

ARTICLE 2 ECHR: Information Technology and the Threat to Disability Rights

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Socio-political background

- Socio-political background to questions surrounding the ethics of information technology.
- Eugenics movement.
- Rapidly ageing population,
- Spiralling healthcare costs.
- Research interests in the human body.
- Organs

Other Interests: Eugenics

- **What is eugenics?**
- Malthus, Galton, Darwin, Sanger
- Wells
 - ‘no pity and less benevolence ...’, we should ‘not be squeamish’ about inflicting death on the unfit, because those who kill the weak will have a ‘fuller sense of the possibilities of life than we possess. They will have an ideal that will make killing worth the while.’

Disability Rights in the Age of Eugenics

- Part of the problem with this ideology:
- Focus on productivity and social utility **over** human dignity and just treatment of individuals.
- Hence its anxiety about those regarded as unfit or unproductive.

Disability Rights in the Age of Eugenics

- Increased scope for eugenic intervention via “agencies under social control” Galton
- The Spine & identity card with biometric data planned.
- Improved access to IT and centralised databases.
- Implications for the disabled/ hereditary disease. Insurance. Organ location. Healthcare costs.

Disability Rights in the Age of Eugenics

Increased scope for eugenic intervention via
“agencies under social control” Galton

- at the beginning of life, by screening for disability, PGD; Insurance implications.
- during life: with prevention of the reproduction of the “unfit”, sterilisation and abortion for disabled people: The Spine represents a threat by permitting efficient *targeting* of the disabled.
- at induced death, euthanasia, of the “unfit”.

Disability Rights in the Age of Eugenics

- Well-known eugenic agendas in the Nazi era (also in the US, Sweden and UK throughout the 20th century).
- ECHR, the Nuremberg Code, the Declaration of Helsinki were a direct result of the eugenics strategies proposed and implemented in Nazi Germany in the name of progress.

Disability Rights in the Age of Eugenics

- *20th Century - “lives not worth living”*
- Reminiscent of the “lebens unwertenlebens”
:“lives unworthy of life”
 - e.g *Permission for the Destruction of the Life Unworthy of Life* Karl Binding and Alfred Hoche (1920)

Disability Rights in the Age of Eugenics

- Eugenicism contrasted with principle of equal dignity.
- Art. 2 Right to life; “Everyone's right to life shall be protected by law.”
- Art. 14 Discrimination
 - All human beings are of *equal value*. All human beings, however physically or mentally incapacitated have an *intrinsic dignity*. Dignity does *not* depend on *qualities or characteristics*.

Disability Discrimination

- *Nuremberg Code*
- *Convention on the Rights of Persons with Disabilities*
- *European Charter* prohibits eugenics.
- *Contra Biomedicine Convention*

Article 2 and Access to Treatment & Care in the UK

- Mental Capacity Act 2005
- Human Tissue Act 2004 and Regs.
- Human Tissue Regulations 2006
- Clinical Trials Regulations 2004

Substitute Decision-making

- Generally, MCA contains gravely irrational proposals involving:
 - “lasting powers of attorney” (Ss 9-14).
 - “court-appointed deputies” (Ss 15-21).
 - “advance decisions” (Ss 24-26)

Substitute Decision-making

Removal of treatment which after *Bland*

includes **food and fluids** and simple cures like antibiotics and insulin

Attorneys Advance decisions and CADs authorise

- Non-therapeutic research on non-consenting patients
- Removal of tissue and organs from non-consenting patients
- Controversial procedures eg non-voluntary sterilisation and abortion on disabled people

Substitute Decision-making

- In most cases no need to go to court.
- No need for any up-to-date account by patient of his wishes regarding treatment.
- Novel agents may be used to authorise lethal decisions to refuse treatment, authorise research upon a vulnerable patient, withhold feeding and even authorise removal of organs.

Substitute Decision-making

- Treatment also includes:
- *Non-consensual* abortion and sterilisation upon mentally disabled patients
- *Re F, Re SG*

Substitute Decision-making

- Where no attorney or advance directive-
- “Court” of Protection
- Secrecy.
- Not an ordinary Court.

Non-therapeutic research / tissue removal

- S. 30 allows non-therapeutic research on non-consenting patients.
- Contrary to other codes and declarations.

Non-therapeutic research / tissue removal

- *MCA 2005* has been enacted in conjunction with
- *Human Tissue Act 2004*;
- *Clinical Trials Regulations 2004* and needs to be read in conjunction with this and also...

Non-therapeutic research / tissue removal

- *Human Tissue Act 2004:*
 - **6 Activities involving material from adults who lack capacity to consent**

STATE RETENTION OF ORGANS

- State retention of organs without consent is law in:
- Spain, Austria, Belgium, Sweden, Denmark, Finland, France, Italy, Norway, Singapore.
- Once medical data is centrally located exact matches may be easily found.

International Conventions

- ***European Convention for the Protection of Human Rights and Fundamental Freedoms***
ECHR(1950)
- Article 2 - right to life
- Article 3 - degrading and inhuman treatment
- Article 6 - right to fair trial
- Article 8 - private life: *Bournewood, Glass*
- Article 14 - discrimination

International Conventions

- ***Nuremberg Code***

- The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision.

Disability Convention

- Ad Hoc Committee. Eighth session, New York, 14-25 August 2006
- CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES
 - 118 signatories 11 ratifications.
- Arts. 10, 15, 16, 17, 23, 25

Disability Convention

- ARTICLE 10 - RIGHT TO LIFE
- States Parties reaffirm that **every human being has the inherent right to life** and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities **on an equal basis** with others.

Disability Convention

- ARTICLE 15 - FREEDOM FROM TORTURE OR CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT
- 1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, ***no one shall be subjected without his or her free consent to medical or scientific experimentation.***

Disability Convention

- ARTICLE 16 – FREEDOM FROM EXPLOITATION, VIOLENCE AND ABUSE
- 5. States Parties shall put in place effective legislation and policies, including women and child focused legislation and policies, to ensure that instances of exploitation, violence and **abuse against persons with disabilities** are identified, investigated and, where appropriate, prosecuted.

Disability Convention

- ARTICLE 17 – PROTECTING THE INTEGRITY OF THE PERSON
- Every person with disabilities has a right to **respect for his or her physical and mental integrity** on an equal basis with others.

Disability Convention

- ARTICLE 23 – RESPECT FOR HOME AND THE FAMILY
- *(c) Persons with disabilities, including children, shall retain their fertility on an equal basis with others.*

Disability Convention

- ARTICLE 25 – HEALTH
- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided other persons, including in the area of sexual and *reproductive health and population-based public health programmes; ...*
- (e) *Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance ...*
- (f) *Prevent discriminatory denial of health care or health services or **food and fluids on the basis of disability.***

Disability Rights in the Age of Eugenics

- Equal dignity doctrine incompatible with such notions as:
- Lives “worth less than zero”, the “damaged specks of humanity” (Toynbee), the “vegetables” best terminated whose organs are nonetheless thought proper for harvesting in the name of the greater good.

Conclusion

- Rapidly ageing Western population.
- Increasing pressures on Health Authorities.
- Powerful scientific and research interests in the human body.
- The power of the new eugenics movement and the population control lobby.

Conclusion

- There must be a realisation of the new threats to disability rights that exist in the age of the new eugenics. Advances in IT permit greater control over the vulnerable in more ways than ever.
- Without proper understanding and care, we invite abuse and homicide of the disabled, elderly and incapacitated.