

Hard to justify limits on genetic screening

A record 160 participants took part in the New Zealand Bioethics Conference in Dunedin this month. Liane Topham-Kindly joined delegates for sessions of the conference themed, Making People Better

The state has no place to play in regulating assisted reproductive technologies so long as there is no evidence of harm, keynote speaker Sheila McLean told delegates.

The professor of law and ethics in medicine at Glasgow University, Scotland, argues the principle behind approaches to reproductive decisions should be that which respects liberty and freedom of choice for parents, given the historical struggle for reproductive liberty.

The possibility of combining IVF with pre-implantation genetic diagnosis (PGD) has increased the number of people who might seek to access IVF with the associated screening technique.

However, many countries are limiting availability based on value judgements about the appropriateness of the intention behind screening.

Professor McLean argues the restrictions cannot be justified, based as they are on untested assumptions.

However, she cautions, she is not intending to claim states have an obligation to make assisted reproductive technologies (ARTs) available to all, or even to everyone who wants them.

"Rather, I am claiming that the state has no role in deter-

mining who should have access and for what.

"That is, first, once the technology is available it should be so without discrimination and, second, the value of reproductive choice mandates either no – or at worst extremely limited – intervention in what services people choose to access."

The legitimacy of state intervention often rests on the precautionary principle "we should move slowly in case harms emerge".

But Professor McLean ques-

tions harm to whom? Harm to the embryo/child?

Even if small harm does eventuate, the harm avoided by PGD to screen out the risk of genetic disorders is likely to be greater, she says.

Coupled with this argument is the notion there is something inherently wrong in selecting against negative genetic propensities, argued strongly by the disability rights lobby.

But, Professor McLean asks, who can blame parents from wishing to give their children

the best start in life?

If sound empirical studies were to show many disabled people were being harmed by PGD through, eg, serious employment discrimination or rising suicide rates because of demoralisation or hostile attitudes, then there would be strong reason to abandon the use of PGD.

But opposition based on assumptions ignores and vastly underestimates the increase in welfare of other individuals that might be gained from PGD.

"My country spends \$1 billion a year on baldness medication, yet 40 million people are denied basic healthcare. What does that say about us as a society?"

Professor Elliott, of the Center for Bioethics at the University of Minnesota, is the author of *Better Than Well*, a book analysing the use of enhancement technologies, achieving self-transformation and better living through medical technology. There are pitfalls and side effects. Antidepressants, for example, are now being used as mood enhancers. Yet studies indicate certain antidepressants can cause suicidal thoughts in non-depressed people.

Professor Elliott himself is neither totally supportive nor totally opposed to enhancement technologies, saying it may be there are some social goods worth giving up, considering what can be gained in enhancement. LTK

To botox or not – there is no answer

Is there a problem with wanting to be happier, smarter or better looking by using enhancement technologies like Botox, and drugs like Prozac and steroids?

US bioethicist Carl Elliott posed the question to delegates and asked exactly "what is the problem?"

It's a question, Professor Elliott says, he often shies away from, preferring not to give an answer, believing it depends on the person, the context and the drug.

"But if I had to give an answer or some general statement then it would be that you are using enhancement technologies to buy individual wellbeing at the expense of

some larger social good."

He gives the example of using steroids to become a better basketball player, this could initiate a "steroids arms race", damaging the game as a whole.

Enhancement technologies can reflect cultural complicity with social prejudices against

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people with certain skin or body types.

Michael Jackson is a prime example of this as he has become less African and more European, potentially making

some people feel ashamed of who they are.

By having Asian eyes altered to the shape of European, having a breast augmentation or giving your son a growth hormone, people are giving in to the pressure European-shaped eyes are better, women should

have large breasts and men should be tall.

He questions what enhancement technologies are doing to us as a society and to our "sensibilities".

Genetic profiling growing reality

Genetic screening in newborns is moving from the realms of science fiction to reality.

Paediatrician and Masonic Fellow in paediatrics and child health at Otago University, Nikki Kerruish, says, while genetic profiling is not set to be implemented in the near future, it is not something to be considered "bizarre" or "hypothetical".

In the UK, the Human Genetics Commission and National Screening Committee produced a report, *Profiling the newborn – Prospective gene technology*, addressing the issue last March.

And, while it says "no" to screening for now, testing on a large scale is feasible with appropriate technologies likely to be commercially available within 20 years.

Profiling involves concurrent detection of multiple gene variants that have been associated with greater risk or predisposition to a particular disease or condition.

The assumption is newborns, parents and the state will be able to use the information to reduce the risk of common conditions like heart disease, diabetes and obesity to improve their health and wellbeing.

But the procedure also raises a host of questions from scientific complexity, to concerns about consent, confidentiality and harmful effects as well as economic factors.

Dr Kerruish considered one of the issues – that of parental reaction to news their child had genetic predisposition to a disease – as part of a larger study at Otago University. A group of babies were tested for the diabetes gene at birth to determine if they were at risk of developing diabetes.

Internationally, there are few studies considering the psychosocial implications of genetic profiling in newborns; however, most quantitative studies show no significant effects.

Dr Kerruish's findings were in line with the international reports with parents whose children did have the gene considering their children no more vulnerable than those parents with low-risk children or children who did not have the gene test.

Ethics of global work need clarifying

As international collaboration between researchers grows, the ethics and regulation of health research can no longer be fully considered within a purely national context.

Health Research Council senior advisor Felicity Wood says New Zealand has to be proactive, rather than reactive.

The challenge will be to develop ethical guidelines and regulation in a global context which recognises New Zealand's cultural values. For, while there are benefits from international collaboration, there are also risks including loss of control and accountability of tissue and information being sent overseas, and a loss of sensitivity to local cultural values.

Questions, such as whether informed consent be given for tissue to be exported and banked overseas where there is little or no future control over the material, and whether it is acceptable for an overseas ethics committee to review research using tissue obtained from New Zealand participants, need to be addressed in the near future, Ms Wood says. LTK

Controversy over use of saviour siblings

More controversial is the possibility of using PGD with HLA typing to create a so called saviour sibling.

Objectors point to the notion of "commodification" of children, ie, a child born to be a saviour sibling is not valued as an end in itself but rather as a means to an end.

But Professor McLean disagrees, saying banning the use of PGD to create saviour siblings will lead to the death of a number of children who could have been saved by sibling donation.

Another argument is around the notion of using PGD for sex selection. While there are some cultures where the availability of preconception sex selection would, undoubtedly, result in male-dominated societies, she argues this is not a reason to restrict its availability in other countries. Professor McLean says there seems little evidence of a demographic disaster.

She cites a study carried out by Dahl and colleagues through surveys in Germany and the UK. In Germany 1094 people aged 18-45 were asked would they want their first child to be a boy or a girl. The vast majority said they did not care (75.7 per cent) while 14.2 per cent preferred a

boy and 10.1 per cent a girl

Asked if they were having more than one child, what would they like, again the majority (58 per cent) said it was of no importance. Just 1 per cent would prefer only boys, 1 per cent only girls, 4 per cent more boys than girls, 3 per cent more girls than boys and 30 per cent would like to have as many girls as boys. The UK findings were similar.

Professor McLean is sorry New Zealand has moved to prohibit PGD sex selection for non-medical reasons, saying this is now set in concrete when she would rather have seen consideration given on a case-by-case basis.

Opening the conference, health minister Pete Hodgson says the Government has been compelled to consider the ethical implications of health research and new medical treatments given the astonishing progress made.

"Indeed, society has increasingly recognised that issues, such as the appropriate use of embryonic stem cells, PGD and xenotransplantation require regulation at national level."

But, he acknowledges, negotiating an appropriate path between preserving scientific progress and setting appropriate ethical boundaries is a difficult challenge. D