



Published by the Progress Educational Trust

## Should persons affected by mitochondrial disorders not be brought into existence?

06 January 2014

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Appeared in BioNews 736

In their article entitled *Is mitochondrial replacement therapy eugenic and incompatible with human dignity?* in BioNews 733, John Appleby, Professor Rosamund Scott and Professor Stephen Wilkinson respond to a written declaration by 34 parliamentarians from 13 of the 47 member states of the Council of Europe which opposed intentional heritable modifications (1).

This declaration stated that 'the creation of children with genetic material from more than two progenitor persons, as is being proposed by the UK's Human Fertilisation and Embryology Authority [HFEA], is incompatible with human dignity and international law' (2). The parliamentarians were concerned that the UK Government may be about to legalise maternal spindle transfer (MST) and pronuclear transfer (PT), which are forms of germline modifications for mitochondrial DNA (mtDNA) disorders which involve the transfer of chromosomes between unfertilised or fertilised eggs respectively (3).

More specifically, Appleby et al question whether these European politicians' objections were appropriate and whether they had correctly interpreted the provisions of the international legal documents which they enumerate.

Appleby et al's comments are useful in seeking to clarify the reasoning and discussions behind these texts. They begin by mentioning Article 24 of the UNESCO's Universal Declaration on the Human Genome and Human Rights which indicates that "'germ-line interventions" could be considered as practices which are "contrary to human dignity"'.

In this regard, they respond to the statement that MST and PT may be detrimental to human dignity by stressing, instead, that the procedures 'would substantially benefit the person (by curing or preventing mitochondrial disease)'. Moreover, Appleby et al suggest that 'It would be perverse if the UNESCO Declaration actually aimed to restrict beneficial therapies because they obstructed the passing on of mtDNA disorders to future persons' and that 'it is difficult to imagine how this could be what its authors intended'.

But were the parliamentarians, therefore, misguided in their declaration? In reply, it may be noted that the response from Appleby et al may not have sufficiently emphasised the fact that an

individual created from these procedures would be a very different person from the one who would, otherwise, have existed with the mitochondrial disease (4). This is because personal identity includes the manner in which the individual was brought into existence comprising the exact date, place and biological characteristics. This identity cannot just be reduced to an individual's genetic constitution.

Thus, what is being proposed by the HFEA is not a form of therapy in which a person is being treated or cured for a disorder. Instead, it is making sure that certain persons are not brought into existence. This is a crucial difference since it then questions the equality in value and worth of every possible future person. Moreover, this equality of all existing and possible future human beings is one of the foundations of inherent human dignity. The complex notion of human dignity, of course, is difficult to define but it does not come in different shapes and sizes. If it did it would be the end of civilised society.

In the context of Article 3 of The Charter of Fundamental Rights of the European Union, which indicates that 'In the fields of medicine and biology... the prohibition of eugenic practices, in particular those aiming at the selection of persons' must be respected, Appleby et al further query whether MST and PT can be considered as eugenic in character.

In this respect, they are right to emphasise that it all depends on the manner in which the concept of eugenics is defined. But the authors continue by indicating that since no degree of coercion is being proposed, then the procedures are either not eugenic or are not necessarily wrong. This, however, is contentious. With respect to definitions, even Sir Francis Galton, who coined the term 'eugenics' in 1883, did not restrict its meaning to coerced procedures. Moreover, it is not because a procedure is consensual that ethical difficulties do not arise.

It is impossible not to have sympathy for persons affected by mitochondrial disorders and nobody can deny that they can experience a lot of profound suffering and affliction. Society should do all it can to find a treatment or a cure to such serious disorders. But this is quite different from making a consensual decision that such people should not be brought into existence. Indeed, because of the equality in value and worth expressed in the inherent dignity of all persons, it is impossible to say that anyone, including persons with mitochondrial DNA disorders or any other dysfunction, should not be brought into existence just because of their genetic constitution. If this did happen, it would amount to a form of ableism which reflects practices that only bring about a particular kind of person, who is considered as ideal, while disability is perceived as a diminished state of being human.

The European parliamentarians were correct, therefore, to be concerned about the legalisation of MST and PT on the grounds of these and the other legal documents which they mentioned. On the basis of the equality of worth and value of all possible future human beings, civilised society cannot accept that a life unworthy of life can ever exist.

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