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

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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.

The proposals outlined in the report could be argued to be merely an extension of established principles of genetic testing in pregnancy to those who are not yet pregnant. The rationale for this extension is that it will increase people's options and choices, enhancing reproductive autonomy. But large-scale screening of young people previously unaware of such testing will give rise to new issues.

This means Dr Callum MacKellar was right to question the ethics of screening in his recent BioNews Commentary. But I think that Dr MacKellar hasn't quite hit the mark with his criticism. His concerns can be divided into two broad areas: (i) whether preconception testing is eugenic; and (ii) that preconception testing necessarily entails selecting against children.

Taking his first concern, Dr MacKellar does not explicitly state whether he believes the report's recommendations will lead to eugenic practices, although he does seem to imply they may contravene some EU legal instruments if put into practice. But if such an interpretation is sound, it would also mean most current prenatal diagnosis also amounts to such a contravention. It may be more helpful to examine what might be wrong with 'negative eugenics' (that is, discouraging couples from having a particular child).

Wikler has already provided a comprehensive conceptual analysis of eugenics and its problems (2). He discussed five 'candidate wrongs' of eugenics, of which he rebuts four and accepts the fifth – unfairness – as an unresolved issue. Twelve years after the publication of this paper, he could still rebut the other 'wrongs' on the same grounds, namely: many social policies affect who is born, modern societies have a broad range of values, and while the state promotes population health, the HGC report emphasises individual choice.

The question of unfairness is important and the HGC report attempts to address this explicitly by claiming preconception screening programmes will mitigate current injustices caused by a patchy

provision of screening. However, guaranteeing that all groups are treated equally is a concern that should remain at the forefront of all genetic screening policies.

Dr MacKellar's second concern is that a judgement about which children are desirable is inherent in any decision to have preconception testing and that if all humans are treated equally there is no need to choose who should live.

Although prenatal diagnosis will mean that some pregnancies do not continue to term, no couple making this decision would want to be labelled as having rejected a child. Couples in this no-doubt difficult situation are using prenatal diagnosis to choose not to raise a child with a particular condition, not to avoid having a particular child.

There is also a difference between opting for prenatal diagnosis and giving up one's child. Dr MacKellar's point that no parents of affected children would exchange their child fails to recognise that, when such a choice is presented in advance, many parents opt for prenatal diagnosis.

This is a personal parental choice based on individual values. Although it is important to ensure enough resources are dedicated to supporting those living with varying abilities, this should not prevent people from exercising their own choices, supported by health professionals. Another issue is Dr MacKellar presumes that the only reason for preconception screening or prenatal diagnosis is to decide whether to terminate affected pregnancies.

Although this is indeed one option, it is certainly not the only option, as the HGC's report describes. Preconception testing will not necessarily lead to prenatal diagnosis because not every carrier of a condition has a carrier partner too.

Even if a couple are both carriers of a particular condition, they might choose to use screening results to plan for the birth of a child with a condition. Using information to facilitate decision-making in a person's wider family is also important.

In my view, therefore, most of Dr MacKellar's criticism of the HGC's report does not stand up to scrutiny. However, while agreeing with the recommendations of the report I would also like to suggest that there are two aspects of the report which require further analysis.

On one of these, the assumption of the HGC that increased choices further reproductive autonomy, I agree with Dr MacKellar. The second is that students are the ideal population for preconception screening. Both of these will be the subject of future comment.

SOURCES & REFERENCES

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2) Wikler D. 'Can We Learn From Eugenics?'
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