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## **Disability & Policy - Survival of the Fittest**

**Rachel Hurst**

I was asked the other day by a newly disabled African why disabled people's rights were so systematically and horribly violated throughout the world? He said that whether he was in Africa or England he always felt a non-citizen and he was wanting to do something about the situation.

My instant response was that if we knew the answer to his question we might have been more successful in getting our rights. I then gave him one reason which I thought could be part of the answer and which I would like to share with you in this discussion on rights and disability .

There is a considerable body of research which has looked at the influence of cultural, social and political history on attitudes to disability and the resulting policies. The collective and individual experience of disability has contributed to this research. Where I feel there has been a gap in our knowledge is in looking at the instinctive survival mechanisms that have had such a strong part to play in the development of social organisation and the relationship of that survival mechanism to the role played by disabled people in society and the resulting policies. I am sure I am not the first person to look at this area, but I know it is not part of the main body of theoretical work on disability. But I think it is an important subject that, however painful, needs to be looked at and given serious discussion, even if, at the end, the theory that I put forward is rejected.

A subconscious desire of both humans and animals is the continuation of their particular species, family, tribe or nation, its evolution and adaptation to the prevailing environment. All of us who have watched the programmes of Desmond Morris and David Attenborough are well aware of the numerous strategies that both animals and humans have devised to ensure that their kind reproduce and flourish. This survival urge is often stronger for the group than for the individual, with some members of a particular group subjugating their own potential for the greater good. Worker bees spend all their energies in ensuring that the Queen Bee gets the right food and keeps the hive going. Some

tribal systems have flourished with similar selective breeding rituals - with the right to breed given to only a few who are sustained by the efforts of the rest of the tribe.

What is common to all survival systems -whether based on the individual or the group – is the instinctive recognition of what makes good reproductive/survival material, how the best material can be obtained and rejection of anything different. Humans have formulated specific cultural and behavioural patterns to ensure that this recognition is supported, either through highlighting sexual maturity by special rituals or through wearing different clothes and by installing taboos against the unacceptable.

How society then organises itself to cope with the tensions and conflicts between the survivors and the rejected has been the basis of much philosophical thought. I do not intend to add my views to those of Aristotle, Marx, Hegel et al, but to suggest that however the organisation evolves it does so through moral codes and laws. Society has to set behavioural guidelines to ensure that it can survive and flourish and that there are mechanisms for rejecting or excluding any individual or group which is seen to threaten that survival. Inevitably, these behavioural guidelines are set by those who consider themselves the survivors and are the dominant group and as a result this group controls the social organisation.

Individual freedom is subsumed to the rules of the dominant group - it is assumed that the individual will want to conform to the rules for the common good -just as the Queen Bee presumably assumes that the workers like rushing around collecting her food so that she can gorge herself and reproduce effectively! There is, however, always the possibility of tension and conflict when an individual or a sub-group feels that their survival is under threat and fights back, as happens in a hive when a new Queen is born.

This analysis shows clearly that the dominant group puts in place laws and moral codes to control the social organisation and to allow it to flourish. They were not put in place to support individual rights and freedoms and could not do so because there was always a controlling mechanism which did not take into account any deviation from what was thought appropriate by the dominant group.

It is only in very recent times that the idea of individual rights and freedoms has been extended to individuals outside the dominant group. Whether this development has happened because society recognises that its survival and

growth depends on diversity rather than purity or whether the excluded have got better at demanding their own survival is open for debate. Ancient legal codes failed to recognise any individual freedom from state ( or dominant group) interference. The first catalogue of rights began as compacts between princes and feudal assemblies and completely excluded those who were in serfdom and not considered able to participate in decision-making. The most historically important of these compacts was the Magna Carta of 1215 which King John was forced to put in place because of threats of civil war - a classic case of the excluded fighting back! This charter did mean a lot to contemporaries and was only relevant to those who were already considered freemen. (Women, of course, were not free, being owned by their fathers or their husbands. ) But Clause 39 gave freemen the right to protection against imprisonment, exile or destruction -"except by lawful judgement of his peers or the law of the land" - and in so doing gave expression to the idea of individual freedom.

The Magna Carta has become the symbol of this freedom ever since and was the influence for further human rights laws in the seventeenth and eighteenth centuries in Britain and France leading up to the American Constitution in 1788. This also ignored individual rights until the first ten amendments formed the Bill of Rights. It was not until the 13th, 14th and 15th amendments that slavery was abolished and women were left out until the 19th amendment. It is only in very recent years that we see the rights of the most excluded groups considered at all and the experience of women, ethnic minorities, indigenous people, disabled people, people of different sexual orientation, creed, colour or age has shown that these rights cannot be implemented unless they are supported by precise laws which change the construction and organisation of society to ensure inclusion and non-discrimination.

For disabled people in particular, the interaction between our right to individual freedom and choice and control over our own lives and our right to non-discrimination and inclusion measures is crucial. Our exclusion has been so systematic and rigorous that there is a need for fundamental changes to society in order to support our inclusion.

So, we are now at a point in history where the tensions and conflicts between the dominant groups and the sub-groups are being openly recognised and solutions are being sought to support the rights of individuals whether they are part of the dominant group or the sub-groups and to support the inclusion of sub-groups. We have United Nations instruments and national laws. We have non-discrimination legislation and codes of practice. We have a world-wide agreement to the universality of human rights and several mechanisms for advertising violations of human rights and even some mechanisms for punishing

violators -either through the courts, economic sanctions or expulsion from the framework of our social unity -the United Nations.

And disabled people are ostensibly part of this universality of human rights. However, unlike any other group, our rights are being seriously threatened by theories and practices of eugenics. The old survival instinct is flourishing within the dominant group when it considers codes of ethics and laws regarding genetics, abortion and euthanasia. And the only group to be rejected in all cases is that of disabled people.

To give a few examples in this country alone: newly-born babies who appear to be disabled are allowed to die or, at best, are not 'officially kept alive'. We legally put 'Do Not Resuscitate' notices on medical files of the elderly and disabled people of all ages with only the permission of the relatives or courts - not the people concerned. Disabled women are encouraged to have sterilisation's and some young girls are sterilised with only permission from their parents or the courts, sometimes against their will. Some churches will not marry disabled people because they are seen as incapable of consummating a marriage and it is their belief that procreation is the only acceptable outcome of a relationship. There is increasing support for the voluntary and involuntary euthanasia of disabled people of all ages as witnessed by the sentences administered by courts to relatives accused of killing their loved ones and the media coverage of cases of people in a permanent vegetative state. Many charitable organisations apparently set up to support people with a specific impairment are spending millions on research to ensure that the impairment gene is eradicated in embryos rather than ensuring that their members and future members have rights and services. Disabled people are often denied medical interventions because their lives are not seen as worth improving. And above all we have abortion laws which forbid abortion after 26 weeks unless the foetus is deemed to be 'disabled' in which case an abortion can be performed at any time up until full term. In other words the baby can be murdered -just because it might be a disabled baby. Although most societies have recognised through the provision of specific laws that it is a violation of human rights to abort or kill babies on the grounds of gender and race, except in the case of a gender or race related hereditary disease, there is no such legal protection for disabled people generally.

All discussion of these subjects is taking place without the inclusion of disabled people, neither the person concerned, their advocate or representatives of disabled people's organisations. In the recent case of a young man of 23 years whose NHS Trust was seeking an application to put a 'Do Not Resuscitate' notice on his files and withdraw life-saving treatment under certain

circumstances, the young man was denied his own advocate and was represented by the Solicitor General -in other words, he was represented by the State.

As is often argued, many of these practices are based on kindness, on society's wish to ease pain and suffering for a life that they believe is not worth living. This is a value judgement, made only from the perspective of the dominant group and is similar to the argument that was used by some cultures to justify the practice of aborting or starving to death girl babies. We know that society has no right to quantify the worth of the life of a girl child -why should it be reasonable to quantify the worth of a disabled person's life? Only last week there were reports in the papers of a mother who is suing her health trust because the amniocentesis test performed ante-natally did not show that her son had spina bifida. She is suing for his and her pain and suffering because he has that impairment.

These situations outlined above are prevalent all over the world - even in the most humane countries. Disabled people are the victims of the human survival instinct which has, over time, been strengthened by a carapace of reasoning and social engineering allowing the dominant group to believe that, despite the gigantic developments in human knowledge and experience, it is rightful and reasonable that disabled people should not survive.

I believe that unconsciously it is this attitude that undermines the progress of human rights and non-discrimination legislation for disabled people and that this different attitude to disabled people as opposed to any other group is not just confined to eugenics. Societies are just not reacting to disability rights legislation in the way they have for other groups.

Research in the USA, four years after the Americans with Disabilities Act (1990) -probably the most comprehensive non-discrimination legislation for disabled people in the world - showed that 40% of disabled people still did not know that it existed and 41% of the non disabled population were just as ignorant.

The practice of racial apartheid is clearly understood to be illegal by humane societies -but not when practised against disabled people as it is through the provision of special and separate facilities and our exclusion from public facilities and utilities.

Ghettoisation, the restriction of a people to one area, is illegal and yet some of the most advanced countries, including our own, are proud of their 'villages' just for disabled people.

It is interesting that enforced confinement in a state-run institution is seen as an acceptable solution for people who have committed a crime against society, in order to ensure the survival and protection of that society. Disabled people too are often confined within institutions on order of the state because society says it cannot look after them in any other way. If disabled people were considered to be 'free' then this institutionalisation would be illegal even under the Magna Carta.

The fact that in so many countries equalisation of opportunities legislation for disabled people is unenforceable and unimplemented has been well documented recently, as disabled people in this country have struggled in vain to obtain fully comprehensive and enforceable anti-discrimination legislation. And yet similar legislation on the grounds of gender and race has some enforcement structures in most of these countries and progress is being made, however slowly and inadequately.

Above all, disabled people and our fundamental freedoms do not feature in mainstream information systems. We are not part of the general news and views or if we do appear, it is generally from the perspective of non-disabled people. This makes it impossible for disabled people to get the information necessary to make their voice heard -a chicken and egg situation -as is the reason why our information is not part of the mainstream. The former UN Secretary-General Perez de Cuellar called disabled people the 'silent emergency'. Perhaps our emergency could be better described as a conspiracy of silence.

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