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Bioethics and disability

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As the UNESCO Declaration on the Human Genome and Human Rights and the European Convention on Human Rights state, the first principle of bioethics must be one of human rights – the rights not only of those already living but also of the prospective human being. The UNESCO Declaration says (Article 2):

‘Everyone has a right to respect for their dignity and for their human rights regardless of their genetic characteristics. That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.’

Despite these international principles, it has become increasingly clear that advances in genetics are producing serious threats, both pragmatic and attitudinal, to the very existence, uniqueness and diversity of disabled people. To make matters worse, these threats are hidden by a virtuous mask of the objectives of cure, enhancement and alleviation of suffering.

The myths, fears and stereotypes around disability and our quality of life dominate decision-making and disabled people are predominantly left out of the debate. In seeing disability merely as a biological commodity, our inherent humanity is lost. In setting objectives of scientific advance that only focus on cure, our potential elimination is sanctified. By ignoring the current understanding of disability as the interaction between a discriminatory and disadvantaging society and a person with impairments, the expenditure on cures far outweighs expenditure on services to support inclusion for disabled individuals. Above all, the threat of eugenic practices further isolates us and ignores the tremendous contribution that disabled people bring to society.

Just like everyone else, disabled people want scientific advances that alleviate pain and help us to participate more fully in our communities. What we question are scientific advances that ignore our intrinsic humanity, that see us merely as a bunch of impaired genes that are only of any use if they can be

enhanced and that regard it as perfectly acceptable to eliminate disabled foetuses because disabled foetuses should not become potential human beings.

Society's attitude to disability is so negative and benefits and services so inadequate that it is not surprising that parents would prefer to have a non-disabled child. The medical profession find many life and death decisions painful and, in the present under-funding of health care, these decisions are often based on cost. However, decisions based on other people's assessment of our quality of life do not uphold our rights, nor do they uphold the rights of parents or families who are put under undue pressure to agree with these assessments.

How can anyone else judge our quality of life? How can quality of life be assessed in just medical or functional terms anyway? Everyone - disabled and non-disabled - relies on relationships, work, friends, community and society as a whole to impact on our quality of life. We all need these external forces to make us feel good about ourselves, to understand what we are as individual human beings, to help us to grow and to contribute. Disabled people need to contribute – not as a rung on someone's ladder to a charitable heaven - but in our own right, with our uniqueness recognised and our diversity celebrated.

Diversity is an essential element of evolution and ecology. Experience has shown that the eradication of any species, be it animal, human or plant, happens at the peril of those remaining. This historical lesson is being completely ignored by geneticists, who go ahead with their discoveries, which they proclaim are only for the benefit of humankind, keeping extremely quiet about the possible outcomes of manipulation of the evolutionary process and therefore of the environment as a whole – not to mention keeping quiet about the enormous profits they make.

Scientists and policy-makers and the general public are fully aware that technological advances must not discriminate on the grounds of race and gender. And yet, disability is seen as a different issue altogether. Despite a growing international awareness of disability as a human rights issue the notion of elimination of our specific diversity is supported and seen as socially acceptable behaviour.

How can society make judgements about what constitutes a good life or what personal characteristics are necessary? Do we really want a society that says you can only contribute if you are young, beautiful, athletic and intelligent. Do we want to be responsible now for making even greater divides between those who are deemed to 'have' (a quality of life) and those who are seen as the 'have nots' –creating an even greater divide between the rich and the poor?

Some things are being achieved to counteract these negative attitudes. Undoubtedly the introduction of non-discrimination legislation in a few countries of the world is having a positive impact. As governments legislate

to ensure that the environment becomes more accessible to disabled people, that information is made available in alternate formats, that education becomes inclusive and employment supported, disabled people become familiar citizens and discrimination is lessened. Unfortunately, none of these non-discrimination laws specifically cover genetic discrimination.

On the down side, countries where there are no legal or ethical frameworks for the protection of individuals are being used as a ready pool for conducting genetic research. An example is China, where research is being conducted on illiterate Chinese people who do not have the luxury of free choice – just as they had no choice over mandatory sterilisation for individuals with genetically linked diseases.

In the last few years, disabled people have come together to discuss bio-ethical issues and the following strategies have been agreed as the very least that should be done to ensure rights and dignity to disabled people:

Future advances and practices must be based on the furtherance of human rights, fundamental freedoms and human dignity, recognising, in particular, the potential rights of the unborn child who may exhibit the difference of disability

- Ethical principles must be based on honesty and integrity and should be formulated in consultation with all responsible stakeholders, including and in particular, disabled people and their organisations.
- Prior, free and fully informed consent of the person concerned must be obtained before any testing or diagnosis. If the person is not in a position to consent, authorisation should be obtained in the manner prescribed by human rights law and guided by the person's best interest. And their best interest must be judged without negative assumptions on quality of life or from the perspective of other interested parties.
- Information given to parents and families must be fully comprehensive, non-discriminatory and without pressure.
- Strategies should be put in place to ensure that the disabled child has an advocate at all stages in the decision-making process.
- Decisions should not be made using arbitrary quality of life assessments, nor should cost factors be used as criteria.
- Disability advocates should be part of all medical training and awareness raising of assessments of potential.

Bio-ethics should be the debate on how genetic and medical advances can be used for the benefit of society. Disabled people are not being given full and equal access to this debate and decisions that are being made seriously threaten our future and humanity. Our exclusion makes it easier for people like Peter Singer, a world-renowned Professor of ethics at Princeton University (USA) to claim that: there is more value in the life of an intelligent monkey than a seriously disabled child' and for many other clinicians and ethicists to say that it is immoral knowingly to give birth to a disabled child. We must be at the forefront of the debate to uphold our human rights to life, dignity and freedom.