



Published by the Progress Educational Trust

## Is preconception genetic testing and screening eugenic?

18 April 2011

By Dr Calum MacKellar

Director of Research, Scottish Council on Human Bioethics

Appeared in BioNews 604

Genetic testing and screening of prospective parents before a child is conceived to examine whether a genetic condition may be passed on is a relatively new area of discussion and debate. The Human Genetics Commission's (HGC) report 'Increasing options, informing choice: A report on preconception genetic testing and screening', published last week, is thus timely and raises several serious ethical issues. These range from the possible inequality of provision of testing and screening in society to the risk that people living with conditions of genetic origin may experience stigmatisation.

But one of the more substantial problems associated to preconception genetic testing and screening is the possibility that it may encourage negative eugenics, which the report defines as the 'organised, deliberate discouragement or prevention of natural reproduction between certain groups of people ... in order to produce offspring who have or lack specific heritable characteristics' (1).

It is interesting that the report does not say where this definition came from. Indeed, several different definitions have been proposed since the term eugenics was coined in 1883 by Galton (1822-1911). This ambiguity being compounded after the first half of the 20th century when the word became loaded with negative connotations and its use was deliberately avoided.

For example, Frederick Osborn (1889-1981), former leader of the American Eugenics Society, said in 1974 that 'Birth control and abortion are turning out to be great eugenic advances of our time. If they had been advanced for eugenic reasons it would have retarded or stopped their acceptance' (2). But others are adamant that - as long as the decision to select a child is made voluntarily by parents - the term eugenics should not be used (3).

The HGC report does not say whether preconception genetic testing and screening is eugenic. This, however, is important since the Charter of Fundamental Rights of the European Union, proclaimed in 2000, says in Article 3 that: 'In the fields of medicine and biology, the following must be respected in particular... the prohibition of eugenic practices, in particular those aiming at the selection of persons' (4). Unfortunately, even in this Charter, there is no definition of what eugenic practices are. But this does not guarantee that the proposals put forward in the HGC report would not contravene this legal document.

My main point of contention within the report, however, is its statement that 'the choices of individuals to use available medical technologies to avoid having a child affected by a serious genetic condition do not entail the judgement that it is undesirable to have affected individuals with that condition in society' (5).

Indeed, it is difficult to see how parents can decide not to have certain kinds of children without making the judgement that some children are undesirable. This seems to be contradictory and raises a crucial problem. If all human beings are born free and equal in dignity, as stipulated in Article 1 of the UN's Universal Declaration of Human Rights, why should a choice between future people be necessary? (6)

When parents decide to have a child, choosing the kind of child to have can only mean preferring one child over another or deciding that a certain kind of child should not be brought into existence. In other words, this decision contradicts the important principle according to which the lives of all human beings have the same worth and value, regardless of their state of health (7).

Suggesting that choice should be available between certain kinds of children may also mean that there is such a thing as a 'life unworthy of life', which was the basis of much eugenic ideology in the first half of the 20th century (8). As the legal ethicist Roberto Andorno says: 'In reality eugenic ideology presupposes stepping from a 'worthiness of life' culture to a 'quality of life' culture, in other words, to the idea that not every life is worthy of being lived, or to put it more bluntly, that there are some lives that do not have any worth' (9).

It is impossible not to be sympathetic towards parents who have children affected by severe disability and suffering. The despair and desolation of parents whose children have died because of a disorder is profound and long lasting. But, when talking to these parents, it is always the disorder and not the child that is the cause of their heartache. Moreover, none of the parents say they would have wanted their child to have been exchanged for another, healthier one. None of them would have made such a choice.

The HGC report suggests one should 'maximise choice in terms of the various reproductive options and to increase reproductive autonomy' (10). But it seems to have overlooked the serious ethical consequences arising from such a zealous view of autonomy and choice. Because of this, it is difficult to have confidence in the HGC's conclusion that 'there are no specific ethical, legal or social principles that would make preconception genetic testing within the framework of a population screening programme unacceptable' (11).

More discussion about UK procedures for selecting people is urgently required since they will have serious consequences for the future of our society.

#### **SOURCES & REFERENCES**

01) Increasing options, information choice: A report on preconception genetic testing and screening

Human Genetics Commission, p. 14 | 04/2011

02) Frederick Osborn, Transcript, Oral History Interview (July 10, 1974), Columbia University, New York, 1977, p.7

Quoted in Diane B. Paul, *Controlling Human Heredity: 1865 to the Present*, Humanity Books, 1998, p 125 |

03) Diane B. Paul, *Controlling Human Heredity: 1865 to the Present* Humanity Books, 1998, pp. 3-4 |

04) Charter of Fundamental Rights of the European Union  
Proclaimed in Nice on 7 December 2000 | *07 April 2011*

05) Increasing options, information choice: A report on preconception genetic testing and screening  
Human Genetics Commission, p. 14. | *04/2011*

06) United Nations' Universal Declaration of Human Rights (1948)  
| *07 April 2011*

07) Roberto Andorno, *Fondements philosophiques et culturels de l'eugénisme sélectif*  
In : J. Laffitte, I. Carrasco de Paula (dir.), *La génétique, au risque de l'eugénisme?* Paris, Edifa-Mame, p. 129-141 | *2010*

08) The term a 'life unworthy of life' (in German 'Lebensunwertes Leben') first occurred in the title of a book by German psychiatrist Alfred Hoche and lawyer Karl Binding, *Die Freigabe der Vernichtung Lebensunwerten Lebens*, Verlag von Felix Meiner in Leipzig, 1920  
|

09) Roberto Andorno, *Fondements philosophiques et culturels de l'eugénisme sélectif*  
In : J. Laffitte, I. Carrasco de Paula (dir.), *La génétique, au risque de l'eugénisme?* Paris, Edifa-Mame, p. 129-141 (my translation) | *2010*

10) Increasing options, information choice: A report on preconception genetic testing and screening, p. 2  
Human Genetics Commission | *04/2011*

11) Increasing options, information choice: A report on preconception genetic testing and screening, p. 20  
Human Genetics Commission | *04/2011*

#### RELATED ARTICLES FROM THE BIONEWS ARCHIVE

##### **Choice, autonomy and eugenics: Thoughts on the HGC's report on preconception genetic testing and screening**

*09 May 2011 - by Dr Ainsley Newson*

As highlighted in BioNews, in early April 2011 the UK's Human Genetics Commission (HGC) published a report supporting preconception genetic testing and screening (1). Preconception screening, which can be broadly described as identifying carriers of genetic mutations to inform reproductive decision-making for the person tested or his/her relatives, is well established in some jurisdictions but relatively unknown in the UK...[Read More]