life with a disability is in no way inferior to life without a disability?" Peter Singer, **Practical Ethics**, 2nd ed., pp.51-5

Quotes

"The promotion of gene therapy has led to people being seen as their impairments, not as sons and daughters or fathers and mothers"

We, people living with genetic disorders, are sons and daughters, husbands and wives, father and mothers, lovers and friends. We are not our impairments, although those impairments have influenced many of our life experiences – both good and bad. Just like everyone else in fact.

What we need is for there to be clearer understanding of the nature of the negative attitudes and widespread discrimination which disables us and how the conception behind and the promotion of gene therapy has helped to exacerbate these. What we need is a greater degree of openness and honesty about the gene therapy project. What we need is no more false promises. What we need is to be fully involved in an informed manner in shaping the entire medical research process, including how money is raised and allocated as between clinical and social needs.

Unless these needs are met we will continue to be considered as little more than sufferers, victims, passive and pitiful objects of other peoples' benevolent concern. We will continue to be owned by the medical establishment. We will continue to be done for until we are done for.

This we most definitely do not need.

Bill Albert, "Curing What? Curing When? Curing How? Gene Therapy And Disabled People", in Ralph Levinson and Michael J. Reiss, eds., **Key Issues in Bioethics**, London 2003, pp. 119-120.

Discussion

What is a cure?

Shouldn't people want a cure?

Does looking for a cure mean you don't want to be disabled?

What's wrong with not wanting to be disabled?

Do people with life-long conditions feel different about cures than people who have had an accident or illness?

Points you may want to discuss

- What is a cure? Is it…
    - Getting rid of an impairment entirely?
    - Making an impairment less severe?
    - Reducing the pain or inconvenience of an impairment?

The disability movement says that disability is not about impairment but about the interaction between impairments and barriers to inclusion.

- Does this mean people shouldn't need or want a cure for their impairment?

- Does looking for a cure signify that you do not want to be a disabled person?

- What's wrong with not wanting to be a disabled person?

- Are there different attitudes amongst disabled people towards the idea of cure because of different impairments? For example, would people with Downs Syndrome or achondroplasia have distinct positions on cure as opposed to

Discussion

What is an impairment?

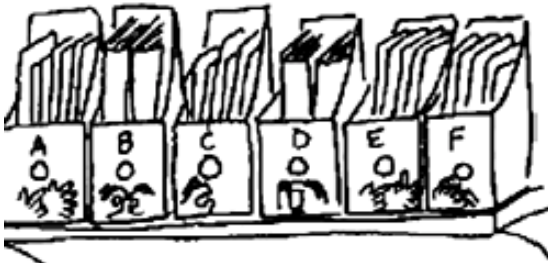
Who decides?

Does looking for a cure mean disabled people are less valued?

someone with MS or a recent spinal injury?

- What is normal and what is an impairment or disorder, and who decides?
- Are impairments diseases? Do they need to be cured or prevented?
- Does searching for a cure demean the lives of individuals presently affected by impairments?

Stuff to read



Coalition for the Advancement of Medical Research (CAMR) Website.
Contains many links to pro-stem cell documents, mainly on debate in US.
http://www.camradvocacy.org/

Darnovsky, Marcy and Newman, Stuart, "Time To Reconsider**?"**
http://www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pageId=67&archive=yes

Harris, J., "Is gene therapy a form of eugenics?", **Bioethics**, no. 7, 1993.
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=retrieve&db=pubmed&list_uids=11651530&dopt=Abstract

Kolehmainen, S., "The Dangerous Promise of Gene Therapy", **GeneWatch**, vol. 13, no.. 2000.
http://www.actionbioscience.org/biotech/kolehmainen.html

Stem Cell Research - Pros And Cons
http://www.experiment-resources.com/stem-cell-pros-and-cons.html

DNR notices
Advance Directives
Access to medical treatment

This section looks at 3 questions about medical care

- **Whether a patient should be revived**
- **Whether a patient should have a particular treatment**

DNR notices
Advance Directives
Access to medical treatment

What are they?

- **Do not resuscitate orders (DNR**) are sometimes attached to a patient's medical chart to indicate there should be no attempt to restart a failed heartbeat or restore breathing by CPR (cardiopulmonary resuscitation). They do not mean “do not treat”. Decisions on whether to issue such a notice must be made in the best interests of the patient with the widest possible consultation among the clinical team, the patient and, if appropriate, the patient’s family. It is the doctor who has the final decision if a patient is unable to consent.

- **Access to medical treatment**, in the context of acute care, is about who makes these decisions and on what grounds. While in most cases such decisions are taken together with the patient and/or the immediate family, in certain instances, for example dementia or severe brain damage, the patient is unable to express a preference. In these circumstances the family should be consulted, but in law the final decision about whether or not to offer or continue treatment, as well as to use a DNR order, remains with the clinicians.

- **How people can tell doctors the care they might want or not want in the future**

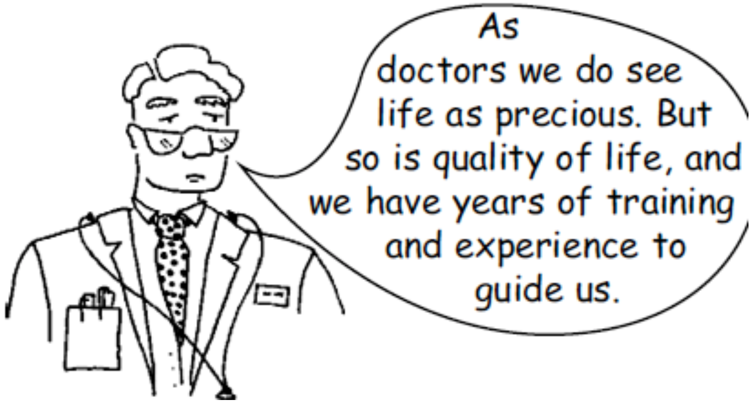
- **Advance directives**, sometimes called **living wills**, are formal documents that let the medical authorities know what procedures a person wants or doesn't want done if they become incapable of making their own decisions. If they are competent at the time of making the directive, with regard to understanding their actions, their wishes not to be treated must be respected, although this does not extend to offering any particular treatment they ask for.

What are the arguments?

Arguments

Doctors know best

The medical establishment supports the use of DNR orders on the basis either that these have been requested by the patient, or because the patient's state of health is so poor that resuscitation would be futile. There are many instances when the latter is the case. For example, only about 5% of cases of CPR result in survival. CPR can cause death to be difficult, painful and traumatic. The same arguments are used for withdrawing medical treatment. The use of advance directives



Arguments

Surely we disabled people are the real experts on the quality of our lives!

offers people a method to avoid having DNR notices imposed or being given unwanted treatment. While patient's wishes are very important, medical professionals are best placed to make the ultimate decisions on the basis of their training and experience, as well as their wider responsibility with respect to allocation of scarce health resources.

Disabled people know best

The use of DNR notices and decisions not to treat, particularly when issued without consent, are problematic and a danger to disabled people because their use is often based on the medical profession's negative assessment of disabled people's quality of life. This is both a principled objection and one based on real experience. For example, until quite recently children with Downs Syndrome were often refused treatment for heart conditions because doctors felt their quality of life was too poor to justify intervention. This is also pertinent to the issue of euthanasia. Parents of other disabled children (see below) have also had to battle for life-saving intervention.

Case studies - things the really happened

Access to medical treatment

Hospital refuses to treat children with Down's Syndrome

While advance directives may appear to be a better alternative for adults, the problem here is that they play on people's fear and ignorance about the reality of living with an impairment. Instead, people should be better informed about social support or palliative care that could be made available.

Case Studies

Access to Medical Treatment – Children with Downs Syndrome

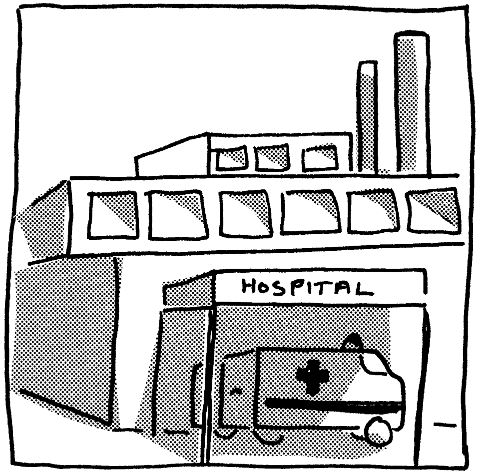
An example of the refusal to treat children with Downs Syndrome was the case of the Royal Brompton Hospital, one of Britain's leading hospitals, which discriminated against children with Down's syndrome because of the belief that operating on them was not worthwhile given their condition.

Parents with Down's children were often told that it would be better not to risk heart surgery, because it would be stressful to look after them until adulthood.

A report of the cardiac surgery department reopens the issue of the medical profession's attitude towards patients and parents of children who are suffering from life-threatening diseases.

Case Studies

Report finds hospital lack of support and lack of resources



It says: 'We accept RBH [Royal Brompton Hospital] doctors may not have been intentionally discriminatory in the way in which treatment was offered to some [Down's] children, but ...We conclude that some doctors, by taking into account non-cardiac concerns and the possible future demands on the family, did not focus sufficiently on what was in the best interests of the child as the patient. As a result the treatment offered was construed by parents as discriminatory.'

The report, which is the result of an enquiry launched in 1999, after complaints were made by families and an independent examination of allegations that the Royal Brompton's death rate in operations on children with Down's syndrome was abnormally high, also condemns the treatment of parents whose children died after heart surgery, claiming they were not ‘adequately supported’, were denied facts about key decisions on their child’s health, and were badly treated when told of children’s deaths. It says the Department of Health did not give the hospitals the resources to deal with the problems they were facing.

http://news.bbc.co.uk/1/hi/health/1255881.stm

Access to Medical Treatment — Child N

The case of Child N is part of a growing controversy over whether patients should control their destiny, and raises some of the most difficult ethical questions in modern medicine. When Nadia’s 11-

Case studies

Family fight for the right to life of their 11-year old daughter

year-old daughter began gasping for breath at home a few weeks ago, she knew the child needed medical help but dared not take her to hospital because she is severely disabled, and Nadia is afraid of doctors concluding that her life is simply not worth saving.

This decision was based on an incident last year when she took her daughter to the Royal London Hospital in East London suffering from a chest infection: when her breathing stopped, Nadia claims she was told it was not worth putting the child on a ventilator to support her breathing and that she should be allowed to die. She says the doctor added that the ventilator would cost more than £1,000 a night.

Eventually the doctors agreed to keep N on an adult ventilator for 48 hours: if she could not then breathe unassisted, the family should let her go. When the consultant's shift finished, the replacement transferred N to Guy's hospital in central London where she was ventilated for two weeks. After three months of treatment, N finally came home: she is now back at a special school The family's solicitor, Richard Stein, argues that the case centres on the basic human right to control one's fate.

Yet many doctors believe the law governing end-of-life decisions is vague for good reason: less flexible rules might not encompass the huge variety of patients with life-threatening conditions.

Are disabled people discriminated against by the NHS? Wilks says 'marginalised' patients could be handled better, but that doctors cannot legally be forced to treat patients against their clinical judgment.

For full article, see Gaby Hinsliff, "Doctors told Nadia to let her child die" , **The Observer** Jan. 4, 2004.
http://observer.guardian.co.uk/uk_news/story/0,6903,1115718,00.html

David Glass's life saved by parents' battle with doctors

David Glass and Mother

DNR
David Glass

David is severely mentally and physically disabled and requires 24-hour attention. In July 1998, when he was 12, he suffered complications after an operation. He was put on a ventilator and doctors told his mother that he was dying and further intensive care would be inappropriate. However, he recovered and was sent home.

Two months later he was readmitted to hospital with a respiratory tract infection. Doctors raised the possibility of using morphine to alleviate his distress but Ms Glass objected, saying she would expect David to be resuscitated if his heart stopped.

Case Studies

European Court of Human Rights said that David's human rights were violated by the doctors

A doctor wrote in his notes: "In the event of total disagreement we should be obliged to go to the courts". A "do not resuscitate" (DNR) order was put in his notes without telling his mother.

David's condition deteriorated and doctors recommended diamorphine, which depresses breathing, to relieve his distress. Ms Glass asked to take David home if he was dying, but a police officer summoned by the doctors advised her that if she attempted to remove him, she would be arrested.
A diamorphine drip was then administered and his condition again deteriorated. His family demanded it be stopped, but a doctor said this was possible only if they agreed not to resuscitate him.

The family then unplugged the drip and resuscitated him themselves, whilst a fight broke out between the family, doctors and police officers. David's condition subsequently improved and he returned home.

Ms Glass took her case to Strasbourg and the European Court of Human Rights ruled that the human rights of a severely disabled boy and his mother were violated when doctors who thought he was dying overrode his mother's objections and gave him diamorphine to ease his death.

The unanimous ruling by seven judges in Strasbourg means that,

Case Studies

except in a clear emergency, doctors should seek high court approval before treating a child against the express wishes of a parent.

The court awarded David Glass, who survived and is now 18, and his mother, Carol, £7,000 in damages and £10,500 in costs for a breach of article 8 of the European convention on human rights, the right to respect for private life.

For full article, see Clare Dyer, "Doctors violated disabled boy's rights", **The Guardian**, March 10, 2004.
http://www.guardian.co.uk/uk_news/story/0,3604,1165989,00.html

Jane's story: "If any of your organs were to fail, you wouldn't want us to resuscitate you, would you?"

DRN – Jane Campbell

In 2003, the Disability Rights Commission (DRC), said that one of its own commissioners, the disabled social care expert Jane Campbell, complained of alarming treatment when hospitalised with a serious illness.

'Jane was asked, by two different doctors, "If any of your organs were to fail, you wouldn't want us to resuscitate you, would you?" 'The reason given was that she would need to be on a ventilator and the assumption was being made that somehow death would be preferable to living with a significant impairment.'
For full article, see Campbell, J., "Choose life", **The Guardian**, Aug. 26, 2003.
http://www.guardian.co.uk/comment/story/0,3604,1029148,00.html

Case Studies

Hospital uses fear of being disabled to get older people to sign living wills

Living Wills

The Hammersmith Hospital Trust is planning to ask older people to write a 'living will' which would inform doctors when to stop medical treatment should their health deteriorate. However doctors intend persuading people to sign such a document by playing on people's negative assumptions about impairment. People will be asked to imagine their life if they had cancer, advanced dementia, were doubly incontinent or 'confined' to a wheelchair.

What is alarming is that yet again the medical profession have deemed themselves 'the experts' in deciding what is an acceptable or unacceptable quality of life. Indeed the doctors will almost certainly fail to mention what support statutory agencies can make available should the individual decide to ignore the 'living will' option.

The decision to introduce this policy was taken after a survey, funded by the hospital trust, showed that older people would rather not have their lives prolonged by medical treatment if they were terminally ill. Instead they would rather be "kept warm, comfortable and free from pain". However, the reality of ceasing medical treatment, which since a recent court decision includes food and water, can mean a slow and painful death.
"UK Hospital's new policy puts pressure on people to refuse treatment", **Disability Tribune**, March 2003.
See http://www.bmj.com/content/320/7250/1640.1.full

Quotes	Quotes
"Disabled patients need more protection."	".. disabled patients now need a commitment that their lives are not held cheap when they fall ill. DRC spokesperson Gaby Hinsliff, G., "Doctors told Nadia to let her child die", **The Observer** Jan. 4, 2004. http://observer.guardian.co.uk/uk_news/story/0,6903,1115718,00.html
"People should have more freedom about how and when to die."	'The debate is now shifting towards at least giving autonomy to people in making decisions about the manner and time of their death.' Michael Wilks, chair of BMA ethics committee

“Life and death decisions are a human rights issue not just a medical issue.”

" We need to take decisions away from the side of the hospital bed. Life and death decisions are a human rights issue not just a medical issue. A fuller and more comprehensive picture will be gained in the context of the individual's life within the family or wider community.

Richard Parnell, Research Manager, Scope, commenting on the case of David Glass

Discussion

How can doctors get it right? If they stop treating someone very sick, are they playing God, or saving that person from a worse agony?

I can't really think that disabled people are being left to die... is it true?

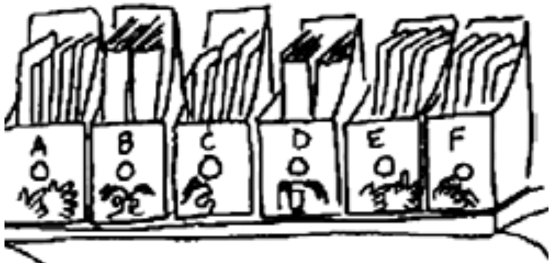
How on earth can you say if someone else's life is worth living?

When I was a teenager I thought 30 was old and past it. Now I'll be glad to live till I'm old. Well, 50 anyway!

Points you may want to discuss

- Why should we upset very ill people by asking them if they want to be resuscitated?
- Some lives are so painful and devoid of quality they are not worth prolonging.
- DNR notices are potentially dangerous for disabled people and should not be allowed.
- Are doctors who decline life-saving treatment to the very sick playing God - or is it more cruel to prolong suffering, for the sake of anguished relatives who cannot let go?
- Are disabled people really being left to die by the NHS?
- How can anyone ever decide whether someone else's life is worth living?

Stuff to read



Anon., “UK Hospital's new policy puts pressure on people to refuse treatment”, **Disability Tribune**, March 2003.
http://www.daa.org.uk/e_tribune/e_2003_03.htm#1

British Medical Association, **Cessation of treatment, non-resuscitation, aiding suicide & euthanasia** , BMA website, 2004.

http://www.bma.org.uk/ap.nsf/Content/6E9702B77042197A80256B6C002D912E?OpenDocument&PreviewStyle=524BD1D1E1C3476A80256E16004A7AE7

Campbell, J., “Choose life”, **The Guardian**, Aug. 26, 2003.
http://www.guardian.co.uk/comment/story/0,3604,1029148,00.html

Dyer, C., “Doctors violated disabled boy's rights”, **The Guardian**, March 10, 2004.
http://www.guardian.co.uk/uk_news/story/0,3604,1165989,00.html

David Glass website,
http://www.members.tripod.com/davidglass1/#%20David's%2017th%20Birthday

Hurst, R., "Assisted Suicide A Briefing Paper", Disability Awareness In Action Website.
http://www.daa.org.uk/assisted_suicide.htm

Euthanasia.com
Information for research on euthanasia, physician-assisted suicide,
living wills, mercy killing
http://www.euthanasia.com/index.html

Hinsliff, G., "Doctors told Nadia to let her child die", **The Observer** Jan. 4, 2004.
http://observer.guardian.co.uk/uk_news/story/0,6903,1115718,00.html

Not Dead Yet, the resistance, Website http://www.notdeadyet.org/

Euthanasia

Euthanasia is killing a person in a painless way

There are many different forms of euthanasia

Euthanasia

What is it?

Euthanasia is the act of intentionally killing a person, painlessly, when this may be construed as beneficial (for example, to relieve suffering) to the person who dies.

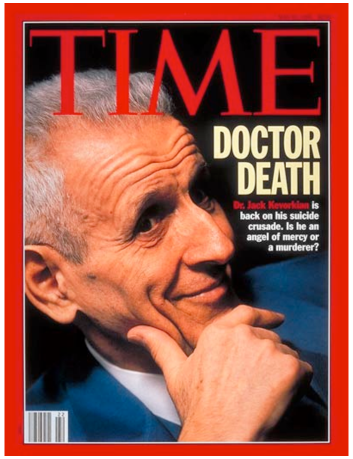
There are different types of euthanasia:

Voluntary euthanasia is at the request of a fully competent person who wishes to die.

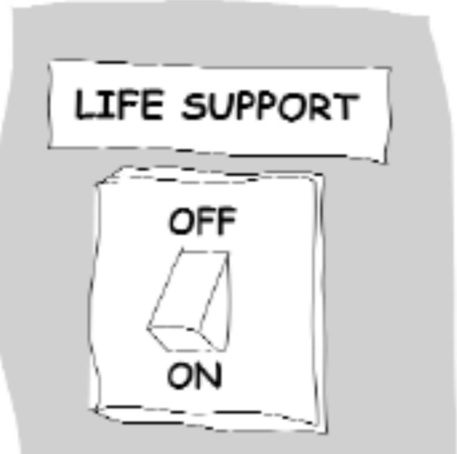
Non-Voluntary euthanasia takes place when a person is unable to consent due to age, physical and/or mental incapacity. An example of this would be the decision to stop artificial feeding and hydration for someone in a Persistent Vegetative State.

Involuntary euthanasia occurs when a dying person could have been but was not asked for their consent, or when a request for continued treatment is refused. Attaching DNR notices to the medical notes of elderly or disabled patients without their knowledge can be considered a form of involuntary euthanasia.

Active euthanasia – meaning to cause death – is illegal in most countries



Passive euthanasia – not giving treatment – is legal



Assisted suicide, which is often considered a form of euthanasia, happens when a person is given the means or the information to kill themselves. A third party is involved but may or may not be present during the act. When a doctor is implicated this is known as "physician assisted suicide." In the US this is most notoriously associated with Dr. Jack Kevorkian, also known as 'Dr. Death'.

Euthanasia can be active or passive,

Active euthanasia describes cases where an action is performed with the intention of causing death. An example of this would be giving a lethal injection. This is currently illegal in the U.K.

Passive euthanasia describes cases where death is intentionally caused by inaction. An example of this would be withdrawing or withholding artificial nutrition or hydration or the use of a ventilator.

There are also times where increasing pain relief such as morphine may shorten a person's life but this is not the intention so is seen as morally different.

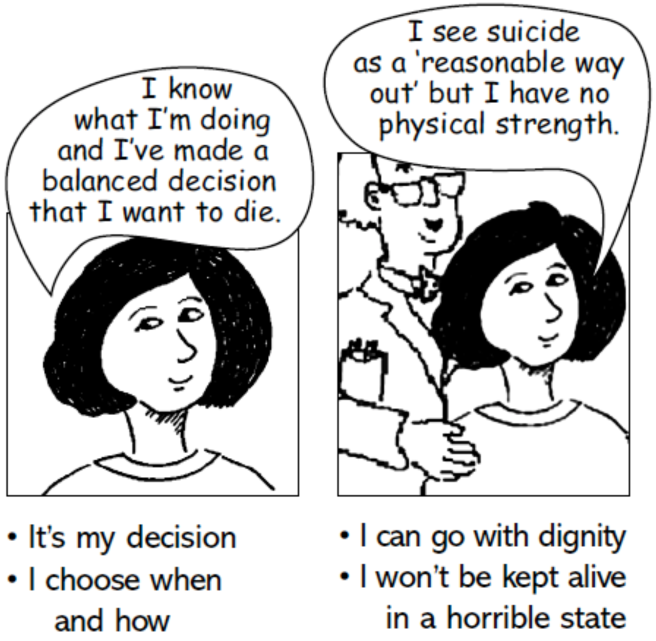
The latter case is an example of the doctrine of double effect. This principle, developed from Catholic moral theology, maintains that an effect that would be morally unacceptable if it came about intentionally would be acceptable if unintended, even if predicted.

Assisted suicide is legal in a few countries and 3 US states.

Arguments

Euthanasia should be made legal

It would give people the choice when and how to die



There are different conditions that have to be met, however assisted suicide (voluntary euthanasia) is (2010) legal in Colombia, the Netherlands, Belgium, Luxembourg, Switzerland and in the US states of Oregon, Washington and Montana.

What are the arguments?

In favour

Pro-euthanasia groups, which include some disabled people, concentrate on voluntary euthanasia and assisted suicide, deeming it a matter of respect for personal autonomy. If someone has an incurable disease or is in great pain they should be afforded the dignity of choosing the manner and time of their death and be assisted if necessary. Furthermore they claim that medical improvements will mean an increasing number of terminally ill people will be kept alive, some against their wishes.

Those who advocate non-voluntary euthanasia, such as Peter Singer, contend that we are in a period when the traditional ideas about the sanctity of life are being overturned by new medical practices which can keep people alive artificially. He argues that in cases such as irreversible brain injury there is a loss of those attributes which make someone a person, such as consciousness, communication, ability to enjoy life and so on. Because of this there is little point in maintaining,

Arguments

Euthanasia should not be made legal

This would disabled people at risk

and every argument for ending, what can be regarded as a life without quality or moral status.

Utilitarians maintain there is no moral difference between killing and allowing to die. If the consequence is death, it does not matter if it is achieved by an act or omission, and it is preferable therefore that the death is brief and painless.

Opposed

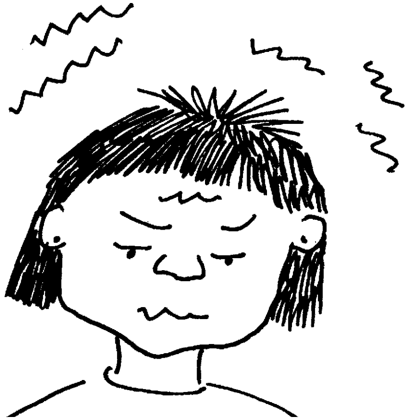
Many arguments against euthanasia start from the proposition, either religious or secular, that all human life has intrinsic value and therefore to take a life in the ordinary course of events is wrong.

Disability rights advocates maintain that if euthanasia or physician assisted suicide was legalised this would put pressure on some disabled people to use them because of a lack of social support, poverty, inadequate health care, social exclusion and internalised oppression. Disabled people are also often more vulnerable than most to undue persuasion and that informed consent would be an illusion. Furthermore, some people who feel they are a 'burden' would be faced with the 'obvious' solution. Overall, the argument is that you should support people to live, not create structures which encourage them to want to die.

Case Studies

A mother in Chicago shot dead her two sons who had Huntington's disease

I have muscular dystrophy and need a lot of assistance. So, do I too deserve a bullet in the head so I will stop being a burden?



Case Studies

'Mercy Killing'

A recent example is the story of Carol Carr, 63, who was charged with two counts of murder last month for shooting to death her two sons, Andy Byron Scott, 41, and Michael Randy Scott, 42. Both men had Huntington's disease and were living in an Atlanta-area nursing home.

The Chicago Tribune published a commentary in defense of Carr's alleged actions. Lewis Whittington wrote of the "nightmarish" existence of living with a "degenerative" disease. And what a parallel living hell it is, he said, to have to be the one who lives with them, who has to bathe them and move their limbs and dispose of their bodily waste.

When he talks about people with degenerative diseases, he's talking about me. I have muscular dystrophy. I need someone every day to help me bathe and move my limbs and dispose of my bodily waste. And when he talks about family members who can't give them the help they need, he's talking about me too. My mother loves me dearly as love her. She would do anything for me. But she's in her

These two brothers did not have enough support

seventies and she just can't do everything I need.

The hell Whittington described is a hell of our own creation. I live in my own condo and a state program pays for people to assist me at home under my direction. My situation is light years away from hopeless. Hope comes in many forms. For me it comes in the form of those who come assist me. Everyone deserves these options that bring hope, whether it's pain management or technology that facilitates communication or whatever.

But it makes me wonder how we ever reached the level of enlightenment necessary to create such programs when we are still capable of treating people like the Scott brothers with such profound contempt. When they need help, we shrug and say it's a family responsibility. When it's too much for the family, we offer no alternatives but surrender to a nursing home or death. No wonder they perceive themselves as hopeless.

How can we call this 'mercy killing'?

Why is it that ???

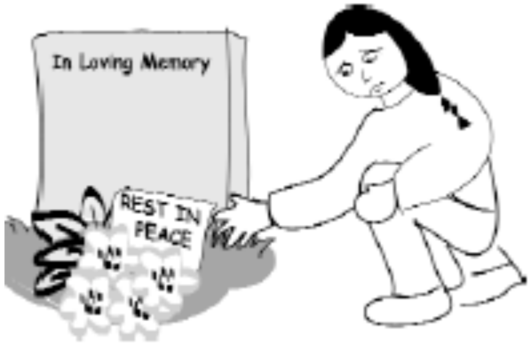
- **Killing a non-disabled person intentionally is always murder**
- **Killing a disabled person intentionally can be 'mercy killing'**

And then we mock their memories by dismissing their deaths with the disdainful oxy-moron of mercy killing. We say killing a human being is murder but killing them is something less.

How demoralizing it is to be reminded just how unwelcome people with disabilities still are in our culture. We should use the death of the Scott brothers to dedicate ourselves to creating the kind of supportive society where no one is ever made to feel like a burden.

Case studies

People should be given help to live …



Not help to die

For full article see Mike Ervin, “There's No Such Thing as a Mercy Killing,” **Chicago Sun Times**, July 21, 2002.
http://www.euthanasia.com/notmercy.html

Why not help people to live?

I was born with spinal muscular atrophy, a so-called "terminal" condition. I cannot lift my head from the pillow unaided and I need a ventilator to help me breathe at night. I use a powered wheelchair and have a computer on which I type with one finger. I have a high-powered and fulfilling job as the head of a major national organisation. More importantly, I am fortunate to live in a borough that provides exemplary social care: a 24-hour personal assistant enables me to have an independent life, to be a wife to my husband and a person to my family and friends.

I know that if this care were to end tomorrow my life would be intolerable and I would consider suicide. Without my care package I would have to give up my job and rely on my husband to care for me. Epithets such as "tragic", "burdensome" and even "desperate" are frequently used to describe disabled people's lives, and unless you are extraordinarily strong it's all too easy for disabled people to succumb to this negativity.

Every day in Britain a disabled person is made fully aware that his or her life is contingent, reliant on the goodwill of others; that it is a life placing untold strain and pressure on somebody who was once their husband, daughter or parent but whose character has been eclipsed by their role as a full-time carer; that rather than a fulfilled life, theirs is a life that has become a burden to others.

Such feelings are well-chronicled in research into why people choose to die. Studies in Oregon and Holland, where euthanasia is legal, revealed that a substantial number of people seeking assisted suicide gave "not wanting to be a burden" as the principal reason for seeking death.

Our underfunded and discretionary systems of health and social care, coupled with rampant discrimination, are having fatal consequences for disabled people. But, rather than tackle these issues head on - to choose life, in Irvine Welsh's now famous phrase - the warping effects of our discourse on disability seem to have made death the only humane option.

Local authorities are having to limit the cost of care packages - often to the lower cost of living in residential care. There are wide discrepancies in provision for disabled people with similar needs; where you live and when you joined the queue are the determining factors for the type and quality of support you receive.

In the 21st century, it is still seen as acceptable for disabled people to

Many disabled people say they have chosen euthanasia because they 'don't want to be a burden.'

This Nazi euthanasia poster reads:

"This person suffering from hereditary defects costs the people 60,000 Reich marks during his lifetime. People, this is your money."

be living in institutions against their wishes, to be denied access to basic support to enable them to enjoy a family or social life, and to be guaranteed no more than the bare minimum of services necessary for day-to-day survival.

The arguments for a right to independent living are complex but vital. What level of independence are we trying to achieve, how integrated should it be with other services such as transport and leisure, who should be entitled to it and who should meet the costs? These are questions that society has a moral priority to answer before we take the path of legislating for assisted death.

Disabled people are still fighting for full participation and inclusion in life. We are decades away from a society embracing the quality of our lives as equal to those of non-disabled people. Only when, or if, this is enshrined in law and reflected in every aspect of our lives should we ever begin to consider legislation that assists people to end their lives.

Without our lives being seen as having equal value, any attempt legally to sanction hastening our death will exacerbate a culture that fears incapacity so much that it wants to extinguish it.

For full article see Jane Campbell, “Choose life”, **The Guardian**, Aug. 26, 2003.
http://www.guardian.co.uk/comment/story/0,3604,1029148,00.html

Quotes

“Medicine cannot be both our healer and our killer.”

The disability movement has helped stop legalised euthanasia.”

Quotes

"While the terror of state-sponsored euthanasia may never grip America as it once did Germany, it is possible that the terror of the euthanasia ethic - tolerated by medicine and an indifferent public and practiced by a few physicians - may grip many invisible and vulnerable Americans. Over fifty years ago, German doctors and courts collaborated to identify millions of people who were labeled 'devoid of value'. Some Americans are labeled the same today: members of a racial or ethnic 'underclass', a sidewalk screamer ... an illegal alien ... a nursing home resident with Alzheimer's disease ... an abandoned migrant worker ... or anyone too old or weak or poor to help himself or herself. For two millennia the Hippocratic tradition has stood for the 'sanctity' of human life. We can alleviate the unbearable in life better than ever before. We can do that and not eliminate life itself. As I have said many times, medicine cannot be both our healer and our killer."
C. Everett Koop, M.D. former US Surgeon General
http://www.euthanasia.com/koop.html

“The energetic commitment of the disabled-rights community, more than any other single factor, has thwarted the assisted-suicide movement. Because disability-rights activists are generally politically liberal, distinctly secular in outlook, and often supportive

Quotes

of abortion rights, the media can no longer caricature assisted-suicide opponents as religious busybodies. Moreover, people who would jump head first off a skyscraper if pro-lifers told them not to will listen to the opinions of disability-rights activists with open minds. As a result, some polls now show a sharp drop in the support for legalizing assisted suicide."
Wesley J. Smith "Disabling Assisted Suicide, Why a deadly movement hasn't been contagious", **National Review Online,** Jan. 19, 2004.
http://www.nationalreview.com/comment/smith200401190806.asp

"Decisions about ending a life should be up to each individual."

"Within the scope of the law, decisions about the end of life should rest in the individual's hands. We believe that no government entity should insist on a particular course of death, and that depriving individuals of either choice or dignity in this process is wrong. In addition, our principles maintain that no physician should be culpable for allowing a terminally ill adult to achieve a peaceful, dignified death according to the patient's own informed and stated wishes."
End of Life Choices http://www.endoflifechoices.org/learn/index.jsp

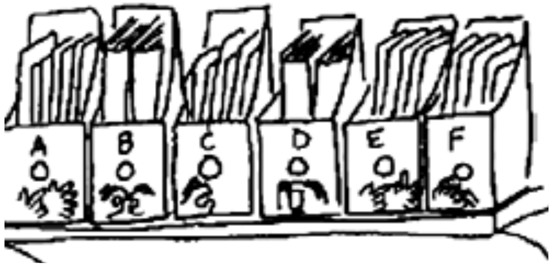
Discussion

Euthanasia – whose human rights?

Points you may want to discuss

- If a competent adult wishes to die, why should we stop them?
- If it is OK to allow someone to die, is it OK to kill them?
- If the consequence is death, it does not matter if it is achieved by an act (active euthanasia) or an omission (passive euthanasia?)
- If you legalise active euthanasia this will increase pressure on disabled people not 'to be a burden'.
- How and when to end one's life is a fundamental human right.
- Legal euthanasia threatens the human rights of disabled people.

Stuff to read



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Appendix 1

More on Bioethics

More on Bioethics

In the 1970s bioethics emerged as a discipline with its own experts, often professional philosophers, to respond to the advances in healthcare. Many hospitals now employ bioethicists to advise on such issues as how to treat terminally ill patients or how to allocate resources. The development of genetic screening, genetic engineering, gene therapy, cloning and other medical practices, have all given rise to profound ethical questions which have become the subject of bioethical enquiry.

For many people it therefore appears that bioethics is the preserve of experts. This is because the discourse of these disciplines tends to be privileged, in effect denying wider access to what are questions of universal concern. This deficit of knowledge has led some disabled people to equate all bio-science with eugenics, while others have seen it as a long-awaited panacea which overrides any ethical problems. But the human rights implications of new developments in bio-science, the ethical and social issues raised for disabled people, makes this an area of key debate.

What are the arguments?

There are a vast array of arguments in and about bioethics, but it is perhaps most useful to consider the competing theories which underpin the subject.

The two most influential theories in moral philosophy, of which bioethics is a branch, are **Deontology and Utilitarianism.**

- Deontology is a duty-based ethics, concerned with the inherent rightness of actions, rather than stressing the consequences. A Deontologist would, after rational reflection, know his duty and therefore the correct thing to do.

- Utilitarianism focuses on the best outcome for the majority, based on their desires or preferences. For utilitarians, the consequences of an action are of primary concern. A Utilitarian has to balance the wishes of all affected by a possible action and plan for the best possible outcome. "…the greatest good for the greatest number.." (JS Mill)

To give an example of how the theories differ, we can examine a critical moral issue.

> At the end of the Second World War, the Americans dropped atom bombs on Nagasaki and Hiroshima. A Deontologist would state that this was wrong due to the loss of innocent life. In utilitarian terms though, the loss of life can be justified because more lives were saved overall as the war ended sooner than it would have without this action.

There are shortcomings in both theories. For a Deontologist, doing one's duty may result in grievous consequences. For example, always telling the truth may mean telling a potential murderer where his quarry is hiding. Duties in any given situation may also be in conflict, making any action problematic.

Utilitarianism on the other hand can lead to the sacrifice of individuals for the greater good. For example, spending health resources in such a way as to maximise numbers of people treated means that those needing expensive treatment may lose out.

Four principles of bioethics

What is often seen as a more practical approach to bioethics, and sometimes known as Principlism, is enshrined in four moral principles.

- Autonomy
- Justice
- Beneficence (doing good)
- Non-maleficence (doing no harm).

These were first proposed in the United States in the1970s and have become widely used as guidelines for making clinical decisions. However, because in practice the principles often clash with each other and there is no hierarchy among them, they don't in themselves provide a simple decision-making formula.

For example, how does one balance the principles of beneficence and non-maleficence towards, and justice for, an unborn child against respecting the autonomy of a woman who wants an abortion?

Virtue Theory

While utilitarianism and deontology, as well as the four principles, may be seen as action-based approaches to ethics, virtue theory stresses that it is the character of the person performing the action which is important. This approach to ethics has its roots in the work of Aristotle, but was re-introduced in the 1950's. Generally, virtue ethicists believe that traditional moral theories fail to acknowledge the importance of the role of inner character traits in ethical decision-making. When deciding what to do, they believe we should look at what the virtuous person would do and strive for maximal decency in all our actions. The main criticism is that it does not help you to decide, because there is no obvious outcome.

> For example, a 14 year old girl, frightened as a result of rape, might very well think that abortion is the right thing to do in that circumstance and nobody should judge her harshly. However, an older person, who, as a result of a loving relationship, accidentally gets pregnant should examine their conscience more rigorously to see whether it is the right thing to do.

As can be seen, the philosophical approaches which inform bioethics are extremely diverse, making it virtually impossible for there to be any definitive answers to the many contentious issues under consideration. To make matters more difficult each approach has been fragmented, with significantly different subsets of assumptions.

It should also be noted, despite the high public profile of some bioethicists, in general they have not had a great deal of influence on health-care decision making. The power ultimately lies with doctors and those in charge of health care budgets.

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Appendix 2

The New Genetics and Disabled People

The New Genetics and Disabled People
The International Sub-Committee of BCODP

The following document was originally produced for consultation and discussion and was approved by BCODP's National Council in February 2000.

Introduction

The issues around clinical genetics and genetic research have given rise to an ethical and moral minefield. However, disabled people can offer an unique perspective which will help everyone chart a way through some dangerous areas of this minefield and out the other side.

As disabled people we know that our lives have a value equal to anyone's. We know that although our impairments may cause us pain or discomfort, what really disables us as members of society is a socio-cultural system which does not recognise our right to genuinely equal treatment.

Facing discrimination is part of our daily lives. We are routinely denied access to transport, mainstream education, employment, information and services. We are routinely patronised, segregated and pushed to the margins of society. This kind of discrimination has led to poverty for the majority of disabled people. We have in this way become the subjects of charity, the objects of other people's pity, and have to fight continually to be recognised as the legitimate subjects of our own lives.

One key reason for this is that society continues to see disability as essentially a medical problem. This is where the new genetics enters stage Right or stage Left, brashly proclaiming its promise of a medical solution for disability. This is very much in line with trends in medicine generally which have narrowed the focus onto the pathology of disease and away form considerations of the broader social experience of illness. Prenatal genetic testing can be seen as the logical extension of this process - the simple equation of disability with genetic "abnormality."

The first thing to recognise, however, is that over 80% of disabled people are not born with their impairment but acquire it. Of those who have an impairment at birth, many of these are not genetically determined. Therefore, even if the threatening promise or the promised threat of a final genetic solution was delivered, disabled people would still be around. As DAN would say, "Get used to it!"

So what are the issues for disabled people posed by recent developments in genetics (screening, testing, gene therapy, cloning, etc.)? Are we on the verge or in the middle of a new, more subtle eugenic offensive which publicly speaks the liberating language of improved health while privately maintaining the more sinister ideal of "improving the human race?"

Does prenatal, or even post-natal, genetic testing or screening foster intolerance against disabled people? If we oppose it will this foster even greater intolerance? Will we be accused of special pleading? ("They would say that, poor things.") Or should we perhaps adopt suggestions that testing should be available only for conditions which result in death in childhood and/or lives characterised by pain and suffering? Of course, this begs the questions of who decides what level of pain and suffering is too high or what is the value of a child (only to become an adult?). There is also the question of how we would go about getting this kind of policy change in a field being driven by a public fear of impairment, the rationing of health care as well as considerations of profit and market share for those developing the genetic tests.

Within the disabled peoples' movement we need to recognise that the moral, ethical and political tangles all this raises are frighteningly complex. We need also to understand that because of this there are likely to be differing and strongly held views among disabled people and these need to be given respect and space within the debate. Therefore, while not everyone will agree with the arguments made in this paper, it is hoped that it will serve as a focus for a constructive dialogue on the road to arriving at an effective and workable consensus on the new genetics for the disabled peoples' movement.

Eugenics

The now widely discredited "science" of Eugenics was founded by Francis Galton, who first used the word in 1883. It comes from the Greek root meaning "good in birth" and to quote Daniel Kevles, "He intended it to denote the "science" of improving human stock by giving 'more suitable races or strains of blood a better chance of prevailing speedily over the less suitable." Eugenics grew out of Darwin's ideas on evolution (Galton was Darwin's cousin) and also partook strongly of the positivist philosophy of the time, which argued, very roughly, that science had the answers for all society's ills. Eugenics was a way that people could scientifically assist a more desirable evolution of their own species. "Desirable" being understood, for example, as similar to middle-class intellectuals, say like Francis Galton.

Clearly, eugenics, then and in all its subsequent guises, has always been a socio-political and cultural ideology which has tried to clothe itself in supposed scientific objectivity. Although science itself is invariably informed by wider social concerns, it should be obvious that which type of people and what traits in people are desirable poses blatantly ideological, not scientific questions.

Sterilisation of "undesirables", a policy which gained widespread support from the late 19th century, was based directly on eugenic ideas about racial (human race) improvement. It was widely practised, particularly in the US, where it became the model upon which in the 1930s the Nazis were to develop their programme for sterilising, which from 1939 developed into the systematic killing of disabled people. In the name of "mercy killing", 100,000 disabled people had been murdered by 1941. This paved the way for Final Solution to the "problem of inferior races" - the mass murder of 12 million Jews, Gypsies, lesbians, gay men and others - which finally exposed the fatal logic of eugenics. Nonetheless, forced sterilisation of people in mental institutions continued into the 1970s in the US and elsewhere, and eugenically-inspired laws relating to marriage and sterilisation continue to exist in many American states.

A Modern Eugenics?

Despite its unsavoury heritage, the eugenics ideal survives. It has changed its costume, but the song is still the same. Class or race, at least for all but the most extreme, is no longer at issue. The biological quality of human populations has now become the target, as advances in genetic engineering seem to hold out the prospect of moving us all closer to Galton's ideal of being "good in birth."

But genetics is not in the least eugenic, say proponents of the new genetics. For example, Hughes writes, "While the biological factors in most forms of inequality are probably slight, genetic technology does promise to create a more equal society in a very basic way: by eliminating congenital sources of illness and disability that create the most intractable forms of inequality in society. We can go to great lengths to give the ill and disabled full access to society, but their disabilities place basic limits on how equal their social participation and power can be." Isn't it desirable, he asks, to rid humanity of disease and impairments? Do we want our children born with muscular dystrophy or cystic fibrosis? If these and other conditions can be prevented with the help of clinical genetic intervention what could possibly be the problem?

There are, of course, a host of ethical issues to consider, but the central fact is that there are still no cures and gene therapy remains a distant prospect. Another key problem that has to be addressed is the way in which a genetic "abnormality" relates to a disease. Except in a few instances, there is never a clear one-to-one relationship and environmental factors always have to be considered.

Although most geneticists would maintain that eugenic excesses were an aberration and not really connected to the science of genetics, David King argues that not only are the histories of genetics and eugenics inseparable, but that there are also powerful eugenic assumptions underpinning current genetic research and clinical practice. He quotes a 1994-5 study of 37 countries by Dorothy Wertz and John Fletcher which found that outside Northern Europe the vast majority of genetic counsellors hold overtly eugenic views and directed their patients accordingly. This seems to confirm McGee's observation that as early eugenicists spoke of improving the gene "pool", at the present time, "Genetic tests are allowing clinicians to play the role of lifeguards." It is also quite clear who they are encouraging to drown.

King further maintains that the danger of a eugenic resurgence, at least in the West, will not come through state coercion but will be more subtly wrapped in the lassez faire cloak of consumer choice. "The danger we will need to guard against," writes King, "is the development of a kind of eugenic common sense, that it is irresponsible to refuse to undergo tests, and that every child has the 'right' to a healthy genetic endowment. ... We will need to be vigilant for eugenics disguised as public health measures."

Abortion = Eugenics?

The major problem caused by the new genetics is that despite the popular conception that genetic treatment is providing cures, there are virtually no new therapies for the vast majority of genetically-identified conditions. Because of this, at the moment, prenatal genetic testing or screening leads not to the elimination of an impairment but can and often does lead (through abortion) to the elimination of a foetus.

Does this kind of selective abortion amount to an attempt to get rid of disabled people? Is it a form of eugenics? If we take this position are we then saying that an embryo or foetus is a potential person with all the rights to protection that this entails? If we are, does this put us in the Right to Life camp and at odds with the idea that a woman should have a right to choose with respect to her pregnancy?

This is how the argument over testing and abortion is generally framed, but to engage with it on these terms is to accept the basic premise that women actually have free choice. As we know, choice is heavily circumscribed by cultural, social and economic pressures and these are powerfully against a woman choosing to continue with a pregnancy after "an abnormality" has been detected. The British abortion laws enshrine this prejudice by not allowing termination after 24 weeks unless a likely problem has been discovered.

We also need to remember that it was in the 1970s that legalised abortion and the development of amniocentesis came together to stimulate an increase in the detection of prenatal genetic conditions. It was pointed out at the time that a society which allows abortion on demand is not likely to question the abortion of a foetus with a genetic difference. This has proved to be the case, with growing public support, at least for genetic screening. The social acceptance for aborting "problemed" foetuses is deep rooted and provides a tough challenge for the disabled peoples' movement.

Brave New World?

Besides the question of prenatal testing and abortion, there is also the broader question of the possibility of "making" instead of "having" children; realising a genetic/eugenic ideal - the perfect person - through screening and/or more invasive genetic engineering. Hughes has even looked forward to parents being able to choose their children's characteristics from a gene catalogue. However, assuming state direction (either through compulsion or incentives), not only would some form of increased genetic homogeneity be problematic, but as the old adage has it, you can't make angels until you know the specifications of heaven. It is within these god-like realms that the Human Genome Project's promise of unlocking the key to human life by complete genetic mapping invites an eugenic interpretation. reference 20 After all, how else are we to decipher the idea of an assumed genetic norm except as one which unifies the outlines of heaven and the image of its angels?

Further to the above point, Jonathan Beckwith, a professor of microbiology and genetics writing in 1974 about genetic screening laws in the US (which he argued represented the beginnings of a new eugenics program) warned:

- "Who will exercise control?
- Who will make the decisions about which genes are defective, and which behaviour abnormal?
- Who will make the decisions about the genetic worth of prospective human beings?"

While we may object to such decisions being made at all, it has been happening in health services informally for years. Furthermore, as Glenn McGee has observed in the near future, "Virtually every culture will have to cope with an unparalleled pressure to conserve social resources by applying pressure to individuals in an attempt to modify their reproductive behavior and other life choices." Other "life choices" are likely to include death, as euthanasia becomes a "choice" for elderly or disabled people whose quality of life is deemed socially insupportable - both personally (people being made to feel they are a burden) and in terms of resources.

Is It All In The Genes?

Another problem which arises from the renewed belief in the power of genetics to provide answers (much in the way the 19th century positivists saw science in general as all powerful) is that there is a real danger of geneticisation wherein human qualities are reduced to a simple function of genetic codes. The complex relationships between people and the environment are ignored and all talk is of genetic predisposition to this or to that. "Geneticization builds upon medicalization, whereby people come to perceive the body in conformity with biomedical categories." This has an all too familiar resonance for disabled people.

As Hughes comments demonstrate, the rise of genetic essentialism (or determinism) may cause people to lose sight or never even gain the understanding of the social, economic, cultural and political bases of disability. This may not seem such a serious problem in countries like Britain where the movement is strong and has started to convince governments to accept, at least in part, the social model. However, we should not be complacent nor minimise the potential risks to disabled people here or in other Western countries. reference 25 Furthermore, in parts of the world where the movement is weak and the social model all but unknown the idea that genetics holds the solution for the "problem of disability" might well unleash nakedly eugenic policies of forced screenings and abortions and perhaps compulsory sterilisation and/or euthanasia. The first two have already happened in China, reference 26 where since July 1996 pre-natal testing has been made compulsory as has the abortion of any "abnormal" foetus.

This leads on to perhaps the most worrying feature of the new genetics. Even if we accept at face value the anti-eugenic statements of its proponents, the new genetics is creating a powerful eugenic sword that could be unsheathed at any moment by a government able and willing to forget the lessons of the 1930s. China provides a chilling example of just this kind of forgetfulness and a warning of what can happen. And when the next country follows the Chinese model? And then the next? What practical value then the 'sincere intentions' of genetic researchers?

Are Impairments Desirable?

Finally, if we embrace the social model of disability and accept that it is not our impairments that disable us but society, should we be overly concerned about the elimination of impairments in any case (at least when it doesn't involve abortion)? Aren't we always saying that we are not "the epileptics" but people with epilepsy - that, in short, we are not our impairments? Are we, for example, against polio vaccine? Has it diminished the value of people who have had polio? Are we proud of our impairments or proud of being disabled people or proud of being ourselves? Can we usefully separate the two things? When is medical intervention acceptable? Only after we are born? When it doesn't mess with our impairments? Does medical intervention (including gene therapy if and when it arrives) equate with the medical model of disability?

We need to be clear about how to respond to these questions because they are sure to be put to us. In the first place, only on the crudest reading of the social model could it be argued that this model is about rejecting medical treatment or research. The medical model itself is not about medical intervention, but rather the medicalisation of disabled people. This is what we reject. Furthermore, whether or not we oppose the eradication of impairments is not a genuine question, for despite years of hype and billions of pounds, the choice of a cure simply does not exist in most cases. It is a question which is, therefore, mischievously beside the point in the real world where the most urgent issue for disabled people is combating the immediate socio-economic causes of disability. We are also not making a case against medical research, but rather one for a more equitable distribution of effort and resources in order that a real difference can be made now in the lives of disabled people.

Horses and Carts/Tails and Dogs

Perhaps, however, we are starting from the wrong place. Rather than what sort of genetic future we want, we should be asking ourselves what sort of society we want and then directing research accordingly. Would it not be preferable to live in a society which did not strive for some sort of unobtainable, and probably undesirable, genetic perfection but instead sought to preserve diversity and enhance standards of human decency?

As disabled people, we find ourselves in the middle of the genetics minefield. From this precarious position we nonetheless have a unique view of the present and future dangers of the new genetics. We must speak out forcefully and effectively. Our view is far too valuable either to keep to ourselves or squander by adopting a sectarian, fundamentalist approach which plays into the hands of those who want to write off disabled peoples' concerns as little more than posturing, ill-informed Luddism. At the same time, we must avoid being intolerant of differing views within the movement as this does not sit well with the sensitivity and moral complexity of the issues raised by the new genetics or the varied, legitimate concerns of disabled people.

The Official Position Statement On The New Genetics

The following statement was originally a “draft statement” put forward by BCODP but was subsequently adopted by BCODP as the Official Position Statement on the New Genetics.

1. The BCODP, as the representative voice of disabled people's organisations in Britain, is greatly alarmed by many of the recent developments in both genetics research and clinical practice, as well as by the ill-informed presentation of these developments.
2. Popular ideas (and much professional opinion) that genetics will unlock the secrets of life and, among other things, lead to a "cure" for disability, has unleashed a new genetic determinism with strong eugenic

overtones. This constitutes a serious threat to disabled people, for we are not disabled by our genes or our impairments but by societies which actively and passively discriminate against us. Our disability is a socio-political not a medical problem. Therefore, far from helping us, the new genetics and the cultural and political ideology which informs it is threatening to foster a more negative image of disability and is likely to lead to increased discrimination against disabled people.

3. As disabled people who have faced sterilisation, prenatal termination, euthanasia and even wholesale elimination in the name of eugenics we attest to the historic and continued links between genetics and eugenics and the dangers this poses for everyone, not just disabled people. The question of the value of a life is far too important to leave to geneticists.
4. We are not opposed to any medical research or clinical procedures where the goal is treatment of illness or the alleviation of pain.
5. We unequivocally support women's right to choose with respect to their pregnancies, for such decisions are made in circumstances unique to each person. However, women must also feel able to continue with a pregnancy, secure in the knowledge that they will be bringing a child into a society which does not discriminate against disabled people. This is because we reject the current framework of prejudice against and fear of disabled people, which the new genetics has considerably exacerbated, and which at the moment works such a powerfully negative influence on women's choice.
6. We assert that to the extent that prenatal testing and "therapeutic abortion" are informed by prejudice against disabled people, the availability of such procedures does not increase reproductive choice. It limits that choice. **reference 27**
7. We affirm that our lives are not only of equal importance to anyone's but also that as disabled people we offer much that is positive to society, not least by demonstrating the inherent value of life itself. This is a vital corrective to the heartless utilitarianism underlying much of the new genetics, which posits a "less messy" society free from the inconvenience of disabled people.
8. The new genetics not only poses a danger for disabled people. We are just the first in the firing line.

Already insurance companies in Britain are lining up to load the policies of those who have evidence of "genetic predisposition" for heart disease or other illnesses, while multinationals are in the process of patenting human genes, our common heritage.

- They've come for disabled people today.
- Who will they come for tomorrow?
- Those children with the supposed "gay" gene?
- Perhaps those with the "criminal tendency" gene.
- Or those who might be alcoholic or too aggressive
- or not intelligent enough.
- Or maybe only those foetuses who might develop heart disease, cancer, Alzheimer's disease, or other costly ailments.

To insure that disabled people do not face increased discrimination because of the new genetics, the BCODP want to see the following take place:

1. That the BCODP be funded to set up a research/monitoring network on the social implications of the new genetics, separate from the genetics/bio-ethics establishment.
2. That representative and accountable disabled people be on policy making bodies with oversight on the new genetics.
3. That there is an end to the explicit discrimination in the abortion law which allows termination after 24 weeks only if the foetus is diagnosed as having a potential impairment.
4. That disability equality training based on the social model of disability becomes a compulsory part of all medical training as well as required for all practising geneticists, genetic councillors and obstetricians.
5. That there is comprehensive social support for parents who have disabled children.
6. That the BCODP formal contact with organisations in Britain, Europe and internationally who have similar

concerns about the new genetics.

7. That we identify the key political forums in Britain and Europe in which to make the collective voice of disabled people heard on this subject.

Appendix 3

Disabled People Speak on the New Genetics

DPI Europe Position Statement on Bioethics and Human Rights - A project funded by the European Commission

Disabled People Speak on the New Genetics

DPI Europe Position Statement on Bioethics and Human Rights - A project funded by the European Commission

Introduction

"All Human Beings are born free and equal in Dignity and Rights"
Universal Declaration of Human Rights, 1948

Nuclear energy is a source of life and a cause of death. If given an opportunity to express their opinion surely the victims of Nagasaki or Chernobyl would have fought for stricter regulation of the practical use of that new scientific knowledge. The same is true of the revolutionary developments in human genetics. Many disabled people are only alive today because of scientific progress generally and new medical techniques in particular, so of course we wish to promote and sustain such advances where these lead to benefits for everyone. But we want to see research directed at improving the quality of our lives not denying us the opportunity to live.

The genetic goal of the prevention of disease and impairment by the prevention of lives judged not to be "normal" is a threat to human diversity. It is a potential Nagasaki for everyone, not just disabled people. The threat is powerful and imminent.

Human genetics poses a threat to us because while cures and palliatives are promised, what is actually being offered are genetic tests for characteristics perceived as undesirable. This is not about treating illness or impairment but about eliminating or manipulating foetuses which may not be acceptable for a variety of reasons. These technologies are, therefore, opening the door to a new eugenics which directly threatens our human rights.

- We are threatened when M. Rietdijk, a Dutch physician and philosopher, writes: "A baby should be killed whenever some physical or mental defect is discovered before or after birth."

- We are threatened when Peter Singer, a professor of bioethics, writes: "It does not seem quite wise to increase any further draining of limited resources by increasing the number of children with impairments."

- We are threatened when Bob Edwards, a world-famous embryologist, says: "Soon it will be a sin for parents to have a child which carries the heavy burden of genetic disease."

- We are threatened by selection which leads to the discarding of potentially impaired embryos.

- We are threatened by abortion laws which discriminate against the birth of disabled children.

- We are threatened by the promise of genetic manipulation to eliminate all those differences that non-disabled people consider unacceptable.

This has all happened before. It must not be allowed to happen again.

We want to live as active, equal and productive members of society, but our perceived value and role as well as our human rights are continually diminished by the questionable medical ideas and discriminatory attitudes spawned by the new genetics.

How can we live as equal citizens in society which uses negative images of us to justify the raising of funds for charity and research. This amounts to using disabled people as evidence of the need for our own elimination. We are continually being disabled by such images. How can we live with dignity in societies that spend millions on genetic research to eradicate disease and impairment, but refuse to meet our needs to live dignified and independent lives?

We cannot. We will not.

The genetic threat to us is a threat to everyone. The value of life must not be reduced to a matter of genetic inheritance. If that is allowed to happen no potential child will be safe from arbitrary selection, no parents will escape the moral burden of making impossible choices and no one will be safe from genetic discrimination.

"Everyone has a right to respect for their dignity…that dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity"
Universal Declaration on the Human Genome and Human Rights, 1997

Our experience as disabled people places us in a unique position to contribute to a comprehensive ethical discourse leading to scientific development which respects and affirms the essential diversity of humankind.

Maintaining diversity is as essential for humanity as it is for life as a whole. Our lives as disabled people celebrate the positive power of diversity. Our experience enriches society. These are our unique gifts to the world.

For ourselves, for everyone,

We will not go quietly into the genetic night.

Position Statement and Demands

DPI Europe is greatly concerned about the threat posed to our human rights by developments in human genetics research and practice and by the fact that our voice struggles to be heard in the ethical and scientific debates. In general we have been considered as little more than the passive subjects both of these debates and of genetic research. This has been a profoundly disabling experience.

We are also concerned that the new genetics is fostering a biologically reductive vision of the world which not only undermines what it is to be human but also devalues the importance of social factors, relationships, mutual respect and the environment in determining everyone's quality of life.

"My guess is that cells will be programmed with synthetic messages within 25 years….The point that deserves special emphasis is that man may be able to program his own cells long before he will be able to assess adequately the long-term consequences of such alterations, long before he will be able to formulate goals, and long before he can resolve the ethical and moral problems which will be raised."
Marshall Nirenberg, Nobel Laureate, 1967

Disability, according to the World Health Organisation, is the interaction between people with impairments and environmental barriers, including those of patronising attitudes and images. The new human genetics and cultural and political ideologies which underpin it are working directly against this definition and instead fosters the concept of disabled people as being no more than their impairments. This medicalisation of disability leads to increased discrimination against disabled people and lends support to the massive financial commitment to human genetic research at the expense of tackling the disabling physical and social environment. It is the negative results of the interaction with this environment which disables us, not our impairments, whether they be genetic in origin or, as is the case with the vast majority of disabled people, caused by illness, accident or armed conflict.

We stress that disabled people do not oppose medical research where the object is genuine treatment or the alleviation of pain. What we do oppose is genetic cleansing, driven by profit motive and social efficiency, informed by prejudice against disabled people and carried out in the name of cure or treatment.

Disabled people have faced enforced sterilisation, pre-natal termination, infanticide, euthanasia and wholesale elimination. We were left out on the hills of Sparta to die, sterilised by "caring" doctors in the US, Scandinavia and Germany and were the first to be driven into the Nazi gas-chambers. We testify to the historic and continued links between genetics and eugenics. These links pose dangers for everyone, not just disabled people.

With respect to the impact of genetics on reproduction, we support women's right to choose with respect to their pregnancies. However, we deplore the context in which these choices are made.

- There can be no informed choice as long as genetic counselling is directive and misinforms parents about the experience of disability.

- There can be no free choice as long as the myths, fears, stereotypes of and discrimination against disabled people continues.

- There can be no free choice if women are under social pressure to accept routine tests.

- There can be no real choice until women feel able to continue with a pregnancy knowing that they will be bringing their child into a welcoming society that provides comprehensive systems of support.

We are concerned that the law in most countries discriminates against disabled people by allowing termination of pregnancies after a specified time, if the prospective child might be disabled, yet such discrimination is widely outlawed on the grounds of race and gender. This medicalisation of the quality of life diminishes the value of disabled people's lives and those of everyone.

We are deeply alarmed that without proper social and medical support, disabled people are often made to feel a social burden and are under pressure to choose the option of legalised euthanasia.

We repudiate the utilitarian ideology which informs much of the new human genetics, particularly the assumption that society would be better off without the inconvenience and expense of disabled people. In contrast, we want to see all clinical practice based on strong principles of justice, ethics and non-discrimination with a respect for diversity, autonomy and fully informed choice.

"… all people have the right to have been conceived, gestated and born without genetic manipulation…."
Council of Responsible Genetics - Genetic Bill Of Rights - 2000

Demands

Recognising that advances in human genetics and medical-based quality of life decisions raise serious ethical issues for both disabled and non-disabled people, issues which must be considered within the framework of the essential enduring diversity of humankind;

We demand that:

1. the use of new human genetic discoveries, techniques and practices are strictly regulated to avoid discrimination and protect fully, and in all circumstances, the human rights of disabled people,

2. genetic counselling is non-directive, rights based, widely and freely available and reflects the real experience of disability,

3. parents are not formally or informally pressured to take pre-natal tests or undergo "medical" terminations,

4. all children are welcomed into the world and provided with appropriate levels of social, practical and financial support,

5. human diversity is celebrated and not eliminated by discriminatory assessments of quality of life, which may lead to euthanasia, infanticide and death as a result of non-intervention,

6. organisations of disabled people are represented on all advisory and regulatory bodies dealing with human genetics,

7. legislation is amended to bring an end to discrimination on the grounds of impairment as exceptional legal grounds for abortion,

8. there is a comprehensive program of training for all health and social care professionals from a disability equality perspective,

9. as the human genome is the common property of humanity, no patents are allowed on genetic material,

10. the human rights of disabled people who are unable to consent are not violated through medical interventions.

Appendix 4

Glossary

GLOSSARY

Achondroplasia – a genetic condition resulting in shortness of stature

AID: Artificial insemination of a woman using donated eggs. Now more commonly referred to as donor insemination (DI) to avoid confusion with AIDS.

AIH: Artificial insemination (of a woman) using husband's sperm.

AIP: Artificial insemination (of a woman) using her partner's sperm.

Amniocentesis: A procedure usually carried out between 14 and 18 weeks of pregnancy. A needle is inserted into the uterine cavity, and amniotic fluid is withdrawn from the amniotic sac in which the foetus is developing. The fluid and the foetal cells it contains may be tested for chromosomal abnormalities in the foetus, most commonly Downs Syndrome and neural tube defects.

Anencephaly: A defect in brain development resulting in small or missing brain hemispheres. A congenital absence of the brain and cranial vault, with the cerebral hemispheres completely missing or greatly reduced in size.

Assisted Reproductive Technologies (ARTs): The collective name for all techniques used artificially to assist women to carry children, including IVF and ICSI.

Bioethics - a branch of ethics dealing with issues surrounding health care and the biological sciences

Biological Reductionism – the concept of reducing our understanding of ourselves to our biology, to our medical condition alone.

Blastocyst: An embryo that has developed for five to six days after fertilisation

Cell: The basic unit of all living organisms. Complex organisms such as humans are composed of somatic (body) cells and germ line (reproductive) cells.

Chorionic Villus Sampling (CVS): A procedure, usually between 8 and 12 weeks of pregnancy, by which a small amount of the chorionic villi from the placenta is biopsied for genetic analysis.

Chromosome: A threadlike structure of DNA and associated proteins which is found in the nucleus of a cell. Chromosomes carry genetic information in the form of genes. Chromosomes occur in pairs, one inherited from the mother and one from the father. There are 23 pairs of chromosomes in each cell.

Clones: genetically identical individuals, produced by artificial or asexual reproduction

Cloning: The production of two or more genetically identical individuals. This is done by nucleus substitution or by mechanical division of a zygote to yield identical cells each of which can form a new individual. Also known as Cell Nuclear Replacement (CNR).

Complex conditions: Conditions caused by genetic inheritance but where other factors such as environment and lifestyle interact to create the outcome (eg cancer, heart disease)

Congenital malformations: Any malformation which is noticed at birth, whether the result of a genetic (inherited) or environmental cause.

CPR – **Cardio-Pulmonary Resuscitation** – this is emergency life-saving treatment given when a patient stops breathing or when the heart stops. It involves the use of either paddles with an electric current to “kick-start” the heart, manual ventilation (bagging), or the use of adrenaline.

Cystic Fibrosis – a genetically inherited condition which affects the sodium balance of all the cells resulting in sticky mucus which impairs the function of all the body’s organs.

Deontology - a theory of bioethics based on duty. Concerned with the inherent rightness of actions.

DNA (DeoxyriboNucleicAcid): The major constituent of chromosomes, and the hereditary material of all living organisms. Genes are made of DNA sequences.

DNR – **Do Not Resuscitate** – a DNR notice is sometimes given to patients in hospital. It means that emergency life-saving treatment (CPR) should not be given in the event of the heart or breath stopping.

Dominant gene disorder: A hereditary condition caused by a single gene which occurs if one faulty copy of the gene is sufficient to produce the condition e.g. Huntington's chorea or Achondroplasia

Donor: Person who consents to allow their gametes or embryos to be used in the treatment of others or for research purposes. Although donors are the genetic parents of children created using their gametes, if the treatment is provided in a licensed centre in the UK they are not the legal parents of these children.

Downs Syndrome – see Trisomy

Duchenne Muscular Dystrophy – See Muscular Dystrophy

Egg: The gamete produced by females during their monthly cycle.

Egg collection: Procedure used in IVF by which eggs are collected from the woman's ovaries by using an ultrasound guided needle, or by using a laparoscope (an instrument used for looking into the abdomen) and a needle. Also known as egg retrieval.

Egg donation: The process by which a fertile woman donates her eggs to be used in the treatment of others or for research.

Egg sharing: An arrangement where a woman seeking IVF treatment undergoes one cycle of treatment in which her eggs are recovered. She then uses a proportion of these eggs in her own treatment and donates the remaining eggs to another woman. The woman donating her eggs receives a reduction in the cost of her treatment.

Embryo: A fertilised egg that has the potential to develop into a foetus.

Embryo biopsy: The removal and culture of one or two cells from an embryo *in vitro* prior to genetic screening.

Embryo division: The splitting of an *in vitro* embryo at an early stage when each section may continue development. This may produce multiple copies of the single original embryo, and may be considered a form of cloning – fission cloning.

Embryo freezing: Embryos not required for treatment in a cycle can be frozen and stored for future use. Freezing is also known as cryopreservation.

Embryo storage: The storage of one or more embryos for future use by freezing (cryopreservation).

Embryo transfer: The replacement of embryos back into the female patient.

Ethics - deciding what is right and what is wrong about how we live our lives.

Eugenic: adjective to describe the idea of promoting the biological improvement of humanity. This has been applied positively and negatively.

Eugenics: literally translates as 'good in birth. A concept first proposed in 1883 by Francis Galton, who was concerned to improve the human stock of the nation.

Euthanasia: The concept of an 'easy death' – the act of killing someone painlessly, especially to relieve suffering from an incurable and painful illness. There are three

types of euthanasia:

- Voluntary euthanasia is at the request of the person who wishes to die,
- Non-voluntary euthanasia is when a person is unable to request it due to physical and/or mental incapacity and the medical profession and the courts of law deem it necessary. An example of this would be the decision to stop feeding and hydrating (giving fluids) to someone who is in a Persistent Vegetative State (PVS)
- Involuntary euthanasia is when someone could have consented or refused but were not asked. For example, the application of Do Not Resuscitate (DNR)

notices to elderly or disabled patients' hospital records without their knowledge. Also includes situations where someone did not want treatment but the decision was overridden.

Flow cytometry (sperm sorting): A method of sperm sorting that involves staining the X and Y chromosome-bearing sperm with different fluorescent dyes, and then sorting them according to the colour. Used for sex selection.

Foetus: The term used for an embryo after the eighth week of development until birth.

Four Principles: A theory of bioethics enshrined in four moral principles of autonomy; justice; beneficence (doing good); non-maleficence (doing no harm).

Fragile X Syndrome: A genetic disorder caused by a constriction of the X-chromosome. Affects both sexes and results in an IQ of less than 50.

Gamete: The male sperm or female egg which fuse together to form a zygote.

Gamete Intra Fallopian Transfer (GIFT): A procedure in which eggs are retrieved from a woman, mixed with sperm and immediately replaced in one or other of the woman's fallopian tubes so that they fertilise inside the body (*in vivo*).

Gene: The unit of inheritance from parents. It stores coded information (DNA) that determines the sequence of a protein, and therefore our characteristics. A specific characteristic arises from the interaction of proteins, cells and tissues and is not determined only by the gene itself. Many diseases occur when the body cannot make a particular protein, i.e. insulin. Everyone inherits two copies of each gene (each copy is called an allele). A typical gene has a thousand letters of code.

Gene Patenting: This enables commercial enterprises to obtain patents on genetic material when discovered and removed from the body, or on manipulations of genetic material . They can then charge anyone wishing to use that discovery in the process of medical research or drug development. The commercial companies say that this patenting is essential to cover the costs of research. Although intended to protect scientific invention, the EU has recently issued a Directive on the Legal Protection of Biotechnological Inventions which permits the patenting of discoveries of human genes and gene sequences. This has already had serious cost implications for some national health services, for example in the UK.

Gene Therapy: Gene therapy involves making changes to the gene in order to treat an inherited medical condition. This could be done by adding a working copy of the faulty gene, by developing genetic-based drug therapy or, as has already been unsuccessfully tried, by imparting a virus, carrying a working copy of the gene, into the faulty gene. There are two kinds of gene therapy:

- Somatic gene therapy - alters the gene in the individual temporarily and ongoing therapy is necessary.
- Germ line therapy (or human genetic engineering) – alters all the cells in the body, including the reproductive cells and therefore can be passed on through reproduction. This therapy is prohibited in most countries at the moment.

Genetic – of the genes

Genetic determinism: The view that we are the sum of our genes. That they predict the impairments and behaviour we will exhibit throughout our lives and that the environment has no real influence.

Genetic disease: Everyone inherits two copies of each gene and these may contain markers (codes) for certain diseases. A dominantly inherited genetic disease occurs when only one faulty copy of the gene is sufficient to produce the disease e.g. Huntington's chorea. A recessively inherited disease only occurs if both copies of the defective gene are present e.g. Tay-Sachs' disease, Sickle cell disease

Genetic engineering: the manipulation of genes by removing genes from one organism and inserting them into the cell of another organism.

Genetics: the science of dissecting our genes and understand which genes contribute to which diseases

Genetic Testing – the science of performing tests on living cells to establish whether certain genes are present. This is done via examining blood or saliva.

Genome: The basic set of genes in the chromosomes in any cell, organism or species.

Gradient methods (sperm sorting): A method of sorting sperm based on the different constitution of X and Y sperm. Used for sex selection.

HFE Act: The Human Fertilisation and Embryology Act 1990.

HFEA: Human Fertilisation and Embryology Authority. The UK body which makes decisions on how new technologies should be used in practice.

HGC – Human Genetics Commission. The UK body which debates new technologies and puts forward proposals for its use.

Human Genome Project: This project has sequenced the complete set of chromosomes that humans pass on to their offspring – commonly known as the Book of Life.
The genetic code is now known but what each bit does and how it works is still a
mystery. Towards the end of the project it was agreed to put the results on the internet, thus stopping commercial concerns rushing out to patent individual genes.

Infanticide: This is the killing of a baby who is thought to be so severely disabled that it is not allowed to survive. Death can be caused by use of sedation and cessation of feeding or happen because no attempts are made to clear the airways. In some countries (notably the UK) a mother who is found guilty of infanticide while she is still breast-feeding or shortly after the birth will be found guilty of manslaughter. For anyone else, the killing would be regarded as murder.

In Vitro Fertilisation (IVF): Patient's eggs and her partner's sperm are collected and mixed together in a laboratory to achieve fertilisation outside the body. The embryos produced may then be transferred into the female patient.

Medical Model – the belief that people are disabled by their impairment

Muscular Dystrophy: A group of muscle diseases, marked by weakness and wasting of selected muscles. Duchenne's & Becker's Muscular Dystrophy are genetic disorders affecting males and can develop from the age of 4 or 5.

Neonatal death: The death of a baby within 28 complete days of delivery.

Nucleus: The part of a cell which contains the genetic material DNA

Preimplantation Genetic Diagnosis (PGD): A technique where couples can have their embryos tested for certain impairments before being implanted in the uterus. A recognised practitioner removes one or two cells from an embryo, and those cells are tested for specific genetic disorders/characteristics before embryo transfer takes place. This allows couples to eliminate the impaired foetus and ensure implantation of a non-impaired foetus. This is now being used for those who are at particular risk of passing on an inherited condition such as Tay Sachs, Duchenne Muscular Dystrophy, Cystic Fibrosis etc. It is carried out using IVF (in vitro fertilisation) techniques.

Preimplantation Genetic Screening (PGS): In conjunction with IVF, where a recognised practitioner removes one or two cells from an embryo, for those cells to be tested to ensure they contain the correct number of chromosomes (known as euploidy) and not more or less than usual (known as aneuploidy). 'Normal' embryos will be selected before embryo transfer takes place.

Pre-natal screening: carried out on large numbers of pregnant mothers to check on abnormalities in the foetus. This will be done by routine procedures such as ultrasound scanning or a simple blood test. As a result of screening, when the foetus is seen to be 'at risk', testing will then be carried out by use of amniocentesis

Pre-natal testing: carried out when the family has a genetic marker or predisposition for a certain condition and the pregnant woman wishes to take the test. This will be done by routine procedures such as ultrasound scanning or a simple blood test.

Pro-nucleus: A small round structure(s) seen within the egg after fertilisation which contain the haploid sets of chromosomes (genetic material of each gamete) surrounded by a membrane. A normal fertilised egg should contain two pro-nuclei, one from the egg and one from the sperm.

Proteins: made up of amino acids and control our characteristics. Genes code for a particular protein that enables us to function. Many diseases are caused when the body cannot make a particular protein.

Proteome: refers to all the proteins in a cell

PVS: Persistent Vegetative State: the condition of living without consciousness, or the ability to initiate voluntary action, as a result of brain damage

QUALYS (Quality Adjusted Life Years): A concept developed by health economists to measure mortality, morbidity and function, on a sliding scale from dead to healthy – plus the "quality" of life you have- plus the increased time of survival resulting from a particular treatment.

Reproductive genetic screening: Involves carrier screening for specific genetic disorders known in the family (e.g. sickle cell anaemia or cystic fibrosis); or pre-natal screening to check on possible abnormalities in the foetus

Recessive gene disorder: A hereditary condition caused by a single gene which occurs if both copies of the defective gene are present e.g. tay-sachs' disease, sickle cell disease, cystic fibrosis

Selective breeding: artificial breeding to select the best characteristics, whereas sexual reproduction always produces variation.

Sex selection: The sex of an embryo is determined using PGD, in order to avoid sex-linked diseases.

Sickle Cell Disease: A hereditary blood disease, mainly affecting people of African, Asian and Mediterranean ancestry. Occurs when the gene is inherited from both parents and produces red blood cells which are distorted through lack of oxygen. Results in Jaundice and Anaemia and leads to high infant mortality.

Single-gene disorder: A hereditary disease caused by a single gene, i.e. when only one faulty copy of the gene is sufficient to produce the disease. (See Dominant, Recessive and X-linked)

Social Model – the belief that people are disabled by their environment and its structures

Stem cell: Reproduce indefinitely and have the capacity to develop (differentiate) into a large number of different cell types.

Tay-Sachs: A baby with this condition seems healthy for the first few months. The child's health gradually deteriorates with progressive destruction of the nervous system leading to physical and mental problems, including paralysis, blindness and generalised debility until the child dies usually before the age of four.

Thalassaemia: A hereditary blood disease, widespread in the Mediterranean countries, Asia and Africa. Leads to a lack of normal function in the red blood cells and people with the disorder require frequent blood transfusions.

Traits: For example, sickle-cell trait, or Cystic Fibrosis trait. A carrier condition where a faulty gene is inherited only from one parent and causes no symptoms.

Trisomy: A syndrome reflecting the presence of three chromosomes of one type instead of the normal human chromosome number of two. An example is Trisomy 21 resulting in Down's syndrome.

Utilitarianism – a theory of bioethics which bases decision-making on the best outcome for the majority.

Virtue Theory – a theory of bioethics which focuses on the virtues of the individual in decision-making. Trying to do one's best.

X-linked single gene disorder: A hereditary condition caused by a single gene, and affecting mainly male children, e.g. Duchenne Muscular Dystrophy

Zygote: The cell formed as a result of fertilisation.

Zygote Intra-Fallopian Transfer (ZIFT): The transfer of embryos to the fallopian tubes for purposes of achieving a pregnancy. Embryos are transferred at the fertilised egg (one cell embryo) stage.